# Informing NDIS market stewardship through consumers' information preferences: An exploratory study

Aviva Elisabeth Beecher Kelk

ORCID identifier: 0000-0002-8782-9537

Doctor of Philosophy

Submitted March 2020

School of Social Work
Faculty of Medicine, Dentistry and Health Sciences
University of Melbourne

Thesis submitted in total fulfilment of the degree requirements.

# Declaration

This thesis comprises only my original work towards the PhD, except where indicated in the preface. Due acknowledgement has been made in the text to all other material used. This thesis is fewer than the maximum word limit in length, exclusive of tables, maps, bibliographies and appendices.

Aviva Beecher Kelk
March 2020

# Contents

# List of tables

# List of figures

# Acknowledgements

I acknowledge the country in which I have carried out this work, and elders past, present and emerging. I have taken inspiration from anti-oppressive methodologies based in Indigenous theory, and this way of thinking has been as powerful as the subject I have explored. At the time of writing, Indigenous Australians are more than twice as likely to have a disability as non-Indigenous Australians. Various access and cultural issues also mean that they are less likely than others to access support though the National Disability Insurance Scheme (NDIS), which is testament to the importance of ensuring that the NDIS is implemented in a way that results in no vulnerable people being missed out.

My deepest gratitude goes to the participants of this research. Thank you for your time and energy. I designed this study to create real-world benefit for you and your families and communities, and I hope that the process of taking part, the end product of this thesis and other publications and the flow-on effect of my research realises even more impact than what I anticipated.

Thank you to my supervisors, Professor Helen Dickinson and Professor Lynette Joubert, for their unique and valuable input and encouragement, for patiently supporting my self-direction and for laughing with me (and at me) when it mattered most. Thanks also to Dr Winsome Roberts for your deeply empathetic and insightful emotional, intellectual and administrative support.

Thanks to Jenna and the team at Clickability for your encouragement and interest, letting me take the time to do this work and telling me, with a straight face, “Don’t worry, there’s nothing that can’t wait until next week.”

Love and appreciation go to my friends and family for the encouragement, proofreading, feedback, active listening, sympathy, scotch and laughter throughout. I have felt so supported and celebrated – may we always be there for each other in work and play.

# Abstract

Australia's policies have historically seen many people with disability (PWD) confined to institutions, abused, neglected and systemically denied the right to self-determination (Barnes & Sheldon, 2010; Oliver, 1992). It follows that many PWD have typically lacked choice over which services are involved in their lives.

An ideology of choice has emerged in the context of publicly funded disability services, influenced by ideas associated with neoliberalism and new public management (Fotaki et al., 2008). Some welfare-state services have been "personalised" (Needham, 2011), such as Australia's National Disability Insurance Scheme (NDIS), which uses a marketplace model to offer consumers choice about what support to purchase (Fawcett & Plath, 2014). The NDIS is not a conventional market in a neoclassical sense – it is a quasi-market, seeking a way to manage considerations of both efficiency and equity. Within this context, there is an important role for "market stewardship" to balance these tensions (Carey, Reeders, et al., 2018).

Choice can create not only self-determination for consumers, but a burden (Glendinning, 2008), and information is required to support the process of NDIS decision-making. However, there is limited evidence about *what* information is required. In this regard, a significant gap exists in the market stewardship literature, especially around knowledge that is driven by consumer preferences rather than provider or government priorities.

This research explores what information is required for NDIS consumers to feel informed when choosing service providers. It is a social work practice research study, examining a problem identified through practice with the aim of addressing it (Sim et al., 2018). Data was collected in two phases. The first utilised semi-structured interviews (n=23) to explore informational issues in depth while gathering data to inform the construction of a survey. This survey comprises the second phase, extending the sample to test the generalisability of the results (n=201).

Results show that word of mouth information from trusted interpersonal relationships is valued, as is information from and about professionals. This suggests that decades of oppression of PWD and professionalisation of service navigation have resulted in consumers' mistrust regarding information from service providers and government (Walsh, Wilson, Baines, & Martin, 2012), which is compounded by the complexity of the new NDIS system (Malbon, Carey, & Reeders, 2018). Participants therefore rely on trusted peers and professionals for reliable information.

This reliance is problematic because it stalls capacity building for both consumers and providers and decreases the urgency to implement market stewardship interventions. Furthermore, it can lead to riskier decision-making and poorer outcomes (Håkansson & Witmer, 2015; Schul & Peri, 2015) and relies on consumers having strong social networks, which puts equity outcomes at risk as well as the success of the insurance scheme.

This thesis contributes new knowledge to the market stewardship literature and also to practice. Academic findings are described above. Practical recommendations include deprofessionalising service navigation in order to decrease the information asymmetry that exists; using peer advisors to distribute information throughout the sector; helping providers create trustworthy information through their marketing collateral; creating sector-wide metrics; investing in shared digital solutions in order to collate and distribute information; and localising NDIS governance so as to create rich local information.

# Glossary

| **Term** | **Definition** |
|---|---|
| AAT | Administrative Appeals Tribunal<br>*This tribunal reviews decisions made by the Australian government, including those by the NDIA.* |
| ABI | Acquired Brain Injury |
| ACCC | Australian Competition and Consumer Commission<br>*This commission regulates industries and provides consumer rights support* (see ACCC, 2019). |
| CALD | Culturally and Linguistically Diverse |
| CRPD | Convention on the Rights of Persons with a Disability. |
| Dignity of risk | A consumer's right to take risks alongside making their own decisions (Marsh & Kelly, 2018). |
| ILC | Information, Linkages and Capacity-Building<br>*This program provides grants to organisations to deliver projects in the community that benefit all Australians with disability, their carers and families (NDIA, 2019c).* |
| Information economy | The aggregate of information outputs that play a supporting role to a market, creating an environment in which stakeholders can become informed prior to making a purchase decision. |
| LAC | Local Area Coordinator |
| Market steward | Groups such as the government and peak bodies who take on various regulatory and protective roles to ensure industries function well. |
| Market stewardship | A practice and literature concerned with ensuring industries function well. |
| NDIS | National Disability Insurance Scheme. |
| Problematisation | A theory that looks at the way policy is shaped by the socio-political conceptualisation of issues rather than by objective facts (Bacchi, 2009). |
| Quasi-market | A market designed to distribute public services (Carey et al., 2018). |
| Salient value similarity (or "value salience") | The perception that another person has similar values to the perceiver (Siegrist et al., 2000). |
| Service navigation | A practice that involves working within systems to reduce complexity, increase access and support consumer decision-making (Donovan, Hampson, & Connolly, 2018). |
| Thin market | A market that has inadequate demand and/or supply (Carey et al., 2019). |
| WPR | What's the Problem Represented to Be. |

# 1 Preface

I have spent the last five years working towards writing the thesis you are about to read. You may never meet me in person, but I want to tell you why I have written it, as it is close to my heart and I have put a great deal of myself into it. I want to start by rolling back about 10 years.

I never really wanted to be a social worker. I tried my hardest to avoid the profession that both my parents had gone into – I studied for a Bachelor of Fine Arts and did my honours thesis in sociology, looking at why women like salsa dancing. While my peers were going on study tours to parts of the developing world to examine the impact of some natural or human disaster, I was going dancing. When I finally finished, I still loved research and still didn't know what I wanted to do. I ended up looking at the ads in the back of the Sydney Morning Herald and came to the uncomfortable but perhaps inevitable conclusion that the work I wanted to do required a master's in nursing, occupational therapy or social work. I sighed and enrolled.

Two years later, I found myself writing the final papers for my master's while working in mental health, finishing a research project in psychosocial oncology, teaching counselling and starting a business. It had turned out that I was taken with every single subject of my social work master's and crafted a specialisation out of the generalist degree I had undertaken by focusing on the enormous policy change that was happening as I was graduating: the trial of the National Disability Insurance Scheme (NDIS).

Additionally, the mental health work I was undertaking was a project that simulated an NDIS environment. Our small team was working with participants from three organisations, offering them to choose participation in a suite of psychosocial support programs across all three services. For me, it was difficult to get enough information about the programs I had not run myself so as to help the participants I was working with feel safe and informed enough to decide to attend. Making a choice and starting something new was a risk for them. Those participants who were under 18 or from culturally and linguistically diverse (CALD) backgrounds found it particularly difficult to engage. On top of this, some of the programs did not run because a staff member had left, because there were not enough participants or because the wind changed. We often did not find out until after we had completed the intake processes, which caused a reasonable amount of distress and confusion.

In addition, if participants had issues that were not purely psychosocial – e.g. homelessness or family violence – I picked up the phone or used social media to access the network of new social workers that I did my master's degree with to get information because I was in an unfamiliar local area and had not yet accrued my own personal service rolodex. I was aware of both the negative impact of siloing services and the power imbalance that came from this asymmetrical access to information: there was no way participants would have access to that kind of quality service information without engaging with professional service navigators with professional networks of their own. Although I already had experience from my placements and research about how difficult it was to make sure that information moved effectively around not-for-profits, I was dumbfounded in relation to the extent, the impact and the negative outcomes of an inefficient information economy in this context.

However, the curious, entrepreneurial part of me was intrigued by the opportunity. I asked my best friend, also a social worker: “What can we do in the NDIS environment that will be helpful, have an impact and make some money?” After months of discussion, she read a line in one of my final assignments that described a “TripAdvisor for disability support services”. That, she said, was it. We founded Clickability, an online NDIS service directory with customer ratings and reviews, at the same time as I started the PhD. Crazy? Sure. I had a fantasy that the data we generated in the business could contribute to the research, and four years later, it has started to become a reality.

The interesting part, however, and the part that brings me to the importance of this study, is why it took so long. When we first started Clickability, we struggled to explain the innovation, especially to people outside the disability sector. Yes, it is the first of its kind in Australia; yes, it is one of the first in the world; and yes, other people have tried and failed; but it has been done before in other industries – it is not new technology or a new concept – so why not just use another regular online customer review site like Yelp.com?

More intriguing was the response we had from service providers when we launched. From some, it was along the lines of: “We knew this was coming, but we didn’t expect it to be so soon.” From others we heard: “We don’t want to listen to customer reviews – it’s just whinging” or “We already have 80% of the market – we don’t need to improve.”

The most interesting thing to us was the response from consumers – they loved Clickability! However, on the whole, they didn’t understand their role in making it work or using it. We developed workshops to help communities understand what it meant to give feedback and enact consumer rights. We helped people understand how, in general, the conversations that had thus far been limited to private peer support groups, publicly funded advocacy services and official complaints processes may support the community, the economy and the NDIS to function effectively.

We won a Westpac Bicentennial Foundation scholarship that allowed us to travel across Australia, and we found the same attitude everywhere. Our solution was not innovative, but it was new, and it was foreign. It required training, capacity-building and a significant amount of confidence and security to use, and that was not even for those who had limited digital access, communication or mobility. There was fear from consumers of providers with regard to being found out that they had written a critical review and their service being withheld.

Interestingly, there was also reluctance from case managers to offer any opinion in case it impacted on a consumer decision. These were the people, like myself in my previous role, who had more information about services than anyone else. They had such fear about contributing their knowledge that consumer self-determination was being negatively impacted. The information economy we were creating? It was not just Yelp.

Things have changed a fair bit in the last four years, but they have also not changed that much. Clickability received three major grants, and its use is increasing over time, so we know that, at some level, there is recognition that it is a good solution to a real problem. There is also evidence: from a top-down perspective (examining the data), there are NDIS packages being underspent; from a bottom-up perspective (talking to the community), Clickability receives phone calls every day asking for help finding services because families have their packages but do not know where to start. We also receive requests for information from support coordinators and even local area coordinators. The workforce is still struggling to keep up with demand, and everyone is feeling it, especially when it comes to support work and allied health.

This lopsidedness in demand and supply also means that many services are so full that they do not feel compelled to concern themselves with creating a high-quality service outside of what is required for compliance because they are not worried about losing business. New businesses are booming but are experiencing growing pains when it comes to scaling, often because they cannot afford the technology they need to support them. Big businesses are surviving on established market share or loaned capital: the last industry peak body report stated that a growing number of their members are making a loss and a decreasing number are making a profit (NDS, 2019). We know that 50% of providers registered to deliver services in the NDIS are not providing services, but the average service navigator has no way of knowing which ones. The government has remained hands-off in the way it is shaping the market or performing "market stewardship"; it has not yet shared much data, even with its local area coordination partners or – to my (reasonably insider) knowledge – even internally. It has certainly not created an information solution that works for consumers and families.

The philosophy of leaving it to the market bothers the social worker in me at a human rights level. Despite Australia's adoption of the Convention on the Rights of Persons with Disability (CRPD), it is clear in the literature and media and from everyday experience that markets are not driven by rights – they are driven by loud voices and confident spending. Consumer rights are a set of principles designed to protect customers in the marketplace, and they were developed especially to manage power imbalances between customers and providers. Considering such issues also inspires me to think entrepreneurially about how to leverage the NDIS marketplace to positively influence human rights; there are established tools to support consumer rights (e.g. Yelp), whereas human rights claims are notoriously difficult to bring to court and uphold.

This thesis is the academic response to my practice solution of Clickability. In two ways now, I have asked how we can use the theory of marketplaces to leverage human rights outcomes for people with disability (PWD). I have an intuitive sense that disability is unique in its particular dynamics, but is this valid according to the literature? Is there anything to be learned that can help stimulate the emerging NDIS economy, empower consumers and help the market be a equalising force? As the founder of a social enterprise, is there anything to be learned about the broader application of business to realise social impact?

The rage that bonds disempowered communities and catalyses change has worked in the first instance – the change has been made, and the NDIS is now a reality; now, the devil is in the detail. When it comes down to it, is consumer feedback still just whinging? Is having a large market share a good enough reason not to improve the quality of services? Will the market and the actuarial needs of the insurance scheme win over the rights of the consumer to choice and control; moreover, will we even know if that's happening?

This is a practice research thesis. It was influenced by having supervisors in both social policy and social work, but it naturally started moving into behavioural economics and sociology as I progressed. The thesis is the response of an entrepreneurial social worker to the tension between market and welfare and an attempt to correct a power imbalance in the way in which policy is constructed. There are all sorts of ways it could have gone if I had had infinite time and resources, and I hope that I or others go there in the future. For now, I have placed my contribution specifically in the market stewardship literature, with a human rights lens and influenced by my experience in social enterprise, codesign and user experience design. I am particularly excited about this being one of the first studies to bring consumer voices into market stewardship, which is, in my opinion, essential to making personalisation work in general and the NDIS in particular.

I conclude the thesis by listing some potential interventions for improving the NDIS information economy, which I see as important acts of market stewardship. I want to note upfront that I am agnostic about who performs the actions needed to make the market work. There are some parties like the National Disability Insurance Agency (NDIA) who are obvious choices for being market stewards, the ones responsible for shaping and intervening. However, I also believe that some less obvious choices could be more impactful and better able to collaborate with consumers. It probably needs to be a mixture of stakeholders; in this sense, I see business, government, NGOs, professional networks and individuals all playing key roles.

The next chapter, and the first from an academic perspective, introduces the key concepts in the remainder of the thesis and the structure I will use to guide the reader through my thoughts, experiments, and conceptual exploration, all of which have led to this thesis' significant and original contribution. I wrote the thesis myself, with the support of my supervisors; I had help proofreading it, but my supervisors were the only people who were knowledgeable in the academic discipline of my thesis.

My intention is that this research will help change the way the market listens to the people who are the experts in what they need: PWD and their families and closest allies on the frontline of daily life. I hope that you enjoy reading it and share it with the people to whom it matters.

Cheers,

Aviva

# 2 Introduction

> *You could do all these processes and spend a month or two months reading annual reports and asking everyone you know and meet them, and it all sounds good, and you could get six months down the track and the service quality's crap… and you could get crap support workers or buy a bad chair and it breaks down... it's not foolproof or risk-proof.*

While it is not traditional to begin by presenting data from the research that a thesis has not yet been introduced, this quote from an interviewee provides an immediate and almost visceral overview to the practice issue being explored – how consumers can feel informed (or not) in disability marketplaces. The Australian National Disability Insurance Scheme (NDIS) promises to reset previous decades of an unequal, fragmented and underfunded disability service offered to Australians with disability through the implementation of a competitive marketplace offering long-needed choice and control to people with disability (PWD). In this context, *decision-making about services* is the actual function and application of choice and control, and with such an extension of consumer choice comes more responsibility, more risk and more need for information to mitigate such risk (McLoughlin et al., 2014). The comment above from one of the research participants in this project illustrates the level of burden felt by many service users when it comes to navigating disability support systems and discerning between providers, which creates a rich theoretical and practical point of departure to explore the new and developing NDIS environment.

This thesis brings theory and practice together in examining the development of the "quasi-marketplace" that is the current NDIS environment. The NDIS market will never simply be open like other mainstream markets; rather, it is designed to distribute services through public funds and is therefore regulated differently to other markets. For example, at the time of writing, NDIS pricing is regulated (NDIA, 2019e), with such markets being known as "quasi-markets" (Carey, Reeders, & Malbon, 2018; Gash, Panchamia, Sims, & Hotson, 2013; Glendinning, 2008).

Because of their different goals, quasi-marketplaces have different needs for "market stewardship", which is concerned with ensuring industries function well and is conducted by "market stewards", such as governments, who take on various regulatory and protective roles and have "ultimate responsibility" (Gash et al., 2013, p. 108) for the market. This applies to mainstream industries as well as quasi-marketplaces. For example, the United States government bailing out the banks after the Global Financial Crisis in 2008 ensured that the economy could continue to function in the way that its stewards believed it needed to, which could be considered an act of market stewardship.

Other acts of market stewardship are concerned with consumer rights, i.e. protecting customers and ensuring they are informed and able to purchase products and services safely and fairly (Needham & Dickinson, 2018). It has been argued that, in quasi-marketplaces especially, there is scope for such solutions to be driven from the "bottom up" by the consumers themselves.

> In a liberal, open society, the government's chief role is to encourage the emergence of collective solutions from within a society that wants greater scope for self-organisation and bottom-up initiative (Leadbeater, 2004, p. 42).

While this thesis remains impartial as to where the responsibility should lie for delivering market stewardship initiatives, it situates itself within the market stewardship literature, examines what is missing from the literature and in practice about how an "information economy" should be shaped so as to best help industry, and looks at what kind of market stewardship interventions could be implemented to ensure that NDIS decision-making has the empowering effect it was intended to have. An information economy refers to "an aggregate of economic activities that produce information outputs" (Pashkevich et al., 2017, p. 23) and is often discussed in terms of the asset that the information represents in and of itself, i.e. where knowledge is a commodity to be traded (e.g. Heeks, 1999; Pashkevich et al., 2017). In this context, however, it is used to refer to the aggregate of information outputs that play a supporting role to a market, creating an environment in which stakeholders can become informed prior to making a purchase decision.

First, this thesis takes a social work practice research approach. This means that it aligns the relevant academic research with the practice context by forming the research questions from issues of practice, shaping the methodology around addressing these problems and feeding new knowledge back into practice (Sim et al., 2018). This definition of social work was taken from the Australian Association of Social Workers' Code of Ethics, aligning with the following international definition of social work practice:

> The social work profession promotes social change, problem solving in human relationships and the empowerment and liberation of people to enhance wellbeing. Utilising theories of human behaviour and social systems, social work intervenes at the points where people interact with their environments. Principles of human rights and social justice are fundamental to social work (AASW, 2010, p. 7).

In line with this definition, the present thesis contextualizes disability in a critical social model underpinned by human rights, positing that society is disabling, that there are subjective experiences of impairment and disablement and that rights are universal (Degener, 2017; Hurst & Albert, 2006). These intertwining notions are a highly complex juxtaposition of subjective and structural issues – much like personalisation itself. Social work takes an ethical stance that is based on the model of the rights of each individual to freedom and wellbeing. It also takes a systems perspective and draws from the social and critical models of disability, noting the influence of environment and context on individual circumstance and concerning itself with social justice as a means of correcting inequality. This thesis uses systems thinking to examine and challenge power dynamics and draws on pragmatist social work research methodologies that not only seek to drive knowledge that adheres to the definition above (Vonk et al., 2007) but also take into account the ethical perspective of the researcher (Dodd & Epstein, 2012; Dowse, 2009; Fawcett & Plath, 2014).

Second, this thesis takes an interpretivist approach to critically examine policy, using key elements of Bacchi's (2009) "What's the problem represented to be?" methodology, which offers a method of exploring the way in which issues are shaped through the construction of policy and a means of creating dialogue between the lived reality of an issue and the policy that governs the way in which it appears in society (Bletsas & Beasley, 2013).

Third, this thesis focuses on examining the ways in which people make decisions in a disability marketplace, and it is one of the first studies to explore this from the bottom-up perspective of the consumer (Leadbeater, 2004). It uses an anti-oppressive methodology to describe the lived practice of how consumer decisions are made, rather than how they should be made according to economic theory or even disability theory (Goodley, 1999). From a practice perspective, this is essential research in the context of the introduction of the NDIS and its ongoing market stewardship.

Having defined several key terms and approaches (also available in the Glossary), this introductory chapter will now provide a short background to the "problem" of disability before outlining the research questions, the study's contribution, and the structure of the thesis.

## 2.1 Conceptual background

This section describes the contextual background of the NDIS and how it has shaped the research in the thesis. Disability affects around 15% of people worldwide. According to the World Health Organisation, this number is growing as chronic health problems such as diabetes, mental illness and obesity proliferate and the proportion of elderly people across the world who are likely to experience disability due to ageing increase (WHO, 2016). In Australia, one in five citizens lives with a disability while another 2.65 million Australians are carers of a person with disability (ABS, 2018). Although it varies with individual circumstances, PWD or people who have someone with disability in their family are more likely to experience low socioeconomic status due to lower employment rates, lower income, extra costs imposed by disability and various other psychosocial risk factors (Barnes & Sheldon, 2010; O'Rance, 2009; Saunders, 2006). Wellbeing outcomes for PWD are particularly low in Australia, which the most recent available data has shown is ranked last amongst Organisation for Economic Co-operation and Development nations in terms of quality of life for PWD (OECD, 2010). In this regard, PWD are less likely to participate in the workforce and are more likely to experience poverty and housing insecurity. This inequality is worsening as these issues become more pervasive (Emerson, 2007; Kavanagh et al., 2013).

The fact that disability influences employment, housing and health demonstrates that it affects not only individuals but also their families and communities; in this sense, as recognised in the AASW Code of Ethics, "social systems have a mutually interdependent relationship with the natural environment" (AASW, 2010, p. 9). However, social work theory also posits that this ecosystem also offers solutions and support through both informal and formal or professional relationships (Connolly & Harms, 2013). For this reason, this thesis uses the term "consumers" to mean PWD; "service users" to mean all those consumers, family members, carers and professionals who navigate the NDIS; and "participants" to mean the sample of service users who took part in this research. As an exploratory study aimed at exchanging knowledge between stakeholders, this thesis contains voices and opinions from all these parties.

The history of disability is marked with oppression, medicalisation, disempowerment and the systemic reduction of individuals' choice and control. Just as in social work practice, this research seeks to contribute to the reduction of oppression and the empowerment of individuals through the generation of original data and knowledge. It is "a meeting point between practice and research" (Epstein et al., 2015). Grounded in practice, this thesis explores theory (Chapters 3 and 4), conducts a rigorous academic experiment (Chapters 5–8), and brings academic findings back to practice (Chapter 9). Its aim is twofold: a contribution to the literature and a contribution to improving outcomes in policy and practice.

The influence of neoliberalism and the value placed on markets has seen a policy movement towards providing citizens with more choice and control (Fotaki et al., 2008). At the same time, there has been a movement towards ensuring that PWD have full access to their right to make choices so as to guide their lives and experience higher levels of self-determination (Power et al., 2014; Rioux & Bach, 1994). According to Mladenov, Owens, and Cribb (2015), these two policy influences are "marketisation" and "social justice", and this language is adopted throughout the thesis in order to contrast and compare the two approaches that have come together to create an environment in which the NDIS has arisen, requiring PWD and their families and carers to use choices to guide their support. This thesis draws from the theory of Bacchi (2009), which examines the way the NDIS is "problematised" within these two approaches and how this, in turn, can guide the shape of potential solutions to operational issues. Since this theoretical background will be discussed in more detail in Chapter 3, the following section will introduce the research questions that have emerged from the practice context.

## 2.2 Research questions

There has been little research into decision-making about disability support services, which becomes particularly relevant when it comes to examining what information is needed in order to create a functional quasi-marketplace in which consumers can make confident choices. The primary research question emerged from this practice problem. In order to address this gap in knowledge, this thesis asks: *What information do service users want in order to feel informed about the purchase of disability care?* Key terms to note in this question are "feel" and "service users". The verb "feel" is used here because the issue being explored is not outcomes or the evaluation of a decision, but rather confidence and a subjective sense of being informed in making a decision. As described above, "service users" include not only consumers but also the wider ecosystem of carers and professionals working in the NDIS environment.

While the main research question was designed to guide the overall study, it was answered by way of three sub-questions, which were designed to generate data from participants that reflects the circumstances under which they feel their decisions are informed:

- How do service users currently make choices?
- How do service users wish they could make choices?
- How would service users advise others to make choices?

These questions and sub-questions were applied through multiple stages of data collection, which are outlined below in the section describing the structure of the thesis. They produced data that met the goals of the methodology and created an original contribution that will be discussed briefly here before moving on to an outline of the thesis itself.

## 2.3 Contribution

This thesis makes multiple contributions, some of which are to the research literature and some to practice. First, all existing market stewardship evidence until now has taken a "top-down" perspective, considering what might be needed to make the market work from a governmental, service provision or demographic stance. In this regard, it contains little-to-no bottom-up evidence, i.e. information that has resulted from consultation with consumers. By creating this type of information, the thesis creates an original contribution to the literature.

As well as taking an original approach, there are specific findings that are unique contributions from this work. The thesis finds that despite assumptions that consumers will make utilitarian, evidence-informed decisions about which providers to choose, service users are experiencing such high levels of uncertainty and risk in the NDIS environment that their preferred means of gathering information is through interpersonal interactions with trusted professionals and peers. They are making decisions based on information sourced from asking each other for advice, seemingly regardless of evidence or other objective measures. In particular, service users are seeking the advice of people who they perceive to be similar to them, even when they have not met them, e.g. on social media. The thesis finds that NDIS participants are informing themselves in this way to mitigate the uncertainty and risk they feel in navigating the NDIS environment and making choices about service purchases. Furthermore, they are relying on word of mouth (WOM) information because of a historical lack of trust in marketing and research materials and the high value placed on peer relationships.

This thesis argues there are problems with service users relying solely on WOM sources of information to navigate the NDIS marketplace. First, it means that purchase decisions being made are based on subjective and inconsistent information that may have lower levels of validity and are therefore likely to result in poorer outcomes (Håkansson & Witmer, 2015). Second, reliance on WOM information risks the unequal distribution of resources in favour of those who have more extensive social networks, and (as described above) many PWD experience high levels of social isolation, which would result in poorer NDIS outcomes for these already-vulnerable groups. Finally, it reduces the demand for the quality or quantity of information to be increased across the industry. In the discussion chapter, this thesis presents various ways of stewarding the market so as to avoid such outcomes. Through these findings and recommendations for practice, this thesis paves the way for a bottom-up approach to market stewardship. This original research creates a baseline for exploring user-centred ways of designing and enacting market stewardship policy in order to ensure that personalisation meets stakeholder goals on both sides of the NDIS market.

## 2.4 Structure

In order to account for the complexity of the topic as well as the interrelation of practice and research, this thesis does not follow a typical linear research design, which therefore necessitates a thorough overview and explanation of the structure. For this reason, this section of the introductory chapter delves more deeply into the structure of the research and outlines the thesis chapters. An overview of the structure has been provided in Table 1 as a point of reference to this outline. This section also foreshadows the contribution to the market stewardship literature that has been made by the new knowledge generated through this thesis.

The personalisation of disability services is underpinned by ideologies of individualism and the market; however, it is also a response to the fight of PWD and their allies for self-determination and the realisation of human rights. As such, there are multiple ideologies underpinning the NDIS and influencing how it is operationalised. Chapter 3 explores these multiple approaches by introducing Mladenov et al.'s (2015) polarisation of marketisation and social justice ideologies in quasi-markets. It argues that they are powerful yet, for the most part, remain hidden from public dialogue, which results in high-level problems with consistency and implementation. Aspects of the NDIS's success hang on these issues being resolved.

Chapter 3 begins by examining the policy environment and with a discussion about the oppression and disempowerment of PWD that reduced their choice and control (Barnes &

Sheldon, 2010; Brueggemann, Feldmeier White, Dunn, Heifferon, & Cheu, 2001; Dewsbury, Clarke, Randall, Rouncefield, & Sommerville, 2004; Flynn, 1993). The chapter explores this history and the accompanying 'waves' of policy and shows how they have been fostered by an international movement to realise better rights for PWD (Degener, 2014; Goodley, 1999; Roets & Goodley, 2008; Vehmas & Watson, 2013). It demonstrates how this shift led to the creation of the United Nations Convention on the Rights of Persons with Disability (CRPD) and to the replacement of the welfare state design with personalisation.

Chapter 3 also describes the concurrent policy trend towards increasing citizen activity and responsibility and shows that this is due to an international policy environment that is increasingly influenced by individualism (Heffernan, 1992). It argues that as aspects of the marketplace are brought into government, there is an increased emphasis on citizen decision-making as a form of realising choice and control. Consequently, the chapter posits that the centrality of consumer decision-making creates the need for relevant and appropriate information to be available to consumers in quasi-markets such as the NDIS in order for them to participate and enact their citizenship rights (McLoughlin et al., 2014).

Further, Chapter 3 identifies market stewardship as the literature and practice relevant to managing potential problems with equity and implementation of the NDIS, including the provision of information. Effective market stewardship actions can help to realise consumer choice and control (Carey, Malbon, Marjolin, et al., 2018). One of the factors required to ensure a functional market is the delivery of an appropriate information economy that facilitates informed consumer decision-making (Martin, 2011; McLoughlin et al., 2014). "Service navigation" is a practice that "better enables people to understand and work with [system] complexity, and to support their informed decision-making" (Donovan et al., 2018, p. 2). It is a consumer-centred process that helps to break down barriers to access to complex systems and supports choice-making.

| **Chapter Title** | **Contents** | **Chapter Summary** |
|---|---|---|
| **3. Policy Context** | Introduction<br>Models of disability<br>Medical model<br>Social and critical models<br>Human rights model<br>Problematisation<br>The waves of policy<br>First wave: Congregate care<br>Second wave: Welfare state<br>Third wave: Personalisation<br>Marketisation versus social justice<br>What is the problem represented to be in the NDIS?<br>Disability in this thesis<br>Chapter Summary | This chapter provides an outline of the policy environment that has led to the introduction of the NDIS.<br>It also introduces the theoretical approach of "What's the problem represented to be?" |
| **4. Literature Review** | Introduction<br>Quasi-market stewardship<br>Navigating complex service sectors<br>Gaps in the market stewardship literature<br>Decision-making<br>Decision-making as a skill<br>Behavioural economics<br>Gaps in the decision-making literature | This chapter outlines the literature relevant to this thesis, in addition to identifying gaps in the market stewardship literature that this study aims to fill. |

| | | |
|---|---|---|
| | Being informed<br>Information use<br>Personalising information<br>Content and metrics<br>Gaps in the information literature<br>Media and channels<br>Using others to be informed<br>Gaps in literature about channels<br>Chapter Summary | |
| **5. Methodology** | Approach<br>Shared principles of the approaches<br>Knowledge exchange<br>Principles of disability research<br>Goals of this research<br>Research Design<br>Ethics<br>Phases 1 and 2: Semi-structured interviews<br>Interview design<br>Interview data collection<br>Interview data analysis<br>Phase 3: Survey of NDIS stakeholders<br>Survey design<br>Survey data collection<br>Survey data analysis<br>Phase 4: Participant reflection and dissemination | This chapter outlines the practice research approach to this research, the methodology, and its implementation. |
| **6. Findings Part 1: Sources of Information** | Participants<br>Advice<br>Sources of information<br>Description of sources<br>Frequently mentioned sources<br>Highly rated sources<br>Chapter Summary | This chapter outlines the results of the first part of the first phase of data collection: semi-structured interviews. |
| **7. Findings Part 2: Content and reflection** | Themes<br>Reflection<br>Who it was easiest to advise<br>What participants learned<br>Chapter Summary | This chapter describes the results of the second part of the first phase of data collection: semi-structured interviews. |
| **8. Findings Part 3: Survey Results** | Survey respondents<br>Stakeholder role<br>Location<br>Gender<br>Age<br>Education<br>Types of disability<br>Comorbidity<br>Service use<br>Number of services and stakeholder role<br>Number of services used and diagnosis type<br>Experience in choosing services<br>Importance of information sources<br>Most important sources of information<br>Why are these the most important sources?<br>Importance of informational content<br>Most important informational content<br>Why is this the most important content? | This chapter describes the results of the second phase of this research: a survey. |

| | | |
|---|---|---|
| | Top sources and content themes<br>Demographic influence on choices<br>Chapter Summary | |
| **9. Discussion** | Introduction<br>Current NDIS information use<br>Information burden<br>Channels<br>eWOM and online sources<br>Summary: WOM in NDIS<br>Why this is happening?<br>Historical dynamics<br>System challenges<br>Service providers<br>Summary: What needs to change<br>Alternatives<br>Change service navigation<br>Using peer advisors<br>Marketing<br>Accessible information and metrics<br>Better use of the internet<br>Localise<br>Summary: Recommendations<br>Reflection on methodology<br>Limitations<br>Chapter Summary | This chapter describes what has been learned from the results of the research and how these learnings contribute to the market stewardship literature; it also makes practice recommendations and examines the success of the methodology. |
| **10. Conclusion** | Thesis summary<br>Contribution<br>Further research<br>Behavioural economics<br>Repeat as a cohort study<br>Looking overseas<br>Chapter Summary | This chapter outlines the contribution of this study, suggests pathways for future research, and concludes the thesis. |
| **Appendicies** | Appendix 1: Ethics approval<br>Appendix 2: Plain language statement and consent<br>Appendix 3: Interview schedule<br>Demographic information collected<br>Preparation: Technical language<br>Questions to be asked about each scenario<br>Scenario 1<br>Scenario 2<br>Scenario 3<br>Scenario 4<br>Further questions from interview schedule<br>Appendix 4: Post-it images<br>Appendix 5: Survey (including PLS)<br>Appendix 6: Phase 4 reflection for interview participants<br>Appendix 7: Social media recruitment – interview<br>Appendix 8: Social media recruitment – survey<br>Appendix 9: Image from thematic collection<br>Appendix 10: All sources (clustered by medium)<br>Appendix 11: Full list of themes and sub themes | This chapter contains relevant appendices. |

*Table 1: Structure of the thesis*

Through a literature review, Chapter 4 demonstrates that there is a gap in the knowledge regarding what consumer-centred market stewardship looks like, even in other industries such as healthcare. This literature review spans several diverse and different bodies of literature (see Figure 5 on page 47). It first looks directly at the market stewardship literature, because this is the area in which this thesis is situated. It finds this literature does not adequately describe what kind of information consumers need to make decisions. Chapter 4 then looks at broader industries through behavioural economics and other literatures to examine what is known more generally about consumer decision-making. While it finds evidence that might be applicable to quasi-markets and the NDIS market, its relevance is unknown, and it is therefore inadequate. Going broader still, Chapter 4 then examines what evidence exists about being informed, and how consumers use and value information generally. Significant gaps exist here also. Finally, Chapter 4 examines literature on various different types of media used by consumers to inform themselves, including word of mouth. Once again, the applicability of this evidence to the NDIS environment is unknown.

The social justice imperative behind this thesis means that it is important, from a rights perspective, to fill this knowledge gap and to do it in such a way that accurately represents consumer experiences, as well as the voices of people who navigate services on their behalf. The key question asked by this thesis, therefore, is what information service users need in order to feel informed when they choose disability support services.

The anti-oppressive human rights lens of this thesis carries through into the design of the methodology in Chapter 5. As one of the first studies in this area, the research is designed to be exploratory. It is a mixed-method study, taking a pragmatist approach and privileging qualitative methodologies in order to be congruent with its anti-oppressive approach (Creswell, 2009; Kaushik & Walsh, 2019; Stone & Priestly, 1996). Located in a practice research framework, it seeks to achieve outcomes through the production of the research in and of itself (Epstein et al., 2015). It also seeks to produce data to create a market stewardship literature that is grounded in human rights and, from a practice perspective, to influence a more equitable NDIS. This chapter also describes how the methodology is aligned with the equity aims of the thesis in general as well as being fit for purpose in its rigour as an exploratory study; it shows how early phases of the research are iterated using participant feedback and content analysis drawn from a grounded theory approach to ensure that it is internally valid according to the participants (Oliver, 2012). In this regard, feedback is used to consolidate the methodology, refine data collection tools, and validate the interpretation of data.

Chapter 5 describes how the first phase of research uses a scenario simulation technique in which research participants are asked to advise a hypothetical NDIS participants about how to choose an NDIS service. Chapter 6 outlines the first section of findings from this phase, the most significant of which relates to the preferences about the ways in which participants would like to consume information and the type of information they want in order to feel informed. Chapter 7 continues to describe findings from these interviews, detailing the content that participants believed was important to helping them feel informed, as well as their reflections on the interview process and what they learned. Results from this phase were used to construct a survey, augmenting the sample by nearly 10 times, from 23 to 224 participants. Chapter 8 describes these 224 participants and outlines the survey findings.

The discussion in Chapter 9 demonstrates how these findings help to fill the gap in the market stewardship literature and make a contribution to the field. After examining the results of both the interview and survey phases of research and bringing them together to identify key themes, Chapter 9 explores what can be said about the information that service users want in order to feel informed when they choose disability support services under NDIS. In this regard, the data consistently shows that service users want trusted interpersonal sources of information in order to feel informed about choosing disability services in the complex social sector environment, in addition to also highly valuing the input of professionals. Further, it finds that trust and confidence in decision-making increases over time and with more experience.

Chapter 9 demonstrates that some of these findings are aligned with the literature, particularly the healthcare field, but that they represent original findings for market stewardship and therefore the NDIS. It contextualises findings in the literature described in Chapter 4 and argues that the history of oppression in disability combined with the complexity of the NDIS have created a high level of uncertainty that is being mitigated through relying on trusted relationships. Chapter 9 describes how the economic rationalism underpinning marketisation approaches to personalisation assume that consumers make autonomous decisions (Beauchamp & Childress, in Gooding, 2013); however, disability culture is highly relational when it comes to decision-making (Gooding, 2013; Willis et al., 2016). Chapter 9 also argues that the complexity of the NDIS environment makes service users feel uncertain and, in order to mitigate this uncertainty, they seek out trusted relationships in the form of interpersonal interactions with trusted peers and professionals.

Furthermore, Chapter 9 argues that service users' reliance on trusted interpersonal relationships and professionals to get information about service providers has the potential to create equity and implementation problems. It posits that better information is needed and that capacity-building is required on both sides of the market in order to create and distribute this information and ensure that it is used – these are key market stewardship actions. Chapter 9 therefore makes practice recommendations, presenting a variety of approaches that may emerge to solve practice problems and promote human rights outcomes as well as solve implementation problems being experienced by the NDIS. This is novel for the market stewardship literature, and the content of Chapter 9 marks the central academic contribution of this thesis. It should be noted that while various market stewardship approaches are described in Chapter 9, this thesis remains agnostic about which groups should take responsibility for delivering them, separating the function of stewardship from stewards themselves. Chapter 10 then provides a conclusion to bookend the thesis.

## 2.5 Chapter Summary

This chapter has outlined the thesis, building on the work of the preface and extending it into the research literature. It has provided a background to the research and delineated the research questions and the contribution of this study to literature and practice. This introduction has also summarised the content of each chapter and its role in building the overall thesis.

This original research stems from a problem experienced through the researcher's social work practice, which relates to a deficit of information available in the NDIS environment, particularly information that is relevant, accessible and trustworthy to consumers. The thesis utilises a practice research approach to generate data from service users with the aim of addressing this problem and answering the aforementioned research question and sub-questions.

In order to contextualise the research in its practice and policy environments, the next chapter will provide more detail about the history of advocacy that resulted in the NDIS, as well as some of the criticism and policy developments relating to personalising policy around the world that have made this thesis particularly relevant.

# 3 Policy context

## 3.1 Introduction

Policy is shaped by ideology and culture. Because of this, there are multiple ways to define and understand the "problem" of disability, and these different definitions and understandings can result in different policy responses. The World Health Organisation defines disability as a combination of both physical *impairments* and also *limitations* regarding a person's ability to undertake activities or participate in society (WHO, 2016). Through such a broad definition, disability can be produced by individual and/or collective issues that are medical (impairments) and/or social (limitations) in nature. In Australia, access to publicly funded disability support through the NDIS is available to those who have diagnoses including mental illness, intellectual disability, physical disability, neurodiversity and chronic illness; whose disability is permanent and significant, resulting in a requirement for support and/or equipment; and who access that support before they turn 65 (i.e. before they become eligible for aged care support) (NDIA, 2019a). Some consumers of Australian disability support services were born with these conditions and others acquired them later in life through illness or trauma. This illustrates that the category of "disability" contains a wide spectrum of diversity and heterogeneity and a one-size-fits-all approach cannot work effectively for every individual in this diverse space; for example, a young child with autism has considerably different needs to someone in their sixties who has become quadriplegic due to a road accident.

This heterogeneity has not always been taken into account in the problematisation of disability. The history of disability policy over the last century is intertwined with shifts in socio-political narratives around the meaning of disability and, in particular, the rights due to PWD. Contemporary disability policy has attempted to bring these threads together. Because of the immense complexity of the issues and its history, it is a sensitive topic that is underpinned by various often-unspoken ideologies. Different conceptualisations of disability have variously led toward policies that are collective or individualist, mainstream or isolationist, choice-proponent or risk-averse. The goal of this chapter is to discover and explore such ideologies by using Bacchi's (2009) "What is the problem represented to be?" (WPR) framework, which is useful to this thesis as a tool to uncover power dynamics involved in the NDIS design and thus how solutions to various problems with implementation may play out in the emerging marketplace that privileges different ways of thinking about disability.

The WPR framework is adopted here because its interpretivist nature allows the reader a clearer perspective of where ideologies are influencing the policy environment. It aligns with key disability studies that offer different models of disability to uncover power dynamics and socio-cultural assumptions (Retief & Letšosa, 2018). This chapter therefore first discusses several models of disability, framing them as different ways of problematising the issues that arise from the condition of impairment. It uses this to introduce Bacchi's (2009) theory on problematisation, which examines the way policy is shaped by the socio-political conceptualisation of issues rather than by objective facts. Underpinned by this framework, the chapter then surveys the disability policy environment over the twentieth and twenty-first centuries and argues that there have been three semi-distinct 'waves' of policy design: congregate care, the welfare state and personalisation. Using the WPR approach, the chapter highlights that the waves are influenced by how disability is problematised and by the wider policy environment.

Thereafter, the chapter argues that the contemporary policy 'wave' of personalisation, shaped by an ideology of choice and control, is underpinned by two main conceptual narratives: marketisation and social justice (Mladenov et al., 2015), each of which have particular ideologies embedded within them. It examines what the coexistence of these two narratives means for stakeholders in the NDIS by describing the NDIS scheme through the WPR approach, uncovering the ways that Australia's disability policy environment has been influenced by both social justice and marketisation priorities. The chapter also highlights that problems emerging in the implementation of the NDIS impact stakeholders whose priorities traverse both social justice and marketisation and argues that, without purposeful intervention in addressing these problems, it is likely that the social justice priorities will be usurped by marketisation.

The chapter then introduces the model of disability adopted within this thesis, which (influenced by social work ethics) privileges a social justice framework. Finally, the chapter briefly introduces the concept of market stewardship as it segues into a literature review in the following chapter.

## 3.2 Models of disability

There are multiple ways of defining disability, which shape both policy and the lived experience of PWD. Professionals, advocates and PWD themselves have written about what it means to have disability and how reconsidering the cause of disablement can influence not only a living definition of disability but also the political and social environment. There are several 'models' of disability that reframe the implications of impairment and uncover cultural and ideological assumptions around disability. Such models are important because they allow for a creative reimagining of both problems and solutions and, in the context of this chapter, help to interpret policy and previous ways of thinking that have shaped the past and contemporary environments. Many models exist – including moral, identity, economic, cultural, charity and limits models (Retief & Letšosa, 2018) – and the most relevant to this thesis (and the ones discussed in this chapter) are the medical model, the social and critical models, and the human rights model.

### 3.2.1 Medical model

The medicalisation of disability was borne from developments in Western biology, science and medicine through the industrial revolution, which examined impairments, labelled "abnormalities", with a medical lens. For example, in the case of mental illness, conditions were considered to be black magic (Flynn, 1993). In the medical model, the problem of disability is viewed as an individual biological or moral deficit in which the solution is medical or another intervention on an micro level (Barnes & Sheldon, 2010; Brueggemann et al., 2001; Dewsbury et al., 2004). If there is no medical intervention available to rectify the problem, disability takes on the narrative of a personal tragedy (Oliver, 1992). Because medical intervention happens at a micro level, the responsibility for being able to participate in society is also placed on the individual.

However, the medical model still takes an "incapacity approach" (Degener, 2017), which assumes that PWD cannot look after themselves or make decisions for themselves and therefore need to rely on family, welfare or charity services. Because this model views disability and associated interventions as biological in nature, medical professionals are the experts as well as gatekeepers of support and services.

### 3.2.2 Social and critical models

This section brings together two models: the social model and the critical model. The social model differentiates between *impairment* – the way a body works – and *disability* – a person's ability to participate in society. In doing so, it rejects the medical model's notion of individual deficit. Instead, the social model interprets the cause of disability as being due to social restrictions and constructs rather than as a consequence of impairment (Barnes & Mercer, 2005; Degener, 2014; Hurst & Albert, 2006; Oliver, 1996; Stone & Priestly, 1996). A simple example to demonstrate this is an individual using a wheelchair being unable to reach the upper storey of a building via a staircase. In the medical model, the cause of disablement would be put down to the individual's limited mobility, while the social model identifies the cause of disablement as the inaccessible infrastructure of the staircase. Using the perspective of the social model, responsibility for access and inclusion is on the wider community (including landowners, architects and proprietors) rather than the PWD or a medical professional (Brueggemann et al., 2001; Gilbert, 2004; Vehmas & Watson, 2013).

Critical disability theory contends that while the social model succeeds in its attempts to politicise a rights discourse and problematise non-inclusive mainstream culture, it disregards the individual's lived experience of disability. Critical disability theory thus attempts to disrupt traditional narratives around which disability is constructed by including phenomenological as well as sociological and political dialogues. It takes a postmodern perspective where the subjective is embraced and power structures are questioned (Goodley, 1999; Roets & Goodley, 2008; Vehmas & Watson, 2013). This model argues that, in reality, PWD are often affected not only by social disablement but also by their impairment. They might experience this physically, emotionally and at the level of their identity (Degener, 2014; Retief & Letšosa, 2018). For example, some people may have positive experiences of belonging to a community of others who have the same disability as they do, while other people may feel frustrated by their disability. Ignoring this subjective reality can result in generalisations about disability that can be equally as incorrect and impractical as if the same assumptions were made about the general public (Oliver, 1996).

Drawing from the same staircase example above, it is possible to introduce a discussion about various solutions to the same problem that could meet individuals' subjective needs and desires. For example, the best practice solution from a social model perspective is a macro intervention, i.e. increasing accessibility to the building by having appropriate infrastructure. However, in the critical model, individuals might consider micro interventions, including adaptive equipment that can help them climb stairs. While for some PWD, the use of such technologies may not be an option (and it is certainly worth acknowledging the financial resources needed to harness these technologies, in addition to the fact that many PWD experience financial hardship), others might welcome it while there may be those who criticise the use of resources going into developing adaptive technology rather than adapting infrastructure. Under the critical model, while disablement is still social and power imbalances still exist, differences of experience and opinion and preference are valid.

### 3.2.3 Human rights model

The final model introduced in this chapter is the human rights model of disability, which builds upon the social model; in this sense, while the function of the social model explains and redefines disability, the human rights model forms a framework for increasing equality through policy and legislation (Beaupert et al., 2017; Retief & Letšosa, 2018). The human rights model stems from work supporting the Convention on the Rights of Persons with Disability (CRPD), which has been adopted by over 150 countries, including Australia (Beaupert et al., 2017; United Nations, 2019). Having meaningful choice and control has been positively correlated with various wellbeing outcomes – especially for PWD whose capacity to choose is often questioned, reducing their ability to enact their human rights (Chenoweth & Clements, 2009; Duffy et al., 2010; Fisher et al., 2010; Hanoch & Rice, 2010) – ensuring that the right to self-determination is one of the central focus points of the CRPD.

A human rights model begins with the premise that having an impairment does not mean a person should have fewer or different rights:

> What makes human rights so special is that they are fundamental and inherent to the person. They cannot be given or taken away from an individual or a group. They are acquired by birth and are universal, i.e., every human being is a human rights subject. Neither social status nor identity category nor national origin or any other status can prevent a person from being a human rights subject. Thus, the absence of impairment is not a prerequisite to be a subject of human rights (Degener, 2017, p. 43).

A human rights model maintains that, regardless of need, the civil, social, economic and political rights of PWD must be upheld (Retief & Letšosa, 2018). To draw from the same example as above, it might be noted that the person using the wheelchair has as much of a right to attend the event on the upper storey of the building as any other person and should not suffer social or other exclusion as a result of their disability.

### 3.2.4 Problematisation

The previous section has demonstrated that different ways of conceptualising disability result in different ways of viewing problems, designing solutions, and designating responsibility, which are summarised in Table 2.

These examples show how interpretation and reinterpretation of disability is shaped by and shapes both the socio-cultural and policy environments. Bacchi (2012) frames this process of iteration as a result of the way that issues are “problematised”, arguing that “policies produce problems” (p. 22). This theory is explored more extensively later in the chapter, but for now, a short summary of its function in this thesis will be provided as context. Bacchi’s (2012) framework is non-positivist; rather, it views problems as the way in which an issue is *problematised*, or the process by which it becomes perceived as a problem. Here, the type and extent of problems that exist significantly depend on the politics of who is describing it, in what context, and for what purpose:

> What one proposes to do about something reveals what one thinks is problematic… [policies] contain implicit representations of what is considered to be the ‘problem’ (Bacchi, 2012, p. 21).

Bacchi (2009) draws from the theory of Foucault (e.g. Foucault, 1972) in taking an interpretivist perspective that questions power dynamics and cultural norms involved in the creation of knowledge. As problematisation of an issue changes, Bacchi (2009) argues, so does the nature of the solution and, in turn, the way that policy is designed and implemented.

| | **Medical** | **Social/Critical** | **Human Rights** |
|---|---|---|---|
| **What's the problem?** | The venue is inaccessible because of my disability. | The venue is inaccessible because it has stairs. | I have the right to access the venue regardless of my impairment. |
| **What's the solution?** | I do not go to this venue. | The venue must install alternative means of access. I might choose to purchase technology that would allow me to access the venue. | All venues should be designed to be all-access as a matter of course. |
| **Whose responsibility is it?** | My responsibility. | The responsibility of the venue, architect, and legislative guidelines. | Universal responsibility. |

*Table 2: The problematisation of disability through three models*

This chapter will now examine the contemporary Australian disability policy environment, noting some of the ways that the issue of disability has been reframed over the last century of policy solutions, before returning to the idea of problematisation in order to gain further insight into the NDIS.

## 3.3 Waves of policy

In combination with an examination of three different models of disability, the above short discussion of problematisation illustrates how ideologies and cultural issues can shape the political environment and affect a person's lived experience of disability. It also shows how one idea influences the next (for example, how the social model influenced the critical and human rights models). This section sets out the history of disability policy through three 'waves' of thinking in order to understand how the contemporary NDIS environment has been shaped by the history that has come before it. The waves, while distinct, are simply descriptions of large themes. Various authors describe the "layering" of policies (e.g. Carey, Kay, & Nevile, 2019; Dickinson, 2016); in this sense, although the layers are different, they are not completely separate from one another, do not replace one another and are often active simultaneously. As it develops according to what is considered important in the political environment at that time, each policy manifests dominant belief patterns about disability while retaining aspects of the others (Dickinson, 2016). It is important to appreciate this because the design and contribution of this thesis is a response to the layers of complexity behind the current policy environment. As Needham and Dickinson (2018) contend, "by providing an understanding of the different possible meanings of personalized care funding, we can better understand the dynamic tensions inherent in the system as actors seek to make a reality of a broad set of policy intentions" (p. 735).

The first wave of policy is characterised by the segregation of PWD from the rest of society; the second is the welfare state, predominantly using a charity model featuring services provided by the church and other not-for profits; and the third features the individual with disability as a consumer, purchasing the services they need. Table 3 provides an overview and comparison of the three waves:

| **Issue** | **Congregate Care** | **Welfare State** | **Personalisation** |
|---|---|---|---|
| Relevant model | Medical model | Social model | Human rights model |
| Responsibility | State policy | Communal | Individual |
| Ideology | Moral | Political | Apolitical |
| Consumer role | Non-citizen | Citizen | Citizen-Consumer |
| Delivery model | Charities | Government | Marketplace |
| Services | Charity | Professional gift | Choice and control |

*Table 3: Comparing the three waves of policy*

### 3.3.1 First wave: Congregate care

The first wave of disability policy was catalysed by ideologies arising from the industrial revolution. During this period, a base level of education was stipulated for the first time in order to make citizens more productive and able to participate in industry. Those who found school difficult because of intellectual disability or differences in their communication or mobility needs were segregated and institutionalised; they were seen to be unfit to participate in society, to the point where, in the early twentieth century, the involuntary sterilisation of women with disabilities in congregate care was legislated in various countries, and while Australia was not one of them, the practice itself was widespread (Duffy et al., 2010; Pfeiffer, 1993).

Until the twentieth century, PWD were most often forced to live in congregate care settings. While this term is still used today to describe group living arrangements in disability settings, in this first wave, people with disability were essentially imprisoned, isolated from family and community and had few rights. This thinking around disability stemmed from the wider socio-economic environment and the priority at the time: productive and standardised participation in industry. However, this policy was also fear-based, driven by the moral and medical ideas about disability in which disability was problematised as moral and economic disruption, the cause of lack of productivity, therefore labelling PWD as unworthy of participation. Policies of segregation and sterilisation are consistent with this context.

### 3.3.2 Second wave: The welfare state

The twentieth century witnessed significant cultural and technological changes that created a shift in the way PWD were perceived, the first of which was the Second World War. Workforce shortages during the war resulted in PWD being encouraged to take employment for the first time (Longmore, 2009), and while soldiers returning from World War 1 were institutionalised, those who returned from World War 2 with physical impairments demanded jobs and accessibility improvements such as curb cuts. Second, due to improvements in emergency medicine and the invention of the seatbelt in 1959, people who experienced traumatic injuries or road accidents were surviving en masse for the first time, many of whom acquired various impairments and disabilities. Likewise, many soldiers injured in the Vietnam war returned with impairments (Cooper, 1999; Pfeiffer, 1993). These waves of people with acquired disabilities demanded access to the type of participation in society that they were accustomed to, which forced a new narrative about what it meant to have a disability, as they and their families advocated for their rights to live in the community, attend non-segregated schools and participate socially and economically.

Two further key events were a photographic essay by Blatt and Kaplan in 1966 that made the horror of institutions public (Ashman, 1989; Wiesel & Bigby, 2015) and the theory of normalisation, which involves ensuring that PWD learn skills that are valued in wider society and brought into the “rhythm” and “routine” of everyday life (Perske, 2004). These ideas became embedded within the broader civil rights movements of the 1960s and 1970s, and the first United Nation declarations involving the rights of PWD were passed in the 1970s (Stancliffe, 2014; Wiesel & Bigby, 2015).

These developments occurred in America before they gained political movement in Australia; however, the influence of normalisation started in the mid 1970s, when

> the signs which warned "Trespassers will be prosecuted" were removed and replaced with others which announced "'Visitors welcome" on the institution gates in Australia (Ashman, 1989, p. 73).

In 1983, the Richmond Report was released, recommending deinstitutionalisation, and the Disability Advisory Council of Australia (DACA) was established to advise the government on disability policy. In 1985, the DACA initiated the Handicapped Programs Review (Ashman, 1989; Ward, 2006), which collected 1,700 submissions on the state of disability services and led to the creation of the Disability Services Act in 1986. This act legislates the requirement to assist PWD to live in the community, increase their independence and maintain employment (Stancliffe, 2014). A few years later, the Disability Discrimination Act 1992 made it illegal to discriminate against PWD in any public arenas, including education, health and employment.

As this brief history has shown, changes for people with physical impairments led to improvement for people with intellectual and psychosocial disabilities. Changes in mental health and disability legislation throughout the twentieth century resulted in dramatic changes to mental health policy (Flynn, 1993); in addition, the 1980s also witnessed improvements in the medications available to people with psychosocial disabilities stemming from psychiatric diagnoses, which meant that, for the first time, many people with psychosocial disability could manage their conditions themselves and often return to work. People with psychosocial illnesses moved to have their rights recognised and respected, especially the right to play a key role in the care of their own health and the right to live in the community (Tomes, 2006). The idea that recovering from mental illness is a process rather than a static status was key to this movement, which became known as the consumer movement or the recovery movement, whose motto of “Nothing about us without us” is still used (Rogers et al., 2009).

These movements led to the mass deinstitutionalisation of people from congregate care and a large wave of PWD moving into the community. This was initially entirely funded through charitable donation but evolved over successive decades through more and more elaborate and complex commissioning systems with ever increasing reporting requirements that moved from inputs (what is being spent) to outputs (what is being supplied or provided) to outcomes (what is the impact created by what is being spent, supplied and provided). This involved the nationalisation of a range of social security services, including housing, education, health, employment and welfare services, the main aim of which was to promote the equal distribution of resources and employment (Johnson, 1987), and here the layering of policy that is based on an ideology of the value of work is noteworthy. This kind of public insurance model had been developing in Europe since the 1880s, but it took hold across many Western countries, including Australia, in the early twentieth century and particularly after the Second World War. It was seen as a response to the combination of the ideals of democracy and the recognition of social rights, combined with an attempt to equalise the consequences of capitalist marketplaces that did not distribute resources in an equal manner (Johnson, 1987).

Since the 1990s, the disability service environment was characterised by blocks of government funding tendered out to service providers for periods of several years based on the predicted need of consumers (Purcal et al., 2009). The success of these services was based on outputs, e.g. the number of people to whom services were provided. Advocates and authors have criticised the community-based services funded as well as the model itself (e.g. Gooding, 2016; MacKinnon & Coleborne, 2003). In fact, traditional welfare-state models of care have been described as highly institutionalised "professional gift models" that create and maintain dependence by classifying PWD as beneficiaries and preventing them from enacting full citizenship rights of equality and contribution (Dickinson & Glasby, 2010; Duffy et al., 2010; Morris, 2005).

#### 3.3.2.1 Peer support

One central tenet of the recovery movement was the condition of mutuality in the helping dynamic, whereby the professional may be an expert in their field, but the consumer is equally an expert in their lived experience and is therefore uniquely placed to offer appropriate support (Mead & Copeland, 2000; Walker & Bryant, 2013). This led to the development of a peer support model, based on the idea that someone who has a lived experience of mental illness will be able to assist more effectively in the recovery process than someone who has not (Miyamoto & Sono, 2012; Rogers et al., 2009). This takes the form of one-on-one or group support or of formal and informal advocacy and may involve informal arrangements, consumers forming their own consumer-led organisations or being employed by traditional providers to work within that structure (Walker & Bryant, 2013). While various systemic and clinical challenges have been identified, this model has various benefits that have been evidenced in the literature, including increased quality of life, decreased hospitalisations and better social and emotional wellbeing (Fukui et al., 2010; Miyamoto & Sono, 2012). Such benefits are reaped by both recipients and providers of peer support, and there is some evidence that although there is a higher level of satisfaction in peer-provided services, even where there are no improved clinical outcomes, it is underutilised in practice (Davidson et al., 1999; Rogers et al., 2009).

This short history of the development of the welfare state continues to demonstrate that issues as wide-ranging as technology, economics, war and activism all influence the problematisation of disability in the public sphere. As thinking about disability and disability advocacy influences the environment and the status quo is challenged, policy changes and responds.

### 3.3.3 Third wave: Personalisation

The third and contemporary wave of disability policy design that has stemmed from this climate is personalisation, a policy environment through which choice and control is provided to consumers of government-funded social services. Such a provision stipulates that, as part of their citizenship, people should make customer-like decisions by means of participation. Just like the other waves of policy, personalisation is influenced by the ideology, culture and policy that has come before it. Where the welfare state was designed around the collective and an ideology that it was government's responsibility to meet citizen needs (Fotaki, 2014), the economic, social and political environment of the contemporary Western world is influenced by the neoliberal belief that individualism is imperative and that deregulated market economies are efficient and able to appropriately allocate resources (Heffernan, 1992).

Personalisation was borne not only from the rights movements described above but also from a global trend towards neoliberalism, which has resulted in the idea of markets in public sector contexts becoming more popular worldwide. It places a high value on the autonomy of the individual, emphasising their right to make choices and their role as a consumer. This ideology has influenced not only the economic environment but also the policy environment, linking citizenship with the right of the individual to make choices. In fact, much of the contemporary literature on social policy rests on the idea of the citizen being a consumer of policy, processes and social services. In this "citizen-as-consumer" paradigm, the individual enacts their citizenship rights by choosing and purchasing social services. The approach of personalisation assumes that the citizen acts as a consumer and that the social services market should respond to their demands by generating appropriate supply, thereby ensuring the needs of vulnerable people are met (Fawcett & Plath, 2014; Fotaki, 2014).

Where the welfare state was seen to be inefficient and to deliver services that were not in demand, introducing a market model to social services was intended to increase the efficiency and effectiveness of government spending and make government more "business-like" in a context where a number of former large-scale government provisions had been privatised or semi-privatised and had (seemingly) led to many improvements (Carey et al., 2019; Dickinson, 2016; Green, Malbon, Carey, Dickinson, & Reeders, 2017). This model also has the potential to result in far greater flexibility of services and service delivery that is consumer-centred, which includes, for example, being designed through bottom-up partnership approaches to ensure that the needs of consumers are of central importance (Australian Commission on Safety and Quality in Health Care, 2011; Leadbeater, 2004).

The movement of ideology from the communal to the individual, and from government provision to reliance on the marketplace, has shaped disability policy, as has the ideology of the disability rights movement enshrined in the human rights model of disability. Much of the literature on personalisation is grounded in the notion of the right of PWD to "full" or "active" citizenship (e.g. Power et al., 2014; Rioux & Bach, 1994). For these authors, (re)instating citizenship and human rights to those PWD who had theirs compromised can be achieved by offering increased choice, control, participation and responsibility (Chenoweth & Clements, 2009; Dodd, 2013; Duffy, 2011, 2012; Duffy et al., 2010). These are concepts that are closely linked with freedom and self-determination, as specifically noted in the CRPD (United Nations, 2019). However, this same movement from communal to individual has depoliticised disability policy. Like markets, personalisation is touted to be "apolitical"; with this change from the welfare state model, which was deeply political, political elements of the structure such as advocacy have been reduced or eliminated altogether (Hasenfeld & Garrow, 2012).

While there are multiple models of personalisation (e.g. Purcal et al., 2009), the common thread is allocations of individual funding – the size of which are influenced by the individual's needs – in order to realise increased consumer choice (Alakeson, 2010; Glasby & Littlechild, 2009). Mladenov et al. (2015) argue that personalisation encompasses a wide range of concepts, including "cost effectiveness, privatisation, consumer satisfaction, choice, autonomy, empowerment, user involvement, or democratisation of expertise" (p. 308). There are many different ways of realising consumer choice and control through personalisation, not all of which create a market. For example, the Norwegian system primarily retains government provision of services but gives citizens choice and control by encouraging them to have a more involved role in managing their lives (Pilling & Christensen, 2014). However, the Australian version of disability personalisation is inspired by the UK version, both of which rely on a marketplace to deliver services (Productivity Commission, 2011). It has been argued that the NDIS is unique in that the speed, geography and diversity of participants that are being included make it particularly complex (Carey, Kay, et al., 2019; Carey, Malbon, Olney, et al., 2018; Needham & Dickinson, 2018). Another factor that makes it different from some other personalised schemes is that it is universal (for those who meet the needs threshold) rather than means tested (Needham & Dickinson, 2018).

## 3.4 Marketisation versus social justice

These models highlight that different ways of interpreting the problem have created different solutions, even under the same umbrella of personalisation. Various authors have examined the different ideologies underlying personalisation. For example, Needham and Dickinson (2018) discuss the different "storylines" underpinning personalisation that shape its operationalisation in different contexts, demonstrating the influence of the social and cultural ideological context on problematisation. Mladenov et al. (2015) argue that the breadth of personalisation results in a lack of clarity about what personalisation entails, allowing for conflicting ideologies to be obscured. In this regard, they contend that such a situation creates "the illusion of a post-ideological consensus in order to accommodate conflicting agendas" (Mladenov et al., 2015, p. 308) and identify two main agendas: marketisation, which values efficiency, and social justice, which brings participants out of an oppressive policy environment and offers them choice, control and increased wellbeing. This language will be adopted throughout the thesis. Table 4 outlines some of the key issues relating to the two agendas of marketisation and social justice that will be addressed below.

| | **Marketisation** | **Social Justice** |
|---|---|---|
| Overview | Personalisation creates economic efficiency | Personalisation creates social equity outcomes |
| Purpose of consumer decision-making | Supply can respond to demand | Their needs as citizens can be met |
| Importance of consumers being informed | Utilitarian purchase choices can be made | Human right of self-determination can be realised |
| Outcome | Efficiency | Wellbeing |
| Politics and power | Irrelevant; the market will govern | Essential to ensure equality |
| Rights | Consumer rights and citizenship rights | What governs the system<br>Citizenship, consumer, human |
| Consumer responsibilities | Making efficient choices and spending money | Understanding their needs |

*Table 4: Contrasting characteristics of marketisation vs social justice*

As reflected in the criticisms of personalisation above, Mladenov et al. (2015) argue that these agendas are not equal and that the value of marketisation is consistently privileged over that of social justice:

> ... whereas personalisation is represented as a mechanism that will revive the welfare state in the 21st century in a non-paternalistic, non-hierarchical, less interventionist form, in actuality it seems to be used as an instrument for welfare state retrenchment through privatisation of services and responsibilisation of service users (p. 309).

Where this dynamic continues to be obscured, the ways in which these different rights frameworks create assumptions in an NDIS environment also remain hidden. This increases the likelihood of the voices and priorities of minority groups being lost, leaving the more powerful voices to dominate the agenda or receive more than their equal share of resources, thus widening existing inequalities that the NDIS is designed to combat (Carey et al., 2017; McLean et al., 2006).

Examining the different models of disability and waves of policy has demonstrated that a different lens applied to the same situation can produce a different problem and/or solution. While the design of the NDIS is unlikely to change significantly, its operationalisation and, in particular, its market stewardship are still developing. The way that concerns are addressed and problems are solved has the potential to be highly influenced by either marketisation or social justice. A crucial theoretical issue is finding a way to bring together – or at least uncover – the dynamics of the two approaches governing personalisation and how they influence the operationalisation of the NDIS. This is one of the key contributions of this thesis, which will be realised through the adoption of Bacchi's (2009) "What's the problem represented to be?" (WPR) approach and applying it to examine some of the issues the NDIS is experiencing in implementation.

## 3.5 What the problem is represented to be in the NDIS

This chapter will now introduce Bacchi's (2009) WPR methodology. While it is not used in its entirety, it serves as an important means of exploring the NDIS environment. This section pays particular attention to the dual ideologies of social justice and marketisation in attendance.

Bacchi's (2009, p. 2) method of critical analysis is to address the following six questions when considering a policy:

1. What's the 'problem' represented to be in a specific policy or policy proposal?
2. What presuppositions or assumptions underpin this representation of the 'problem'?
3. How has this representation of the 'problem' come about?
4. What is left unproblematic in this problem representation? Where are the silences? Can the 'problem' be thought about differently?
5. What effects are produced by this representation of the 'problem'?
6. How/where has this representation of the 'problem' been produced, disseminated and defended? How has it been (or could it be) questioned, disrupted and replaced?

Question 1 helps to clarify the issue being problematised in policy, working backwards from the policy to the issue itself; question 2 encourages a critical epistemological and ontological interrogation of how the knowledge that informs the issue being problematised has been formulated, identifying assumptions that underlie the problematisation. Examining binaries, key concepts and categorisation may be considered to assist the critical approach; question 3 asks how the background context of the problem has shaped the power dynamics and norms embedded in the issue, the focus of which is on the process of problematisation over time; question 4 encourages critical thinking about what has been left out of the problematisation, either deprioritised or silenced, and what this says about the power dynamics; question 5 examines how the problematisation of an issue impacts the lived experience of the issue, either through the discourse or subjective experiences of individuals involved with regard to the influence on their identity or lives; and question 6 asks how this problematisation has been reproduced and maintained as an important narrative about the problem and how the reproduction may be interrupted (Bacchi, 2009, 2013; Carson & Edwards, 2011; Goodwin, in Bletsas & Beasley, 2013).

The application of these six questions creates opportunity to question the status quo, examine structural issues, consider the impact on the experience of minority groups, and uncover obscured ideological and ethical perspectives. The interpretivist approach to policy analysis these questions offer is an ideal lens through which to examine the policy environment in the context of this thesis' social work and social justice priorities. Because the NDIS is still being implemented at the time of writing, it is not possible to thoroughly answer all the questions, particularly around the effects of the policy. However, Bacchi's (2009) approach is used in this thesis to examine the NDIS's design and aspects of its operationalisation by offering a way to explore the different narratives that underpin it. Therefore, Bacchi's (2009) approach will be adapted and used to prompt critical insights around the design and operationalisation of the NDIS, exposing where each model and past wave of policy is alive within it and how the dynamics of power are influenced through the prioritisation of both marketisation and social justice aims. In order to consider how the problem of disability is represented in the NDIS, the design of the NDIS policy and scheme will first be examined.

### 3.5.1 NDIS design

In Australia, the personalisation of disability services at the national level is being conducted through the NDIS, administered by the National Disability Insurance Agency (NDIA). The NDIS is an insurance system delivered through a competitive marketplace, with the narratives of marketisation and social justice embedded right from its inception (Dickinson et al., n/d). It was initiated at the 2020 Summit, a forum run by former Australian prime minister Kevin Rudd, and then explored in an inquiry by the Productivity Commission. This high-level action was then augmented by grassroots support, with an industry campaign called *Every Australian Counts* starting in 2011 (Thill, 2015), which was founded and funded by an industry alliance that included all frontline stakeholders: charitable service providers, carers and consumer peak bodies. This campaign gave the NDIS the political push it required to be funded, collecting hundreds of thousands of signatories pushing for a new disability support system that would be properly funded and meet the needs of the industry (National Disability and Carer Alliance, 2019). Legislation was eventually passed in parliament with bipartisan support. In his second reading of the bill in 2012, John Alexander MP stated: "The NDIS represents Australian values: a fair go and helping those who face challenges for reasons beyond their control. No side of politics has a mortgage on these values" (Commonwealth Parliamentary Debates, 2013, p. 1396). Not only are these dual representations of markets and personalisation different, but they are so intertwined in the NDIS policy that they are indeed obscured (Mladenov et al., 2015). Figure 1 outlines the development of the NDIS through reforms to disability policy in Australia.

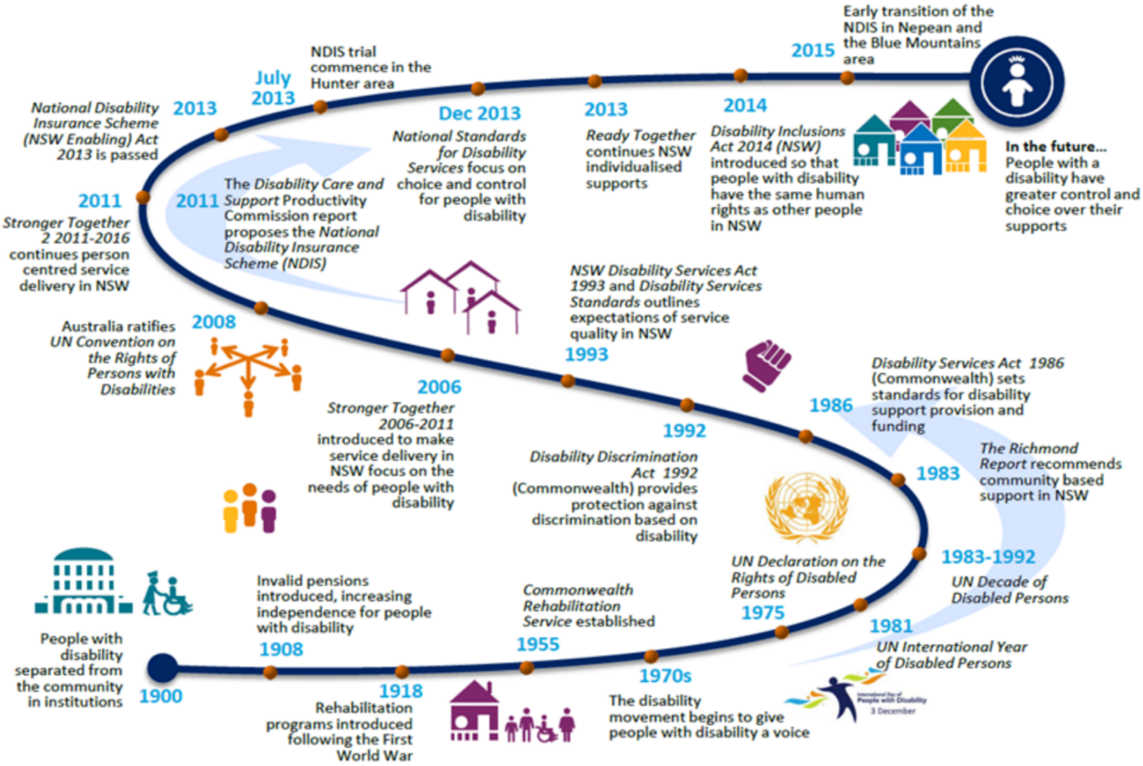


*Figure 1: The Disability Reform Journey, 1900–2017 (Source: Bagshaw, 2017)*

The NDIS has been labelled the most significant and complex social reform since the implementation of Australia's public healthcare scheme (Baker, 2012; Carey, Malbon, Olney, et al., 2018; Carey & Matthews, 2015; Malbon, Carey, & Reeders, 2018). The design of the NDIS was established in a report published by Australia's Productivity Commission, which found that the current disability support sector was "underfunded, unfair, fragmented, and inefficient" (Productivity Commission, 2011, p. 2) and offered no choice or certainty of service to PWD. The Productivity Commission contended that the NDIS would

> [provide] insurance cover for all Australians in the event of significant disability... to fund long-term high-quality care and support (but not income replacement) for people with significant disabilities... [and] better link the community and people with disabilities, including by using not-for-profit organisations. It would also provide information to people, help break down stereotypes, and ensure quality assurance and diffusion of best practice among providers (Productivity Commission, 2011, p.2).

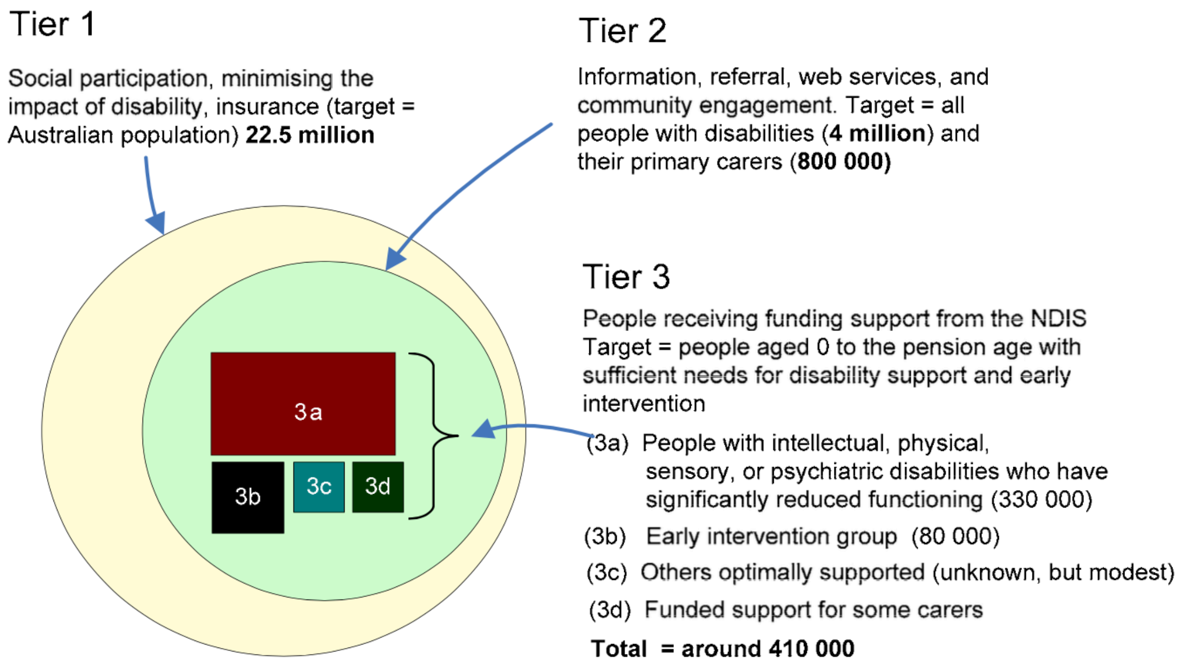
The NDIS more than triples government spending on disability services, from around $8 billion to a predicted $22 billion per annum (NDIS, 2016; Productivity Commission, 2011), significantly increasing the size of the industry.

In its most basic form, the NDIS is an insurance scheme, whose success depends on actuarial goals, including a significant number of PWD and carers returning to work, as well as a reduced lifetime cost of PWD to the public budget. It is a core federal government allocation, partially funded by an extra half percent on the public healthcare tax, which generates only a third of the costs (Needham & Dickinson, 2018). The Productivity Commission reported that the NDIS would be financially worthwhile with only an annual $3,800 gain per participant and predicted an overall 1% increase in GDP by 2050 as a result of its implementation (Productivity Commission, 2011). From an economic perspective, the NDIS is certainly desirable, and the way in which it is funded and posed as a safety net for all Australians supports the social and human rights models of disability.

The NDIS is designed to be delivered through direct budgets allocated to individuals. Funding is allocated as it is considered to be "reasonable and necessary" (Foster et al., 2016), meaning that "a support or service:

- must be related to a participant's disability;
- must not include day-to-day living costs not related to your disability support needs, such as groceries;
- should represent value for money;
- must be likely to be effective and work for the participant; and
- should take into account support given to [the participant] by other government services, …family, carers, networks and the community" (NDIA, 2019g).

These two concepts are intended to guide the allocation of budgets in order to ensure that people get what they need within communal norms and that their funding will enable them to achieve their goals. For example, two people may have the same impairment but very different goals or environments that result in different funding amounts. Due to the actuarial nature of the scheme, there is an emphasis on early intervention, with the idea that upfront expenditure on young people will reduce their lifetime costs. It is intended that 460,000 individuals with permanent disability, including up to 50,000 consumers with psychosocial diagnoses, will receive NDIS funding packages to be spent on specialist support services (Battams, 2017; Carey & Matthews, 2017), which represents around 11.5% of the four million Australians with disability (Productivity Commission, 2011). The remaining Australians with disability will be supported by a connected pool of funds delivered through an Information, Linkages and Capacity-Building (ILC) program, which aims to upgrade the non-specialist service environment to support PWD in participating socially and economically in society. This is illustrated in Figure 2 by an image taken from the Productivity Commission report (2011).



Tier 1

Social participation, minimising the impact of disability, insurance (target = Australian population) **22.5 million**

Tier 2

Information, referral, web services, and community engagement. Target = all people with disabilities (**4 million**) and their primary carers (**800 000)**

Tier 3

People receiving funding support from the NDIS Target = people aged 0 to the pension age with sufficient needs for disability support and early intervention

(3a) People with intellectual, physical, sensory, or psychiatric disabilities who have significantly reduced functioning (330 000)

(3b) Early intervention group (80 000)

(3c) Others optimally supported (unknown, but modest)

(3d) Funded support for some carers

**Total = around 410 000**

*Figure 2: The three tiers of the National Disability Insurance Scheme 2009 and population estimates (Productivity Commission, 2011, p. 6)*

The NDIS market is currently regulated, but it is intended that it will be deregulated in the future. It has been argued that deregulation has the potential to make space for more innovative service options and efficient business models (NDIA, 2019e; Souza & Lambides, 2019), which will be positive for both marketisation and social justice outcomes. From a social justice perspective, some authors have expressed the concern that this could create a two-tiered system, in which those who can afford better information or better services will pay for them and those who cannot afford to pay will miss out (e.g. Fawcett & Plath, 2014), while others have argued that the complexity of the NDIS system will add to this problem, creating further inequity for those who cannot easily navigate it (Collings et al., 2016).

### 3.5.2 The 'problem' of disability

Having established that both social justice and marketisation narratives exist in the conceptualisation and structure of the NDIS, this section looks at the way the problem is represented. The "problem" of disability within the NDIS is represented in two different ways: as a social justice issue of exclusion and as a marketisation issue with a primary concern around economic return on investment. Both are essential for a quasi-market to function, but as social work research, this thesis prioritises the social justice approach.

From a social justice perspective, the problem echoes the social model of disability: society is inaccessible and inequitable for PWD. As shown in Chapter 2, PWD and their carers are less likely to be employed or to have good health, and they are more likely to be of low socioeconomic status (Emerson, 2007; Kavanagh et al., 2013; O'Rance, 2009; Saunders, 2006). They are not afforded choice in important areas of their lives, and this influences their ability to enact self-determination (Dowse, 2009; Gooding, 2016). Society excludes PWD through infrastructure and through culture. Knowledge about disability is often created in a way that excludes the perspectives of PWD (Newell, 1999; Oliver, 1992). Services that they need for living their lives are inadequate, inflexible and under-resourced, and because the sector is so heterogeneous, the one-size-fits-all approach of the welfare state is not only inappropriate and ineffectual but also patronising and exclusionary.

Second, the marketisation narrative is concerned with economics. Within this narrative, the problem of disability in the NDIS response is that PWD and their carers are often unable to contribute to the economy through working, paying taxes and spending money (Mladenov et al., 2015). At the same time, they cost the economy more than people without disabilities due to their impairments, creating extra health, education and other costs, which can result in poverty for the families and reduce their capacity for choice and control in their lives, while also negatively impacting gross domestic product (GDP) at a macro level.

While these economic problems could be solved through increased expenditure in a welfare state model, markets are seen as an ideal way to ensure choice and control at the same time as resolving them. Consumers will be asked to decide what they want, and this will produce a supply of services that is competitive, responsive and relevant. Having this choice and control is a matter of concern to both social justice and marketisation approaches. The investment in the NDIS returns more choice, more funding and more control, which should lead to better outcomes of health and wellbeing. From a social justice perspective, it should allow PWD the same access to resources as other citizens.

However, there are a series of assumptions underpinning the implementation of an NDIS market. First, there is an assumption that PWD can and want to be consumers and that they will be able and willing to navigate the market, take purchase risks and make decisions. In order to do this, consumers must know what they need and feel able and confident to ask for it. Second, there is a presupposition that choice is desirable and that it will benefit the way in which people live their lives and experience their rights. Third, there is an assumption that providers will interpret these needs correctly and be in a position to respond. Finally, while there is awareness that change management is required in the architecture of the NDIS (e.g. Carey & Matthews, 2017), there is either a presupposition that this will grow as the system develops or a notable silence regarding change management in the NDIS policy environment.

The guidance provided by Bacchi's (2009) framework has illustrated that there is a strong narrative about rights forming part of the policy environment out of which personalisation has developed. However, the narrative of neoliberal markets is equally as strong and is of concern to advocates and academics alike. Different models of personalisation ensure that consumers have choice and control but offer a variety of frameworks for customer protection. While a thorough analysis of the various narratives around personalisation has been conducted (Needham, 2011), there has been little attempt to bring them together in a way that might resolve conflicts, allow collective measures of success to be developed or lead to the implementation of a deep and sustainable version of personalisation that is grounded in social justice imperatives.

### 3.5.3 Choice as positive

Underlying all of these assumptions is an expectation that having more choice will create meaningful change for PWD. The narrative of choice and control is important for the neoliberal model of citizenship but also for a person with disability in their position as both a holder of rights and a citizen. Embedding choice and control into citizenship models and social service provision appeals to proponents of social justice as well as proponents of marketisation; in this regard, it captures the imagination of stakeholders on both sides of the political spectrum (Needham, 2011).

> From both perspectives, choice is seen as 'a good in itself', although the origins differ. A liberal/market approach has a top-down emphasis, with a consumer being seen as an atomistic agent with wants, whereas the human rights perspective operates from the bottom up, viewing an individual as a person with rights (Fawcett & Plath, 2014, p. 754).

The above quote neatly illustrates these two perspectives, which, despite their very different ideologies, have overcome potential conflict because of this key issue that they agree on. Indeed, there is a great deal that is agreed upon between the two personalisation narratives, and there is certainly no problem at the design level; however, when it comes to implementation, the narratives come into conflict. In this regard, market stewards need to balance the needs and expectations of various stakeholders, including PWD, families and carers, different political perspectives and the taxpayer. In taking these perspectives into account, they are balancing them with economic sustainability and if and how consumer choice needs to be curtailed. An example illustrating these tensions is the various cases of people who are denied entry to the NDIS on the basis that they have not exhausted all medical options for treating injury first (see Decision Summaries such as AAT, 2018). Another example of the operationalisation of the NDIS, and particularly relating to the choice and control of services and treatments, is that in most cases there is a need for medical assessments of functional impairment to acquire an NDIS package. Its continuity requires a clinically proven intervention, regardless of a consumer's preference. This is reminiscent of a medical model and places a marketisation approach at a higher priority than a social justice approach. This example highlights that, when faced with balancing stakeholder needs in operationalising the NDIS, market stewards are forced to privilege either a consumer's right to choice and control or an economic outcome.

In fact, significant concerns exist around the understanding that choice does not necessarily lead to increased empowerment for consumers (Fawcett & Plath, 2014; Kendrick et al., 2017). As Fawcett and Plath (2014) contend, "there is more to personal control than having a budget allocation and the choice of service providers" (p. 753); indeed, for most consumers, it is the *outcome* of having choice and self-determination that is important rather than the *process* of choosing, which can be burdensome (Glendinning, 2008). Lent and Ardent (2004) explore this tension and preface the necessity and utility of choice with three qualifiers:

- It resolves a problem with service delivery;
- The problem can be perceived by users through their direct, day-to-day experience of the service;
- The operation of user choice is integral, rather than incidental, to the resolution of that problem" (p. 6).

Essentially, choice must be meaningful rather than tokenistic, and it must result in clear outcomes.

This means that personalisation is not in itself a positive force for enacting rights. Rather, it requires the right context, tools and education to facilitate positive outcomes. This sentiment is found in Leadbeater's (2004) spectrum of personalisation, which spans "shallow" personalisation – in which choice is tokenistic, e.g. relating to choice of provider – to "deep" personalisation, in which systems themselves are meaningfully co-created with service users. Figure 3 illustrates these differences, drawing from Leadbeater's theory. Significant risks have been identified from a rights perspective in relying on a marketplace to distribute welfare services, and the literature on personalisation focuses substantially on such discussions. It has been noted that just as consumer demand can be reverse-engineered by the market, the market may not respond appropriately to meet individual needs and wants, especially if doing so is not economically advantageous. Rather, scholars have expressed concerns that existing disadvantages may be replicated and magnified by the implementation of a deregulated market system (Fawcett & Plath, 2014). Likewise, there is doubt about the assumptions that competition will result in greater efficiency and cost-effectiveness and that for-profit providers will be more successful in embracing these qualities (Meagher, 2010). In short, those who problematise personalisation within a social justice narrative question whether their priorities will be obscured by the more influential marketisation approaches.

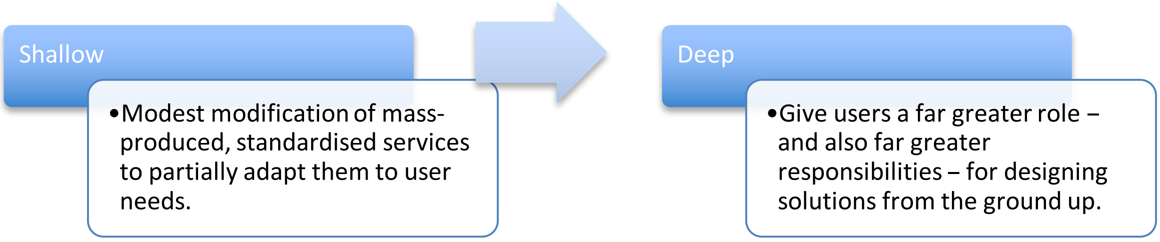


*Figure 3: Qualities of "shallow" to "deep" personalisation (Leadbeater, 2004, p. 21)*

### 3.5.4 NDIS operationalisation: Problems and solutions

Creating a market is difficult, and not only did Australia start from a low baseline, but the way the NDIS has been operationalised means that there has also been a requirement to do it at a high speed during roll-out (Malbon, Carey, & Dickinson, 2018; Malbon, Carey, & Reeders, 2018). There are various operational problems on both sides of the market (for example, see NDS, 2019; UWA, 2019), some of which relate to supply and demand and are likely to be resolved over time (Souza & Lambides, 2019), but market stewardship is still required to enable the market in the short term and ensure that the NDIS is well set-up in the long term.

There is no way to be sure yet what the effects are of the representations of disability under the NDIS; however, it is already clear that significant challenges and benefits to individuals and families are emerging (Green et al., 2017; NLS, 2015). The expectation of the consumer to be the decision-maker demands sophisticated consumership by service users of disability support; in this regard, not only must they make informed choices about their care, but they also must identify their needs, which is difficult for a group of people who have rarely been required to do so before. Further, consumers must advocate these needs to be met within the available supply of support services and find means to demand the supply of more appropriate services where they cannot be met.

For PWD and families who are able to articulate their needs and advocate for themselves, the NDIS is a welcome change, where they are likely able to receive adequate funding and navigate the service landscape to ensure they have their needs met and achieve their goals. However, significant challenges exist for those who are unfamiliar with decision-making regarding disability services, have little or no experience navigating the sector or have difficulty communicating or making decisions. Thus, participants of personalised schemes who are more able to advocate for themselves often achieve better outcomes, and other participants are less likely to realise benefits (Anttonen, 2012; Booltink, Genugten, & Lako, 2015; Botti & Iyengar, 2006; Carey, Malbon, Marjolin, et al., 2018; Jilke, 2015; Needham, 2016; Riddell et al., 2005; Williams, Dickinson, & Robinson, 2010). This highlights that while choice and control in a marketised environment might work for some families, the particular circumstances and history of others mean that it will be difficult to assertively enact their consumer rights and have their needs met. Without education, informed choice and platforms for self-advocacy, there is a significant risk that these consumers will be excluded and not have their needs met (Fawcett & Plath, 2014; McLoughlin et al., 2014).

In this light, it is useful to continue examining the operationalisation of the NDIS in order to highlight aspects of the NDIS process that produce and defend the dual issues of social justice and marketisation. One aspect is the multiple ways that packages of money can be managed and the ways this extends and limits choice and control. NDIS funding packages can be administered via the NDIA or a third party – in which case consumers can choose only providers who are registered with the NDIS – or directly to that individual or a family member, who choose to spend it on any service provider. This means that those people who are able to take a more active role in managing their funds are likely to have more choice. A second issue relates to the providers who are offering NDIS services. At the time of writing, there are around 22,000 NDIS registered providers, and although limited data is released by the NDIA, it is known that only 67% of these are actually providing services to NDIS participants (NDIA, 2019i). It is currently very difficult for families to distinguish between these providers and make informed decisions about who to choose. A third issue is the limited NDIS workforce. The Productivity Commission noted in their 2010 report that there would need to be substantial workforce growth to realise the goals of the NDIS (Productivity Commission, 2011). This has not happened as yet, which means that many registered providers simply do not have the resources to grow (NDS, 2019).

As a result of these issues, only around 70% of the full amount of NDIS packages are being spent at the time of writing (NDIA, 2018a). This varies by cohort, location and timing, and while there is currently no empirical evidence available about the causes, it could be reasonably assumed that some are a result of insufficient service offerings; some are a result of the challenges of navigating a complex service sector; and some are a result of the difficulty of breaking down goals and making challenging decisions that greatly affect day-to-day life. Additionally, the literature speaks to the particular difficulty that Indigenous groups, people with psychosocial diagnoses, or those with particularly complex intersectional or comorbid diagnoses have with navigation (Collings, Dew, & Dowse, 2016; Grant, Chong, Zillante, Beer, & Srivastava, 2016; Hancock et al., 2018; Soldatic, Toorn, Dowse, & Muir, 2014; Townsend, White, Cullen, Wright, & Zeeman, 2018; Williams & Smith, 2014). This is the result of complex systems and inadequate information, which will be discussed in the following chapter.

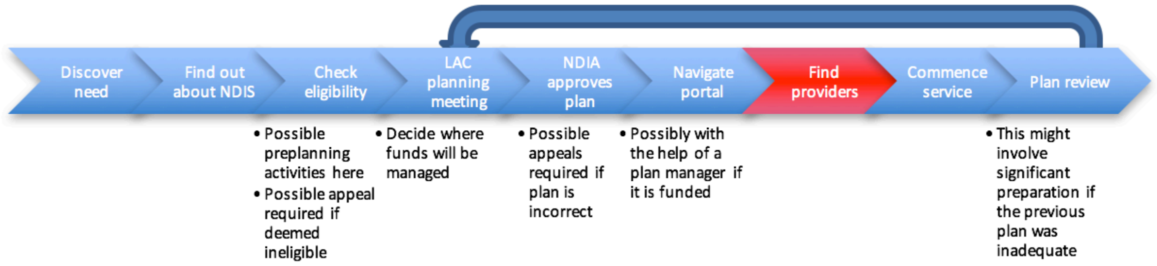


*Figure 4: NDIS user journey, with the information search stage highlighted in red (Author's own)*

There are various aspects of NDIS operationalisation designed to combat these problems. For example, there is some service navigation assistance available for consumers, with one way being through a Local Area Coordinator (LAC). The process by which a consumer is allocated funding is through an LAC, who is an individual allocated to collect information from participants for approval by an NDIA planner (see Figure 4 for an overview of the NDIS journey). The LAC then plays a role in implementation, sometimes by assisting (either formally or informally) the choice process by suggesting service providers. It is also the LAC's role to carry out community engagement, information provision and capacity-building for a fifth of their allocated resources (NDIA, 2016b); however, they often have limited ability to enact this work meaningfully due to their heavy administrative burden (Warr et al., 2017).

Another way to support consumers who struggle to navigate service options is the allocation of support coordination. These consumers may be allocated extra funding to employ a support coordinator whose role it is to connect them with services. Thirty-nine percent of participants currently have such funding (NDIA, 2019i). In other personalised schemes, it has been found that a great deal of this coordination work falls on family members and carers (Jones et al., 2014), which is likely also to be occurring in the NDIS. Additionally, various brokers are emerging in the marketplace who play an informal coordination role for consumers. These people charge a referral-fee arrangement with participating service providers. While these arrangements have resulted in positive outcomes for participants (Needham, 2013; Riddell et al., 2005; Williams & Dickinson, 2016), there has been some criticism of brokers in the personalised environment due to their lack of independence (Leece & Leece, 2011; Quach, O'Connor, & McGaffigan, 2010). Brokerage is a fee-for-service arrangement with regard to negotiating choice and control, thus crossing boundaries between social justice and marketisation approaches. By paying for service matching under current market mechanisms that charge somewhere between a 3 and 15% brokerage fee, up to $3 billion of NDIS service provision budget may be being relinquished to intermediaries. This is a problem because the insurance scheme is designed to function when this money is spent on outcomes. This issue could be partially resolved by having good information, thereby reducing the need for brokers and intermediaries.

### 3.5.5 The importance of information

Depending on the way these problems are viewed, the issues with the operationalisation of the NDIS could just be about individual service navigation and decision-making skills. However, they are also related to having information available. This thesis argues that making a market work and having good information to support it must be a matter of central concern to the NDIA and other market stewards. Further, it is important for there to be consistent research into best practice from both top-down and bottom-up in order to make sure that the NDIS is on the right track with regard to addressing the disempowerment and unmet needs of Australians with disability. The NDIA itself has stated the following:

> Information is critical to the functioning of markets and it can be used to improve business and investment decisions, facilitate targeted expansion, or assist participants to connect with providers prepared to offer a service. In general, access to accurate, timely, and relevant information will assist the market to function optimally (NDIA, 2018c, p. 5).

In their 2018 Market Enablement Framework, the NDIA (2018b) pointed out that the provision of information was likely to be the most frequently enacted market stewardship intervention, especially before the market reaches a state of maturity.

Despite this need, there is no clear policy about what an information economy should look like for the NDIS. Therefore, this study focuses on determining what information service users want in order to feel informed when they choose disability support services. It is particularly timely research because the NDIS is still in its early stages; in addition, other than public healthcare services, it is the first Australian sector of many (including aged care and disability employment services) to be personalised, so it is particularly important to get it right.

## 3.6 Chapter Summary

This chapter introduced the idea of problematisation, arguing that there are two central frameworks – social justice and marketisation – through which personalisation is problematised, and it used Bacchi's (2009) approach to explore how this changes the way problems are diagnosed and solutions are developed in the NDIS. In line with a social work code of ethics, this thesis privileges the rights perspective. The present chapter has examined how disability is defined and problematised, creating meaning and shaping solutions, interventions and policies. It provided a short history of disability policy, personalisation and the NDIS, which highlighted that there are multiple ways of defining disability, each of which has shaped policy and lived experience. Looking at the waves of policy, it is clear that different ideologies and cultural issues have shaped policies, which have in turn affected people's lived experience; it is also apparent that each wave influences the next. While there are many different ways to implement personalisation, Australia has chosen a unique insurance model delivered through an (eventually) deregulated marketplace. There are two main contrasting and potentially conflicting perspectives underpinning the problematisation of disability that has resulted in the NDIS: an ideology that values social justice for PWD and an ideology that values marketisation.

While the design of the NDIS is unlikely to change, its operationalisation is still being shaped. Both marketisation and social justice storylines are essential for quasi-markets to flourish, and it is likely that the NDIS works because of the commonalities between the two approaches. Australia is a post-welfare state, neoliberal country, and without bipartisan support, the NDIS may not have been successful. However, it has been shown that there is a tendency for social justice be deprioritised in quasi-marketplaces. Therefore, it is important to influence the NDIS at this time so that social justice values are embedded in practice, as some of the problems that have arisen have been caused by the high speed at which it has been operationalised (Buckmaster & Clark, 2018; Carey, Kay, et al., 2019; Carey, Malbon, Olney, et al., 2018).

If appropriate support does not exist to protect consumers – including a consumer-centred information economy – there is a danger that the market model of personalisation can cause consumer desires to be shaped through the marketplace when meeting consumer needs is not economically worthwhile or when consumer voices are not heard (Dowse, 2009; Fawcett & Plath, 2014). In this regard, intentional market stewardship will be required to make it successful (Kendrick et al., 2017). In order to look at the way in which it is rolled out and bring together the issues in both theory and practice – including issues of consumer protection, market design and provision of information – the next chapter will examine the role market stewardship could play in shaping the way in which the policy environment regards the problematisation of disability. With this in mind, the thesis will now turn to the literature in order to examine what is already known about the topics of decision-making and information economies in an environment of personalisation.

# 4 Literature review

## 4.1 Introduction

Consumers in quasi-markets require information to ensure they can use their resources effectively and realise choice and control (Baxter & Glendinning, 2011; Martin, 2011; McLoughlin et al., 2014). Having appropriate information available is a result of "effective" market stewardship (Dickinson, 2017, p. 9). This chapter will revisit some of the key terms defined in the introduction as they are central to the thesis. Most importantly, "market stewardship" refers to the regulating role of governing bodies in creating and overseeing a market (Gash et al., 2013). Chapter 3 examined NDIS policy and personalisation theory, using a Bacchian approach to frame the problematisation inherent in this environment, and found that the provision and consumption of information is central to the functioning of a "quasi-marketplace", which refers to those markets such as the NDIS that are used to distribute public sector resources (Carey, Reeders, et al., 2018; Gash et al., 2013; Glendinning, 2008). Market stewardship is particularly relevant to new industries such as the one forming around the NDIS because there are significant unknowns about how they will develop.

However, this chapter highlights that little is known about how information is used in a personalised quasi-market environment, what information is needed, and how it should be distributed in order to achieve consumer choice and control under both marketisation and social justice priorities. In this regard, ensuring that this gap is filled will allow market stewards to establish a clear approach to the provision of information. This chapter argues that market stewardship can align the dual values of social justice and marketisation underpinning the NDIS and that intentional steering of the new marketplace through the provision of information could alleviate some of the conceptual conflicts inherent in personalisation and help to ensure a social justice agenda survives a marketisation approach to policy. In addition, it suggests that this may be accomplished through the design and application of consumer-centred interventions and, in particular, a consumer-centred information economy.

The present chapter examines the body of literature on market stewardship to ascertain what is already known about the type of information service users want in order to feel informed when choosing disability support services under the NDIS. It shows that there are significant gaps in knowledge around what consumer-centred market stewardship might look like when it comes to establishing an information economy. In particular, the existing evidence takes a top-down approach rather than being consumer-centred. Furthermore, there is little known about how to distribute information to consumers – for example, which media is most informative – and what kind of information is needed in an NDIS environment to ensure that consumers can make informed decisions about the services they purchase.

Finding the market stewardship literature limited in scope, this chapter then explores the disability and wider literatures to examine what is known about navigating complex service sectors and the way that consumers make decisions and use information to make informed decisions that align with a social justice agenda. It concludes by outlining the gap to which this research contributes and arguing that it is important to create more knowledge about information for both social justice and marketisation aims. Figure 5 below illustrates the flow of this chapter through these bodies of literature.

*Figure 5: The flow of the literature review in Chapter 4*

## 4.2 Quasi-market stewardship

As the previous chapter has shown, the success of a marketplace hinges on informed decision-making, which is consistent from both marketisation and social justice perspectives. While the need for market stewardship is not unique to the disability sector, the nature of stewardship is different in quasi marketplaces. By their very nature, quasi-markets cannot simply function like conventional markets because they are intentionally shaped by governments for the purpose of delivering social services and public resources. Many governments therefore have policy in place describing the scope of their role as stewards of these markets. There is a small but growing body of literature exploring market stewardship in the context of personalised services, much of which originates out of the NDIS context (e.g. Bosher, 2017; Carey, Dickinson, et al., 2018; Carey, Malbon, Marjolin, et al., 2018; Carey, Reeders, et al., 2018; David & West, 2017; Malbon, Carey, Marjolin, et al., 2018).

Market stewardship is a broad concept and, particularly in the field of quasi-markets, its scope is uncertain and ambiguous in the literature due to the complexity that social sector services bring with them (Carey, Dickinson, et al., 2018; Carey, Malbon, Marjolin, et al., 2018; Carey, Reeders, et al., 2018; Gash et al., 2013). Market stewardship is a field of research and practice concerning itself with making industries function well so that they can realise the outcomes and goals for which they were intended, or "mitigate the risks, regulate the markets and more evenly spread potential opportunities" (David & West, 2017, p. 342). Market stewardship is therefore relevant to having a rigorous discussion around ensuring that the NDIS has a flourishing information economy and informed consumers.

Market stewardship is the responsibility of "market stewards", i.e. those governing groups or organisations whose role it is to shape markets, protect consumers and support suppliers (Gash et al., 2013). Various systems of protection and support are created and funded by these parties. In Australia, for example, there is commonwealth legislation that guides Australian consumer law to protect customers and ensure their rights to safety, information and redress (ACL, 2019). To enact this legislation, there is a legal system consisting of commonwealth and jurisdictional tribunals – such as the Australian Competition and Consumer Commission (ACCC), which administers the policies created by the legislation (ACCC, 2019), and the Administrative Appeals Tribunal (AAT) – to ensure there is a system by which consumers can advocate for their rights (AAT, 2019). There are also industry-specific ombudsmen and commissions, as well as publicly funded legal aid, all of which provide information, advocacy and support to consumers (e.g. Commonwealth Ombudsman, 2019; Legal Aid, 2019). In the context of the NDIS, the major market steward is the NDIA (NDIA, 2019d), and since 2018 the NDIS Quality and Safeguards Commission has also taken a role, with specific powers to suspend or ban individuals or companies from operating within the scheme (NDIS Quality and Safegards Commission, 2019). These consumer rights systems are relevant given that ensuring the even spread of opportunity is particularly essential in a quasi-marketplace where issues of citizenship, social justice and equity are pertinent (Carey, Dickinson, et al., 2018; Carey, Malbon, Marjolin, et al., 2018; David &

West, 2017; Gash et al., 2013; Malbon, Carey, Marjolin, et al., 2018). It is worth noting, however, that although market stewards have the "ultimate responsibility" (Gash et al., 2013, p. 108) for identifying problems and ensuring quasi-markets succeed, there are many actions of stewardship that can be taken by a variety of stakeholders who may not be labelled stewards under normal circumstances.

While some of this research has come out of the UK context, much of the recent Australian work in this area has come out of the *Public Service Research Group* and *Centre for Social Impact*, both at the University of New South Wales. One such paper describes the role of market stewardship in quasi-markets as a function of citizenship protection and preventing inequality:

> When markets are used to deliver social services, as in [the NDIS], market stewardship is seen as going beyond ensuring minimum protections for citizens, to ensuring that public good and public value are delivered to citizens...Here, the role of government is expanded to guard against inequities, including inequities in the ability of citizens to exercise choice and control in market arrangements. Market stewardship is essential to ensure the social contract between government and its citizens is maintained (Malbon, Carey, & Reeders, 2018, section 5.3).

Hence, market stewardship is essential for both marketisation and social justice goals, both of which are key to success in quasi-marketplaces. Carey, Kay, and Neville (2019) note that market stewardship is additionally important due to the "dialectical relationship" (p. 502) between funding packages and markets, in which each requires the other to exist in order to function. Consequently, they stipulate the need for a clear approach towards shaping the market.

The following section examines the role of market stewardship in the NDIS. Finding it lacking, it examines evidence from other quasi-markets, drawing from literature in the UK context and even from another social services sector – healthcare. It then looks more broadly to what is known about navigating complex service systems. Finally, it outlines the main gaps found in the market stewardship literature.

### 4.2.1 NDIS market stewardship

This section examines what is known about the NDIS's market stewardship policies and actions. While it looks briefly at how these have been explored in the literature, not much has been published as yet, so the majority of knowledge comes directly from NDIS policy documents. The NDIA Market Enablement Framework describes the NDIA's market stewardship role as "monitoring, evaluation, oversight and, where necessary, intervention" (NDIA, 2018c, p. 4), in addition to outlining an expectation that the need for stewardship of the market will decline over time as the market matures. The NDIA describe its key stewardship roles as providing information, building consumer and community capacity, changing market settings (for example, compliance and quality guidelines) and, where necessary, commissioning services where markets are failing (NDIA, 2018c). As described in the NDIS Market Approach Statement, the NDIS identifies the "aim of market stewardship [as creating] an efficient and sustainable marketplace through a diverse and competitive range of suppliers who are able to meet the structural changes created by a consumer driven market. More specifically, this involves:

- enabling existing and emerging suppliers to mature at an appropriate and sustainable rate;
- providing an environment for innovation in planning and delivery of supports; and

- building strong business integrity systems and processes and capability" (NDIA, 2016a, p. 4).

The NDIA has already taken various actions to this end, which include iterating the hourly rate that registered providers can charge for their services in the regulated market environment (e.g. NDIS, 2019) and the provision of specific data points via quarterly reports distributed on the NDIS website (e.g. NDIA, 2018a). Policy frameworks delineating ILC outcomes (e.g. NDIA, 2015) also shape the emerging market, as do decisions about which applications for ILC grants are funded. Furthermore, decisions made through NDIA appeals processes about which services and how much funding is reasonable and necessary also influence the market, some through informal precedent and others through formal case law (see AAT, 2019).

However, in addition to the NDIA, there are other federal and state bodies, advocacy groups, peak bodies and interested parties who may see their role as influencing NDIS market development. The literature has discussed this mixed accountability in the NDIS system, offering evidence around the split this creates in areas of care outcomes, workforce, advocacy, public money and market stewardship (Hough, 2018; Malbon, Carey, & Dickinson, 2018; Malbon, Carey, & Reeders, 2018). This complexity makes it difficult to maintain a consistent means of resolving problems and enforcing transparency, which, it is argued, reduces the ways the NDIA is held accountable. Furthermore, this complexity of accountability creates a situation in which the personal responsibility of consumers is heightened (Dickinson et al., 2014).

Additionally, in the NDIS environment, there are various organisations that provide advocacy and support to the specific cohort they represent and may be considered to be enacting market stewardship (Green & Mears, 2014). For example, National Disability Services (NDS) is a membership organisation of not-for-profit providers, and Inclusion Australia is a national peak advocacy body for consumers with intellectual disability. In theory, the independence of these organisations allows them to advocate for the needs of the parties they represent. An example of actions NDS has taken is compiling annual reports about the challenges their service provider members are experiencing in order to advocate for changes to the NDIS and support providers to remain financially viable (e.g. NDS, 2018a, 2019). An example of an action one of the state bodies belonging to Inclusion Australia has taken to support their consumer cohort is running expos and conferences to showcase service providers in local areas (VALID, 2019).

In these few short paragraphs, different examples of formal and informal market stewards and market stewardship in the NDIS environment have been outlined, which have given context to the necessity and also the breadth of market stewardship functions and the different shapes they can take when applied to the priorities of various stakeholders. Regardless of what model of disability is used, advocacy and protection is necessary in the NDIS context – it is unrelated to the impact of impairment. All quasi-markets need shaping and, sometimes, active intervention, and all consumers with and without disabilities need advocacy and protection measures (ACCC, 2019). The role of market stewardship is to shape the emerging NDIS market, present solutions to problems with supply and demand, and ensure that customers have access to appropriate information to help them make purchases.

The literature suggests that the NDIS is, as yet, unprepared for this challenge (Kendrick et al., 2017; Malbon, Carey, Marjolin, et al., 2018; Soldatic et al., 2014), and the complexity of mixed accountability with various policy and operational aspects of the scheme compounds the problems (Malbon, Carey, & Reeders, 2018). A parliamentary committee was appointed to undertake inquiries into certain aspects of the NDIS, and it identified various dilemmas in the NDIS environment relating to market stewardship:

> The challenges for both participants and service providers to transition to a market-led service delivery model cannot be underestimated. Creating a participant enabling environment and developing a competitive marketplace is vital to the success of the Scheme. However, during the course of this inquiry, the committee heard that the NDIA, as the lead market steward, has often failed to put in place in a timely manner the appropriate measures and initiatives to support the development and growth of the disability support marketplace to meet demand. The roles, responsibilities and activities of all those responsible for market stewardship are unclear. This is impeding the development of strategies to address key emerging issues in the development of the market (Commonwealth of Australia, 2018, p. 3).

Market stewardship interventions are shaped by the problematisation of disability in the NDIS context but also have the capacity to influence the policy environment. Therefore, market stewardship also provides a pathway to shape the operationalisation of the NDIS so that social justice is embedded within the marketisation model.

Carey et al. (2018) conducted a thorough review of the international market stewardship literature in order to illuminate existing interventions that may be applied to the NDIS environment. This review looked at how the Australian government may influence the development of supply and demand in the emerging NDIS market. It specifically looked for evidence around stewardship practice, solutions, interventions and actions. The recommendations this paper made related to pricing, increasing resources to build the NDIS market in rural and remote areas, and forcing providers to take certain actions so that no participant will miss out on support altogether regardless of their location or circumstances (Carey et al., 2018). This review uncovers a lack of evidence about information economies in quasi-markets; however, it demonstrates the breadth of market stewardship in general and also the variety that is required in the NDIS environment in particular.

The NDIS spans a wide community of people who need diverse stewardship responses. Just as personalisation is a response to the ineffectiveness of a one-size-fits-all approach, market stewardship may need similarly personalised attention, particularly when it comes to information that is a lynchpin in creating a successful market. Indeed, the literature highlights that information should be created in consultation with stakeholders in order to ascertain the most accessible format, access points, source and content of information for each group that will interact with it (Maglajlic, Brandon, & Given, 2000; McLoughlin et al., 2014; Walsh et al., 2012). At the same time, this will result in the best outcomes for both social justice and marketisation priorities.

Highly personalised consultation may be challenging for market stewards, however Carey and Matthews (2017) suggest that governments need to increase their risk tolerance in times of change and adjustments caused by the implementation of quasi-markets and to develop ways of quickly designing, testing and learning. This type of lean co-design is essential to the design of an appropriate information economy (McLoughlin et al., 2014), in addition to also aligning with social justice and consumer-movement thinking. As Australian advocate Mark Bagshaw states:

> People with lived experience of disability must be at the core of every aspect of the management, design and delivery of the NDIS if it is going to deliver the support people need to participate in every aspect of our society (Bagshaw, 2015).

Adhering to these principles is important in order to personalise information around the heterogeneous needs of the Australian disability sector.

### 4.2.2 Healthcare

This chapter incorporates relevant healthcare literature and examines potential implications for the NDIS context. The present section examines why the healthcare literature is being drawn on for evidence of market stewardship and information use. In this regard, it is particularly relevant for a few reasons. First, there is significant overlap in the population targeted in this literature in the sense that medical diagnosis is often a gatekeeper to access disability funding, even under the NDIS. Second, the biopsychosocial impact of disability means that consumers who access disability services are also likely to be regularly accessing healthcare services. Third, the complexity of disability and healthcare decision-making is comparable; for example, the need to make long-term decisions, sometimes on behalf of children, parents or spouses, is frequently found in both areas (Victoor et al., 2012). It is therefore logical to draw examples from the healthcare literature to inform this review where evidence in the market stewardship space is lacking.

However, the body of knowledge about healthcare cannot simply be transposed into the disability sector due to the very different problematisations of illness versus disability and consumership versus being a patient. The healthcare literature, for the most part, does not privilege a rights or self-determination approach, and its clinical and professionalised nature is in line with a medical, rather than social, model of disability (Mladenov et al., 2015). As Pfeiffer (1993) argues:

> Disability policy is not health policy, not employment policy, not special education policy, not housing policy, nor transportation policy, but it covers these concerns (and others), yet not in the way in which specialists in those fields usually do (paragraph 26).

The model of disability employed in this thesis is drawn from a critical social model and underpinned by human rights, but the healthcare literature is still primarily embedded in the medical model, which restricts the application of this literature to the disability space and highlights the need for original research in the NDIS market. However, the lack of evidence in the disability space has prompted this review to examine the healthcare literature in order to explore what is known about the information customers need to feel informed when they make decisions.

The healthcare industry has a much longer history of marketisation, especially in the USA, and therefore has more evidence than disability to draw from. The maturity of the market over decades has resulted in developments such as value-based healthcare (e.g. Zhao et al., 2015) and personalised medicine (e.g. Jackson & Chester, 2015; Katsios & Roukos, 2019), which, despite criticism (e.g. Mladenov et al., 2015), are at least on face value designed to support patient choice and control. The growing biomedical trend towards molecular diagnostics and genomic testing of personalised medicine is, however, not relevant to this discussion; likewise, value-based healthcare relies less on patient decisions or self-determination and more on clinical outcomes. Rather, the relevance of this literature to personalised disability support comes from the current trend away from professional decision-making and towards self-directed care, which is in line with the third wave of policy described in the previous chapter. Healthcare literature offers evidence about the information patients use to select their hospitals and clinicians. Consequently, there is also literature about healthcare marketing, which has closely examined how healthcare consumers make decisions and best use information (Bates & Gawande, 2000; Dobele & Lindgreen, 2011; Liang &

Scammon, 2011; Snipes et al., 2005; Tu & Lauer, 2008). This is drawn upon in the rest of this chapter, including the next one which examines the impact of sector complexity on consumer decision-making and information.

### 4.2.3 Navigating complex service sectors

The design of the NDIS means that making a decision about which service provider to choose is inextricably linked to navigating a complex system. This section examines the literature describing the ways that complex social services systems have historically relied upon service navigators and to what extent the NDIS so far continues this tradition.

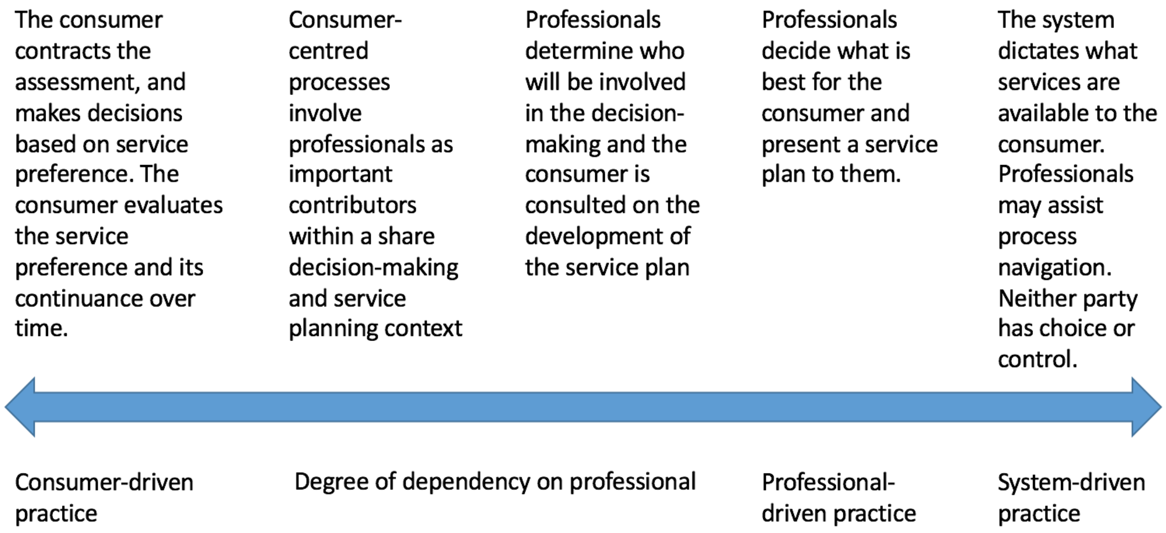
The complexity of the disability support system itself contributes to the difficulty of creating and managing information. It is particularly important that systems are easy to navigate if choice and control are going to be realised under the NDIS because the literature shows that the effects of systems problems on individual issues are not well understood by consumers (Gibbs, Sangl, & Burrus, 1996). For example, various clinicians act as gatekeepers to Australian disability support services; as described above, NDIS applicants are often required to provide medical documentation of their functional impairments from various doctors in order to gain access to the disability support sector (NDIA, 2019i). These system complexities can make personalised support systems difficult to navigate and can also impact a consumer's ability to assess the quality of a service.

As part of a market stewardship approach, the literature highlights that an information economy should include capacity-building and training for consumers, staff, carers and advocates about how to navigate systems and use information to make decisions (Baxter & Glendinning, 2011; Edgman-Levitan & Cleary, 2006; Hibbard, Slovic, & Jewett, 1997; Maglajlic et al., 2000; Walsh et al., 2012). Strengthening local connections could also assist with this process because using existing social networks is effective for conducting capacity-building (Maglajlic et al., 2000) and is a good outcome in itself from a social work perspective (Connolly & Harms, 2013).

Additionally, decades of professional service navigation have created considerable information asymmetry, which refers to one group having more access to information than another, thus creating a situation "where consumers have difficulty judging the need for and quality of the services they receive" (Forsyth & McGough, 2014, p. 6). In the case of the Australian disability sector, professionals have access to more and better information about services and systems than consumers, and they do not always exchange it fairly nor appropriately (Mortelmans et al., 2006). This occurs due to medical-model assumptions that PWD are incapable of navigating the service sector without assistance, but also because social services systems are so highly complex that formal training and/or considerable experience is often needed to navigate them effectively (Donovan et al., 2018; Smith, 2001).

Professionals in the disability sector are often asked to assist with service navigation and decision-making. This includes offering supported, surrogate or shared decision-making processes (discussed further below) as well as applying their expert service navigation skills (Davidson et al., 1999; Gooding, 2013), in addition to helping consumers understand their own needs before starting the NDIS process, especially for people with intellectual disabilities, who "must be equipped with the skills to identify and articulate their own needs and provided access to mechanisms and resources to act on them" (Dew, Collings, et al., 2019, p. 402) in order to realise the benefits from personalisation.

Donovan et al. (2018) developed a Service Navigation Relational Autonomy Framework (SNAF) that, based in social work theory, supports participant-centred practice development and social justice aims within an increasingly marketised environment. The authors list four principles guiding service navigation as “the reinforcement of ethical practices; fostering self-determination; supporting transitions and wellbeing; and mobilizing service systems” (Donovan et al., 2018, p. 4). The SNAF is a framework that has been designed to assess the suitability, ethics and outcomes of decision-making in quasi-markets and exists on the continuum between autonomy and dependence (see Figure 6), and it is important to consider in the context of NDIS decision-making. Figure 6 adds a fifth dimension to the continuum: system-driven practice. While the NDIS is intended to offer more choice, it is possible that a thin market (characterised by a lack of supply and/or demand) or inadequate information flow could limit choices to the point where there are few options or only a single option (Carey et al., 2019). The literature suggests that this is especially likely in rural and regional areas (Dickinson, 2017; Ellem et al., 2019), as well as for people with complex needs (Ahmed, 2009; Collings et al., 2016; Ellem et al., 2019). Preventing this situation is one of the key roles of market stewards.



The consumer contracts the assessment, and makes decisions based on service preference. The consumer evaluates the service preference and its continuance over time.

Consumer-centred processes involve professionals as important contributors within a share decision-making and service planning context

Professionals determine who will be involved in the decision-making and the consumer is consulted on the development of the service plan

Professionals decide what is best for the consumer and present a service plan to them.

The system dictates what services are available to the consumer. Professionals may assist process navigation. Neither party has choice or control.

*Figure 6: Autonomy/dependency continuum. Adapted by author from Donovan et al. (2018, p. 6)*

There is evidence in other settings that points towards the influence of professional service navigators on participant choices. Studies have shown, for instance, that the only consistent influencers of patient choice in the healthcare sector are clinicians (Dobele & Lindgreen, 2011; Snipes et al., 2005; Victoor et al., 2012). There is some tension here from a social justice perspective because it is challenging to ensure that consumers have adequate safeguarding and protection to be confident in their decision-making yet are able to take appropriate risks.

However, while relationships may be an important factor in decision-making, decisions made purely based on trusting other people’s advice – while sometimes necessary in a complex environment with little information – are not necessarily based on an informed choice (Liang & Scammon, 2011). While WOM information will be discussed further below, the point here is that despite the complexity of the NDIS, consumers and their allies must find ways to increase their confidence in making decisions about which services to purchase. This will allow them to receive appropriate support, achieve their goals and realise good outcomes, which is positive from both social justice and marketisation perspectives, allowing the NDIS to function as a personalising and equalising force and achieve its actuarial goals. At present, most of the service navigation literature is for, by and about professionals (e.g. the above theory from Donovan, Hampson, & Connolly, 2018).

## 4.3 Gaps in the market stewardship literature

The previous section has reviewed the literature concerning quasi-marketplace stewardship and, finding the NDIS context lacking in depth, introduced healthcare as a potentially comparable literature base. However, as Chapter 3 outlined, the particular scope and complexity of the NDIS is unprecedented, and the literature argues that the implementation issues being experienced are therefore unique (Carey et al., 2018; Carey et al., 2019; Needham & Dickinson, 2018). If this is true, it is likely that there are limits to the applicability of other literatures from European or American contexts or from other sectors (Dickinson, 2017).

There are three specific gaps in the market stewardship literature that are relevant to this thesis. First, and importantly from a social justice perspective, the market stewardship literature primarily examines top-down interventions that are designed to make it easier for suppliers to provide purchase options that the government believes will meet consumer needs, and in the case of regulation, safeguarding the supply. In the context of the NDIS, this means examining census and other data for patterns of likely consumer needs to shape supply, which is directly opposite to theory about the way markets should work. Neoclassical economic theory states that supply should be driven by demand, thus ensuring that consumers' needs are met and that they will be willing to pay for what is on offer (Cogan et al., 2005). As has been established, quasi-markets are different to regular markets, so there is a limit on the direct application of economic theory.

Top-down market stewardship interventions work to directly influence supply with regard to meeting anticipated demand rather than listening to demand in order to influence supply. Building a market is a significant task, and this top-down approach helps to ensure that consumers' basic needs are met in the foundational period. However, as a long-term practice, it may not be so different to the tendering process in the "unfair, fragmented, and inefficient" (Productivity Commission, 2011, p. 2) welfare state model, which funded organisations based on predicted need rather than using a bottom-up method of extending choice and control to customers. Especially when it comes to information, conducting market stewardship top-down and targeting providers has the potential of maintaining an environment that does not listen to consumer need, promote responsive or innovative service design, or where PWD can enact their consumer rights by influencing the supply side of the NDIS industry. For this reason, it is likely to meet neither social justice nor marketisation imperatives.

The second gap in market stewardship literature is in regard to practical evidence relating to how to provide information to consumers. There is little indication of what is important to include from the perspective of a consumer in terms of key metrics relevant in choosing service providers. Rather, the literature has focused on government funding or policy that influences the actions of providers (as per the previous discussion of recommendations in Carey et al., 2018). This means that consumers are unable to compare two possible choices in an evidence-based way, with a secondary impact that service providers also have limited data about quality services that will attract consumer demand. Instead, they continue to use much of the same language as they did in the welfare state model, which was jargon-heavy and designed to appeal to professional service navigators rather than consumers. Where information is not designed for consumers, the existing inequality of the welfare state may be maintained in the NDIS environment. Once again, without knowledge about how to provide information to consumers, neither social justice nor marketisation aims will be fully met.

Third, this review highlights that there is a gap relating to existing knowledge about how to increase consumers' service navigation and decision-making skills. There is some discussion in the NDIS literature about the need for capacity-building on both sides of the market (e.g. Battams, 2017; Kendrick et al., 2017), and market stewards themselves also need to increase their capacity to prevent problems and attend to those who are at risk of missing out (Malbon, Carey, & Reeders, 2018; Soldatic et al., 2014). In most instances, it is clear that the intended result is easy navigation of the system through a combination of well-informed, confident consumers and, on the other side of the market, responsive providers who can innovate and offer adequate, high-quality supply. While it is clear that the speed of change and multiple levels of expensive, complex compliance is problematic for both sides of the market (Hough, 2018; Kendrick et al., 2017), it is unclear what this capacity-building work should actually entail, how key milestones of its success might appear, or how it should be delivered.

Instead, the interventions found in the review encouraged the use of professionals, brokers and third parties, such as support coordinators or LACs, to offer information, which will have the effect of maintaining information asymmetry (Quach et al., 2010). This will be discussed in more detail below, but, in brief, it maintains existing inequalities and is therefore problematic from a social justice perspective. However, it is also problematic from a marketisation perspective, as it can create an environment in which it is expected that a considerable percentage of funding will be clipped by intermediaries, rather than going towards services. This could risk the actuarial assumptions underpinning the NDIS, which are already accounting for a decrease in spending on support coordination over the coming years.

In short, there is insufficient information about information economies and consumer decision-making in the literature to answer the question of what information service users need in order to feel informed about the services they choose. The next section will broaden the review of the literature to examine what is known about consumer decision-making in the disability sector and also in general marketplaces.

## 4.4 Decision-making

It is important to explore some of the unique facets of consumer decision-making as well as information itself because information exists to guide decision-making, and decision-making is the actual function and application of choice and control. This section examines the role of decision-making in the NDIS, in addition to also exploring the "skill" of decision-making and how this can create a burden for consumers with and without disability. Finally, it looks to the behavioural economics literature for evidence of how information can be shaped to ease consumer decision-making.

Just as in any market, consumer decision-making is integral to the success of the NDIS, which is not simply due to the rights framework of choice and control underpinning the NDIS or the marketisation approach that views citizens as consumers; rather, it is because neoclassical economic assumptions are embedded in the marketisation of disability services. As already stated, in order for supply to be shaped by demand under the NDIS, consumers need to make informed decisions about what to purchase so that the market can respond

(Fawcett & Plath, 2014; Fotaki et al., 2008). This assumes that a consumer's preferences will efficiently, effectively and equitably shape industry around their needs (Lent & Ardent, 2004) and that consumers know what they want and are able to make utilitarian decisions about their needs.[1]

Various studies have examined the process of consumer decision-making, many from the perspective of marketing. Searching for information is a key stage of decision-making; however, more recent studies have theorised that this process has become more of a loop, where consumers continuously seek information and evaluate their alternatives, adding or deleting brands and other options from their internal choice set based on various criteria (McKinsey, in King, Racherla, & Bush, 2014; Panwar, Anand, Ali, & Singal, 2019). The main literature relevant to this thesis is that related to the information search stage because finding the right information can facilitate the evaluation of alternatives, cause the consumer to feel informed, and lead to a decision about which NDIS provider to purchase services from.

The influence of behavioural psychology has drawn economics away from concerns with how consumers *should* behave in theory to examining how they *do* behave in practice. More often than not, consumers both with and without disability have imperfect information and make imperfect decisions (Dijs-Elsinga et al., 2010; Dixon et al., 2010; Victoor et al., 2012). Behavioural psychology is the study of people's behaviour and is relevant to this thesis because it examines the links between thoughts, emotions and actions and has been applied to consumership. For instance, it has been found that the way consumers say they would behave hypothetically is not always evidenced in their choice-making (Bernstein & Gauthier, 1999; Edgman-Levitan & Cleary, 2006; Schnellenbach, 2012). This is especially relevant in the disability sector because information is imperfect, it is difficult to get clear information about what best practice looks like, and, as discussed above, the complexity of social services and the government creates a high level of uncertainty for consumers (Bernstein & Gauthier, 1999; Dijs-Elsinga et al., 2010; Edgman-Levitan & Cleary, 2006; Hanoch & Rice, 2010; Hibbard et al., 1997, 1998).

### 4.4.1 Decision-making as a skill

Yet another challenge in using a market to distribute social services results from the challenge of decision-making itself. Devine, Dickinson, Brophy, Kavanagh, and Vaughan (2019) describe consumer decision-making in quasi-markets as "multi-faceted" (p. 2) and contend that there are so many barriers to enacting decision-making that it actually has the potential to *restrict* choice and control. Indeed, decision-making is a skill, and as disability advocates and other authors have argued, it is one that many people who have a disability are perceived as incapable of enacting (Devine et al., 2019; Dowse, 2009; Gooding, 2013; Jenkinson, 1993). For this reason, a body of literature about how to support decision-making is growing as the human rights model of disability becomes more accepted (e.g. Davidson et al., 2015; Gooding, 2013; Kohn & Blumenthal, 2014) and is increasingly being introduced into policy (for example, there have been changes to Victorian legislation through the Mental Health Act 2014 that promote consumer decision-making and advance care planning [Victorian Government, 2019]).

---

[1] "Utilitarian decisions" refer to those that are well informed and rational and are the inevitable, objective consequence of a person being both willing and able to seek out all the relevant, objective, rational information they need to make a decision (Dixon et al., 2010; Hibbard et al., 1997). It is out of the scope of this research to look at the outcomes of decisions. Consequently, when the phrase "good decision" is used, it refers to a decision that the consumer subjectively feels was informed.

However, contention around choice is an ongoing issue in the disability studies literature. Chapters 2 and 3 discussed the attention that has been paid to disability rights, where choice is seen as a means to self-determination (Fotaki, 2014). On the one hand, it is important to ensure that PWD have choice, while on the other it is important to ensure that they are informed and supported to understand and manage the consequences of their decisions. Therefore, disability research in this area has focused on issues of rights, legal capacity and decision-making that is supported, shared or surrogate (Baxter & Glendinning, 2011; Brophy, Bruxner, & Wilson, 2014; Maglajlic et al., 2000; Martin, 2011; Walsh et al., 2012). It has also looked at the dignity of risk – a consumer's right to take risks alongside making their own decisions (Marsh & Kelly, 2018). Although a focus on the process of decision-making is important, it does not examine the content of what information is required. This gap means that the existing literature is not sufficient to ensure that service users are informed in the NDIS environment, which is a gap this thesis seeks to contribute to filling.

Because decision-making is a skill, there are multiple systemic reasons why PWD may not be confident decision-makers that have nothing to do with impairment. Prior to the NDIS environment, most consumers were offered no choice. This means that, first, they have had little experience in making decisions, and second, they therefore have very little experience to draw from (Maglajlic et al., 2000). Fear, mistrust and lack of knowledge about systems, rights and options influence consumers to avoid risk. They may make decisions based on their current experience and choose options that they are already familiar with. Furthermore, as discussed earlier, many consumers' navigation and decision-making experience, even over long periods of using support services, is reliant on professional service navigators, which has prevented them from building their knowledge, skills and confidence (Donovan et al., 2018).

PWD are not the only consumers who need to make decisions. The drive of market stewards to ensure consumers can make decisions and understand the consequences of their decisions is universal. It is also universal to ensure consumers can be involved in decision-making processes that support them in avoiding negative outcomes where possible by having information that is relevant, complete and sufficient. This thesis does not examine outcomes but rather the process of decision-making in terms of how this information should look to ensure consumers feel informed. Much of the literature on this topic is not in the disability sector but in the field of behavioural economics.

### 4.4.2 Behavioural economics

A significant proportion of the literature that exists relating to consumer behaviour and decision-making comes from behavioural economics. This thesis is situated in market stewardship and takes a social work perspective, and while this places the field of behavioural economics out of its scope, it is important to acknowledge its relevance. Behavioural economics is the meeting of the disciplines of economics and behavioural psychology, investigating how consumers can make decisions more easily. This is often called "benevolent paternalism" or "libertarian paternalism" (Schnellenbach, 2012) because it examines how consumers can be influenced to make a particular choice that is considered "optimal" by a governing party. This influence is often implicit or hidden and aligned with either a commercial or political motive. For example, behavioural economics has been used to develop policy in the UK and Australia across environmental, civic and town planning, poverty reduction and public health sectors (Anand & Lea, 2011; Defra, 2007; Department of Health, 2004; Engwicht, 2005; Gsottbauer & van den Bergh, 2011; Hursh & Roma, 2013; Jones, Pykett, & Whitehead, 2010; Low, 2011; Oliver, 2013; Tudor Edwards, Charles, &

Lloyd-Wiliams, 2013). Former British Prime Minister David Cameron established a behavioural economics institute (Behavioural Insights Team, 2014); in Australia, the Productivity Commission had a 2008 round table discussion examining behavioural economics (Productivity Commission, 2008), and the Australian state of New South Wales has a dedicated behavioural insights unit (NSW P&C, 2019). Such actions result in interventions intended to influence citizens to make decisions that these governments consider to be healthier or more beneficial in some way and are examples of a move away from "hard" levers of governance (those which openly reduce choice) to "softer", policy-based ones which, for example, might be perceived to influence rather than restrict choice (Prouctivity Commission, 2008; Schnellenbach, 2012).

Because of these implicit attempts to influence customers towards the goals of large-scale public health outcomes, much of the healthcare literature about decision-making has been conducted in relation to behavioural economics principles. For example, public health policy may be concerned with encouraging a citizen's decision to give up smoking or eat healthy food. According to Dolan, Hallsworth, Halpern, King, and Vlaev (2010), "influencing behaviour is central to public policy" (p. 7). Particularly as the importance of choice in enacting citizenship has increased, scholars concerned with consumer decision-making in public policy often look towards behavioural economics for how to guide consumers to make utilitarian decisions (Dixon et al., 2010; Hanoch & Rice, 2010; Kolstad & Chernew, 2009). Therefore, it is relevant to examine the potential application of behavioural economics to the disability sector where consumer decisions will have an impact on society and on Australia's GDP for decades into the future.

Behavioural economics offers several methods of influencing decisions, many of which involve limiting or shaping the information made available to a consumer (Thaler & Sunstein, 2008). Decision-making is heavily reliant not only on the availability of information but also on the ease with which it can be processed, which means that having more information is not necessarily better for a consumer (Bettman et al., 1991). In this regard, a greater amount of information can increase the decision-making burden and result in poorer choices being made (Bernstein & Gauthier, 1999; Gibbs, Sangl, & Burrus, 1996; Hibbard & Jewett, 1997; Hibbard et al., 1998; Thaler & Sunstein, 2008). In fact, more information is likely to produce more conflicting information. This increases the decision-making burden for consumers, who in the end make poor choices more frequently (Bernstein & Gauthier, 1999; Gibbs et al., 1996; Hibbard & Jewett, 1997; Hibbard et al., 1998).

Consequently, a key behavioural economics strategy is supporting consumers to avoid making poor decisions as a result of having too much information (Hostetter & Klein, 2013). For example, the amount of information made available may be intentionally restricted (perhaps showing only the "top three" available options), or the process of decision-making may be gamified (through, for example, a quiz) (Hamari & Koivisto, 2013; Huotari & Hamari, 2012). Presenting comparative, rather than sequential, information is also beneficial as it creates less reliance on consumers' memory (Samson, 2015). Another method is to influence the process of choice by nudging people towards particular outcomes, which may be achieved through intelligent default options for those who do not or cannot make decisions; by presenting information that compares risks and gains, as people often make decisions based on risk or loss aversion; or even by introducing immediate losses to discourage poor choices (Thaler & Sunstein, 2008).

It is worth noting that all of these solutions heavily influence decision outcomes without offering transparency about the process – many are designed to nudge consumers towards an implicit goal or support a hidden agenda. This is problematic from a social justice perspective, making behavioural economics interventions less relevant to this thesis, but they may have broader relevance in the NDIS environment. In fact, the idea of having intelligent default options was one of Carey et al.'s (2018) recommendations for the NDIA. Interestingly, none of these other consumer-focused behavioural economics interventions were listed in that review, which suggests that there is an overlap but also a considerable gap between market stewardship and behavioural economics. Once again, this is out of the scope of the present thesis, but it will be touched on again in the discussion as a potentially interesting point of departure for further research, especially as the NDIS market matures.

### 4.4.3 Gaps in the decision-making literature

While there is practical evidence in the decision-making literature about what consumers need to feel informed, there is limited evidence about the type of information needed. While behavioural economics theory and practice have been applied to the public health and health sectors, this could not yet be applied to the NDIS because there is a low level of public information and data available. Additionally, there is tension between freedom of choice and self-determination and the goals of behavioural economics interventions or brokerage. This has particular significance in the disability sector because of the social justice side of making sure that people have self-determination, and the same rights dynamic does not necessarily exist in health and public health.

## 4.5 Being informed

This section will review the evidence in the disability and wider literatures about the way consumers use information to make decisions. Reinforcing the need identified above for diverse information content and media, this literature highlights that different people use information in diverse ways and that factors such as age and illness influence the ways people use information. The previous section touched on the need for comparable information to decrease the burden on consumers, which means that it is important to develop objective research and metrics in the NDIS environment.

### 4.5.1 Information use

The importance placed on decision-making in contemporary citizenship does not necessarily recognise the complexity of making utilitarian decisions about human services. Much of the complexity in making these decisions is driven by how difficult it is for consumers to find and process meaningful information (Bettman et al., 1991). The cost of finding and processing information can be burdensome to consumers both with and without disability (Baxter & Glendinning, 2011; Martin, 2011; McLoughlin et al., 2014; Walsh et al., 2012), especially when it comes to choosing services rather than products (Mangold et al., 1999; Snipes et al., 2005). Therefore, in the new, complex NDIS marketplace, it is essential from both social justice and marketisation perspectives for the information economy to make it as easy as possible for consumers to find and process information.

There are factors that influence the difficulty of decision-making outside of whether a service or a product is being purchased. For example, demographic factors influence how difficult it is for consumers to use information effectively. Studies have shown that people who have low numeracy and literacy skills or whose native language is different from the one that the information is published in are likely to make an uninformed decision or no decision at all (Faber et al., 2008; Hanoch & Rice, 2010; Maglajlic et al., 2000; Victoor et al., 2012). On the other hand, parents, those with chronic health conditions who need specific types of care (and therefore have fewer choices to make), people making decisions for the first time who have no pre-existing relationships, and those with higher incomes and more education are more likely to use information well (Victoor et al., 2012).

While many NDIS service users will be managing chronic health conditions requiring specific support and also making decisions for the first time, the fact that disability is correlated with lower education, economic health and wellbeing outcomes (ABS, 2010) means that many PWD have a greater probability of using information less effectively and making uninformed decisions. This could place the choice and control underpinning the NDIS marketplace design at risk, indicating that, from both social justice and marketisation perspectives, it is imperative to develop more knowledge about the way in which disability consumers use information and also to ensure that market stewardship interventions are suited to consumers.

### 4.5.2 Personalising information

It has been noted that the disability sector is characterised by heterogeneous stakeholders, which creates the need for heterogeneous information designed and produced to meet the needs of diverse stakeholders (Baxter & Glendinning, 2011; Maglajlic et al., 2000; Walsh et al., 2012) because information is influenced by whom and for whom it is being prepared. The content, relevance, accessibility and therefore quality of information changes with the priorities of the stakeholder.

Additionally, it is not just different points of view but also fraught relationships and power dynamics between stakeholders that influence information, sometimes creating tension between what is relevant and appropriate for one stakeholder versus another. One paper written in the UK context found that

> the complex relationships between these stakeholders can range from rivalry and suspicion through to co-operative mutual support, synergy and interdependence. In other words, there is a wide and contested set of requirements which may need new roles and responsibilities to be instantiated if live, reliable and effective [sources of information] are to be created (Walsh et al., 2012, p. 675).

As Chapter 3 showed through a discussion of the waves of policy, there has been a complex and oppressive history of problematisation of disability. Due to the layering of each of these waves, the complexity, rivalry and suspicion in the disability sector remain to a certain degree. Rivalry and suspicion are also due to conflicting problematisations of disability or personalisation (e.g. the medical versus social models or the social justice versus marketisation approaches). In the UK, it has been found that this socio-political layering adds layers of complexity to informational issues, deeply affecting the purpose and structure of market stewardship in general and any information economy in particular (Walsh et al., 2012). For this reason, ensuring consumers’ interests are represented in the production and distribution of information has been both necessary and difficult for effective market stewardship.

Certainly, the healthcare literature reveals that the content and format of information needs to be made accessible to the stakeholder in question in order to make it easy (possible) to consume (Victoor et al., 2012). For example, information is often difficult for consumers with low health literacy to interpret when it is created by health or marketing professionals, as most consumers do not understand or process technical information well (Hibbard et al., 1998). With such a heterogeneous NDIS sector, it is worth considering how to define and meaningfully segment each stakeholder group in the Australian context and find out what they need, including whether they are more concerned with a social justice or marketisation approach. For example, there may be a large difference between providers and people with intellectual disability in values and skills, which will shape the way they want to consume information and what information is important to them; there may or may not be a smaller difference between sole traders and multi-million dollar charities, or between the informational needs of people with intellectual disability versus people with acquired brain injuries. It is also worth examining where commonalities exist in order to be as effective and efficient as possible with the production of universally applicable information. Information needs to be easily understood by consumers; for example, it must be free of jargon, and when addressing culturally and linguistically diverse (CALD) or Indigenous communities, resources should be produced in those communities' languages. Additionally, these communities need targeted, affirmative action in information distribution to ensure that their particular needs are met rather than expecting them to be able to use material that has been developed for other groups (Dew, Vaughan, et al., 2019; Maglajlic et al., 2000).

Ensuring that information is correct and reliable is another challenge. Maintaining sources of up-to-date information is also important and is recognised as a challenge by service navigators (Baxter & Glendinning, 2011; Maglajlic et al., 2000; Walsh et al., 2012). In the context of the NDIS, where the market of registered providers has, at times, grown by up to 70% in 12 months (as indicated by, for example, NDIA, 2018a), this challenge is real. To ensure reliability for service users, information about disability services should be obtained from transparent and trusted peer and professional sources (Bernstein & Gauthier, 1999; Edgman-Levitan & Cleary, 2006; SPRU, 2000) because information is more reliable when it is perceived to be unbiased. This begs interrogation into the Australian disability sector, as a concern about whether information is biased echoes the suspicion resulting from a history of paternalism and information asymmetry, in addition to also suggesting that finding ways of distributing trustworthy information is central to the success of the NDIS from both social justice and marketisation perspectives inasmuch as consumers need to make confident decisions for their own self-determination and for the industry to flourish and grow.

Finally, information sources should be easily found with visible access points (Maglajlic et al., 2000; Walsh et al., 2012). Australia's geography exacerbates the issues raised in the literature (Ellem et al., 2019), which suggests that despite some international evidence being available, there is benefit to conducting domestic research.

### 4.5.3 Content and metrics

Metrics and indicators are not very well understood in the disability sector, especially those relevant to consumers. Metrics are units of measurement that can be counted and compared to one another, assisting with monitoring progress, identifying changes and designing interventions (Land et al., 2011). There is some resistance to using indicators in the human services industry because they are seen to be a move towards standardisation and deskilling of the workforce (e.g. Baines, 2006). However, metrics and indicators are important for informed decision-making because they can allow consumers to more accurately compare options (Bettman, Johnson, & Payne, 1991).

In the healthcare sector, there are several metrics about providers that are known to influence consumption decisions. First, a consumer's previous experience is consistently identified as an important factor, as are the recommendations of their general practitioner (GP; Victoor et al., 2012). While price is another easy metric and comparator, it is limited and does not account for the quality of a service (Faber et al., 2008), and it is certainly not universally relevant in the NDIS before the market is deregulated because prices are primarily fixed. Other factors that are important to healthcare consumers include health outcomes, a provider's reputation, customer service and interpersonal communication, waiting time, price, value for money, travel burden, after-hours access, choice of clinician, and the amount of paperwork required (Victoor et al., 2012). While most of these factors are likely to be relevant in an NDIS context, their particular influence on and importance to consumers in a disability service environment is unknown. It is important to understand metrics in the NDIS industry in order to produce appropriate information that would aid decision-making and allow better market stewardship infrastructure to be created. More importantly, it could raise the quality of decisions being made.

Just as there is a need for clearer universal metrics to provide more evidence, there is a need for market stewardship interventions to make existing evidence available to consumers. A central part of assessing the utility of a decision is being able to monitor and evaluate its outcome; however, due to the complexity and uncertainty in social care settings, many consumers distrust their own decision-making, even when they have the information they need (Bernstein & Gauthier, 1999). In one Australian example, a participant with a psychosocial disability asked: "How do I make the right decision if I don't know what the outcome of my decision will be?" (Brophy et al., 2015, p. 14). In the field of disability, motherhood concepts like "choice", "control" and "inclusion" are frequently used and can be more difficult to measure than products or outcomes in other industries. As Leadbeater (2004) describes,

> the goods and services the public sector provides are not always neatly packaged in the way that stereos, cars and computers can be. Many public services are fuzzy [and] difficult to define and pin down, for example the value of community safety. The qualities of these public goods cannot be assessed and encapsulated in the way that the features of a computer can be described in technical language (pp. 49–50).

In particular, relationship-based outcomes can be difficult to define and measure. Human services are prolific in the NDIS sector, with up to 75% of funding going towards support workers (NDIA, 2018a), and these "fuzzy" qualitative and relational outcomes require different measurement tools than products or medical symptoms. This uncertainty is likely to be a pervasive issue for PWD, the NDIS system, and service providers alike. It calls for appropriate and regular evaluative processes to be embedded into the NDIS system, as well as supporting PWD and service navigators to independently evaluate choices (Maglajlic et al., 2000). Anticipated or actual change outcomes should be clearly articulated by service providers in order to reduce uncertainty and assist consumers to know precisely what they are purchasing, as well as to compare their options effectively (Samson, 2015). Additionally, standardising relevant quality measures across services and sectors will create the possibility of using comparative measures when deciding between services, thus adding to the available metrics.

This speaks to the necessity for building Australian disability research, matching NDIS data to other large datasets, and making these publicly accessible (Llewellyn et al., 2014; Llewellyn et al., 2017). Llewellyn et al. (2017) have conducted two audits of Australian disability research and, in the latest report, stated that the lack of transparency of NDIA data and its incompatibility with other datasets (including census data) is limiting the depth to which outcomes can be assessed. It is imperative from both social justice and marketisation approaches to offer enough evidence to help consumers evaluate their own experiences, especially when decades of limited choice will undoubtedly affect many people's capacity to benchmark against their own experiences.

### 4.5.4 Gaps in the information literature

The above section on being informed has shown that there is some literature about how consumers use information to inform their decisions about social services and some about the content that the information should display. It also addressed some of the unique conditions in Australia affecting information availability that have not been researched. However, very little has been drawn from the disability sector or applied to the NDIS environment. Equally, there is a gap when it comes to bottom-up evidence asking consumers what information they need in order to feel informed. Where this section discussed some of the important factors in consumers' information use, the following section looks at how the information should be distributed and what is known about the media and channels through which consumers find information in the context of service decision-making.

## 4.6 Media and channels

Due to the charity model of social welfare described in Chapter 3, and given how recently personalisation has been put in place, the majority of the literature on distributing information in the disability sector is concerned with increasing donations rather than informing consumers (Chang & Lee, 2015; Cockrill & Parsonage, 2016; Das et al., 2008; Sargeant et al., 2008). Some of the literature has examined the imagery of PWD in this media and has used the social model to critically analyse the image of consumers portrayed through charity advertising (e.g. Barnett & Hammond, 1999; Doddington et al., 1994; Eayrs & Ellis, 1990; Waltz, 2012). This is not relevant – there has already been discussion around the necessity of shaping information to the needs of particular stakeholders.

There is some evidence from the UK context concerning how an information economy should look, which states the need for heterogeneity in the media used. Information must be available in a wide range of personalised, audience-appropriate and diverse formats that are relevant to consumers and other decision-makers (Baxter & Glendinning, 2011; Maglajlic et al., 2000; Walsh et al., 2012). Channels should include directories, peer advice, face-to-face professional advice, comparison and cross-referencing, taster sessions, helplines, outreach, and a mixture of online and paper copies of information (Maglajlic et al., 2000; Walsh et al., 2012).

However, there is limited evidence about what channels are most effective, let alone which views the consumers themselves share. Rather, the bulk of the literature examined in the following section concerns itself with non-autonomous decision-making and using other people as support and channels for information.

### 4.6.1 Using others to be informed

The purist notion of an individual consumer making a utilitarian decision demands they do this alone; however, various disciplines have challenged the idea that consumers are autonomous and even whether there is value in such autonomy (Gooding, 2013). This section first examines various ways that non-autonomy has been presented in the literature and then issues of trust and the use of WOM – both in person and online – as a means of acquiring information about services in disability and healthcare.

The value of autonomy has been challenged in the field of social work, which, as the introductory chapter described, conceptualises individuals as part of an ecosystem of other people and influences. Social work theory considers the whole ecosystem rather than just the individual, as it attempts to build on communal strengths that support the individual's wellbeing (Connolly & Harms, 2013). As stated in the AASW Code of Ethics:

> Social workers need an understanding of the social, political and historical context in which decisions are made, the human relationships, the management decisions and the involvement of multiple interests, all of which impact on decisions and the situational context in which they are made (AASW, 2010, p. 14).

It is not within the scope of this thesis to examine all the literature that discusses the relationship between autonomy and dependency because this would span several large fields of literature. Instead, it will introduce one key idea featured in the disability studies literature: relational autonomy. This concept describes a situation in which an individual (with or without disability) makes decisions with the support of others in their ecosystem, where autonomy, or at least the enjoyment of autonomy, is seen as an *inter*dependent rather than independent: "individuals rely to a greater or lesser extent on others to help them make and give effect to decisions" (Gooding, 2013, p. 435). The role of professional service navigation has already been discussed, and for PWD, decision-making about services may include using professionals. However, it may also involve using family members and carers to help make decisions, particularly because consumers perceive the advice of their friends and family to be unbiased and therefore trustworthy (Willis et al., 2016). This leads to a review of the literature relating to trust.

#### 4.6.1.1 Trust

The literature on trust is highly interdisciplinary (Wellstead, 2019), and looking briefly at its role in economics will provide a background for further discussion. It has been shown that there are deeply psychological influences with regard to decision-making. Especially when making complex decisions such as those that arise in the disability sector, consumers almost always have imperfect information, are unable to carry out adequate research, and are considerably influenced by their personal circumstances (Willis et al., 2016). Where uncertainty and risk exist, consumers invest trust in systems or other people as a means of reducing complexity, or as Beckert (2004) puts it, as a "tranquiliser" (p. 3). Trust allows consumers to suspend uncertainty in order to continue making decisions and purchases (Smith, 2001). From a marketisation perspective, trust is important in making the NDIS market work because it helps consumers make purchases even through the complexity.

Furthermore, evidence shows that where trust exists, consumers use less caution and make risker and more frequent purchases (Klein & Shtudiner, 2016). Where there are no trusting relationships to be relied upon and consumers have to use their analytical skills, they make more accurate and less risky decisions (Schul & Peri, 2015). For example, consumers are more likely to purchase a product or service when they trust the people creating, supplying, selling or regulating it (Kim, 2016; Steinke et al., 2012). In a context where there is no human contact and consumers cannot rely on 'gut feeling' (Smith, 2001, p. 6), they are likely to research their options more thoroughly.

A point of agreement between the social justice and marketisation perspectives is that good information is preferable over dependency on trusting relationships, albeit to achieve an outcome of self-determination for social justice and to achieve a more utilitarian decision for marketisation (Fotaki, 2014). This is another point at which different approaches agree on the end despite disagreement on the means. Once again, it is clear that multiple storylines are layered into personalisation and marketplaces as deeply as differentiating between how the most trusting relationships are interpreted.

It is interesting to consider the dialogue between service providers and consumers as a transaction of trust. Beckert (2004) terms consumers "trust-givers" and suppliers "trust-takers", and while trust is usually conceptualised as an action of the consumer as a trust-giver, Beckert (2004) argues that there is insufficient academic attention given to the role of the trust-taker, whose job is usually thought of simply being to provide the conditions necessary for the trust-giver to act. However, Beckert (2004) also points out that service providers must actively produce the impression of trustworthiness by presenting themselves in a way that allows consumers to make a confident purchase. In fact, there are theoretical differences in opinion on how trust is created and maintained between trust-giver and trust-taker – whether it is created through the transactional relationship, is a product of confidence in the wider system, or is earned over time (Håkansson & Witmer, 2015; Murdach, 2009; Natalier & Willis, 2008). The way this applies in an NDIS environment is worth examination. The market stewardship literature would benefit from a deeper understanding about how different types of trust play out in an NDIS environment in order to ensure that where there is uncertainty, confident decision-making can still be maximised. This thesis will contribute to filling such a gap.

A perceived alignment of values is known to create trust between consumers and provider, called salient value similarity, which is formed by a consumer's assessment of what they perceive the trust-taker's values to be in comparison to their own (Siegrist et al., 2000). This is particularly interesting in the emerging NDIS marketplace because while a service user's values cannot be easily changed, the way that narratives are built around them and the way that trust-taking is performed can change. For example, a disability services provider with a poor or neutral reputation could implement careful marketing techniques, which may reform the ways that they present their values and change the resonance a consumer feels between their own values and what the "new" provider offers them. In turn, this could make the consumer more likely to trust and purchase services from the provider. A merger arrangement between two established providers could have a similar effect.

While this is important from the perspective of relational autonomy, it is also highly relevant to the wider NDIS industry from both social justice and marketisation perspectives. Knowing what service providers need to do in order to build and maintain trust with customers and potential customers would be a valuable addition to the market stewardship literature and practice. However, various studies have shown that providers are struggling to adapt to the new marketplace (e.g. Battams, 2017; Malbon et al., 2019; NLS, 2015), and a study conducted by Green et al. (2017) highlighted that the introduction of the competitive market environment has reduced providers' desire to share information about themselves, which suggests that willingness to implement any suggestions may be limited and brings the discussion to a different type of trust that occurs at a micro rather than meso level: social trust.

Social trust is a form of relational autonomy that creates space for elective substitute decision-making; it is the trust invested in others, often professionals, to make decisions on a consumer's behalf, and it is used in order to reduce uncertainty when the consumer lacks the time or expertise to become properly informed themselves, often because of the complexity involved in the decision (Siegrist et al., 2000). When a consumer relies on a specialist doctor for medical information leading to a decision, they are investing trust in order to make a risky and complex decision about which they are unable to obtain adequate information by themselves. In this sense, social trust can be seen as a proxy for confidence and informed choice (Schul & Peri, 2015).

While social trust can be positive if a good relationship exists, it can also be problematic if there are limits to the trust and communication between consumer and professional (Maglajlic et al., 2000). For example, most consumers trust LACs to fairly assess needs, support coordinators to make good referrals and allied health clinicians to apply best practice techniques. Often, these people are gatekeepers, and consumers are not easily able to take a different pathway; in this regard, trust is forced, and unbiased intermediaries, peer support, advocacy and independent brokerage are needed to mitigate consumer fear and mistrust (Baxter & Glendinning, 2011; Maglajlic et al., 2000; Walsh et al., 2012). Such support is a form of market stewardship. Although it is required to some extent in every industry, from the perspective of a social justice framework, a focus on education and capacity-building is an important alternative to reliance on professionals, combined with ensuring public access to independent and reliable information (Leadbeater, 2004).

Trust and confidence are not easy to quantify, as noted in Ozawa and Sripad’s (2013) systematic review, which found 45 different tools for measuring trust in the health sector, nearly all of which measured the doctor-patient relationship as opposed to systems or other social contextual issues. While this literature on trust is most likely to be applicable to the NDIS environment, it is unknown exactly how the theory will materialise due to the complex socio-political history, multiple levels of problematisation and intricate human relationships that are at play. It would be valuable to market stewardship to gain more knowledge about the Australian situation, with a view to thoroughly scoping the impact of trust.

#### 4.6.1.2 Word of mouth (WOM)

Relational autonomy can take the form of WOM information, defined as “an exchange of thoughts, ideas, or comments between two or more consumers, none of whom is a marketing source” (Bone, cited in Dobele & Lindgreen, 2011, p. 6). This can happen formally or informally (Dobele & Lindgreen, 2011). Consumers who have more personal experience are less likely to seek out WOM information (Snipes et al., 2005; Wilson & Peterson, 1989). There is a reasonable amount of literature on this type of information, the majority concerned with marketing and commercialisation rather than the consumers’ right to be informed. Certainly, it has not been explored in a market stewardship context, and while there is a small body of literature looking at the application of WOM information in a healthcare decision-making context, and there is some evidence that it is heavily relied upon in the Australian aged care sector (Hobbs, 2020), it has not been applied in a disability setting.

Snipes, Ingram, and Jiang (2005) contend that the types of sources people use will vary according to how much time they have to search for information and the risk they perceive they are undertaking in their purchase. They argue that WOM has the biggest impact in reducing risk for consumers in choosing healthcare services. Dobele and Lindgreen (2011) add that in the healthcare sector, where there is significant information asymmetry between clinicians and patients, consumers increasingly use WOM sources of information to manage the uncertainty introduced by this asymmetry. In the healthcare sector, they argue, this uncertainty is increased by patients’ reliance on professionals and by how difficult it is for patients to judge the quality of services that are based on the expertise of those professionals (Snipes et al., 2005). There is evidence that this same dynamic exists in the Australian aged care sector, with 60.9% of consumers surveyed by Hobbs (2020) reporting that they rely on trusted individuals to help them select a service provider.

#### 4.6.1.3 eWord of Mouth (eWOM)

Although face-to-face WOM has been found to be more persuasive than written material (Herr et al., 1991), the internet is making online WOM information more readily available (Bates & Gawande, 2000). In fact, eWOM has its own dedicated body of literature. King, Racherla, and Bush (2014) define eWOM as “any positive or negative statement made by potential, actual, or former customers about a product or company, which is made available to a multitude of people and institutions via the Internet” (p. 167). Their systematic review of 190 papers revealed that eWOM differed from regular WOM in that it has the capacity to be widespread and permanent and to engage whole communities and that there is the possibility of anonymity or deception in these interactions.

There has been very little exploration of this in the disability or market stewardship literature. Hobbs’ study of aged care participants revealed less than 6% of consumers had used the internet to find information about their service options (Hobbs, 2020). There are some studies examining the use of social media by PWD (e.g. Caton & Chapman, 2016; Ellis et al., 2013; Obst, 2010; Obst & Stafurik, 2010), much of which has to do with creating social and community connections or safeguarding, with only a small amount focusing on finding information (Wang et al., 2017). This body of literature demonstrates that there are various reasons for consumers to use eWOM. In this sense, some consumers use online platforms to gain a feeling of community solidarity (King et al., 2014; Liang & Scammon, 2011; Schindler & Bickart, 2004). Interestingly, Obst and Stafurik (2010) argue that this is a reason for PWD to engage in online communities in a more general sense.

Second, according to Bensing et al. (2000, p. 2), “patients are experts in the experience with their symptoms, and physicians are dependent on patients for this expertise”, and consumers often have expertise that outweighs that of the clinician. This resonates with the peer support literature outlined in Chapter 3 and even notions surrounding personalisation that challenge power norms by “acknowledging ‘lay’ forms of knowledge and expertise” (Mladenov et al., 2015, p. 309). Liang and Scammon (2011) argue that this shared expertise suggests that policymakers could be leveraging eWOM for shaping public health interventions and outcomes. By inference, it might also be able to be leveraged for market stewardship.

Third, consumers use eWOM, particularly social media, because there is a far greater number of people from whom to seek advice. In particular, the internet gives consumer access to “weak ties” (King et al., 2014; Schindler & Bickart, 2004), which are “connections that previously would have been isolated and hard if not impossible to connect” (King et al., 2014, p. 171). Because of this dynamic, consumers have more and potentially higher quality information and can access information that may be more credible or reliable due to the presentation of both negative and positive experiences from people who have (assumedly) first-hand experience. Finally, consumers are able to consider providers to which they would otherwise not have been exposed (Constant et al., 1999). However, it also means that the quality of the information is more difficult for consumers to assess (King et al., 2014).

### 4.6.2 Gaps in the literature about channels

This section has outlined the limited evidence that exists relating to which channels are most effective for informing consumers in social service sectors. Much of the literature reviewed has been taken from healthcare or wider industries and, as with previous sections, the applicability of this evidence to the disability sector is unknown.

Additionally, much of this literature has been drawn from the fields of marketing and/or behavioural economics; while some of it is driven from public health concerns, most is concerned with increasing the success of marketing campaigns and has little interest in positive health or social justice. Therefore, while some interventions may be successful from a marketisation perspective, they may not realise social justice outcomes. There are also some particular issues related to PWD that are likely to impact the relevance of this evidence to the NDIS context. For example, PWD have unequal access to digital resources (Goggin, Hollier, & Hawkins, 2017), which means that eWOM sources of information may be less accessible to them, with implications for market stewardship interventions around larger-scale digital equity issues. All these issues present gaps in the literature, and those that have already been identified continue to be relevant in this section relating to media and channels of information. For example, there is evidence around the need for diverse media, but the lack of bottom-up evidence results in what it means to a customer to feel informed being unknown.

## 4.7 Chapter Summary

This chapter has provided a review of the literature relevant to the research topic. It has looked at quasi-market stewardship, navigating complex systems, decision-making, information use and media requirements. It has demonstrated that there is very little direct evidence about what information is needed to support consumer decision-making and service navigation in the NDIS environment. Those papers that address the topic have come from particular niche perspectives, such as mental health, and create an ad hoc body of literature rather than a deep or broad exploration of NDIS market stewardship. Healthcare and other social service marketplaces provide some evidence that infer knowledge relevant to the disability space, but there is no certainty around applicability to this context. There is almost no literature examining what consumers think they require to be informed or taking a rights-based social justice perspective; rather, most of the literature has come from a public health or marketisation approach. Knowledge and evidence are mostly top-down rather than consumer-centred, and very little is known about the information consumers need to feel informed when they make purchase decisions about disability services and about how to provide information to consumers. Regardless of whether the social justice or marketisation approaches are prioritised, these gaps are problematic, which this thesis will contribute to filling.

This chapter has also provided many examples about the practical reasons market stewardship needs to be developed. These have been primarily related to making information easier to find and use in order to increase the ease and efficacy of consumers making decisions about NDIS service providers. Most knowledge until this point has been driven from a top-down approach examining how consumers are likely to behave or what their needs are likely to be, rather than what is important to them and what makes them feel informed and confident to make a decision. It is the latter condition that is most likely to create a vibrant NDIS industry that supports rights through a thriving marketplace full of innovative and responsive service options. This is the most desirable outcome from both social justice and marketisation approaches.

To successfully see consumers' rights placed at the centre of the NDIS, relevant research must be conducted with consumers to produce knowledge that informs market stewardship in this context. To transfer this knowledge into practice, solutions must be designed with each stakeholder in order to ensure success and accountability for them all. This is important from social justice as well as marketisation perspectives. If tensions due to the existence of dual problematisations cannot be resolved, the NDIS may not meet its outcomes and the expectations of all stakeholders, and ultimately the consumer is likely to be the group whose priorities will be disregarded (Fawcett & Plath, 2014). A logical first step in constructing informational resources for the NDIS is to conduct an exploratory study to uncover what consumers need to know so as to make an informed choice and how they might come to know it. The next chapter will describe how to conduct such research and will do so using an anti-oppressive methodology aligned with both the Bacchian interpretivist theoretical approach explained in the previous chapter and a social justice approach.

# 5 Methodology

## 5.1 Introduction

The issues described in Chapters 3 and 4 have demonstrated a high level of complexity in the NDIS marketplace, which is the result of multiple sets of values, stakeholders and priorities in policy, theory and practice, as well as an implementation that is taking place at a high speed. In order to explore this environment thoroughly, such complexity must be taken into account in the research design; in this regard, a simple, linear or test methodology will be insufficient for exploring the issue at hand. Therefore, this thesis takes a practice research framework, which is a social work methodology specifically designed to take complexity into account.

While this research looks broadly at some of the issues arising in the NDIS environment, it is designed to interrogate the information needed by consumers to support decision-making about NDIS providers. This research project emerges from a need for better information that has been identified by the community through the researcher's own practice. It is highly relevant to families who need to navigate the NDIS, in addition to also being relevant to professional service navigators and social workers who may be employed in support coordination, brokerage, personal assistance or planning roles in the NDIS environment and will need to provide information as part of their role in supporting consumers' decisions regarding the purchase of support services. It is also highly relevant to advocacy groups, peak bodies and governments involved in market stewardship because they can use it to inform legislation, policy and practice. Likewise, it is relevant to suppliers of disability support who may alter their governance, policies or procedures to ensure that the industry is designed in a way that supports informed decision-making and high-quality service provision.

This chapter begins by describing the context of the research. It examines the frameworks that support the approach, drawing from other anti-oppressive methodologies of Indigenous and disability research principles. The chapter then outlines and justifies the research design. It describes the research questions and the use of mixed methods with different stages and different types of data collection, showing that the methodology used in this project ensures a model of informed choice-making for consumers, grounded in the market stewardship literature. It is worth noting, given the fast pace of change of the NDIS, that data were collected across 2017 and 2018. This chapter further demonstrates that the design of the research itself complements the overall practice research goals and the social justice aims of the project.

## 5.2 Approach

In line with its social justice aims, this research takes a capacity-building approach through its methodology, seeking to add value to individual participants and the disability sector as a whole, while generating information for the purposes of research. The methodology seeks to parallel the content, placing the objective of increasing consumer literacy and facilitating an exchange of knowledge between stakeholders at the centre of the collection, analysis and dissemination of data.

There are three broad areas that support both anti-oppressive theory and practice that this methodology draws from: social work practice research, in its ethical framework and stance with practice-based research principles (as per AASW, 2010; Epstein et al., 2015); emancipatory disability research theory, which responds to the history of oppression of PWD described in previous chapters; and anti-oppressive research, which has been further developed through approaches contained in Indigenous research theory (e.g. AIATSIS, 2011; Humphrey, 2000; Laycock, Walker, Harrison, & Brands, 2009; Pyett, 2002a, 2002b; Walker, Eketone, & Gibbs, 2006). This section describes each of these approaches before highlighting three of the principles they share that are included in this methodology: capacity-building and benefit to participants, advocacy for social justice, and collaboration between stakeholders. It then describes how and why this research incorporates these principles.

The first paradigm is the social work practice research approach, which has been defined and redefined through a series of papers developed out of the discussion between international social work researchers over the period of a decade. The first iterations (see Austin et al., 2014; Salisbury Forum Group, 2011) began by looking at the relationship between social work research and practice, describing them as intertwined and relational (Epstein et al., 2015). These statements set out goals that guide social work practice research to align with social work ethics, including concepts such as critical reflection, curiosity, collaboration and participation, contending that "practice research involves the generation of knowledge of direct relevance to professional practice and therefore will normally involve knowledge generated directly from practice itself in a grounded way... [it is] a meeting point between practice and research" (Epstein et al., 2015, pp. 711–712). These statements also describe the robustness and rigour of methodologies, including the way that the dissemination of results and engagement of stakeholders should occur to align with this approach. The latest iteration of a statement regarding social work practice research in the New York Statement of 2014 added the issue of evidence-informed practice to the conversation around practice research, in addition to also creating significant discussion about the central role of service users in research and the need to holistically account for diversity in the design of research, which includes "expand[ing] stakeholder involvement… to multiple stakeholders that include service users" (Epstein et al., 2015, p. 713). It is this point that is most relevant to the rest of this section, which will be further developed by looking at critical anti-oppressive disability research methods and Indigenous emancipatory research methods.

The practice of critical disability research has developed because PWD and their carers have often been the subjects of targeted research through a medical model understanding of disability, policy and intervention that has been rooted in a paradigm of oppression and marginalisation (as described in Chapter 3). As Goodley (1999) explains, "disability research with participants can fall into research on participants—when the only person benefiting is the researcher and their career aspirations" (p. 46). Research design has often been so divorced from the needs and realities of the community that its members have disputed the legitimacy of the resulting data or disregarded it altogether (Oliver, 1996; Stone & Priestly, 1996).

Building disability research design around an epistemology of emancipation is imperative to remedying this history and aligning policy and practice with social work values of advocacy, human rights and social justice. In this regard, there have been considerable developments in critical disability research practices (Goodley, 2013; Oliver, 1992, 1998; Stone & Priestly, 1996; Tregaskis & Goodley, 2005). Alongside the social model, these practices view PWD and their allies as customers of services, rather than as beneficiaries of charity (Stone & Priestly, 1996b). Research methods must challenge colonial history through practices of advocacy, empowerment and emancipation and the adoption of contemporary models of disability (Dewsbury, Clarke, Randall, Rouncefield, & Sommerville, 2004; Gilbert, 2004; Goodley, 1999; Humphrey, 2000; Oliver, 1992, 1996; Stone & Priestly, 1996). Specific techniques for ensuring these practices are realised through research are discussed below.

The third and final approach discussed here is Indigenous research, which is utilised because although the researcher does not identify as Indigenous, there is extensive value and applicability of these approaches to social work practice research and disability research in particular. Anti-oppressive disability research practices have been likened to those described by other minority gender, age, race and sexuality groups (Beckett & Wrighton, 2000; Dewsbury et al., 2004; Goodley, 1999; Stone & Priestly, 1996). Indigenous literature, in particular, offers a broad and contemporary view of anti-oppressive epistemological research paradigms with anti-oppressive, post-colonial themes similar to those in the disability literature (AIATSIS, 2011; Humphrey, 2000; Laycock et al., 2009; Pyett, 2002b, 2002a; Walker et al., 2006). This literature outlines various theories for ethically designing, implementing and evaluating Indigenous and disability research; for example, the Australian Institute of Aboriginal and Torres Islander Studies calls for "full participation" of Indigenous communities (AIATSIS, 2011), Pyett, Waples-Crowe, and van der Sterren (2009) outline collaborative participatory practices, and Laycock et al. (2009) describes "holistic" methods. Additionally, some Indigenous research models offer a less prescriptive process and are more of an approach to engagement, e.g. Kaupapa Maori principles of Indigenous research, described by Walker et al. (2006, p. 333) as "more and less than a paradigm, a form of resistance and agency, and a methodological strategy". These echo social work practice research principles, which describe themselves as "a meeting point between practice and research that needs to be negotiated every time and everywhere it is established rather than a specific research method" (Epstein et al., 2015, p. 712).

Ethical research practices are well developed in the Australian Indigenous context and are highly relevant to Australian disability research, an example of which is Australia's National Health and Medical Research Council (NHMRC) guidelines. The NHMRC is a commonwealth-funded peak body for health research, whose role it is to develop and monitor ethical standards for the $AUD900 million of research it funds each year (NHMRC, 2019). While the NHMRC Road Map for Indigenous health research is based on the concept of research as advocacy in order to advance wellbeing (NHMRC, 2002), NHMRC guidelines on conducting research with PWD are primarily centred on concerns about participants' capacity to consent rather than on building capacity (NHMRC, 2007). This is testament to how much work there is still to do in disability research and policy and the need for sensitive practice research that adheres to the principles common to all three approaches. These issues will be discussed in the following sections.

### 5.2.1 Shared principles of the approaches

Social work practice research, critical disability research and Indigenous research frameworks all incorporate principles of emancipatory or anti-oppressive research. They have themes in common, notably building the capacity of participants of research and ensuring that research can be used for advocacy and social justice in a practice context. Many of these themes have also been incorporated into mainstream research principles, including those set by the NHMRC (2002, 2007). While they use different language, all three of these bodies of literature share key principles: capacity-building and ensuring benefit to participants, using research as advocacy for social justice, and co-creating and involving multiple stakeholders.

#### 5.2.1.1 Research as advocacy

The first shared principle is that research should advocate for social justice and change for participants' lives. Advocacy is 'inherently political' (Buckley, 2007), and emancipatory research practices are political in nature. The NHMRC Road Map for Indigenous health research calls for community inclusion and participation in the research process, holding notions of shared expertise and equality between researcher and research subjects and capacity-building (NHMRC, 2002), i.e. research should promote "resilience and wellbeing" (NHMRC, 2010). In the practice research literature, this is described as "a commitment to empower and address social justice issues through practice" (Epstein et al., 2015, p. 711). In critical disability studies, it has been described as "accountable disability research" (Goodley, 1999, p. 43) that is "based on the social model of disability and aims to promote social change" (Gilbert, 2004, p. 301) by "challenging oppression and facilitating the self-empowerment of disabled people" (Stone & Priestly, 1996, p. 6).

#### 5.2.1.2 Capacity building and benefit to participants

The second shared principle is that research should not only contribute to general advocacy but also realise immediate improvements and practice benefits to participants (Oliver, 1992). In the disability literature, Stone and Priestley (1996) describe the function of a researcher as an agitator for this end by asking: "What will the research achieve in terms of improving the lives of those whose selves become 'sources' and whose meaning becomes 'material'?" (p. 6) The outcome for participants of research as well as the community as a whole is central. This sentiment of capacity-building and benefit is also found in the social work practice framework, which states that "findings [should be] interpreted and disseminated through dialogue with service users and practice [so that they can address] concrete and pragmatic issues" (Epstein et al., 2015, p. 712). Finally, Indigenous literature uses the term "reciprocity" (NMHRC, 2003) to describe the dynamic of ensuring that participants as well as researchers realise positive outcomes from the research. Knight et al. (2004) describe these as "research outcomes that provide equitable benefits of value to Indigenous communities or individuals" (p. 4). In all studies, these benefits should be defined by the communities themselves. In this study, the topic came directly from practice, and the research findings will inform future work.

#### 5.2.1.3 Collaboration and co-creation

In this same vein, the final principle is that research should involve collaboration with community members and research participants. Research conducted through a practice research or other social justice lens has the capacity to contain diversity and empower heterogeneous communities, such as the disability community. This is important because the same sense of suspicion that keeps consumers of disability services from trusting service providers (Walsh et al., 2012) keeps them from trusting researchers. Especially within a medical model environment, PWD have been the subjects of research, often without consent, and have shared deep and vulnerable information about themselves without receiving the benefits of the research (Goodley, 1999; Oliver, 1992). Additionally, PWD are asked so many questions about themselves in the course of accessing services that voluntarily doing research may be one request too many. This is the point of the critical disability research paradigm – ensuring that research comes from the community and is controlled by the community, promoting a sense of importance and safety (Stone & Priestly, 1996). The same principle in the Indigenous literature discusses the importance of community control of the research and collaboration with research team (Isaacs et al., 2011; Pyett, 2002a; Pyett, Waples-Crowe, & Sterren, 2008; Pyett et al., 2009). Social work practice research instructs research to "expand stakeholder involvement and dialogical methods from an earlier focus on practitioners and researchers to multiple stakeholders that include service users, educators, agency managers, and policy makers [in order to create] ...shared value creation and shared understandings" (Epstein et al., 2015, p. 713) around the priorities of research. Each of these three approaches have a clear link to collaboration with consumers. There is one further concept this thesis uses with regard to consumer collaboration: knowledge exchange.

### 5.2.2 Knowledge exchange

A principle that informs the collaborative, eco-systemic approach in this thesis is knowledge exchange, in which researchers, research subjects and other stakeholders all learn from one another and create a social impact (King, 2014). It is a communication process that turns the monological tradition of empirical evidence into a dialogue – data is interpreted and shaped by multiple partners and stakeholders. This thesis adapts and develops the idea of knowledge exchange, combining it with the three principles above to create an active, collaborative research process informed by an epistemology that comes from lived experiences of disability.

Using the concept of knowledge exchange, research can be used to weave together different epistemological paradigms, essential in the disability sector where principles of diversity apply. The idea of exchanging knowledge in this thesis is used to weave together the diversity that exists between different stakeholder viewpoints and overcome some of the mistrust and rivalry that was identified in the previous chapter (Walsh et al., 2012) in order to examine what commonalities exist between the experiences of service users. In weaving these views together and taking a practice-oriented approach, advocacy, community development, education and social action are intertwined and non-linear. This aligns with the practice research approach, which describes a process of "dialoguing with a polyphony of voices" (Austin et al., 2014, p. S10).

Like the Kaupapa Maori research paradigm (Walker, Eketone, & Gibbs, 2006), the knowledge exchange model is more of a conceptual guideline than an instructional manual. In complex sectors such as disability, where the subjective and diverse lived experiences of institutionalism, exclusion and prejudice interplay with 'objective' demographic and epidemiological realities, knowledge exchange can provide a means to connect these paradigms. Equally, it can connect diverse disabled and non-disabled epistemologies: the phenomenological, qualitative, community-based knowledge that contrasts starkly with the positivist economic rationalism that drives a majority of health and welfare policy. Knowledge exchange provides a pathway to advocacy and empowerment in both research and practice (King, 2014). It links well with other principles of disability research, which will be discussed next.

### 5.2.3 Principles of disability research

To satisfy the need for plurality, Stone and Priestly (1996, pp. 10–11) created the following six principles to guide empowering research with the disability community:

1. The adoption of a social model of disablement as the epistemological basis for research production.
2. The surrender of claims to objectivity through overt political commitment to the struggles of disabled people for self-emancipation.
3. The willingness only to undertake research where it will be of practical benefit to the self-empowerment of disabled people and/or the removal of disabling barriers.

4. The evolution of control over research production to ensure full accountability to disabled people and their organisations.
5. Giving voice to the personal as political whilst endeavouring to collectivise the political commonality of individual experiences.
6. The willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people.

These six points reflect the theory discussed in Chapters 3 and 4, as well as the shared principles described above.

While this thesis has academic goals and is designed to make a clear contribution to the market stewardship literature, it is situated firmly in a context of practice and is intended to have wide dissemination and influence in order to impact on and improve current practice. The research methodology for this thesis is informed by a practice research paradigm, where the topic arises from a critical practice need and the results of the research feed back into practice (Epstein et al., 2015). Thus, through its academic contribution, this project seeks to achieve the following practice outcomes:

- Create interdisciplinary knowledge that will inform practice via dialogue from and between multiple stakeholders.
- Create a framework for information that will inform consumer choice-making under the NDIS.
- Privilege the social justice approach of personalisation, empowering PWD with data that will help to reduce information asymmetry in the disability sector.

Research questions and methodology were designed to accomplish these practice goals at the same time as making a significant contribution to the academic literature.

### 5.2.4 Goals of this research

With the above six principles in mind, specific goals for this project were developed in order to ensure that it would meet the research aims of emancipatory research, incorporate mixed methods, and include research as advocacy, capacity-building, benefit to participants and collaboration:

1. Gathering feedback from community members on research design and results prior to, during and after research.
2. Carefully developing appropriate consent and confidentiality tools.
3. Ensuring that immediate benefit is reaped by individual participants and groups simply through their participation.
4. Using reflection with participants and other community members to triangulate the interpretation of results, both during and after data collection.
5. Distributing results in lay language to participants.
6. Distributing results to the wider community, stakeholders and policymakers.
7. Embedding accountability processes for results being actioned.

The project was conducted in several phases, where each phase informed the next and the learnings from one was fed into the other, thus helping to build practice and knowledge through meeting these seven goals.

## 5.3 Research design

The main research question emerged from consideration of the issues identified in practice and discussed in the first three chapters: *What information do service users want in order to feel informed about the purchase of disability care?* This primary question was further divided into three sub-questions in order to be able to form a response from participants:

- How do service users currently make choices?
- How do service users wish they could make choices?
- How would service users advise others to make choices?

This research designed a methodology within which these questions would be predominant and out of which data could be drawn about whether NDIS service users feel their decisions are, or would be, informed.

This study used mixed methods in order to meet the need for the plurality of approaches described within the emancipatory and social work research practices. According to the disability literature, traditional positivist approaches such as randomised control trials do not support multiple voices and multiple truths in the way that a qualitative paradigm can (Stone & Priestly, 1996). However, a qualitative methodology does not necessarily remove disabling barriers, nor does it illustrate wider patterns of disablement at a societal level. Like the critical and human rights models of disability bringing new angles to the social model, there is a need to use both qualitative and quantitative approaches to research in order to fully explore the complex nuances of oppression (Stone & Priestly, 1996).

A pragmatist approach has been adopted in order to bring together these multiple requirements. Pragmatism accepts that multiple truths and realities can exist, and and it offers a way to bring together these pluralities in a way that is suitable for the particular research context, based on the desired outcome of the research. In this colourful example provided by Kaushik and Walsh, (2019), the differences between positivism, constructivism and pragmatism are illustrated.

> For a more positivistic researcher, an object with flat surface and four legs would always be a table. For a constructivist, based on her/his perspective, the same object would be a table if s/he was eating off it, a bench if s/he was sitting on it, and a platform if s/he was standing on it. However, a pragmatist would define the object based on its utility, for instance, the object would be a table if s/he intends to eat off it, a bench if s/he intends to sit on it, and a platform if s/he intends to stand on it. In this example, it is important to notice that the pragmatist would not define the object based on what it is or what it is being used for, but rather based on how it would help the pragmatist achieve her/his purpose (Kaushik and Walsh, p. 4).

In this way, it is highly appropriate for a social work approach to adopt a pragmatist approach in order to bring together rigour and subjective experience. It is appropriate for this thesis in particular, where there are goals which include practical outcomes around market stewardship and consumer rights. Despite the interpretivist stance of the researcher to epistemology, a pragmatist approach is taken. Within this paradigm, preference is given to the qualitative framework in this thesis as it is congruent with the anti-oppressive methodological approach as well as with practice research principles (Creswell, 2009; Stone & Priestly, 1996). Likewise, the incorporation of knowledge exchange principles supports these goals of plurality and practicality.

Data was collected through a sequential mixed method design conducted in three phases (Creswell, 2009). The first phase of data collection for this research utilised semi-structured interviews, which were exploratory, using qualitative consultations to validate and refine interview scenarios, the interview schedule and facilitation tools (Kvale, 2007). Thematic repetition was sought through Phase 1 to ensure that the case studies and probing questions were effective and to identify and fix any methodological problems and validate the interview schedule and accompanying tools. Phase 2 extended the interview sample and saturated results, which were used to create the survey tool for Phase 3 (Gibbs, 1997; van Teijlingen & Hundley, 2001). Phase 3 was a survey, which was used to test the generalisability of results found in Phases 1 and 2 with a larger and more diverse audience. Table 5 provides an overview of each phase alongside the goals (described above) that were met with each phase.

| Phase | Purpose | Method | Format | Goals (p. 84) |
|---|---|---|---|---|
| Phase 1: Semi-structured interviews | Test and refine interview schedule in both one-on-one and group format | Qualitative | 1 x interview and 1 x focus group (total 5 participants) | 1, 2, 3, 4 |
| Phase 2: Semi-structured interviews | Extension of qualitative sample | Qualitative | Extension of sample (total 23 participants) | 1, 2, 3, 5 |
| Phase 3: Survey of NDIS stakeholders | Extension of sample for triangulation and testing generalisability of results | Mixed methods – quantitative questionnaire plus qualitative explanations | Survey (total 201 participants) | 1, 2, 3, 6 |
| Phase 4: Participant reflection and dissemination | Participant feedback | Qualitative reflection | Blog, email to participants, emails back from participants | 1, 3, 4, 5, 6 |
| | Distribute results, including back into practice paradigm | Distribution of results | For example, thesis, publications, blogs, and talks | 6, 7 |

*Table 5: Summary of the research methodology*

## 5.4 Ethics

After finalising the research design, ethics approval was sought prior to the study's commencement and was gained in July 2016 through University of Melbourne's Arts Faculty's Human Ethics Sub-Committee (see Appendix 1). The major risks identified were:

1. The potential for a participant's capacity to give consent to be limited by their disability.
2. Social pressure on participants to take part in the interview if prompted by their service provider.
3. Participants experiencing distress.
4. Divulging confidential information.

These issues were mitigated by using plain language statements with regard to verbal and written consent; ensuring interviews took place outside of service provider infrastructure; and allowing participants to have support people where requested. Interview participants were supplied with a plain language statement (PLS) outlining the project (see Appendix 2).

Directly before the interview, the PLS was explained verbally and consent was gained verbally and audio recorded.

These potential risks were judged to be outweighed by the potential benefits for both the participants and PWD in general. Exclusion criteria supported the ethical structures by ensuring that participants were able to give informed consent (as per Table 2 above). The study was carefully designed to minimise the potential risks for participants, and it was observed that participants welcomed the opportunity to share their views and experiences as they had previously had limited opportunities to do so. Furthermore, the interviewer was a social worker, sensitive to the emotional experience of the participants, connected to referral networks, and able to deal with any distress responsibly and supportively. The low risk of participants experiencing discomfort or distress was outweighed by the importance of their experience and voices being represented in research into changes to disability services that directly affect them. The protective rights accorded to at-risk groups in qualitative research need to be considered alongside other human goods, such as the promotion of voice, agency and active citizenship – to which the interview material is directed.

Confidentiality was upheld by separating personally identifiable information from the results, which were marked with allocated participant pseudonyms while all participants were de-identified in reporting. Data was stored securely on the researcher's personal computer and backed up using cloud storage services, both of which were password-protected.

## 5.5 Phases 1 and 2: Semi-structured interviews

The first two phases of research were conducted using a qualitative semi-structured interview format. Creswell (2014) recommends exploring processes, activities and events by using such methodologies. In the case of this research, which sought to explore the processes, activities and events surrounding decision-making about services, such an approach was well suited and helped to create a situation in which participants could consider the research question and sub-questions. Scenario simulation was used in the interviews.

### 5.5.1 Interview design

Scenario simulation uses a set of "hypothetical events set in the future" that allow participants in the process to imagine themselves in this future (Kahn, as cited in Amer, Daim, & Jetter, 2003, p. 23). This futurist technique has grown in popularity since the Second World War and has been increasingly adopted by corporate organisations and governmental bodies to identify possible futures and make better choices (Chermack et al., 2001). Coates (2000) describes the reason for the increase in popularity of this type of methodology: "The world has become more complex and at the same time it presents ever larger elements of ignorance or unfamiliarity… Scenarios come to the rescue. They are educational, and integrative in dealing with the complex new factors" (p. 2). Integrating education and stimulating thought about complex new factors in an uncertain future has applicability for capacity-building with participants as well as considering the disability sector at present. This approach was suited to the present study because talking about choice and control is difficult and abstract, and having a scenario that allowed the participants to externalise and objectify their experiences was useful for generating data.

Scenarios were constructed through the method described by Coates (2000) and validated through the factors outlined by Amer et al. (2003), as listed in Table 6. Phase 1 sought to solidify these steps and, in particular, to evaluate the scenarios as per Stage 6 of Coates' (2000) stages of constructing scenarios. The scenario simulation took the form of a semi-structured interview in three sections.

| Factors for validation of scenarios | Stages of constructing scenarios |
|---|---|
| • Plausibility, that the scenarios could reasonably occur;<br>• Consistency, that the scenarios are internally logical and valid;<br>• Relevance, that the scenarios are meaningful and have utility to participants;<br>• Differentiation, that there are at least two scenarios so as to identify variation between possible futures;<br>• Creativity, that the scenarios change the participants' thinking<br>(Amer et al., 2003, p. 36). | 1. Identify the area of concern<br>2. Define the important variables that will shape outcomes<br>3. Identify themes<br>4. Create the scenarios<br>5. Write the scenarios<br>6. Evaluate the scenarios<br>7. Optional: Create a uniform style between the scenarios<br>(Coates, 2000, pp. 3–4). |

*Table 6: Constructing and validating scenarios*

The semi-structured interviews were conducted through four activities:

1. The first asked participants to give advice about sources of information to assist others' decision-making.
2. The second asked them to analyse the advice they had given.
3. The third asked them to rank the sources they had identified.
4. The fourth was a short reflection activity.

Demographic information was also collected from interview participants. The full interview schedule can be found in Appendix 3. These activities will now be described in detail.

#### 5.5.1.1 Advice activity

In the first activity of the interview, participants were presented with four scenarios that followed a hypothetical journey through the NDIS. These scenarios were constructed by the researcher and emerged directly from professional practice in the field. They were influenced by events that frequently occur for colleagues, practitioners and other service users in the NDIS service navigation space. In this way, the issues that led to the formation of the question also led to the formation of the scenarios. Scenarios were as follows (see Appendix 3 for accompanying images and text):

1. The first scenario was Brian, who had received an NDIS package and needed to choose a support coordinator.
2. The second was Naomi, who had support coordination and needed to choose an attendant care agency.
3. The third was Lim, who needed equipment.
4. The fourth and final one was Mamadou, who needed an allied health sole trader for his son who had autism.

Only the final scenario mentioned a particular diagnosis; all other scenarios simply outlined support needs in order to be in line with NDIS policy.

Participants' answers were explored for detail on two issues. The first was what sources of information could be used, and the second was what content such information should include. The semi-structured nature of the interview meant that participants were asked some or all of the following questions about each of the four scenarios (Petrakis & Laxton, 2017):

- What should they ask to help them decide? Who should they ask?

- What other things should they do to help them decide?
- All things being equal, which should they choose?
- Do you have any other advice for them?

Questions prompted participants to offer advice on each scenario, reflect on their own experiences, and imagine what information they would ideally want. This multi-layered approach was taken in order to triangulate and internally validate participants' responses through hypothetical, experience- and advice-based responses. All comments, sources and content were recorded. This allowed participants to visualize and remember sources they had already listed and have a visual representation of how much content they had generated for each scenario.

This advice activity was designed to answer sub-question 3: *How would service users advise others to make decisions?* This activity also elicited some interesting vignettes about participants' own experiences, which addressed sub-question 1: *How do service users currently make choices?* It generated information that would contribute to materials comprising Phase 3 and met goals 1, 2, 3 and 5.

#### 5.5.1.2 Analysis activity

This second stage of the interview conducted an initial round of content analysis with participants, which was implemented to ensure that the research was in line with the principle of collaboration and co-creation outlined in the research approach above. The analysis activity was conducted using a critical reflective research practice (Glaser & Strauss, 1967), asking participants to arrange the sources of information into themes. In order to accomplish this, participants were probed with questions that elicited information about the parent/child relationship of the thematic content they had produced. An example of this process can be found in Figure 7. By allowing patterns to emerge from the data through this collaborative approach, a range of service-user voices were presented through the research. This process gave further insight into why the advice had been given, was highly participatory, and also informed the formal analysis of the data. It met research goals 1, 3 and 4, in addition to also meeting the research design goal of preparing material (top themes that are important) for Phase 3.

**Researcher:** Customer service came up a few times, price came up a few times, communication came up a lot, didn't it? "Are you going to make me feel looked after," "Are you going call me on the phone," or customer service. Is that the same thing… are customer service and communication the same thing?

**Interviewee:** Yeah, I think so, yeah. Probably… customer service is probably a bit of a broad term. Yeah.

**Researcher:** Okay. Does it mean something else? Separate to communication?

**Interviewee:** Yeah, probably, yeah… communication probably fits underneath customer service, I think.

*Figure 7: Example of participant reflection*

#### 5.5.1.3 Ranking activity

This third activity was designed to deliberately explore reasons and experiences for the value participants placed on different information sources. Participants were asked to select their three favourite sources of information and to rank them in order of how desirable the sources were in relation to one another. Most participants shared why they chose those three and explained why the sources were the most desirable. This activity addressed sub-question 2:

*How do service users wish they could make choices?* It also accomplished the goal of preparing materials (a ranked top 10 sources) for Phase 3.

#### 5.5.1.4 Reflection activity

In this fourth and final activity, participants were asked which scenario they found easiest to give advice for and why. They were also asked to reflect on what they had learned throughout the interview that they found unexpected or was new to them. This activity met goal 4 and was primarily in support of knowledge exchange and contributing to an ongoing Phase 4, extracting value and ensuring that participants felt they had seen benefit to themselves as well as to the research process. It also became a rich source of data and contributed to answering the primary research question and all three sub-questions.

#### 5.5.1.5 Demographic information

Demographic information was drawn from participants alongside these activities. It was drawn first from objective measures that the literature review suggested may be causal of various behavioural differentiators (i.e. age, area of residence, gender, and highest education level achieved). It had a secondary measure of how much experience the participant had with relevant choice-making, which was allocated 3 points (significant personal or professional experience), 2 points (experience once or twice), or 1 point (little experience).

### 5.5.2 Interview data collection

Phase 1 piloted the interview schedule by applying it in one interview and one small focus group. The Phase 1 sample was drawn from the researcher's immediate professional network. Phase 1 was successful in meeting its aims of testing, iterating and validating the tools and schedule for Phase 2. This is illustrated in Figure 8. Methodological problems were saturated after consultation with four pilot participants.

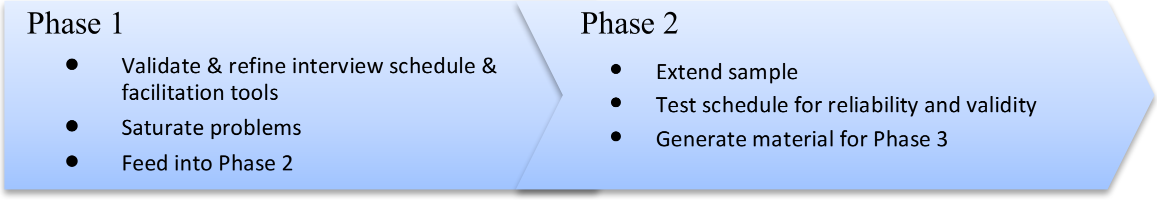


*Figure 8: Phases 1 and 2 aims*

#### 5.5.2.1 Focus groups vs interviews

Phases 1 and 2 used a combination of focus groups and interviews (see Figure 9 for details). The intention behind using focus groups as well as interviews was to examine the interaction between participants in order to elicit data regarding their experiences and needs (Gibbs, 1997), a method in line with knowledge exchange principles that value community participation and meeting. Focus groups were comprised of up to four participants, which is on the low end of a regular focus group size (Kitzinger, 1995). "Mini-groups" of this size are used for several reasons; first, as a result of recruitment challenges, where there is a small population size, the resources needed to secure more participants are greater. Second, it also helps to facilitate participants' involvement. Greenbaum (1998) also acknowledges "the general unwillingness of some target groups to be involved" (p. 3), and having smaller groups is a tool to increase the salience of the topic to the members of the group and encourage their genuine input (Gibbs, Sangl, & Burrus, 1996).

Interviews lasted around 45 minutes, whereas group sessions lasted around 90 minutes. Phase 2 was informed by Phase 1, in that adjustments from the first stage were incorporated into the focus groups and interviews. Phase 2 incorporated the adjustments drawn from Phase 1. Focus groups continued to run for around 1.5 hours (Gibbs, 1997) and interviews for around 60 minutes.

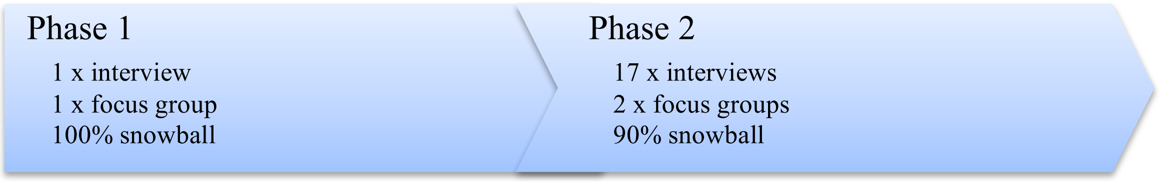


*Figure 9: Phases 1 and 2 implementation details*

#### 5.5.2.2 Sample

Participants opted into the research during informal discussion of the research process, following which a formal invitation was extended via email and/or direct messaging on social media (see Appendix 2). All participants were given a $30 Coles gift voucher as a token of thanks. All participants aligned with nominated inclusion and exclusion criteria that were designed to ensure that they were able to offer appropriate information and to do so safely and in line with ethical considerations (see Table 7).

| **Inclusion Criteria** |
|---|
| ● People who have made a decision in the past about which service provider to use through any disability scheme (e.g. NDIS, TAC, Workcover, and ISP)<br>● Carers, family members, support workers and case managers of people who have chosen providers |
| **Exclusion Criteria** |
| ● People (or their carers, parents or support workers) who are unlikely to be eligible for either NDIS payments or ILC services, or whose conditions are treated in a healthcare context only<br>● People aged under 18<br>● People who are unable to legally give consent<br>● Carers/support workers when the interviewee is the person with disability |

*Table 7: Inclusion and exclusion criteria*

It is noteworthy that the inclusion criteria lists not just consumers, but also “carers, family members, support workers and case managers”. This is in line with the articulation of the research question in Chapter 2, where it is noted that various stakeholders are involved in decision-making about NDIS services, and argued that market stewardship concerns all of them. This is aligned with the theory underpinning this thesis, which is that various different priorities, conflicts and other issues to do with marketisation and social justice exist and interplay in the NDIS environment. As an initial piece of research in this area, this study includes all stakeholders, and examines results for evidence of similarity and difference between their opinions.

The researcher created partnerships with six disability service providers, peak bodies and advocacy networks in an attempt to purposively sample focus groups so as to have representation from the major segments of the NDIS marketplace, thereby increasing the chances of this research being generalisable. These providers and advocacy groups represented carers, people with physical disabilities, intellectual disabilities, parents, people with psychosocial disabilities, support workers and professional care coordinators across Australia. Two relationships were formalised through approved research applications to the organisations. Despite such extensive formal and informal networking, very few interview participants came to the study through these relationships. Some who were connected with the project, particularly carers, declined to participate when they learned that it would take up to an hour of their time.

This purposive sampling was therefore combined with snowball sampling in order to generate a sample size that would meet the aims of Phase 2. The majority (90%) of the sample for Phase 2 was gathered through the researcher's own network, primarily through posting on social media (see Appendix 7 for the advertisement). In order to make it easier to achieve the aim of thematic saturation, focus groups were supplemented with further one-on-one interviews. A breakdown of the way in which each group participated can be found in the table below. By the end of Phase 2, the following groups were represented by the research participants, all of whom are variously linked to disability:

- Carers of people with intellectual or cognitive disability;
- People with physical disability;
- People with psychosocial disability;
- Parents of children with disability;
- Support workers; and
- Referrers, planners or care coordinators.

It should be noted that this due to the snowball sampling technique, this sample did not include consumers with a diagnosis of intellectual disability.

| | |
|---|---|
| **Focus group 1** | 3 x carers |
| **Focus group 2** | 3 x referrers, planners, and care coordinators |
| **Focus group 3** | 2 x carers |
| **Interviews** | 1 x carer<br>6 x professionals<br>8 x PWD |

*Table 8: Stakeholder roles of participants in the interviews*

#### 5.5.2.3 Changes made after Phase 1

There were two minor changes made to the scenarios as a result of the pilot, the first of which was to make all scenario consumers over 18 so as not to confound answers with issues relating to consent. There was also a short disclaimer added to the start of the equipment-based scenario: "Let's assume all three providers can give her exactly the wheelchair she wants." This ensured that the discussion centred around the quality of the provider rather than the equipment.

Phase 1 demonstrated that the jargon used in the interview specifically related to the NDIS process. While all participants were familiar with personalised schemes, not all had been through the NDIS assessment process or familiarised themselves with the policy. The researcher refined some of the preamble to include information about NDIS Local Area Coordinators and the role a support coordinator plays in the NDIS system.

In a further attempt to make it easier to achieve the aim of thematic saturation and to overcome the burden of participating in the research that was disclosed by carers, in-person interviews were supplemented with online interviews. Around half of the interviews in Phase

2 were conducted online (see Table 9 for a breakdown of the numbers). This mode of interviewing has been shown to increase the accessibility and availability of a qualitative sample, and in this case allowed the researcher to extend the scope of the purposive sample across state and even international boundaries with ease while also extending ease of access to participants with mobility restrictions (Bertrand & Bourdeau, 2010; Janghorban et al., 2014; Petrakis & Laxton, 2017; Sullivan, 2012). The same Microsoft PowerPoint presentation from Phase 1 was used via screen-sharing technology, and instead of post-it notes, a Microsoft Word document was used to compile and rank participants' comments and suggestions (see Appendix 9 for a screenshot). It gathered the same amount or more data than the interviews that were conducted face-to-face, decreased the average length of the interview from 60 to 45 minutes, and removed barriers and costs to data collection for both the participants and the researcher.

| **In person** | **Online** |
|---|---|
| 3 x focus groups<br>4 x interviews | 10 x interviews |

*Table 9: Platform on which the interviews were performed*

### 5.5.3 Interview data analysis

Analysis examined the ways that issues of relevance were raised by participants, rather than examining participants' feelings about them. As such, it was considered a content analysis. In line with Creswell's (2014) recommendations for the exploration of processes, activities and events, a grounded theory approach was taken for the analysis of qualitative data collected in the semi-structured interviews in Phases 1 and 2. Grounded theory is an approach to qualitative data collection that does not use predetermined codes or hypotheses but rather takes an inductive approach in order to develop original theory (Oliver, 2012). It starts with individual cases and uses the emerging data to push past preconceptions and develop original high-level theory (Charmaz, 1994, 2006). Grounded theory is often used in a social work context because it can act as a means of distancing vulnerable research participants from being identified through results and can incorporate the social work researcher's practice knowledge and allow for the translation of complex problems into simpler theory and therefore an easy application of results back into practice (Gilgun, 1994; Oliver, 2012; Strauss & Corbin, 1994).

#### 5.5.3.1 Coding

Data from semi-structured interviews was analysed iteratively with Microsoft Excel and by hand. A multi-stage content analysis was used to winnow data and aggregate it into themes (Creswell, 2014; Guest, MacQueen, & Namey, 2012). First, an open coding technique was used reflexively in interviews, which acted as the first iteration of analysis of the qualitative data, collating all sources of information, concerns and content identified by participants. This approach allowed the coding framework to emerge through the data and to be interpreted in an inductive manner (Corbin & Strauss, 2007; Strauss & Corbin, 1990, 1994) by clustering sources and content into groups. A form of axial coding took place as some participants spontaneously discussed relational elements of these codes and themes, for example, that one theme was an umbrella for several others and therefore a code. Probing questions were used to elicit self-reflection from other participants around their sense-making about patterns between themes.

In the analysis following interviews, there were two main uses of open coding in the interpretation of these two sets of data. The first was to identify and make sense of the sources of information that participants identified, which included a process of weighting and ranking in order to illustrate preference, while the second was to identify and make sense of the remaining data. These followed Creswell's (2014) seven steps of qualitative data analysis, which are iterative and non-linear but include organising the data for analysis, reading all the data, coding the data and labelling categories with a term, using the data to get a description of each category, advancing how to represent each category in terms of the overall narrative, interpreting the data and validating its accuracy (Creswell, 2014). Codes were developed only from the information collected from participants rather than from any that might have been predetermined from the literature.

#### 5.5.3.2 Analysing sources of information

The sources of information identified by participants were the data to be analysed, the establishment of which required two stages of coding. First, all sources mentioned by all research participants were collated in Microsoft Excel. Those that used different words to describe the same or very similar concepts were merged, e.g. "Facebook forums", "Twitter" and "blogs" were all consolidated into "social media". Second, for the purposes of analysis, the similarities between these sources were mapped out using axial coding. Multiple mentions of the same source in one interview or focus group were counted as one.

The next stage was to analyse the importance of these sources of information to participants, whose top three most valued sources of information were given 3 points (most desirable), 2 points (second most desirable), and 1 point (third most desirable). Several participants chose equal first or second sources, which were divided by the total number of points so that each participant had 1 full point distributed. The ranked sources were then presented as a top 10 list. A simple regression model was used to analyse rankings against which demographic features made a person more likely to value a particular source. This analysis was conducted in order to test hypotheses the researcher had formed around the influence of education and choice-making experience on the participants' ability to think of ways to make decisions.

#### 5.5.3.3 Analysing the content of information

The third stage of analysis was winnowing the rest of the content, revealing that the majority of the remainder of the data concerned itself with what information about the NDIS should contain. Just like the sources, this data about content was listed out, and an open coding technique was applied. Second, axial and selective coding were applied to establish categories and relationships between the categories. Unlike traditional grounded theory methodologies, the selective coding was considered deductively as well as inductively in order to compare patterns already identified in the literature. In this regard, codes were iteratively clustered into categories based on participant anecdotes, informed by themes already uncovered in the literature. This was still in line with Creswell's (2014) seven steps, adding a new angle to the representation of each category in terms of the overall narrative in order to prepare the data for analysis.

#### 5.5.3.4 Focus group versus interview analysis

The way that data from one-on-one interviews was analysed versus focus groups requires some attention. Around half the participants engaged in semi-structured interviews via a focus group. On analysing the results, it was clear that this method did not produce different results to the interviews. Rather, it produced a higher quantity of similar results. Through

Phase 1, the researcher became aware that the conversation could not be separated into the opinions of each participant in a focus group because the process was iterative, i.e. when participants reflected on their experiences, this affected the flow of the conversation for everyone and the interview was experienced as a group. The one exception was the ranking activity, which was completed individually. As a result, there were 17 "cases" in the initial analyses, but 23 when it came to ranking. In the ranking activity, one set of parents completed it together as they had gone through the same experience and were in full agreement with one another on the desirability of particular sources. These have been included as separate cases with identical content as it was statistically important to the analysis; otherwise, it would have influenced the overall percentage and ability to compare.

## 5.6 Phase 3: Survey of NDIS stakeholders

While the first phase refined the interview schedule for the second phase, the second phase generated content to extend into Phase 3. Phase 3 comprised both qualitative and quantitate data collection through a cross-sectional online survey, comprised of material developed through the semi-structured interviews (see Appendix 5 for the full survey, consent and plain language statements). The reason for bringing these mixed methods together again comes back to a pragmatist epistemology, which is underpinned by the idea that knowledge is social, and based on experience (Kaushik & Walsh, 2019). Combining the two methodological techniques allows this research to bring together "objective" deductive and "subjective" inductive forms of inquiry, contributing to the practical goal of positively impacting the policy environment with data that is appropriately meaningful and generalisable.

### 5.6.1 Survey design

Surveys are designed to produce data that quantitatively describes trends and opinions of a particular sample of people (Creswell, 2014). The purpose of the survey in this research was to triangulate the interview results and to test the generalisability of the results with a larger sample. Where the semi-structured interviews drew primarily from the sub-questions, the survey was created to generate a statistically significant answer to the primary research question regarding what kind of information people need in order to feel informed when choosing disability support services. A survey was appropriate to achieve this goal owing to its ability to quickly and efficiently indicate patterns in large populations from smaller samples (Fowler, in Creswell, 2014). In the case of this study, given the large range and wide geographic location of PWD, family members and professionals making decisions about disability services, drawing out patterns quickly was necessary for the feasibility of the research project. This made the online survey an ideal design despite the fact that this method introduced biases towards those with higher digital literacy.

#### 5.6.1.1 Demographic information

Participants were asked demographic questions because the secondary goal of this phase was to add statistical significance to the existing sample and begin to test the influence of demographic differences, e.g. whether greater education and experience affected the manner in which participants negotiated the information-seeking processes.

#### 5.6.1.2 Rating importance of media

Survey participants were offered the top 10 types of media generated from the semi-structured interviews and were asked which were most important to them when considering which disability support service to use, in addition to the reason for their choice.

#### 5.6.1.3 Ranking importance of content

Survey participants were offered the top 10 themes of content generated from the semi-structured interviews, which they were asked to rank in order of most to least important, and were given the option of explaining their first choice. In order to efficiently acquire the greatest potential national reach, the survey was constructed digitally on SurveyMonkey. The aim was to collect 149 a minimum returned surveys, which would allow a margin of error of 8% on the NDIS participant population, an appropriate margin for an exploratory study. While the sample was extended to include carers and professionals, this minimum sample size was surpassed.

The aim of Phase 3 was to use a survey in order to extend the sample to test the generalisability of results. While the qualitative data collected in the first phases offered depth from a constructionist perspective, the third phase added significance to the results. This gave the research a greater amount of scientific rigour, and from a pragmatist perspective, increased the confidence with which the thesis could answer the research question relating to what information people need in order to feel informed about choosing disability services. The survey instrument was constructed in consultation with a statistician from the University of Melbourne. It compiled the top 10 ranked sources and the 10 clustered themes. Participants were asked to rank these in order of desirability and importance, with the option to explain their reasons for the highest ranked positions qualitatively. Participants were also asked the same demographic differentiators as were collected in the semi-structured interviews.

### 5.6.2 Survey data collection

A total of 201 surveys were completed, more than the initial goal. The same industry partnerships with service providers, peak bodies and advocacy groups as described previously were leveraged for distribution of the survey in order to achieve statistical significance and reach under-represented diagnosis and age groups. However, owing to the lack of success in recruiting for interviews, a convenience sampling methodology was also used, and the surveys were distributed online via the researcher's social media. A snowballing technique was also utilised through the researcher's professional networks and social media.

While more participants responded to the survey than anticipated, it was not an adequate number to be statistically generalisable from a population perspective and to be able to make generalisations about the impact of demographic features on preference. Likewise, due to the snowball sampling that led to the majority of respondents, there was limited salience with characteristics of the disability sector. However, as an exploratory study, this research met its aims – there was enough saturation to be able to make generalisable claims and therefore to answer the main research question with input from all these people who are linked to disability and the NDIS as consumers, carers and professionals.

### 5.6.3 Survey data analysis

Qualitative responses to the survey were collected and analysed in Microsoft Excel using the same codes that emerged from the analysis of semi-structured interviews. First, Microsoft Excel was used to undertake descriptive analysis for all variables in the survey (Creswell, 2014). Second, further analysis was undertaken in SPSS using a variety of statistical significance tests to establish what relationships, if any, existed between demographic variables and informational preferences.

In general, chi-square tests were used to examine the strength of the associations between categorical variables, such as the associations between demographic variables and what participants regarded as important. To interpret the associations in the tables, relevant row or column percentages were examined. For their validity, chi-square tests rely on the expected frequencies in cells being sufficiently large. When the dimensions of the relevant table were not 2 x 2, chi-square tests were used. If the percentage of cells with an expected frequency of less than five was less than 20%, and the minimum expected frequency was greater than one, the result of the test was regarded as reliable; otherwise, the P-value was disregarded.

To reduce the occurrence of tables with small expected frequencies, some pooling of categories was carried out. Sources of information were generalised as "important" (those that participants allocated scores of 4 and 5) or "not important" (those that participants allocated scores of 1, 2 or 3). Inspection of the data suggested that this could be done with the minimal loss of discrimination. For some tables, the variables considered were ordinal (in particular, age, amount of choice experience, and level of education). In such cases, there was the possibility of examining the strength of the association arising from the structure of the variable(s). For a table involving two ordinal variables, or an ordinal variable and a binary categorical variable, the "linear-by-linear" test was used and interpreted. In 2 x 2 tables, the P-value from Fisher's exact test was used as this does not require large expected frequencies.

#### 5.6.3.1 Data combinations

There were 10 sources of information that respondents could nominate (they could also nominate none at all). It was of interest to determine the numbers of respondents who nominated each of the 4,096 possible combinations (many of these counts were zero). For example, a respondent could report that they value, as sources of information, "friends", "workers" and "Google". Using a binary transformation scheme, all possible combinations were defined and the associated counts obtained. This identified a relatively small number of combinations with substantial numbers of respondents for each; a much larger number of combinations had a small number of respondents, and many of the logically possible combinations had no nominations from respondents, one reason for which was that most respondents nominated a relatively small number as "important"; in addition, since there were 4,096 possible combinations and 201 respondents, many could not be used. This very fine and exhaustive classification was then pooled, using the most common combinations and an "other" category for all those nominated by a small number of respondents; this grouped classification was then used in the analysis. The same approach was used for content combination.

## 5.7 Phase 4: Participant reflection and dissemination

This research sought to be generative, to exchange knowledge between stakeholders, and to give immediate value and capacity-building both to individual participants and to the disability community as a whole. In this regard, participants were given the opportunity to provide feedback on process and results. This was less of a discrete phase and more of an approach, which was built into other phases as shown in Figure 10. As discussed earlier, after Phase 1, participants were invited to give feedback on the interview schedule. After the rest of the interviews at the end of Phase 2, results were disseminated to all participants and feedback was sought on the validity and reliability of the results from a participant perspective before being fed into the survey (see Appendix 6). All participants who gave their time for an interview were thanked with a gift voucher. Finally, results of the whole thesis have and will continue to be disseminated to key industry stakeholders such as LACs and made public via blogs, talks, presentations and articles.

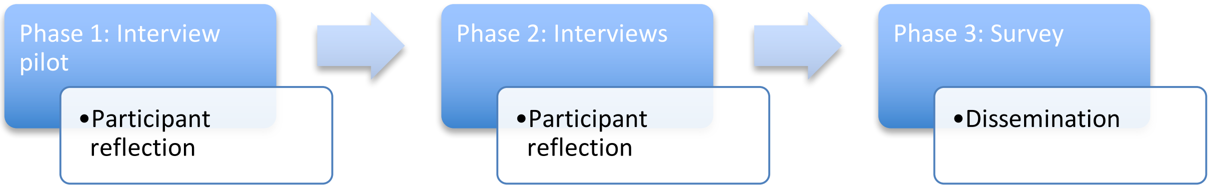


*Figure 10: Participatory phases of research (Key: white is participatory and blue is the stages of research)*

Phase 4 took place between the qualitative and quantitative phases, and through dissemination of results also. A summary of the results was distributed to all participants from Phases 1 and 2. Ten percent responded with comments and feedback on the findings. However, as this was as much an approach as a phase, there were several questions built into the semi-structured interview schedule that facilitated participant reflection, including what they had learned. There was also educative information built in about the NDIS because, at the time, it was in its early stages and not all participants, even those who had already taken part, were familiar with it. Results demonstrated that learnings were profound for some people, greatly affecting their practice as referrers and/or their future decision-making process as consumers or carers.

## 5.8 Chapter Summary

This chapter has described the approach, design and implementation of the research process used in this thesis to understand what information service users need in order to feel informed when choosing services under the NDIS. It has explained that the study draws on emancipatory research principles from disability and Indigenous methodologies and utilises a social work practice-based research framework. In addition, it has demonstrated that the approach taken in the methodology is not only adequate for addressing the research question but is also consistent with a social justice approach through the ways it engaged participants and will feed results back into the community and practice. The mixed methods and reflection processes align with social work practice research, anti-oppressive and emancipatory methodologies and critical disability studies frameworks for inclusive, capacity-building and empowering research. This allows the thesis to meet practice as well as research aims to fill the gaps identified in the literature. The next chapters will outline the results of the research, starting with those from the semi-structured interviews.

# 6 Findings Part 1: Sources of information

This chapter is the first of three that report on the findings of this research. It describes the results of the interview phases of the study, identifying issues that contribute to answering the research question: *What information do service users need in order to feel informed when purchasing services under the NDIS?* As the previous chapter explained, the semi-structured interviews were exploratory, leveraging the methodology of scenario simulation to explore sub-questions relating to how service users currently make choices, how they wish they could make choices, and how they would advise others to make choices. In addition, Phase 1 consolidated the structure, language and tools for Phase 2, which tested the interview schedule for reliability and validity with a larger, diverse audience and informed the development of materials for the survey.

This chapter is structured in four parts. It starts by describing the characteristics of participants that took part in the interviews. The second part of this chapter examines the advice given by participants to the case studies by looking closely at the sources of information they identified. It describes each source of information with excerpts from the interviews and examines the frequency with which each source was mentioned. The chapter then looks at participants' rankings of the most desirable sources of information, leaving the following chapter to examine emerging themes as well as the reflection part of the interviews. It shows that while many sources of information were mentioned in interviews, those that allowed participants to consult other people were particularly valued by all stakeholder groups.

## 6.1 Participants

Twenty-three people in total participated in the semi-structured interviews (see Table 11), all of whom have been given pseudonyms in this thesis. Six participants primarily identified as carers (26%), eight identified as consumers (35%) and eight were primarily professionals in the sector (35%). The age of the participants spanned from those their 20s to their 60s; the mean age of the participants was 35 and the median age was 30. In terms of the participants' education levels, twelve (52%) had achieved postgraduate education, nine (39%) tertiary education, and one high school education (4%).

| NAME | ROLE | STATE | GENDER | AGE | DIAGNOSIS | EDUCATION | FORMAT | NETWORK |
|---|---|---|---|---|---|---|---|---|
| **Amanda** | Consumer | Victoria | Female | 40 | Physical | Postgraduate | Interview | Researcher |
| **Andrew** | Professional | NSW | Male | 35 | Cognitive | Tertiary | Interview - online | Researcher |
| **Brad** | Carer | Victoria | Male | 35 | Cognitive | Postgraduate | Focus group | Researcher |
| **Caryn** | Professional | NSW | Female | 30 | Cognitive | Postgraduate | Interview - online | Researcher |
| **Chris** | Consumer | NSW | Male | 45 | Various | Tertiary | Interview - online | Researcher |
| **Daniel** | Consumer | Queensland | Male | 30 | Physical | Tertiary | Interview - online | Researcher |
| **David** | Professional | Victoria | Male | 30 | Psychosocial | Postgraduate | Focus group | Researcher |
| **Dean** | Carer | Victoria | Male | 35 | Cognitive | Postgraduate | Focus group | Researcher |
| **Emily** | Consumer | Victoria | Female | 30 | Physical | Tertiary | Interview - online | Researcher |
| **Jayson** | Professional | Victoria | Male | 30 | Psychosocial | Postgraduate | Interview - online | Researcher |
| **Jimmy** | Consumer | Queensland | Male | 30 | Physical | Postgraduate | Interview - online | Researcher |
| **Joe** | Consumer | Queensland | Male | 30 | Physical | Tertiary | Interview - online | Researcher |
| **Phil** | Carer | Victoria | Male | 30 | Cognitive | Postgraduate | Focus group | Researcher |
| **Pip** | Professional | Victoria | Female | 30 | ABI | Postgraduate | Interview | Researcher |
| **Sam** | Professional | Queensland | Male | 30 | Physical | Tertiary | Interview - online | Researcher |
| **Sandra** | Carer | Victoria | Female | 35 | Cognitive | Postgraduate | Focus group | Researcher |
| **Sarah** | Carer | Victoria | Female | 55 | Cognitive | Tertiary | Interview - online | Service Provider |
| **Susan** | Professional | Victoria | Female | 30 | Psychosocial | Tertiary | Interview | Researcher |
| **Suzi** | Professional | Victoria | Female | 35 | Psychosocial | Postgraduate | Focus group | Researcher |
| **Tara** | Carer | Victoria | Female | 45 | Cognitive | Postgraduate | Focus group | Researcher |
| **Tim** | Consumer | Victoria | Male | 30 | Psychosocial | Tertiary | Interview | Service Provider |
| **Will** | Consumer | Victoria | Male | 35 | Psychosocial | High | Interview | Researcher |

*Table 10: Participant demographics of Phase 1*

Participants were asked what kind of diagnosis brought them to the sector. Six of the participants recorded psychosocial disability and six physical disability (26% each); eight were connected to people with cognitive disability (35%); one with experience around acquired brain injury; and one with various comorbidities (4% each).

As described in the previous chapter, data collection was challenging, which will be discussed further in Chapter 9. Snowballing was therefore deemed the best method of recruitment. The majority of the sample was collected through researcher networks, which is reflected in the frequency of results and sample characteristics. Only two of the 23 participants were drawn from service provider networks while the vast majority (91%) came through the researcher's own networks. Table 11 and Figure 11 illustrate these demographic features of the sample.

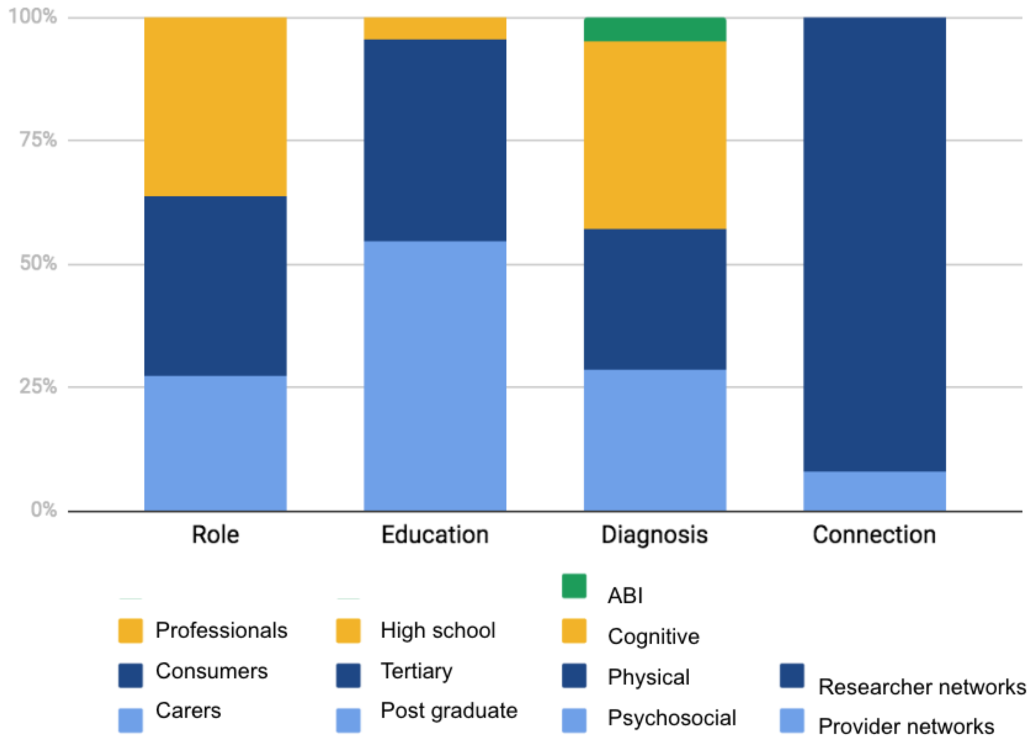


*Figure 11: Sample characteristics of Phase 1*

## 6.2 Advice

This section outlines the sources of information that participants recommended in the scenarios. It starts by describing the collection of the data and then each source of information that arose. It then looks at the top 10 sources by the frequency with which the sources were mentioned and the way that participants ranked their importance.

### 6.2.1 Sources of information

Participants mentioned an average of 10.5 sources of information each during the interviews. This was skewed by the focus groups as they generated more content through social interaction and group members prompting one another with discussion. In this regard, the groups generated an average of 12.8 sources per session.

Forty-two sources of information were cited 165 times by the 23 individuals involved in Phases 1 and 2 of the research. These were coded into twenty-nine categories using open coding as described in Chapter 5. Both these lists are provided in Table 12 below in alphabetical order of the condensed list of sources.

| **Condensed list of sources A-Z (n=29)** | **Full list of sources (n=42)** |
|---|---|
| Advocate/support person | Advocate |
| Agency websites | Agency websites<br>Read values, mission, vision<br>Notify them online |
| Brand | Brand |
| Brochure | Brochure |
| Broker | Brokers |
| Call the agency | Call them<br>Call with client on speakerphone<br>Cold call |
| Community notice board | Community notice board |
| Email | Email |
| Existing relationships | Existing relationships |
| Expos | Expos |
| Friends/family/guardian/WOM | Ask peers<br>Family<br>Guardians (i.e. VCAT)<br>WOM |
| Google | Google<br>Internet in general |
| GP | GP |
| Have a trial | Have a trial |
| Interview | Interviews |
| Interview management | Interview CEO or managers |
| Literature | Literature |
| Meet the frontline worker | Meet the worker<br>Take a support person |
| Multi-criterion decision-making tool | Multi-criterion decision-making tool |
| Official awards | Official awards |
| Other clients | Other clients |
| Professional | Ask professionals<br>OT<br>Support coordinator |

| | |
|---|---|
| Professional network | Professional networks<br>Case conferences |
| Reviews and complaints | Complaints<br>Facebook reviews<br>Testimonials<br>Reviews |
| Send me information | Email me<br>Post it to me<br>NDIS lists |
| Service agreements | Service agreements |
| Social media | FB forums<br>Social media<br>Apps<br>Twitter |
| Visit | Visit |

*Table 11: Full and condensed lists of sources*

### 6.2.2 Description of sources

Each item on the condensed list is described below using examples drawn from the interviews. This is the longest part of the present chapter and one of the most significant. Each source has various points of interest identified by participants, which are listed in alphabetical order and illustrated with quotes from the interviews.

#### 6.2.2.1 Advocate

This refers to engaging the services of a professional advocate. One consumer said: *"I would probably suggest [...] that he talk with a local advocate who can hook him into local services and I suppose help him to articulate to each service what he needs, so then he can make an informed [decision about] which service is then going to fit his needs."* This emphasises the need for local information. A carer, Sarah, agreed: *"There are advocacy organisations that can point you in the right direction for you, so that's a good professional organisation that you can use to get closer to what you might need. They would certainly give you tips."* It is noteworthy that both these people specifically spoke about advocates assisting not only in the selection of services but also in the clarification of needs. It is also interesting that a case management role is being described here. This is not traditionally what advocacy is intended for and, in general, is unlikely to be financially sustainable under an NDIS model.

#### 6.2.2.2 Agency websites

This category refers to reading the website of the supplier. Interviewees had various intentions in reading websites and mentioned various sections of websites in particular. For example, Amanda stated that she would look at the *"mission, vision, history, 'About Us' link on the website… even reading through an annual report, seeing how they present their business."* She later stated that when looking at the supplier website, she would *"see how they present themselves, what information they provide or don't provide. If it looks like they've got their act together or not, [whether it's] personal or very corporate… the image they present from their website."*

Amanda interpreted this as an indicator of the culture and competence of a company, and websites were also used by participants as indicators of the level of expertise and trustworthiness of a supplier. Sandra related a relevant story: *"When we were having trouble finding [a supplier], I sent a few websites [to an advisor and asked], 'What do you think of these people?' And [the advisor] came back and said, 'Look, you know, this woman… couldn't possibly specialise in everything she says she does,' and that made me suspicious of her. Why are you just throwing it all up on your website if this isn't really your area of expertise or you only have a nominal expertise? Are you going to treat my child the same way you treat any other child with another disability?"* She continued: *"You can tell lots of things from their website. Not only can they spell or, you know, if they're a polished professional organisation if they, you know, put their credentials front and centre, if they have their philosophy on their website and that just says a lot about who they are."* Sandra's partner Brad added, *"Yeah, and like some websites will have the thing that they do, but they'll also provide links to useful resources and that kind of shows in general an interest in patient wellbeing."*

This sense of integrity being indicated by an interest and involvement in wellbeing beyond a service delivery minimum is a repeating theme. Brad continued: *"Sometimes, in those vision statements or philosophy or 'About Us', you can read between the lines… I mean, do they mention how great they are, but they don't mention anything about patient wellbeing? They'll try to put a positive spin on it, but sometimes what they don't say is just as revealing as what they do say, so I think being a critical reader of their website is really useful."* Suzi echoed this sentiment: *"I feel like sometimes if you go on that internet thing, you're seeing the marketing team."* This raises a question about whether NDIS service users will have the capacity to be critical readers as the competitive NDIS environment drives suppliers to invest more in sophisticated marketing materials. There is already some indication in this small sample that the impact of education is significant.

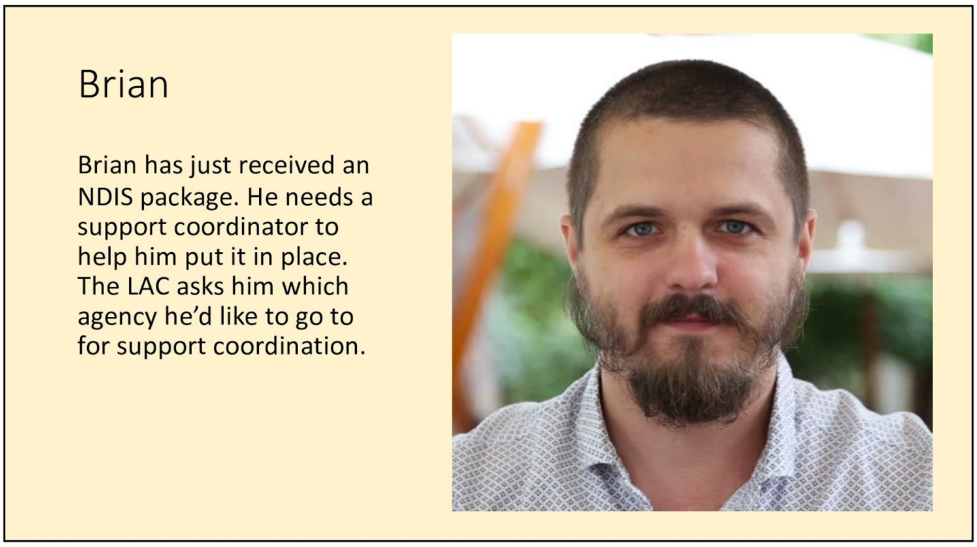
Websites were also seen as an indicator of professionalism and effort. For example, Sandra stated: *"If they've got an old website that was built in the 90s, or looks like it was built in the 90s, and you know they just can't be bothered, you think, 'Well this a mum and pop shop.' And if so, okay, maybe, but if this is an organisation that pretends to be professional, pretends to be accredited, it doesn't look good if they haven't got a web presence, so that would immediately raise alarm bells."* Caryn, a professional, echoed this sentiment less delicately: *"The reason I didn't say websites for a lot of them is because a lot of service provider websites are crap […]. I've gone on the websites of other service providers and haven't been able to get the information I want."* The literature review produced evidence that this sector needs to catch up digitally and these anecdotes suggest that the community is experiencing this as a problem and that it is impacting negatively on the effective use of the information economy that already exists.

For some interviewees, there was such concern over the validity and trustworthiness of the information presented on supplier websites that they were discounted as a valid source of information. Suzi went so far as to say: *"I think, for myself, I'd probably look at the website, but I'd probably look at it quite critically, thinking in the same space, like, 'Yeah, here's some more fluffy stuff.' [For that reason] when it comes to people that I work with, I probably wouldn't recommend looking at websites as much."*

Suzi was expressing concern that the people she worked with would not have the capacity to read the information critically. This was a sentiment shared by Sandra: *"You need to know when you find a website… is it bullshit or is it real?"* This is certainly a highly paternalistic approach that may be a hangover from a welfare state mentality; yet, at the same time, as stated above, the high proportion of people with cognitive impairment who will be receiving NDIS packages makes it a real issue. It is important to consider the duty of care of the information economy to provide (or at least support) quality assurance and safeguarding of the information itself and what informational safeguarding might look like in an NDIS environment.

### 6.2.2.3 Ask a trusted professional

Most participants recommended asking a trusted professional for advice. Illustrating the range of workers this might entail, Pip stated about the first case study (see Figure 12): *"We don't know what kind of things Brian's got going on in his life, but I'm assuming that he has some existing relationships with support workers or health professionals, so they could be people he could ask [...], or his case manager if he has one, or maybe another worker that he's had contact with in the past, or even a support worker he may have had a relationship with."* It is noteworthy that she even suggested leveraging a non-current relationship. A consumer, Emily, agreed: *"If [the person] had any advocate involved or a case manager, I'd be conversing with them… I'd be discussing with my/her OT service on board to discuss the different options and what's available."* These comments, and the frequency of this theme in general, are initial indicators of the importance of relationships and advice-seeking for the interviewees.



Brian

Brian has just received an NDIS package. He needs a support coordinator to help him put it in place. The LAC asks him which agency he'd like to go to for support coordination.

Figure 12: Scenario 1 of the four interview scenarios

### 6.2.2.4 Brand

Brand came up fairly often in discussions about which piece of equipment to purchase (as Brad and Sandra joked about the third case study (see Figure 13), *"[Lim should choose the] one with the coolest sounding name!")*. However, this category was also used to describe the "look and feel" of the service supplier, or the "vibe" as some participants called it. One professional, Jimmy, stated that if there were three equal options, this would be his main differentiator: *"I think, with any service, it probably comes down a little bit to brand or marketing, seeing what are the biggest or what looks professional, I suppose."* A consumer, Will, agreed on this being a differentiator: *"Maybe something, even though it's quite ridiculous, by brand. Yeah. Brand of the place… the nature of the workers."* Once again, the inference that brand is related to professionalism and the nature of the workers is noteworthy.

Lim

Lim uses a wheelchair. As part of her NDIS funding, she's going to get a new chair so she can do the sport she loves. Lim has recommendations from three of her team mates for three different equipment providers.

*Figure 13: Scenario 3 of the four scenarios*

Jimmy mentioned how well a supplier fit him personality, and when probed stated that *"it also goes into a little bit of branding, I think. What's conveyed via branding… I think brand and marketing is very much tied to… which are happy, personable. I think they're similar."* He also tied the size of the organisation into a story about branding: *"When you think about being [a small organisation] in touch with needs, that's branding… what they convey, as well as being what is directly linked to – 'We have a good feeling,' or something like that."* The connection for him between a supplier's brand and size and his own sense of cultural fit and emotional wellbeing is interesting.

### 6.2.2.5 Brochures

There seems to be general agreement that a brochure contains the same information that can be found on a website, and these were interchangeable for a few people. In fact, Susan stated: *"I print out information for my clients to take home: contact details including location and map, 'About Us' section, what they offer. If they don't have a brochure to download, I put bits and pieces together from the website."* Consequently, brochures are necessarily only a minor part of the informational process. For Tara, one of the carers, the next part of the process is therefore *"calling them […] so you can get deeper than the brochure. The brochure effectively is a website […]. It's the next level of information, so you find them there, you get down to there, and then you might call them."* Tara's comment indicates a subjective sense of process and a hierarchy of information, which will take them from baseline research to ultimate decision.

On looking at Mamadou's decision (see Figure 14), one consumer felt that brochures could shed light on the particular qualifications and standards of an allied health professional in the fourth scenario:

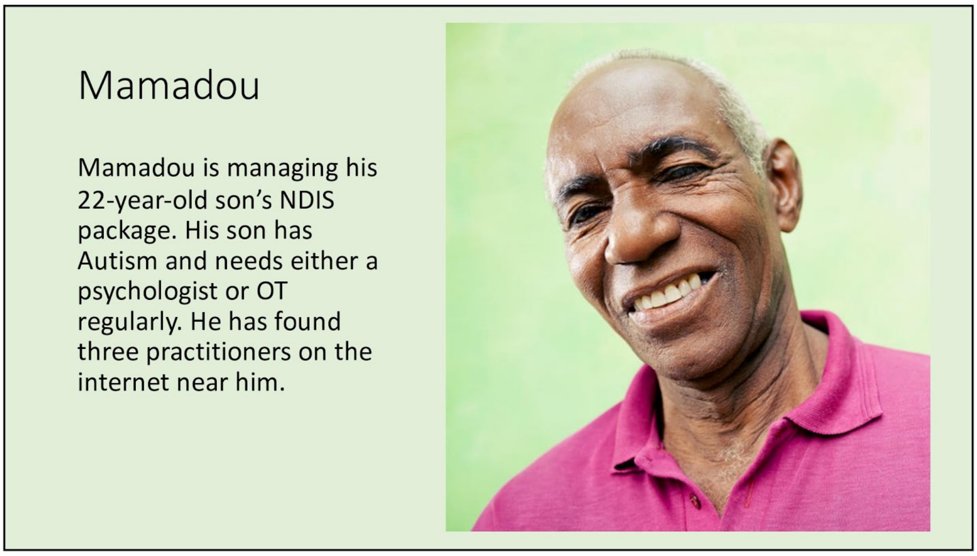
*Interviewer*: What else should he do to get some information about these three people?

*Joe*: Maybe ask for a flyer or brochure or something.

*Interviewer:* When he reads the brochure, what information would he be trying to see?

> *Joe*: I guess what they do and what they've helped clients work through.
>
> *Interviewer:* So, when you say, "What they do," do you mean like their qualifications or experience? Or what is it you mean?
>
> *Joe*: Yeah, just qualifications, or what specific area they're focused on, or something like that… in case it's specific, you know?

Joe's interest in establishing a supplier's specialties was not unique to brochures; rather, it was echoed many times throughout the results.



Mamadou

Mamadou is managing his 22-year-old son's NDIS package. His son has Autism and needs either a psychologist or OT regularly. He has found three practitioners on the internet near him.

*Figure 14: Scenario 4 of the four interview scenarios*

An excerpt from a focus group illustrates the ambivalence around the trustworthiness of brochures. This echoes what was already described in the section above on websites and may speak to the validity (or the cause) of these two sources appearing to be somewhat interchangeable:

> *Phil*: I'd trust an interview far more than I'd trust a brochure.
>
> *Tara*: Yes, I would, [be]cause it's two-way communication, more likely.
>
> *Interviewer*: Do you trust a brochure equal to what you trust a testimonial or a complaint or a review?
>
> *Phil*: Depends on the content. If it was a government report saying that all of these complaints had been registered, or it was a massive thing, I would probably hold that pretty high.

This reiterates the finding in the literature review that the impact of interpersonal communication outweighs any written material, even if the content is identical. It also raises the issue of trustworthiness of, first, government information sources and, second, of testimonials, which will be discussed in detail below.

#### 6.2.2.6 Brokers

Dean, a mental health professional who was as yet unfamiliar with the particularities of the NDIS system, stated: *"I bet there are independent consultants and stuff cause that exists in the aged care system. Independent people that just… you can employ to tell you where to go."* Further discussion revealed that it was the independence that was valued. Interestingly, most brokers have established relationships with particular suppliers and are not independent. Brokers were not brought up by other participants.

#### 6.2.2.7 Call the agency

There were various reasons for phoning the agency, one of which was just as a more efficient way of collecting information than reading online, as outlined by Caryn: *"[...] maybe call five local organisations with some questions that [the customer] has, like how much per hour do you charge? Are you available after 11:00 on weekdays? And just get the answers from each and present that information to [the customer]."*

Phone calls were an important part of the process, but for many people this was a step in a larger process rather than being a standalone action. For example, Amanda advised: *"After she's thought about those things, ring and speak with the agencies and meet them face-to-face. After she's done a choice from online research, call and say, 'Hi, I'm thinking of starting support with you, can I meet you face-to-face,' and see what they're like, see what their attitude is like to help refine that decision-making."* Indeed, for several participants, assessing "their attitude" was part of the value of phone calls, i.e. as a tool to assess a supplier's communication and customer service. Suzi advised: *"If the first person you're talking to on the phone [is] super rude to you [...], go with how you feel about an agency."* Additionally, it was suggested that assessing how a supplier genuinely felt about meeting in person prior to the engagement of service (another source of information, as discussed below) was the main purpose of a phone call.

Another purpose stated by several participants was to ascertain *"if they had capacity to start the support as soon as I needed them"* (Andrew), which was important information they would not be able to find elsewhere. It was a means to get service faster, as Caryn relayed: *"I remember on my team we had a really, really proactive OT who would just call up and politely heckle the equipment company every day, and it just sped up the process because they were sick of hearing from her."* This indicates that having the ability to advocate for oneself achieves positive service outcomes.

When it came to an allied health worker, however, the phone call was more of a mutual assessment of personality fit and expertise – it was also an indicator of the worker's emotional investment. According to Tim, *"Some of them, when you call them, you can have a long conversation with them that goes for more than five minutes. That's a good indicator about whether... it's about helping you or if it's just about getting another client."* The issue of a provider's willingness to have a long conversation or meet in person prior to service engagement was meaningful to service users and was used as an indicator of service quality.

#### 6.2.2.8 Community notice board

This was a source suggested by only one consumer, Will: *"Community noticeboards... I am a bit old fashioned, so I, yeah... community noticeboards I like, but the internet is how it's done these days."* This suggests that despite his eventual ranking of community noticeboards as his preferred way of consuming information, he recognised that the internet has overtaken this method for many people (see the section below on Google).

#### 6.2.2.9 Existing relationships

Several participants identified using existing relationships as a source of information and a means of managing the change burden. Pip asked whether *"[the scenario customer has] an existing relationship with an agency? I am an adult, and I have been in the system, and I'm now moving to a different system, and my natural thing is saying, 'I don't know how much change I want to do.' I'm probably going to stick with where [the person I care for] is. So I* *want to know from the existing people, I know I'm going to keep going… so can I just keep something consistent."*

Emily also suggested asking an existing provider for a referral recommendation: *"I suppose if a potential client is already embedded with a service, whether it be a health service or disabilities or what have you. Asking whether they have any kind of sister organisations that kind of work in coordination to provide services that, you know… one service might have and have a bit of a gap in their service delivery, so they refer the participant onto another service that they recommend to fill that gap."* Here, Emily's thoughts also seemed to project a sense of trust onto a referral from an existing relationship.

#### 6.2.2.10 Expos

Expos were identified by Chris, Emily and Susan as useful sources of information about services. Susan specifically stated that she found them useful for mapping services in the local area. The following excerpt from the interview with Chris, the consumer, explained his thoughts on why he found them useful:

> *Chris*: You can sort of sit down with multiple people and talk about different things, you know, so you can have a clinician sitting down with an entity support worker, or sitting down with some families who've been living with this for decades where some people have, you know...
> *Interviewer*: Alright, so it's about having a lot of different people in the same place. And is that about… trying to find different people's opinions on the same things?
> *Chris*: It's not necessarily opinions, but it's knowing the different aspects, the real-world mechanisms, and understanding the situations, you know?

Chris' response indicates that there is some intricacy involved in the "mechanisms" and "situations" that can best be clarified through interpersonal communication with a variety of stakeholders, allowing him to get a three-dimensional view of a supplier. This, in turn, implies that there are multiple dimensions of a supplier to be viewed.

#### 6.2.2.11 Google

This refers to general keyword-based internet research as opposed to specifically looking at agency websites, social media or reviews. For example, Pip explained that she'd *"Google whatever specific support service I needed, like I'd just Google that, and I'd put my postcode or something if I wanted to make it specific."*

Andrew made the point that this is a normal way to seek information in other service industries: *"If you want to get a plumber, I wouldn't call my friend and ask them who their favourite plumber was; I would Google plumbers and see who could come and fix my tap today. Do you know what I mean? That's how I would approach accessing any other service."* He also went on to acknowledge, however, that disability support is *"a more complex sort of service dynamic than just getting a plumber."* This raises the question about whether the complexity can be reduced or whether the information-seeking is inherently and inevitably as complex as the current status quo of the service sector.

Brad and Sandra noted that, as academics, they were able to apply their research skills to the information-seeking process, including the use of Google:

> *Sandra*: […] we had to be proactive, but we were pretty happy doing our own research. That's kind of our thing, but I know that a lot of other parents online have been very anxious about [it].
> *Brad*: They don't have those [social] connections [that we have].

> *Sandra*: Or the research skills! You need to know when you find a website… is it bullshit or is it real? The ability to read medical and scientific papers, so we've got that as well, so we can know if something is really evidence-based or if it's hocus-pocus. So, I think that a lot of our research skills have come in really handy.

This speaks to the skill involved in gathering information, which places a burden on individual capacity. Additionally, assuming good research is indicative of effective choices is suggestive that education may have a causal relationship with decision-making.

#### 6.2.2.12 General practitioner (GP)

Several interviewees with representatives from each stakeholder group suggested asking their general practitioner for advice about where to go for services. Often, GPs were mentioned in the same breath as other allied health or support workers. Pip advised to *"speak to your GP or any other workers that you have, like a lot of them are linked in with other services,"* while Susan recommended asking a GP due to their knowledge of the local area: *"If there are any recommendations he would make, I suppose specifically with his physical health as well, if there are any concerns there, the GP might have a good knowledge of the local supports as well that he might be able link in with […]. Also, if they have a good relationship with their GP and they're seeing them under the mental healthcare plan, I generally even get them to speak to their GP, who generally has a list of recommended people they refer to, and get their opinion on it as well."* Here, she placed a high value on local knowledge.

Susan also provided a caveat of trust, and Caryn echoed this sentiment: *"If she has a personal GP or a physio that she really trusts and has worked with for a while, or even one that she's [been] working for a little while and trusts, maybe get them to help weigh in on the situation."* Perhaps for the same reason, and as will be shown is the same with regard to asking professionals in general, a GP's opinion seemed to be thought of less readily and weighted less highly than that of family and friends. Pip's comment illustrates this: *"I would ask my family or friends or peers… and also speak to my GP… [be]cause they might have some sense of what's going on and who's out there and who's doing what."*

#### 6.2.2.13 Interview management

Several participants said it would be important to speak with the managers of a supplier in order to assess the processes, procedures and flexibility of the organisation. The following excerpt of an interview with a consumer illustrates this:

> *Jimmy*: There's no sort of direct way within the system to ask if any one [supplier] is better or the other.
> *Interviewer*: Can we unpack, 'Is one better than the other?' What do you mean?
> *Jimmy*: I think it comes down to knowing the managers. So, I think there's a degree in knowing which would be more personable, and so the only way to sort of do that would be to see whether they can arrange with your support coordinator to go and meet some agencies, actually talk to them to get that personal feel.
> *Interviewer*: What does 'personable' mean?
> *Jimmy*: Personable is about... firstly, being happy and obviously not sad or someone you can have a laugh with or something […]. By the same token, I think if some conflict arises, the person will deal with it in an appropriate manner and that sort of thing.

Another consumer, Joe, added that he would speak with management in order to ascertain *"how much they're charging on top… just say you get the carer's wage then the fees on top of that."* These comments demonstrate that although there are practical reasons for having these conversations – they are requesting information about conflict management and business modelling that is unlikely to be available publicly – there is still a high degree of importance placed on the interpersonal aspects of the interaction.

#### 6.2.2.14 Literature

Evidence was suggested as a source of information. Two participants who suggested it were academics, and their comments about their confidence with research has already been recorded above. Jayson expressed some struggle with regard to evaluating whether suppliers put more emphasis on relationships or clinical evidence: *"[I am] an evidence-based clinical [practitioner] in a very evidence-based service, [but] then there's other services where it's almost more focused on building rapport and having a good engagement and then… not that that's a bad thing, but it's like… that's 90% of it. Then there's kind of some other intervention around that when that's not such a primary [focus]. I don't know what the kind of balance is, but sometimes it felt like it was all about engagement."* Jayson's comment seems to be in line with other evidence collected here so far, i.e. the interpersonal is valued over the clinical evidence.

#### 6.2.2.15 Meet the frontline worker

This was an important source of information for many participants, particularly when advising customers about choosing support workers and allied health professionals. First, there was recognition by interviewees of the intimacy involved with some aspects of support work and the need for consumers to feel safe and secure in vulnerable settings. Sandra explained that she would not make a decision to use a supplier before meeting her frontline worker *"because you don't want somebody to come over who's gonna give you the creeps, especially if they're going to get you out of bed every day, something so intimate… that would be the final thing, like not making a decision until you met the person that was going to be working with you, not just the worker representative of that agency but whoever's going to be working with you… just to make sure that you trust them coming into your house. They're going to have a key!"*

Daniel expanded on this point, discussing the importance not only of safety but also of a good personality match with support workers and *"your agency giving you a good worker. It's their job to not just give you anyone and not just give you whoever's available. Like my agency, my facilitator especially was [great]. She came and met me and we spoke about what kind of things we would want the carer for. So, in this case, it's getting in and out of bed [and…] showers. And then she went straight into what… kind of person I was… and took time to do simple things like write down my interests and get a feel for what kind of person I am, and then she went away and searched for a million different carers and did a bit of trial and error, and [she] made it very clear that it was okay for me to meet someone and not like them and say no."* It is discernible from Daniel's comments that he consciously retained his right as a customer to refuse the service if it is inappropriate, which to him meant not having the right personality match, and further that this assertive attitude was supported and encouraged – and possibly even initiated – by the agency facilitator.

Tim spoke about the burden of meeting potential frontline workers, which he recommended *"if possible, [but] it's easier said than done for disabled people to meet the people before they actually do it. I know that's been a big stress for me, so at times, not normally, but I've had to just go with the first [option]."* While meeting various support workers may result in better service, it can be economically, emotionally and physically draining for consumers.

Chris also emphasised the importance of a frontline worker being a good match not only for the consumer but also for the family: *"You're going to want to have at least one face-to-face meeting with just the parent, and then the parent and the son, and the son, or whatever the configuration may be."* This point came up several times and will be discussed further in later sections.

Caryn suggested that there were various different ways of meeting support workers: *"You know, they can come to his service agreement meeting or just he can come in to a meet-and-greet."* She also described some of the benefits to the business of such "meet-and-greets": *"When I was working at (company), we got a call from a family who was sort of hesitant about bringing their package anywhere because they only earn so much money. And one was older, he was in his twenties, so I went and just [had an] hour-long hangout kind of thing, and they didn't end up bringing their package to us but referred five other families because their package was under review, but they just really appreciated the offer to meet their son. So yeah, I guess [my advice is] trying to see which one is willing to meet and put a bit of that time in because if he's bringing a year's worth of sessions to the table, it's worth knowing that he's is going to like the person and if it's going to work."* Once again, the issue of a supplier being willing to meet arose; however, the clear benefits this professional saw for her organisation are also compelling.

Despite the benefits of meeting frontline workers and how much interviewees valued and expected it, there was some appreciation of how difficult it is for suppliers to find suitable staff, let alone have them available to meet prior to a service agreement being signed.

#### 6.2.2.16 Multi-criterion decision-making tool

A carer who was a researcher suggested this tool – a matrix that weighs up relevant metrics and supports an informed decision. However, Caryn suggested something similar when asked about her ideal preferences for consuming information: *"I can go online and compare blenders, and I can know the exact width of the propellers within five minutes, and I can compare… I can't do that with service providers. I go on the websites, they're shithouse… I literally want to be able to click on four different services and get a grid. Go on the Apple website and do it for computers is just literally what I'm talking [about]. That's what I want. That's why Apple is very successful [...]. It's like when you go on Best Buy and click on all the different, you know, fancy buy-or-lease laptops and you can compare how much memory they have, all that stuff right next to each other in a little grid. Something like that, you know?"* This is reminiscent of Andrew's comments about choosing a plumber.

#### 6.2.2.17 Official awards

David and Tim stated that they may look for official awards the supplier or allied health professional had gained, for which they would look online. They suggested awards in line with checking complaints and/or official qualifications. For example, David stated that in order to judge *"the quality of care, I suppose… as the service, you'd want to advertise it somehow. I don't know if there are service awards or… I'm sure there are things, gold stars that they could put on there."* This raises the question of what metrics and standards exist.

#### 6.2.2.18 Other customers

Participants suggested asking about the experience of existing customers of the suppliers they were considering. This has been kept separate to asking friends and family as it featured people with whom the advisee had no prior relationship. In her suggestion to ask other customers, Sandra made a comparison to another industry: *"She can even ask the agencies* *for client referrals, like, you do that when you get a building contractor, [so] why not?"* There was some discussion about where these people would be found – through testimonials online, through the supplier, or through social media – and the discussion primarily centred around the potential bias of the source. In order to maximise trustworthiness, Tara suggested asking a third party rather than a supplier for client contacts: *"Ask if [your support coordinator] had other clients she's referred to them and have there been any problems or anything she can share about those clients' experiences."*

### 6.2.2.19 Professional networks

Various professional networks exist along demarcations both of expertise in a particular diagnosis groups – for example, ABI or mental health networks – and qualifications – for example, each allied health group has their own professional network. This category also included professionals calling other professionals for advice, where it is a peer relationship. This category arose infrequently due to the nature of the questions being centred around a scenario simulation of a customer, who would unlikely have access to such networks.

### 6.2.2.20 Reviews and complaints

Nearly every participant said they would like to be able to successfully search the internet specifically for reviews of suppliers, while some also mentioned seeking out official complaints that had been made against the suppliers. People suggested comparison platforms – including Facebook reviews, Google reviews, Google Maps reviews, newspaper articles and Clickability – and comparing what they wanted to Whirlpool, eBay and TripAdvisor.

For Jimmy, reviews were a second-best option after speaking to unbiased existing clients of the supplier: *"You can't really ring the providers and ask to speak to their customers, so whether there's some sort of third-party reviewing platform in which you can link up with others and what they say."* This was the same for one of the professionals: *"I suppose in lieu of having friends that you can ask, 'Is this a good service,' looking for reviews and other stuff online."*

Caryn claimed that she would want to look at *"somewhere that provides a structured comparison between the three different options [...]. So, I guess thinking about like Facebook reviews, Google reviews, or even some of the other kind of online product sites they might just ask a couple of basic questions, like an eBay rating, like if you're getting five stars for three different fields, but is that feedback specific to the kind of supplier. So, I guess what I'm saying there is… is there a comparison site that's a lot more tailored to this kind of service? So it's going to have [information] about user experience… How did they find out about the product? Is there any limitations? Why did they choose them? Would they choose them again? So, getting in-depth specific research, asking the right questions, not just asking, 'How was your buying experience?'"* Andrew agreed, but acknowledged that this does not yet exist in the disability marketplace: *"I'd love to say that there was like enough reviews out there. I think that there should be more opportunity for people with disabilities to review services."* Jayson agreed, advising the customer to use *"support groups or online platforms that compare these services and allow people to provide online feedback. Also, things like Google reviews and Facebook reviews to check people's ratings there, but ideally somewhere that's designed to collect the users' experience."*

Andrew continued to reflect on his comment: *"Reputation I think is really key in the sector, more than most. I think a restaurant can still get customers with a bad TripAdvisor review, but I think in a disability sector, bad word spreads really quickly, as it should, I think."* It is not within the scope of this thesis to explore the truth of this statement, but the intention behind Andrew's words comes back to the emphasis placed on WOM in the disability sector.

#### 6.2.2.21 Send information

Some participants wanted information posted to them in hard copy. There was one suggestion that the NDIS lists should be posted to customers as a matter of course. Email was also seen as an effective way of getting basic information. As stated by David, *"I think you should have [the NDIS lists] delivered to you in the post or email."*

However, emailing was also seen as an indicator of second-rate communication. Daniel, a consumer, advised one of the scenarios to assess *"how easily accessible they were, were the providers local, when speaking with them did you have to… was it always over the phone or were you able to see someone face-to-face, which you would think would make you get more out of a face-to-face interview than you would over the phone or by email."* This shows again the value placed on interpersonal communication as a source of information.

Another consumer, Sam, talked about the process he would likely take in exploring his options: *"I'd probably check their website out [and] then email them [because] I'm not very good on the phone."* For Sam, email simply provided a sense of safety and another medium to communicate through. This is likely to be particularly important for people whose speech is affected by their disability.

In terms of content, one participant wanted NDIA's list of registered providers to be emailed or posted to her. Several people were surprised to learn that there are no quality indicators on the list (see NDIA, 2019b).

#### 6.2.2.22 Service agreements

The contracts that bind consumers into official service relationships with suppliers have particular legal and financial caveats. For example, David advised consumers to ask, *"Can they tell you exactly what service you're going to receive, how much it's going to cost, what the whole thing is going to look like, without unexpected surprises and stuff?"* From Tara's perspective as a customer in other industries, not having "unexpected surprises" included terms and conditions around trialling the service and having a cooling-off period and other aspects that both personalise the service and make it flexible around changing consumer needs. This awareness indicates some sophistication around consumership, but a lack of awareness about the particularities of contracts in the disability sector.

#### 6.2.2.23 Social media

Social media has featured in the description of the sources, e.g. in consulting other customers. This is indicative of it being not just a source of information, but actually a way to connect with other people. Word of mouth as a source itself will be discussed below. This section aims to highlight those aspects of interpersonal connection via social media that are unique.

Facebook was the most commonly mentioned source of social media information. Twitter also came up, as did blogs. Facebook forums were mentioned in particular as a trustworthy source of information as they attract consumers and family members with similar diagnoses or experiences. As Sandra explained: *"Often, your peers on Facebook [are] a much closer relationship to what you're going through than your friends and family."* Social media can be used to extend a social circle, as noted by Pip: *"I'm part of an online Facebook group for siblings actually, and a lot of people ask about support coordinators."* Andrew noted that *"you get mixed results from [Facebook forums] at times, but I think it's still good to ask people who are in that sort of... safe sort of environment if you don't have many people that you know personally with plans or what not."*

In fact, like reviews, social media was often seen as a proxy for asking existing clients for unbiased testimonials. Sandra's advice reflects this: *"Another thing that [the customer could] do is going on Facebook onto her specific disability forum, or the Facebook page for disability sport that she plays, and say, 'Hey guys, has anybody ever worked with these three people? What do you think?'"*

Social media also seemed to be a proxy for asking friends and family. The following excerpt of the conversation with Sam underlines this point.

> *Interviewer*: What is it about Facebook that you like getting information from there?
> *Sam*: Just the ease of use… like friends and that who might've used similar service
> *Interviewer*: Cool. So actually, you're asking your friends? Is what you mean?
> *Sam*: Yeah.

Tim's comment illustrates a further aspect of this issue: *"Sometimes, I put a public Facebook status out and say, 'Does anyone know if there are any good Xs in Y?' [So rather] than going through the person who's trying to sell you the service, going through the person who's receiving the service is a lot more valuable."* This comment first reflects an assumption that Facebook users responding to the question have no vested interests and second articulates the value that a lack of bias creates value.

Participants identified several drawbacks to information found on social media. Tim identified one of them as locally relevant information: *"Online communities can be helpful, but it's difficult to find something specific to your area. But there can be, say, if I really loved [X interstate company] and someone in NSW said they're really good, I would say 'I don't know about X there but X here is really good.'"* This raises a question about the relevance of information across geographical regions, where we assume that there may be differences in structure, culture and service quality across the same regions. Another drawback to social media is getting too many varied responses. Andrew explained his concern: *"[You] put something on an open group, and you then have like 400 people writing reviews about providers, and because experience is so varied for each person, you then become more confused than you actually were when you started."*

#### 6.2.2.24 Trial

This describes a free, no-strings-attached session or series of sessions with a supplier prior to the service agreement being finalised as a tool to assist the decision-making process. In one focus group, Pip remarked that they would like to be able to have *"one session free that's sort of like trying out."* Tara added: *"So, it's try before I buy... I've got a cooling-off period."* Another member of the focus group observed that *"it's interesting that you got to the kind of 'let's try it first' kind of stuff because often when you do these sorts of things people go, 'Oh I didn't even know you could ask for that.'"*

#### 6.2.2.25 Visit

Especially with allied health professionals, visiting the clinic or counselling space was important to several participants in order to help gauge comfort levels or, as Suzi put it, *"going in and visiting and sussing them out."* Susan, discussing how she prepares her participants for new services, said that after she had *"seen a site and chatted to the workers, I can get a feel for it... the pace and atmosphere. A lot of the people I work with have anxiety,* *so the temperament of where they are really impacts on them, so being able to prepare and plan, give a heads-up about what they might experience when they're there and how we can prepare and have it not be too stressful."* This highlights the importance of the physical and cultural environments for some participants. It also begs the question of how suppliers can create an easy and cheap means of collating and distributing the most relevant information for their target market in order to provide high-quality marketing materials.

A visit was also recommended as a means of testing the accessibility of the physical space (at which point, several anecdotes of wheelchair inaccessible suppliers were shared) and the transport situation: how easy it is to get there and whether the location is appropriate. Tim explained that *"distance with a regular [allied health] visit will be a factor because it'll have to be someone close-ish to go to a medical appointment regularly."* Location was a theme that came up regularly and will be discussed later.

Many suppliers run open forums – for example, open days – or sessions educating people about the NDIS ("*interviews for what to expect,"* as one participant put it). These were posed as a potential source of information about the supplier and a chance to meet the staff and see the venue. Unlike expos, they only show a single provider, but they show them in depth. One focus group had a discussion reflecting on the actual content delivered in a supplier-run interview format when asked whether they would rank it more highly than other sources of information:

> *Phil*: [I would attend in order] to gain further information. Yeah, it's really part of resources, isn't it? It's a form of resource, so it's a brochure essentially…
>
> *Interviewer*: Okay. You don't necessarily trust it more than you would trust a brochure or website?
>
> *Phil*: I'd trust the interview far more than I'd trust the brochures.
>
> *Tara*: Yes, I would because it's two-way communication, more likely.
>
> *Phil*: Yeah, you get a feel for something… someone.
>
> *Tara*: Especially if it's being held in a venue where the service might be provided.

This demonstrates the perceived value of high-touch, in-person information sources, even if they have the same content as other sources.

#### 6.2.2.26 Word of mouth (WOM)

Also included in this category is family, friends and guardians, as well as peers and community members. This quote from Amanda illustrates why: *"It's hard… between asking family and friends and peers. I'd do them both nearly the same – doing those informal ask-arounds."* In this sense, it's the quality of these conversations as informal that categorises them together.

Every participant mentioned friends and family as a key source of information. One professional, Andrew, even went so far as to recommend that a customer "broaden your group of peers" in order to get more information. He reflected that the mother of one of his participants *"uses the net but doesn't necessarily use it to get support information – she calls me for those things or asks her friends those things."* This demonstrates the trust the community has in WOM over the internet.

It often came up that the opinions of those consulted were more highly valued when their experiences were similar to that of the asker. Brad recommended asking about others' experiences "if she knows other people with similar needs." Pip agreed, putting significant weight to this shared experience: *"He could also ask people that he knows and trusts, like his* *peers or friends, who might also have support coordination or know someone who does. And if anyone has a good experience with the service, then I think that means a lot."* Here, in advising the customer to ask friends of friends, it appears that similar experiences are given more weight than existing relationships. This was pervasive. For example, Caryn advised Brian to *"[consult] with other people who have disabilities if he knows them. If he's comfortable to, getting his family involved because families of people with disabilities often have a lot of experience with disability. And you might not want to… that might be the whole point of the NDIS… to get my family out of my business, but I think trying to get as much information as possible from a few sources is good. And asking for that help… getting your family's opinion, talking to friends who use service providers."*

Naomi

Naomi has an NDIS package. She uses a wheelchair and needs someone to help her to get in and out of bed each morning and evening. Her support coordinator tells her there are three agencies in her area she can choose between.

*Figure 15: Scenario 2 of the interview scenarios*

Caryn gave this same advice to Naomi (Scenario 2; see Figure 15), but with a slightly different caveat: *"[Ask] family, friends, [and] people in her community that also have similar disabilities to her or similar needs and have service providers and can recommend… or can say, 'This one didn't work for me'. Obviously, she should judge herself, like if someone says, 'This person didn't work because they're really cheery in the morning,' and that doesn't bother her. Yeah, talking through it with people who've had similar experiences can teach you something even if you don't take their advice."* In this regard, Caryn considered that some critical assessment is needed of other people's advice and its relevance to one's own consumer experience and personal preferences.

Pip said she would advise the people she works with differently from how she would behave herself *"because I have a really good social network that I can rely on for support and help [which] my client might not… [be]cause I would definitely ask my friends… most of my friends are social workers [...]. For a client, I mean, I would always recommend them, I would say like, 'If you've got any mates who have accessed these services, then talk to them.' But if they didn't have that, which like a lot of people I work with are pretty socially isolated, so I probably wouldn't suggest that to them then."* This raises an important point: social capital is needed for WOM to function successfully as a reliable source of information about NDIS suppliers.

## 6.3 Hierarchy and order of information

Several comments throughout these interviews implied a hierarchical response to information search, whereby consumers had a particular order in mind about which information was most relevant at what stage of their search process. For example, in the section about calling the agency, Amanda lists *"After she's thought about those things, ring and speak with the agencies and meet them face-to-face. After she's done a choice from online research, call and say, 'Hi, I'm thinking of starting support with you, can I meet you face-to-face,' and see what they're like, see what their attitude is like to help refine that decision-making."* Using this and drawing together other data described above, Figure 16 illustrates the decision-making and information search process. It starts with considering one's own needs, moves to publically available information such as brochures and internet, then uses interpersonal sources of information – on and offline – and finally, contacting the agency directly on the phone, and then face-to-face, all before actually trying the service.

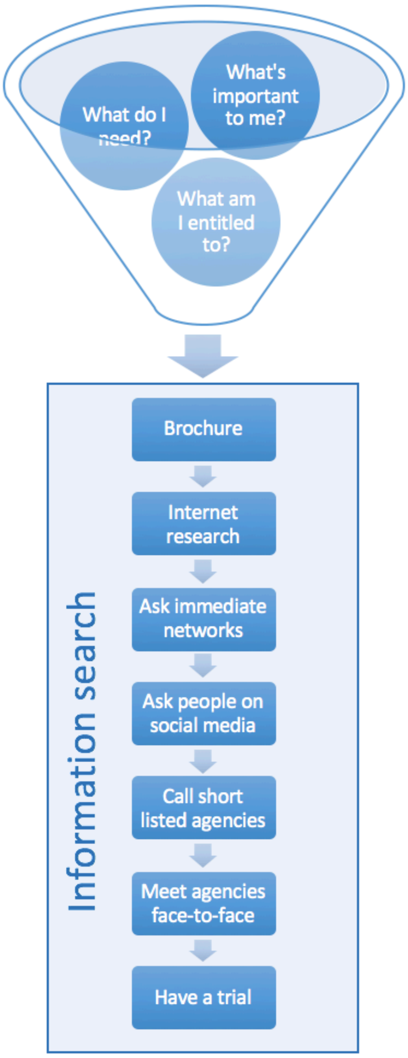


*Figure 16: Hierarchy of information search as represented in interview data*

## 6.4 Frequently mentioned sources

As demonstrated by Figure 17 and Table 13, the 10 most frequently mentioned sources were:

1. WOM (9.7%)
2. Reviews/complaints (9.7%)
3. Meeting the frontline worker (7.9%)
4. Asking a trusted professional (7.9%)
5. Agency websites (7.3%)
6. Social media (6.7%)
7. Calling the agency (6%)
8. Googling (6%)
9. Asking other clients (4.9%)
10. Interviewing management (4.3%)

This list highlights that there is only an incremental decrease of frequency across the 10, with only a 5% difference between the popularity of the first (9.7%) and tenth (4.3%) most frequently mentioned sources. Figure 16 illustrates these top 10 most frequently mentioned sources of information.

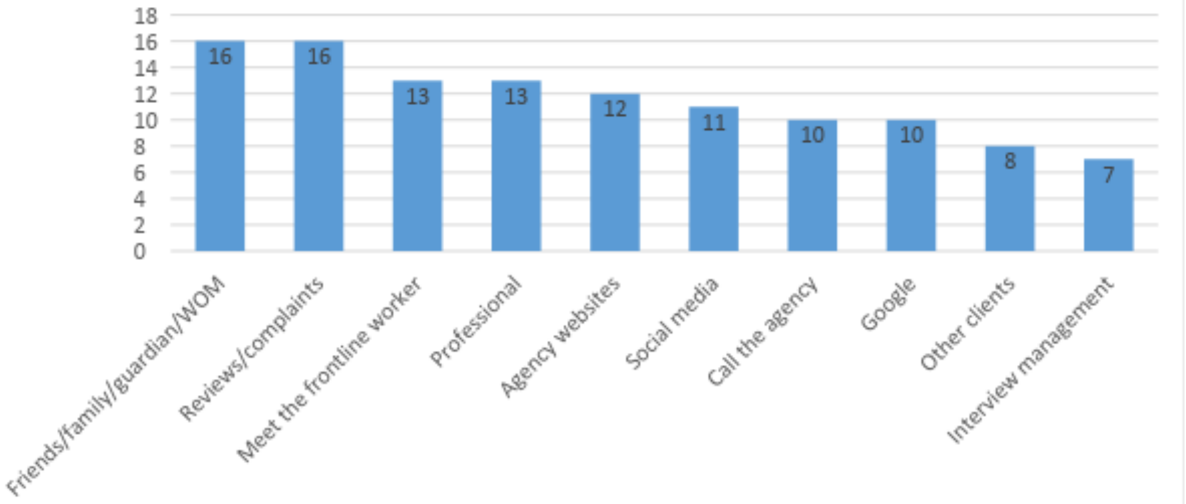


*Figure 17: Top 10 most frequently mentioned sources of information by number of mentions*

This table records which sources were cited by each participant and sorts them in order of total mentions of each source of information.

| | **Amanda** | **Andrew** | **Brad/ Sandra** | **Caryn** | **Chris** | **Daniel** | **David/Suzi/ Pip** | **Emily** | **Jayson** | **Jimmy** | **Joe** | **Sam** | **Sarah** | **Susan** | **Tara/Phil/ Dean** | **Tim** | **Will** | **TOTAL** |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| WOM | 1 | 1 | 1 | 1 | 1 | | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 16 |
| Reviews/complaints | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | | 1 | 1 | 1 | 1 | 16 |
| Meet the frontline worker | 1 | 1 | 1 | 1 | 1 | 1 | | 1 | 1 | 1 | 1 | | | | 1 | 1 | 1 | 13 |
| Professional | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | | | 1 | 1 | | | 1 | 1 | 13 |
| Agency websites | 1 | | 1 | 1 | 1 | 1 | 1 | 1 | | | 1 | 1 | | 1 | | 1 | 1 | 12 |
| Social media | 1 | 1 | 1 | | 1 | | 1 | 1 | 1 | | | 1 | | 1 | 1 | 1 | | 11 |
| Call the agency | 1 | | | 1 | 1 | 1 | 1 | 1 | | | | 1 | | 1 | 1 | 1 | | 10 |
| Google | 1 | 1 | 1 | 1 | | 1 | 1 | | | | | 1 | | | 1 | 1 | 1 | 10 |
| Other clients | | 1 | 1 | | 1 | | 1 | | 1 | 1 | | | 1 | 1 | | | | 8 |
| Interview management | | | | 1 | 1 | 1 | | | 1 | 1 | 1 | 1 | | | | | | 7 |
| Brochure | 1 | | | | 1 | | | 1 | | | 1 | | | 1 | 1 | | | 6 |
| Trial | | | 1 | | 1 | | | | | | 1 | | | | 1 | 1 | | 5 |
| Visit | 1 | | | | | | 1 | | | | 1 | 1 | | 1 | | | | 5 |
| Advocate | | | | | 1 | | | 1 | | | | | 1 | 1 | | | | 4 |
| Existing relationships | | | | | 1 | | | 1 | | | 1 | | | | 1 | | | 4 |
| GP | | | | 1 | | | 1 | | | | | | | 1 | | | | 3 |
| Interview | | | | | 1 | | 1 | 1 | | | | | | | | | | 3 |
| NDIS lists | 1 | | | | | | 1 | | | | | 1 | | | | | | 3 |
| Expos | | | | | | | | 1 | | | | | | 1 | | | 1 | 3 |
| Email me info | | | | | | | 1 | | | | | 1 | | | | | | 2 |
| Post me info | 1 | | | | | | 1 | | | | | | | | | | | 2 |
| Brand | | | | | 1 | | 1 | | | | | | | | | | | 2 |
| Broker | | | | | | | 1 | | | | | | | | | | | 1 |
| Professional network | | | | | | | | | | | | | | 1 | | | | 1 |
| Official awards | | | | | | | 1 | | | | | | | | | | | 1 |
| Community notice board | | | | | | | | | | | | | | | | | 1 | 1 |
| Service agreements | | | | | | | 1 | | | | | | | | | | | 1 |
| Literature | | | 1 | | | | | | | | | | | | | | | 1 |
| Multi-criteria decision-making tool | | | | | | | | | | | | | | | 1 | | | 1 |
| TOTAL | 12 | 7 | 10 | 9 | 15 | 7 | 18 | 12 | 7 | 5 | 9 | 11 | 4 | 12 | 10 | 9 | 8 | 165 |

*Table 12: Sources of information ranked by importance*

Notably, this top 10 overwhelmingly features interpersonal sources of information. Out of a total 165 mentions of sources of information, 62% were face-to-face and 35% were online; in addition, physical (print) media comprised only 5% while all others combined were 3%. This breakdown is illustrated in Figure 18 below, which highlights that the number of times interpersonal sources were mentioned was more than double the second most mentioned category (online media).

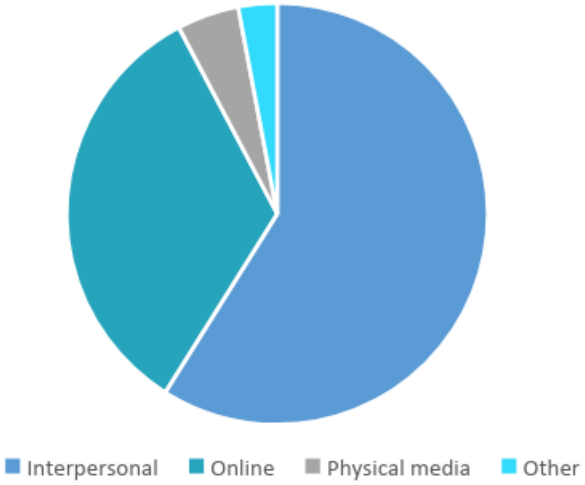


*Figure 18: Sources of information by media type (see Appendix 10 for a detailed list)*

## 6.5 Highly rated sources

Participants were asked to rank their top three sources in terms of desirability. In this regard, the researcher asked questions such as: “If you had it all your way, how would you ideally like to make a decision?” As described in Chapter 5, these were scored so that each participant was allocated an identical weight of one point across their preferences. The top 10 sources by ranking can be found in Figure 19 below:

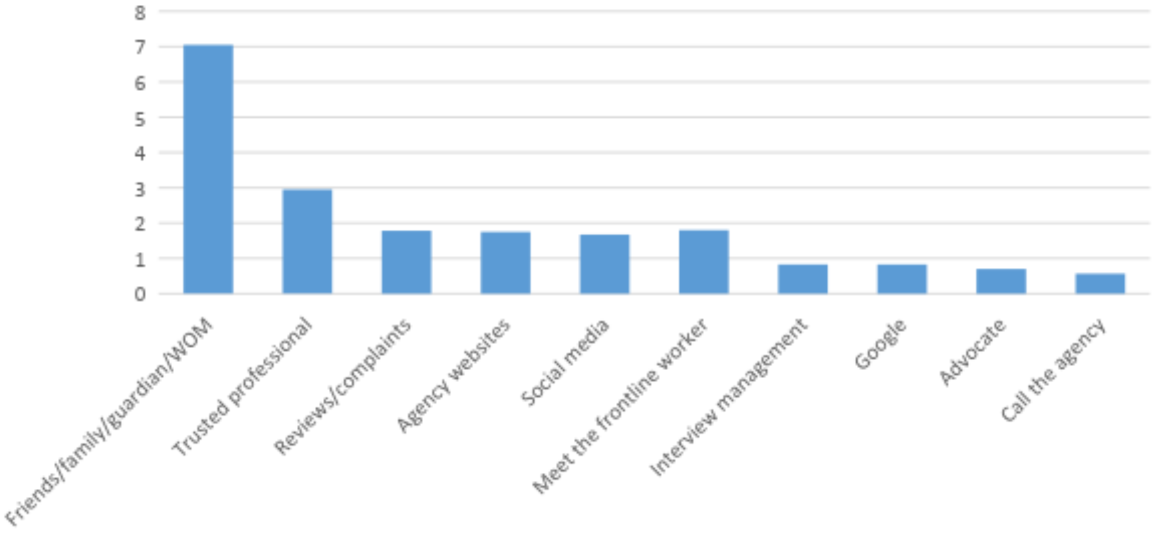


*Figure 19: Top ranked sources of information by ranking*

It is noteworthy that the results are very similar to the top 10 by frequency, which provides confidence and validity to the results, suggesting that they are not simply an artefact of the methodology. The tables below show the differences numerically, which are minor, with the exception of “Ask other clients”, which dropped 17 places out of the top 10. This may suggest that the abovementioned proxies of social media and reviews are more desirable sources of the same information.

| Frequency | | | Ranking | | |
|---|---|---|---|---|---|
| Friends/family/guardian/WOM | 16 | 9.70% | Friends/family/guardian/WOM | 7.05 | 30.65% |
| Reviews/complaints | 16 | 9.70% | Professional | 2.95 | 12.83% |
| Meet the frontline worker | 13 | 7.88% | Meet the frontline worker | 1.80 | 7.83% |
| Professional | 13 | 7.88% | Reviews/complaints | 1.78 | 7.75% |
| Agency websites | 12 | 7.27% | Agency websites | 1.75 | 7.61% |
| Social media | 11 | 6.67% | Social media | 1.67 | 7.28% |
| Call the agency | 10 | 6.06% | Interview management | 0.83 | 3.60% |
| Google | 10 | 6.06% | Google | 0.83 | 3.60% |
| Other clients | 8 | 4.85% | Advocate | 0.70 | 3.04% |
| Interview management | 7 | 4.24% | Call the agency | 0.57 | 2.46% |

| | |
|---|---|
| Other clients* | -17 |
| Call the agency | -3 |
| Reviews/complaints | -2 |
| Agency websites | 0 |
| Friends/family/guardian/WOM | 0 |
| Meet the frontline worker | 0 |
| Google | 0 |
| Social media | 0 |
| Professional | 2 |
| Interview management | 3 |
| Advocate | 5 |

*Table 13: Illustrating the difference in top 10 sources between frequency and rank by source*

The sources below the top 10 feature several equally-scored sources in both frequency and ranked sources, making comparison less significant. Statistically, this occurred partly because participants were only asked to rate the sources they identified; consequently, some with low frequencies are therefore absent from the ranking altogether because the average number of sources identified by an individual interview was only about 30% of the total number of sources identified by the sample as a whole. Socially, this may also suggest that while it is possible to think of multiple sources, the practice of finding and using the sources identified is less desirable.

In examining this ranked list through the lens of the media cluster, none of the top 10 ranked sources are physical or other types of media – 60% are face-to-face and 40% are online sources.

## 6.6 Chapter Summary

This chapter has described the sample of people that participated in the interview phase of the research. It listed and described all the sources of information named by interview participants and then examined the top 10 sources of information by how frequently they were mentioned in the interviews and how highly they were ranked by participants. While there was some value placed on digital sources of information, the results found that interpersonal sources of information were the most frequently mentioned and the highest valued.

The next chapter discusses the themes that emerged from the interviews in terms of the content of information that participants valued, in addition to also examining the data that came out of the interviews through the reflection exercise.

# 7 Findings Part 2: Content and reflection

While the previous chapter discussed the sources of information about services that emerged in Phases 1 and 2 of the research, this chapter describes the results of the content analysis to illustrate the most highly valued content and some detail about the experiences participants had that influenced these values, which reveals a central theme of trust. This chapter also describes the results of the reflection section of the interviews, reporting on the exercises offered to participants. It begins by looking at which scenario was easiest for participants to advise and, from there, segues into examining the meta themes that arose through the interviews and focus groups. As with the sources in the previous chapter, each theme is described and illustrated with quotes and excerpts. Finally, the chapter examines what participants learned through the interview process.

## 7.1 Themes

A total of 72 themes were identified through the interviews and focus groups, the full list of which can be found in Appendix 10. As described in Chapter 5, these were clustered into 10 sub-themes using open coding. The 10 sub-themes in alphabetical order are: having appropriate staff; availability of services; costs and contracts; customer-centricity; empowerment and collaboration; location, access and delivery; organisational structure; staff having relevant qualifications and expertise; responsive, reliable communication; and experiencing feelings of trust and safety. As with the sources in the previous chapter, each of these themes is described with vignettes drawn from workshops for illustration. Thereafter this chapter outlines the data from the reflection activities in the interviews.

### 7.1.1 Appropriate staff

This was already touched upon in the previous chapter in the description of meeting frontline staff as a source of information. It included not only whether there is a sense of safety and connection through meeting particular criteria such as age and gender, but also whether there is an appropriate personality match and the service user can choose their own worker and control their own roster. Participants were also concerned with the particular baseline training and qualifications of support workers.

The other side of the issue of appropriate staffing was related to suppliers' workforce management strategy, which was raised by several interviewees who, from personal experience, were concerned about suppliers' capacity to fill support work shifts as promised in a service agreement. Andrew advised that one should *"choose a provider that's most willing to cooperate with other providers because no matter how many providers say they can do two-times-a-day seven-days-a-week, they won't be able to – they'll have staff call in sick, they'll have staff leave. Choose a provider that's willing to collaborate […]. If [someone needs support] every day... it might be seven days a week, two times a day. You might need three or four staff to provide that support. You want to make sure the agency can provide all the staff. If not, engage all three [agencies] and use them as a team."* Amanda also mentioned workers' rights: *"what's their workforce strategy? That's nearly a question I'd ask these days. How do they treat their workers? Do they have high turnover or stable staff?"*

### 7.1.2 Availability

Various issues were raised around timeframes of service, e.g. whether there are waiting lists, what hours are available, and whether there could be flexibility around school or work commitments – these issues were primarily raised by professionals. Consumers were keen to know how long the service agreement lasted and therefore the probable length of time of the working relationship. When it came to purchasing services from allied health professionals in particular, they wanted an indication of a willingness to work with them on a long-term basis. Interviewees also wanted to know if they could manage their own rosters and make changes within 24 hours of their booking, especially when it came to support workers. Minimum shift time was also raised. According to Daniel, *"if you want a carer to do something that requires not very much time at all, like getting someone out of bed isn't really a long shift, so a lot of carers aren't really keen for that [...]. The two carers that I have now live less than 10 minutes away, so even though I only have them for an hour for every shift, [it works out]."*

### 7.1.3 Costs and contracts

Many of these issues have been described in the description of service agreements in the previous chapter. Another issue that nearly all interviewees raised was cost, which included using price as a metric of comparison between suppliers, getting value for money, and asking about what packages or discounts the supplier might offer on the purchase of multiple services. When asked about how to differentiate between two similar services, cost was often referred to; however, there was a caveat of assessing quality over a period of time. For example, Chris said that *"if they're all the same quality, I'd pick the cheapest, [but] if any issues arose, I'd definitely want to look at switching because I'm wary of the cheapest thing."*

Tim, a mental health consumer stated that *"the actual process of finding someone is really tolling and really difficult and really expensive. If you want a good one, you're going to go through at least five people. If you're on a mental healthcare plan like me, that's half your sessions gone. And not just that – for people with mental illness… it's a lot of legwork to find someone who has good reviews and doing that whole process and being like we'll have one session, it's very emotionally and physically tolling because you get your hopes up... what if this person's really good, I might get a bit better, be able to cope with things better in his case… and especially the monetary cost, too."* This highlights that there are multiple barriers to getting information at present that need to be managed for consumers to find what they need in an appropriate way.

### 7.1.4 Customer-centricity

Many interviewees raised issues about the extent to which suppliers could personalise services and products to their needs and preferences and help them achieve their goals, which included consistency of workers and responsive communication, in addition to the flexibility and innovation to personalise the service around customers' and their families' needs, e.g. establishing and meeting expectations, part of which is clarifying service users' current needs and planning for the future, including emergencies. Another part of meeting expectations is what the agency would *not* do, i.e. what their physical, cultural or religious limitations might be. In this regard, Chris provided an edgy example: *"Some entities would balk at the idea of taking a client to Sexpo."*

### 7.1.5 Empowerment and collaboration

This theme centres around whether a supplier can increase a service user's independence, or simply deliver a service. Many interviewees posed questions about how customers could get more involved in the organisation and how their feedback and complaints would be managed. They were also concerned about whether the supplier would help them navigate the NDIS system and provide high quality reports for NDIS assessments. This implies that not only do participants want to ensure that they get the most out of their NDIS package, but choice and control is also dependent on being able to navigate the wider system together with the people who help them make decisions.

The other aspect of this theme is collaboration: first, with families, and in particular with members of the family other than the main recipient of services; and second, with external agencies and workers. For example, Caryn advised Mamadou – who was looking to find an allied health professional to work with his son – to ask potential suppliers the following questions: *"Can you teach me things? Is it just sessions with [my son, or] can I spend some of that money and you and I have half an hour together and you give me some strategies? What's your service delivery model? Is it just one-on-one with [my son] or can you support me, too? And if I pay for the time and set up the meeting, or prep for the meeting and set it up, can you have a meeting with [my son]'s manager at Target?"*

Another example was provided by Sandra: *"I've seen some mums complain that their physios don't seem to be giving them anything to do with the children, [so they're thinking about their supplier], 'This person's okay, but I can't see [that] things are changing really with my child,' and obviously they're not getting enough [information] to know whether their child is performing well or what could be done, so [they have] no idea where they are on the scale of things."* This is an excellent example of the overlap between good communication and collaboration and how it can lead to a feeling of either empowerment or disempowerment.

### 7.1.6 Location, access and delivery

Nearly every research participant raised the issue of access to a supplier, which included transport options and also the question of whether the product or service could be delivered through an outreach model or if the consumer would have to travel to receive them. For example, Pip asked: *"Is it accessible for Brian? Can he get in there… not just transport-wise, but when he gets there, is the building easy to get into?"* Multiple interviewees had examples of suppliers with inaccessible offices, and several stated that traveling for an hour would be a significant barrier for them. Also included in this theme was the quality and consumer access to IT systems for billing and scheduling.

### 7.1.7 Organisational structure

Various issues concerned interviewees in terms of the internal structure of the supplier, which included whether they are a for-profit or not-for-profit organisation, how big they are and how old they are. As Amanda explained, *"if they're an NGO or a for profit, it might impact on their quality of service delivery. You might be making judgments of, 'Are they in it for the money or are they in it to provide good support to me.' Or maybe if they're too big, 'Am I customer one of 3,000? Am I going to really get quality support provided by a coordinator that knows my needs and I don't have to keep repeating it to five different people because the agency's so big and there's 10 coordinators in the office?'"* This theme also included the brand and image of the organisation, i.e. how they chose to market themselves, which was discussed in the previous chapter in the section on "brand" as a source of information.

### 7.1.8 Relevant clinical qualification and expertise

A common concern of the interviewees was whether there was sufficient worker and organisational expertise to meet their particular needs. Sandra explained that she and her husband were *“insisting on credentials… we’re more insisting on rigour, you know, do you have experience in this area? When you talk to me, do you sound like you know what you’re talking about?”*

Another common theme and possible differentiator between suppliers was how specialised the service was with the customer’s diagnosis or other particular circumstances, and therefore with their needs. As Tim explained, “*the more specialised it is, the better it seems to be for me.”* Andrew had similar sentiments: *“A person with a spinal cord injury may find that a [case manager] from a spinal cord injury specific service has a lot of great networks for the type of support that they are after, but if a person with an intellectual disability went to them, they might not find that [they’ve] got the best network [for them].”*

Expertise, several consumers and carers said, could be demonstrated through someone asking the right questions. For example, Sandra said she would know that an allied health practitioner was an expert *“if they told me specific things that I didn't already know about [my daughter]. If they could look at her and go, ‘Oh, I see she's doing this and this and this, but maybe we need to do this and that.’”* Another example from Tim was *“knowing the background on, say, Asperger’s or depression or whatever and then sort of being able to, in whatever polite way, find those answers. ‘Brian, do you need help with x, y, z? How are these things going?’ You know? Because asking someone, ‘How are you?’… automatically, most people go, ‘Yeah, I’m okay’ or ‘I’ve had a shit day,’ but normally it’s a lot of background stuff.”* And yet another example from Tim was that *“a good psychologist will recognise [my symptoms] before I tell them.”*

Other particulars in this theme include an allied health professional’s clinical approach and suppliers’ sector knowledge, including how well they understand the systems in which they work (in this case, the NDIS). Another way to demonstrate this would be through compliance with with quality standards, e.g. having evidence of registration with the NDIS where necessary or continuing professional development.

### 7.1.9 Responsive and reliable communication

The importance of communication was repeated in nearly every workshop, and communication was seen to be a proxy for a variety of other important aspects of service, including customer service, trust, reliability and respect; however, communication has its own theme because it was so integrally important to every interviewee. An example of the influence of the quality of communication came from Emily, reflecting on her current circumstances: *“[Communication is] actually a current issue with one of my service providers. As a result, at the moment I'm thinking of actually giving them the flick and putting on another service provider.”*

Sarah indicated that respect is seen from whether staff spoke to her or directly to her son: *“I like people who engage with my son. He’s non-verbal, and he’s very gentle and very shy with people when he first meets them… professional people. So, I really like professionals that will actually talk to him, not just to me, so that when they come out in the waiting room… I just remember from when he was a child, a doctor came out and immediately greeted [my son] first before me. I loved that. I just thought it was such a respectful thing.”*

Caryn expressed her frustration at poor communication but also her feeling that she needed to acquiesce to it in order to get the service that was needed: *"[Someone close to me] has an amazing worker who's worked with him for like seven years, who works for [a particular supplier], and mostly [the supplier is] good, but with trying to organise a new work placement, they just never call back, like it's a lot of bullshit. But we stay with them because of [the worker]."* In the emerging NDIS marketplace, it is becoming easier to self-manage or to use a third party to employ a worker directly. In situations like these, suppliers who have poor communication are likely to put themselves at risk of losing both customers and workers.

#### 7.1.10 Trust and safety

The theme of trust includes feeling heard, understood and respected. For Pip, this included *"cultural needs or social needs […] people's beliefs and values and whatever religion they are,"* but it was also an indicator of a successful interpersonal relationship. Sarah explained that *"respect is up the top for the person with disability and for the family if there are other people involved. It works both ways, so the family need to respect the carer, or the paid carer, and the paid carer needs to respect the person with the disability and any family members involved."*

A significant aspect of this is, on the one hand, "trusting your gut" about particular relationships and, on the other hand, looking for signs of the professional "going above and beyond", which, for several consumers, demonstrated care. Tim explained that a supplier's willingness to spend time answering his questions prior to engaging in service delivery was *"a good indicator about whether it's about helping you or if it's just about getting another client."* Trust also includes feeling confident that the supplier is not biased and does not have competing interests – that the customer's needs are central. Several interviewees mentioned reputation and the supplier's values, and Will pointed out that *"how active they are in the community… how active they are at community events"* is the way a supplier can demonstrate their reputation and commitment to purpose.

For Andrew, the NDIS is changing the way quality is represented: *"I think [the things that impact reputation are changing] as the sector changes and as people want different things, so a provider's reputation may previously have been based on really simple things like their location or the quality of their transport. That's changing. Now, reputation will be based more on […] the people you employ and their dedication to helping people achieve their goals."* If this is true, it may indicate a marketplace becoming more sophisticated and empowered.

## 7.2 Reflection

Participants were asked two key reflective questions in the interviews, and this section outlines the results of this exercise. The first part describes opinions relating to which scenario was the easiest to advise, while the second looks at what participants learned by being involved in the interview process.

### 7.2.1 Who was the easiest to advise?

Sixteen of the participants elected the case to whom they found it easiest to give advice (see all scenarios in Appendix 3). Five (31%) selected cases 3–5, who were looking for services and equipment, while only one participant (6%) selected Scenario 1, who was looking for a support coordinator, despite the fact that there were more sources mentioned for Brian (scenario 1) on the whole. Emily, who selected Scenario 1, had a support coordinator herself and felt it was the easiest *"because I find that very relatable... I do have a bit of knowledge in real life."* The very small number of participants that chose this scenario as the easiest to advise suggests it is challenging to navigate the system and that participants' lack of experience reduced their confidence in doing so.

In fact, 10 of the sixteen cited similar reasons of personal experience in making it easier to give advice. For example, consumers stated the following: *"Because I've only recently just gotten my chair, so probably it's fresh in my memory"*; *"Because I've got personal experience"; "I probably had more in common with [the case]"; "Because I'm most familiar."* Emily went further, stating that it was dependent on the similarities between parties when positioning herself both as an advisor and advisee: *"I suppose it's dependent on the lived experience of each person and each person offering advice."*

This also extended into the group of professionals, arguably with more self-reflection and conviction. For example, Jayson stated that *"I had more experience... [and felt that] I'd be able to provide more relevant information. And that is thinking about what some of the differentiating factors are, but also... the clinical provisions that the service can provide. So thinking about this [case], I have more of an understanding as to what he might need from a service, based on my experience having worked with clients in that age range and those kind of needs."* For some professionals it was more about doing no harm. To illustrate, Caryn stated: *"I don't know how comfortable I would be to give people advice on service providers unless I'd had experience with them, just thinking about it, you know?"* This raises an interesting issue: professionals are mandated to do no harm and want to facilitate families making their own choices in order to have more control over their lives, but this research also suggests that professionals are more capable of making informed choices in such an immature marketplace.

The other reasons participants cited for finding various cases easier to advise than others included a perception of the customer having a broader interpersonal network of support to draw on; the participant feeling they had inadequate information about the customer's particular needs; and the particularities of equipment versus human services. For example, Andrew stated that he found it easier to advise Case 2 *"because she had what seems like a bit of a broader network at the start and because there's a lot more options out there for that type of support than there is for OT and psych or for coordination for that matter."* Jimmy agreed with the efficacy of an available social network in assisting decision-making: *"It's so easy to speak to other people that have used those services. You don't have to jump through many hoops just to say, 'What do you think' sort of thing."* Tim remarked that he chose Case 3 *"because the other two, I don't know, needed to know more in terms of the severity of and the intensity of, whereas if it's getting a wheelchair, you just know a lot of what needs to be done."* Amanda agreed that, for her, the easiest one to advise was related to *"equipment because it's such a short burst [...]. It's probably the least complex out of all of them. Not that it's less important, but it mightn't be as ongoing, and it's easier to change where you purchase your equipment from than it is to pull out of your personal care provider and go to another one; that's a harder thing to do."*

This provides an interesting reflection on the complexity involved in choosing human services as opposed to products, and there was no consensus among participants about which was more difficult. A professional stated that "*it's a big question, especially with the* *equipment one, because with service, you do two sessions, and you can [change] someone if it's not working. With a piece of equipment, returning it or getting it changed can be tough.*" He was not the only one to have this opinion; for example, Susan stated that she found Case 2 most straightforward "*because the services were coming to her home, it was mostly around what they could offer her… when, how, what was the best fit."* Sandra agreed: *"With like a physio, if she's not giving us good service, we just dump her and get another one. Whereas if your wheelchair breaks, you have to go back to your original provider."* It is remarkable yet unsurprising that the two participants who particularly discussed this topic were professionals with extensive experience at guiding participants to choose human services.

Further evidence about this aspect of decision-making came from Daniel, who stated that it was easiest to advise Case 2 *"because it was to do with carers specifically, so I suppose it was a little bit more personal rather than like businessy. I'm not real business-minded, but I can relate it back to past carers if it's about carers that I've had dealings with, rather than dealing with a business."* This illustrates the very different issues that come up with choice in such a heterogeneous marketplace – when it is limited to which support worker one should choose, the factors are micro and relational: gender, age, interests, values, location and availability. However, when there is suddenly choice at a meso or organisational level, this raises a great deal of unknown questions about business structure and how to assess the quality of human services, which lead to a customer feeling the need to assess their choices against unknown metrics of unknown value.

### 7.2.2 What participants learned

The final interview question asked what participants had learned through the process, prompting some interesting thoughts and ideas. Reflections on the sector related to the enormity of the change represented by the NDIS and how underdeveloped the industry is. As David pointed out, *"whether [the existing sectors] settle in the right layout or not is a different matter."* Related to this, others commented on the difficulty of how referrals are traditionally made on the wisdom and experience of particular senior workers. There was a comment about the impact of the siloing of, for example, alcohol-and-other-drugs and homelessness services from mental health, which will become more and more problematic as the NDIS separates mental health further from these services. Some participants also commented about the differences between making decisions about purchases in this sector when compared to others. Examples of these comparisons came up in the previous results chapter, where metaphors were given about choosing plumbers and blenders.

Several carers and consumers reflected on their own choice-making processes. Some came up with specific things they felt they should do next time they had a choice to make about suppliers, for example, having a checklist or engaging more with online communities. For Tim, *"there are probably people I can ask if I need assistance because I trust those people. They're in the same system and know what works and what doesn't. You're not doing this giant thing; you're just cutting to the good parts."* Emily commented that while they had thought a lot about how to attain a positive personality match with support workers, this interview also caused her to consider practical elements. Yet another participant, reflecting on her experience of NDIS, stated that although she had some choice, there were a few suppliers she was using but felt she had not actively chosen. She reflected that the interview *"kind of actually made me wake up and realise [that] I shouldn't be just looking to one or two providers […]. I should actually be surveying a lot more providers to select services I need."*

Other participants reflected in a more abstract way. For example, one carer realised how much of his process is implicit and appreciated the opportunity to make explicit *"what I've been doing for the last 10 years."* As Daniel put it, *"it's made me think of what we had to think of when we were going through those processes because I don't think you think about it at the time. I think you just… tick boxes for forms and answer questions but don't reflect, and I suppose this has been a chance to reflect [and] actually consider what did occur."* This illustrates the potential for the new NDIS system to create a different type of consumership, one that goes beyond "just ticking boxes". However, this is not without its problems. In fact, the last impression from service users was the enormity of the task ahead and what it might cost them. According to Tara, *"I've not had to make any decisions, and now I go, 'Holy shit, there's a lot to'… it's just never been a question anybody's ever asked us, and now we have to make a decision, and now I see how much we've got to go through. And I definitely see some of the benefits, but I also see the challenge."*

Suppliers and referrers reflected that there were ways they could be operating more effectively. For some, the simple process of reflecting on and analysing "the things I regularly think about" was useful, as opposed to "just ticking boxes." Others realised that there were ways they could improve their practice in terms of the content with which they support people to make choices: *"It's helped me think about location, […] who to choose, and what sort of questions to ask,"* or that there are *"things that other people have said that I wouldn't have thought about."* This is powerful, as a central role of support coordinators – which is going to become less funded – is to capacity-build with consumers in order to be able to do this work themselves; in the meantime, it is market-shaping work.

Rather than thinking about content, other referrers reflected on the process of service navigation and how they could be more consumer-centred in their practice. As Andrew explained: *"Probably some of those things that I jump to straight away as a coordinator might not be the most important ways to get information for people I support. [For example, the mother of someone I support] uses the net but doesn't necessarily use it to get support information. She calls me for those things or asks her friends those things. And I just sent her a link to [a site I found] and said, 'Check this out it looks really cool, it might work well for your son.' And that might not be the best way to give her that information. She'd probably get that information better from us sitting down and having a conversation around that and going through the website together rather than me just sending her the link and calling that support coordination."* Andrew also reflected that after having focused on the importance of WOM for the majority of the interview, they would make a case to reduce their organisation's marketing spend and invest solely in this area.

The last theme when participants were asked what they had learned was an appreciation of how complex the decision-making process is, or as Andrew put it: *"It's a more complex sort of service dynamic than just getting a plumber."* Suzi remarked that they had considered new *"ways to support people to make choices for themselves in the future,"* but *"at the same time I'm understanding it's so complex. At what point in time can you put expectations on other people to think about these things themselves? It's really hard."* Amanda described the difficulty: *"It's quite an extended process […]. It would probably take you a few weeks to do all this – to find the networks, do the research, [and] get online. If it's a complex path and you've got multiple parts to your plan, you need to do this for multiple elements in your plan […]. You're making these decisions for every one of those things in your plan, one person. For someone with a complex plan, that's a lot of work and a lot of decision making."* However, she considered whether, longitudinally, there might be greater efficiency: *"Further* *down the track… 10, 20 years… you might have refined the decision-making process a bit more or you feel like you've increased your confidence and capacity to be making decisions based on the info you're seeing, so it might be a learned skill… so the more you do it, the more they gain confidence, [and] they'll get to know the pathways to navigate and work out what they need. As we go on through the years, that'll become an easier process for people, not all, but as they work out the system. […] it still is complex."* This idea of complexity will be picked up in the discussion.

Other issues raised in the reflection question related to the need for consumers to have digital literacy, access to the internet, and the networks informing them that particular resources are available to them. In this vein, the cognitive capacity of NDIS consumers to make decisions and risks around self-determination also arose. As Amanda noted, *"70% of the NDIS [participants have an] intellectual disability. Their capacity to make choices like this [is affected. So], how much of these decisions could get taken away from them if a parent of an adult child or guardian or nominee starts making the decisions for them… because it's quite complex process to go through."* Indeed, as the literature review illustrated, supported decision-making is an essential component of a rights framework for PWD, and the importance of this framework will increase as choice increases.

Amanda summarised the complexity beautifully: *"You could do all these processes and spend a month or two months reading annual reports and asking everyone you know and meet them, and it all sounds good, and you could get six months down the track, and the service quality's crap, and you could get crap support workers or buy a bad chair and it breaks down... it's not foolproof or risk-proof."* This raises the question about what level of risk is acceptable – zero risk is not possible and, according to the principles of dignity of risk outlined in Chapter 4, is not desirable. Later chapters of this thesis will look at ways that this type of uncertainty may be decreased for participants by having information and processes that support consumer decision-making.

## 7.3 Chapter Summary

This chapter has examined the content of information consumers want in order to feel informed when they make decisions about what services to purchase and has shown that the core value of trust is woven through the data. The results in this chapter have also raised issues around decision-making burden, risk and uncertainty. The following chapter, the final results chapter, describes the survey results, with the aim of determining whether the same themes were identified in a wider population.

# 8 Findings Part 3: Survey results

While Chapters 6 and 7 described the results of Phases 1 and 2 – the semi-structured interviews – this chapter examines the data that was generated in Phase 3, the survey phase. The methodological goal of the survey was to extend the sample by mixing methods, drawing in quantitative rigour in order to test the generalisability of interview results with a wider population of NDIS service users. The methodology chapter already acknowledged some of the sampling limitations, but despite these, Phase 3 met its goals as an exploratory study by collecting participants' demographic data, including information about service use and choice experience, preferences about the top 10 sources of information and the content of information that emerged from the first phases of research.

This chapter is structured in the same way as the survey itself. It first describes participant demographics and compares these to external data sources that show patterns in NDIS and wider populations in order to explore the similarities and differences in the sample. It also examines the types of services used and the amount of experience participants had in choosing services prior to taking part in the research. It then looks at the importance of information sources and content, and analyses participants' reasons for electing importance as such. Interestingly, it finds very little variation of results by demographics, stakeholder role or any other variables – rather, it finds that other than in a small number of instances, results are consistent across all these factors. Further, this chapter raises issues that are relevant to the discussion in the next chapter about participant- and social justice-centred market stewardship and the NDIS information economy.

## 8.1 Survey respondents

This first section of this chapter examines the demographics of the 201 respondents who completed the survey. It first looks at the type of stakeholder they were (participant, carer or professional) before determining their location, age, gender and level of education. Finally, the section examines the types of disability represented in this survey, including patterns of comorbidity represented.

### 8.1.1 Stakeholder role

"Stakeholder role" refers to whether respondents identify as a PWD, a family member or carer, a professional in the disability sector or something else. Respondents were able to select multiple roles. All respondents responded to the question. Of the 201 people who responded to the survey, 59 identified as PWD, 74 as a parent or carer of someone with a disability and 104 as professionals in the disability sector. Three identified as "other" and listed these as being either an activist or an academic. This is recorded in table 15.

| Role | Count | Percentage |
|---|---|---|
| PWD | 59 | 29% |
| Parent or carer | 74 | 36% |
| Professional | 104 | 51.5% |
| Other | 3 | 1.5% |

*Table 14: Stakeholder roles of survey respondents*

Of the professionals, five were social workers from non-disability backgrounds, such as oncology; however, they identified as regularly making referrals to disability services in the course of their work. These people were counted as professionals in the disability sector working in a disability type – "chronic illness". On full roll-out, the NDIS will service 460,000 participants and require a workforce of 162,000 full-time equivalent staff (DSS, 2017), which means that professionals were overrepresented by almost five times in this sample. It is reasonable to assume that this was a result of the snowballing sample collection method, and particularly the use of social media, leveraging the networks of the researcher as a professional in the sector.

Thirty (15%) respondents identified as having multiple stakeholder roles. The Venn diagram in Figure 20 illustrates the considerable amount of overlap in the roles of this sample. The ABS cites that 37.8% of carers also identify as having a disability (ABS, 2013). Twenty-two of the sample identified as being both these stakeholders, which is underrepresented at around 11%.

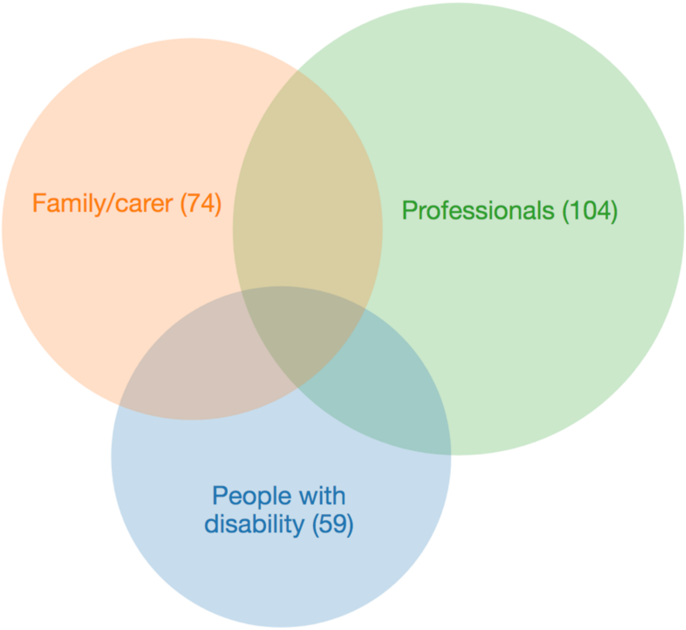


*Figure 20: Overlapping roles of survey respondents*

### 8.1.2 Location

Respondents were asked which state they lived in via a single-answer multiple choice question. All respondents answered the question. The majority (59%) of respondents were located in Victoria, 17% were from NSW, and the remaining six states and territories comprised 23%. Figure 21 below compares the percentage of survey respondents with the distribution of NDIS participants and funding (NDIA, 2019d), and there is a large discrepancy in respondents for most states. It is reasonable to assume that this was a result of the snowballing sample collection method and the more extensive social and professional networks of the researcher in Victoria and Tasmania than other states.

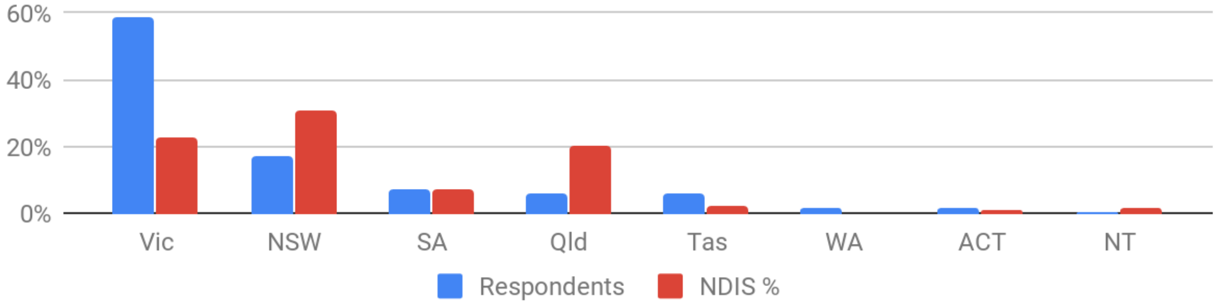


*Figure 21: Survey respondent location versus NDIS distribution by state (NDIS participant data taken from state Market Position Statements, June 2016)*

### 8.1.3 Gender

All respondents indicated their gender in a single-answer multiple choice question, from which 154 respondents indicated they were female, 43 were male, and 4 people were transgender or preferred not to say. This is illustrated in Figure 22.

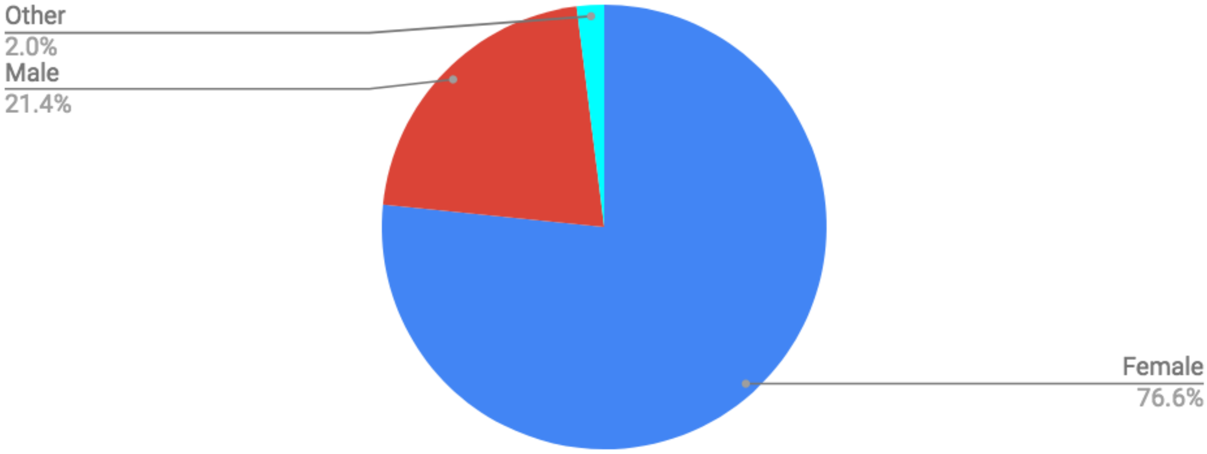


*Figure 22: Gender breakdown of survey respondents*

#### 8.1.3.1 Gender: Sample vs population

The majority of respondents (77%) were female, and while this is echoed in wider disability population statistics, females are overrepresented in the sample in each stakeholder group, as illustrated in the Figure 23 below.

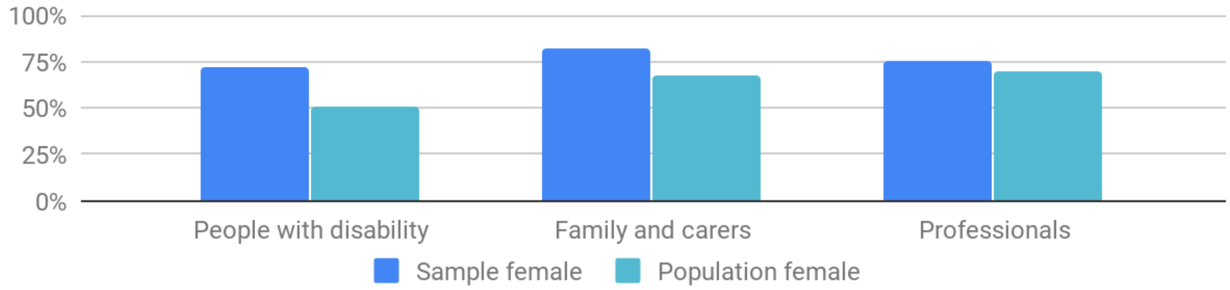


*Figure 23: Sample vs population who are female (data taken from ABS, 2013a, 2013b; NDS, 2018)*

### 8.1.4 Age

All respondents indicated their age group in a single-answer multiple choice question. The most frequently represented age group was 25–34. It is reasonable to assume that this was a result of the snowballing sample collection method and particularly the use of social media by the researcher. Figure 24 illustrates the age-group breakdown of all the respondents.

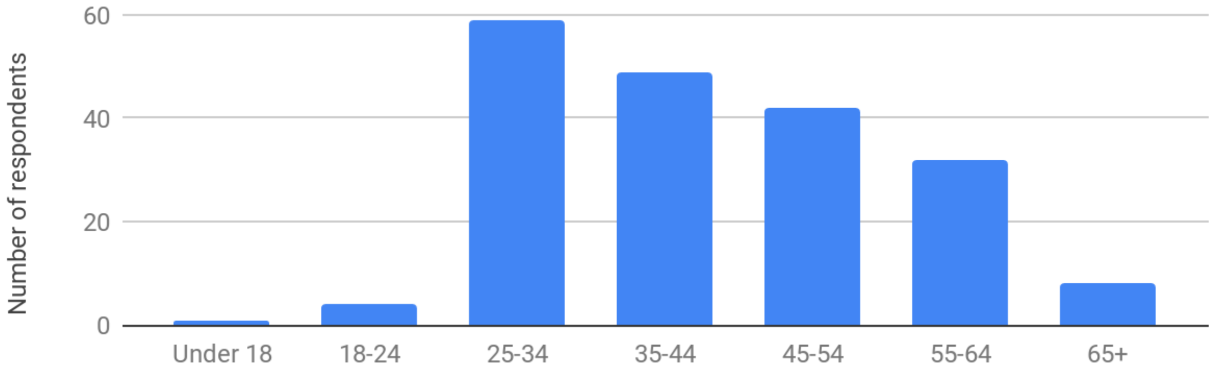


*Figure 24: Age breakdown of survey respondents*

#### 8.1.4.1 Age: Sample vs population

In comparison to the general population, age groups 25–54 were overrepresented by about two times, and all other age groups were underrepresented. Age group 55–64 was the closest to the general population, as described by ABS five-year increments. Figure 25 illustrates the sample in comparison to the general population.

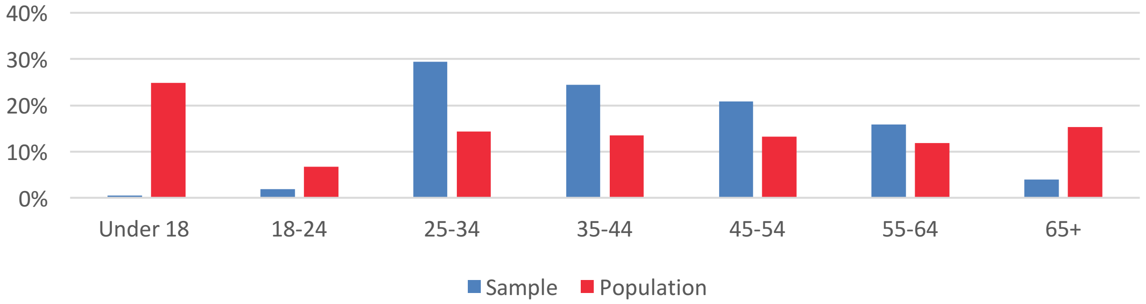


*Figure 25: Age breakdown of respondents in comparison to the total population (source: ABS, 2019)*

Figures 26–28 break down the age of the survey respondents by stakeholder role and illustrate the similarities and differences to external data.

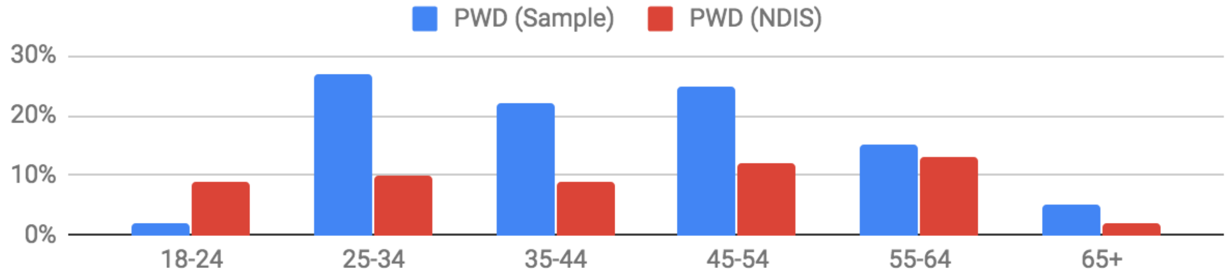


*Figure 26: Age of PWD in the sample vs the NDIS (source: NDIA, 2019a, p. 21)*

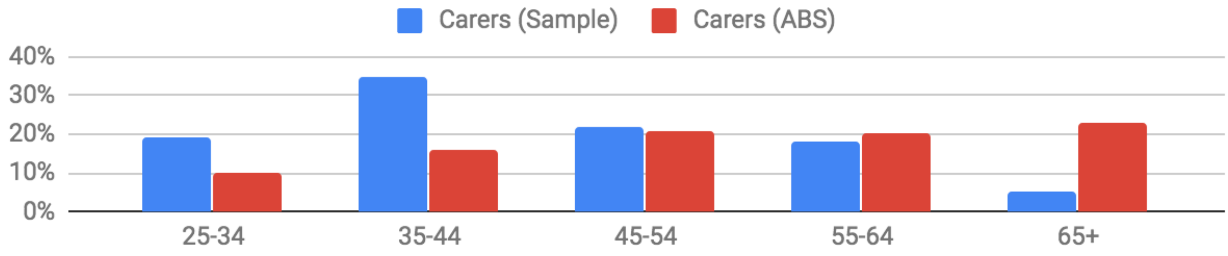


*Figure 27: Age of carers in the sample vs the wider population (source: ABS, 2013)*

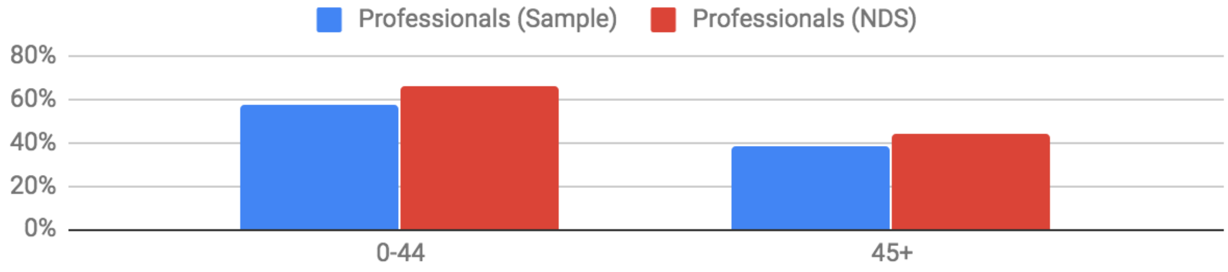


*Figure 28: Age of professionals in the sample versus the industry (source: NDS, 2018)*

This sample has an overrepresentation of people in the 25-54 age groups in the consumer stakeholder group, and it excluded people aged under 18, which comprise 9% of the population according to NDIS data. Carers were overrepresented between 25 and 54 years and under represented at age 65+. Professionals were fairly well matched to NDS data (NDS, 2018b).

### 8.1.5 Education

All respondents answered the single-answer multiple choice question about the highest level of education they had completed. The vast majority of respondents had completed a bachelor's degree or higher education (see Table 18). Those with high school or trade certificates comprised only 17% of the sample.

| | Total | PWD | Family | Professionals |
|---|---|---|---|---|
| Prefer not to say | 3.0% | 1.0% | 1.0% | 1.0% |
| High School | 10.6% | 5.1% | 4.5% | 1.0% |
| Trade certificate | 6.6% | 2.0% | 3.5% | 1.0% |
| Bachelor's degree | 39.9% | 15.7% | 9.6% | 14.6% |
| Post graduate | 51.5% | 10.1% | 14.1% | 27.3% |

*Table 15: Education level of survey respondents*

When divided by stakeholder role, it is unsurprising that professionals have, on average, a higher level of education than the other groups, as illustrated in Figure 29.

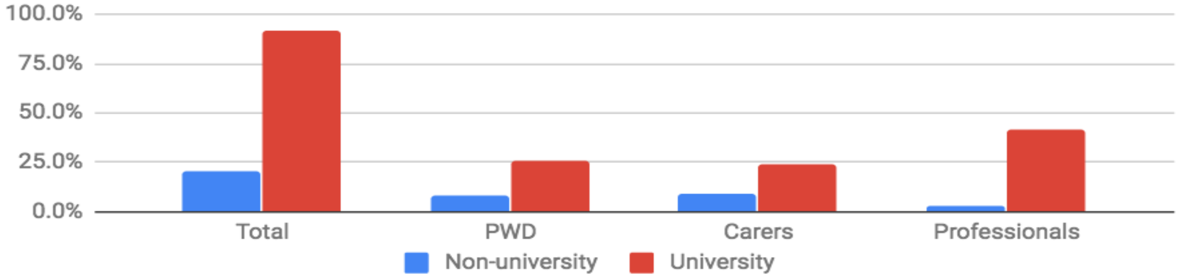


*Figure 29: Tertiary- vs non tertiary-educated respondents by stakeholder group*

In the wider Australian population, 41% of PWD have completed high school only, 28.4% have completed a trade certificate, and 17% have completed a bachelor's degree (ABS, 2010). In this regard, the sample is unrepresentative of people with a lower level of completed education (see Figure 30), which is reasonable to assume was a result of the snowballing sample collection method.

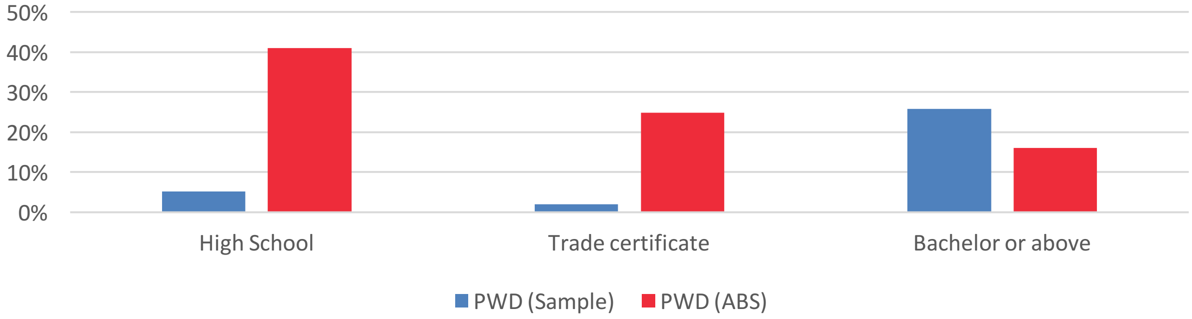


*Figure 30: Education levels of PWD in the sample compared to the wider population (source: ABS, 2010, 2018)*

### 8.1.6 Types of disability

All respondents answered the multiple-choice question asking what type of disability was most relevant to them or the people with whom they work. Respondents were able to select as many as were relevant. Options included an "other" category, which resulted in categories of chronic disease and chromosomal diagnoses being added to the choices. The largest representation was from mental health diagnoses, followed by physical and intellectual disabilities, autism spectrum, acquired brain injury (ABI) and various neurological disorders (see Figure 31). Because chronic disease and chromosomal disabilities were opt-ins from the "other" category, they comprise only a small number of respondents and are presumably not representative even of the sample. For this reason, they have been excluded from further results.

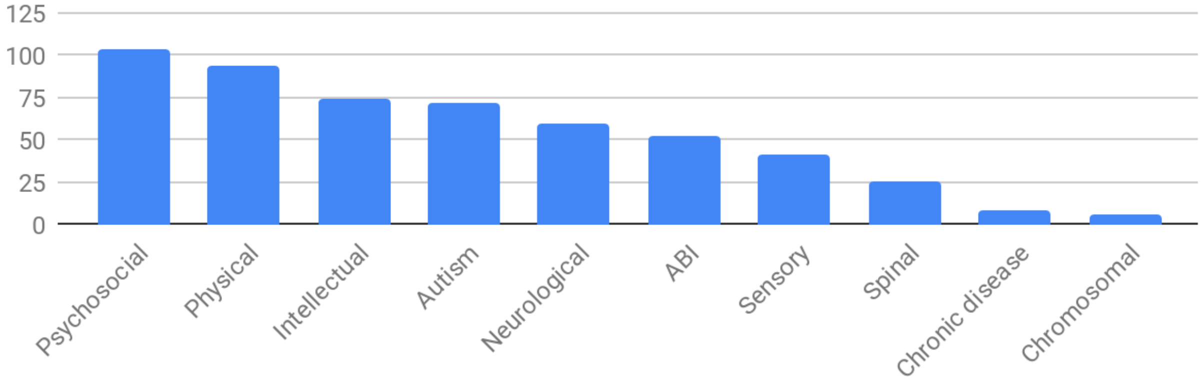


*Figure 31: Types of disability most relevant to respondents*

#### 8.1.6.1 Types of disability in the sample vs the NDIS

Limited data is available to compare these patterns to the NDIS population; however, the data that is available is illustrated in Table 20 in comparison to the sample. Mental health is overrepresented in comparison to the NDIS, but it might be representative of the community at large. It may also be oversampled because the primary researcher previously worked in mental health, so the snowballing sample would be influenced by such networks. Additionally, one of the more active recruitment partners was a mental health specialist organisation.

| **Diagnosis type** | **Sample** | **NDIS (March 2019)** |
|---|---|---|
| Psychosocial | 52% | 9% |
| Intellectual | 37% | 26% |
| Autism | 36% | 30% |
| Neurological | 30% | 5% |
| ABI | 26% | 4% |
| Sensory | 20% | 7% |
| Physical | 47% | 12% |
| Spinal | 13% | 1% |

*Table 16: Sample diagnoses compared to NDIS diagnosis groups (NDIA, 2019f)*

### 8.1.7 Comorbidity

Comorbidity has not been thoroughly taken into account in the above table and graph; however, the majority of respondents (59%) indicated that multiple disability types were relevant to them. The table below shows those who reported comorbidity broken down by role in order to see if this high percentage was simply due to professionals working with people with a variety of different disabilities. While there is certainly a larger proportion of professionals working across multiple disability types, both consumers and family members reported a high level of comorbid diagnoses, as illustrated in Figure 32.

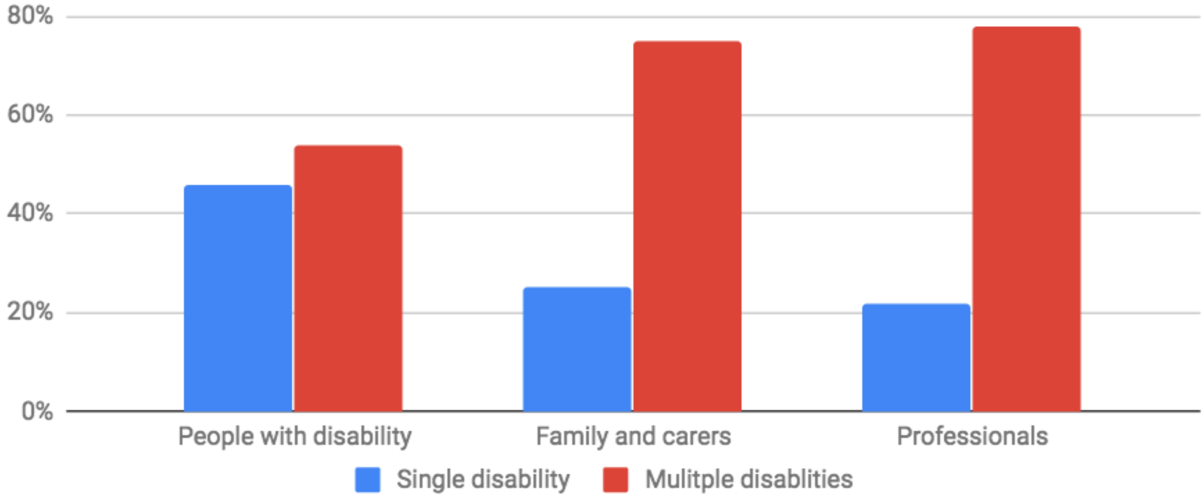


*Figure 32: Single vs comorbid (multiple) disability type by stakeholder role*

Data was separated by diagnosis type in order to explore whether there was a correlation with comorbidity (see Table 21). The lowest comorbidity was mental health, implying that the greatest number of diagnoses were mental health only; however, this was still 76%. People who had or worked with PWD related to acquired brain injuries and spinal injuries as well as sensory disabilities have nearly a 100% comorbidity rate.

| **Diagnosis type** | **Comorbidity (%)** |
|---|---|
| Spinal | 96% |
| Acquired brain injury (ABI) | 90% |
| Sensory | 90% |
| Neurological | 88% |
| Autism spectrum | 88% |
| Intellectual | 85% |
| Physical | 80% |
| Mental health | 76% |

*Table 17: Instance of comorbidity in relation to survey respondents*

## 8.2 Service use

All respondents indicated the types of services they used or supported others to use. They were able to select as many options as were relevant, in addition to also having the choice of "other" with a text box, the input for which added accommodation and respite to the existing list. As this was an opt-in through the "other" selection, it is underrepresented and is excluded in further calculations. Allied health was the most frequently used service type, with 81% of respondents stating they used allied health services (see Figure 33).

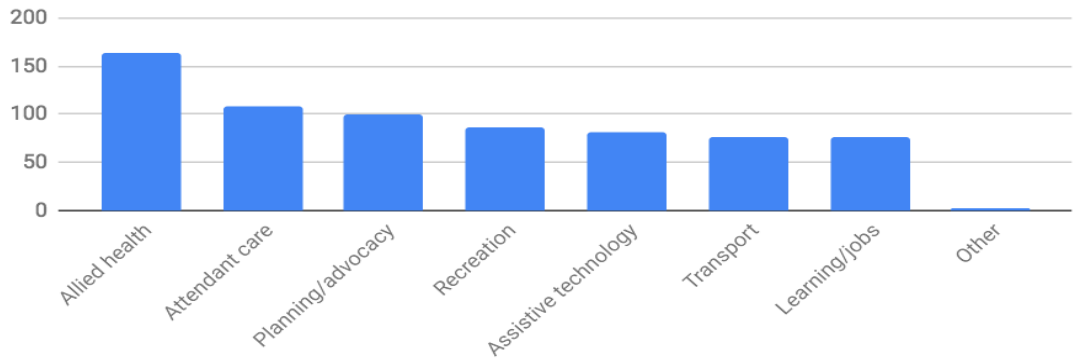


*Figure 33: Services used by survey respondents*

| **Service type** | **Count** | **Percentage** |
|---|---:|---:|
| Allied health | 163 | 81% |
| Attendant care | 109 | 54% |
| Planning, advocacy and coordination | 100 | 50% |
| Recreation | 86 | 43% |
| Assistive technology | 82 | 41% |
| Transport | 77 | 38% |
| Learning and employment | 77 | 38% |
| Other | 3 | 2% |

*Table 18: Services used by survey respondents*

Unfortunately, equivalent data from the NDIS environment is not public at the time of writing. Service providers who choose to register with the NDIA so they can offer services to agency-managed participants must elect to provide one or more categories of service. The comparable public data set used in Table 22 is the number of registered providers registered to offer services in each NDIS category. However, as mentioned in Chapters 3 and 4, around half of these providers are not actually providing the relevant services (NDIS, 2019), and many providers choose not to register. While this is the best data available, it is inconclusive as it does not correspond exactly to either what services organisations actually provide or the frequency with which services are used by participants.

There was a high rate of allied health use, which is consistent across all three stakeholder groups. This is shown in Figure 34 below. When excluding the "other/none" category, the least used by PWD was personal and attendant care. Family members and carers used transport the least, as did professionals. Assistive technology is the other service that professionals used the least often. There is an underrepresentation of PWD using attendant care when compared to the NDIS data, which suggests that over 49% of funds are being used for this purpose (NDIA, 2019f).

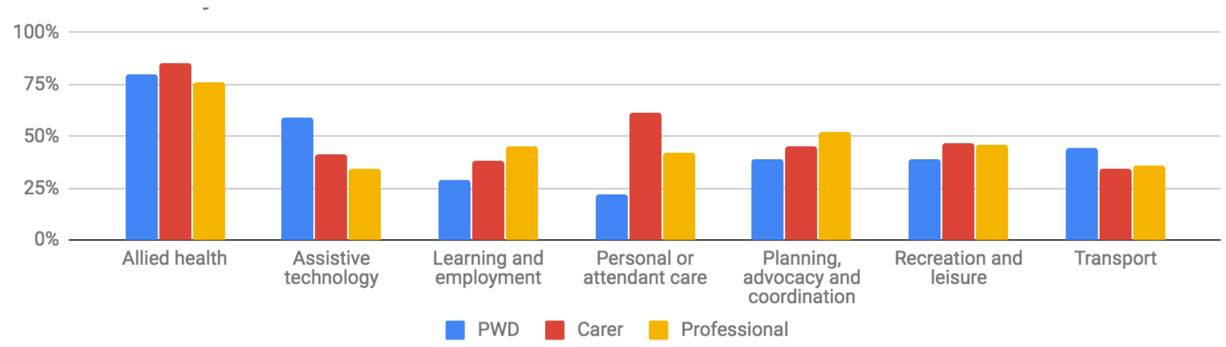


*Figure 34: Service use by stakeholder role*

### 8.2.1 Number of services and stakeholder role

Figure 35 shows the count of services used, split by user role. The only respondents who stated that they used no services were retirees or academics, which explains the lack of PWD or carers in the 0-services section. The average number of services used by all groups was 3.5–3.6 services (see Figure 35). The biggest group in the professionals is one service type, which suggests that the sector is rather segmented in the way it works and that most professionals are delivering a single service type.

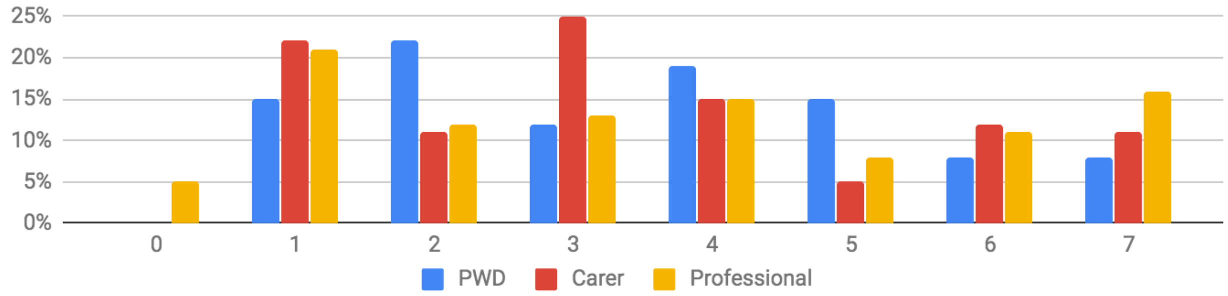


*Figure 35: Number of services used by stakeholder role*

### 8.2.2 Number of services used and diagnosis type

Figure 36 shows the average number of services used by each diagnosis type. There is around a 30% difference in the number of services used by people with chromosomal-related diagnoses, who use an average of 3.2 services, and PWD related to spinal issues, who use an average of 4.6 services. This analysis does not account for patterns of comorbidity.

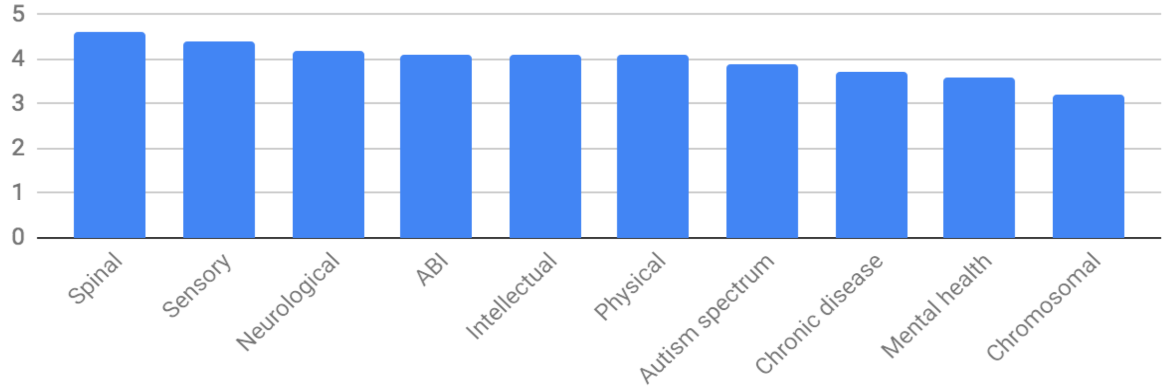


*Figure 36: Number of services by diagnosis type*

## 8.3 Experience in choosing services

Respondents were asked to nominate how much experience they had with choosing disability and mental health services, and 100% of them responded to this question. They were asked to select one of the following options from most to least:

I choose services most weeks
I choose services annually
I've chosen services several times
I've chosen services once or twice
I've never chosen disability services

For further analysis, these were converted to integers as follows:

I choose services most weeks = 5
I choose services annually = 4
I've chosen services several times = 3
I've chosen services once or twice = 2
I've never chosen disability services = 1

Using this scoring, it can be calculated that the mean is 2.7, the median is 3, and the overall standard deviation is 1.04. Although the standard deviation indicates some difference between respondents' experiences, the data indicates that, overall, the majority of the sample have chosen services several times but do not have extensive experience. Figure 37 shows the various percentages of respondents' choice experience.

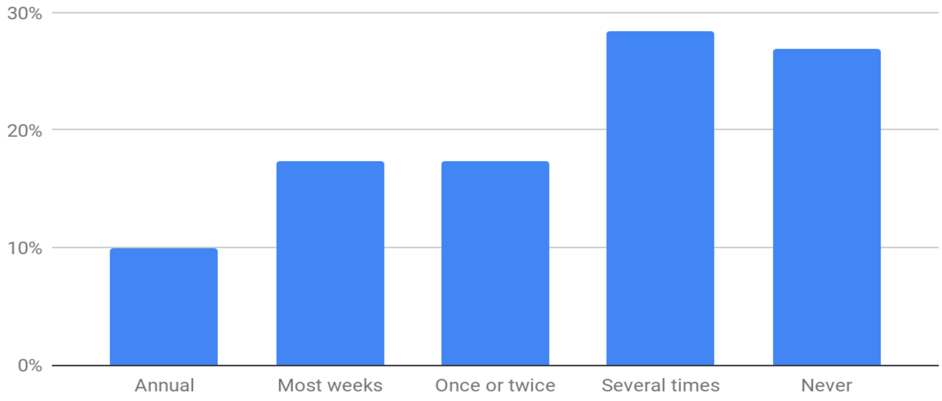


*Figure 37: Frequency of respondent service choice-making*

## 8.4 Importance of information sources

Respondents were asked how important each of the 10 information sources were to them feeling informed when making a decision about which service to choose. One hundred percent of respondents answered this question. Each of the 10 sources was rated on a 5-point scale from "not important" to "very important". Because the response options were presented as equidistant points along a line, it is reasonable to treat the scale as an interval scale. As above with choice-making experience, this scale allows conversion to an integer:

Very important = 5
Quite important = 4
Fairly important = 3
Slightly important = 2
Not important = 1

Just as with the application of integers to the amount of experience above, this allows a calculation of average responses to assess average importance of each source.

It also allows the calculation of standard deviations, which helps to quantify variation around the mean and make statements as to the level of variation in one set of responses compared with another. The variety of averages in Table 23 shows that there is some variation in score, and the variety of the standard deviations shows that there was variation in responses to information sources.

| **Information Source** | **Average** | **Standard Deviation** |
|---|---|---|
| Information from meeting the person who will be working with you | 4.4 | 0.8 |
| Advice from a trusted professional | 4.1 | 0.9 |
| Online reviews and complaints from current and past customers | 3.6 | 1.1 |
| Advice from friends, family or guardian | 3.5 | 1.1 |
| Advice from a professional advocate | 3.5 | 1.2 |
| Advice from your GP | 3.1 | 1.3 |
| Agencies' websites | 3.0 | 1.1 |
| Social media (e.g. Facebook) | 2.5 | 1.2 |
| Google | 2.5 | 1.1 |

*Table 19: Frequency and standard deviation of information source rating*

About 50% of respondents selected four or more service categories, which meant that these people were probably thinking about disability services quite generally when rating the value of information sources. The other half of respondents were likely to be considering services more specifically, so we might expect more variation. For example, if a respondent was thinking about taxi drivers, advice from a GP is useless, but if they were thinking about allied health, then it might be useful. Table 24 examines only those respondents who selected three or fewer service types.

| **Information Source** | **Average** | **Standard Deviation** |
|---|---|---|
| Information from meeting the person who will be working with you | 4.4 | 0.8 |
| Advice from a trusted professional | 4.1 | 1.0 |
| Advice from friends, family or guardian | 3.6 | 1.1 |
| Online reviews and complaints from current and past customers | 3.6 | 1.1 |
| Advice from a professional advocate | 3.3 | 1.3 |
| Advice from your GP | 3.2 | 1.3 |
| Agencies' websites | 2.9 | 1.1 |
| Social media (e.g. Facebook) | 2.5 | 1.2 |
| Google | 2.4 | 1.1 |

*Table 20: Ratings from respondents (101) who only tick 1-3 service types*

Excluding those respondents who might have been thinking more generally about service types does not have a great effect on the order of the sources of information. This means that, at least as expressed in these ratings of importance, respondents were indicating a general attitude toward the information sources – it did not depend on the type of services they used.

### 8.4.1 Most important sources of information

The next survey question asked respondents to identify the most important of the 10 sources of information they had rated and to describe why it was most important. 81% of respondents answered this question. Ten respondents listed two to three equally important sources of information, so there were 213 responses although only 191 respondents answered this question.

"Meeting the person who will be working with me", "asking a trusted professional", and "WOM" were the information sources most consistently identified as most important ($x2 = 20\%$, $p \geq 0.05$). Qualitative comments revealed some overlap between asking a trusted professional, a GP and advocate; they also showed overlap between online sources, namely reviews and social media, Google and agency websites. As was mentioned in the previous chapter, social media also has interpersonal facets. The following section will describe each of these themes and provide example quotes to illustrate them. There are two additional sources that were not in the survey: "personal experience" and "multiple sources". While these were opt-in sources resulting from analysis of qualitative comments (and are therefore likely to be underrepresented), they are interesting nonetheless, given that the rate of selection was comparable with others that had arisen in Phase 1 of the research. Figure 38 shows the most important sources, and the following section describes them in more detail.

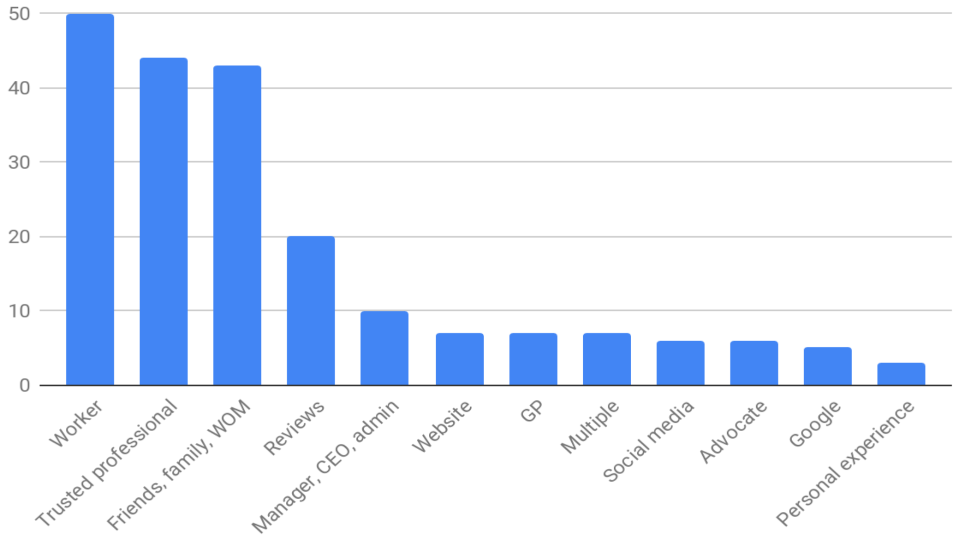


*Figure 38: Most important sources of information*

### 8.4.2 Why are these the most important sources?

Below, comments are summarised about each of the 10 sources. There are also two additions: personal experience and multiple sources. In this regard, personal experience was noted by only 1% of respondents and was an opt-in response. The small number may not be relevant as it was not one of the 10 to choose between; however, it might be noteworthy that there were not more people who identified it as a factor despite the fact that it appeared in the results in Chapter 7. Additionally, it is implicit in a number of the categories. Three percent of respondents specifically noted that multiple sources of information are necessary. Some noted that it is important to look at multiple sources of information because multiple stakeholders are involved. Others wrote that it depends on the type of service they are choosing as to which source of information they would find most important; or that it would change depending on whether they are looking for services for themselves or for a client because they have an extensive professional network from whom they could ask advice, where their clients' support networks are more limited.

#### 8.4.2.1 Meet the person who will be working with me

This was the most highly rated source of information, with 23% of responses listing it as the most important. One of the main reasons for this is an opinion that meetings inform them about their compatibility and therefore the likelihood of achieving good outcomes. A variation on this is that respondents felt that through a face-to-face meeting with the worker, they can tell whether they can trust them and whether they will be respected and not just viewed as a source of income. Some respondents felt they could use this source of information to assess the workers' expertise and communication and whether they will collaborate with their community. Others stated that workers are unbiased and have valuable experience about the service.

#### 8.4.2.2 Advice from a trusted professional

Just over a fifth (21%) of comments listed advice from a trusted professional as the most important source of information. Respondents trusted professionals to be informed and up-to-date and therefore to give good advice. They were keen to leverage professionals' experience with other clients – both good and bad things about providers – and to get objective advice from them. One respondent explained: *"By 'advice', I don't so much mean opinion or recommendation ('I think X service is good'), but rather intelligence (e.g. 'They have large staff turnover')."*

#### 8.4.2.3 WOM

20% of comments indicated that WOM, particularly from consumers and families with experience, is most important. These comments demonstrate a belief from the respondents that the experiences of people who are like them or understand them provide the most reliable, accurate information. For example, one participant wrote that *"personal knowledge about a service and the level of service provided can be very powerful. It can be more accurate than the marketing material provided by the provider themselves."*

#### 8.4.2.4 Reviews and complaints

Comments revealed that for some of the 9% of respondents for whom reviews were most important, they were a proxy for WOM for people who are homebound or have limited social capital. They are valued because of a belief that real (authentic) reviews tell the truth and are unbiased and jargon-free. For some people, they are a tool to be used to verify other information, suggesting that while they are the most important source, they are not the only one.

#### 8.4.2.5 Manager/CEO

Around 5% of relevant comments used in the content analysis listed speaking to the management of an agency as the most important source of information so that they could ask questions directly about their specific needs and make judgements about the nature of the organisation. For example, one participant wrote that by meeting management, *"I can assess the systems and processes as well as the workplace culture and ethos of the organisation."*

#### 8.4.2.6 Social media

Only 3% of respondents stated that social media is the most important source of information, which is at odds with the qualitative data described in the previous chapter, suggesting that the mechanism itself is not important, and it is used as a way to interpersonally connect with other people rather than with organisations. For survey respondents, there was a belief that if a company makes an effort in their social media, they probably make an effort elsewhere. They also felt that the unbiased good and bad aspects of an organisation can be found in online reviews on social media; this suggests that social media and reviews have a significant crossover. There was also the suggestion that the information on social media is more up-to-date than on websites, which rarely get updated.

#### 8.4.2.7 Advice from a professional advocate

The 3% of comments that listed professional advocates as the most important source of information did so because advocates have lived experience and are unbiased. For example, one participant stated that advocates are *"neutral, objective, informed and able to offer pros and cons."* There was significant overlap with comments made about professionals and general WOM.

#### 8.4.2.8 Agency websites

Out of all the comments included in the content analysis, 3% stated that websites are the most important source of information, which was especially relevant for service users who were seeking details about an agency. It was also valued because it allowed respondents to do research at a time and place suited to them rather than having to rely on others. However, even these positive comments revealed that information listed on agency websites can be out-of-date. There were calls for websites to be clear and concise and list services provided as well as contact details. As noted by a participant, *"if a company makes an effort with their website, you can assume they make an effort with their services."*

#### 8.4.2.9 Advice from GP

There was a qualitative overlap between valuing the GP as the most important source of information and "trusted professionals" in general. For those who specifically named their GP as being an important source of information, they noted the existence of a long relationship with their GP and a history of trusting their referrals. Others noted that their GP is a gatekeeper to all support services and that this adds to their importance as a source of information.

#### 8.4.2.10 Google

Comments revealed a significant overlap between Googling and agency websites. For the 2% of comments valuing this source most highly, Google is the "first port of call. I need to be able to find an organisation's details."

## 8.5 Importance of informational content

Respondents were asked to rank the 10 types of content identified in the interview phases of the research process as most important (1) to least important (10). All respondents answered this question. Figure 27 below shows how highly people rated each content idea. Lower scores mean that they were rated as more important. Standard deviations reveal that there is some variance between respondents; in this sense, there is a larger amount of variation in the averages of the first five than in the second five, and the biggest variation was around "good communication", which was also in the top five.

The accompanying qualitative question asked respondents to explain their choice of most important content. While the content analysis was carried out on the qualitative comments, some changes were made because the comment listed a "most important" factor that was different from the one that the respondent had ranked most highly in the survey. This resulted in a slight variation between the number of times each was ranked first and their average importance.

### 8.5.1 Most important informational content

In order to further analyse the data provided by respondents through their rankings, only those sources that were ranked first or second have been taken to signify "important" (and therefore the rest as "unimportant") in order to create a binary option, which creates more statistical significance (see Figure 39 and Table 25).

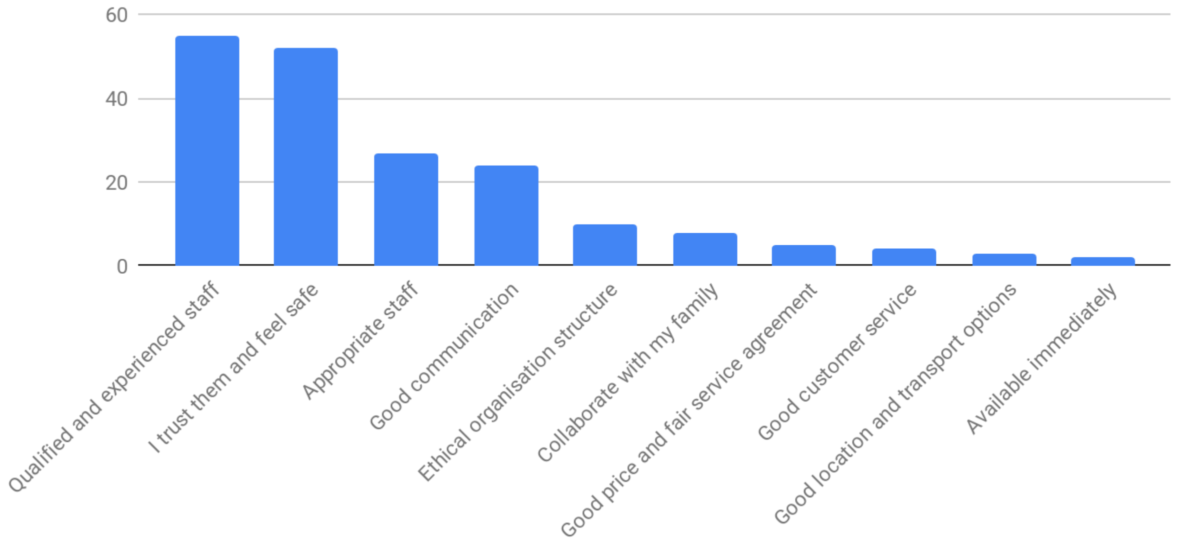


*Figure 39: The frequency that each source was ranked in first or second place*

| | Average importance | Standard deviation | Rated #1 |
|---|---|---|---|
| I trust them and feel safe | 3.7 | 2.2 | 52 |
| Qualified and experienced staff | 3.9 | 2.8 | 55 |
| Good communication | 4.3 | 3.0 | 24 |
| Appropriate staff | 4.5 | 2.7 | 27 |
| Good customer service | 5.9 | 2.3 | 4 |
| Collaborate with my family | 6 | 2.4 | 8 |
| Ethical organisation structure | 6.5 | 2.5 | 10 |
| Good price and fair service agreement | 6.5 | 2.3 | 5 |
| Good location and transport options | 6.9 | 3.0 | 3 |
| Available immediately | 6.9 | 2.8 | 2 |

*Table 21: Types of content listed by average importance (lower number = more important)*

### 8.5.2 Why is this the most important content?

Below, comments are collated about each of the 10 types of content of information. Ninety-four percent of survey respondents provided a qualitative response that explained their choice of highest ranked content. The ratios in the prose below describe the percentage of all qualitative responses collected.

#### 8.5.2.1 Qualified staff

Just under a third of respondents (29%) ranked well-qualified staff as the most important factor in choosing a service, the reasons for which were that service recipients need technical or expert assistance to realise outcomes, that their diagnosis is complex and specific and that they want their workers to understand their needs without having to train them, and that research and evidence are important to them. Others stated beliefs that good training means the service recipient being understood, safe, having better communication, or being able to effectively navigate the complex NDIS system. One parent illustrated these points with the following comment: *"Staff skill level directly impacts my son's experience of himself in his life, his opportunities to learn or participate in the community and his level of dignity and nurturing at home. Without that, everything in his life is so unstable that my caring role is 40–50 hours more a week. We are already burnt out after years of challenges with his health and advocacy, so I just need to know that workers will provide the support he needs and in a respectful and appropriate way."*

#### 8.5.2.2 I trust them and feel safe

At 27%, this factor was ranked second most frequently as the most important. It had the smallest standard deviation and the highest average rank, the implications of which are discussed in the next chapter. Many respondents noted that PWD have a high level of vulnerability, including those with histories of trauma, and/or that the services rendered are personal. For this group, trust is seen to mitigate the risk and the power that services have. Others believe that therapeutic relationships are more important than interventions themselves, which are based on trust. There was an interesting disagreement, however – while some people saw that trust is a result of all the other factors, others believed that trust has to come first, i.e. that the service is ineffective without it, and they would not use the service if it were missing.

#### 8.5.2.3 Appropriate staff

Appropriate staff means those with a good personality match, as opposed to high qualifications. This was ranked most highly by 14% of respondents. These respondents believed that well-matched staff are a requirement for good outcomes and that an appropriate fit is more important than qualifications or good communication. A passionate quote from one participant illustrates this point well: *"I'll walk over broken coals for really good staff members – I'll put up with crappy communication and not great customer service, and honestly I don't care if the staff are qualified and experienced… I care if they can do what I need."*

#### 8.5.2.4 Good communication

Thirteen percent of respondents ranked good communication as the most important factor in their support services. It ranked an average of 4.3 out of 10 in the ranking scale. There was the highest difference in standard deviation here, meaning that there was a discrepancy between respondents, the reasons for which were that it is seen as part of the treatment or intervention itself, assisting with navigating complex systems, and that it manages expectations and keeps support on track, allowing problems to be fixed immediately or even preventatively. Respondents also stated that good communication creates trust and ensures that service provision is customer-centric.

#### 8.5.2.5 Ethical organisation structure

Only 5% of recipients ranked an ethical organisation structure as most important to them. This group stated that if the organisation's values are right, it will provide a good service and will be customer-centred. Additionally, it would mean that the organisation's culture is good and the staff are more stable, resulting in a sustainable source of support. For example, a participant expressed the opinion that *"how the organisation is structured and their core purpose demonstrates to me where their heart lies and why they do what they do. This makes a huge difference in service delivery and indicates that their goals align with mine."*

#### 8.5.2.6 Good price and fair service agreement

This was most important to 3% of respondents, who identified that expensive services are a barrier to realising good outcomes. One respondent stated that ensuring value for money is important to them as a recipient of public insurance: *"The plan is financial and needs to span 12 months. No matter how great the service, if I run out of money, I will not be able to pay them if they are too expensive. Cheapness without quality and effectiveness must also be avoided as I will not be having my needs met. Value for money is also my commitment back to the system and Australians, who deserve that money be used sensibly and with care. It is financial responsibility for the finance granted."* The low ranking is puzzling, as it was one of the most frequently mentioned factors in Phases 1 and 2 of the research.

#### 8.5.2.7 Good customer service

Two percent of respondents rated good customer service as the most important factor. Comments suggest that good customer service is significantly related to good communication, so these factors may be seen as proxies for each other. Respondents justified their choice of ranking this as most important with the opinion that good customer service means more flexible and consumer-centred services, while others stated that it represents value for money and not having to waste time following up requests: *"Everyone's personal situation is different, and sometimes questions need to be asked or flexibility is required with the service. If I can't easily speak with a provider to develop plans and solutions over time, that wouldn't work. You can't spend 45 minutes on hold waiting for answers on a weekly or daily basis."*

#### 8.5.2.8 Location and transport

Ensuring that the location of the service and/or having appropriate transport options to get there was rated most important by 2% of respondents. There were various reasons given: one respondent stated that they are busy and see travel as a waste of time, while others identified travel as a significant barrier to realising outcomes, especially in rural and remote areas.

#### 8.5.2.9 Available immediately

One percent of respondents ranked a service being available immediately as the most important factor in their decision-making because they or their clients require support now to maintain their wellbeing and see positive outcomes. In this regard, one respondent wrote: *"I'm a busy professional, so when I need help, I usually need it now."*

#### 8.5.2.10 Collaborate with my family

The 4% of respondents who ranked this most highly believed that working with family is central to seeing good outcomes. For example, one respondent stated that *"the participant and their families or house staff know the participants as well as the participant knows themselves… any new organisation or service provider needs to be inclusive and discuss general issues […] with the family and support staff."*

## 8.6 Top sources and content themes

Whether examined by frequency, rating or ranking, the top 10 sources of information preferred by respondents changed in order but were consistent across each stage of the research (see Table 26). These top sources were "meeting your worker", "asking advice from a trusted professional", "reviews" and "WOM". There was a significant drop in importance after the top three places: the fourth place for most preferred source of information was ranked more than 50% lower than the third. This shows that the results around the type of media consumers want to use is consistent and is therefore likely to be generalisable. All four of these media are forms of interpersonal communication.

| **WORKSHOP** | | **SURVEY** | |
|---|---|---|---|
| **Frequency** | **Ranked** | **Average** | **Ranked** |
| WOM | WOM | Worker | Worker |
| Reviews | Professional | Professional | Professional |
| Worker | Reviews | Reviews | WOM |

*Table 22: Consistent top three sources of information in both phases of research*

Just as there were clear top preferences for interpersonal sources of information that make services users feel informed, there was a clear top four preferences for the content of the information that respondents of this research wanted in order to make an informed choice about disability services. The average and ranked top selections of content can be seen in Table 27: trusting and feeling safe with staff; ensuring staff are qualified and experienced; ensuring an appropriate match with staff; and having good communication with the provider. Just as with sources of information, there is a substantial drop after these four, with all other content themes scoring and ranking less than half as important by survey respondents overall. Once again, this shows that the results are internally consistent and that there is a heavy value on interpersonal relationships and trust.

| **Average** | **Ranked** |
|---|---|
| I trust them and feel safe | Qualified and experienced staff |
| Qualified and experienced staff | I trust them and feel safe |
| Good communication | Appropriate staff |
| Appropriate staff | Good communication |

*Table 23: A consistent top four important content was produced through average and overall ranking*

## 8.7 Demographic influence on choices

The analysis reveals that the influence on informational preferences of demographic and other characteristics, service use and choice experience is limited. A hypothesis was formed from the qualitative phase that stakeholder role, choice experience and education may influence the value that respondents place on different types of content and media. For this reason, tests were run with the survey data to examine whether there was any statistical significance to disprove these hypotheses. In this regard, there is no statistical significance in the content respondents ranked as important; through all stratification, this was only influenced by frequency. Likewise, there were no statistically significant findings in the content respondents ranked as most important; through all stratification, this was only influenced by frequency. To reiterate, these findings showed insignificant differentiation even between stakeholder role, which suggests that at present, the experience of consumers, professionals and carers are aligned when it comes to their informational requirements and preferences in navigating the NDIS.

The few significant patterns that did emerge will be discussed below. However, the way in which people placed importance on particular sources of information was statistically significantly influenced by choice experience, impairment type, service use, education and age. Additionally, the ways that people elected the most important source of information were statistically significantly influenced by choice experience and disability type. All significant correlations with disability type were negative (see Table 28).

| **People who have...** | **...are likely NOT to place the most importance on** |
|---|---|
| Physical disability | WOM |
| ABI | Reviews |
| Neurological disability | Meeting the worker |
| Autism | |
| Learning disability | |

*Table 24: Influence of disability type on source preference*

Disability type, service use, education and age have a limited influence. More choice experience led to placing more importance on meeting the worker and less on websites and GPs, which indicates that choice experience is a factor in choice behaviour and suggests that it may also influence the extent to which a service user participates in a marketplace and feels informed. While a larger sample may alter the results, the lack of statistically significant patterns in the ranking of the importance of content indicates that the ranking itself was consistently the most influential factor for every respondent and is likely to be generalisable.

## 8.8 Chapter Summary

Phase 3, the survey phase, was successful in its goal to triangulate and test the generalisability of results from the interview phases. The representativeness of the sample to wider disability statistics was limited, but it was appropriate for an exploratory study, and the findings described in this chapter were relevant to addressing the research question. Furthermore, the influence of demographics was limited, and there were four top sources of information and four top items of content that were generalisable – all of which involved some kind of interpersonal information exchange. The next chapter will discuss the meaning of these results and contextualise them within the literature.

# 9 Discussion

## 9.1 Introduction

As Chapters 6, 7 and 8 demonstrated, participants of this research place high value on interpersonal information regardless of whether they are a consumer, carer or professional. The NDIS is a complex system that has created an uncertain environment for service users. Trust is a subjective assessment of the probability of another party doing what they said they would do, in a context where there is an impact of these promised actions on the trust-giver (Gambetta, 2000). Trust becomes a proxy for certainty in consumer transactions in times of uncertainty (Beckert, 2004; Smith, 2001), and this is reflected in the results presented in this thesis, which show that research participants want to trust in order to feel they are informed in making a purchase decision in the uncertain NDIS environment. Therefore, assessing the reliability and relevance of information most often comes down to the trustworthiness of the purveyor of that information. In fact, while Chapter 4 showed that the way information is distributed is important, the results in Chapters 6–8 suggested that within the current NDIS environment, the channels are more important than the content of information.

This chapter argues that just as reliance on interpersonal information does not resolve uncertainty around system problems or unknowns about providers, neither does it satisfactorily mitigate the risk service users are being asked to bear by making such choices. The present chapter brings the research findings together with the evidence from the literature presented in Chapters 3 and 4. In so doing, it shows that, regardless of whether the NDIS is problematised through a marketisation or a social justice lens, service users' reliance on trusted interpersonal relationships is problematic for two main reasons. First, uninformed decisions are unlikely to result in good outcomes (Håkansson & Witmer, 2015). Second, a heavy reliance on social networks may result in a two-tiered system where resources are attracted by those service users who have stronger social networks and end up being unequally distributed (Carey et al., 2018; Fawcett & Plath, 2014).

Mitigating these risks is a matter of market stewardship. It requires intervention to create an appropriate information economy and support NDIS service users to enact choice and control by being adequately informed about their decisions. However, owing to the gaps in the market stewardship literature, it is unclear how interventions should be designed. As Chapter 4 argued, continuing to invest in top-down market stewardship risks social justice aims; in this sense, although PWD may theoretically have their needs met, they are not empowered consumers, do not really have choice, and are unable to shape the market. Restricting choice and control by performing market stewardship in this top-down manner risks maintaining a welfare-state structure and continuing reliance on professional service navigators, even within the structure of a market.

This chapter shows how the research in this thesis makes three key contributions to the literature. First, issues surrounding information requirements in quasi-markets have not been well examined in general, let alone in the field of disability. This thesis has contributed insights to what kinds of information service users need in order to feel informed in these contexts. Second, the NDIS is a new system, and there is still only a small body of literature, and an even smaller one based on unique datasets. Thus, this study has contributed to the emerging field of NDIS research. Third, this thesis has focused on the experience of service users, which is a unique contribution in the field of market stewardship.

This chapter is structured in four parts, the first of which examines what Chapters 6–8 suggest is currently happening with information and decision-making around services in the NDIS; the second discusses why this is happening and argues that there is a need for change; the third section looks at alternatives and makes recommendations for practice solutions to realise these changes, reintroducing Bacchi's WPR theory; and the fourth reflects on the success and limitations of the methodology.

## 9.2 Current NDIS information use

As Chapter 5 described, this study asked a sample of PWD, carers and professionals working within the NDIS system what information they want in order to feel informed when deciding which disability services to purchase. The research topic was derived from gaps in the literature and contemporary problems identified in practice. The analysis in Chapters 6–8 found that participants of this research often do not trust information supplied by providers, and the system is confusing and overwhelming. Participants therefore use WOM sources of information from trusted interpersonal sources. However, using WOM and eWOM information can be just as problematic for participants as trying to find other types of information. Trust is highly valued in WOM exchanges, and value salience is important in building trust in eWOM situations in particular. "Salient value similarity" is the perception that another person has similar values to the perceiver (Siegrist et al., 2000). This section examines these issues and discusses what this research demonstrates about the use of information to support service navigation in the NDIS.

### 9.2.1 Information burden

Chapter 4 described the use of WOM in the healthcare sector in situations where uncertainty about purchases is high and information asymmetry reduces consumers' confidence in their ability to make purchase decisions (Dobele & Lindgreen, 2011; Snipes et al., 2005). While the extent of the applicability of healthcare research to the NDIS environment was unclear, findings from this thesis confirm that these same factors exist in the NDIS environment. There is a high level of uncertainty about purchases, significant information asymmetry, and low participant confidence. The complexity of the NDIS and the fast rate of change compound these issues.

Consequently, participants of this study, at a superficial level, behave similarly to healthcare consumers. Chapters 6, 7 and 8 revealed that participants of this research place an extremely high value on trusted interpersonal sources of information. In fact, all four of the top ranked sources of information in the study are forms of interpersonal communication: (1) WOM; (2) meeting workers; (3) asking professionals; and (4) reading online reviews. Likewise, all of the top ranked content is about relationships: (1) I trust them and feel safe; (2) qualified and experienced staff; (3) good communication; and (4) appropriate staff. While there were some minor differentiators by diagnosis type or service use (discussed below), these top most valued sources and types of information were valued by consumers, carers and professionals alike. As Chapter 8 described, "interpersonal information" is information gathered through interpersonal dialogue with other people, either in person or online. This resonates with the definitions given of WOM and eWOM in Chapter 4 (Bone, in Dobele & Lindgreen, 2011; King et al., 2014).

As Chapter 4 showed, WOM is used when consumers experience a burden around choice-making because they either cannot find or cannot easily process other types of information

(Dobele & Lindgreen, 2011; Snipes et al., 2005). It describes various ways in which systems and individuals try to decrease the burden of decision-making and increase the quality of purchases (Bernstein & Gauthier, 1999; Gibbs et al., 1996; Hibbard & Jewett, 1997; Hibbard et al., 1998; Spicker, 2012; Thaler & Sunstein, 2008). Through the research in this thesis, the burden of information and decision-making for participants is also apparent. For example, an interviewee stated that even if there was a complete set of information, it would take months to carry out adequate research, especially if there are multiple service components of an NDIS plan.

Such barriers cause participants of this research to find creative ways of mitigating or avoiding the burden they produce. For example, some participants reported using existing relationships with providers to reduce choice burden by giving up choice altogether – either staying with a supplier with whom they have an existing relationship (even if it is not ideal) or by asking this provider for a referral if they need a service that the provider cannot supply. These same issues are identified in the behavioural economics literature described in Chapter 4. This suggests that that there could be applicability of behavioural economics techniques to the NDIS field in order to help consumers make easier decisions, in addition to also demonstrating the necessity of having diverse, accessible information designed around consumers' needs. This will be further discussed below in the section on recommendations.

While Chapter 4 suggested that using WOM information is a way to simplify and consolidate information (Dobele & Lindgreen, 2011), evidence from this thesis highlights that WOM information can actually add to the burden. For example, the findings identify drawbacks and challenges to relying on meeting staff to get information. While there is agreement that meeting various staff members would likely result in the purchase of better service, participants stated that it is economically, emotionally and physically draining to meet and select staff themselves. In another example from this study, service users feel the burden of having too much information after receiving a high quantity and variety of advice – one interview participant noted that critical assessment is needed with regard to the relevance of other people's advice, even when a high level of trust exists.

This finding highlights how challenging it is for consumers to navigate complex systems like the NDIS (Donovan et al., 2018; Snipes et al., 2005). Professionals, carers and consumers alike consistently reported feeling overwhelmed by the complexity of the sector, the decision-making process, and the need for digital and system literacy in properly performing service navigation. For example, participants in the interview phase of this study found it most difficult to advise the person trying to find a support coordinator, despite this scenario receiving the largest quantity of advice overall. Choosing a support coordinator is a proxy for choosing someone to help navigate the NDIS system and select services. Participants' difficulty in doing so suggests that it is challenging to navigate the NDIS system, that they have a low level of confidence to do it themselves, and that service navigation involves expertise that is not commonly understood. While this thesis collected responses from professionals, carers and consumers for reasons described in Chapter 5, future research could gather deeper responses from each of these stakeholder groups to see if and how differences emerge.

### 9.2.2 Channels

This section discusses what media participants of this research prefer to consume information through and what influences those preferences. Chapter 4 showed that consumers are more influenced by face-to-face WOM than written communication (Herr et al., 1991), and this research found the same pattern in an NDIS environment. Findings suggest that the more interpersonal WOM communication is, the greater level of trust service users have of it, and therefore the more trust they have of the provider in question. For example, participants would rather have face-to-face contact than email interactions when seeking out information. In fact, participant ranking of the data shows that the value of interpersonal communication outweighs any written material, even if the content is identical – email and phone calls are simply a less desirable way to communicate.

Disability type influences the channels people use. This thesis shows that, in particular, those service users who are not neurotypical are likely to place a high value on interpersonal communication. Of those involved in the research, only people with physical disabilities are less likely to rate WOM as most important, whereas participants with intellectual, psychosocial disability or brain injury consistently prefer to use interpersonal sources of information. This resonates with the findings of Riddell et al. (2005), in that people with physical or sensory disabilities were most likely to opt into individualised funding in the UK before it became compulsory in 2013. This suggests that similar barriers exist for people who are neuro-atypical, in addition to highlighting the importance of ensuring the industry supplies information in diverse formats that is audience-appropriate and addresses both system- and service-level navigational issues (Baxter & Glendinning, 2011; Maglajlic et al., 2000; Walsh et al., 2012).

Participants of the research often want to talk to professionals to obtain information. The findings show that there are some groups of people who are more likely to seek out information from professionals, e.g. consumers and carers with more education. As they age, participants become *more* likely to value the advice of professionals. This is an extension of what is known about decision-making in healthcare, which indicates that older people trust the advice of medical professionals whereas younger people seek out other sources of information (Tu & Lauer, 2008; Victoor et al., 2012), suggesting that this is applicable to the disability sector. Additionally, results in this thesis reveal that people with spinal injury and psychosocial disability prefer to speak to a GP for advice. This might speak to the interface between the Australian health and disability sectors and the gatekeeping role GPs have traditionally played in the allocation of further support services, but it is worth exploring in further research. For example, future research could look at the interface between health and disability sectors from a consumer perspective and examine power issues. Logically, participants using less-specialised and medicalised support such as employment or leisure services are not likely to consult their GPs.

As research participants gain more choice experience, they place more importance on meeting their workers; however, they are less likely to think that this is the most important information. This reinforces the literature introduced in Chapter 4, which shows that as consumers gain more experience or knowledge of the service, they place less value on interpersonal information (Snipes et al., 2005). Furthermore, the literature highlights that there is an economy of scale whereby longer periods of decision-making and more frequent decision-making make the process easier over time. There is a strong possibility that this might happen in the NDIS environment as consumers gain more customer experience in repeat plans and/or a range of providers.

### 9.2.3 eWOM and online sources

Chapter 4 showed that healthcare consumers use social media for clinical, procedural and emotional information (Liang & Scammon, 2011), which was echoed in this thesis. The findings in Chapters 6–8 suggest that NDIS service users are increasingly using online sources of information, primarily service providers' websites and social media. Furthermore, they are often using these sources as a proxy for WOM.

As Chapter 6 demonstrated, participants of this research often advise case studies to ask friends-of-friends for advice or to use social media to do the same. This shows how consumers of disability services have preferences similar to those seeking healthcare services, who trust their peers online to have "expertise based upon their personal experiences giving them credibility that may exceed that of health professionals" (Liang & Scammon, 2011, p. 323), or what Dobele and Lindgreen (2011) describe as "experiential credibility" (p. 24). In this thesis, providing a similar diagnosis, support needs and life experience are also important factors in establishing trust and authority around the value of the information service users had to share with one another. This confirms the applicability of Liang and Scammon's (2011) finding that similar demographics and health conditions are the foundation of "similar experience" for consumers communicating online. According to Siegrist et al. (2000), such salience is established through a "rapid, implicit, unarticulated, and automatically elicited… [assessment of] verbal statements, actions, and/or identity" (p. 355) through which someone establishes that similarity exists between them and another. An extension this thesis offers to theories on value salience is that finding advisors with shared experience is of such high value to participants that some talked about investing time in broadening their peer networks in order to get better information. Not only does value salience create a higher level of trust in another's advice, it also increases a participant's confidence that they will be able to *give* relevant advice to another person.

The findings in Chapters 6–8 suggest that receiving advice about services from people with similar experiences is often given more weight than existing relationships with people with different experiences. For example, participants' primary reason for valuing social media and reviews is to source information from peers whom they perceive to be similar to themselves and whose advice and experiences they therefore trust to be unbiased (Dobele & Lindgreen, 2011; Willis et al., 2016). In this sample, there is a very high level of trust in people on social media, even those "weak ties" (King et al., 2014; Schindler & Bickart, 2004) that service users have not met before, as long as there is perceived value salience. For participants of this study, as for participants of Dobele and Lindgreen's (2011) study of mothers seeking healthcare services, social media has the benefit of being low-touch, reducing barriers in its ability to "confirm information, understand options and reduce information search anxiety and time" (p. 24) where, for example, meeting potential workers face-to-face is burdensome for NDIS service users. In a further example of how social media reduces barriers to information access, the preference of people with physical disability is to use internet content to find information, namely social media and Google, indicating that trustworthy peers are easier to find and seek out advice from on social media. These participants are using the internet mostly in situations where they cannot easily access interpersonal sources of information.

While these findings confirm that similar patterns exist in disability as in healthcare (e.g. the results of Håkansson & Witmer, 2015), the difference in the research from the literature is the importance placed on *trust* and *relationships*. The trust in WOM is not simply related to the content but the fact that it is content provided via a particular person. The importance of experiential credibility and value salience is extremely high in the disability sector. This resonates with the reasons given in Chapter 3 for success of peer support models: even online, someone who has a lived experience will assist more effectively in the recovery process than someone who does not (Miyamoto & Sono, 2012; Rogers et al., 2009). This is an original contribution to the literature regarding the consumer input required in the creation of a responsive disability marketplace.

Reviews are often included by participants in a more general category of online sources of information. As shown in Chapter 4, online reviews are valued by healthcare and other consumers for the same reasons that they use other sources of eWOM: as “a surrogate” for other WOM sources (Schindler & Bickart, 2004, p. 20). This thesis finds that NDIS service users who use support work are less likely to value reviews, which may speak to the centrality of the individual relationship between support worker and consumer over the governing organisation. Alternatively, it may speak to reviews of individual workers being less reliable than reviews of organisations owing to the same relationship. This contrasts with the healthcare literature, which, as described in Chapter 4, finds that when consumers select physicians, they ask friends and family for recommendations (Tu & Lauer, 2008). However, this thesis finds that people with ABIs, regardless of service use, are also unlikely to place the highest importance on reviews. While this may simply be due to the small sample size, it may speak to the ways they consume information. The statistically significant difference between the cohort of people with ABIs and others certainly highlights the need for diverse information as described in the literature in Chapter 4 (Maglajlic et al., 2000; McLoughlin et al., 2014; Walsh et al., 2012).

Another online source of information is agency websites, which are consistently suggested as key sources of information in the results of this study; however, findings also indicate mixed evidence of their value. This is echoed in the healthcare literature described in Chapter 4, which shows that people who are younger, more educated and with a higher socioeconomic status are more likely to trust websites (Kim, 2016). However, when it comes to age, the opposite is suggested by this thesis – participants are more likely to value information found on agency websites as they get older. Furthermore, some participants of this research do not value websites highly because they can “see the marketing team” in them, which means that it seems disconnected from the real experience of the service. Interestingly, this research also shows that participants are less likely to value the information they find on provider websites as they gain more consumer experience. Chapter 4 showed that as consumers gain more customer experience, their consumer behaviour changes; for example, they rely less on WOM (Snipes et al., 2005; Wilson & Peterson, 1989). While this thesis has also highlighted changes in consumer behaviour as they gain experience, it has also pointed out that they *lose* trust in the information service providers display on their websites. In fact, overall, there is low trust in agency websites from participants of this study. As well as critical reading of the content, this could be due to the construction of the websites themselves – participants in this study noted difficulty of use and the unprofessional design of many agency websites (as well as more longstanding mistrust of providers, which has already been discussed). Evidence from Chapter 4 indicates that this negatively influences the development of trust in the information displayed (Kim, 2016). Results of this study suggest that NDIS service users believe that content, design and ease of use are indicators of a provider’s culture, competence and professionalism.

Additionally, Chapter 4 highlighted that there is low digital literacy in the disability sector on both sides of the marketplace (Goggin, Hollier, & Hawkins, 2017). Some of the low participant trust in websites could also be due to a lack of prior experience with internet-based research. This requires further research and would be a worthwhile step in building evidence around possible market stewardship interventions.

### 9.2.4 Summary: WOM in NDIS

The findings of this thesis suggest that there are various similarities between NDIS and healthcare environments, which include the high level of WOM information used and the experiential credibility gained by peer advisors over time. Additionally, face-to-face information is more influential and valued than written or other information. Like healthcare, NDIS is perceived by service users to be complex and highly based on services and to produce unclear outcomes; as a result, both sectors are highly reliant on professionals for decision-making. In both sectors, reliance on WOM decreases over time and service-user confidence increases.

However, there are also key differences in relation to the system and the individual experiences of decision-making in the NDIS environment. First, there is extreme diversity required in the supply of NDIS-related information, and the nuance in disability type and service type in this study has not yet been explored in the literature. Although healthcare recognises the need for diverse informational material, it may not have adequately representative samples to generalise about disability marketplaces.

Second, GPs have less influence overall, and there is less reliance on reviews for choosing individual staff members or workers. There is more value placed on salience alongside experiential credibility in the NDIS environment, and not only is less trust placed on agency websites, but this decreases as consumer experience increases. In terms of system issues, each NDIS plan requires multiple decisions, which adds a burden to the process. Even those people relying on WOM can feel the burden of too much information, and the next section will explore why some of these dynamics occur.

## 9.3 Why is this happening?

Where the previous section explored the findings about service users' use of information and decision-making, this section examines the dynamics behind these results. Taking into account the issues outlined in Chapter 3 that are unique to the NDIS context, this chapter discusses why they might be happening. It discusses historical patterns, system challenges and issues relating to service providers.

### 9.3.1 Historical dynamics

The first aspect relates to patterns established in previous waves of policy. The data in this thesis suggests that NDIS service users rely heavily on professionals, and information asymmetry still exists. This is reinforced by the lack of trust that still exists and the consequential lack of demand for system or provider information. As a result, this section argues that intermediaries (rather than consumers) are currently shaping the market.

Chapter 3 described the decades of oppression of PWD and the lack of choice they experienced in previous waves of disability policy (Coleborne, 2003; Gooding, 2016; Purcal et al., 2014), in addition to showing how this created a deep mistrust of systems, government and service providers (Walsh et al., 2012). The findings of this thesis that NDIS service users prefer to rely on trusted personal and peer networks instead of systems indicate that there is still low consumer confidence in providers and government. While Chapter 4 reported that this reliance also exists in healthcare situations (Liang & Scammon, 2011; Tu & Lauer, 2008), the particular history of PWD adds a unique layer of complexity. The findings of this thesis suggest that this lack of confidence is not only a consequence of an uncertain and complex new policy environment or the transformation to a marketplace, but it is also rooted in decades of oppressive policy. The NDIS environment requires a group of people who have been actively denied any decision-making about their lives to make decisions in order to receive support. This suggests that long-term investment will be required from market stewards to remedy and change the dynamic and realise a successful marketplace.

Chapter 4 showed that consumers are encouraged by professionals and others to value non-autonomous decision-making processes, in addition to reporting that supported decision-making is an essential component of rights frameworks for PWD (Dowse, 2009; Gooding, 2013), one that is likely to increase in importance as the need to make choices increases with the NDIS. This was echoed in Chapters 6–8, which showed that, in addition to formal supported decision-making practices, interpersonal communication is used to find information and overcome uncertainty. In essence, feeling informed is found to be a proxy for not the most informative, but rather most trusted information. This is a key contribution to the literature because it shows that the importance of ensuring trust and relationships are built into any market stewardship interventions.

#### 9.3.1.1 Professionals as sources of information

Chapters 3 and 4 showed that relationships between staff and service user are key to the organisation and delivery of social sector services (Smith, 2001) and the NDIS in particular (NDIS, 2019). As Chapter 4 highlighted, disability and healthcare consumers historically rely on professionals for decision-making input, service navigation and even accountability for outcomes (Donovan et al., 2018; Malbon, Carey, & Dickinson, 2018; Snipes et al., 2005; Tu & Lauer, 2008; Victoor et al., 2012; Wilson & Peterson, 1989). Chapter 4 recognised that decision-making about social services takes place on a spectrum whereby consumers are more or less reliant on professionals (Davidson et al., 2015; Donovan et al., 2018; Gooding, 2013). Results of the current study reinforce these findings. Although WOM from family and friends is still valued more highly than asking a trusted professional for advice, participants of this study trust professionals as sources of information, especially when a long-term relationship with that professional exists. Participants outlined the importance of using interpersonal relationships with professionals to get information about those professionals in order to help aid decisions.

First, interpersonal interactions with professionals are valued by participants in this study because they are perceived to provide an accurate, subjective assessment of the staff with whom participants would be interacting through their NDIS purchases, i.e. it is above and beyond WOM as described in the literature. By meeting staff, participants of this study reported being able to obtain information about the product or service that is not available elsewhere or, in fact, through any means other than an interpersonal interaction. Such information includes the qualification and professional experience of staff but also participants' subjective impressions of the staff members' interpersonal skills and the nature of the relationship that exists between staff and consumer within the context of the organisational culture. Especially in the case of allied health providers, participants are more likely to achieve positive clinical and psychosocial outcomes as a result of having this type of information. Other than formal qualifications, of particular concern to research participants is professionals' experience of their diagnoses or needs, e.g. whether they are familiar with psychosocial disability. This concern around experience is of relevance not only to allied health professionals but also to non-clinical workers in support work fields and service navigators such as LACs and support coordinators.

Second, participants highlighted the importance of using interpersonal relationships with professionals to get information about services. In this sense, participants expect that in speaking to a professional face-to-face, they will be able to gather information about the agency or service that is not public. An example given by one interview participant was knowing which service providers have waiting lists or how many staff are in an agency's pool. In both of these examples, this information would indicate how soon and how consistently a service might be received. This reliance on professionals for otherwise private information that is pertinent to decision-making is a symptom of the information asymmetry that exists (Mortelmans et al., 2006). It is an unsatisfactory dynamic for a marketplace that relies on consumers having satisfactory information to be able to make their own decisions and do their own navigation. Reliance on professional system navigators is problematic for the NDIS from both marketisation and social justice perspectives. It maintains dependence on a paid service and allows the NDIS to remain complex instead of exerting pressure to make it more accessible for the end user to navigate themselves. Especially from a social work perspective, it is important for market stewards to consider ways that macro changes may result in the NDIS system becoming more consistent, transparent and simple alongside any micro capacity-building exercises, which will be discussed in the following section.

### 9.3.2 System challenges

Chapter 3 showed that the NDIS system is complex, with mixed forms of accountability creating complexity at a structural level, and a high speed of roll-out combined with geographical and diversity challenges creating operational complexity (Dickinson et al., 2014; Malbon & Matthews, 2017; Malbon et al., 2018; Malbon et al., 2019). One consequence of this complexity is that it is challenging to collate, regulate and distribute NDIS information. In not doing this important work, however, service users necessarily have a high reliance on trusted relationships to navigate the system. This is problematic for social justice and marketisation reasons, which will be discussed next.

Chapter 3 discussed how, in theory, NDIS supply responds to demand (Fawcett & Plath, 2014; Fotaki et al., 2008). The same supply and demand issues that apply to services may well apply to information – without demand for it, it may not be supplied. Consumers may not be demanding information owing to low expectations about its relevance and reliability, which creates a vicious cycle whereby not having good information reinforces the inactions of market stewards and the lack of information (as illustrated in Figure 40 below), in addition to also reinforcing the acceptability of a highly complex system that requires professional service navigation to realise outcomes.

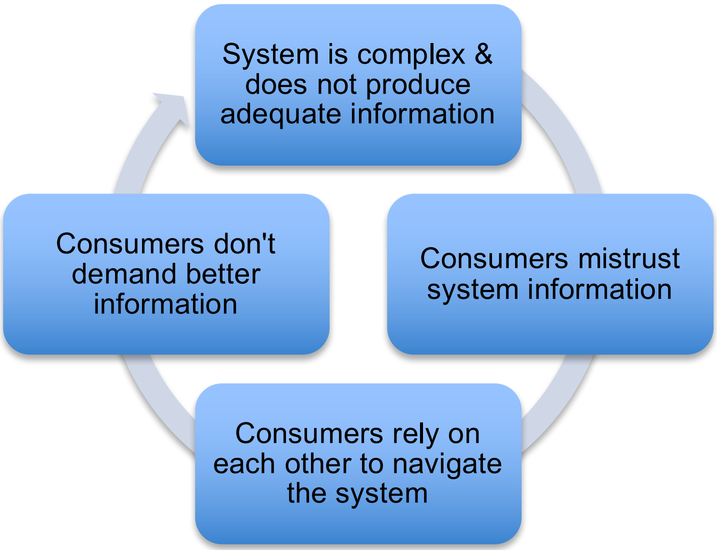


*Figure 40: Complexity creates a vicious cycle*

A deadlock exists in the NDIS – a level of system navigation is required in order to receive support coordination to assist with system navigation. In this regard, a service user must understand their needs, know they need assistance and know to ask for it in their package allocation (Dew et al., 2019). As Chapter 3 showed, LAC roles are designed to support this navigation work and create connections between NDIS service users and non-specialist local services; however, due to the pressures of the fast roll-out as described in Chapter 4, LACs primarily function as NDIS planners. Additionally, as government representatives, LACs are restricted in how they can recommend services or guide service navigation (NDIA, 2016b).

Despite some intermediaries being restricted in their ability to make service recommendations, the literature and data indicate that intermediaries are shaping the market. Chapter 4 discussed some of the benefits and challenges to market stewardship presented by brokers and intermediaries (Baxter & Glendinning, 2011; Maglajlic et al., 2000; Quach et al., 2010; Walsh et al., 2012). The findings of the current study suggest that support coordinators, plan managers, brokers and other intermediaries are shaping the NDIS market as consumer choices are guided by these individuals. This raises similar issues to those reported in the UK literature. Whether intermediaries are compensated via a commission as brokers, the information they use to assess provider options and the type of information they provide to families influence the choices available to consumers and the purchase decisions they make. Indeed, the literature and research findings both show that participants' feelings of trust are increased by the knowledge that advisors are independent and unbiased (Dobele & Lindgreen, 2011; Willis et al., 2016).

The last issue about system complexity stems from the NDIS being primarily a service-based market. Chapter 4 reported that, by their very nature, services tend to be more complex than products and that interpersonal information is particularly influential when it comes to de-risking service- rather than product-related purchases (Dobele & Lindgreen, 2011; Mangold et al., 1999; Schindler & Bickart, 2004; Snipes et al., 2005). In this study, there was disagreement amongst participants as to whether a decision around the purchase of NDIS services or products is riskier. This remains unresolved, but it is an interesting concept for market stewards and academics of market stewardship to explore in future work.

### 9.3.3 Service providers

Consumers' mistrust of service providers has been discussed previously. However, because of the current lack of formal market stewardship, providers are playing key roles in the creation and distribution of information by default. Furthermore, through their marketing, they are incidentally taking the role of what Chapter 4 called "trust-taking" (Beckert, 2004). The job of the trust-taker in an environment that values trust so highly is to create an impression of salient value similarity (Beckert, 2004). In this regard, Chapter 4 showed that there are multiple dimensions to a supplier being considered trustworthy in the healthcare sector (Håkansson & Witmer, 2015; Murdach, 2009; Natalier & Willis, 2008). The findings of this chapter revealed the important factors as the marketing team being connected with the frontline experience; websites being user friendly, accessible, responsive and accurate; all staff being friendly and having clear customer service processes; organisations being responsive, communicative and available to consumers; and the culture and ethos of the organisation being positive.

Chapters 6–8 showed that participants of this research assess a provider's quality through their experience, cultural fit and systems. For example, participants consistently define a provider's integrity and trustworthiness by a worker going over and above what is promised, e.g. when staff are generous with their time on the phone and when they are happy to meet for a get-to-know-you session without charging. Service users appear to be looking for evidence of intrinsic motivation and care on the part of providers that is not commercially driven. This finding contributes new knowledge to the literature on trust outlined in Chapter 4 that is specifically related to the disability industry.

Also relevant to trust-taking is brand, perceived by participants of this study as not just a logo or collateral but as extending to factors such as the professionalism and nature of workers and even to organisation size, cultural fit and the emotional wellbeing of the staff. One participant described how good branding and alignment influence her to choose a particular provider; they create the illusion of value similarity that creates the right conditions for the service user to give trust. Chapter 4 highlighted that various aspects of healthcare providers are assessed by potential customers, including "tangible characteristics of support staff, such as the politeness of receptionists" (Dobele & Lindgreen, 2011, p. 24). The present study has demonstrated that this finding is replicated in the disability context. For participants of this research, their assessment of the fit of a service includes receptionists and intake workers as well frontline workers.

This demonstrates that there is information about an organisation's ethos, structure, conflict resolution and culture that is important to service users and suggests that although providers often describe their values on their websites, this is insufficient to make consumers trust them. In addition, it further demonstrates that this culture is felt by consumers from the first administrative interaction with a provider through to receiving regular service. In fact, participants indicated that even customer service is a form of marketing because it translates into positive WOM, regardless of whether or not the consumer decides to purchase that service. This suggests that providers should invest in the customer service skills of their staff and perhaps even look to recruiting from industries such as hospitality, where these skills are trained and valued. In addition, it also implies that having the right staff and ensuring they have a high level of wellbeing is important to acquiring and retaining customers. Even in an NDIS competitive marketplace with slim profit margins in some segments of the industry, business modelling should be structured to invest in staff.

Marketing, customer service and technology affect providers' trustworthiness in the eyes of service users. However, these are expensive systems to develop, and many providers, especially smaller ones (which are likely to provide a higher quality service [Needham et al., 2015]), lack the resources and/or expertise to do this. Very few shared service solutions exist, the implications of which will be further discussed later in regard to practice alternatives.

### 9.3.4 Summary: What needs to change

Chapter 4 showed that trust diminishes the need and opportunity for consumers to develop analytical decision-making skills (Shul & Peri, 2015) and that it is used "as a means to confirm information, understand options and reduce information search anxiety and time" (Dobele & Lindgreen, 2011, p. 24). The findings of this study confirm that this dynamic also exists in the NDIS environment and that WOM referrals are used to relieve uncertainty in the same way the literature suggests happens in healthcare.

Relying on trust to make NDIS decisions is not beneficial in the long term to individual service users or the system as a whole. The literature shows that it can create poorer decisions and outcomes (Håkansson & Witmer, 2015), and the data in this thesis suggests that it reduces the need for consumers to develop service navigation skills. It threatens marketisation and social justice outcomes, and market stewards need to encourage alternative ways of becoming informed. Ironically, reliance on trust also decreases the urgency for NDIS market stewards to build an appropriate information economy, which means that change is less likely in the short term. This risks building problematic dynamics into the NDIS in its formative years of operationalisation that may be hard to rewrite.

Additionally, while relying on interpersonal relationships for information seems to decrease the subjective experience of risk for a participant, Chapter 4 showed that, in fact, it leads to less cautious, riskier decision-making (Klein & Shtudiner, 2016; Shul & Peri, 2015). In this regard, it is less likely to lead to positive outcomes than being informed (Haakonson & Witmer, 2015), which makes reliance on interpersonal information problematic for the NDIS, i.e. poor outcomes could undermine the insurance model. Evidence from the literature demonstrates that it is likely that uncertainty compounds such a dynamic, increasing consumers' experience of risk and their likelihood of making uninformed decisions or no decisions at all (Baxter & Glendinning, 2011; Bettman et al., 1991; Dobele & Lindgreen, 2011; Maglajlic et al., 2000; Martin, 2011; McLoughlin et al., 2014; Snipes et al., 2005; Victoor et al., 2012; Walsh et al., 2012). The high level of uncertainty experienced by new consumers means that this is a real risk for the NDIS.

Carey and Matthews (2017) argue that the NDIA needs to be guided by an architecture that supports risk and fast learning in order to encourage adaption and experimentation. This thesis argues that market stewardship should include accountability not only to the multiple governmental bodies described in Chapters 3 and 4 but also to all stakeholders, including consumers and families. Operationalising this will require market stewards to take risks, but the data in this thesis suggests that there will be a high return on investment in the form of service-user sophistication and engagement that will mitigate the risk. It will also require market stewards to consider particular the importance and urgency of various competing needs, prioritising one approach over another, in the manner of a Bacchian WPR approach. The following section makes practice recommendations, examining ways that this might be achieved and how the various approaches might be brought together.

## 9.4 Alternatives

This thesis argues that the status quo needs to change in order to realise good outcomes for both PWD and the NDIS. The fact that both the literature in Chapter 4 and the results of this study have shown that decision-making improves with experience (Snipes et al., 2005) suggests that many NDIS service users will be able to acquire the skills and knowledge they need to navigate the purchase of services over time. From a practice perspective, this research has shown that individual micro-level capacity-building interventions, including the provision of appropriate information, are important to decrease the time it would otherwise take consumers to accrue experience and knowledge first hand. This has the potential to build not only individuals' capacity but also the skills and knowledge of networks and the community as a whole as the NDIS progresses. While there are various mentions of capacity-building as a market stewardship function (e.g. Carey et al., 2018; NDIA, 2018b), it is unclear what activities this requires in practice and how it interacts with other factors, for example, information.

Various alternative ways of becoming informed in the NDIS were suggested in Chapter 4, as well as in the data, and this section presents some of them as practice recommendations. The Bacchian theory discussed in Chapter 3 described how two different approaches of marketisation and social justice coexist in the NDIS environment. It showed that while they differ in many ways, both of these approaches place a high value on ensuring consumers are able to make informed decisions. In this vein, each of these alternatives align with both social justice and marketisation priorities. They would require a range of investment, inputs and resources, and they will produce different outcomes that may or may not be compatible with one another at an overarching policy level. They may also require different groups of people to deliver them, once again demonstrating the difference between a function of market stewardship, and a steward. This too is likely to require consideration around what the problem is represented to be, so that resources can be adequately distributed and these actions taken by appropriate parties. Additionally, these recommendations have been drawn from the extensive literature review as well as the qualitative and quantitative data produced in this study, because the size and nature of the sample mean that while it is statistically generalisable, it is not representative. This means each recommendations will not cover all needs of all stakeholders. Rather, the need identified in the literature review for a diverse and personalised information economy to match the needs of the heterogeneous disability community is still relevant.

### 9.4.1 Change service navigation

There have been various considerations in this thesis of NDIS intermediaries such as LACs, support coordinators, brokers and advocates. It has been noted that LACs' restriction with regard to making referrals is problematic; the requirement for an NDIS participant to know the system well enough to request funding for support coordination is also problematic; and further, that all of these intermediaries, paid and unpaid, are shaping the market by default.

A central role of support coordinators is to capacity-build with consumers to be able to do service navigation work themselves, and there is NDIS funding for plan managers to do the same. As Chapter 4 reported, various social workers have noted that there is great potential for support coordinators, plan managers and LACs to be involved in capacity-building so that service users can learn to do this important service navigation work for themselves (Donovan et al., 2018; Fawcett & Plath, 2014). The first and perhaps most difficult step of service navigation, and the one that investment in capacity-building and education could expedite, is pre-planning, which involves goal setting and having enough insight to predict a consumer's needs and desires. It is challenging to plan for unknown future circumstances and, as Chapter 4 showed, it is an important and skilled aspect of professional service navigation to predict such circumstances based on previous experience, best practice and, in the case of LACs, policy. Furthermore, this can be a therapeutic process in itself (Donovan et al., 2018). Many organisations are offering pre-planning services in the form of books, workshops, apps and consultations (e.g. CoAbility, 2019; Leap in!, 2019; MS Connect, 2019). Market stewards might consider exposing all new NDIS participants to training or engagement in order to help them clarify their needs and focus decision-making on a particular set of providers.

Another path would be to change the nature of service navigation in the NDIS, making it freely accessible and consumer-centred. This alternative may involve providing more assistance with service navigation or building it into the NDIS system through, for example, providing funding to advocates or having a minimum allotment of support coordination per person. There are some movements in this direction, e.g. the specialist support coordination stream for service users with exceptionally complex needs (NDIA, 2018b). However, the data in this thesis has shown that it is not just people with complex needs that need help. On the contrary, professionals, carers and consumers alike felt they needed support in this study. Data suggests that different levels of support are required, some relating to the complexity of needs and others relating to the type of service required, for example, equipment or personal care. While this has been reported in the non-peer reviewed literature, it is a contribution to the academic literature. This alternative would require industry-wide resilience to risk as described by Carey and Matthews (2017). In relying on a marketplace, it is important to consider service users' dignity of risk and their right to make "poor" decisions alongside their increased responsibility in the same manner as non-disabled consumers (Marsh & Kelly, 2018).

Chapters 3 and 4 discussed how as consumers move from being recipients to customers of service, they take on as much responsibility and risk as they receive access to rights (Dowse, 2009). Participants of this research reported feeling risk, partially because of the weight of the consequences they need to bear with the expectation of increased decision-making. Some of the factors that lead to the perception of greater risk for participants of this research are financial while others are interpersonal; some relate to the length of commitment attached to the purchase and others to the difficulty of change if something goes wrong. For example, two consumers noted that changing allied health professionals would be burdensome. In another example, there was disagreement amongst participants as to whether a decision around the purchase of human services or equipment and products is riskier. While Chapter 4 showed that there is evidence that the purchase of services is most difficult (Mangold, Miller, & Brockway, 1999; Snipes, Ingram, & Jiang, 2005), it is possible that purchases like wheelchairs (in the example given in this scenario) have more riding on them than most product purchases and are therefore more challenging than the literature suggests. This is unresolved and out of the scope of this thesis, but it is an interesting question for market stewards and academics of market stewardship to explore in future research. Other important questions for market stewards to address relate to how much risk it is reasonable to expect consumers to hold and which aspects of this risk can be mitigated through high-quality information.

Providing this type of capacity-building support would be a way of realising marketisation aims by improving decision-making processes and social justice aims by capacity-building with consumers. Furthermore, it would be a way of responding to consumer need that creates system accountability towards the customer. In a situation where the problem is represented as the consumer requiring increased information and autonomy in order to enact their rights and responsibilities, this might be a suitable intervention. However, it would require significant, immediate and expensive system and culture change at a macro systems level that may be challenging to resource in the NDIS environment at this stage.

### 9.4.2 Use peer advisors

The use of peer advisors may be another way to build a successful NDIS information economy. Chapter 4 showed that the accessibility of internet-based information gives consumers an “opportunity for learning [which] means that they can become the ‘information elite’, evolving from support seekers to support providers” (Liang & Scammon, 2011, p. 329). These findings have practice implications for the use of peer networks to support the distribution of information in the NDIS environment. Chapter 3 established that peer support in the mental health sector has proven benefits for clinical, psychiatric, social, emotional and wellbeing outcomes (Fukui et al., 2010; Miyamoto & Sono, 2012) and, further, that it is underutilised in practice (Davidson et al., 1999; Rogers et al., 2009). The literature combined with the findings of this thesis suggest that there would be benefit in investing in peer advisors to support the development of an information economy in the NDIS. In the same way that mental health peer advisors are uniquely placed to offer recovery support through their lived expertise (Mead & Copeland, 2000; Walker & Bryant, 2013) and consumers of healthcare share information online about their conditions that displays “credibility that may exceed that of health professionals” (Liang & Scammon, 2011, p. 323), this study recognises how lived experience creates a level of information and trust among NDIS service users that would be hard to replicate in any other way.

This type of NDIS information-seeking already happens online. The data in this thesis shows that many research participants use social media to get information from their peers. Unlike in the healthcare sector, this study has shown that specialised and expert NDIS advice is often unrelated to formal education, qualifications or knowledge about evidence or outcomes. Rather, for many participants, expertise is gained either through life experience or having deep knowledge about a local area. Liang and Scammon (2011) state that eWOM could be more effectively leveraged by policymakers to support public health initiatives, for example, by using social media to gain insight into consumer experiences and to distribute important policy information. Demonstrating that these literatures can be extended into the NDIS context is a contribution of this thesis.

Implementing the regular use of peer support models to distribute information in the NDIS environment would be beneficial from both marketisation and social justice perspectives – they would create a high level of value salience and therefore trust for prospective customers, encouraging a positive purchase decision. Second, this type of network aligns with the priorities of consumer rights movements, taking a step towards correcting existing information and power asymmetries and working towards deprofessionalising service navigation. This would require meso-level stewardship actions, and some consideration around funding models to make it economically viable and sustainable.

### 9.4.3 Develop provider marketing

The remaining alternative market stewardship approaches include interventions that may be contributed to by providers. Many of them suggest the use of shared services to mitigate issues of low capacity and financial hardship in order to manage the issues identified above and simultaneously ameliorate the finding from Chapter 4 that there is decreasing collaboration in the NDIS environment (Green et al., 2017). This first approach is about how providers being transparent about their services can produce relevant and trustworthy information for consumers to consider. It argues that this contributes to the NDIS information economy and plays a role in market stewardship.

The research in this thesis speaks to the active role of the trust-taker in making the market work (Beckert, 2004) and the potential for a provider to greatly influence the information economy. A company can contribute to this stewardship work through its marketing. The findings show that providers must build trustworthiness in the way they produce marketing material, evidence and information about navigating the system in order to acquire new customers and compete in the marketplace. This contributes to the market stewardship literature by extending Beckert's (2004) theory around trust-taking and trust-giving into quasi-markets.

This pathway stimulates a consumer-centred information economy at a meso level. At present, because of the commercial drive of providers' marketing, consumers do not trust this information (Gelb & Johnson, 1995). This market stewardship intervention would require suppliers to provide relevant information about their services in diverse formats that consumers trust. While findings from the research in this thesis provide a suitable baseline for the type of content and media that consumers trust, organisations must take a collaborative approach to put together their own marketing material as per the literature described in Chapter 4 (Maglajlic et al., 2000; McLoughlin et al., 2014; Walsh et al., 2012).

These meso-level actions could be directed by macro-level policy. Stewards could create guidelines for providers on marketing, transparency, information, metrics, format and lists that are useful and use their governance to make these guidelines public, thus creating useful information for service users. This could happen at a macro level and involve regulation of advertising, an example of which is legislation preventing healthcare professionals from using testimonials to advertise clinical services (state-based Health Practitioner Regulation National Laws) (AHPRA, 2019). Alternatively, it could simply be driven by providers taking on market stewardship responsibilities. With a stewardship approach that requires transparency around factors that are important to service users, providers could speak to the issues that are important to consumers. This approach might be most appropriate where the problem of having adequate information is represented to be the responsibility of the market, i.e. providers.

Smaller providers can often not afford to invest financial resources in sophisticated marketing and communications, so this pathway would mean that these providers may be disadvantaged. Alternatively, investment from peak bodies or other market stewards in shared services could make these more affordable to providers of all sizes. Additionally, consistent comparison metrics and platforms would be needed to offer good insight into very different sized providers. This leads to a short discussion in the following section around the importance of research and metrics to developing informed consumers.

### 9.4.4 Create accessible information and metrics

Chapter 4 showed that the NDIS industry requires the development of consistent sector-wide information to create certainty in comparing providers, assist consumers in reducing uncertainty in their decision-making and decrease the reliance on interpersonal information (Baxter, Glendinning, & Clarke, 2008; Martin, 2011; McLoughlin et al., 2014). Chapter 4 highlighted that information about best practice outcomes is not often produced in a format that is digestible by the average citizen, let alone someone with a disability who is statistically likely to be less literate and/or have lower digital access (Faber et al., 2008; Victoor et al., 2012). Appropriate, relevant and accessible points of comparison are required for consumers to make informed decisions (Samson, 2015), and research and information must be made accessible to a diverse audience. While this information is unlikely to relieve consumers' desire for relationship-based information, it is critical for the industry becoming more informed and also for benchmarking about the type of information that is relevant to ensuring accountability towards service users. This intervention might be prioritised where there the problem of inadequate and incomparable market information is represented to be the responsibility of the NDIA or Commonwealth government, as it will require macro-level stewardship. It has the capacity to meet both marketisation and social justice approaches, especially if the metrics collected represent what is important to consumers as well as other stakeholders.

Due to the block funding arrangements in the waves of policy described in Chapter 3 (Purcel & Fisher, 2014), the disability industry has been built on the measurement of outputs, and there are very few other comparable metrics at present. The NDIA itself does not, at the time of writing, have a consistent approach to outcome measurement. Furthermore, much of the existing evidence in the disability sector is health-related; psychosocial outcomes of self-determination and increasing capacity are more difficult to measure. Likewise, Chapter 4 showed that trust and confidence are not easy to quantify (Ozawa & Sripad, 2013) and that the quality of human services is more complex to assess than the quality of products (Mangold et al., 1999; Snipes et al., 2005). A contribution of this thesis is the finding that if choice is limited to which support worker one should choose, the factors are micro and relational: gender, age, interests, values, location and availability. When there is choice on a meso level, e.g. around which care agency one should choose to supply the support worker, complex questions are raised about how to assess the quality of human services organisations.

The findings of this thesis suggest that there is enough consistency between healthcare and disability consumer information-searching that behavioural economics interventions such as those discussed in Chapter 4 (Bernstein & Gauthier, 1999; Gibbs et al., 1996; Hibbard & Jewett, 1997; Hibbard et al., 1998; Spicker, 2012; Thaler & Sunstein, 2008) may also be helpful in the NDIS. For example, the health literature described in Chapter 4 showed that more information is not necessarily better (Bernstein & Gauthier, 1999; Gibbs et al., 1996; Hibbard & Jewett, 1997; Hibbard et al., 1997; Spicker, 2012; Thaler & Sunstein, 2008) and does not counter complexity but rather adds to it. This problem of too much information causing complexity has also been identified in the findings of this thesis. The extension of the behavioural economics literature to a disability setting is a contribution of this thesis.

### 9.4.5 Use the internet effectively

There are various practice ideas that stem from this chapter's earlier analysis of online information use in the NDIS context. Although Chapter 4 showed that there is low digital competence, digital access and digital literacy in the disability sector (Goggin et al., 2017), Chapters 6, 7 and 8 found that participants of this study place a much higher emphasis on online sources of information than physical or print media. This suggests that the disability industry should increase its digital sophistication in the NDIS marketplace in order to support the emerging information economy. Participants of this research stated that they do not trust marketing materials due to commercial goals. This might be mitigated by illustrating the look and feel of frontline services and sharing both positive and negative consumer experiences, for example, through the use of consumer testimonials or videos. While this will be financially difficult for many providers to do alone, it might also provide impetus for shared services and increasing collaboration between suppliers.

Another application for online solutions is to combat the challenge of collating, regulating and updating local information in a commonwealth scheme. Chapters 3 and 4 discussed some of the particular challenges of operationalising personalisation in Australia (Dickinson, 2017; Llewellyn et al., 2017), and the same challenges apply to growing the information economy. For example, the same limited relevance of policy across geographical regions due to differences in geography, policy, structure, culture and service quality also applies to the relevance of information. Chapter 3 highlighted a heavy reliance on WOM and professional service navigation (Leece & Leece, 2010; Quach et al., 2010; Scourfield, 2008). This literature, in combination with the findings of the present thesis that local information is valuable, presents a key practice recommendation, which is to leverage technology in order to create databases with localised information that can be created, maintained and used by community members, including intermediaries and professional service navigators. Such stakeholder investment would ensure that information would be relevant to local communities and would overcome the UK problem by creating commonwealth linkages.

These solutions, one meso and one macro, might be most applicable where the problem is represented to be the efficient distribution and maintenance of information. These solutions have the capacity to meet social justice and marketisation goals where they are designed around the informational needs of consumers, and codesigned with consumers to ensure they meet functional requirements for accessibility and ease of use.

### 9.4.6 Localise solutions

Alternatively, purely local solutions may be the most beneficial for developing the information economy, which would involve leveraging the strong relationships and the high value placed on interpersonal communication that this study has identified in the Australian disability community. One way to do this would be by localising the NDIS in smaller areas, giving LAC partners more freedom to establish governance and processes for the production and distribution of information as best suits their community. This would allow them to design and adapt information for the requirements of smaller communities and draw on peers and other community members to support one another. In fact, this is in line with one of the market stewardship recommendations outlined in Chapter 3 – to decentralise the system and give authority to local communities to negotiate information flow (Carey et al., 2018).

Another way may be hyper-localising, i.e. creating solutions for either very small groups or individuals, which this thesis has already considered in Chapter 4 through discussion about how micro providers can offer a higher quality of service than large ones, partly because of their ability to personalise services (Needham et al., 2015). At the time of writing, the specific personalisation of services is not a commercially viable option for most service providers, especially incumbent ones that, as Chapter 3 showed, are struggling financially (NDIS, 2019). If the problem of finding information in the NDIS was represented to be that the a one-size-fits-all approach was stalling social justice and marketisation outcomes, the micro personalisation of information and services might become a primary market stewardship approach. There would be a requirement to adjust pricing models and capacity-building with service providers around business modelling. This would not be financially feasible as an immediate solution for the majority of the marketplace.

### 9.4.7 Summary: Recommendations

This section has listed six alternative approaches to NDIS service users' reliance on WOM and professional service navigation. They have been drawn from literature review and data collected in this study. These alternatives are recommendations for practice, a key aspect of the social work practice research framework in which this research is based. They are aligned with Bacchian thinking about what the problem is represented to be, and are unique in that they each have the capacity to produce positive outcomes from both marketisation and social justice perspectives. A practice recommendation for market stewardship is to help consumers and families become confident enough to be their own service navigators. Chapter 4 also indicated that with increased experience and knowledge, consumers rely less on trust, and the results of this research also reflect this (Snipes et al., 2005). This means that it is possible for consumers and families to develop the skills to navigate the NDIS and choose services without the support of WOM or professionals, or for peer navigators to do this work. This is an important social justice outcome, but one that is equally important in a marketisation approach.

The other consistent requirement for many of these approaches is to increase collaboration and shared services in order to support small and emerging providers to compete in the marketplace. "Capacity-building" for service providers includes increased awareness of ways in which to be accountable to consumers and produce information in a way that increases service-user trust as well as lifting the quality, accessibility, diversity and relevance of information in the marketplace.

Bacchian thinking around what the problem is represented to be in the NDIS will shape market stewardship priorities, in turn influencing which interventions appear most desirable. It will also influence who is responsible for implementing them. Chapter 3 discussed the mixed accountability in the NDIS (Malbon, Carey, & Dickinson, 2018; Malbon, Carey, & Reeders, 2018), which raises a question around who should be responsible for implementing the market stewardship alternatives described here. While it likely falls to the NDIA to ensure that problems are identified and actions are taken and to incentivise or fund them, other parties such as advocacy groups, peak bodies, local governments, providers and/or the Quality and Safeguarding Commission may be better placed to perform the actions. This suggestion that accountability for market stewardship actions may be formally spread across various stakeholders without official steward status is a contribution of this thesis.

## 9.5 Reflection on methodology

This section reflects on the methodology and looks at whether the practice research goals were met. The research process set six goals to ensure that advocacy, education and capacity-building were built into the methodology, the first of which was gathering feedback from community members on the research design and results prior to, during and after research. This was actioned through the first phase of research – which piloted the interviews and sought feedback from participants – and between the interview and survey phases, when results were distributed to all interview participants for comment. The second goal was developing appropriate consent and confidentiality tools, which was ensured by using lay language in recruitment materials and interviews. In addition, language in interviews was iterated with participant feedback to ensure it was accessible.

The third goal was to ensure that immediate benefit was reaped by individual participants and groups simply through their participation, which was accomplished in the interviews through the reflection phase. While interviews, focus groups and surveys were designed to produce data that was of benefit to the research agenda, they were also constructed as educational interventions with immediate co-benefits to participants. As a result of reflecting on their values and skills, participants reflected that they were better prepared for choice-making under the NDIS. Each participant felt that they had received some benefit from their participation in the research and had learned something significant about their practice of service navigation.

The fourth goal was to use reflection with participants and other community members to triangulate the interpretation of results, both during and after data collection. The process in the interviews of conducting an initial round of thematic analysis accomplished this goal, which will be discussed further below. The fifth goal was distributing results in lay language to participants, which was carried out after the interview phase. The sixth goal was distributing results to the wider community, stakeholders and policymakers, and the seventh and final goal was to embed accountability processes for the results being actioned.

This chapter has made original contributions to research and practice based on statistically significant information gathered from over 220 people who are linked to disability. This group had different backgrounds, ages and roles sharing their experiences. The data that has come from that exchange of knowledge has informed theory that will shape sector recommendations and literature from a consumer perspective, empowering service users at a policy level while simultaneously taking into account the impact of different narratives.

It is worth reiterating that this study was exploratory, including professionals and carers in its sample. While there were statistically significant patterns in the findings, and it met its goals in terms of creating a dialogical knowledge exchange process between stakeholders, this research does not represent the cohort of NDIS participants. It is also important to acknowledge that each participant of this research spoke enough English and had enough digital literacy to have provided data, and this is disproportionate of the disability community (Goggin et al., 2017). In this sense, it is highly likely that there are more extreme needs and opinions than arose from this sample.

## 9.6 Limitations

While this study achieved its goals and produced original data, there are some limitations to the design and implementation of the research, which include biases introduced through the sampling methodology, the size of the sample and restrictions on best-practice anti-oppressive design.

Participants were to be drawn from industry partnerships with six service providers. However, this method of recruitment was unsuccessful at first: two partnerships produced only a few candidates and none were produced in the case of four partnerships. This was possibly due to the divorce between research and practice that occurs in the social service sector, which the social work practice research framework was essentially developed to help combat (as per Dodd & Epstein, 2012; Epstein et al., 2015; Sim et al., 2018). Those people who have contact with consumers are time poor in the NDIS environment as they move to a model where they need to consider billable hours for the first time. These frontline workers are generally not engaged in research, and it is not their priority. Reluctance to recruit might also have stemmed from a sense of duty of care or protectionism towards consumers or might simply have been due to how busy providers are transitioning into the NDIS. Additionally, several carers who were potential research participants were abandoned after several attempts to contact them (one said that an hour was too long, even if the interview was conducted online). Having a disability and caring for someone with a disability is time consuming, which is another barrier to opting into research.

As a result of these industry partnerships being unsuccessful as recruitment channels, a snowballing sampling methodology was more relied upon than intended, the consequence of which was that while participants met the inclusion and exclusion criteria, the sample was biased towards the primary researcher's own demographic and those in her network. Likewise, the survey recruitment channels being primarily online and the survey itself being online biased the sample towards those who are not only literate but also digitally literate. Further research should, in particular, survey the preferences of people with intellectual disability and acquired brain injuries, non-English speaking communities, and others who are likely to have a lower level of literacy and digital literacy.

A second limitation of this study was the small sample size, which restricted the amount of statistical certainty with which results can be generalised. Although there was enough saturation to conclude that this data was statistically generalisable, there was some indication that there could be significant correlation and influence of demographic characteristics. This suggests that an extension of the sample may be worthwhile in order to interrogate the influence of demographics and choice experience on decision-making. While this is appropriate for the methodology as an exploratory study, there are some limitations to the methodology in comparison to best anti-oppressive practice as described by Stone and Priestly (1996). For example, the primary researcher is not disabled; most analysis took place without PWD; and responses from PWD have been conflated in these results with other stakeholders.

## 9.7 Conclusion

This chapter has built on the findings in Chapters 6–8 to bring new information to the market stewardship and NDIS knowledge base. It has discussed study participants' preference for interpersonal information, and the historical and contemporary complexity of the NDIS, which confounds some of the issues around the ways in which service users consume information. In addition, it examined service navigation and discussed ways in which it could be deprofessionalised, allowing more people to use information and make decisions more effectively. The chapter then made recommendations for practice and for implementing information solutions and outlined the study's contribution to filling the three gaps exposed in the market stewardship literature. Finally, the chapter reflected on the research methodology and discussed its limitations.

In general, many of the findings support the results of other studies and literature reviews; however, very few have specifically been applied to the disability sector. There are particular factors surrounding disability that make this data unique and demonstrate that a contribution has been made. The resonance with other literature also suggests that the small amount of evidence in the disability sector can be quickly boosted by adapting and adopting evidence from healthcare and other service-seeking bodies of literature. The following chapter will conclude this thesis.

# 10 Conclusion

This is the concluding chapter of the thesis, which outlines the background, theory, methodology, findings and contribution of the research, in addition to describing further research that might be undertaken to continue exploring the topic and answering the research question. The chapter shows that the thesis has made a clear original contribution to the literature and to practice and has filled the gap it set out to explore by answering the research question posed.

## 10.1 Thesis summary

The thesis began by situating itself in the context of the NDIS and basing itself in the social justice outcomes underpinning social work theory. Chapter 2 then introduced dual problematisations of personalisation: marketisation and social justice (Mladenov et al., 2015). The Bacchian framework of problematisation introduced in Chapter 2 helped to gain insight into the ideologies of marketisation and social justice embedded in personalisation. Using elements of the “What’s the problem represented to be?” (WPR) approach highlighted power dynamics and the ways in which particular aspects of NDIS policy have, in fact, *produced* problems (Bacchi, 2009). The chapter also contextualised the high-level theory goal of this research, which was to embed social justice imperatives into the marketisation model in order to see how informed choices could benefit both approaches in future research.

Chapter 3 found significant gaps in the market stewardship literature. Most notably, there was a lack of bottom-up market stewardship interventions that place consumers at the centre of the marketplace. It found that little is known about the type of information needed for consumers to feel informed about the decisions they make relating to disability services; in addition, it found that equally little is known about how to provide such information or design an information economy. Chapter 3 also discussed decision-making in the disability sector and the importance of relational autonomy and trust, professional decision-making, the lack of evidence about disability services and the difficulty producing and disseminating relevant metrics for human services.

Chapter 3 also continued to draw from Bacchi’s (2009) WPR approach and described, from a marketisation perspective, the importance of PWD feeling informed about the NDIS. It outlined how this was important for creating confident consumers who are able to make utilitarian purchases (Bacchi, 2012), thereby spending money and pushing the NDIS economy forward. The chapter also noted that, in the case of the NDIS, confident consumers also create positive social justice outcomes as PWD get their needs met, can participate in social and economic areas of their lives and attain their goals. Chapter 3 showed that the NDIS was designed to overcome the fragmentation and inequality of the welfare state model. It argued that if an information economy is not designed for customers in a way they can value and use in order to make informed choices, the existing inequality is likely to continue. Without knowing what information consumers need to make informed decisions, social justice and marketisation goals are at risk of remaining unmet. This chapter thereby identified a practice gap in addition to an area where research was lacking.

Chapter 4 examined the literature to determine what knowledge exists about the type of information needed to inform NDIS service users. It situated the study and research problem in the market stewardship literature and found significant gaps therein, including a general lack of evidence around what information is required, particularly from the perspective of consumers, and just as little evidence around how to action change. Finding these gaps, Chapter 4 looked to the health, disability and behavioural economics literature to explore what other studies may exist to address the research concern. WOM was found to be a common response to consumer uncertainty, especially in healthcare, where there were high levels of information asymmetry.

Chapter 5 described the research methodology, which was designed to take an anti-oppressive approach at the same time as filling the gap in the literature. It addressed the question of what information service users want in order to feel informed when choosing disability support services. It sought to work from a consumer-centred perspective that privileged a social justice rather than marketisation lens. Chapter 5 showed that the methodology aimed to establish what informational market stewardship may look like from the perspective of service users within the NDIS environment. The research project sought to answer the question broadly by addressing three sub-questions:

1. How do service users currently make choices?
2. How do service users wish they could make choices?
3. How would service users advise others to make choices?

These were answered in the first two phases of research through the use of scenario simulation in an interview format, while the following data collection phase extended this sample by use of an online survey. These phases were interspersed by reflective activities with participants, which added value to content as well as ensuring that the research was meeting methodological goals about participant collaboration and empowerment.

Chapters 6 and 7 described the data that was generated from the interviews, revealing numerous sources of information and content of information preferred by service users. Data showed that across the small sample of 22 interview participants, a high level of thematic and content saturation was attained. Further analysis of this data in Chapter 6 condensed these sources into the top 10 that were most highly valued by all 22 participants. In Chapter 7, it also classified the content into 10 themes.

Chapter 8 described the results from the survey phase of research, in which 201 participants were asked to rate each of the 10 sources and rank each of the 10 content themes in order of importance and explain the selection of the most important source and content theme. The results, when compared to those from the interviews, were credible, dependable and transferable: a consistent top three most important sources of information and top four content themes emerged, all of which were concerned with acquiring information through interpersonal sources.

The discussion in Chapter 9 showed yet again the complexity of holding two conflicting marketisation and social justice approaches to problematising disability and personalisation in a single system. It argued that with trust and WOM being so central to consumer decision-making, the NDIS market is at risk of failing from both perspectives. Chapter 9 demonstrated how the new knowledge generated by data collected in this thesis has made a clear contribution to the literature. While limitations to the methodology were acknowledged, suggestions were made about how this study may be extended to create more knowledge and deeper understanding of the issues raised, particularly in the field of market stewardship.

Chapter 9 also presented six recommendations for practice, which came in the form of new approaches to capacity-building on both sides of the market. They included helping families learn to navigate services and systems themselves, using peer advisors, helping providers to invest in marketing, creating metrics and accessible research, using the internet more effectively, and localising systems to leverage the strengths of relationships in the disability sector. The analysis was purposefully agnostic about who the right group was to perform these actions, as actions of stewardship are neither synonymous with or restricted to stewards themselves. These recommendations constitute an original contribution to practice. Further contributions will now be outlined in more detail.

## 10.2 Contribution

Uncertainty is a key factor of decision-making and, from an economic and sociological perspective, increases the necessity for trust. With complex systems and in periods of change, uncertainty is heightened. This research demonstrated that a high level of uncertainty and risk is being experienced by participants of the NDIS, and the literature highlights that this is one of the products of having a poor information economy (Smith, 2001). One of the participants' primary reasons for desiring interpersonal sources of information was as a means of mitigating uncertainty and risk in the NDIS environment. Trust is being used to make decisions in a framework of relational autonomy and to create an illusion of certainty in the marketplace where there is none (Beckert, 2004; Smith, 2001).

This thesis has exposed some reasons for the disability sector currently using trust, some of which are a result of uncertainty as the NDIS is rolled out while others are a result of the systematic disempowerment of PWD. Through answering the research question, the data uncovered the lasting power of cultural legacy from previous waves of policy, which is being reflected at macro, meso and micro levels – it is apparent in the ways in which government systems and stewardship practice responses are being developed, the ways in which marketing is being conducted and trust is being performed by providers, and the ways in which families are navigating systems and choice-making.

Neoliberal economics assumes actors to be autonomous and rational in their consumership (Heffernan, 1992) and New Public Management assumes it of people in their citizenship (Leadbeater, 2004; Vidler & Clarke, 2005). However, this research has shown that the primary approach to decision-making under the NDIS is relational rather than autonomous, and for over 460,000 Australians with disability, this is innately linked with enacting their citizenship as they purchase services that will allow them to access their rights (Duffy, 2010, 2013). This is an important outcome from a social justice perspective. When considered in relation to a history of oppression, a lack of self-determination and no trust in systems or service providers, and little transparency and accountability, it is understandable how a reliance on trust has emerged.

Relying on interpersonal information is not beneficial for the NDIS from either marketisation or social justice perspectives. Participants' desire for trust does not make sense in a mature, centralised market system with an appropriately sized individual package of support; a large number of appropriate, high-quality providers to choose between; and the opportunity to shop around and move between locations. While the NDIS is still in a nascent stage of development, building a system that relies on interpersonal advice is problematic. First, WOM is not easily scalable, a factor that is demonstrated by participants' use of social media as a proxy for true interpersonal sources.

Second, WOM does not offer a reliable framework or metrics for comparing providers or allowing the supply side of the market to respond to demand. Evidence shows that a consumer relying on trust, while they will make more frequent and risky purchases that may benefit the industry as a whole, will not use their analytical skills and will therefore make poorer decisions (Klein & Shtudiner, 2016; Schul & Peri, 2015). The availability and trustworthiness of non-interpersonal information in the disability sector is so low that consumers in the NDIS environment may not be able to make decisions at all if it were not for trusting relationships, so from this perspective it is beneficial. However, the use of good information is preferable for utilitarian economic outcomes (Fotaki, 2014). Additionally, participants' desire to trust others' experiences over their own is problematic in a new market environment in which those others are just as likely to be inexperienced.

From a social justice perspective, reliance on interpersonal relationships for information is not desirable either, despite social work valuing strong social networks for the promotion of positive health and wellbeing outcomes and as "fundamental to the functioning and well-being of individuals and society" (AASW, 2010, p. 9). The disability community is over-affected by social isolation, especially for people with cognitive and psychosocial disability and for many who live in specialist accommodation (Power, 2013). While many of these consumers have family members and others supporting their decisions in various ways, they comprise around 75% of NDIS participants (NDIA, 2019f). Despite market-wide interventions through the ILC funding stream, consumers are still relying on WOM advice for decisions six years into the NDIS. Social media is being used as a proxy for WOM in some cases, while social trust and reliance on professionals is being used in others. However, these tools are at a micro-level, and they do not necessarily increase a consumer's capacity to make confident decisions. If WOM remains the main source of information without any targeted social interventions or greater investment in professional service navigation, inequality is likely to be maintained and reinforced by the information economy.

This discussion has shown that the research in this thesis contributes new knowledge to the market stewardship literature and the literature on disability and the NDIS. The research in this thesis provides evidence that helps to fill the three gaps identified in the market stewardship literature. It contributes to the first gap by taking a bottom-up approach, asking consumers and other decision-makers what kind of information they need. By taking a grounded theory approach, allowing patterns to emerge from the data rather than from existing policy or literature, a range of voices belonging to people who navigate the NDIS first hand have been presented through the research. Evidence has thus emerged that describes what kind of information is needed in the NDIS directly from the voices of service users by taking a bottom-up approach to information-gathering about market stewardship and filling the first gap in the literature.

With regard to the second gap, this study has produced evidence about the type of information service users of the NDIS want in order to feel informed. While some of their preferences reflect those identified in the health literature, there are some key differences. In relation to the second gap identified, which described the lack of evidence of the type of information consumers need, a key finding that does resonate with the health literature is that many different stakeholders produce a requirement for many types of information (Walsh et al., 2012). There was also evidence indicating that age, diagnosis and service use create different informational needs, which was also reflected in the health literature.

This thesis also produced knowledge about what capacity-building consumers need, filling the third gap identified in the literature. In this regard, there is a need to build consumer confidence (Bernstein & Gauthier, 1999; Brophy et al., 2015). As a baseline, there is an existing cultural assumption of incapacity, creating a belief in this case that PWD are unable to make decisions (Dowse, 2009; Gooding, 2013; Jenkinson, 1993). However, this exists in combination with real, subjective, NDIS-participant experiences of risk and uncertainty and an insufficient information economy. Finally, there are real impacts of disability, which mean that some NDIS consumers need support, advocacy and capacity-building the same way as in other areas of their lives (Fawcett & Plath, 2014; McLoughlin et al., 2014).

The existing market stewardship evidence does not align with the need for better information to support marketisation or social justice aims. Rather, because market stewardship has taken a top-down, provider-centric approach until now, it neither aligns with the idea that the demand side of the market should shape supply nor supports consumers' desire for relational autonomy that this study has highlighted. The top-down market stewardship approach does not build consumer capacity to make utilitarian demands, nor does it create scalable approaches to information provision or a sophisticated marketplace. There is an underlying tension between the stated goals of the NDIS, the reality of operationalising it according to the available NDIS data and the boundaries of the current market stewardship literature. In order to prevent the market stagnating, market stewardship needs to take a different approach, starting with the strengths and challenges that currently exist in the disability community. All markets require shaping, and consumers in all industries need navigation and decision-making support. This research has provided new insights into how market stewards may prioritise their efforts in the NDIS market, contextualised in the particular history surrounding it.

## 10.3 Further research

This thesis is an exploratory study in an area that has received little attention. It has carried out some analyses and drawn conclusions that contribute original knowledge to the literature. There are several theoretical interpretations that would be both useful and interesting for uncovering further nuances in the data or extending the study, which are behavioural economics frameworks and repeating the study with an altered methodology or in a different location. These will be briefly described, including a short description of why they might add to knowledge.

### 10.3.1 Behavioural economics

One of the key reasons for valuing interpersonal information is as a way of reducing the burden of choice where there is no other trustworthy data or metrics. Multiple burdens on consumers were cited throughout the study: the burden of choice, the burden of too much information, and the burden of too much change. Behavioural economics looks at how to reduce these burdens and still obtain good outcomes. This thesis has been designed, conducted and written from the perspective of a social work research practitioner situated between social work and social policy; however, there are significant insights that could be gained from examining the results of the research from the perspective of behavioural economics. This data could act as a baseline for further research into how to support different people to make informed decisions and to learn from their peers' choices. It would be best supported by a bigger sample with a wider spread of demographic difference and in combination with outcome data. In essence, the next question to ask is not only how to feel informed but also how to ensure good outcomes and therefore the success of the goal of personalisation and the CRPD. The challenge in such research will be to balance market imperatives with supported decision-making through intelligent behavioural economics triggers and reduce the various burdens identified in this data. This was out of the scope of the present thesis, which was grounded in social work and social policy.

### 10.3.2 Repeat as a cohort study

The impact of uncertainty has been a key theme in the findings and discussion. In time, levels of uncertainty will reduce as the NDIS stabilises and structures around it such as the AAT have more case law on which to base decisions (and become more consistent). At the same time, the general amount of choice experience of NDIS participants and their families and allies will grow because they will have had several assessments and reassessments each year or every two years. As the industry develops, regardless of any market stewardship, LAC partners and service providers will also have increasing sophistication as they gain experience. All of this natural maturity will change the degree of uncertainty experienced by service users and would be likely to change the results if this study were repeated. While this has not been designed as a cohort study, it would be interesting to repeat this study and compare the results to another snapshot in time, which would show whether the NDIS is maturing from a grassroots perspective and whether market stewardship interventions are successful in the consumer experience.

### 10.3.3 Looking overseas

Although such analysis was beyond the scope of this thesis, it might be worth looking at models of personalisation that exist in other places around the world and what solutions these models can offer in terms of both the central goal and recommendations that flow from there. The UK and Australian version of personalisation relates to giving individuals the money to make the decisions themselves. In this context, there is often a meeting of personalisation and individual budgets in the literature and an active marketplace. In contrast, personalisation in Norway has delivered choice without budgets; rather, all providers are state-funded, and they co-design service solutions together. The Norwegian perspective is that true economics does not work in welfare, so we will not get third parties in but will still provide choice. These are two very different examples of personalisation in practice, which may shed light on how best to implement change or prioritise values. It would be interesting to repeat the study conducted in this thesis in countries that problematise disability differently in order to see how this impacts the experience of participants, their need for information and the ways they feel they need to be supported by an information economy. This would add more deeply to the market stewardship literature, as it would indicate which levers most greatly affect consumer needs and the design of information economies, in addition to supporting the development of new marketplaces.

## 10.4 Chapter Summary

This thesis has created new knowledge and has thus contributed to the research literature. The literature review revealed a gap in knowledge about what the information economy needs to look like in the newly personalised NDIS quasi-marketplace. It showed that this is a matter for market stewardship, but that there was a significant gap in knowledge in this area. This thesis has argued that where the goal is to have an NDIS marketplace fuelled by sophisticated consumer demand, it is important to privilege a social justice perspective. It is necessary to incorporate a person-centred, bottom-up approach to see what the demand side needs in order to be able to play its part. It is important to name and identify competing perspectives and approaches in this as well as in the wider personalisation literature. Above all, from a practice perspective, it is essential to research to understand what an information economy should look like – for this to be of central research and practice concern as a concept – and to continuously share governance responsibilities and collaborate with service users to create information so that informational policy responses are designed to support consumers' decision-making.

# 11 References

AASW. (2010). Code of Ethics. Australian Association of Social Workers.

AAT. (2018). Allen and National Disability Insurance Agency [2018] AATA 3851. https://www.aat.gov.au/decision-summaries/decision-summaries-may-2019/allen-and-national-disability-insurance-agency-201

AAT. (2019). NDIS: Can we help? https://www.aat.gov.au/apply-for-a-review/national-disability-insurance-scheme-ndis

ABS. (2009). Disability Prevelance [Australian Bureau of Statistics]. http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4446.0main+features42009

ABS. (2010). Health and socioeconomic disadvantage. Australian Bureau of Statistics. http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4102.0Main+Features30Mar+2010

ABS. (2013a). Carers, Charachteristics. 4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2012. http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/5968BE956901DD79CA257D57001F4D89?opendocument

ABS. (2013b). Disability, ageing and carers, Australia. Summary of Findings, 2012: Disability – Characteristics. Australian Bureau of Statistics.

ABS. (2018). Disability, Ageing and Carers, Australia: Summary of Findings, 2018. Australian Bureau of Statistics. Accessed at https://www.abs.gov.au/ausstats/abs@.nsf/0/C258C88A7AA5A87ECA2568A9001393E8?Opendocument

ABS. (2019, December 19). Feature Article—Twenty years of population change (Feature Article). https://www.abs.gov.au/ausstats/abs@.nsf/0/1CD2B1952AFC5E7ACA257298000F2E76?OpenDocument

ACCC. (2019a). Consumer protection [Australian Competition and Consumer Commission]. https://www.accc.gov.au/consumers/consumer-protection

ACCC. (2019b, May 14). Australian Competition and Consumer Commission [Text]. Australian Competition and Consumer Commission. https://www.accc.gov.au/

ACL. (2019). Consumers and the ACL – Australian Consumer Law. http://consumerlaw.gov.au/consumers-and-the-acl/

Ahmed, M. (2009). Personalisation “patchy” for complex needs clients. Community Care, 1755, 5-5 1p. cin20.

AHPRA. (2019). Testimonials in health advertising. Australian Health Practitioner Regulation Agency.

AIATSIS. (2011). Guidelines for Ethical Research in Australian Indigenous Studies. Australian Institute of Aboriginal and Torres Strait Islander Studies, Australian Government.

Alakeson, V. (2010). International development in self-directed care. Issue Brief (Commonwealth Fund), 78, 1–11.

Amer, M., Daim, T., & Jetter, A. (2003a). A review of scenario planning. Futures: The Journal of Policy, Planning and Futures Studies, 46, 23–40.

Amer, M., Daim, T., & Jetter, A. (2003b). A review of scenario planning. Futures: The Journal of Policy, Planning and Futures Studies, 46, 23–40.

Anand, P., & Lea, S. (2011). The psychology and behavioural economics of poverty. Journal of Economic Psychology, 32(2), 284–293.

Anttonen, A. (2012). Welfare State, Universalism and Diversity. Edward Elgar Publishing.

Ashman, A. F. (1989). Change and disability services in Australia: A ten year retrospective. Australia and New Zealand Journal of Developmental Disabilities, 15(2), 73–80. https://doi.org/10.1080/07263868900033541

Austin, M. J., Fisher, M., & Uggerhøj, L. (2014). Helsinki statement on social work practice research. Nordic Social Work Research, 4(sup1), 7–13. https://doi.org/10.1080/2156857X.2014.981426

Australian Commission on Safety and Quality in Health Care. (2011). Patient-centred care: Improving quality and safety through partnerships with patients and consumers. Australian Commission on Safety and Quality in Health Care.

Bacchi, C. (2009). Analysing Policy. Pearson Higher Education AU.

Bacchi, C. (2012). Introducing the “What’s the Problem Represented to be?” Approach. In Bletslas, A. & Beasley, C. (Eds.), (2012), Engaging with Carol Bacchi: Strategic interventions and exchanges (pp. 21–24), Adelaide: University of Adelaide Press.

Bagshaw, M. (2015, July 24). A new NDIA Board? A litmus test for the NDIS. The Able Movement. http://www.theablemovement.com.au/a-new-ndia-board-a-litmus-test-for-the-ndis/

Bagshaw, M. (2017). NDIS Impact, Needs and Planning Project: Final Report and Business Plan. Central and Eastern Sydney Primary Health Network. https://www.cesphn.org.au/preview/ndis/1622-ndis-impact-needs-and-planning-project-final-report-and-business-plan/file

Baines, D. (2006). Forum: “Whose needs are being served?” Quantitative metrics and the reshaping of social services. Studies in Political Economy, 77(1), 195–209. https://doi.org/10.1080/19187033.2006.11675118

Baker, A. (2012). The New Leviathan: A National Disability Insurance Scheme. Centre for Independent Studies.

Barnes, C., & Mercer, G. (2005). Disability, work, and welfare: Challenging the social exclusion of disabled people. Work, Employment and Society, 19(3), 527–545.

Barnes, C., & Sheldon, A. (2010). Disability, politics and poverty in a majority world context. Disability & Society, 25(7), 771–782. https://doi.org/10.1080/09687599.2010.520889

Barnett, J., & Hammond, S. (1999). Representing disability in charity promotions. Journal of Community & Applied Social Psychology, 9(4), 309–314. https://doi.org/10.1002/(SICI)1099-1298(199907/08)9:4<309::AID-CASP515>3.0.CO;2-7

Bates, D. W., & Gawande, A. A. (2000). The Impact Of The Internet On Quality Measurement: Word-of-mouth advice about providers is gaining respectability through the Web. Health Affairs, 19(6), 104–114. https://doi.org/10.1377/hlthaff.19.6.104

Battams, S. (2017). Emerging Issues for the National Disability Insurance Scheme. Health Outcomes International. https://doi.org/10.13140/RG.2.2.25561.31841

Baxter, K., Glendinning, C., & Clarke, S. (2008). Making informed choices in social care: The importance of accessible information. Health Soc Care Community, 16(2), 197–207. https://doi.org/10.1111/j.1365-2524.2007.00742.x

Baxter, Kate, & Glendinning, C. (2011). Making choices about support services: Disabled adults’ and older people’s use of information. Health & Social Care in the Community, 19(3), 272–279. a9h.

Beaupert, F., Steele, L., & Gooding, P. (2017). Introduction to disability, rights and law reform in Australia: Pushing beyond legal futures. Law in Context, 35(2), 1.

Beckert, J. (2004). Trust and the Performative Construction of Markets. Conference Papers -- American Sociological Association, 1–34. https://search.ebscohost.com/login.aspx?direct=true&db=sih&AN=15928802&site=ehost-live

Beckett, C., & Wrighton, E. (2000). ’What Matters to Me is not What You’re Talking About’—Maintaining the Social Model of Disability in “Public and Private” Negotiations. Disability & Society, 15(7), 991–999. https://doi.org/10.1080/713662019

Behavioural Insights team. (2014, 2017). The Behavioural Insights Team. http://www.behaviouralinsights.co.uk/

Bensing, J. M., Verhaak, P. F., van Dulmen, A. M., & Visser, A. P. (2000). Communication: The royal pathway to patient-centered medicine. Patient Education and Counseling, 39(1), 1–3. https://doi.org/10.1016/s0738-3991(99)00107-x

Bernstein, A. B., & Gauthier, A. K. (1999). Choices in health care: What are they and what are they worth? Medical Care Research Ad Review, 56(1), 5–23.

Bertrand, C., & Bourdeau, L. (2010). Research interviews by Skype: A new data collection method. In J. Esteves (Ed.), Proceedings from the 9th European Conference on Research Methods., 70–79.

Bettman, J. R., Johnson, E. J., & Payne, J. W. (1991). Consumer decision making. Handbook of Consumer Behaviour, 44(2), 50–84.

Bletsas, A., & Beasley, C. (2013). Engaging with Carol Bacchi: Strategic interventions and exchanges. University of Adelaide Press.

Booltink, L., Genugten, M. L. van, & Lako, C. J. (2015). Vulnerable Consumers in the Deregulated Dutch Health System. 1068. https://repository.ubn.ru.nl/handle/2066/144290

Bosher, L. (2017). A vibrant market for NDIS housing. Parity, 30(4), 14.

Botti, S., & Iyengar, S. (2006). The dark side of choice: When choice impairs social welfare. Journal of Public Policy and Marketing, 25(1), 24–38.

Brophy, L., Bruxner, A., & Wilson, E. (2014). Consumer choices about mental health support services. VICSERV. http://dro.deakin.edu.au/eserv/DU:30061988/wilson-consumerchoices-2014.pdf

Brophy, L., Bruxner, A., Wilson, E., Cocks, N., & Stylianou, M. (2015). How Social Work Can Contribute in the Shift to Personalised, Recovery-Oriented Psycho-Social Disability Support Services. British Journal of Social Work, i98–i116. sih.

Brueggemann, B., Feldmeier White, L., Dunn, P., Heifferon, B., & Cheu, J. (2001). Becoming Visible: Lessons in disability. College Composition and Communication, 52(3), 368–398.

Buckley, S. (2007). Advocacy Strategies and approaches: Overview. Association for Progressive Communications. http://www.apc.org/en/node/9456

Buckmaster, L., & Clark, S. (2018). The National Disability Insurance Scheme: A chronology (p. 28). Parliament of Australia.

Carey, G., Dickinson, H., Kavanagh, A., Duff, G., Gilchrist, D., Chand, S., & Alexander, D. (2019). Market capacity framework: An approach for identifying thin markets in the NDIS. Centre for Social Impact.

Carey, G., Dickinson, H., Malbon, E., & Reeders, D. (2018). 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 & Administration, 52(1), 387–407. https://doi.org/10.1111/spol.12321

Carey, G., Kay, A., & Nevile, A. (2019). Institutional Legacies and "Sticky Layers": What Happens in Cases of Transformative Policy Change? https://journals.sagepub.com/doi/abs/10.1177/0095399717704682

Carey, G., Malbon, E., Marjolin, A., & Reeders, D. (2018). National disabilty markets: Market stewardship actions for the NDIS. Centre for Social Impact.

Carey, G., Malbon, E., Olney, S., & Reeders, D. (2018). The personalisation agenda: The case of the Australian National Disability Insurance Scheme. International Review of Sociology, 28(1), 20–34. https://doi.org/10.1080/03906701.2018.1425084

Carey, G., Malbon, E., Reeders, D., Kavanagh, A., & Llewellyn, G. (2017). Redressing or entrenching social and health inequities through policy implementation? Examining personalised budgets through the Australian National Disability Insurance Scheme. International Journal for Equity in Health, 16(1), 192. https://doi.org/10.1186/s12939-017-0682-z

Carey, G., & Matthews, M. (2015). Better methods for delivering adaptive regulation in public management: An application to the NDIS. Regulatory Institutions Network.

Carey, G., & Matthews, M. (2017). Methods for delivering complex social services: Exploring adaptive management and regulation in the Australian National Disability Insurance Scheme. Public Management Review, 19(2), 194–211. https://doi.org/10.1080/14719037.2016.1148194

Carey, G., Reeders, D., & Malbon, E. (2018). Quasi-market shaping, stewarding and steering: A meta review of the evidence and next steps. Unpublished.

Carson, L., & Edwards, K. (2011). Prostitution and Sex Trafficking: What are the Problems Represented to Be? A Discursive Analysis of Law and Policy in Sweden and Victoria, Australia. Australian Feminist Law Journal, 34(1), 63–87. https://doi.org/10.1080/13200968.2011.10854453

Caton, S., & Chapman, M. (2016). The use of social media and people with intellectual disability: A systematic review and thematic analysis: : Vol 41, No 2. Journal of Intellectual & Developmental Disability, 41(2), 125–139.

Chang, C.-T., & Lee, Y.-K. (2015). Effects of message framing, vividness congruency and statistical framing on responses to charity advertising: : Vol 29, No 2. International Journal of Advertising`, 29(2), 195–220.

Charmaz, K. (1994). The grounded theory method: An explication and interpretation. In Glaser, B.G. (1994), More Grounded Theory Methodology: A Reader. Mill Valley, CA: Sociology Press.

Charmaz, K. (2006). Constructing Grounded Theory: A Practical Guide through Qualitative Analysis. SAGE.

Chenoweth, L., & Clements, N. (2009). Funding and service options for people with disabilities: Final report. Griffith University.

Chermack, T., Lynham, S., & Ruona, W. (2001). A review of scenario planning literature. Futures Research Quarterly, Summer, 7–31.

CoAbility. (2019). NDIS Pre-Planning—CoAbility—Victoria. CoAbility. https://coability.com.au/ndis-pre-planning/

Coates, J. (2000). Scenario planning. TechnologicalForecastingandSocialChange, 65, 115–123.

Cockrill, A., & Parsonage, I. (2016). Shocking People Into Action: Does It Still Work?: An Empirical Analysis of Emotional Appeals In Charity Advertising. Journal of Advertising Research, 56(4), 401–413. https://doi.org/10.2501/JAR-2016-045

Cogan, J. F., Hubbard, R. G., & Kessler, D. P. (2005). Making Markets Work: Five Steps To A Better Health Care System. Health Affairs, 24(6), 1447–1457. https://doi.org/10.1377/hlthaff.24.6.1447

Collings, S., Dew, A., & Dowse, L. (2016). Support planning with people with intellectual disability and complex support needs in the Australian National Disability Insurance Scheme. Journal of Intellectual & Developmental Disability, 41(3), 272–276. https://doi.org/10.3109/13668250.2016.1151864

Commonwealth of Australia. (2018). Report: Joint Standing Committee on the National Disability Insurance Scheme.

Commonwealth Ombudsman. (2019). Home—Commonwealth Ombudsman. https://www.ombudsman.gov.au/

Commonwealth Parliamentary Debates, H. of Representatives. (2013). National Disability Insurance Scheme Bill 2012: Second Reading (p. 275). http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;db=CHAMBER;id=chamber%2Fhansardr%2F27c8c7aa-70e7-442b-8ceb-93bd0691de92%2F0180;query=Id%3A%22chamber%2Fhansardr%2F27c8c7aa-70e7-442b-8ceb-93bd0691de92%2F0179%22

Connolly, M., & Harms, L. (2013). Social work: From theory to practice. Cambridge University Press.

Constant, D., Sproull, L., & Kiesler, S. (1999). The Kindness of Strangers: The Usefulness of Electronic Weak Ties for Technical Advice. Organization Science, 7. https://doi.org/10.1287/orsc.7.2.119

Cooper, M. (1999). The Australian Disability Rights Movement Lives. Disability & Society, 14(2), 217–226.

Corbin, J., & Strauss, A. (2007). Basics of qualitative research: Techniques and procedures for developing grounded theory. Sage.

Creswell, J. (2009a). Research Design: Qualitative, Quantitative, and Mixed Methods Approaches. Sage.

Creswell, J. (2009b). Research Design: Qualitative, Quantitative, and Mixed Methods Approaches. Sage.

Creswell, J. W. (2014). A Concise Introduction to Mixed Methods Research. SAGE Publications.

Das, E., Kerkhof, P., & Kuiper, J. (2008). Improving the Effectiveness of Fundraising Messages: The Impact of Charity Goal Attainment, Message Framing, and Evidence on Persuasion. Journal of Applied Communication Research, 36(2). https://www.tandfonline.com/doi/abs/10.1080/00909880801922854

David, C., & West, R. (2017). NDIS Self-Management Approaches: Opportunities for choice and control or an Uber-style wild west? Australian Journal of Social Issues, 52(4), 331–346. https://doi.org/10.1002/ajs4.23

Davidson, G., Kelly, B., MacDonald, G., Rizzo, M., Lombard, L., Abogunrin, O., Clift-Matthews, V., & Martin, A. (2015). Supported decision making: A review of the international literature. International Journal of Law and Psychiatry, 38, 61–67.

Davidson, L., Chinman, M., Kloos, B., Weingarten, R., Stayner, D., & Tebes, J. K. (1999). Peer Support Among Individuals With Severe Mental Illness: A Review of the Evidence. 23.

Defra. (2007). A framework for pro-environmental behaviours. Department for Environment, Food and Rural Affairs.

Degener, T. (2014). A human rights model of disability. In Blanck, P. & Flynn, E. (2016), Routledge Handbook of Disability Law and Human Rights (pp. 47-66). Routledge: Oxen.

Degener, T. (2017). A New Human Rights Model of Disability. In The United Nations Convention on the Rights of Persons with Disabilities (pp. 41–59). Retrieved from https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

Department of Health. (2004). Choosing health: Making health choices easier. HM Government Department of Health.

Devine, A., Dickinson, H., Brophy, L., Kavanagh, A., & Vaughan, C. (2019). 'I don't think they trust the choices I will make.' – Narrative analysis of choice and control for people with psychosocial disability within reform of the Australian Disability Employment Services program. Public Management Review, 0(0), 1–21. https://doi.org/10.1080/14719037.2019.1648700

Dew, A., Collings, S., Savage, I. D., Gentle, E., & Dowse, L. (2019). "Living the life I want": A framework for planning engagement with people with intellectual disability and complex support needs. Journal of Applied Research in Intellectual Disabilities, 32(2), 401–412. https://doi.org/10.1111/jar.12538

Dew, A., Vaughan, P., McEntyre, E., & Dowse, L. (2019). "Our ways to planning": Preparing organisations to plan with Aboriginal and Torres Strait Islander people with disability. Australian Aboriginal Studies, 2, 3.

Dewsbury, G., Clarke, K., Randall, D., Rouncefield, M., & Sommerville, I. (2004a). The anti- social model of disability. Disability & Society, 19(2), 145–158. https://doi.org/10.1080/0968759042000181776

Dewsbury, G., Clarke, K., Randall, D., Rouncefield, M., & Sommerville, I. (2004b). The anti- social model of disability. Disability & Society, 19(2), 145–158. https://doi.org/10.1080/0968759042000181776

Dickinson, H. (2016). From New Public Management to New Public Governance: The implications for a 'new public service.' In J. Butcher & D. Gilchrist (Eds.), The Three Sector Solution (1st ed.). Canberra: ANU Press.

Dickinson, H. (2017). Individual funding systems: What works? Evidence Base, 2017(3). https://doi.org/10.21307/eb-2017-003

Dickinson, H., & Glasby, J. (2010). The personalisation agenda: Implications for the third sector. Third Sector Research Centre.

Dickinson, H., Malbon, E., Carey, G., & Weier, M. (n/d). Administering personalized disability schemes: Who bears the cost? The case of Australia's National Disability Insurance Scheme. u/p.

Dickinson, H., Needham, C., & Sullivan, H. (2014). Individual Funding for Disability Support: What are the Implications for Accountability? Australian Journal of Public Administration, 73(4), 417–425.

Dijs-Elsinga, J., Otten, W., Versluijs, M., Smeets, H. J., Kievit, J., Vree, R., van der Made, W., & Marang-van de Mheen, P. (2010). Choosing a hospital for surgery: The importance of information on quality of care. Medical Decision Making, Sept-Oct, 544–555.

Dixon, A., Robertson, R., Appleby, J., Burge, P., Devlin, N., & Magee, H. (2010). Patient choice: How patients choose and how providers respond. The King's Fund.

Dobele, A., & Lindgreen, A. (2011). Exploring the nature of value in the word-of-mouth referral equation for health care. Journal of Marketing Management, 27(3–4), 269–290. https://doi.org/10.1080/0267257X.2011.545677

Dodd, S. (2013). Personalisation, individualism and the politics of disablement. Disability & Society, 28(2), 260–273. https://doi.org/10.1080/09687599.2012.699283

Dodd, S.-J., & Epstein, I. (2012). Practice-Based Research in Social Work: A Guide for Reluctant Researchers (1 edition). Routledge.

Doddington, K., Jones, R. S. P., & Miller, B. Y. (1994). Are attitudes to people with learning disabilities negatively influenced by charity advertising? Disability & Society, 9(2), 207–222. https://doi.org/10.1080/09687599466780221

Dolan, P., Hallsworth, M., Halpern, D., King, D., & Vlaev, I. (2010). Mindspace: Influencing behaviour through public policy. Cabinet Office and Institute for Government.

Donovan, J., Hampson, R., & Connolly, M. (2018). Service navigators in the workforce: An ethical framework for practice. Asia Pacific Journal of Health Management, 13(2), 1.

Dowse, L. (2009). 'Some people are never going to be able to do that'. Challenges for people with intellectual disability in the 21st century. Disability & Society, 24(5), 571–584. https://doi.org/10.1080/09687590903010933

DSS. (2017). Guaranteeing the National Disability Insurance Scheme—2017 Budget. Australian Government Department of Social Services. https://www.dss.gov.au/sites/default/files/documents/05_2017/final_budget_fact_sheet_template_2017_2_0.pdf

Duffy, S. (2010). The Citizenship Theory of social justice: Exploring the meaning of personalisation for social workers. Journal of Social Work Practice, 24(3), 253–267. https://doi.org/10.1080/02650533.2010.500118

Duffy, S. (2011). A fair society and the limits of personalisation. The Centre for Welfare Reform.

Duffy, S. (2012). The limits of personalisation. Tizard Learning Disability Review, 17(3), 111–123.

Duffy, S. (2013). Designing NDIS: an international perspective on individual funding systems. The Centre for Welfare Reform.

Duffy, S., Waters, J., & Glasby, J. (2010). Personalisation and adult social care: Future options for the reform of public services. The Policy Press.

Eayrs, C. B., & Ellis, N. (1990). Charity advertising: For or against people with a mental handicap? British Journal of Social Psychology, 29(4), 349–366. https://doi.org/10.1111/j.2044-8309.1990.tb00915.x

Edgman-Levitan, S., & Cleary, P. (2006). What information do consumers want and need? Health Affairs, 15(4), 42–56.

Ellem, K., Baidawi, S., Dowse, L., & Smith, L. (2019). Services to young people with complex support needs in rural and regional Australia: Beyond a metro-centric response. Children and Youth Services Review, 99, 97–106. https://doi.org/10.1016/j.childyouth.2019.01.033

Ellis, K., Goggin, G., & Goggin, G. (2013, October 30). Disability and Social Media. The Social Media Handbook. https://doi.org/10.4324/9780203407615-15

Emerson, E. (2007). Poverty and people with intellectual disabilities. Mental Retardation and Developmental Disabilities Research Reviews, 13(2), 107–113. https://doi.org/10.1002/mrdd.20144

Engwicht, D. (2005). Mental speed bumps: A smarter way to tame traffic. Envirobook.

Epstein, I., Fisher, M., Julkunen, I., Uggerhoj, L., Austin, M. J., & Sim, T. (2015a). The New York Statement on the Evolving Definition of Practice Research Designed for Continuing Dialogue: A Bulletin From the 3rd International Conference on Practice Research (2014). Research on Social Work Practice, 25(6), 711–714.

Epstein, I., Fisher, M., Julkunen, I., Uggerhoj, L., Austin, M. J., & Sim, T. (2015b). The New York Statement on the Evolving Definition of Practice Research Designed for Continuing Dialogue: A Bulletin From the 3rd International Conference on Practice Research (2014). Research on Social Work Practice, 25(6), 711–714.

Faber, M., Bosch, M., Wollersheim, H., Leatherman, S., & Grol, R. (2008). Public reporting in health care: How do consumers use quality-of-care information? A systematic review. Medical Care, 47(1), 1–8.

Fawcett, B., & Plath, D. (2014). A national disability insurance scheme: What social work has to offer. British Journal of Social Work, 44, 15.

Fisher, K., Gleeson, R., Edwards, R., Purcel, C., Sitek, T., Dinning, B., Laragy, C., D'Aegher, L., & Thompson, D. (2010). Effectiveness of individual funding approaches for disability support. Australian Government Department of Families, Housing, Community Services and Indigenous Affairs.

Flynn, L. M. (1993). Political impact of the family-consumer movement. National Forum, 1, 8.

Forsyth, L., & McGough, K. (2014). Unleashing value: Rethinking regulation in the human services sector. KPMG.

Foster, M., Henman, P., Tilse, C., Fleming, J., Allen, S., & Harrington, R. (2016). 'Reasonable and necessary' care: The challenge of operationalising the NDIS policy principle in allocating disability care in Australia. Australian Journal of Social Issues, 51(1), 27–46. https://doi.org/10.1002/j.1839-4655.2016.tb00363.x

Fotaki, M. (2014). Can consumer choice replace trust in the National Health Service in England? Towards developing an affective psychosocial conception of trust in health care. Sociology of Health & Illness, 36(8), 1276–1294. https://doi.org/10.1111/1467-9566.12170

Fotaki, M., Roland, M., McDonald, R., Scheaf, R., Boyd, A., & Smith, L. (2008). What benefits will choice bring to patients? Literature review and assessment of implications. Journal of Health Services Research & Policy, 00(0), 1–7.

Foucault, M. (1972). The archaeology of knowledge and the discourse on language. Pantheon Books.

Fukui, S., Davidson, L., Holter, M., & Rapp, C. A. (2010). Pathways to Recovery (PTR): Impact of peer-led group participation on mental health recovery outcomes. Psychiatric Rehabilitation Journal, 34(1), 42.

Funding | NHMRC. (2019). NHMRC. https://www.nhmrc.gov.au/funding

Gambetta, D. (2000). Can We Trust Trust? In Gambetta, D. (Ed.), Trust: Making and breaking cooperative relations (Electronic edition, pp. 213–237). Oxford: Blackwell.

Gash, T., Panchamia, N., Sims, S., & Hotson, L. (2013). Making public service markets work: Professionalising government’s approach to commissioning and market stewardship. Institute for Government.

Gelb, B., & Johnson, M. (1995). Word-of-mouth communication: Causes and consequences. Marketing Review, 15(3), 54–58.

Gibbs, A. (1997). Focus Gropus. Social Research Update, 19.

Gibbs, D. A., Sangl, J. A., & Burrus, B. (1996a). Consumer perspectives on information needs for health plan choice. Health Care Financing Review, 18(1), 55–73.

Gibbs, D. A., Sangl, J. A., & Burrus, B. (1996b). Consumer perspectives on information needs for health plan choice. Health Care Financing Review, 18(1), 55–73.

Gilbert, T. (2004a). Including people with learning disabilities in research: Issues and possibilities. Health and Social Care in the Community, 12(4), 298–308.

Gilbert, T. (2004b). Including people with learning disabilities in research: Issues and possibilities. Health and Social Care in the Community, 12(4), 298–308.

Gilgun, J. F. (1994). A Case for Case Studies in Social Work Research. Social Work, 39(4), 371–380. https://doi.org/10.1093/sw/39.4.371

Glasby, J., & Littlechild, R. (2009). Direct Payments and Personal Budgets (third Edition): Putting Personalisation Into Practice. Policy Press.

Glaser, B., & Strauss, A. (1967). The discovery of grounded theory: Strategies for qualitative research. Transaction Publishers.

Glendinning, C. (2008). Increasing Choice and Control for Older and Disabled People: A Critical Review of New Developments in England. Social Policy & Administration, 42(5), 451–469. https://doi.org/10.1111/j.1467-9515.2008.00617.x

Goggin, G., Hollier, S., & Hawkins, W. (2017a). Internet accessibility and disability policy: Lessons for digital inclusion and equality from Australia. Internet Policy Review, 6(1). https://policyreview.info/articles/analysis/internet-accessibility-and-disability-policy-lessons-digital-inclusion-and

Goggin, G., Hollier, S., & Hawkins, W. (2017b). Internet accessibility and disability policy: Lessons for digital inclusion and equality from Australia. Internet Policy Review, 6(1). https://policyreview.info/articles/analysis/internet-accessibility-and-disability-policy-lessons-digital-inclusion-and

Gooding, P. (2013). Supported Decision-Making: A Rights-Based Disability Concept and its Implications for Mental Health Law. Psychiatry, Psychology and Law, 20(3), 431–451.

Gooding, P. (2016). From deinstitutionalisation to consumer empowerment: Mental health policy, neoliberal restructuring and the closure of the ‘Big bins’ in Victoria. Health Sociology Review, 25(1), 33–47. https://doi.org/10.1080/14461242.2015.1134261

Goodley, D. (1999). Disability research and the “researcher template”: Reflections on grounded subjectivity in ethnographic research. Qualitative Inquiry, 5(1), 24–45.

Goodley, Dan. (1999). Disability research and the “researcher template”: Reflections on grounded subjectivity in ethnographic research. Qualitative Inquiry, 5(1), 24–45.

Goodley, Dan. (2013). Dis/entangling critical disability studies. Disability & Society, 28(5), 631–644. https://doi.org/10.1080/09687599.2012.717884

Grant, E., Chong, A., Zillante, G., Beer, A., & Srivastava, A. (2016). The NDIS, Housing and Indigenous Australians living with a disability. Parity, 27(5), 25–26.

Green, C., Malbon, E., Carey, G., Dickinson, H., & Reeders, D. (2017). Competition and collaboration between service providers in the NDIS. Centre for Social Impact, UNSW.

Green, J., & Mears, J. (2014). The implementation of the NDIS: Who wins, who loses? Cosmopolitan Civil Societies Journal, 6(2), 3915.

Greenbaum, T. L. (1998). The Handbook for Focus Group Research. Sage.

Gsottbauer, E., & van den Bergh, J. C. (2011). Environmental Policy Theory Given Bounded Rationality and Other-regarding Preferences. Environmental and Resource Economics, 49(2), 263–304.

Guest, G., MacQueen, K., & Namey, E. (2012). Applied Thematic Analysis. SAGE Publications, Inc. https://doi.org/10.4135/9781483384436

Håkansson, P., & Witmer, H. (2015). Social Media and Trust—A Systematic Literature Review. Journal of Business and Economics, 6(3), 517–524.

Hamari, J., & Koivisto, J. (2013, June 5). Social motivations to use gamification: An empirical study of gamifying exersise. 21st European Conference on Information Systems, Utrecht, Netherlands.

Hancock, N., Smith-Merry, J., Gilroy, J., Yen, I., Llewellyn, G., & Bresnan, A. (2018). NDIS and psychosocial disability – the Victorian story: Insights and policy recommendations from expert stakeholders [Text]. http://apo.org.au/node/139141

Hanoch, Y., & Rice, T. (2010). The economics of choice: Lessons from the US health-care market. Health Expectations, 14, 105–112.

Hasenfeld, Y., & Garrow, E. E. (2012). Nonprofit Human-Service Organizations, Social Rights, and Advocacy in a Neoliberal Welfare State. Social Service Review, 86(2), 295–322. https://doi.org/10.1086/666391

Heeks, R. (1999). Reinventing Government in the Information Age: International Practice in IT-Enabled Public Sector Reform. Routledge. http://ebookcentral.proquest.com/lib/unimelb/detail.action?docID=169687

Heffernan, W. J. (1992). Social welfare polcy: A research and action strategy. Longman.

Herr, P. M., Kardes, F. R., & Kim, J. (1991). Effects of Word-of-Mouth and Product-Attribute Information on Persuasion: An Accessibility-Diagnosticity Perspective. Journal of Consumer Research, 17(4), 454. https://doi.org/10.1086/208570

Hibbard, J., & Jewett, J. (1997). Will quality report cards help consumers? Health Affairs, 16(3), 218–228.

Hibbard, J., Jewett, J., Engelmann, S., & Tusler, M. (1998). Can Medicare beneficiaries make informed choices? Health Affairs, 17(6), 181–193.

Hibbard, J., Slovic, P., & Jewett, J. (1997). Informing consumer decisions in health care: Implications from decision-making research. The Millbank Quarterly, 75(3), 395–414.

Hobbs, B.M. (2020). Choosing care: the difficulties in navigating the home care package market. Consumer Policy Research Centre: Victoria.

Hostetter, M., & Klein, S. (2013). In Focus: Using Behavioral Economics to Advance Population Health and Improve the Quality of Health Care Services. Quality Matters. http://www.commonwealthfund.org/publications/newsletters/quality-matters/2013/june-july/in-focus

Hough, A. (2018, November). All care, no responsibility? Government treatment of providers under the National Disability Insurance Scheme and the NDIS Quality and Safeguarding Scheme. 14th Australia and New Zealand third sector research conference, Sydney, Australia.

Humphrey, J. (2000). Researching disability politics, or, some problems with the social model. Disability and Society, 15(1), 63–85.

Huotari, K., & Hamari, J. (2012, October 3). Defining gamification—A service marketing perspective. 16th International Academic MindTrek Conference, Tampere, Finland.

Hursh, S., & Roma, P. (2013). Behavioural economics and empirical public policy. J Exp Anal Behav, 99, 98–124.

Hurst, R., & Albert, B. (2006). The social model of disability, human rights and development cooperation. In Albert, B., In or out of the mainstream (pp. 24–39), Leeds: University of Leeds.

Jackson, S. E., & Chester, J. D. (2015). Personalised cancer medicine. International Journal of Cancer, 137(2), 262–266.

Janghorban, R., Roudsari, R. L., & Taghipour, A. (2014). Skype interviewing: The new generation of online synchronous interview in qualitative research. International Journal of Qualitative Studies on Health and Well-Being, 9(1).

Jenkinson, J. (1993). Who shall decide? The relevance of theory and research to decision-making by people with a intellectual disability. Disability, Handicap and Society, 8(4), 361–375.

Jilke, S. (2015). CHOICE AND EQUALITY: ARE VULNERABLE CITIZENS WORSE OFF AFTER LIBERALIZATION REFORMS? https://onlinelibrary.wiley.com/doi/abs/10.1111/padm.12102

Johnson, N. (1987). The welfare state in transition. Wheatsheaf Books.

Jones, K., Netten, A., Rabiee, P., Glendinning, C., Arksey, H., & Moran, N. (2014). Can individual budgets have an impact on carers and the caring role? Ageing & Society, 34(1), 157–175. https://doi.org/10.1017/S0144686X12000748

Jones, R., Pykett, J., & Whitehead, M. (2010). Governing temptation: Changing behaviour in an age of libertarian paternalism. Progress in Human Geography, 35(4), 483–501.

Katsios, C., & Roukos, D. (2019). Individual genomes and personalized medicine: Life diversity and complexity. Personalized Medicine, 7(4), 347–350.

Kaushik, V., & Walsh, C.A. (2019). Pragmatism and a research paradigm and its implications for social work research. Social Sciences, 8(255), 1-17.

Kavanagh, A. M., Krnjacki, 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 for Equity in Health, 12(1), 73. https://doi.org/10.1186/1475-9276-12-73

Kendrick, M., Ward, M., & Chenoweth, L. (2017). Australia's national disability insurance scheme: Looking back to shape the future. Disability & Society, 1–18. https://doi.org/10.1080/09687599.2017.1322493

Kim, Y. (2016). Trust in health information websites: A systematic literature review on the antecedents of trust. Health Informatics Journal, 22(2), 355–369. https://doi.org/10.1177/1460458214559432

King, A. (2014). Knowledge Exchange Action Research: Creating Impact with Social Science Research. https://doi.org/10.4135/978144627305013508889

King, R. A., Racherla, P., & Bush, V. D. (2014). What We Know and Don't Know About Online Word-of-Mouth: A Review and Synthesis of the Literature. Journal of Interactive Marketing, 28(3), 167–183. https://doi.org/10.1016/j.intmar.2014.02.001

Kitzinger, J. (1995). Qualitative research: Introducing focus groups. British Medical Journal, 311(7000), 299.

Klein, G., & Shtudiner, Z. (2016). Trust in others: Does it affect investment decisions? Quality & Quantity, 50(5), 1949–1967. https://doi.org/10.1007/s11135-015-0245-6

Knight, J. A., Comino, E. J., Harris, E., & Jackson-Pulver, L. (2009). Indigenous Research: A Commitment to Walking the Talk. The Gudaga Study—an Australian Case Study. Journal of Bioethical Inquiry, 6(4), 467–476. https://doi.org/10.1007/s11673-009-9186-x

Kohn, N. A., & Blumenthal, J. (2014). A critical assessment of supported decision-making for persons aging with intellectual disabilities. Disability and Health Journal(7), 40–43.

Kolstad, J. T., & Chernew, M. E. (2009). Quality and consumer decision making in the market for health insurance and health care services. Medical Care Research Ad Review, 66(1), 28S-52S.

Kvale, S. (2007). Doing interviews. Sage.

Land, K. C., Michalos, A. C., & Sirgy, M. J. (2011). Handbook of Social Indicators and Quality of Life Research. Springer Science & Business Media.

Laycock, A., Walker, D., Harrison, N., & Brands, J. (2009). Supporting Indigenous Researchers: A Practical Guide for Supervisors. Cooperative Research Centre for Aboriginal Health.

Leadbeater, C. (2004). Personalisation through participation: A new script for public services. Demos.

Leap in! (2019). Leap in! NDIS Planning – Apps on Google Play. https://play.google.com/store/apps/details?id=com.planready&hl=en_AU

Leece, J., & Leece, D. (2010). Personalisation: Perceptions of the Role of Social Work in a World of Brokers and Budgets. British Journal of Social Work, 41(2), 204–223. https://doi.org/10.1093/bjsw/bcq087

Leece, Janet, & Leece, D. (2011). Personalisation: Perceptions of the Role of Social Work in a World of Brokers and Budgets. British Journal of Social Work, 41(2), 204–223. sih.

LegalAid. (2019). National Disability Insurance Scheme Service—Legal Aid NSW. https://www.legalaid.nsw.gov.au/what-we-do/civil-law/national-disability-insurance-scheme-service

Lent, A., & Ardent, N. (2004). Making Choices: How Can Choice Improve Local Public Services? New Local Government Network.

Liang, B., & Scammon, D. L. (2011). E- Word- of- Mouth on health social networking sites: An opportunity for tailored health communication. Journal of Consumer Behaviour, 10(6), 322–331. https://doi.org/10.1002/cb.378

Llewellyn, Gweneth. (2014). Report of audit of disability research in Australia supplement. Centre for Disability Research and Policy.

Llewellyn, Gwynnyth. (2017). Audit of disability research in Australia update report 2017. Lidcombe, NSW : Centre for Disability Research and Policy, University of Sydney. https://trove.nla.gov.au/version/253932709

Longmore, P. K. (2009). Making Disability an Essential Part of American History. OAH Magazine of History, 23(3), 11.

Low, D. (2011). Behavioral analysis and policy design: Examples from Singapore. World Scientific.

Lowitja Institute. (2012). Knowledge Exchange. http://www.lowitja.org.au/knowledge-exchange

MacKinnon, D., & Coleborne, C. (2003). Introduction: Deinstitutionalisation in Australia and New Zealand. Health and History, 5(2), 1–16. https://doi.org/10.2307/40111450

Maglajlic, R., Brandon, D., & Given, D. (2000). Making Direct Payments a Choice: A report on the research findings. Disability & Society, 15(1), 99–113. a9h.

Malbon, E., Alexander, D., Carey, G., Reeders, D., Green, C., Dickinson, H., & Kavanagh, A. (2019). Adapting to a marketised system: Network analysis of a personalisation scheme in early implementation. Health & Social Care in the Community, 27(1), 191–198. https://doi.org/10.1111/hsc.12639

Malbon, E., Carey, G., & Dickinson, H. (2018). Accountability in Public Service Quasi-markets: The Case of the Australian National Disability Insurance Scheme. Australian Journal of Public Administration, 77(3), 468–481. https://doi.org/10.1111/1467-8500.12246

Malbon, E., Carey, G., Marjolin, A., & Reeders, D. (2018). Interventions to address market problems in the National Disability Insurance Scheme: A review of the evidence. Unpublished.

Malbon, E., Carey, G., & Reeders, D. (2018). Mixed accountability within new public governance: The case of a personalized welfare scheme in early implementation. Social Policy & Administration, 53(1), 156–169. https://doi.org/10.1111/spol.12446

Mangold, W. G., Miller, F., & Brockway, G. R. (1999). Word- of- mouth communication in the service marketplace. Journal of Services Marketing. https://doi.org/10.1108/08876049910256186

Marsh, P., & Kelly, L. (2018). Dignity of risk in the community: A review of and reflections on the literature. Health, Risk & Society, 20(5–6), 297–311. https://doi.org/10.1080/13698575.2018.1519115

Martin, M. (2011). Informing self-directed support: A discussion. Newcastle: Newcastle University Business School.

McLean, G., Sutton, M., & Guthrie, B. (2006). Deprivation and quality of primary care services: Evidence for persistence of the inverse care law from the UK Quality and Outcomes Framework. Journal of Epidemiology and Community Health, 60(11), 917–922. https://doi.org/10.1136/jech.2005.044628

McLoughlin, I., Bayati-Bojakhi, S., Purushothaman, K., & Sohal, A. (2014). Informational Requirements and Client-centred Disability Care: Issues, Problems and Prospects in Australia. Social Policy and Society, 13(4), 609–621.

Mead, S., & Copeland, M. E. (2000). What Recovery Means to Us: Consumers' perspectives. Community Mental Health Journal, 36, 315–328.

Meagher, G. (2010, June 21). Is choice the enemy of equality? Transforming Care Conference.

Miyamoto, Y., & Sono, T. (2012). Lessons from Peer Support Among Individuals with Mental Health Difficulties: A Review of the Literature. Clinical Practice and Epidemiology in Mental Health : CP & EMH, 8, 22–29. https://doi.org/10.2174/1745017901208010022

Mladenov, T., Owens, J., & Cribb, A. (2015). Personalisation in disability services and healthcare: A critical comparative analysis. Critical Social Policy, 35, 307–326. https://doi.org/10.1177/0261018315587071

Morris, J. (2005). Citizenship and disabled people: A scoping paper prepared for the Disability Rights Commission. Disability Rights Commission.

Mortelmans, K., Donceel, P., & Lahaye, D. (2006). Disability management through positive intervention in stakeholders' information asymmetry. A pilot study. Occupational Medicine, 56, 129–136.

MS Connect. (2019). NDIS Pre Planning | MS (Support & services). https://www.ms.org.au/support-services/individual-assessment/ms-pre-planning.aspx

Murdach, A. D. (2009). Making Difficult Decisions. Social Work, 54(4), 371–373.

Natalier, K., & Willis, K. (2008). Taking responsibility or averting risk? A socio-cultural approach to risk and trust in private health insurance decisions. Health, Risk & Society, 10(4), 399–411. https://doi.org/10.1080/13698570802167413

National Disability and Carer Alliance. (2019). Every Australian Counts—About. Every Australian Counts. Retrieved from https://www.everyaustraliancounts.com.au/about/

NDIA. (2015). *ILC Policy Framework | NDIS.* Retrieved from https://www.ndis.gov.au/community/information-linkages-and-capacity-building-ilc/ilc-policy-framework

NDIA. (2016a). *NDIS Market Approach: Statement of Opportunity and Intent.* Canberra: NDIA.

NDIA. (2016b). *Draft grant agreement terms and conditions: NDIS partners in the community program.* https://www.dss.gov.au/sites/default/files/ndis_-_partners_in_the_community_-draft_grant_agreement.pdf

NDIA. (2018a). *4th quarterly report: 2017-18 Q4.* Retrieved from https://www.ndis.gov.au/about-us/publications/quarterly-reports

NDIA. (2018b). *Improved NDIS planning for people with complex support needs | NDIS.* Retrieved from https://www.ndis.gov.au/news/1002-improved-ndis-planning-people-complex-support-needs

NDIA. (2018c). *Market Enablement Framework—NDIA.* Retrieved from ndis.gov.au.

NDIA. (2019a). *Am I eligible | NDIS.* Retrieved from https://www.ndis.gov.au/applying-access-ndis/am-i-eligible

NDIA. (2019b). *Find a registered provider | NDIS.* National Disability Insurance Scheme. Retrieved from https://www.ndis.gov.au/participants/working-providers/find-registered-provider#provider-lists

NDIA. (2019c). *Information, Linkages and Capacity Building (ILC) | NDIS.* Retrieved from https://www.ndis.gov.au/community/information-linkages-and-capacity-building-ilc

NDIA. (2019d). *Market position statements | NDIS.* Retrieved from https://www.ndis.gov.au/providers/market-information/market-position-statements

NDIA. (2019e). *National Disability Insurance Scheme Pricing Strategy.* Canberra: NDIA.

NDIA. (2019f). *Quarterly Report Quarter 4 201819 National Dashboard.* Retrieved from https://www.ndis.gov.au/about-us/publications/quarterly-reports

NDIA. (2019g). *Reasonable and necessary supports | NDIS.* Retrieved from https://www.ndis.gov.au/understanding/supports-funded-ndis/reasonable-and-necessary-supports

NDIA. (2019h). *Types of disability evidence | NDIS.* Retrieved from https://www.ndis.gov.au/applying-access-ndis/how-apply/information-support-your-request/types-disability-evidence

NDIA. (2019i). *COAG Disability Reform Council Quarterly Report 30 September 2019.* National Disability Insurance Agency. Retrieved from https://www.ndis.gov.au/about-us/publications/quarterly-reports

NDIS. (2016). *Introduction to the NDIS for providers. National Disability Insurance Scheme.* Retrieved from http://www.ndis.gov.au/providers/ndis-providers

NDIS. (2019). *NDIS price increases for a sustainable and vibrant disability services market | NDIS.* Retrieved from https://www.ndis.gov.au/news/1992-ndis-price-increases-sustainable-and-vibrant-disability-services-market

NDIS Quality and Safeguards Commission. (2019). *Home | NDIS Quality and Safeguards Commission.* Retrieved from https://www.ndiscommission.gov.au/

NDS. (2018a). State of the disability sector report 2018. Centre for Applied Disability Research.

NDS. (2018b). Australian disability workforce report. NDS.

NDS. (2019). State of the disability sector report 2019. National Disability Services.

Needham, C. (2011). Personalising Public Services: Understanding the personalisation narrative. The Policy Press.

Needham, C. (2013). Personalization: From day centres to community hubs? Critical Social Policy, 34(1), 90–108. https://doi.org/10.1177/0261018313483492

Needham, C. (2016). The Boundaries of Budgets: Why should individuals make spending choices about their health and social care? In J. Butcher & D. Gilchrist (Eds.), The Three Sector Solution (1st ed.). Canberra: ANU Press.

Needham, C., Allen, K., Hall, K., McKay, S., Carr, S., Littlechild, R., & Tanner, D. (2015). Micro-Enterprises: Small enough to care? (p. 26). University of Birmingham.

Needham, C., & Dickinson, H. (2018). 'Any one of us could be among that number': Comparing the Policy Narratives for Individualized Disability Funding in Australia and England. Social Policy & Administration, 52(3), 731–749. https://doi.org/10.1111/spol.12320

Neville Isaacs, A., Pepper, H., Pyett, P., Gruis, H. A., Waples- Crowe, P., & Oakley- Browne, M. A. (2011). 'What You Do is Important But How You Do it is More Important.' Qualitative Research Journal, 11(1), 51–61. https://doi.org/10.3316/QRJ1101051

Newell, C. (1999). Encountering Oppression: The Emergence of the Australian Disability Rights Movement. Social Alternatives, 18(1), 47–52.

NHMRC. (2002). The NHMRC Road Map: A Strategic Framework for Improving Aboriginal and Torres Strait Islander Health through Research and Final Report of Community Consultations on the NHMRC Road Map. National Health and Medical Research Council.

NHMRC. (2007). Section 1: Values and principles of ethical conduct. https://www.nhmrc.gov.au/book/section-1-values-and-principles-ethical-conduct

NHMRC. (2010). The NHMRC Road Map II: A strategic framework for improving the health of Aboriginal and Torres Strait Islander people through research. NHMRC: Australia. National Health and Medical Research Council.

NLS. (2015). Evaluation of the NDIS: Initial report. National Institure of Labor Studies, Flinders University.

NSW P&C. (2019). About us—Behavioural Insights. https://www.dpc.nsw.gov.au/programs-and-services/behavioural-insights/about-us/

Obst, P. (2010). Online psychological sense of community and social support found through membership in disability-specific websites promotes well-being for people living with a physical disabilty. Journal of Community & Applied Social Psychology, 6, 525–531.

Obst, P., & Stafurik, J. (2010). Online We are All Able Bodied: Online Psychological Sense of Community and Social Support Found Through Membership of Disability-specific Websites Promotes Well-being for People Living with a Physical Disability. Journal of Community & Applied Social Psychology, 20, 525–531. https://doi.org/10.1002/casp.1067

OECD. (2010). Sickness, Disability and Work: Breaking the Barriers – A Synthesis of Findings across OECD Countries. Organisation for Economic Co-operation and Development.

Oliver, A. (2013). From Nudging to Budging: Using Behavioural Economics to Inform Public Sector Policy. Journal of Social Policy, 42(4), 685–700.

Oliver, C. (2012). Critical Realist Grounded Theory: A New Approach for Social Work Research. The British Journal of Social Work, 42(2), 371–387. https://doi.org/10.1093/bjsw/bcr064

Oliver, M. (1992). Changing the social relations of research production? Disability, Handicap and Society, 7(2).

Oliver, M. (1996). DEFINING IMPAIRMENT AND DISABILITY: ISSUES AT STAKE. In C. Barnes & G. Mercer (Eds.), 'Exploring the Divide (pp. 29–54). The Disability Press. http://disability-studies.leeds.ac.uk/files/library/Oliver-ex-div-ch3.pdf

Oliver, Michael. (1992). Changing the social relations of research production? Disability, Handicap and Society, 7(2).

Oliver, Michael. (1996). DEFINING IMPAIRMENT AND DISABILITY: ISSUES AT STAKE. In C. Barnes & G. Mercer (Eds.), 'Exploring the Divide (pp. 29–54). The Disability Press. http://disability-studies.leeds.ac.uk/files/library/Oliver-ex-div-ch3.pdf

Oliver, Michael. (1998). Theories of disability in health practice and research. BMJ : British Medical Journal, 317(7170), 1446–1449.

O'Rance, L. (2009). The geography of disability and economic disadvantage in Australian capital cities. Australian Institute of Health and Welfare.

Ozawa, S., & Sripad, P. (2013). How do you measure trust in the health system? A systematic review of the literature (Vol. 91C). https://doi.org/10.1016/j.socscimed.2013.05.005

Panwar, D., Anand, S., Ali, F., & Singal, K. (2019). Consumer Decision Making Process Models and their Applications to Market Strategy. 15(1), 9.

Pashkevich, V., Haftor, D., & Pashkevich, N. (2017). The Swedish Information Economy: Current Evidence and Key Government Policy Implications. 23–28. http://urn.kb.se/resolve?urn=urn:nbn:se:lnu:diva-75606

Perske, R. (2004). Nirje's Eight Planks. Mental Retardation, 42(2), 147–150. https://doi.org/10.1352/0047-6765(2004)42<147:NEP>2.0.CO;2

Petrakis, M., & Laxton, S. (2017). Intervening Early with Family Members during First-Episode Psychosis: An Evaluation of Mental Health Nursing Psychoeducation within an Inpatient Unit. Archives of Psychiatric Nursing, 31(1), 48–54. https://doi.org/10.1016/j.apnu.2016.07.015

Pfeiffer, D. (1993). Overview of the Disability Movement: History, Legislative Record, and Political Implications. Policy Studies Journal, 21(4), 724–734. https://doi.org/10.1111/j.1541-0072.1993.tb02169.x

Pilling, D., & Christensen, K. (2014). Policies of personalisation in Norway and England: On the impact of political context. Journal of Social Policy, 43(3), 479–496.

Power, A. (2013). Making space for belonging: Critical reflections on the implementation of personalised adult social care under the veil of meaningful inclusion. Social Science & Medicine, 88, 68–75.

Power, A., Lord, J., & DeFranco, A. (2014). Active Citizenship and Disability: Implementing the Personalisation of Support. Cambridge Books Online. http://dx.doi.org/10.1017/CBO9781139342711

Productivity Commission. (2008). Behavioural economics and public policy [Roundtable Proceedings]. Productivity Commission, Canberra.

Productivity Commission. (2011). Disability Care and Support: Productivity Commission Inquiry Report (Overview and Recommendations). Commonwealth of Australia.

Purcal, C., Fisher, K., & Meltzer, A. (2009). Social insurance for individualised disability support: Implementing the Australian National Disability Insurance Scheme (NDIS). In Social policy review 28: Analysis and debate in social policy.

Purcel, C., & Fisher, K. (2014). Analysing Choice in Australian Individual Funding Disability Policies. Australian Journal of Public Administration, 73(1), 88–102.

Pyett, P. (2002a). Towards reconciliation in Indigenous health research: The responsibilities of the non-Indigenous researcher. Contemporary Nurse: A Journal for the Australian Nursing Profession, 14(1), 56–65.

Pyett, P. (2002b). Working together to reduce health inequalities: Reflections on a collaborative participatory approach to health research. Australian and New Zealand Journal of Public Health, 26(4), 332–336.

Pyett, P. M., Waples-Crowe, P., & Sterren, A. E. van der. (2008). Challenging our own practices in Indigenous health promotion and research. Health Promotion Journal of Australia : Official Journal of Australian Association of Health Promotion Professionals, 19(3), 179–183. https://doi.org/10.1071/he08179

Pyett, P., Waples-Crowe, P., & van der Sterren, A. (2009). Engaging with Aboriginal communities in an urban context: Some practical suggestions for public health researchers. Australian and New Zealand Journal of Public Health, 33(1), 51–54.

Quach, E., O'Connor, D., & McGaffigan, E. (2010). Supporting people with disabilities in managing individual budgets: The role of support brokers. Professional Case Management, 15(1), 29-37 9p. cin20. https://doi.org/10.1097/NCM.0b013e3181b5ecc4

Ramcharan, P, Leighton, D & Laragy, C. (2013). *It's my choice!* Inclusion Melbourne and RMIT: Melbourne.

Retief, M., & Letšosa, R. (2018). Models of disability: A brief overview. HTS Teologiese Studies / Theological Studies, 74(1). https://doi.org/10.4102/hts.v74i1.4738

Riddell, S., Pearson, C., Jolly, D., Barnes, C., Priestley, M., & Mercer, G. (2005). The development of direct payments in the UK: Implications for social justice. Social Policy and Society, 4, 75–85.

Rioux, M., & Bach, M. (1994). Disability is not measles: New research paradigms in disability. Roeher Institute.

Roets, G., & Goodley, D. (2008). Disability, citizenship and uncivilised society: The smooth and nomadic qualities of self-advocacy. Disability Studies Quarterly, 28(4).

Rogers, E., Kash-MacDonald, M., & Brucker, D. (2009). Systematic Review of Peer Delivered Services Literature 1989 – 2009. Boston University, Center for Psychiatric Rehabilitation. http://www.bu.edu/drrk/research-syntheses/psychiatric-disabilities/peer-delivered-services/

Salisbury Forum Group, T. (2011). The Salisbury Statement. Social Work & Society, 9(1). https://www.socwork.net/sws/article/view/2

Samson, A. (ed). (2015). The behavioral economics guide 2015 (with an introduction by Dan Ariely). http://www.behavioraleconomics.com. http://www.behavioraleconomics.com

Sargeant, A., Hudson, J., & West, D. (2008). Conceptualizing brand values in the charity sector: The relationship between sector, cause and organization. The Service Industries Journal:, 28(5). https://www.tandfonline.com/doi/abs/10.1080/02642060801988142

Saunders, P. (2006). The Costs of Disability and the Incidence of Poverty. Social Policy Research Centre.

Schindler, R. M., & Bickart, B. (2004). Published Word of Mouth: Referable, Consumer-Generated Information on the Internet. Online consumer psychology: Understanding and influencing consumer behavior in the virtual world, 32, 35-61.

Schnellenbach, J. (2012). Judges and norms: On the political economy of soft paternalism. European Journal of Political Economy, 28, 266–277.

Schul, Y., & Peri, N. (2015). Influences of Distrust (and Trust) on Decision Making. Social Cognition, 33(5), 414–435. https://doi.org/10.1521/soco.2015.33.5.414

Scourfield, P. (2008). Going for Brokerage: A Task of “Independent Support” or Social Work? British Journal of Social Work, 40(3), 858–877. https://doi.org/10.1093/bjsw/bcn141

Siegrist, M., Cvetkovich, G., & Roth, C. (2000). Salient Value Similarity, Social Trust, and Risk/Benefit Perception. Risk Analysis, 20(3), 353–362. https://doi.org/10.1111/0272-4332.203034

Sim, T., Austin, M., Abdullah, F., Chan, T. M. S., Chok, M., Ke, C., Epstein, I., Fisher, M., Joubert, L., Julkunen, I., Ow, R., Uggerhøj, L., Wang, S., Webber, M., Wong, K., & Yliruka, L. (2018). The Hong Kong Statement on Practice Research 2017: Contexts and Challenges of the Far East. Research on Social Work Practice, 29(1), 3–9. https://doi.org/10.1177/1049731518779440

Smith, C. (2001). Trust and confidence: Possibilities for social work in “high modernity.” The British Journal of Social Work, 31(2), 287–305. https://doi.org/10.1093/bjsw/31.2.287

Snipes, R., Ingram, R., & Jiang, P. (2005). Information Search in Health Care Decision-Making. Journal of Hospital Marketing & Public Relations, 15(2), 33–53. https://doi.org/10.1300/J375v15n02_03

Soldatic, K., Toorn, G. van, Dowse, L., & Muir, K. (2014). Intellectual Disability and Complex Intersections: Marginalisation under the National Disability Insurance Scheme. Research and Practice in Intellectual and Developmental Disabilities, 1(1), 6–16. https://doi.org/10.1080/23297018.2014.906050

Souza, F., & Lambides, M. (2019). Fulfilling the life potential of Australians with a disability thrugh customer-directed choices. University of South Australia.

Spicker, P. (2012). Personalisation falls short. British Journal of Social Work, 1–17.

SPRU. (2000). Information needs of disabled young people. Social Policy Research Unit, University of York.

Stancliffe, R. J. (2014). Inclusion of adults with disability in Australia: Outcomes, legislation and issues. International Journal of Inclusive Education, 18(10), 1053–1063. https://doi.org/10.1080/13603116.2012.693395

Steinke, F., Fritsch, T., & Silbermann, L. (2012). A Systematic Review of Trust in Automation and Assistance Systems for Older Persons’ Overall Requirements. ETELEMED, 155–163.

Stone, E., & Priestly, M. (1996a). Parasites, pawns and partners: Disability research and the role of non-disabled researchers. British Journal of Sociology, 47(4), 699–716.

Stone, E., & Priestly, M. (1996b). Parasites, pawns and partners: Disability research and the role of non-disabled researchers. British Journal of Sociology, 47(4), 699–716.

Strauss, A., & Corbin, J. (1990). Basics of qualitative research: Grounded theory procedures and techniques. Sage.

Strauss, A., & Corbin, J. (1994). Grounded theory methodology. In Denzin, N.K. & Lincoln, Y.S (Eds.) Handbook of qualitative research (pp. 273-285), California: Sage.

Sullivan, J. (2012). Skype: An Appropriate Method of Data Collection for Qualitative Interviews? The Hilltop Review, 6(1), 54–60.

Thaler, R., & Sunstein, C. (2008). Nudge. Yale University Press.

Thill, C. (2015). Listening for policy change: How the voices of disabled people shaped Australia’s National Disability Insurance Scheme. Disability & Society, 30(1), 15–28.

Tomes, N. (2006). The Patient As A Policy Factor: A Historical Case Study Of The Consumer/Survivor Movement In Mental Health. Health Affairs, 25(3), 720–729.

Townsend, C., White, P., Cullen, J., Wright, C. J., & Zeeman, H. (2018). Making every Australian count: Challenges for the National Disability Insurance Scheme (NDIS) and the equal inclusion of homeless

Aboriginal and Torres Strait Islander Peoples with neurocognitive disability. Australian Health Review, 42, 227–229.

Tregaskis, C., & Goodley, D. (2005). Disability Research by Disabled and Non- Disabled People: Towards a Relational Methodology of Research Production. International Journal of Social Research Methodology, 8(5), 363–374. https://doi.org/10.1080/13645570500402439

Tu, H. T., & Lauer, J. R. (2008). Word of mouth and physician referrals still drive health care provider choice. Research Brief, 9, 1–8.

Tudor Edwards, R., Charles, J. M., & Lloyd-Wiliams, H. (2013). Public health economics: A systematic review of guidance for the economic evaluation of public health interventions and discussion of key methodological issues. BMC Public Health, 13.

United Nations. (2019). Convention on the Rights of Persons with Disabilities (CRPD). https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

UWA. (2019). Six years and counting: The NDIS and the Australian disability services system—A white paper. University of Western Australia.

VALID. (2019). Having a Say | VALID. https://www.valid.org.au/having-say

van Teijlingen, E., & Hundley, V. (2001). The importance of pilot studies. Social Research Update, 35. http://eprints.bournemouth.ac.uk/10149/1/SRU35_pilot_studies.pdf

Vehmas, S., & Watson, N. (2013). Moral wrongs, disadvantages, and disability: A critique of critical disability studies. Disability & Society, 29(4), 638–650. https://doi.org/10.1080/09687599.2013.831751

Victoor, A., Delnoij, D., Friele, R., & Rademakers, J. (2012). Determinants of patient choice of healthcare providers: A scoping review. Health Services Research, 12, 272.

Victorian Government. (2019). Advance statements. https://www2.health.vic.gov.au:443/mental-health/practice-and-service-quality/mental-health-act-2014-handbook/recovery-and-supported-decision-making/advance-statements

Vonk, M. E., Tripodi, T., & Epstein, I. (2007). Research Techniques for Clinical Social Workers. Columbia University Press.

Walker, G., & Bryant, W. (2013). Peer support in adult mental health services: A metasynthesis of qualitative findings. Psychiatric Rehabilitation Journal, 36(1), 28–34. https://doi.org/10.1037/h0094744

Walker, S., Eketone, A., & Gibbs, A. (2006a). An exploration of kaupapa Maori research, its principles, processes and applications. International Journal of Social Research Methodology, 9(4), 331–344.

Walker, S., Eketone, A., & Gibbs, A. (2006b). An exploration of kaupapa Maori research, its principles, processes and applications. International Journal of Social Research Methodology, 9(4), 331–344.

Walsh, S., Wilson, R., Baines, S., & Martin, M. (2012a). 'You're Just Treating Us as Informants!' Roles, Responsibilities and Relationships in the Production of Children's Services Directories. Local Government Studies, 38(5), 661–680. https://doi.org/10.1080/03003930.2012.676439

Walsh, S., Wilson, R., Baines, S., & Martin, M. (2012b). 'You're Just Treating Us as Informants!' Roles, Responsibilities and Relationships in the Production of Children's Services Directories. Local Government Studies, 38(5), 661–680. https://doi.org/10.1080/03003930.2012.676439

Waltz, M. (2012). Images and narratives of autism within charity discourses. Disability & Society, 27(2), 219–233. https://doi.org/10.1080/09687599.2012.631796

Wang, W., Wu, Y. C. J., Yuan, C.-H., Xiong, H., & Liu, W.-J. (2017). Use of Social Media in Uncovering Information Services for People with Disabilities in China. The International Review of Research in Open and Distributed Learning, 18(1). https://doi.org/10.19173/irrodl.v18i1.2621

Ward, M. (2006). The vision of the Disability Services Act 1986: A never-ending struggle. Journal of Intellectual & Developmental Disability, 31(4), 253–254.

Warr, D., Dickinson, H., Olney, S., Hargrave, J., Karanikolas, A., Kasidis, V., Ozge, J., Peters, D., Wheeler, J., & Wilcox, M. (2017). Choice, control and the NDIS. University of Melbourne.

Wellstead, A. (2019). Trusting Datification Through Labification. T07P03 - The Design of Policy, Governance and Public Service, 1–30.

WHO. (2016). Disabilities. World Health Oranisation: Health Topics: Disabilities. http://www.who.int/topics/disabilities/en/

Wiesel, I., & Bigby, C. (2015). Movement on Shifting Sands: Deinstitutionalisation and People with Intellectual Disability in Australia, 1974–2014. Urban Policy and Research, 33(2), 178–194. https://doi.org/10.1080/08111146.2014.980902

Williams, I., & Dickinson, H. (2016). Going It Alone or Playing to the Crowd? A Critique of Individual Budgets and the Personalisation of Health Care in the English National Health Service. Australian Journal of Public Administration, 75(2), 149–158. https://doi.org/10.1111/1467-8500.12155

Williams, I., Dickinson, H., & Robinson, S. (2010). Joined-up Rationing? An Analysis of Priority Setting in Health and Social Care Commissioning. Journal of Integrated Care, 9(1), 3–11.

Williams, T. M., & Smith, G. P. (2014). Can the National Disability Insurance Scheme work for mental health? Australian & New Zealand Journal of Psychiatry, 48(5), 391–394. https://doi.org/10.1177/0004867414530007

Willis, K., Collyer, F., Lewis, S., Gabe, J., Flaherty, I., & Calnan, M. (2016). Knowledge matters: Producing and using knowledge to navigate healthcare systems. Health Sociology Review, 25(2), 202–216. https://doi.org/10.1080/14461242.2016.1170624

Wilson, W. R., & Peterson, R. A. (1989). Some Limits on the Potency of Word-Of-Mouth Information. ACR North American Advances, NA-16. http://acrwebsite.org/volumes/6874/volumes/v16/NA-16

Zhao, M., Haley, D. R., Spaulding, A., & Balogh, H. A. (2015). Value-based purchasing, efficiency, and hospital performance. Health Care Manag (Frederick), 34(1), 4–13. https://doi.org/10.1097/HCM.0000000000000048

# 12 Appendices

## 12.1 Ethics approval

Dear Associate Professor Dickinson

I am pleased to advise that the Humanities and Applied Sciences Human Ethics Sub-Committee has approved the following project:

Project Title: Diversity in decision-making: Codesigning informed choice under the National Disability Insurance Scheme
Researchers: A/Prof H Dickinson, A Beecher Kelk, and Prof L B Joubert
Ethics ID: 1646976

The project has been approved for the period: 09-Sep-2016 to 31-Dec-2016

A signed letter confirming this approval will be forwarded to you shortly.

It is your responsibility to ensure that all people associated with the project are made aware of what has actually been approved.

Research projects are normally approved to 31 December of the year of approval. Projects may be renewed yearly for up to a total of five years upon receipt of a satisfactory annual report. If a project is to continue beyond five years, a new application will normally need to be submitted.

Please note that the following conditions apply to your approval. Failure to abide by these conditions may result in suspension or discontinuation of approval and/or disciplinary action.

(a) Limit of Approval: Approval is limited strictly to the research as submitted in your project application.

(b) Variation to Project: Any subsequent variations or modifications you might wish to make to the project must be notified formally to the Human Ethics Sub-Committee for further consideration and approval. If the Sub-Committee considers that the proposed changes are significant, you may be required to submit a new application for approval of the revised project.

(c) Incidents or Adverse Effects: Researchers must report immediately to the Sub-Committee anything which might affect the ethical acceptance of the protocol including adverse effects on participants or unforeseen events that might affect continued ethical acceptability of the project. Failure to do so may result in suspension or cancellation of approval.

(d) Monitoring: All projects are subject to monitoring at any time by the Human Research Ethics Committee.

(e) Annual Report: Please be aware that the Human Research Ethics Committee requires that researchers submit an annual report on each of their projects at the end of the year, or at the conclusion of a project if it continues for less than this time. Failure to submit an annual report will mean that ethics approval will lapse.

(f) Auditing: All projects may be subject to audit by members of the Sub-Committee.

If you have any queries on these matters, or require additional information, please contact me using the details below.

Please quote the ethics ID number and the title of the project in any future correspondence.

On behalf of the Sub-Committee, I wish you well in your research.

## 12.2 Plain language statement and consent

THE UNIVERSITY OF
MELBOURNE

### SCHOOL OF SOCIAL WORK

### Diversity in Decision-Making

Hello! You’re invited to participate in research for a PhD at the University of Melbourne.

**What is the research about?**
This research is about how people decide which disability service provider to use. It is important because the National Disability Insurance Scheme (the NDIS) is starting this year, and there are 460,000 people with disability and their families who will have to decide which disability service provider to use. Most of those people have never had to choose before, and there isn’t much information available that helps people choose which service provider to use.

We want to talk to people who have already decided which service provider to use through the National Disability Insurance Scheme (NDIS), Transport Accident Commission (TAC), Workcover or Individual Support Package (ISP) about how they decided and how they would advise others to decide. We will talk with about 250 people altogether. We hope that we will be able to create some information that helps people know how to choose a service provider.

**What will you need to do?**
If you agree to participate in the project, we will ask you to have an interview. We will talk for between 30 minutes and 1 hour. We can talk at the University of Melbourne or somewhere else you feel comfortable.

Your answers won’t be shared with your service provider or the NDIS, TAC, Workcover or ISP. Nothing you say will change your relationship with the researchers, the University of Melbourne or your service provider. We can talk to find a suitable time and place for the interview. You are welcome to bring family members or carers with you.

During the interviews, we will take some handwritten notes and record what you say on a voice recorder that will transcribed afterwards. You will be able to pause or stop the interview at any time.

**How will your confidentiality be protected?**
We will record our conversation so that we can remember what we said afterwards and listen to it again. We will also transcribe what was said into a Microsoft Word document. We will keep the recordings and documents on a computer that is password protected. We will keep them for at least five years, in line with the University of Melbourne’s data storage policy, at which time they may be securely destroyed if they are no longer useful.

We will make every effort, within the limits of the law, to protect your confidentiality. If you tell us something that's dangerous or illegal, we may have to tell the police or someone else about what you've said. All interviews and discussions conducted for the project will be anonymous, and we will use made-up names when we talk about and publish the findings. However, it is possible that your data may be subject to subpoena, freedom of information or mandatory reporting. It is also possible that people familiar with your individual circumstances may guess your identity in our final research report.

**How will the information be used?**
We will write some articles about what we find out. We will publish the articles in academic journals and on the internet. We will also write a thesis that will become a PhD.

**Do I have to take part?**
No! Participating in this research is completely voluntary. If at any time during the process you do not wish to continue, you can tell the researcher you want to withdraw and your interview or involvement in a discussion will end. You may also withdraw your consent to participate in the project at any time after the interview.

The University of Melbourne Human Research Ethics Committee has approved this research. If you're worried about this project or something we've done at any point, you can call the Executive Officer, Human Research Ethics, The University of Melbourne on 8344 2073 or fax them on 9347 6739.

**Feedback:**
You can get a copy of the transcript of your interview on request by contacting Aviva Beecher Kelk via email at avivabk@student.unimelb.edu.au. If you like, Aviva will also give you a summary of the research findings at the conclusion of the project. You will have the option to give feedback at that point. Aviva can also provide links to copies of publications resulting from this research. The research summary can be provided in an accessible format to people with vision impairment on request.

**This research is being conducted by:**

Aviva Beecher Kelk
Melbourne Social Equity Institute
University of Melbourne, Vic 3010
avivabk@student.unimelb.edu.au

Prof. Lynette Joubert
School of Social Work
University of Melbourne, Vic 3010
ljoubert@unimelb.edu.au

A/Prof Helen Dickinson
School of Government
University of Melbourne, Vic 3010
helen.dickinson@unimelb.edu.au

**Who can I call if I want some more information?**
If you have any questions or concerns about the research, please contact Aviva Beecher Kelk by email at avivabk@student.unimelb.edu.au.

**Consent:**
Before you participate in the research, we will explain what is involved. If you need assistance to understand what is involved, that assistance can be provided on request. You will be asked to verbally consent to participating in the research and your answer will be recorded. Your verbal, recorded consent indicates that you understand the nature of the research and that you are a willing participant. The interview questions are not intrusive, but there is a risk that talking about your disability or experience accessing services may cause you some distress or discomfort. If you are uncomfortable about the discussion or the interview environment at any time during the interview, please let the interviewers know.

If you need support after the interview or focus group, you can contact any of these helplines:

- Lifeline (13 11 14)
- Reachout (www.reachout.com)
- BeyondBlue (1300 22 4636)
- Headspace/Kids helpline for anyone under 25 (1800 55 1800)
- Mindspot (1800 61 44 34)
- Black Dog online forums (https://www.blackdoginstitute.org.au/getting-help/black-dog-clinical-services/our-support-groups)
- SANE (1800 18 7263)
- Carer helpline (1300 554 660)

**What should I do next?**
Please send us an email or give us a call if you want to talk to us about anything to do with this project.

If you would like to participate, please tell us that you've read and understood this information by signing the consent form on the front page.

Sincerely,

Aviva Beecher Kelk

Doctoral Researcher
School of Social Work
University of Melbourne

THE UNIVERSITY OF
MELBOURNE

## SCHOOL OF SOCIAL WORK
## Diversity in decision-making

Name of participant:
Name of person providing decision-making support (if applicable):
Name of researchers: LYNETTE JOUBERT, HELEN DICKINSON, AVIVA BEECHER KELK
Date:

1. I consent to participate in this project. The details have been explained to me, and I have been given a written plain language statement to keep.
2. I understand that my verbal consent will be recorded and will be retained by the researchers.
3. I understand that after I sign and return this consent form, it will be retained by the researcher.
4. I understand that my participation will involve an ***interview/focus group***, and I agree that the researcher may use the results as described in the plain language statement.
5. I acknowledge that:

(a) the possible effects of participating in the ***interview/focus group*** have been explained to my satisfaction;

(b) I have been informed that I am free to withdraw from the project at any time without explanation or prejudice and to withdraw any unprocessed data I have provided;

(c) the project is for the purpose of research;

(d) I have been informed that the confidentiality of the information I provide will be safeguarded subject to any legal requirements;

(e) I have been informed that, with my consent, the ***interview/focus group*** will be audio-taped, and I understand that audio-tapes will be securely stored;

(f) my name will be referred to by a pseudonym in any publications arising from the research; and

(g) a summary of the research findings will be made available to me.

I wish to give feedback on the draft of the project report on research findings ☐ **yes** ☐ **no**

This participant verbally consents to participate in this research: YES NO

Participant signature: Date:

## 12.3 Appendix 3: Interview schedule

### 12.3.1 Demographic information collected

| | | | |
|---|---|---|---|
| Age | | Funding schemes your participants have used (circle) | NDIS<br>Workcover<br>TAC<br>DHHS ISP<br>Private<br>Fee-for-service |
| Gender | | | |
| Postcode | | | |
| Relationship to consumer | | | |
| Age of consumer | | | |

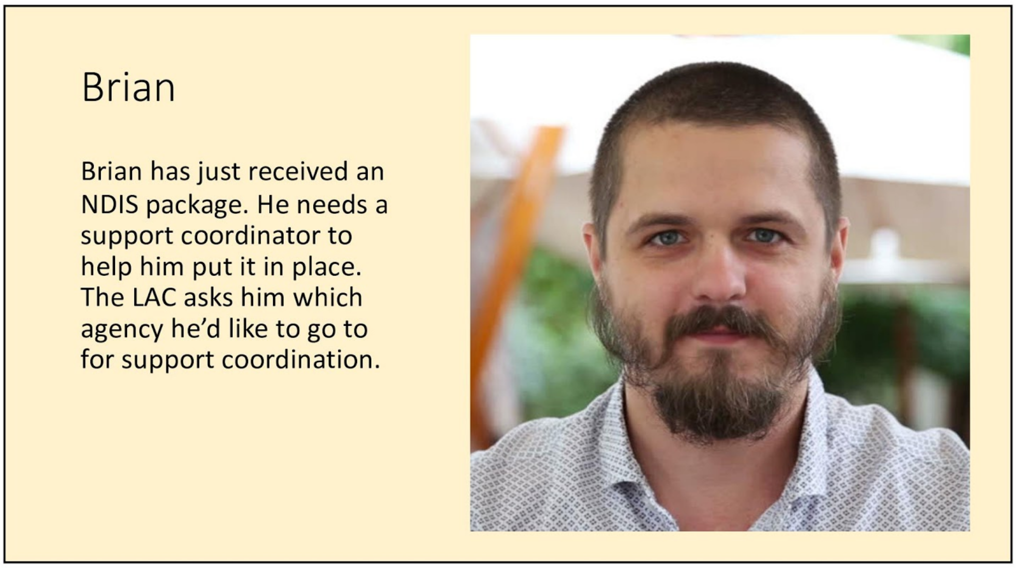
### 12.3.2 Preparation: Technical language

1. National Disability Insurance Scheme (NDIS)
2. Package
3. Local Area Coordinator (LAC)
4. Support Coordinator
5. Occupational therapist (OT)
6. Agencies

### 12.3.3 Questions to be asked about each scenario

1. What should they ask to help them decide? Who should they ask?
2. What other things should they do to help them decide?
3. All things being equal, which should they choose?
4. Do you have any other advice for them?

### 12.3.4 Scenario 1



Brian

Brian has just received an NDIS package. He needs a support coordinator to help him put it in place. The LAC asks him which agency he'd like to go to for support coordination.

### 12.3.5 Scenario 2

**Naomi**

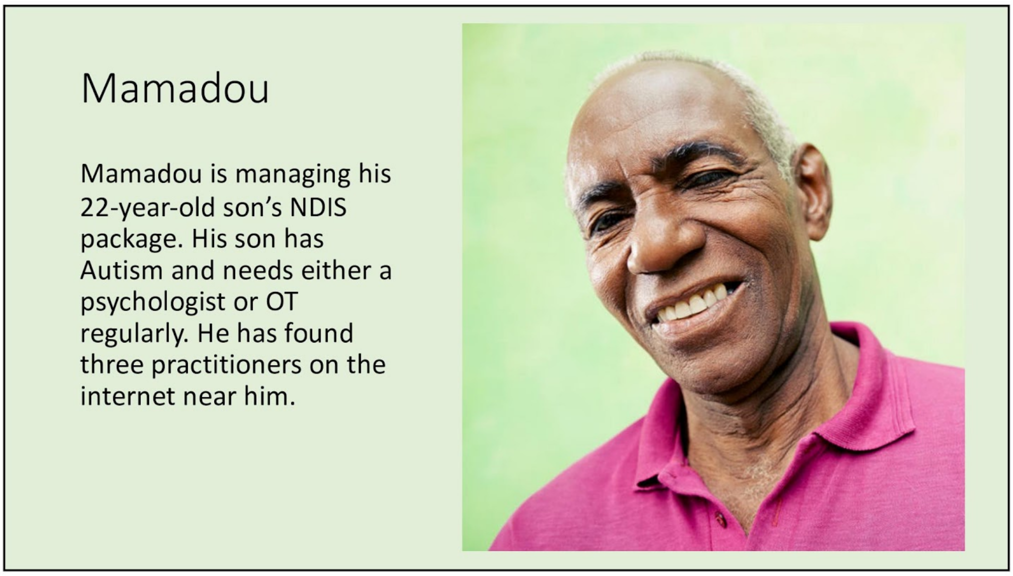
Naomi has an NDIS package. She uses a wheelchair and needs someone to help her to get in and out of bed each morning and evening. Her support coordinator tells her there are three agencies in her area she can choose between.

### 12.3.6 Scenario 3

**Lim**

Lim uses a wheelchair. As part of her NDIS funding, she's going to get a new chair so she can do the sport she loves. Lim has recommendations from three of her team mates for three different equipment providers.

### 12.3.7 Scenario 4



Mamadou

Mamadou is managing his 22-year-old son’s NDIS package. His son has Autism and needs either a psychologist or OT regularly. He has found three practitioners on the internet near him.

### 12.3.8 Further questions from the interview schedule

Reflection on scenarios

- What came up?
- Who are there most ideas about? Why is that?
- What are the themes?

Desirability of sources

1. Rank the potential sources of information in terms of desirability.
2. What’s making each one more or less desirable?

Reflection on the whole interview

- Who was it easiest to give advice to? Why? Which of them did you most identify with?
- Have you had to decide between service providers? How did you decide?
- What advice do you wish you had when you were deciding? What information did you have? What information do you wish you’d had?
- For example, expos, pamphlets, websites, testimonials, YouTube, Facebook groups, Facebook business pages.
- Who was there? Who do you wish was there? Who gave you information and which was most valued or trusted, e.g. GP, case manager, friend, or advocate.
- Is there anything else you’d like to tell me?

Debriefing questions

- What did you learn?
- What else are you taking with you?
- What are you curious to know from the research?

## 12.4 Post-it images

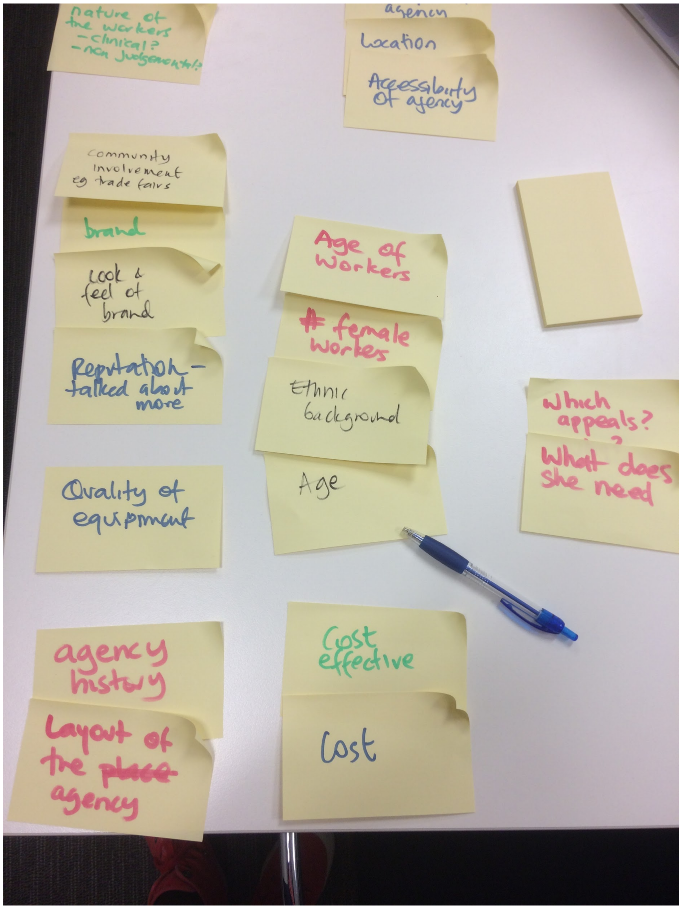


*Figure 41: Post-it notes from the semi-structured interviews conducted in person*

*Figure 42: E-post-it notes from the semi-structured interviews conducted online*

## 12.5 Survey (including PLS)

### Feeling informed about choosing disability services

*Hello! My name is Aviva. I'm doing a PhD at the University of Melbourne. I aim to find out what information people want to help them choose disability services so that I can help to make it easier to navigate the NDIS. This survey has 10 questions and will take about 10 minutes. If you want more information, keep reading. If you're ready to start, scroll down and get going!*

**What is this research about?**
This research is about how people decide which disability service provider to use. It is important because the National Disability Insurance Scheme (the NDIS) is starting this year, and there are 460,000 people with disability and their families who will have to decide which disability service provider to use. Most of those people have never had to choose before, and there isn't much information available to help people choose which service provider to use. We hope that we will be able to create some information that helps people know how to choose a service provider.

**What will you have to do?**
We will ask you to do a 10-minute online survey, which you can do on any computer or mobile device that has an internet connection.

**How will we use your data?**
Your answers won't be shared with your service provider or the NDIS, TAC, Workcover or ISP. Nothing you write will change your relationship with the researchers, the University of Melbourne or your service provider. You are welcome to ask carers or support workers to help you. You can stop doing the survey at any time.

Your answers will be stored online through SurveyMonkey. SurveyMonkey doesn't use your answers at all, although they do collect information about how you came to their website, what kind of computer or mobile you're using and your IP address.

We will keep the records on a computer that is password protected. We will keep them for at least five years in line with the University of Melbourne's data storage policy, at which time they may be securely destroyed if they are no longer useful.

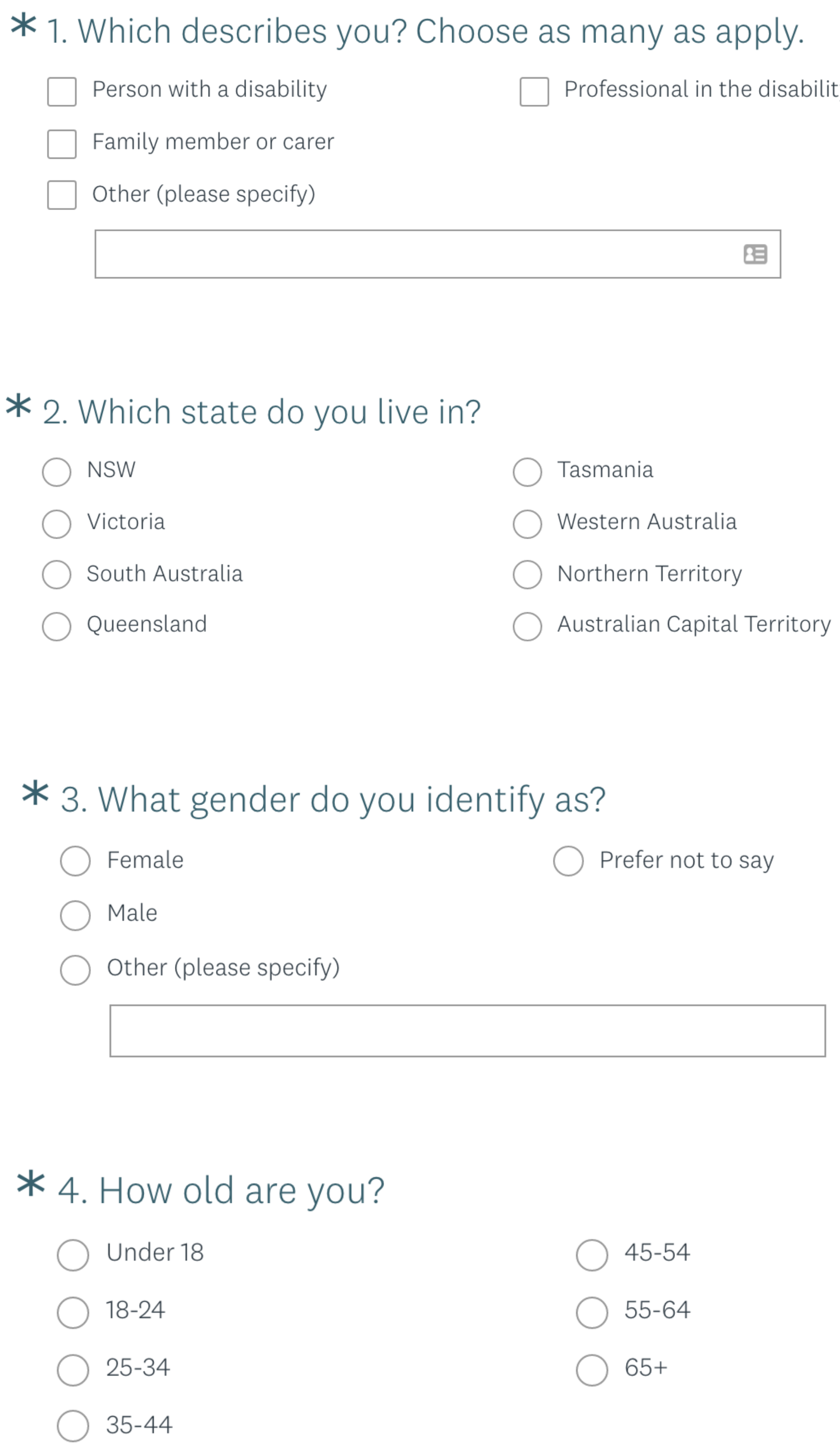
We will make every effort, within the limits of the law, to protect your confidentiality. All surveys are anonymous, and we will use made-up names when we talk about and publish the findings. However, it is possible your data may be subject to subpoena, freedom of information or mandatory reporting. It is also possible that people familiar with your individual circumstances may guess your identity in our final research report.

**Where will this research be published?**
We will write some articles about what we find out. We will publish the articles in academic journals and on the internet. We will also write a thesis that will become a PhD.

**Where should you go with questions or concerns?**
The University of Melbourne human research ethics committee has approved this research. If you're worried about this project or something we've done at any point, you can call the Executive Officer, Human Research Ethics, The University of Melbourne on 8344 2073 or fax them on 9347 6739.

If you have any questions or concerns about the research, or you'd like a copy of the results of the survey, contact me via email at avivabk@student.unimelb.edu.au. I can also provide links to copies of publications resulting from this research. The research summary can be provided in an accessible format to people with vision impairment on request.

By continuing with the survey, you give your consent to participate in this research. Participating is completely voluntary.



* 1. Which describes you? Choose as many as apply.

☐ Person with a disability
☐ Family member or carer
☐ Other (please specify)
☐ Professional in the disability sector

* 2. Which state do you live in?

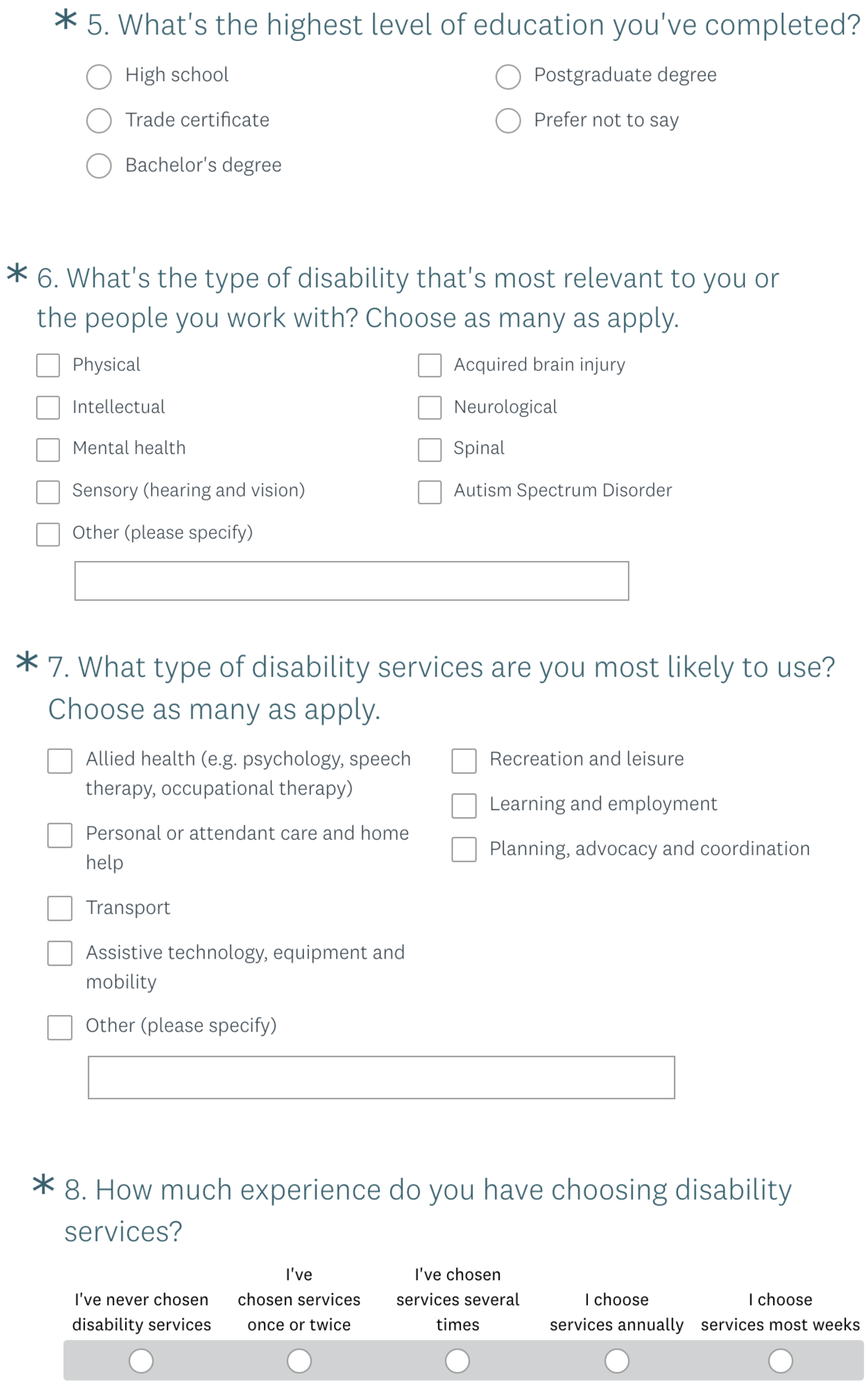
○ NSW
○ Victoria
○ South Australia
○ Queensland
○ Tasmania
○ Western Australia
○ Northern Territory
○ Australian Capital Territory

* 3. What gender do you identify as?

○ Female
○ Male
○ Other (please specify)
○ Prefer not to say

* 4. How old are you?

○ Under 18
○ 18-24
○ 25-34
○ 35-44
○ 45-54
○ 55-64
○ 65+



* 5. What's the highest level of education you've completed?

○ High school
○ Trade certificate
○ Bachelor's degree
○ Postgraduate degree
○ Prefer not to say

* 6. What's the type of disability that's most relevant to you or the people you work with? Choose as many as apply.

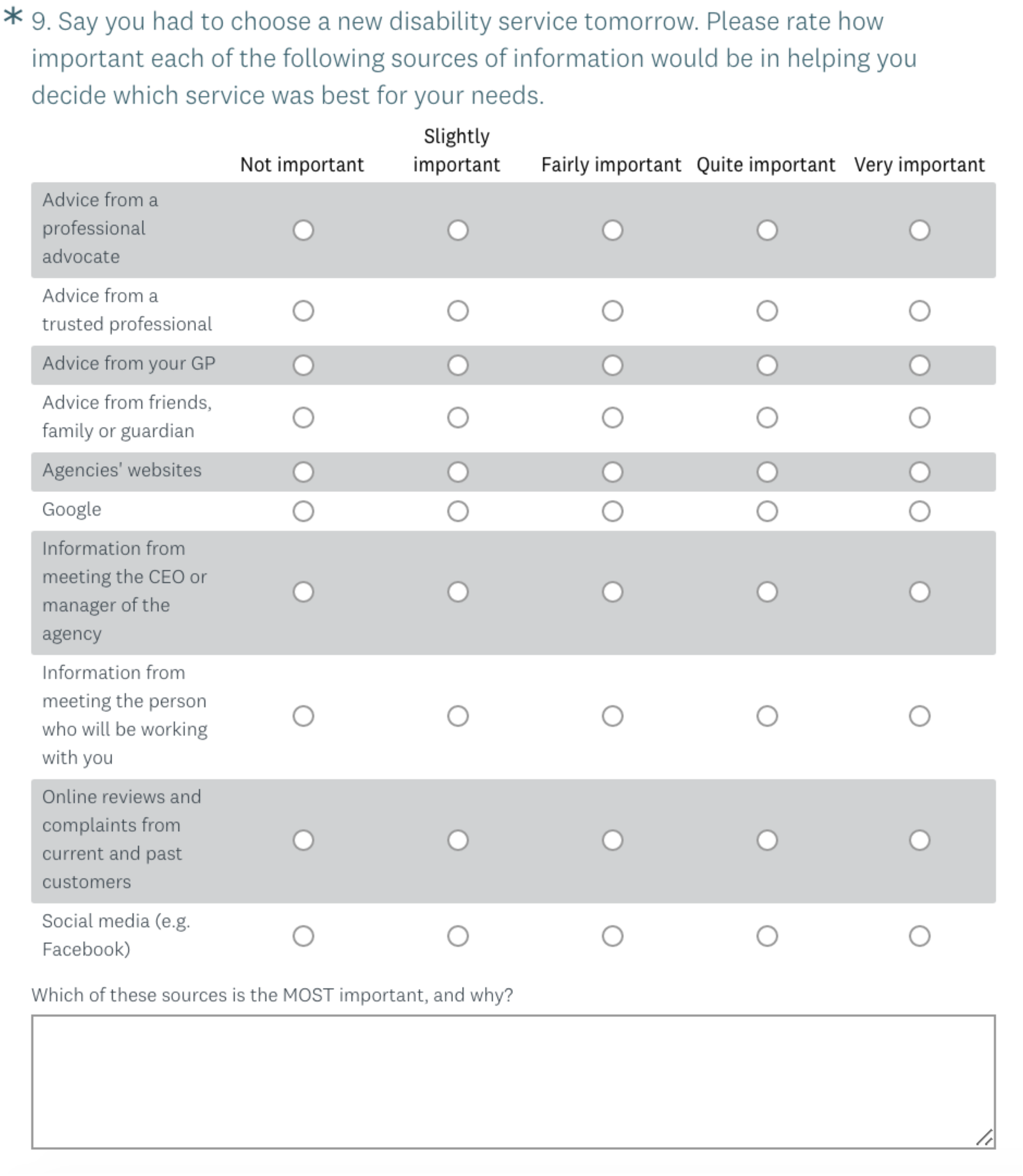
☐ Physical
☐ Intellectual
☐ Mental health
☐ Sensory (hearing and vision)
☐ Other (please specify)
☐ Acquired brain injury
☐ Neurological
☐ Spinal
☐ Autism Spectrum Disorder

* 7. What type of disability services are you most likely to use? Choose as many as apply.

☐ Allied health (e.g. psychology, speech therapy, occupational therapy)
☐ Personal or attendant care and home help
☐ Transport
☐ Assistive technology, equipment and mobility
☐ Other (please specify)
☐ Recreation and leisure
☐ Learning and employment
☐ Planning, advocacy and coordination

* 8. How much experience do you have choosing disability services?

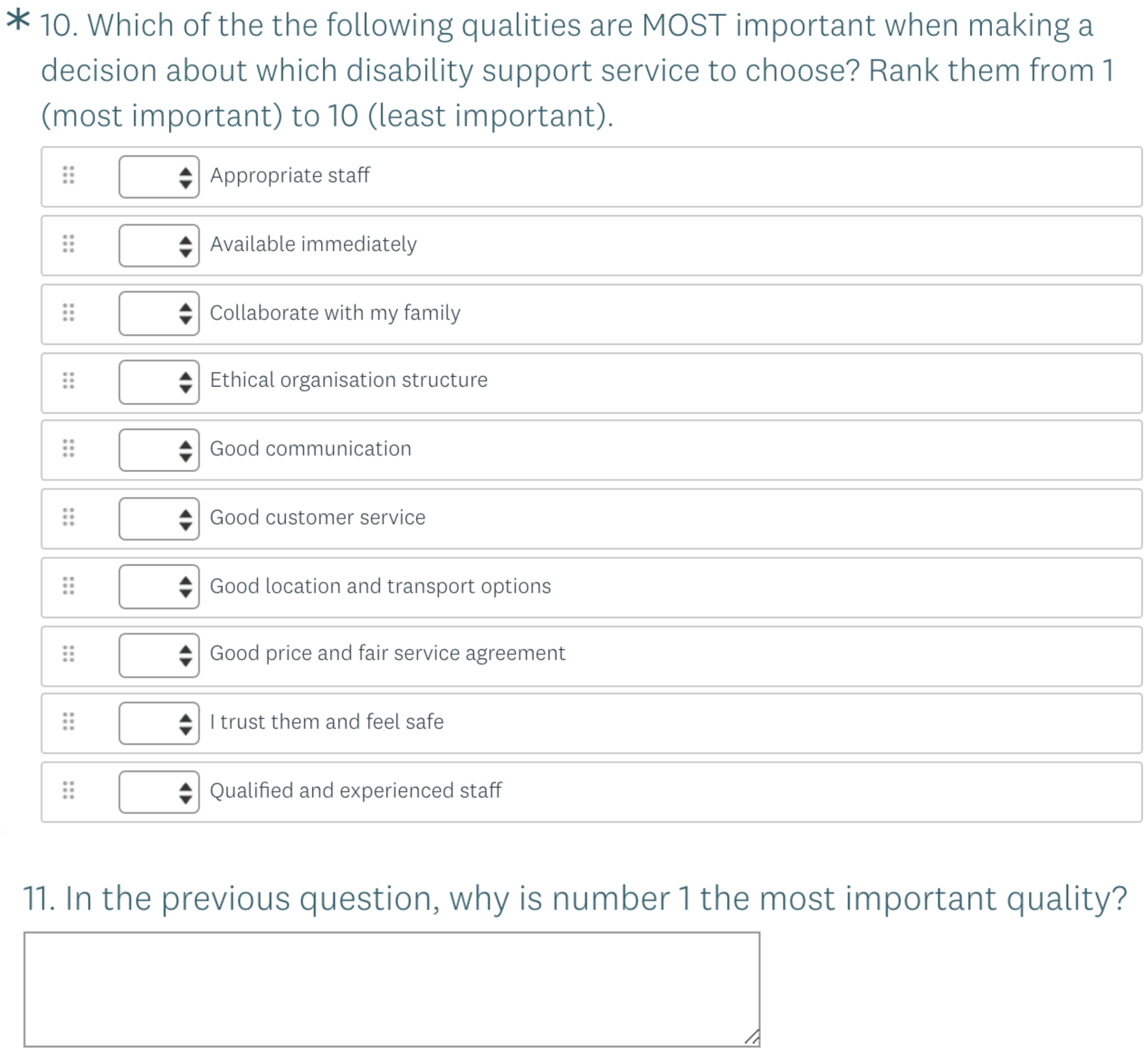
| I've never chosen disability services | I've chosen services once or twice | I've chosen services several times | I choose services annually | I choose services most weeks |
|---|---|---|---|---|
| ○ | ○ | ○ | ○ | ○ |



* 9. Say you had to choose a new disability service tomorrow. Please rate how important each of the following sources of information would be in helping you decide which service was best for your needs.

| | Not important | Slightly important | Fairly important | Quite important | Very important |
|---|---|---|---|---|---|
| Advice from a professional advocate | ○ | ○ | ○ | ○ | ○ |
| Advice from a trusted professional | ○ | ○ | ○ | ○ | ○ |
| Advice from your GP | ○ | ○ | ○ | ○ | ○ |
| Advice from friends, family or guardian | ○ | ○ | ○ | ○ | ○ |
| Agencies' websites | ○ | ○ | ○ | ○ | ○ |
| Google | ○ | ○ | ○ | ○ | ○ |
| Information from meeting the CEO or manager of the agency | ○ | ○ | ○ | ○ | ○ |
| Information from meeting the person who will be working with you | ○ | ○ | ○ | ○ | ○ |
| Online reviews and complaints from current and past customers | ○ | ○ | ○ | ○ | ○ |
| Social media (e.g. Facebook) | ○ | ○ | ○ | ○ | ○ |

Which of these sources is the MOST important, and why?



* 10. Which of the the following qualities are MOST important when making a decision about which disability support service to choose? Rank them from 1 (most important) to 10 (least important).

- Appropriate staff
- Available immediately
- Collaborate with my family
- Ethical organisation structure
- Good communication
- Good customer service
- Good location and transport options
- Good price and fair service agreement
- I trust them and feel safe
- Qualified and experienced staff

11. In the previous question, why is number 1 the most important quality?

## 12.6 Phase 4 reflection for interview participants

Hi there,

I'm writing to update you on how my research is going. This document is seven pages long, but it only contains 800 words.

You don't have to read or respond to this, but you can if you like. I'd be interested to hear what you think. Any comments you send me will shape the way I write about what I'm learning.

I've finished all my workshops. I've put some information here about what I found and how I've made sense of it.

There is a short page on each of the following:

1. Summary of the workshop I did with you
2. Sources of information
3. Correlation between the sources and demographics
4. Ranking of the sources
5. Definition of "desirable" information
6. Themes that came out

I've asked you what you think on each page. There's no right answer!

Feel free to get in touch if you want to ask anything or make any comments.

Cheers,

Aviva

### SUMMARY

Just to remind you what we did… I showed you a series of people who had some choices to make on their NDIS journey.

I asked you some of these questions about each of these people:

- What should they ask to help them decide? Who should they ask?
- What other things should they do to help them decide?
- All things equal, which should they choose?
- Do you have any other advice for them?

Then I asked you:

- To cluster your answers into groups;
- To rank the top three ways you'd like to get information in an ideal world;
- Who it was easiest to advise; and
- What, if anything, you learned while we were speaking?

### SOURCES

I ran this workshop with 23 people in total. Between everyone, 72 sources of information were mentioned! Wow! Lots of them were similar, so I condensed them into a list of 29, which is below. What do you think about this list?

**Condensed list of sources**

1. Broker
2. GP
3. Professional
4. Advocate/support person
5. Professional network
6. Other clients
7. Friends/family/guardian/word of mouth
8. Expos
9. Social media
10. Google
11. Agency websites
12. NDIS lists
13. Email me info
14. Official awards
15. Reviews & complaints
16. Literature
17. Multi-criteria decision-making tool
18. Existing relationships
19. Call the agency
20. Interview management
21. Meet the frontline worker
22. Trial
23. Visit
24. Workshop
25. Post me info
26. Brochure
27. Community notice board
28. Brand
29. Service agreements

## CORRELATION

I talked to several consumers, carers and people who work in the disability sector. I asked you about how much experience you had choosing services before, and I also asked you about your level of education. I looked at how many sources of information were mentioned, and I broke it down to see if any of these things affected how many ways of finding information you could think of.

I've put that in the graph below. It looks like professionals who do this work every day find it easier to think of ways of getting information. It looks like more experience makes it easier. It looks like more education also makes it easier.

What do you think?

## RANKING

I asked you to rank your top three ways of getting information. The graph below shows the top 10 that were ranked as a group.

I'm not surprised that the most trusted source was word of mouth, but I am surprised at how much more trusted it is by the group. These statistics as well as a lot of your comments suggest to me that, as a community, we would rather get (and give) advice from people we think are like us – even if we don't know them sometimes – than from a professional.

What do you think?

### DEFINITION

I wanted to make a definition about what makes a source of information "desirable". I looked at all the words you used to tell me why you chose your top three sources of information. I wrote this definition:

*Information that is trusted and reliable due to the confidence the recipient has in the genuine similarity of the giver's life experiences to their own, and therefore in the relevance of the giver's perspective, values and opinions.*

What do you think? Does that seem right and true to you?

### THEMES

I also examined what you said you wanted to know when you looked at the different sources of information. I found 72 things! I condensed them into 10 groups. This list is below, ordered alphabetically.

1. Appropriate staff
2. Availability
3. Costs and contracts
4. Customer centricity
5. Empowerment and collaboration
6. Location, access and delivery
7. Organisational structure
8. Relevant clinical qualification and expertise
9. Responsive, reliable communication
10. Trust and safety

Do you have any thoughts about these themes?

## 12.7 Social media recruitment – interview

I'm looking for consumers, carers, family members and case managers to talk to me about choosing disability and mental health service providers! It's for my PhD research. We can do this any Friday in August, and there's a $30 Coles gift voucher in it for you... contact me for more info.

## 12.8 Social media recruitment – survey

I'm nearly finished* my PhD! Woohooo! I'm researching what information people want to help them choose disability or mental health services under the NDIS.

I'd love your help with a survey. It has 11 questions and takes about 10 minutes. It's here: https://lnkd.in/e4cDE2U

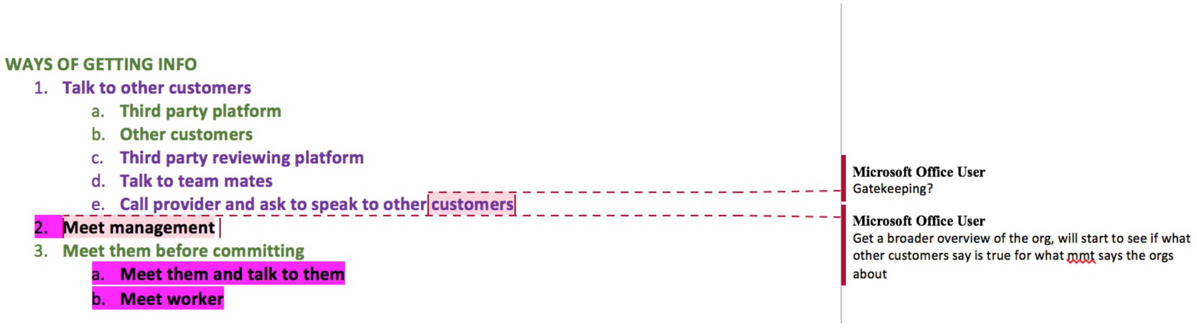
People with disability, family members, carers, support workers and anyone else who's involved in choosing services are invited to respond.

Could you help me by filling it in, sharing it with a relevant group or tagging a friend who could help?

Watch this space to hear what I find out.

* You know, give or take two years.

## 12.9 Image from thematic collection



WAYS OF GETTING INFO

1. Talk to other customers
    a. Third party platform
    b. Other customers
    c. Third party reviewing platform
    d. Talk to team mates
    e. Call provider and ask to speak to other customers
2. Meet management
3. Meet them before committing
    a. Meet them and talk to them
    b. Meet worker

**Microsoft Office User**
Gatekeeping?

**Microsoft Office User**
Get a broader overview of the org, will start to see if what other customers say is true for what mmt says the orgs about

*Figure 43: Analysis of the top three themes from the semi-structured interviews conducted online*

## 12.10 All sources (clustered by medium)

1. Interpersonal (n=17)
    a. WOM
    b. Broker
    c. GP
    d. Professional
    e. Advocate
    f. Support person
    g. Professional Network
    h. Other clients
    i. Friends/family/guardian
    j. Expos
    k. Call
    l. Interview management
    m. Existing relationships
    n. Meet worker
    o. Trial
    p. Visit
    q. Workshops
2. Online (n=8)
    a. Social media
    b. Google
    c. Websites
    d. Email me a pack
    e. NDIS lists
    f. Complaints
    g. Reviews
    h. Awards
3. Physical media (n=3)
    a. Post a pack
    b. Brochure
    c. Community notice board
4. Value-based information (n=3)
    a. Brand
    b. Company values
    c. Service agreements
5. Literature (n=1)
6. Multi-criteria decision-making tool (n=1)

## 12.11 Full list of themes and sub themes

1. Responsive and reliable communication
2. Appropriate staff
    a. Qualification and training
    b. Age, gender and ethnicity
    c. Personality and interest match
    d. Can I choose my own worker?
    e. Can I control my own roster?
    f. Are there enough staff in the pool?
    g. What's the workforce strategy?
    h. Workers' rights
3. Clinical qualification
    a. Specialist
    b. Experience
    c. Have sector knowledge
    d. Ask the right questions
    e. Demonstrate their knowledge
    f. Clinical approach
    g. Understand the system/s they work in (incl. NDIS)
    h. Have awards and comply with standards
4. Organisational structure
    a. For profit/NFP
    b. Size of organisation
    c. Age of organisation
    d. Vibe, brand, image and presentation
    e. Private/sole trader/clinic/agency
5. Customer-centric
    a. What are the consumer's preferences?
    b. Consistent
    c. Flexible, responsive and personalised
    d. Easy referral/intake process
    e. Innovative
    f. Establish and meet expectations
    g. Achieve outcomes/goals
    h. Meet my needs
    i. Clarify my needs
    j. What happens when my needs change?
    k. Emergency plans
    l. What won't the staff do (e.g. physical, cultural or religious limitations)?
6. Location, access and delivery
    a. Local
    b. Delivery location
    c. IT systems (e.g. billing and scheduling)
    d. Access/transport
    e. You come to me or I come to you
7. Time boundaries
    a. Timeframe of working relationship
    b. Hours of availability (incl. weekend/after hours)
    c. Can I make changes within 24 hours of my booking
    d. Short delivery timeframe (e.g. waiting lists)

    e. Minimum shift times
    f. Waiting lists
8. Costs and constraints
    a. Price
    b. Value for money
    c. What else can they offer?
    d. Packages/discounts
    e. Ease/cost to change contract
    f. Cancellation and/or exclusion policy (e.g. miss three and you're out)
    g. Post-sale support (e.g. with equipment)
9. Empowerment and collaboration
    a. Help me understand the system
    b. Deal with and educate the whole family, not just PWD
    c. Increase my independence or just give me a service?
    d. Consumer participation: Can I get involved in the org?
    e. Openness to feedback and complaints procedure
    f. Give good referrals
    g. Collaborate with other agencies and external workers
    h. Quality reports for me and funder (e.g. NDIA)
10. Trust and safety
    a. Trust
    b. My comfort level
    c. Going above and beyond
    d. Feel heard, understood and respected
    e. Bias/competing interests
    f. Reputation
    g. Organisation's values

**Author/s:**
Beecher Kelk, Aviva Elisabeth

**Title:**
Informing NDIS market stewardship through consumers' information preferences: An exploratory study

**Date:**
2020

**Persistent Link:**
http://hdl.handle.net/11343/241405

**File Description:**
Final thesis file