School of Management and Marketing
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Creating NDIS Impact -
Getting the Right Mix of Choice and Control in Australia's Disability Sector

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Declaration

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007) – updated March 2014. The proposed research study received human research ethics approval from the Curtin University Human Research Ethics Committee (EC00262), Approval Number #HRE2018-0653.

Signature: ....

Date: 22 April 2024

ABSTRACT

The research explored the inherent promise in the NDIS of choice and control for people with disabilities and assessed whether it was being delivered and what governance practices could assist it being realised.

The thesis explored how people with disabilities made decisions about themselves, and about the services they accessed, and considered popular governance frameworks in use by service providers to incorporate the voice and views of people with a lived experience of disability.

The research incorporated a mixed methods approach with a quantitative component using surveys and a qualitative component using interviews. Not surprisingly it found a level of confusion exists about governance and what it constitutes. The research also found a level of ambiguity in relation to terminology about people, and assumptions about the function they perform in the marketplace.

The recommendations provided some tangible tools to use in governance to overcome the ambiguity by clarifying the purpose of engagement with people with disability and better describing the level of power they can expect to exert in decision-making. The research also included recommendations for application in the disability sector, as well as in sectors working primarily with other cohorts of vulnerable and/or marginalised peoples.

Ultimately the research found that involvement of people with disabilities in decisions that impact upon them, and in the broader governance of services they access and policies they respond to, will be a key success factor in them achieving the outcomes they desire in life and creating the impact the NDIS has always promised.

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This thesis, like all, has required dedication and commitment from not only the student researcher, but all of those around him. As that student researcher, and author of this thesis, I take this small opportunity to acknowledge those who helped me through the journey.

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1. Contents

PREFACE

I have worked for many years in the Australian Indigenous Affairs sector. Initially working as a public servant in the Aboriginal and Torres Strait Islander Commission (ATSIC), I was later promoted to work in the Commonwealth Department of Health and Ageing. With this transition to the health sector, I found further career progression after leaving the Public Service within the not-for-profit sector.

This experience took me through numerous regional towns in Australia (Kalgoorlie 1994-98, Port Hedland 1998-2002, Alice Springs 2002-2005, Broome 2006-2011). It was at this point in 2011 that I decided to return to the city and take up a position with a large not-for-profit organisation, Therapy Focus. This also saw a change from the health sector to the disability sector.

It was not long before I drew parallels between sectors. In Indigenous Affairs, I heard Aboriginal leaders pleading with bureaucrats to “do it with us, not for us” and in the disability sector, the cry was to do “nothing about us without us”. This is where the itch started and grew from. To look into why people, deemed vulnerable by societal rhetoric, should feel so disempowered as to be pleading for a say in matters that affected them.

With so much excitement and promise associated with the inception of the National Disability Insurance Scheme (NDIS) in Australia, I thought the time was right to scratch that itch. Using the NDIS as a case study, I wanted to determine if there was evidence of the changes actually empowering people and delivering lasting improvements in care. The promise of choice and control for people with disabilities led me to ask the Research Question “Which governance frameworks are effective at empowering people with disabilities to access care services in the community?”

Along my professional journey, I found the public participation spectrum IAP2 Spectrum | IAP2 Australasia (IAP2 2020) whilst working in general practice supports in the Kimberley region. The Spectrum resonated with me due to its simplicity and versatility and made sense to me in how to engage with both General Practitioners as well as members of the public. It offered a structured framework to guide involvement of members of the public in the design, planning, implementation and evaluation of health services. This was particularly important for me working in a remote region with a high population of Aboriginal people to whom English was a second language and Western medicine often a convoluted nuisance.

Having used the IAP2 Spectrum in multiple projects in differing environments, the same theme emerged. How could everyone be assured of the right level of involvement for the circumstance? Rather than be dictated to about which level of participation a member of the public could have, I started to ask how the public themselves could determine the level of involvement? In answering this question, I started thinking of decision-making matrices. Rather than develop and test a matrix as part of the research, I decided to investigate if any of the many models already produced were actually working.

To scratch this itch the research investigated what governance mechanisms did seem to be delivering choice and control. The doctoral journey started while I was still in Perth working for Therapy Focus. In 2019 I returned to Broome and, with ethics approval in place, embarked on the research proper. Now working at Boab Health Services in the Kimberley region of Western Australia, the focus was on people with disability, but with everyday reminders of the cries from Australia's Indigenous peoples. Always was, always will be…

Along this doctoral journey it has been both deflating and euphoric to realise that there was a community of interest looking at the same issue: one I now term "consumer governance". Deflating to realise one was not the first to identify such an important issue and to attempt to solve it. And euphoric to comprehend the issue was bona fide and that there were many other like-minded people putting intellectual effort behind the matter. It was a pedagogical moment when I realised this would be an evolutionary thesis and not necessarily a revolutionary one.

I knew that co-design as a concept was nothing new. Many would argue it was the secret to the Roman Army's success with its ability to incorporate feedback and ideas from its soldiers – on armour, artillery, weapons and even diet. But in a modern context it was still somewhat humbling to acknowledge my journey went back a long way with Arnstein (1969) first proposing a participation model as early as the late 1960s. And a little frustrating to know Arnstein was proposing a solution to James Charlton's (1998) "nothing about us without us" provocation some 30 years prior to him issuing it, and yet 25 years since that provocation we are still trying to implement Arnstein's ideas of co-design to ensure the voice of people with disabilities is heard and we are making decisions with them and not without them – hence terming it a "provocation".

The provocation may have disheartening connotations, but what is heartening is the general direction the Australian society is moving. It has adopted a National Disability Insurance Scheme, with every State and Territory in the country signing up to it. And in 2023, the Australian nation considered and voted on a Referendum to acknowledge First Nations people in the Constitution and to create a Voice to Parliament. Whilst not successful, the campaigning that occurred certainly would have served to raise awareness of the benefits of people having a voice for themselves and being able to influence decisions that impact them. It was also a year during which the media reported the Board of the National Disability Insurance Agency (NDIA), the government authority that administers the NDIS, had over 50% people with disabilities on it.

I continue my work with vulnerable people and am happy to have scratched the itch enough to have a sound understanding of why to involve people in their care, how to involve them in decision-making about matters that affect them, and how to co-design broader services on a population level. I am happy that this research has answered my Research Question and has met the Research Objectives. I am also happy the research has equipped me with some valuable tools that I can share so that others working with people with disabilities, and other vulnerable cohorts, can likewise understand why to involve people in decision-making and how to – explaining all the way that choice and control may differ according to the decision and/or its impact. This to me is a good outcome from an applied doctorate such as the Doctor of Business Administration.

1. INTRODUCTION

This research was conducted to investigate the research question “Which governance frameworks are effective at empowering people with disabilities to access care services in the community?” The topic was chosen by me as it seemed so much promise had been made of the National Disability Insurance Scheme (NDIS) reforms, especially in relation to choice and control, yet the people I worked with and for seemed frustrated by the reforms, rather than empowered by them. Hence the actual title of the thesis: “Creating NDIS Impact – Getting the Right Mix of Choice and Control in Australia’s Disability Sector”.

When taking up the role at Therapy Focus in 2011, it was a particularly interesting time in Western Australia (WA) where the journey with the disability sector reforms were seemingly that much more complex than in other State jurisdictions. With a State Government riding the wave of a resources boom, there was a confidence that WA could do things better than the Commonwealth, and that sharing anything with a federated bent was simply WA subsidising the rest of the poorer States that made up that Commonwealth.

And this was especially true for the disability sector. WA had a proud heritage in this sector, with the usual century year old benevolent institutions (think Senses WA for example), but also a 30-year-old statutory body to commission and regulate services to people with disabilities. Not just a mainstream government agency, or even part of a larger agency, WA had its own Disability Services Commission (DSC) with legislated powers. Indeed, the model was deemed so successful that the WA Government established the Mental Health Services Commission some 20 years later to mirror the Disability Services Commission.

So, when in 2013 the Australian Government announced the implementation of a NDIS across the nation, there was somewhat of an upheaval in WA. The WA Government, via the DSC, was adamant it could do a better job than a national NDIS. The service providers in WA supported the WA Government and believed such a move to a Commonwealth administered Scheme would be a retrograde step.

Yet in speaking with a person with a disability one day she reminded me that that was the view of service providers, self-deluded in their own sense of benevolence. They wanted to call people with disabilities their customers and move towards a more corporate model – they wanted to entrench their vested interests and tighten their control over the sector. To that person that day she was a commodity, and those service providers were her age-old captors.

It was these differing viewpoints, so obvious in the sector, that led me to investigate with my own research. This thesis asks people if they feel in control of decisions that impact upon them. It explores their input to decision making at both the individual level, organisational level and for some, at the state and national policy levels. It seeks the views of people with disabilities, their carers, those service providers that provide care, and the peak bodies that represent them, on how much choice and control people have. It asks what works well and what needs to be improved. And it seeks to understand, from the differing viewpoints, how people with disabilities can be empowered further and what needs to be done to ensure they are central to decisions that impact upon them. That they have the right level of input to governance where that governance involves outcomes that they will live with.

The research is important because there are problems with the conventional wisdom that underpin the NDIS social reform. The launch of the NDIS in Australia is premised on the assumption that people with disabilities will benefit from having more choice and control. However, when speaking with people with disabilities it is clear that some are not enjoying a newfound empowerment. That the choice and control must actually be genuine and impactful for it to have the desired outcome. And where this is not the case, it can actually lead to further disempowerment. Hence the need to identify governance mechanisms that are succeeding in empowering people with disabilities and if possible, to conflate these mechanisms into governance and decision-making frameworks that *include* people with disabilities, both collectively and individually. These frameworks should, for example, guide the level of input people might have that is commensurate with the impact of the decision on them.

To address the research question “Which governance frameworks are effective at empowering people with disabilities to access care services in the community?” I have established four main objectives to guide the research:

1. Develop a shared understanding of what empowerment is, and what its relationship is to self-determination;
2. Determine, from the perspective of people with disabilities, whether or not they are empowered to express their self-determination as intended by legislated service standards and as enshrined in the United Nations Convention on the Rights of People with Disabilities (UN 2007);
3. Delineate between popularly used concepts in the literature including consumer, client, customer and citizen; and
4. Determine the success of commonly used governance frameworks that increase choice and control in decision-making for people with disabilities and identify preferred governance frameworks for different decision-making environments.

Central to this thesis is the concept of power. Power that is defined in its most basic form as the ability or capacity to do something or act in a particular way. If applying the socio-political lens, it can be defined as “the ability to act or have influence over others”, derived from the seminal sociologist Max Weber’s definition:

> *“within a social relationship, power is any chance (regardless of the basis of this chance) to carry through one’s own will (even against resistance).”*
> *(Wallimann et al 1977, p231)*

For the purposes of this thesis, it will apply to this definition as this thesis considers power from a societal standpoint, when inter-relationships are important between individuals and there is reason to consider the relationship of power between them.

It is this ability to have influence over others, and how that manifest in policy, that is core to understanding how decision-making can empower or disempower. Such is the duality of power in all of its forms (Charlton 1998: 26). It is central to whether or not a person is in control, or not. Simply put:

> *“Those with power control; those without power lack control.” (Charlton 1998: 30)*

For the NDIS to succeed in Australia, it must deliver on its promise to deliver *choice and control* to people with disabilities. It must fundamentally transfer power from systems and structures to the people those systems and structures were meant to serve. This transfer of power in this way was the central theme espoused in James Charlton’s seminal 1998 work Nothing About Us, Without Us.

It is interesting how vulnerable people from vastly differing cohorts can all report the same sense of disempowerment. The activist movements of all minority groups representing vulnerable people have at some point called for more control over matters affecting their lives. From the Mental Health, Indigenous Affairs, Disabilities, Aged Care sectors and any other sector where provision for surrogate decision-making is commonplace and systemic advocacy is a necessary reality, the genuine participation of people receiving services can be at risk. This thesis has taken into account the experiences in differing sectors, but specifically addresses the research on the disability cohort to ensure manageable and accessible sample sizes for research.

Whilst this thesis focuses on the disability sector, there are changes being made in multiple sectors across the world. It is not a static environment and from the start of this research in 2016 to its publication, there have been advances with the rollout of the NDIS in Australia, and with broader social reforms across the world. There is growing recognition that:

> *“…the experiential knowledge of these people is pivotal in making decisions that affect their lives.” (Charlton 1998: 17).*

The advances of the NDIS since its inception on 1 July 2013 are notably marked by the announcement in November 2020, some seven and half years since starting, that the National Disability Insurance Agency (NDIA) will form a Participant Engagement Panel (NDIS Nov 2020). The aim of this Panel is to enable the Agency to better hear the views of harder to reach participants and to better design services to meet their needs. It is an example of a governance framework that is designed to include the person with a disability in decision-making. It is also an admission by government that it needs to improve how it engages with people with disability, especially those people further marginalised in society due to aspects of intellectual disability, cognitive impairment, Indigenous ethnicity, or even remoteness.

It is engagement with people with disability that is key to achieving the aims of the national reform – choice and control for people with disabilities to enable empowerment to live independent and fulfilling lives. It is this engagement that will see the transition from people who are disempowered to empowered.

The vast change from disempowered to empowered is probably best viewed through the changes in society's perception of mental health conditions. This perception drew the ire of critical thinkers like Michel Foucault, with his provocations in *Madness and Civilization: A History of Insanity in the Age of Reason* (1961). He and others have tracked the shift from what was a policy paradigm designed for the "criminally insane", where people were incarcerated in institutions, to a contemporary framework built on strengths recognition, recovery in the community, and mental health and ongoing wellness. In fact, it is just this change over time that makes the inclusion of psychosocial supports under the NDIS so problematic. With an emphasis on recovery and perpetuation of wellness, mental health no longer fits comfortably with actuarial risk treatment of permanent disabilities across one's lifespan – something Foucault may have been heartened by if he had lived to see the changes.

Looking at the changes through a more local lens, the changes are evident within a lifetime. Mr Clive Lambert, who was formerly the Executive Director of the Slow Learning Children's Group (now Activ) in Western Australia, stated the following in relation to people with intellectual disabilities:

> "I watched community attitude towards people with intellectual disability change from one where they were typified as "children" no matter what their age, to the realisation that they are people with dreams and aspirations which must be acknowledged and enabled." (Lambert 2011, p10)

Indeed, the community has moved to a place where it is now actively denouncing the disempowerment of people with disabilities. Campaigns like *The R Word* (https://citizen-network.org/resources/the-r-word.html) to actively identify and cease the use of the derogatory word “retard” are gaining momentum the world over. Note that whilst *The R Word* campaign was local to Western Australia and was run by Avivo, a service provider renowned for its person-centred practice, its theme resonated universally, especially as the spotlight was put on scripts from Hollywood blockbusters, like *Tropic Thunder* and its reference to “going full retard” https://knowyourmeme.com/memes/full-retard by one of the characters.

The Literature Review Chapter (Chapter 3) acknowledges the many calls to action by many groups of people over the ages, and for whom the slogan “Nothing about us, without us” from South Africa (Charlton 1998, Franits 2005) has come to encapsulate a desire to control one’s own destiny. To change the locus of control from an external one to an internal one. To empower oneself, rather than be disempowered by a bureaucracy, a system, a structure, a society.

I described an itch that needed to be scratched earlier in this thesis and that was because there seemed a discord in what people were saying and what people seemed to be experiencing. It formed an idea that choice and control was not what it seemed. The proposition that came to underpin this idea was threefold:

1. The transfer of power intended by contemporary social policies is well intended, but incomplete in practice;
2. Those transferring power believe the transfer is further progressed than those receiving the power; and
3. The transfer of power to the person with a disability is unique and different in each individual case.

This proposition came from me perceiving a similar sense of disempowerment when working in the Aboriginal Affairs and Disability sectors in Australia; from seeing social reforms implemented, with the advent of the Aboriginal and Torres Strait Islander Commission (ATSIC) and more recently the NDIS; and from working with both Aboriginal people and people with disabilities and seeing their individual and collective reactions to the intended journey of empowerment, including cynicism at both the individual and community levels. In the case of ATSIC, the government abolished it after just 12 years operation, with the then Prime Minister John Howard describing it as “a failed experiment in self-determination” (Sydney Morning Herald 2004).

I am not the only one noticing the shortcomings of social policy in meeting the desired end of control transference and empowerment of vulnerable people. Over the past two decades there has been a growth in the practice of co-design whereby consumers are incorporated in the planning, design, implementation and evaluation of services they are accessing. This thesis will also examine social policy reforms and the increasing trend to incorporate the views of those with the lived experience.[1]

The transfer of control principle, from the system to the people with a disability, was present throughout the NDIS’s implementation.   The Productivity Commission explained the separate levels of control that could be exercised in the management of plans by reference to a restaurant metaphor – from eating in a restaurant, to cooking at home, and possibly a bit of each (Productivity Commission 2011, 31). This concept was implemented via the legislation and is now manifest in the NDIS guidelines for plan management (https://www.ndis.gov.au/participants/creating-your-plan/ways-manage-your-funding). I have taken this metaphor and explored it in the research. Both quantitative and qualitative research programs have asked the question: which role do people most align with – consumer, customer, client or citizen (or other)? In relation to the metaphor, the consumer probably most aligns best with the restaurant choice, as the choice is limited to the menu options presented and the restaurant decides how much of each ingredient is used, what level they are cooked to, and what manner they are served in. The customer and client resonate with the hybrid choice as they have some control when choosing to cook at home. And the citizen aligns with the in-home choice as in this scenario they can cook when they want, using what they want, in portions that they decide, and can eat it at the table or in front of the TV (for example). The question is whether the

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[1] Separate to this research, but applied in practice, I have already contributed a case study of contemporary governance good practice in co-design (Burrows 2017) to Governance International, based at the University of Birmingham

citizen is deemed to have more empowerment than the consumer, or if that is simply what suits the individual in that decision-making process on that particular day.

This research also seeks to investigate why there is a prevailing disenchantment among vulnerable people, and specifically people with disabilities. There is a sense that empowerment strategies are misguided, evidenced by slogans “do it with us, not to us” from Aboriginal Affairs, or from James Charlton’s seminal provocation “nothing about us, without us” (1998) which he says emanated from South Africa, although it was also evident in Mexico and other countries (Charlton 1998, 16). His adoption of the phrase as the title of his 1998 publication went on to become the mantra for the disability sector the world over. The question this researcher asks is “Why, more than 20 years later, are people with disabilities still chanting the same mantra?”

Charlton knew the phrase represented a transferable theme. He knew that similar sentiments were being expressed by vulnerable people frustrated by a lack of true engagement, or even a genuine intent to engage – from people living with HIV in South Africa, to impoverished peasants in Mexico. In applying it to people with disabilities he specifically noted:

> *“’Nothing About Us Without Us’ requires people with disabilities to recognise their need to control and take responsibility for their own lives. It also forces political-economic and cultural systems to incorporate people with disabilities into the decision-making process…” (Charlton 1998, 17)*

This is the journey Charlton describes from disempowerment to self-determination.

Australia is also familiar with the mantra. The exact same sentiment played out publicly in February 2016 upon the handing down by Malcolm Turnbull of his first Close the Gap report as Prime Minister (Turnbull 2016). The response from the Social Justice Commissioner, Mick Gooda, sums up the feeling of many vulnerable people:

> *"The Prime Minister has been quoted extensively in saying, 'Do things with us not to us'. [Opposition leader] Bill Shorten said exactly the same thing.*

> *"We have heard these words before. We take them with good heart but there's got to be a carrying out of that new relationship so I think we're entitled to be a little bit cynical about it until it starts happening." (NITV 2016)*

When canvassing the literature, it is clear that the intent is there to empower vulnerable people, at least in the developed world. The UK has embedded consumer governance into its health (NHS 2005) and education (Farrell 2000) policy frameworks. And the topic is very much alive in Australia through both these frameworks and now in aged care via consumer directed care reforms (DSS 2016). It is also at the heart of the NDIS reforms via the principles of choice and control (NDIS 2016).

This investigation is as relevant today as it was when Charlton was researching in the 1990s. Commentary on the shortcomings of the NDIS in Australia is ongoing, despite the metrics published by government. Lead influencers like Professor David Gilchrist have identified the lack of genuine engagement with stakeholders, including people with disabilities, as contributing factors (Gilchrist 2017). Gilchrist went on from his study of person-centred planning processes to publish a White Paper that called for:

> *"A national governance model and policy framework allowing for policy and investment to be informed collaboratively by all involved in the system including people with disability, governments and provider peak bodies." (Gilchrist, Knight, Edmonds, Emery 2019)*

Despite these calls by Gilchrist et al., there remains a tendency to "build the aircraft whilst it's being flown" – a tendency that leads to further criticism of the NDIS and headlines like "Where is the 'choice and control' for NDIS participants?" (Turnbull 2019). It could be argued that a level of versatility is important for such a large social reform, and that pragmatism must have a place in the ensuing policies. The criticism is not in terms of progress over perfection, but rather that the government has launched such a change program with so little of the basic infrastructure in place. That good, established, State systems are being dismantled before the Federal system is ready to fund the, often critical and 24 hours a day, care and supports required by people with disabilities. And rather than stopping the changes to consolidate, the rollout continues with ever greater vigour.

Choosing people with disabilities as a representative cohort of vulnerable people, this research seeks to investigate their perceptions, as well as that of their service providers, peak bodies and advocacy agents, and the government and philanthropists that support them. The ultimate aim is to determine whether or not they are truly empowered, and the success or otherwise of governance structures and their decision-making regimes, which contributed to that level of empowerment.

From the outset it is important to qualify that this review is largely concerned with developments occurring in developed countries, specifically Australia. It examines to some extent the trends happening more broadly in the disability sector, especially some of the leading practices from Canada and the UK for example. However, it does not purposefully examine the issue from the perspective of developing countries, where estimates may claim up to 90% (Charlton 1998) of people with disabilities in the world actually live. This is important to note as analysis by the World Health Organisation and World Bank have re-stated the prevalence of disabilities from 10% of the world's population in the 1970s to 15% by the early 2000s (WHO 2011, p28). In actual numbers this translates to over one billion people in the world living with a disability, and over 185 million people living with a profound disability that severely limits their day-to-day functioning (WHO 2011, p29). This prevalence is also likely to increase over time as people live longer, as chronic diseases become more entrenched in populations, and as diagnostic tools improve (WHO 2011, p44). How the more liberal trends of incorporating the consumer voice into decision-making are adopted in developing countries is recommended later in the thesis as a topic for further research. This research will help identify models of governance that work well and might be considered for implementation when resources are available and committed to assist people with disabilities in these developing (or low income) countries.

As raised in the Preface to this thesis, there are parallels between the disability sector and other sectors representing the interests of marginalised people. Indeed, the National Disability Insurance Scheme, enacted in 2013, was preceded by two decades by the Aboriginal and Torres Strait Islander Commission (ATSIC) Act 1989. The Objects of the ATSIC Act were as follows:

> *"The objects of this Act are, in recognition of the past dispossession and dispersal of the Aboriginal and Torres Strait Islander peoples and their present disadvantaged position in Australian society:*
>
> ***(a) to ensure maximum participation of Aboriginal persons and Torres Strait Islanders in the formulation and implementation of government policies that affect them;***
>
> ***(b) to promote the development of self-management and self-sufficiency among Aboriginal persons and Torres Strait Islanders;***
>
> *(c) to further the economic, social and cultural development of Aboriginal persons and Torres Strait Islanders; and*
>
> *(d) to ensure co-ordination in the formulation and implementation of policies affecting Aboriginal persons and Torres Strait Islanders by the Commonwealth, State, Territory and local governments, without detracting from the responsibilities of State, Territory and local governments to provide services to their Aboriginal and Torres Strait Islander residents."*
>
> *(Aboriginal and Torres Strait Islander Commission Act 1989, Part 1, Section 3 – emphases added)*

It is clear in the wording of the Objects that the government had a clear intention to address the disempowerment and disadvantage being experienced by Aboriginal people, and to do this by involving Aboriginal people in all aspects of decision making about matters that impacted upon them.

Likewise, there are Objects in the *National Disability Insurance Scheme (NDIS) Act 2013* that seek to address the disempowerment of people with disabilities and their marginalisation in the broader community. These Objects are as follows:

> *(a) in conjunction with other laws, give effect to Australia's obligations under the Convention on the Rights of Persons with Disabilities done at New York on 13 December 2006 ([2008] ATS 12); and*
>
> *(b) provide for the National Disability Insurance Scheme in Australia; and*

(c) support the independence and social and economic participation of people with disability; and

(d) provide reasonable and necessary supports, including early intervention supports, for participants in the National Disability Insurance Scheme launch; and

(e) enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports; and

(f) facilitate the development of a nationally consistent approach to the access to, and the planning and funding of, supports for people with disability; and

(g) promote the provision of high quality and innovative supports that enable people with disability to maximise independent lifestyles and full inclusion in the mainstream community; and

> *(ga) protect and prevent people with disability from experiencing harm arising from poor quality or unsafe supports or services provided under the National Disability Insurance Scheme; and*

(h) raise community awareness of the issues that affect the social and economic participation of people with disability, and facilitate greater community inclusion of people with disability; and

(i) in conjunction with other laws, give effect to certain obligations that Australia has as a party to:

> *(i) the International Covenant on Civil and Political Rights done at New York on 16 December 1966 ([1980] ATS 23); and*
>
> *(ii) the International Covenant on Economic, Social and Cultural Rights done at New York on 16 December 1966 ([1976] ATS 5); and*
>
> *(iii) the Convention on the Rights of the Child done at New York on 20 November 1989 ([1991] ATS 4); and*
>
> *(iv) the Convention on the Elimination of All Forms of Discrimination Against Women done at New York on 18 December 1979 ([1983] ATS 9); and*
>
> *(v) the International Convention on the Elimination of All Forms of Racial Discrimination done at New York on 21 December 1965 ([1975] ATS 40).*

> *(National Disability Insurance Scheme Act 2013, Part 2, Section 3 -emphases added)*

Whilst the Objects in the NDIS legislation do not speak to disadvantage as they do in the ATSIC legislation, the Principles do address neglect, abuse and exploitation. And both certainly speak to the need to include their target cohorts in the decision-making of matters that impact upon them. They also seek to empower their respective cohorts to participate in the broader society. The focus on the NDIS to not only involve the disability cohort, but to transfer legitimate choice and control is explicitly stated above in the Objects, and is reiterated in the Principles:

> *4. General principles guiding actions under this Act*
>
> > *(1) People with disability have the same right as other members of Australian society to realise their potential for physical, social, emotional and intellectual development.*
> >
> > *(2) People with disability should be supported to participate in and contribute to social and economic life to the extent of their ability.*
> >
> > *(3) People with disability and their families and carers should have certainty that people with disability will receive the care and support they need over their lifetime.*
> >
> > ***(4) People with disability should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports.***
> >
> > *(5) People with disability should be supported to receive reasonable and necessary supports, including early intervention supports.*
> >
> > *(6) People with disability have the same right as other members of Australian society to respect for their worth and dignity and to live free from abuse, neglect and exploitation.*
> >
> > *(7) People with disability have the same right as other members of Australian society to pursue any grievance.*
> >
> > ***(8) People with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise choice and control, and to engage as equal partners in decisions that will affect their lives, to the full extent of their capacity.***

(9) People with disability should be supported in all their dealings and communications with the Agency so that their capacity to exercise choice and control is maximised in a way that is appropriate to their circumstances and cultural needs.

(10) People with disability should have their privacy and dignity respected.

(11) Reasonable and necessary supports for people with disability should:

- *(a) support people with disability to pursue their goals and maximise their independence; and*
- *(b) support people with disability to live independently and to be included in the community as fully participating citizens; and*
- *(c) develop and support the capacity of people with disability to undertake activities that enable them to participate in the mainstream community and in employment.*

(12) The role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected.

(13) The role of advocacy in representing the interests of people with disability is to be acknowledged and respected, recognising that advocacy supports people with disability by:

- *(a) promoting their independence and social and economic participation; and*
- *(b) promoting choice and control in the pursuit of their goals and the planning and delivery of their supports; and*
- *(c) maximising independent lifestyles of people with disability and their full inclusion in the mainstream community.*

(14) People with disability should be supported to receive supports outside the National Disability Insurance Scheme, and be assisted to coordinate these supports with the supports provided under the National Disability Insurance Scheme.

(15) Innovation, quality, continuous improvement, contemporary best practice and effectiveness in the provision of supports to people with disability are to be promoted.

(16) Positive personal and social development of people with disability, including children and young people, is to be promoted.

(17) It is the intention of the Parliament that the Ministerial Council, the Minister, the Board, the CEO and any other person or body is to perform functions and exercise powers under this Act in accordance with these principles, having regard to:

- *(a) the progressive implementation of the National Disability Insurance Scheme; and*
- *(b) the need to ensure the financial sustainability of the National Disability Insurance Scheme.*

5.General principles guiding actions of people who may do acts or things on behalf of others

It is the intention of the Parliament that, if this Act requires or permits an act or thing to be done by or in relation to a person with disability by another person, the act or thing is to be done, so far as practicable, in accordance with both the general principles set out in section 4 and the following principles:

- ***(a) people with disability should be involved in decision making processes that affect them, and where possible make decisions for themselves;***
- *(b) people with disability should be encouraged to engage in the life of the community;*
- *(c) the judgements and decisions that people with disability would have made for themselves should be taken into account;*
- *(d) the cultural and linguistic circumstances, and the gender, of people with disability should be taken into account;*
- *(e) the supportive relationships, friendships and connections with others of people with disability should be recognised;*
- *(f) if the person with disability is a child—the best interests of the child are paramount, and full consideration should be given to the need to:*
  - *(i) protect the child from harm; and*
  - *(ii) promote the child’s development; and*

> *(iii) strengthen, preserve and promote positive relationships between the child and the child's parents, family members and other people who are significant in the life of the child*
>
> *(National Disability Insurance Scheme 2013, Part 2, Sections 4-5 – emphases added)*

It is fair to conclude that there is a confluence of themes in legislation addressing disadvantage and marginalisation of Australia's Indigenous peoples and people with disabilities respectively. The emphases (bold print) show that both pieces of legislation seek to increase the involvement of their respective target cohorts, thereby increasing their control over decisions impacting them and ultimately their empowerment. How they did this was different in practice, however. The major difference was in relation to how funds were distributed. Both social reforms were delivered by statutory Commissions, but whereas ATSIC sought to distribute funds via programs, with elected Regional Councils being the delegates on a geographical basis, the NDIS sought to transfer decision-making on funds attribution directly to the beneficiary; to the individual person with a disability. This is a core difference between government program funding of old and the newer neoliberalist consumer-directed funding that is occurring across aged care, disability care and health care today. Therefore, for the purpose of this thesis, I have limited the review of literature to the cohort of people with disabilities in the first instance.

This thesis will examine the literature to ascertain the prevalence of consumer-based decision-making in governance frameworks. It will ask people with disabilities, and their carers, what their experiences have been and how they believe their voices are heard in decision-making and will finally make recommendations from the common themes identified from the analysis of the research. In the Recommendations Chapter (Chapter 8) I will also present a model to inform the involvement of people with disabilities in decision-making – a model that can be transposed to other vulnerable cohorts.

I have presented the thesis in a traditional format with Introduction (Chapter 1), Literature Review (Chapter 3), Methodology (Chapter 4), Findings (Chapters 5 and

6), Conclusion (Chapter 7), Recommendations (Chapter 8) and Limitations (Chapter 9) chapters. I have also added a Context (Chapter 2) chapter before the Literature Review to ensure the reader has at least an overview of the somewhat nuanced disability sector in Australia and specifically in Western Australia, and some idea of the social reforms culminating with the implementation of the National Disability Insurance Scheme.

The Literature Review chapter (Chapter 3) is non-traditional in that it does not seek to establish a gap in research, but instead appraises the historical and contemporary literature to identify the growth in consumer involvement in policy design into what we know today as codesign. It also identifies the continuing need to invest in and refine this process to ensure consumer needs are met and gives examples of industry commentary that justify this investment, as one would expect of applied research in a program such as a Doctor of Business Administration. The Findings chapters (Chapters 5 and 6) are separated into qualitative and quantitative respectively to reflect the mixed methods approach that was used in the research. The Recommendations chapter (Chapter 8) is drawn from both the research and my own experience as a practitioner in the industry. And the Conclusion (Chapter 7) and Recommendations (Chapter 8) chapters show clearly how the findings from this research can, and must, be applied to not just the disability sector but across broader cohorts of vulnerable and marginalised peoples. To involve people in decisions that impact upon them. To address their needs, close the gap in numerous life metrics, and build true equity in our society going forward.

It is hoped that this research scratches that itch that underpin the three-part proposition. That it goes some way to address the discord in expectations about choice and control, both perceived and real, and that it makes recommendations that can be implemented in the sector and which creates an expectation that the involvement of consumers in decision-making, and in broader governance at all levels, is essential for good practice in contemporary delivery of community care services. This exploration of consumer governance and its relationship to choice and control in decision-making, and ultimately empowerment, will all help address the four Research Objectives and answer the Research Question “Which governance frameworks are effective at empowering people with disabilities to access care services in the community?”

2. THE CONTEXT - THE AUSTRALIAN DISABILITY SECTOR: THE EVOLUTION OF ITS GOVERNANCE, POLICIES AND INSTITUTIONS

2.1 Introduction

This thesis is presented as part fulfilment of the requirements for the award of Doctor of Business Administration (DBA). A DBA thesis differs from a Doctor of Philosophy (PhD) thesis in that it is an applied study; one undertaken within the profession or industry that the researcher works. In this instance it is a study of governance within the disability sector in Australia. Given I have industry knowledge, this chapter is presented to the reader as an explanatory memorandum. It is written as a historical guide to the Australian disability sector, with a specific focus on the Western Australian disability sector - a sector that has undergone huge changes in recent years. These changes aim to bring consistency to supports for people with disabilities across the country and introduce a level of control over those supports not seen before. It is written to provide the reader context of a discrete and unique human service sector, and to explain the roles of various stakeholders within that sector. It is hoped that this context will prepare the reader to engage with the thesis, without the need for in depth knowledge of the disability sector in Australia, or the need for industry-specific experience. In addition to this Chapter, there is also a Glossary of commonly used terms which can be found at Appendix 8.

Mahatma Gandhi is purported to have once said that a measure of a nation's civility is the way it treats its most vulnerable (Atkins 2018). Now challenged and attributed to multiple authors, it has become a mantra for many champions of social justice. Maybe it is this reflective awareness that has pushed modern societies to examine how they treat vulnerable people and how they can act to mitigate the vulnerability, whatever that may be, or whatever the cause. The notion of civility certainly lives on, with the theme recently referenced in an emotional call to action by three prominent disability advocates in Western Australia:

> *“Every person deserves a good life. And every person with a disability deserves a good life. Often, this takes some extra help. This is where the concept of disability support has come from: society’s humane response to the challenges disability can pose.”* (Bartnik et al. 2022, p2)

For people with disability, it has been a long road to have rights recognised and assertive policies implemented to change the conventional wisdom. And it is a continuing journey on that road. Whilst we have changed from a model to incarcerate the criminally insane, to one that enables people with intellectual disabilities to access the health care they need, there is still reference to these same people’s over-representation in the criminal justice system in modern policy (Commonwealth of Australia 2021, p18).

2.2 The Australian Context

The journey of the disability sector in Australia was the same as any other until Federation; scantily resourced colonies facing their own tyrannies of distance from supplies and supports from a Crown located some 15,000 kilometres away on the other side of the world. It was with Federation in 1901, with the inception of a united Commonwealth, that some sectors gained a level of national coordination. And with that, a level of economy with resources. Initial powers of the Commonwealth centred around taxation and defence, but as technology has improved, it has become increasingly about communications (How has power shifted to the Australian Government from the states since federation?). And with the signing of the Covenant of the League of Nations following the end of the first World War in June 1919 (National Archives of Australia 2010) to becoming a founding member of the United Nations (UN) from November 1945 and an almost 80 year history of involvement in the UN and all of its multilateral agencies and commissions (United Nations), the Commonwealth has increasingly represented the interests of the nation to the world stage. In relation to the disability sector, this also included Australia being an original signatory on the UN Covenant on the Rights of People with a Disability from March 2007 (https://humanrights.gov.au/our-work/disability-rights/united-nations-convention-rights-persons-disabilities-uncrpd).

That is not to say the Commonwealth had no involvement in the disability sector until 2007. Its first foray into the sector was with the introduction of the Invalid Pension in 1908. Then during the war years a focus on rehabilitation of returned soldiers, including the establishment of the Commonwealth Rehabilitation Service in 1948. Such needs at the time were largely medical related and as a such a medical model responded. But as the prevalence of different types of disabilities changed over time, as with attitudes, the medical model gave way to a more community-based model with more normal interactions with the local community (Considine 2022, p117-118).

Whilst welfare in the community was initially the responsibility of States, the effect of raising taxes to pay for such responsibilities has meant the Commonwealth has taken an increasing interest in how those taxes have been spent. States have maintained responsibility for direct service provision – in sectors like hospitals, policing, and education, while the Commonwealth has taken responsibility at a policy and commissioning level. And in the case of non-acute health care (i.e. outside of hospitals), the Commonwealth has taken direct responsibility with discrete grant funding and with Medicare. Likewise, from 2013, the Commonwealth has taken direct responsibility for funding disability with the inauguration of the National Disability Insurance Scheme (NDIS). Many believe the inception of the NDIS was predicated on recommendations from the Productivity Commission (2011), however its origins can be traced as far back as 1972 when then Prime Minister Gough Whitlam commissioned an inquiry into a national compensation scheme (Considine 2022, p113).

The Commonwealth started taking a more active role in the sector during the Whitlam Government (1972-75) with the advent of the Handicapped Person's Welfare Program (HPWP) which was activated via the associated Handicapped Program Assistance Act (1974) which in itself was seen as innovation with the enablement of funding for non-government organisations to provide services like accommodation and/or care (Soldatic & Pini 2012, p184). Momentum continued during the Fraser Coalition Government (1975-83) period, but it wasn't until the Hawke-Keating Governments (1983-96) that the first national representative body was established: Disabled People's International (Soldatic & Pini 2012, p184). The

Howard Coalition Government (1996-2007) looked to change the focus from community led advocacy to individuals and their families (Soldatic & Pini 2012, p187), and it wasn’t until the Rudd-Gillard Labor Governments (2007-13) that more formal moves were made by the Commonwealth to take charge of the disability sector, in line with its Social Inclusion Agenda and its emphasis on inclusion, participation and public consultation (Soldatic & Pini 2012, p189).

2.3 The Western Australian Context

Rather than examining how this change has occurred throughout Australia, this thesis has concentrated on the journey in Western Australia specifically. This is primarily because the researcher was resident in this State during the research, but also because this State was the last to sign up to the full implementation of the NDIS, only agreeing to the new arrangements from December 2017. Whilst every State could claim special status in some regard, the WA Government was calling special status in every regard in relation to the disability sector. The previous Barnett Liberal Government in WA was adamant that it would operate a superior, parallel system that would be compatible with the NDIS. It was only with the election of the McGowan Labor Government in 2017 that the decision was made to cash out local responsibilities and join the federal model (Government of Western Australia 2022).

The history of disability services in Western Australia is one of enlightened evolution, from a very paternalistic start, with powers vesting in the Crown of the Colony, to a very autonomous statutory body, the Disability Services Commission, that was the envy of the nation and the basis for a mirror-like Mental Health Commission. The WA Government Department of Communities provides a historical overview of policy changes on its website https://www.disability.wa.gov.au/understanding-disability1/understanding-disability/history-of-disability-services/ (Department of Communities), which is summarised in the table below.

1900s Hospitals for the insane

- Period dominated by lack of everyday supports for families and only shared accommodation in a asylum type institutions - very unsafe and unsupportive

1940's-50's Birth of the Associations

- Period characterised by the coming together of families to form associations of interest. Examples included the Spastic Welfare Association and the Slow Learning Children's Group

1950's-60's New Policy Direction

- Formal recognition of thre needs of people with disability and a separation of mental health from intellectual disability

1970's Social Training Model

- The development of social training plans and programs for people with disability with a view to develop skills to enable transition from segreated supports to integration with mainstream community supports

1981 International Year of People with Disabilities

- A time to raise awareness of issues facing people with disabilities, count them for the first time in the Census, and develop a national approach to meeting their needs

1985 Review and Consultation

- Introduction of the Home and Community Care (HACC) Program to provide services in the home on an individual needs basis, and review of disability services leading to Commonwealth Disability Services Act 1986

1986-1991 Federal and State funding reform

- A period of well intentioned confusion as reform was introduced to move segreated programs (e.g. sheltered workshops; nursing homes) into the community - resistance from parents. Malaise led to further reform with the Commonwealth State Funding Agreement issuing in a new range of community-based programs (e.g. vacation care; holiday camps)

1986-1991 WA Specific Reforms

- A series of legislative changes and subsequent bureacratic changes culminated in 1993 with the establishment of the Disability Services Commission - a government department specifically working with people with disabilities , with its own dedicated Minister - an Australian first

2012 My Way

- The focussed trial to enhance the Local Area Coordinator roles introduced in 1988 to ensure greater emphasis on localised supports and person-centred planning - the beginning of the WA NDIS trial program and the precursor to WA's entry into the nationally operated NDIS from 2017

The WA Government has chosen these time epochs to denote major changes in policy that saw a change in how services were delivered that had a positive impact on people with disabilities. Changes that saw people with disabilities having more say in services they accessed or supports they received. From my own experience I noted the number of present-day leaders of service organisations that trained as Social Trainers through the 1970's. Indeed the final Director General of the Disability Services Commission, prior to the transition to NDIS, was Dr Ron Chalmers, a former Local Area Coordinator.

The start of the social training movement was the start of "the system" seeing people with disabilities as real people. The start of recognising the sovereignty of the human being. It led to a critical mass of people in the human service sector who were aligned with the concept of choice and control for people with disabilities, and person-centred care focussing on the needs expressed by the person with disability.

Whilst the WA Government decided to join with the National Disability Insurance Scheme, there are many in the state who lament the decision. They wished for a federated version of the Scheme whereby WA would continue to manage its own Scheme which would have been compatible with the national Scheme. In losing the right to manage they have continued to express their scepticism of the nationally operated Scheme and have pointed to its shortfalls in comparison to the older State model, which they claim was already fit-for-purpose and delivering individualised services (Bartnik, et al. 2022).

Authors of this paper, three distinguished disability advocates and service operators, have pointed to the strengths of the older Western Australian system as being:

1. Governance and collective leadership
2. Connection to people with disability
3. Partnership with disability service providers
4. Sustainability for organisational capability (Bartnik et al. 2022 p9-10)

In other words, the authors saw the real strength of the Western Australian system prior to the NDIS as relationship based. A highly interconnected and trusting system that knew people with disabilities and could respond to their needs promptly and effectively. The authors also pointed to some weaknesses in the older system:

1. Waitlists
2. Psychosocial disabilities disjointed via health system
3. Lack of interstate portability
4. Disconnection between the WA system and Commonwealth funded employment services (Bartnik et al. 2022, p10-11)

These shortfalls are no small matter, with all now in agreement that the nationally operated Scheme is delivering more needed services to more people than ever. It is meeting the needs of people with mental health issues that were previously unmet. It is allowing people to move around Australia and access the marketplace with the same funded resources; and it is making real efforts to transition Scheme participants into meaningful employment where possible. Whilst still not succeeding overwhelmingly on this last point, the Scheme is sure to invest more energy to this end as it works to realise one of its primary objectives to invest early to offset future lifelong support costs for people with disabilities – and to show the public that investments in people with disabilities can turn them from an economic burden to an economic contributor – as the Productivity Commission foresaw in its Inquiry (Productivity Commission 2011).

2.4 The National Disability Insurance Scheme (NDIS)

The disability sector is not alone with change at this time. Indeed the same title for that recently published industry thought paper referenced above is the title used by Meaningful Ageing Australia as a public awareness initiative to promote real and meaningful engagement with consumers in that sector. See https://seemeknowme.org.au/.

Australia was not unique in how it responded to the civil rights movements that grew in momentum across the world in the 1950s and 1960s. From the successful 1967 Referendum whereby the Constitution was changed to enable Aboriginal people to be counted as part of the Australian population and for the Commonwealth to make laws in relation to Aboriginal people (https://aiatsis.gov.au/explore/1967-referendum) to the humble beach umbrella origins of the Aboriginal Tent Embassy on the grounds of what is now the Old Parliament House in Canberra on 26 January 1972, the movement has grown and developed and included increasing cohorts of vulnerable and marginalised Australians.

From the passing of the Racial Discrimination Act in 1975, to the Sex Discrimination Act in 1984, the Disability Discrimination Act in 1992, and the Age Discrimination Act in 2004, there has been a trend to enshrine vulnerable peoples' rights, and protections, in legislation. Further to the legislation, Australia has also declared its support for various conventions on the world stage at the United Nations. It signed the UN Convention on the Rights of People with Disabilities 2006 at the first opportunity on 30 March 2007, along with other supporting nations. And like many other nations, Australia included a qualification with its signature, but unlike other nations which typically qualified jurisdictional limitations, Australia qualified its stance on supported decision-making, and on access to health care by foreign nationals (UN 2022).

In signing the UN Convention Australia committed to an ongoing journey of change, especially in relation to the recognition of the rights of people with disabilities to make their own decisions and be in control of their own lives. The UN Convention has a simple purpose:

> *The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. (UN 2007, p4)*

In revising the final drafts of the National Disability Insurance Scheme Bill (2013), the Labor Party insisted on the inclusion of guiding principles in the Bill's Objects, to ensure alignment with the Convention and to ensure people with disabilities had choice and control.

The National Disability Insurance Scheme was not the first attempt at a nationally consistent approach to supports for people with disabilities. The *Disability Services*

Act 1986 was national legislation that set out how the States and Commonwealth would work together to deliver quality supports to people with disabilities. What changed from this legislation to the newer National Disability Insurance Act 2013 was the change from the welfare mentality to the opportunity paradigm (Campanella, Edmonds 2020). Or as John Walsh put it – from looking at disabilities as a problem, to looking at disabilities as a solution (IPPA 2022).

John Walsh was a key influencer of the change in thinking. A person with a disability himself, he introduced the actuarial approach. His view was that society should share the risk of disability, given anyone was susceptible to disability at birth and from any point on with acquired disability or major trauma-caused disability. A fundamental change inherent in the NDIS was therefore the insurance aspect of the funding for supports.

The NDIS was conceptualised through a Productivity Commission review (Productivity Commission 2011), which John Walsh oversaw as a Commissioner. Recommendations from the Productivity Commission were then incorporated into the NDIS legislation. Key to these recommendations was the assumption that people with disabilities, if in control of their own decisions, and able to choose their appropriate supports, could gain a level of independence that could enable them to become economic contributors – that is, employed in the workforce. As employees they would be generating national wealth, rather than detracting from it. Hence the solution paradigm that Walsh referred to. Key to this was the principle to identify the disability early and intervene as early as possible to ensure best chance for supports to enable independence. In other words, intervene early in one’s life to offset future life-long costs of supports.

Another key change introduced with the NDIS was the transfer of funding to the control of the person with a disability. Prior to the NDIS, the government (State or Federal) would contract service provider organisations to deliver services to a defined number of people with disabilities. Whether they be accommodation beds, therapy hours, or community access visits – they were all contracted outputs of some form. And service providers either specialised in one or more output areas or were comprehensive providers catering for all ages and all needs. Where this was the case the service providers tended to specialise in a diagnosis area of disability, for example autism or cerebral palsy.

With the advent of the NDIS, and the promise to transfer choice and control to the person with disability, the change was made to the funding to transfer contracts from service providers to the individual person. The funding was therefore "individualised". Each person with a disability had a plan with the National Disability Insurance Agency (NDIA); the agency that oversees the NDIS. And that plan included a number of goals that in turn had detailed a number of supports to achieve the strategies, and a budget for those supports.

Once agreed, the budget would be funded in one of three ways. It was either agency managed, whereby the NDIA would make payments against claims for service by service providers – in line with the plan. Or if preferred by the person with a disability, the funds could be transferred to a plan manager; an intermediary of sorts. The plan manager could help the person with a disability identify and pay for a support coordinator as well as all the supports that the coordinator subsequently sourced, keeping an eye out for quality and value for money. Or finally, where the person with disability preferred, and was deemed with the capacity to do so, the funds might be transferred to the person with disability to self-manage and to pay the bills directly.

These changes were designed to move the person with disability from a disempowered consumer at the mercy of the providers, to an empowered customer with purchasing power. The changes are surely happening – probably too quickly for some service providers, and not quickly enough for some people with disabilities. Upon resigning from the National Disability Insurance Agency Board in August 2020, John Walsh was quoted as saying:

> *"It's great that the NDIS has changed a lot of peoples' lives, but I feel it's still the tip of the iceberg. It's changed people's lives still within a paradigm of welfare so that the control really is still held by governments and the service-provision industry rather than people with disability themselves." (Walsh, J. in Campanella, Edmonds 2020)*

What is certain is the move to individualised services is continuing. The aged care sector, for example, has for the most part dismantled its previous grant funding schemes and replaced them with the Commonwealth Home Support Program – where grants are paid to providers to meet specific needs of clients in their care (Australian Government 2022).

The challenge for the disability sector is to respond to the massive investment into the sector. Not only was it drastically underfunded and under-resourced as the Productivity Commission identified (Productivity Commission 2011), but it was also charged with addressing the unmet long-term psycho-social needs in the community. This means in many areas of Australia the lofty ideals of choice and control for the person with disability are being met by unspent allocations and part-realised plans due to thin markets of service providers. In remote areas there may be no suitable providers to buy services from and so even though the person with a disability has a plan and their plan has suitable goals, strategies and supports, there may simply be no provider to purchase services from, so the allocated funds remain unspent at year's end. And needless to say the person with a disability lives with needs which are unmet throughout the year. These are impediments which exist in Australia not by design, but simply because of limitations and the ongoing tyranny of distance in this vast and sparsely populated country.

The table below explains some of the changes that have occurred with the introduction of the NDIS in Australia:

Pre-NDIS	**Post-NDIS**
Services provided were determined by what providers wanted to provide	Services provided are determined by what people with disabilities want to access
Government purchased services from providers via "block" contracts	Government funds people with disability to purchase services according to an agreed NDIS plan

Service providers accountable to government	Service providers accountable to people with disabilities and to government
Informal supports (e.g. family carer) assumed free	Informal supports able to be planned for and paid (in some instances)
Services triaged and delivered on a priority basis (often waitlists)	Services delivered according to access and payment (less waitlists, but dependent on market strength)
Services often grouped for economies of scale (e.g. Group Homes)	Services more likely to be individualised (e.g. Supported Independent Living)
Services accessed when available	Services accessed early in life to minimise life-long costs of supports
Disabilities defined according to diagnostic evidence (excluded health-related disabilities – e.g. diabetic foot amputees)	Disabilities defined according to functional independence (includes health-related disabilities, as well as psycho-social disabilities)

2.5 Roles and relationships

Before finishing this chapter, it is worth noting the different roles in the sector. Central to the sector, and its reason for being, is the person with a disability. Supporting that person are families and carers. Paid supports are usually provided by service providers. These service providers can range from solo practitioners to multinational conglomerates. It should be noted that some of the support work, and day-to-day care, that was previously provided for free can now be charged as a reasonable and necessary support. This means family members and friends can also be classified as service providers if they are now providing funded supports, although there are significant controls on these types of supports.

Of the service providers, there are many main types of providers. There are for-profit commercial enterprises and there are purpose driven not-for-profits. There are those that were traditional communities of interest, usually around a type of disability. There are specialist providers that focus on a single area of care like therapy or employment for example. And there are newer peer-led providers that are typically led and managed by people with disability in the interests of people with disability. Service providers can join a number of peak bodies to assist in representing their views as a collective voice. The main peak body for providers in Australia is National Disability Services (NDS), which organises itself on a federated structure of State-elected committees. There are other peak bodies for various purposes. Western Australian Individualised Services (WAIS) represents the views of providers committed to involving the voice of people with disability, especially in relation to accommodation options. The Western Australian Council of Social Services (WACOSS) also serves to represent providers' interests on broader social issues. Usually, these peak bodies will charge a nominal membership fee. And there are advocacy bodies which have some semblance of peak body status, but often do not have the same membership structures. Advocacy bodies are usually focused on a single cause which needs attention, rather than peak bodies which can advocate on behalf of their members for any number of causes. Advocacy bodies in Western Australia include organisations like Ethnic Disability Advocacy Centre (EDAC), and Sexuality Education Counselling and Consultancy Agency (SECCA).

There is also a new, somewhat burgeoning role, in the intermediary. This role is doing one of two things – either case managing the supports and assisting the person with disability to access providers, or they are case managing the funding on behalf of the person with disability. This role is new and unique to sectors with individualised funding. There has also been a change to government which previously was the purchaser but has transferred that function to the person with disability. The government now plays a role more akin to regulator, especially with the advent of the Quality and Safeguards Commission. Another new role is the introduction of the NDIS Planner; a role within the NDIS. This role is responsible for working with the person with disability to identify their life goals, detail the strategies to achieve the goals, identify the supports required to achieve the strategies, and the budget to purchase the supports. And as per the NDIS legislation and all associated guidelines, the supports identified must be deemed "reasonable and necessary" (NDIS 2013).

As with any thesis that takes time to compile, the world does not stop for literature to be reviewed, or for interviews to be held and research to be collated and presented. So is the case with this thesis. At the time of finalising and preparing for submission, the Australian Government, via the Minister for the NDIS Bill Shorten, has announced a review into the NDIS (https://www.linkedin.com/feed/update/urn:li:activity:6987979286309707776/), with a final report to be delivered by October 2023. A timely announcement given the obvious agitation by thought leaders in the sector who claim, "we are not there yet" (Bartnik et al. 2022, p2) and who remind us:

> *"In a humane society, failure is not an option for vulnerable people or the organisations on which they rely." (Bartnik et al. 2022, p14)*

These Western Australians will be hoping the Review takes up the suggestions made in the industry thought paper to invest in the following areas:

1. Local collective leadership and collaboration
2. Trusting and enduring relationships with people with disabilities
3. Stronger partnerships with mainstream and community organisations (Bartnik et al. 2022, p1)

In other words, they hope the Review will try to rebalance the NDIS from a transactional Scheme approach back to a more relational approach, given this is after all a Scheme for people delivered by a human service sector within a humane and civil society.

3. LITERATURE REVIEW

In approaching the literature to determine the priorities for this research, a number of aspects were examined. The first was an exploration of the cry for help by people with disabilities – culminating in the mantra “Nothing About Us Without Us” – and an examination of issues raised in the seminal piece of work by James Charlton (1998) of that same title.

The second aspect involved an investigation of the involvement of people with disabilities in decision-making and the current trends with the execution of choice and control in addressing that mantra – trends that show a level of commitment to co-design with people with disabilities. This investigation addresses the rise in this method of design and explores its application in a contemporary sense in policy and in service planning, design, delivery and evaluation.

The third aspect involved identifying how co-design has been incorporated into the design and rollout of the NDIS in Australia. This involved an examination of the legislation and an exploration of the trends and initiatives that are currently supporting people with disabilities, as participants in that Scheme, to meet their needs. Central to this was an examination of the central tenets of the Scheme: “choice and control” for people with disabilities, and the transference of that control from parties within the existing system, to people with disabilities in the new system.

Finally the review explored the current academic literature and media commentary to ascertain the success or otherwise of current policies, especially those based on co-design principles, in meeting the needs of people with disabilities. This final component of the literature review identified the shortcomings of current practices and identified the gaps in practice that need to be addressed. From this it articulates elements of successful governance models as well as barriers to effective empowerment. It is this last step that is essential to address the Research Question, “Which governance frameworks are effective at empowering people with disabilities to access care services in the community?”

In short, this literature review will address:

1. The identification of (dis)empowerment
2. The increasing trend to co-design with people with disability
3. The NDIS and government policy and regulation
4. Academic and media commentary on the NDIS and similar reforms

The paragraphs that follow are split into these four main areas. They have been titled thematically to provoke a sense of evolution, but the numbers also correspond to the aspects described above.

3.1 Nothing About Us Without Us

When studying the literature, it is hard to consider the concept of empowerment without also considering its antithesis: disempowerment. This is something James Charlton knew all too well.

> *"…because the needs of people with disabilities and the potential for meeting these needs are everywhere conditioned by a dependency born of powerlessness, poverty, degradation, and institutionalisation."* (Charlton 1998, 3)

However, there has been a gradual policy shift in the last two to three decades, from disempowered to empowered, that has led to

> *"…a historic break with the traditional perception of disability as a sick, abnormal, and pathetic condition."* (Charlton 1998, 10)

It is a gradual shift because many commentators trace the origins of the shift back to the introduction in the United Kingdom of the Elizabethan Poor Laws in 1601 (Ramcharan 2016). This was the first attempt by a society to support vulnerable people in a systemic manner; to alleviate the suffering of the "deserving poor". Ramcharan (2016) talks of the rise of institutions from the 1850s as society looked to medicine for answers, and then more recently from institutions to the community from the 1970s onwards. This latter movement is acknowledged by the World Health Organisation as the move from the medical model to the social model (WHO 2011, p4) – a move characterised by a transition in which:

> *"…people are viewed as being disabled by society rather than by their bodies" (WHO 2011, p4)*

The definition of empowerment, based on participation of consumers, must encompass a transfer of power from the public to the individual (Arnstein 1967, p216) as well as the exercise of independence and sense of individual effectiveness (Alam 2009, p279). Only in considering the duality of empowerment, as is evident in citizen theory (Ranson and Stewart 1989, p13), will we see self-determination manifest for people with disabilities. This duality explains the requirements for citizenship are both the condition for civitas – a friendly and cooperative society - plus autonomy for people to participate freely in that society (Ranson and Stewart 1989, p13).

As self-determination manifests, it is important to determine in what realm and to what degree this occurs. Many researchers reflect on the notion of consumers as sovereign beings. Indeed Charlton acknowledged that people with disabilities, once empowered with a raised consciousness, became less interested in "the welfare of the handicapped … and (more) interested in the human rights of people with disabilities" (1998, 115). That is, empowered people with disabilities become people that can effect influence from economic, political or social perspectives (Dahlberg 2008, p265; Litva et al. 2008, p81).

In progressing the research on participation, some reference to the acknowledged global agenda is important. The UN Convention on the Rights of Persons with Disabilities sets its Purpose from a human rights perspective, stating the intention for signatory states to

> *"…promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (UN 2007)*

This rights-based approach is further emphasised in the preamble, with specific mention of how these rights manifest in relation to decision-making on matters that impact upon them:

> *"…persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them." (UN 2007)*

The Convention on the Rights of People with Disability was first presented to the United Nations in New York on 13 December 2006. Since then, as at 5 January 2022, it has been signed by 164 states and ratified by 184 states (UN 2022). It then beckons the question of why, if so clearly articulated in a UN Convention that is so widely subscribed to, should people with disabilities still feel so marginalised? Why do they feel so disempowered in a policy environment that should actually support empowerment and self-determination?

This question forms part of the proposition of this thesis – that the policy environment remains largely aspirational and in fact the day-to-day experiences of people with disabilities lags behind this UN Convention and the promises made by such social reforms as the National Disability Insurance Scheme in Australia. It is noteworthy that alongside the aspirational policies are the omnipresent "Close the Gap" type metrics. Similar to the targets so prominent in Aboriginal Affairs, these metrics are evidence that people with disabilities are not experiencing the same life outcomes as people without disabilities (AIHW 2020).

As prima facie evidence of the disparity in life expectations, the Australian Institute of Health and Welfare (AIHW) measures metrics across both health and social determinants of health parameters. Some examples of these are presented below as an excerpt from the AIHW website:

Health	*54% of people with disability (aged 18 years and over) have hypertension, compared to 27% of those without disability*
Justice	*47% of adults with disability have experienced violence after the age of 15, compared with 36% of those without disability*
Education	*1 in 3 people aged 15 and over with disability, who left or never attended school, have completed Year 12, compared with 2 in 3 people without disability*

Employment	*48% of people with disability aged 18-64 are employed. This is lower than those without disability (80%)*

(AIHW 2022)

These metrics clearly show a person living with a disability in Australia today does not have the same life expectancies, both in longevity and in quality, to those people not living with a disability. This disparity underpins the state of disempowerment that exists and which is a key objective for the National Disability Insurance Scheme to address. Whilst a person with a disability may not experience the same life expectancies as someone without a disability, even with the best of care and supports, they should be able to live their life to the fullest, with as much control over their life choices as possible. This is how the NDIS seeks to address the Convention on the Rights of Persons with Disabilities and reduce the societally imposed barriers to quality of life.

It can be argued that disadvantage is not the same as disempowerment. That indeed a disadvantaged person can feel empowered, and an empowered person can also at times be disadvantaged, and the omnipresent classification of people with disabilities as something less than able is of itself disempowering. And furthermore, a disadvantaged person who is disempowered may be rendered more disadvantaged by that very disempowerment. This is best explained by the ableist phenomenon whereby an able-bodied person may use the expression “confined to a wheelchair”. For a person with a disability the wheelchair is a mobility aid that assists them to move around. Their choice to access and use the aid is one of empowerment, not disempowerment. But society’s ongoing predisposition to focus on the negative, to judge the imperfection, to see the disability rather than the person, means that this disempowerment continues and is perpetually reinforced. It is not an internal locus of control for the person living with a disability, but rather a projected perception by the society within which they live. And it is this prevailing attitude that is the focus of *Australia’s Disability Strategy 2021-31* (Commonwealth of Australia 2021).

In line with the United Nations Convention on the Rights of People with Disabilities, and the Australian NDIS legislation (Commonwealth of Australia 2013), the Disability Strategy adopts the social model of disability whereby:

> *"It recognises attitudes, practices and structures can be disabling and act as barriers preventing people from fulfilling their potential and exercising their rights as equal members of the community." (Commonwealth of Australia 2021, p5)*

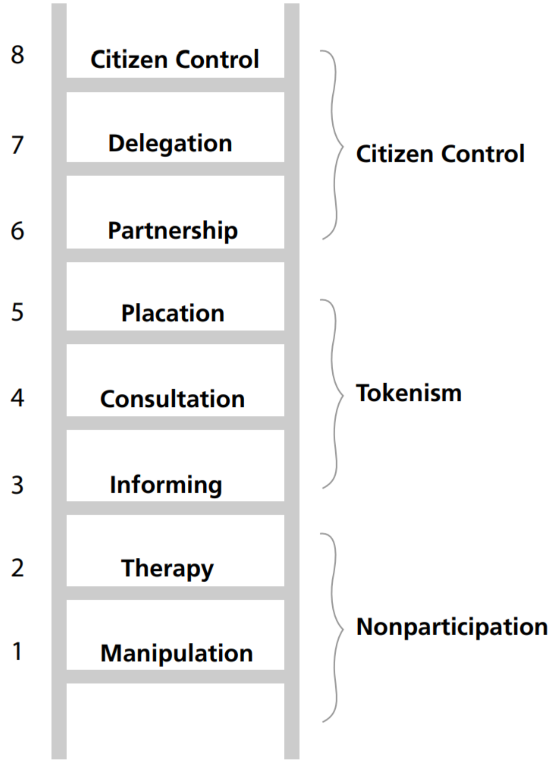
Of the seven outcome areas specified in the Strategy, one is dedicated to changing community attitudes. This outcome area, with its four policy priorities, is focused on building a more inclusive society and ultimately in improving community attitudes towards people with disabilities. The Strategy sees this as equally important as removing barriers in the built environment (Commonwealth of Australia 2021, p33). Herein lies the interesting distinction between disadvantage and disempowerment. The former is a function of the person's disability. The latter is a function of the prevailing attitudes in society and has less to do with the person or their disability. The fact both are addressed in the recent Strategy suggests disempowerment is just as real as disadvantage in contemporary Australian society and is very real for people with disabilities.

3.2 The Age of Co-Design

3.2.1 Co-Design

Governance models, if designed to do so, can serve the purpose of embedding the voice of the person with a disability, to varying degrees, and facilitating it being heard when decisions are made. Beyond the formal governance structures there is a move to hear that voice on an everyday basis. One way to do this is through a process called co-design. It is popular today, although it had its roots in engineering and design theory, often associated initially with Scandinavia and urban developments (Storvang 2020). It is a process that involves the consumer in the design phase so that the product (or service) better meets their needs as the end-user (Storvang 2020).

Co-design is not new, with roots going back half a century to the start of participation theory. Sherry Arnstein developed a ladder of citizen participation in 1969. The metaphor of a ladder was used to portray the different steps from a disempowered involvement to a more empowered involvement where there was some control over decisions being made, and ultimately to a position of the consumer having full control and thereby being referred to as a citizen. The ladder looked like this:



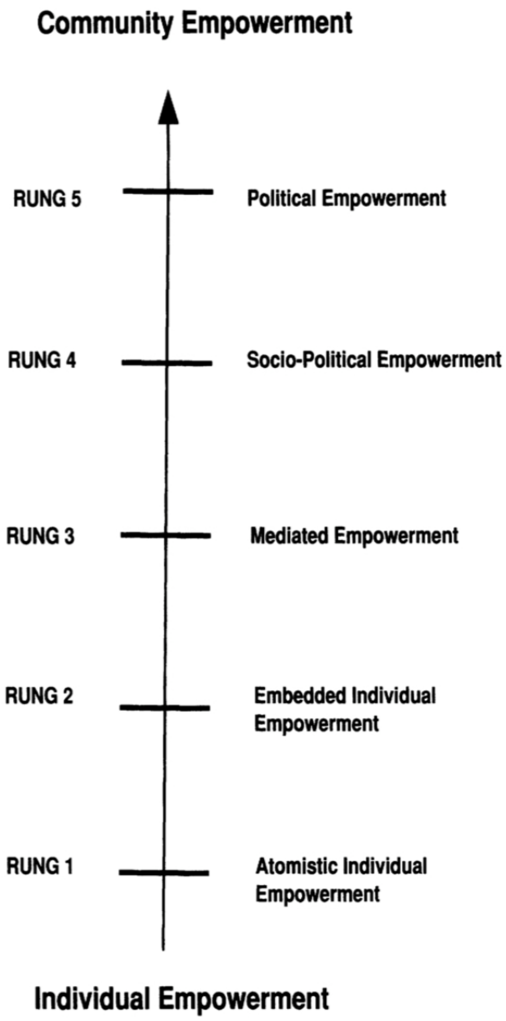
Arnstein's Ladder (1969)
Degrees of Citizen Participation

(accessed from https://www.citizenshandbook.org/arnsteinsladder.html)

Understanding the context of Arnstein's work is important to understanding the growth of its influence on citizen participation into the future. Initially working as a social worker and then in community relations for a hospital, Arnstein was introduced to public policy via a chance meeting with a Kennedy family member (AACOM). This meeting led to Arnstein working directly to the Kennedy Administration in a role with the Commission on Juvenile Delinquency. From this role she became increasingly involved in engagement strategies with minority groups, including her major contribution to the national strategy to desegregate the US hospital system

(AACOM). Later she worked for the Johnson Administration where she became involved in leading citizen engagement strategies to guide the “Model Cities” urban renewal programs as part of that Administration’s “War on Poverty” (AACOM) and in response to America’s growing civil rights movement.

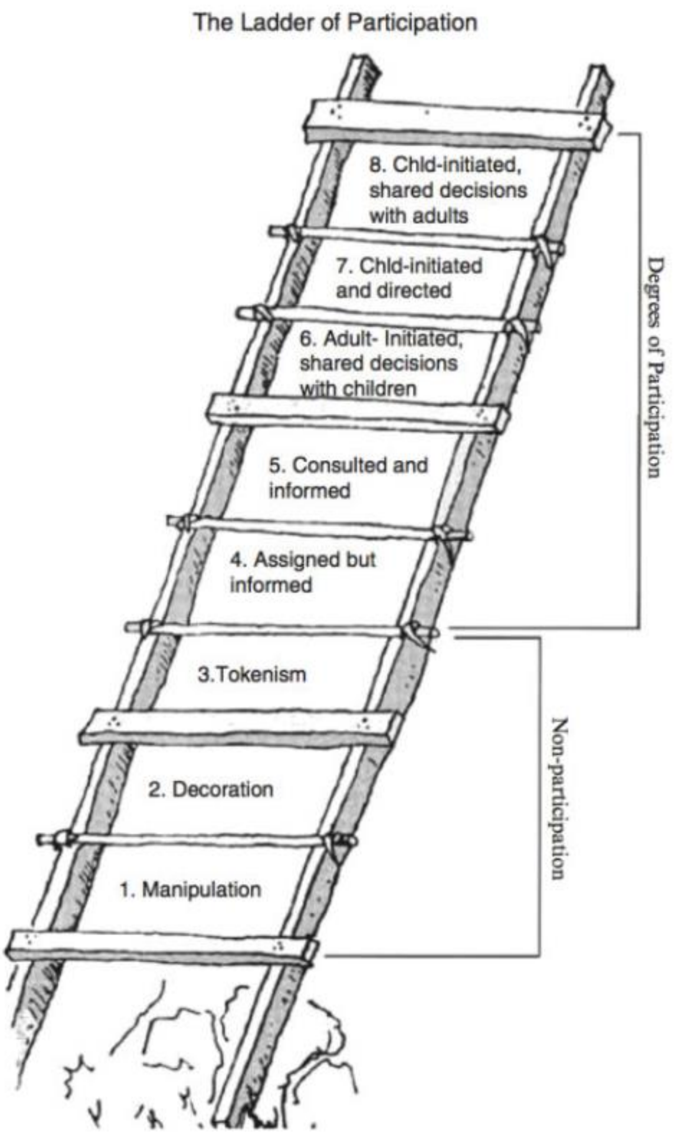
Arnstein not only built a conceptual framework to engage members of the public, or citizens, but she also showed the value of doing so when engaging those members who were socially dislocated and/or disadvantaged. Her work was continued by Elizabeth Rocha (1997) with her Ladder of Empowerment (Rocha 1997). This model of engagement built on Arnstein’s ladder by addressing one of its limitations – the static functionality of citizens. Rocha concentrated on building empowerment into the model so that citizens could move up the ladder and become more empowered in their decision-making. It also delineated between individual decision-making and growth of empowerment individually to contribute to an informed and empowered collective (Rocha 1997). A copy of this ladder is below:



Ladder of Empowerment (Rocha 1997)

(accessed from https://organizingengagement.org/models/ladder-of-empowerment/)

Also advancing Arnstein's framework was the work of Roger Hart who developed a Ladder of Children's Participation (1992) which, similar to Arnstein, looked at increasing agency in decision-making as one goes up the ladder. This model had application to professionals working with minors and informed not only public policy, but teaching, Scout Leaders, coaches and all manner of child related industries (Hart 1992). A copy of this ladder is below:



Ladder of Children's Participation (Hart 1992)

(accessed from https://organizingengagement.org/models/ladder-of-childrens-participation/)

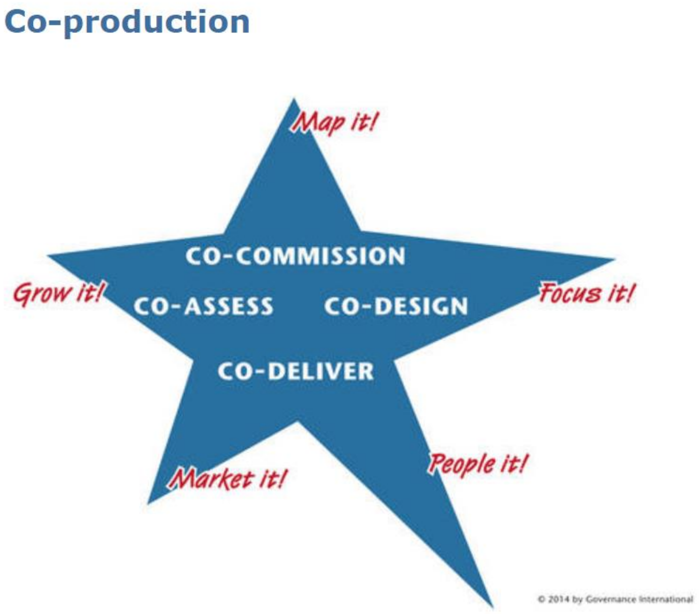
Following from Arnstein's Ladder, the more contemporary and commonly known International Association for Public Participation (IAP2) Spectrum came to the fore from the 1990s, with its last formal update in 2014 (Hussey 2019). The IAP2 Spectrum simplifies engagement to just five stages as per the below diagram:

(accessed from https://iap2.org.au/wp-content/uploads/2020/01/2018_IAP2_Spectrum.pdf)

The five steps can be briefly paraphrased as follows:

1. Inform – To provide the public with the decision and the rationale for the decision (e.g. the name of a new public place)
2. Consult – To seek views of the public prior to making a decision (e.g. seeking input via a competition to name a new public place)
3. Involve – To involve the public in the project and to garner public views to help make decisions that reflect the community (e.g. involving traditional elders in providing traditional language suitable for a new place name)
4. Collaborate – To involve the public in many aspects of the project, from planning, design and implementation, and allow the public to input to decisions (e.g. involving members of local community to design walkways, paint murals, and write signposts for a new public place)
5. Empower – To hand over decision-making to the community and allow the community to make decisions about the project, from planning through to implementation (e.g. establish a steering community of community representatives and let that committee guide the project, making all essential decisions)

What grew from Sherry Arnstein working in a government administration to advance strategies aimed at reducing poverty, evolved into a global practice of citizen engagement and public participation used by all manner of practitioners in government, non-government and not-for-profits, and the corporate sector as well. Whilst the IAP2 Spectrum remains in vogue today with a large and diverse community of practice, there is a more general push to incorporate consumers, end-users, community members, laypersons, in planning of all manner of aspects of everyday life. This broad involvement of the consumer (and all other cohorts mentioned) is broadly deemed co-creation, or co-production. Co-creation has in itself a number of sub-elements including Co-commissioning, Co-designing, Codelivering, and Co-assessing. See the model described by Governance International in the diagram below:



Available from https://www.govint.org/our-services/co-production/

Again, each of these concepts can be paraphrased as:

1. Co-commission – Involving members of the public in determining the need for services and prioritising those needs according to resources available

2. Co-design – Involving members of the public to contribute to the design of services, with a focus on tailoring resources to meet local needs

3. Co-deliver – Involving members of the public in the local service workforce and oversight bureaucracy to deliver services to members of their community

4. Co-assess – Involving the public in the evaluation of services, ensuring that feedback is heard and addressed in a timely fashion, enabling localised accountability to the public beneficiaries.

Storvang delineates between co-production (or its equivalent, co-creation) and co-design in the following manner:

> *"…in co-design, people are involved in the development process even though they are not trained in design processes or in internal processes. This is different from co-creation, where mainly experts are involved…" (Storvang 2020, p177)*

From reviewing the literature it is clear that a modern participation framework, centred around co-design and co-production, has evolved. The policy environment has changed from the radicalism of the 1960's where Arnstein first agitated for change to increase the consumer voice. A change that in its nature was a socially liberal and socially democratic move to recognise the legitimacy of the consumer as central in the decision-making and to transfer power to the consumer through a structured engagement tool. Radical as it aligned with agitation being stirred up through the civil rights movement in America at the time and radical in that it sought to transfer power from the established elite to the deprived and poor (AACOM).

As the concept of citizen participation became more widely used, and more mainstream, the radicalism of the 1960's changed to the neo-liberalist ideas of the 1970's where there was broader acceptance of the role of consumers as beneficiaries and the need to consult with them as beneficiaries to ensure needs were being met and resources were being well utilised. Neoliberalism also brought with it a faith in the marketplace and in service providers meeting the needs of consumers, rather than the default safety net that was the State-run institutions (Gooding 2016). This change coincided with the move to community-based care, rather than the prevailing institutional care that had been provided in the past, which in turn supported the development of the care industry with the proliferation of further providers, especially the purpose-driven not-for-profit organisations that came to supplement the more established faith-based providers.

From its roots in the banking and capital markets in Chile in the 1970s (Connell et al 2009, p331) neoliberalism was alive and well in Australia from the 1980's, with examples such as the employment services sector being largely outsourced from government into the private sector. However in this move to honour the free market, there has been little research on how that outsourcing has impacted providers in the markets it created (Considine 2010, p64). The focus on individuals and their access to effective markets has taken the shine away from many previously cherished resources, especially in the broader benevolent welfare sector, or third sector. As one author, using a dichotomized Marxist-Foucauldian lens, puts it:

> *“recent history is understood in terms of a motivated shift away from public-collective values to private-individualistic values. Stories about “neoliberalism” thereby succeed only in finessing a set of interminable conflicts between equally compelling values of individualism and collectivism, autonomy and responsibility, freedom and obligation.” (Barnett 2005, p8)*

Trends identified by Barnett (2005) include the changing consumer expectations towards public entitlements, the decline of deference involving shifts in taste, trust, access and expertise, and probably most importantly the refusals of the subordinated and the emergence of anti-paternalistic attitudes (Barnett 2005, p10). It is the latter point that is particularly relevant to this thesis, with the empowerment of people with disabilities the objective of the NDIS reforms and the transfer of power from the established service provider institutions to the individuals – that is, a rebuking of the paternalistic attitudes of those who thought they knew best, and a commitment to actually ask the person with a disability themselves. Put simply, under neoliberalism:

> *“Needs formerly met by public agencies on a principle of citizen rights, or through personal relationships in communities and families, are now increasingly likely to be met by companies selling services in a market.” (Connell et al 2009, p331)*

The neoliberal bent to free markets, and the expected benefits of efficiency that entailed, certainly paid heed to the elements of paternalism that no doubt did exist prior to its adoption. However neoliberalism isn’t without its own flaws. When talking of the values of the not-for profit sector, Considine (2003) noted the values of mutuality, fairness and participation which he saw as follows:

> *“The first was the right of each client to obtain the best possible service (civic rights). The second was a belief that by helping particular kinds of clients, such as young people or the disabled, the organisation would promote a more*

> *just welfare society (social justice). The third was the notion that the agency was contributing to improved local opportunity (community building).” (Considine 2003, p69)*

It is this moral fabric that is so valuable in the tapestry of society that is at risk if price becomes the determining factor, or where economic policy overrides social policy. A point made recently by Bartnik et al (2022) when suggesting relationships need to take precedence over transactions in a disability support system.

Whilst neoliberalism is obviously alive and well in contemporary Australian human services policy and practice, and indeed the current NDIS, it is not an end point in itself. Giving people choice and control over decisions that impact upon them, and access to a free market from which to purchase services, is an objective, but so too is growing that person’s independence and supporting them to be an economic contributor in their own right. The Nordic-type social investment model of “inclusive growth” that is currently being developed by the Organisation for Economic Cooperation and Development (OECD) and the Bretton Woods Institute appeals in Australia as it is deemed more sustainable that the neoliberal “growth first” strategy (Deeming & Smyth 2015, p301). This is not a point lost on stakeholders in Western Australia with the State Disability Strategy 2020-2030 Action Plan having jobs and participation as the second objective of the first of four strategic pillars. The expected outcome is described in the plan as follows:

> *“People with disability have opportunities for meaningful and inclusive employment and economic independence.” (WA Government 2020)*

The neoliberal approach that underpins the NDIS, with its ambition to empower the most vulnerable clients to shape and control their own services (Considine 2022, p138), is an approach to bring the consumer into the decision-making by individualising the services and in the case of the NDIS, transferring the payment to the person with a disability to purchase services.

With neoliberal origins in the 1970’s, there was further change in co-design thinking in the 1990’s in line with broader socially democratic thinking with the major push for consumers’ involvement in design and planning in relation to urban renewal programs (Alam 2009) through to citizen participation in co-production today (Janamian 2016, Stainton 2017), with very well defined models as presented above. This evolution, and the resultant transference from disempowerment to empowerment, is probably most clear in the mental health sector, where the changes over time have manifested a transition from incarceration and institutionalisation (disempowerment) towards community living and in-home supports (empowerment) guided by consumers active in the governance structures (Gooding 2016).

It is clear in the new millennium that the consumer's voice is here to stay. Sherry Arnstein lived long enough to see her principles adopted in mainstream planning, with the concept of the ladder incorporated into American Institute of Certified Planners (AICP) Code of Ethics and Professional Conduct (AACOM). Incorporating the views of consumers in the design, planning, implementation and evaluation of services they access is mandatory for organisations wishing to obtain certification in many human service sectors. The various requirements are set out below as examples of the growing need to listen formally to the needs of consumers:

Standard Type	Specific Standard relating consumers
ISO 9001:2015 Quality Management[2]	4.2 Understanding the needs and expectations of interested parties
National Mental Health Standards 2010 (Commonwealth of Australia 2010)	3 Consumer and carer participation
National Standards for Disability Services 2013 (Australian Government Department of Social Services 2013)	2 Participation and Inclusion

Central to all six of the Disability Standards is the principle of "person-centred planning" and the need to promote choice and control in decision making for people with a disability (Australian Government Department of Social Services 2013, p9).

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[2] available by paid subscription only

Specific to the localised geography of this research, being Western Australia, a recent partnership between the Government of Western Australia and the peak advocacy body People with Disability WA, has seen the publication of resources Co-Design Guide (People with Disabilities WA 2019A) and Co-design Toolkit (People with Disabilities WA 2019B) to encourage co-design. These “Connect With Me” resources have been developed with the aim of increasing the capacity of people with disabilities to contribute, and for service organisations to include and involve, and the community to embrace, the views of people with disabilities.

The “Connect With Me” initiative has produced a welcome resource that will tackle the tokenistic appointments that often happen to Boards of community care services, especially to the unpaid not-for-profit Board positions. Those appointments to Boards tend to occur where it is felt someone with a lived experience, whether that be a disability, Aboriginal culture, or Lesbian, Gay, Bisexual, Transgender, Intersex or Queer (LGBTIQ), or other minority and/or underrepresented group, should be represented on the Board. Such appointments can place people in vulnerable positions where they are expected to be representative of vast cohorts, some of whom they have no right to speak on behalf of. Sometimes they are fulfilling a function of post-decision “rubber stamping”. Issues with appointments of people with a disability to Boards are recognised:

> *“…the appointment of a board member should not be tokenistic. Doing this will be recognised quickly and the person appointed will lose credibility.” (Geraghty 2017, 7)*

The “Connect With Me” resources have been developed in conjunction with people with a lived experience who have experience in governance, have been in these vulnerable positions, and have learnt from prior mistakes to not only show what should be done to build the capacity of prospective Board members with a lived experience, but also the Boards to which they will be appointed. Such an approach should allow for a mix of specialist business skills (e.g. law, accounting, marketing), with representative skills (the lived experience). The ”Connect With Me” resources are certainly aligned with the aspiration to socialise disabilities in the public policy framework in Western Australia and nurture a more inclusive society going forward (Fleay 2022).

The evolution in co-design has extended throughout the world – from Sherry Arnstein who first conceptualised consumer participation, through the well-known and used International Association for Public Participation Spectrum, to the more nuanced Governance International's Co-production Framework. There is also a growing repository of best-practice case studies which specifically address co-design. An example from the Western Australian disability sector[3] is available here: Burrows Case Study 2017 (Burrows 2017).

Co-design is at a point where it is now accepted practice to involve the consumer at the centre of their care. Stanford University is proposing civic engagement models like the 5 Es of Entice, Enter, Engage, Exit and Extend (Kanagasingam 2018). Hence the term "person-centred practice", or "patient-centred practice" as it relates to the health sector for example. In this regard, Harvard University is looking beyond technological advances in health care to see the benefits of strong engagement via profiling patients and fine-tuning engagement according to patient profile (Deichmann, van der Heijde 2017). In fact some would say that co-design is not just essential in best practice today but is at the cutting edge of design for tomorrow. Hence why design thought leaders IDEO have built on all of this knowledge and expertise and have produced *The Field Guide to Human-Centered Design (2015)* and why they say:

> *"In a world that's heating up, speeding up, and increasingly interconnected, there's so much that can't wait – and can be made better. We believe that a more sustainable, equitable future is for all of us to design." (IDEO 2022)*

This move to embrace co-design in social service design, planning and implementation has continued to a point where by 2020 there was a call by the International Association for Public Participation for an International Year of Participation (https://iap2.org.au/about-us/international-year-of-engagement/). The

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[3] I am responsible for this case study and am the published author of it on the Governance International website

value of individual engagement in co-design is being leveraged to advocate for the collective involvement of the consumers', or the publics', voice.

It is certainly a move in vogue with the Australian Government as we enter the 2020s. Whilst the Aboriginal and Torres Strait Islander Commission was abolished as "a failed experiment in Indigenous self-determination" some 15 years ago, the (now ex) Minister for Indigenous Australians, Mr. Ken Wyatt, an Aboriginal person himself, has called for a National Co-design Group, made up of 16 senior Aboriginal people who will work with the National Indigenous Australians Agency to "develop models for a national voice to government". (Wyatt 2020) Questions likely on many Australians' minds as they went to vote in the Referendum in late 2023 was no doubt "How were Aboriginal people involved in the co-design for the Voice to Parliament and how many were actually involved?"

However even with the widespread adoption of co-design, it is clear we are still missing the mark. This point is not lost on the Australian Federation of Disability Organisations (AFDO) as raised in its media outlet "Disability Loop" in March 2016:

> *"It means doing away with the outdated and inequitable view of people with disability and their families as clients and recipients first, and instead treating us as experts with true capacity to help build the NDIS." (Australian Federation of Disability Organisations 2016)*

Whilst there is certainly room to improve, it is timely to reflect on how far we have come as a society, since the days of caring for the impoverished outcasts (Charlton 1998) to today where we have aspirations to treat everyone as equal citizens. Our desire to embrace co-design is well intended and admirable, but as the ADFO (2016) article suggests, it was never meant to be easy.

One reason it might not be easy is the assumption that one can co-design with a large group of heterogenous people. Or conversely, that all people with disabilities are the same and have the same needs. This was a point that obviously played on the mind of prominent Aboriginal elder, Dr Robert Isaacs, during his long and distinguished public service career:

> *“This is a contentious point, and one that angered many Aboriginal people who thought that I should be ‘on their side’ no matter what their role in any issue. This wasn’t right – never has been and never will be. An Aboriginal person can advocate for other Aboriginal people, but that doesn’t mean they have to support every single Aboriginal person in every single decision they make or behaviour they display.” (Isaacs 2021, p222)*

In fact it is likely that both of these factors are at play with the rollout of the NDIS in Australia. As Storvang et al. point out, the research on co-design communities is very limited at this stage (2020, p177). This dearth in research is being addressed in part by Governance International, based at the University of Birmingham, through the accumulation and publication of best practice case studies in co-design from around the world.

It is important we take stock of previous experiences in empowerment and build on them. Again, the Aboriginal Affairs sector gives us a poignant reminder of the importance of learning from past mistakes, with former Prime Minister John Howard justifying the abolition of the statutory body ATSIC as a failed experiment in separate representation and elected representation (Pratt 2004), or as the media would have us believe “a failed experiment in self-determination” (The Sydney Morning Herald 2004). Given the similarity of the intent between the ATSIC legislation and the more contemporary NDIS legislation, there are ongoing concerns that commitment to the Objects relating to choice and control, as stated in the legislation, may be similarly discarded when deemed “uncomfortable” or “too hard” by a government.

The movement is evident to genuinely involve vulnerable people in decisions that impact upon them. The move to co-production, co-design and co-creation is topical today in both industry (Janamian et al 2016. pS12; KPMG 2015) and academia (Wampler and Hartz-karp 2012; Alford 2014). With clarity of vision on what constitutes value creation for the consumer, the platforms for engagement are becoming increasingly sophisticated. Ranging in type (e.g. cognitive, emotional, behavioural), level (from non-engaged to highly engaged), and in duration (one-off, recurring and continuous), opportunities are being created in many sectors to purposefully engage with all manner of vulnerable people to co-create (Janamian et al 2016). In the words of these authors, this is changing the role of consumers:

> *"…from being 'users and choosers' to becoming 'makers and shakers' of services" (Janamian et al 2016, pS12)*

Whilst these may be buzzwords of the new millennium, bordering on being a fad (Alford 2009, p24), it should be remembered that the success of co-design will be measured in genuine empowerment of the person with a disability. Done well it could realise substantial benefits but done poorly and it may do more harm than good and serve to further disempower the person it was intended to benefit (Gilchrist et al. 2019, Evans 2015).

Another aspect of co-design that needs to be considered is the benefit beyond the person with a disability. The model of "Partnership" touted by KPMG (KPMG 2015) shows an interaction between individual and the community sector, government, and private industry as per the diagram below:

Source: KPMG International, 2015.

(KPMG 2015)

This sense of holistic partnership is explored in public policy, with a recent case study analysis undertaken by Butcher et al. to identify how collaboration between sectors can occur in a co-design environment (Butcher, J. et al. 2019). This study concludes that this level of collaboration is required to address the “wicked” social problems that society faces today and that:

> *“the traditional bureaucratic model of public administration is not up to the task of addressing complex social problems” (Butcher et al. 2019)*

It is this same thinking, of holistic collaboration and incorporating co-design with people with a lived experience, which was evident in the Productivity Commission’s analysis of financing the NDIS and in making the brave recommendation to government to proceed with the Scheme’s implementation.

> *"there would be some savings over the longer-run from the fruits of early intervention, the fiscal gains from reduced income support as people with disabilities and carers increase their economic participation, and from the likelihood of increased productivity in the current, disjointed, disability system." (Productivity Commission 2011)*

The thinking was that as funds were invested early by government, people would require less supports. The carers required to care for people would be reduced as people became more independent. And both the people with disabilities and their carers would be able to contribute to private industry, thereby supporting the markets with economic growth through their participation as labour. The important point being made by the Productivity Commission and KPMG is that the empowerment of a person with a disability also empowers the community and the broader economy.

There have been moves locally, in Western Australia, to adopt the elements of co-design. For example, the WA Council of Social Services developed principles for co-design (WACOSS 2016) while the WA Government partnered with the peak body People with Disabilities WA, to produce not just a guide (PWDWA 2019A) for service providers to undertake co-design with people with disabilities, but also a training toolkit (PWDWA 2019B). The training toolkit was intended to raise awareness of the benefits of co-design and then build the capacity of the sector to do it.

In an advance on just engaging consumers, there is a move to tailor governance practices to serve people with disabilities. The establishment of micro-boards is a relatively recent development, with legal entities being established with those closest to the vulnerable people in charge of decisions, taken in conjunction with the vulnerable person (Jay 2011). With provision for self-managed funding under the NDIS, this could well be an idea that grows in popularity in the near future. Given its small and intensely personal nature, it could see a whole new level of engagement with people with disabilities. However the same fundamental flaws associated with "assumptions on behalf of" will need to be addressed, regardless of how small and intense the relationships in the governance model. Even with a small number of people all working with the person with a disability at the centre of decision-making, if that centre shifts and surrogate decision-making appears, then the Tennessee

Williams' sentiment of "relying on the kindness of strangers" (https://www.goodreads.com/work/quotes/142449-a-streetcar-named-desire) becomes very real (Williams 1951).

Forcing co-commissioning, co-design and co-production on to the sector may be another option to progress empowerment. In British Columbia the government has introduced the Representation Agreement Act 1996 which seeks to mandate supported decision-making based on informal relationships which explicitly presumes the capability of all individuals to make decisions affecting their own lives (Jay 2011). Whilst noble, without monitoring of compliance backed by a regime of sanctions, or rewards to incentivise compliance, it will only contribute to the plethora of engagement frameworks already in existence (Wright 2015, p66).

Indeed the question as to whether government should impose mandates, quotas or ratios, or regulate involvement through any other quality assurance regime, is one that the corporate sector has grappled with for decades. The Australian Stock Exchange's (ASX) Corporate Governance Council has developed and refined the *Corporate Governance Principles and* Recommendations, now in its third edition, and has continuously increased the rigour around reporting on diversity. Recommendation 1.5 specifically addresses the need for gender diversity and suggested reporting on gender equity (ASX Corporate Governance Council 2014, p11).

3.2.2 Governance Frameworks

With such an emphasis on consumer choice and control, or empowerment, as directed by government, it is no wonder there is a parallel effort in the broader society, including academia, the service sector, the professional associations, and advocacy bodies, to incorporate the voice of the consumer. This section shows how the intentions of co-design, explained in the previous section, are manifested in contemporary governance practices.

The purpose of this thesis is to investigate governance frameworks that empower people with disabilities to access community care services. In such an investigation it is worthwhile to outline some of the commonly used governance mechanisms that are designed to involve the consumer and to then link to participation frameworks to determine what may work well.

There are many mechanisms that can be used to include the voice of the consumer, not in the least being feedback from service users for example. However, in the context of this investigation, and to answer the research question specifically, the focus has remained on governance frameworks, rather than more transactional mechanisms like feedback. That is not to say feedback should be ignored by organisations or should not be used in conjunction with these frameworks. Indeed, it should be. To be included in this research as a Governance Framework, the involvement of a consumer should resemble a structural inclusion – for example something that can be designated on an Organisational Structure Chart, or be seen as an inclusion in, rather than a function that remains outside, the organisation.

A quick point of clarity to begin with. There is much rhetoric about canvassing the voice of people with a lived experience of disabilities. According to the NDIS, this lived experience can include a person living with a disability. But it can also include a carer, a parent of a child with a disability, a teacher or teacher's aide, a therapist, or even a housemate (https://www.ndis.gov.au/about-us/glossary). That is, the cohort of people with a lived experience of disability is a broader cohort that includes people with a disability, which themselves can be seen as a subset of the lived experience cohort. Whilst each person has a valued contribution, it is not the same line of sight as that of a person with a disability, which the same glossary, with reference to the UN, defines as:

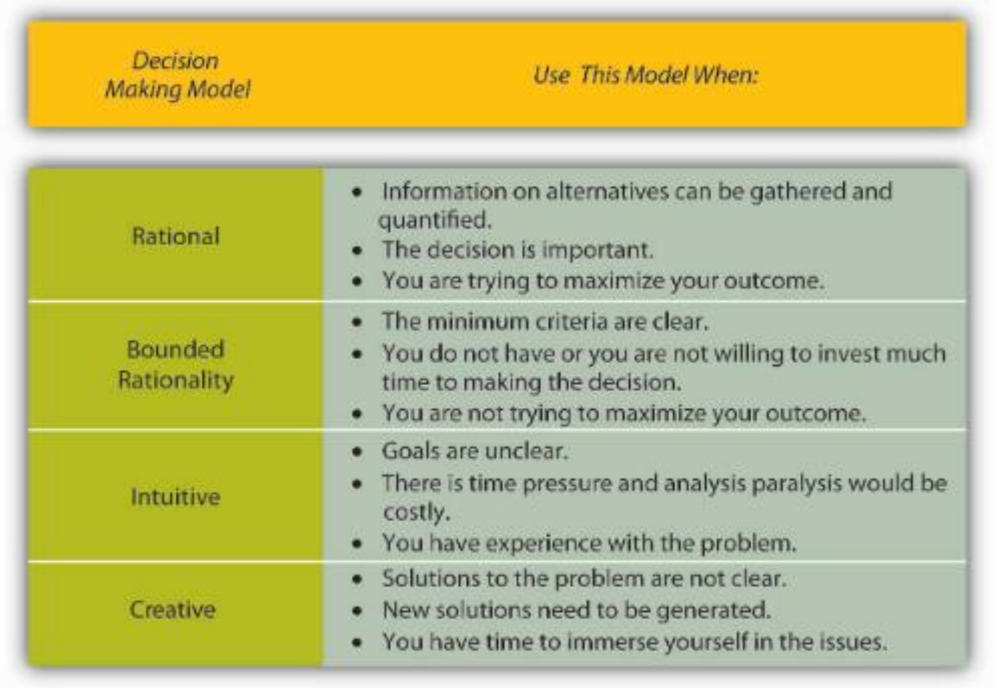
> "A person who has long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."
> (https://www.ndis.gov.au/about-us/glossary#p)

It is a line of sight filtered by different lenses with different assumptions overlayed. When considering governance frameworks, it is worthwhile discerning which voice needs to be heard. If it is the voice of a person with a disability, then the framework should cater for just that, and not the broader cohort of people with a lived experience. This is especially since that broader cohort is still firming in its conception as part of social policy and as yet lacks clarity:

> *"…there is a strong tendency for the term 'lived experience' to be used with little or no clarification about what it might mean or imply." (McIntosh & Wright 2019, p450)*

In testing the hypotheses presented in this thesis, I have paid close attention to governance that involves people with disability. I have looked at structures, policies, processes and engagement strategies that enhance the involvement of people with disabilities and supports them to take an active role in governance; or at least in its simplest form – in decision-making that impacts upon the individual.

Decision-making can be a study in itself. The four main models of decision-making are described below:



Decision Making Model	Use This Model When:
Rational	• Information on alternatives can be gathered and quantified. • The decision is important. • You are trying to maximize your outcome.
Bounded Rationality	• The minimum criteria are clear. • You do not have or you are not willing to invest much time to making the decision. • You are not trying to maximize your outcome.
Intuitive	• Goals are unclear. • There is time pressure and analysis paralysis would be costly. • You have experience with the problem.
Creative	• Solutions to the problem are not clear. • New solutions need to be generated. • You have time to immerse yourself in the issues.

Principles of Management by University of Minnesota available from https://open.lib.umn.edu/principlesmanagement/chapter/11-3-understanding-decision-making/ (author anonymous)

When making decisions and choosing which model to apply, it is important to know how much involvement stakeholders should have. Or how much community engagement should be undertaken, which itself can change depending on the situation faced. This was the assertion put forward by Vroom and Yetton in their Situational Leadership theory (Vroom 1976). Understanding this is key to deciding which model to choose and whether to use a rational type framework like the Kepner-Tregoe framework (Kepner, Tregoe 1965) which identifies key criteria needed in a decision and weights them as priorities. Or a bounded rational model like the RACI (Responsible, Accountable, Consulted, Informed) framework (https://www.racisolutions.com/), or what is commonly referred to as a Responsibility Charting Framework, which focuses on who needs to be involved in decisions and at what level. It is the purposeful use of these models that will best engage with external stakeholders and empower consumers to have choice and control in the decision-making.

When talking about governance, the Governance Institute defines governance as "the way one organises themselves and their resources to achieve their objectives" (GIA 2013). Governance can include structures (e.g. an organisational hierarchy), policies (e.g. controls and parameters), processes (e.g. decision-making processes), and engagement (e.g. involvement of external stakeholders). Where this governance design is specifically aiming to increase the input of a consumer (or user) group, I have broadly termed it "consumer governance" – hence the title of this thesis.

In relation to community care services the involvement of consumers in governance more broadly, and in decision-making more directly, is generally seen as positive, although many authors report there is little evidence of it actually occurring. A keynote search was undertaken of the Curtin University library database using the following search terms: "involving consumers in governance" and "involving consumers in decision-making" and of the articles returned, only a few were directly associated with consumers and governance in relation to community care services. Of the articles chosen on first page search returns, only seven addressed consumers in governance and of those articles, five cited a lack of research on consumer involvement in governance (Shih et al 2022, Lowe et al 2021, Butterworth et al 2019, Allen et al 2012, Zeitz et al 2010). Where there was evidence of consumer involvement, it was reported to be undertaken poorly, and with less than expected outcomes (Allen et al 2012, p 252-254). In fact, the most recent study referenced here is a study of consumer engagement during the covid-19 pandemic and concluded:

> *"consumer representatives were the ones that shifted the partnership from the level of 'inform' and 'consult' to 'empower' during the pandemic... 'Empowerment', in this context, was in the ability of the consumer representatives to defy the prevailing absence of their involvement in the system and service and to initiate alternative and novel ways to bring the voices of patients, families and communities together and into service design and decision-making" (Shih et al 2021, p1999)*

Of note here is the authors’ assertion that it took something as drastic as a pandemic to create favourable circumstances to catalyse the action of involving consumers – probably due to the overwhelming public threat being faced and the need for public compliance – and that it was largely the actions of the consumer representatives that brought about their involvement. Of note also in this quote is the author’s reference to the IAP2 Spectrum in describing the level of empowerment consumers had, which is discussed later in this chapter.

Where a literature review has been undertaken into community representation in hospital board decision-making, the results were likewise sparse. Findings indicated where there has been engagement it has likely been in the form of a quality subcommittee (Murray 2015) and obstacles/impediments to engagement were cited as:

> *“there are a number of challenges to effectively developing the process of community representation in hospital governance: ambiguity and the potential for escalated indecision; inadequate value and consideration given to it by decision makers resulting in a lack of time and resources needed to support the community engagement strategy (time, facilitation, budgets); poor support and attitude amongst staff; and consumer issues, such as feeling isolated and intimidated by expert opinion.” (Murray 2015)*

And whilst there is broad recognition for the benefits of involving the consumer in their care, there is still a need to verify the benefits as to date the evidence is low and the data is subject to bias (Lowe et al 2021).

Where you do find evidence of consumer involvement is in industry reports, professional association requirements, quality standards, and even security exchange listing rules. Again, aspects of these requirements are discussed later in this chapter. Maybe one of the issues that leads to the poor evidence is the lack of transcendence from ideological concept to practical application. Whereas the NDIS Code of Conduct requires the involvement of consumers (described herein as a “code-covered person”), it does not specify how to do so:

> *"In providing supports or services to people with disability, a Code-covered person must:*
>
> *(a) act with respect for individual rights to freedom of expression, self-determination and decision-making in accordance with applicable laws and conventions" (NDIS Code of Conduct 2018)*

Without some practical guidance of how service providers or their employees should act or respect, the concept remains a good idea, but with little traction in the real world. Or as Shih et al put it, without the impetus created by a pandemic, the involvement of consumers in health governance was "relatively slow-moving" (2021, p1999).

It seems the Australian Government has recognised this in recent years and has put effort into building a repository of resources for people to access on "community participation". It has a public service wide framework for engagement and participation (Australian Government 2021) as well as the NDIA having a webpage dedicated to community participation (https://www.ndis.gov.au/community/community-participation). On this webpage it discusses possible engagement techniques and cites the following as examples of its own engagement:

- Independent Advisory Council
- Reference groups
- Participant First Engagement Initiative
- Research and evaluation (https://www.ndis.gov.au/community/community-participation)

The NDIA has increased its own mechanisms to involve consumers, probably with the most recent appointments of people with disabilities to the NDIA Board, including celebrated sportsman Kurt Fearnley as the Chairperson. But also because it cannot espouse best practice of consumer engagement unless seen to be doing it itself.

Involving consumers and engaging with their communities is important, but doing it in the right way is more important. Whilst the NDIA is making the effort to engage, there is still a strong element of paternalism, even in the language on the webpage.

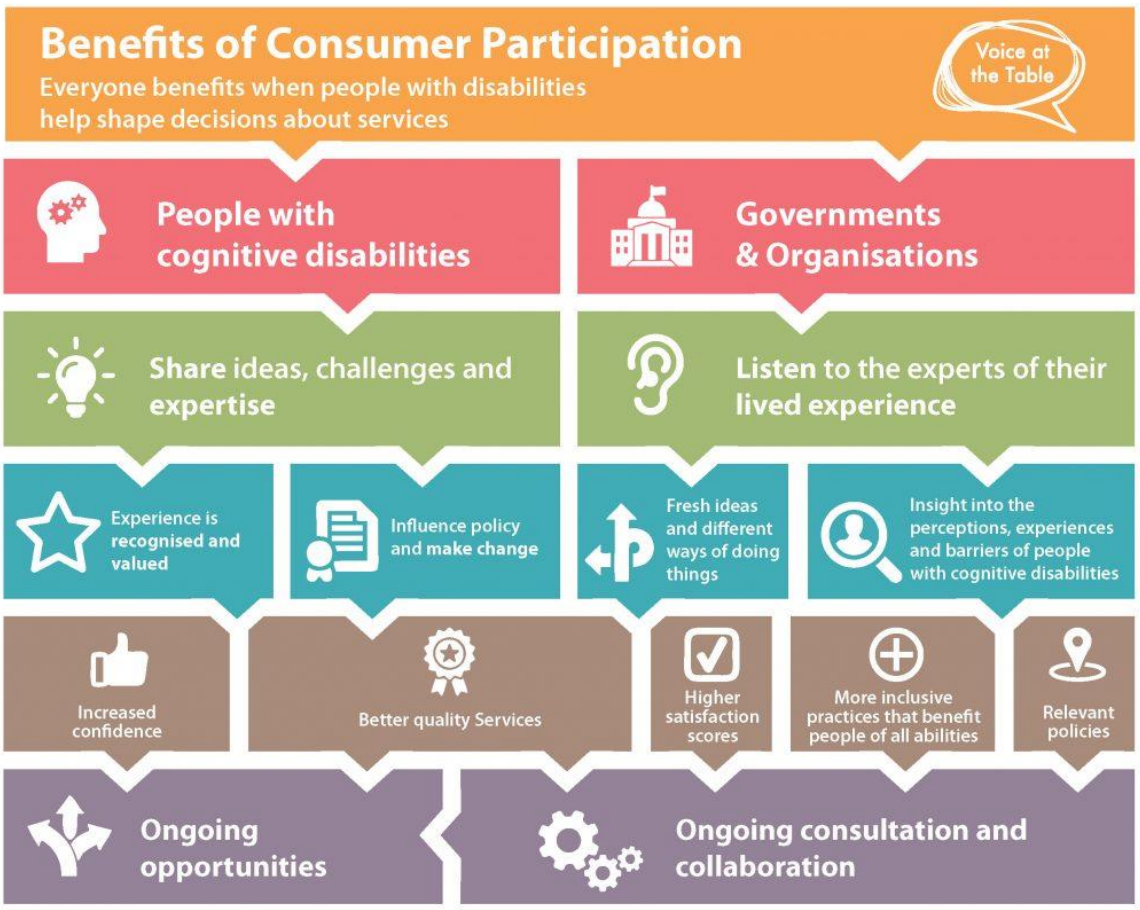
Only at the bottom of the page does it state the agency will also listen. But then it goes on to state it talks "to" participants, rather than "with".

> *"We share information about what's happening in the Scheme and what's changing – and most importantly, we listen.*
>
> *We **talk to** people around the country, at NDIA information and consultation meetings, disability expos, in person and online."* (https://www.ndis.gov.au/community/community-participation - emphasis added)

A slight nuance, but one this thesis is showing to be an important one and one that underlies the frustration of people with disabilities still not being properly listened to and included. Indeed this was the conclusion of a study into disability legislation which found:

> *"Examination of Australian disability legislation suggests that there is a strong legislative intention to support positive outcomes such as inclusion, but limited implementation, with continued heavy reliance on segregated services." (Stancliffe 2019, p1060)*

Getting the process right and optimising the value of the voices of consumers, especially when they be people with disabilities, is not only an aim for service providers and government, but is quickly becoming a requirement via the various industry standards and codes that must be complied with for registration purposes. A valuable resource from Victoria which helps in getting this journey right is "Voice at the Table" (accessed https://voiceatthetable.com.au/). The benefits of getting this journey right are illustrated by Voice at the Table in the following infographic:



(Accessed via https://voiceatthetable.com.au/about-us/vatt-community-organisations/ retrieved 230705)

Some of the more common governance mechanisms that are recommended either by the NDIA via their webpage, by Voice at the Table, or by other industry bodies including the Australian Commission on Quality and Safety in Healthcare and its associated National Safety and Quality Health Service (NSQHS) Standards (available https://www.safetyandquality.gov.au/standards) are listed below. These may also involve people with disabilities.

1. Representative Board / Skills Based Board

The Representative Board is probably the oldest model of governance, whereby people with a common interest – often the parents of children with a disability for example, or people with a vision impairment - would come together with the common objective of improving their position and advocating for special consideration. Over time many of these early model examples have evolved to become sophisticated skills-based models running large and complex operations with high turnovers, large numbers of staff and volunteers, and thousands of service recipients that they are responsible for. Examples in Western Australia include the Slow Learning Children's Group which has become WA's largest provider Activ, the Crippled Children's Association which has become Rocky Bay, and the Spastic Centre which now operates as Ability WA. Each of these modern versions of the original organisations now operates with a Skills Based Board made up of people with requisite business skills and the ability to discharge their director duties per the Corporations Act 2001 and to meet the requirements of the multitude of other legislation and regulation that now relates to service provision for vulnerable people in Australia. But in doing so, they invariably adopt one or more of the below models to ensure they still have access to the views of those they represent and/or service.

2. An Advisory Committee

This model usually involves a select group of people containing a mix of people with disability and people with a lived experience who have an advisory function and may have selected decision-making capacity. An example is the Customer Reference Group run by Therapy Focus, a disability service provider in Western Australia. The membership of the Group ranges from six to 10 and it advises the senior management team on policies and practices (e.g. the Restraints Policy). More recently the Group has been empowered to call for nominations and then decide the finalists and end winner of the People's Choice Award for champion therapist who in their view has made the biggest positive impact in a person with disabilities life.

Where this Advisory Committee has a broad representation of views, including people with disabilities, people with a lived experience of disabilities, service providers and peak bodies and advocates (for example), the Committee may take on a broader community governance type role (Bartnik et al. 2022, p9). According to Bartnik et al., this was the virtue of the previous Disability Services Commission operating for 30 years in Western Australia and was the underpinning of the perception of a superior Western Australian disability services sector prior to the NDIS. It was a system whereby:

> *"This wide ownership reflected inclusive strategic planning and a focus on individualised funding and support, rather than services based on diagnosis." (Bartnik et al. 2022, p9)*

3. An expert panel of advisors

This model usually comprises a small group of four to eight people with a niche experience that is deemed essential to understanding the needs of people with disabilities. It may be a special diagnostic group (e.g. people with vision impairment, or people living with cerebral palsy for example). Or it may also include people with a special skillset (e.g. an architect with experience in home modification designs for people with disabilities).

4. A pooled panel of advisors

An emerging trend is to have much larger panels of advisors to advise across numerous issues and circumstances. Pools can be as large as 2,000 people as is the case with the Ability First Panel which has been established by pooling all 20+ member organisation advisory committees to establish one large group of people with disabilities willing to contribute ideas and advice. The idea of having such a large panel is to ensure the needs of all can be canvassed and addressed. If only working with a small number of advisors, you may get insights to vision impairment and cerebral palsy but have no insights for people with autism for example. By having a much broader panel of willing advisors, they can be called upon for special interest input as required. Another more recent version of this approach is the current (2022) research project being operated by La Trobe University which involves a Rural Health Consumer Panel with members drawn from people interacting with the health system and living all over country Australia (https://www.latrobe.edu.au/news/announcements/2022/join-australias-first-rural-health-consumer-panel).

5. An ex-officio Board member

This is a somewhat dated governance model which incorporated the voice of someone in an unofficial capacity. It enabled a regular visitor (sometimes management, sometimes experts) to attend and contribute to meetings. It is less popular today with the *Corporations Act 2001* (Section 9, Subsection (b)(ii)) clearly focussing on the function of a role and not the title, meaning even an ex-officio member of a Board can be held responsible for the Board's performance if they are deemed to substantially influence the decisions of that Board.

This model, whilst still in use, is often seen as outdated and paternalistic as it can require a person with a disability to attend meetings and participate without the formal recognition and possibly access to supports to meet the responsibilities. Many governance professionals would suggest this model today is best suited as a bridging mechanism to introduce someone to governance with a view to full appointment in due time.

6. An appointed Board member

More contemporary than the ex-officio model is the appointed model. This allows Boards to determine that having a disability, or a lived experience of disability, is a desired skillset on the Board, much like legal or accounting skills. It enables Boards to appoint a person with disability as a requisite skillset and to contribute to decision making with this skillset at the fore of their decision-making. Many would argue this is a preferred model, however it does have limitations.

There is a limit to the number of people that have a disability and who also have the other skills (e.g. financial literacy) to be able to discharge their duties (e.g. due diligence) and who actually want to be a director of an organisation. There is a limit on the ability of one person with a disability to be truly representative of all disabilities and be able to fairly represent everyone's needs without some personal influence of their own experience. And there may be some limitation simply due to a cohort's capacity to discharge duties, as with people with intellectual disabilities for example. Notwithstanding these limitations, one should never assume that it cannot be done!

When it is done, and done well, there is a benefit to the Board as a whole as it gains insights to the service user cohort that it may not previously have had – especially in relation to deeper perceptions and understandings, or real life translations. It often has a broader benefit to the employees of the organisation as they see the Board leading from the top and living the values of the organisation; values that often resemble “Inclusion” and “Respect” for example. The person gains from feeling valued as a contributor to something larger than themselves, and they then often share that experience with others in the service user cohort who themselves become interested in contributing. This works to reduce the “us and them” stigma that often surrounds a service delivery environment and gets people believing they are on the same team. And the skills and experience learned by the person by contributing as a team with other professionally skilled persons, adds to their own ability to function as an individual; to navigate complex systems like the NDIS, and to make decisions that are considered. It is not a guarantee in itself, but if done well can lead to benefits for both individual and organisation alike.

7. A two-tiered Board

Another somewhat dated governance structure that was used largely by academic institutions like private schools, and by religious organisations, is the two-tiered Board (GIA 2013). This model of governance reserved special rights for a select group of people, including at times a power of veto. It typically separated the day-to-day oversight from the core function of maintaining the values and culture of an organisation. Whilst faith-based providers could get along with a corporate structure and manage service provision, the church might maintain a background involvement that ensured services were delivered in line with the church ethos for example, and that staff appointed were canvassed for their alignment with that ethos.

8. A peer-led Board

A peer-led Board is a more contemporary model of governance that is gaining momentum under the NDIS with its promise of choice and control. These are organisations that are led by people with disabilities, usually with at least 50% of the Board and most senior management positions filled by people with disabilities. The attraction of this model is its promise to focus on the needs of service recipients, given the intrinsic empathy its leaders have for the needs of those service users. Examples of this model of governance in the Western Australian disability sector include Valued Lives and My Place and to a lesser extent, Avivo. This model has been identified as a preferred model by the National Disability Insurance Agency for aspects of capacity building in the sector as per program guidelines issued previously for prior grant rounds.

Notwithstanding the obvious advantages the model has, it too has limitations. These include access to people with disability who have the requisite skills to run large and complex service organisations. There is also the assumption that people are always acting in the best interests of their peers, which may not always be the case.

In addition to the frameworks that can be used to engage people with disabilities, there are also some logistical matters that can be addressed to support the involvement of consumers in governance. Supports may include some of the following, as suggested by Voice at the Table (VATT 2022) and further by the Australian Institute of Family Studies (Frawley 2020):

- Using Plain Simple English in written papers
- Allowing enough time for discussion
- Providing a travel reimbursement to cover out-of-pocket expenses
- Paying a sitting fee to acknowledge and value unique contributions
- Accessing a support person / sign language interpreter
- Defining language
- Removing barriers to access

For further information, community representatives can access the Top 10 Tips from the Voice at the Table Website (Voice at the Table 2022).

Choosing which governance framework to use is a challenge and depends largely on the types of decisions the consumers are expected to make as discussed later in this chapter. What this quick overview shows is the different mechanisms commonly used and which may be adopted as softer approaches in comparison to the directly appointed Board member approach. This is necessary to ensure people with disability can contribute to the level of their capacity, and that their contribution is valued and utilised:

> *“…highlight the need for an equal commitment to the tangible and intangible aspects of support; in particular, the importance of the attitudes of those ‘in power’ to ensure these boards are well supported and the input of people with intellectual disability is heard and valued. This suggests that support for participation must be multidimensional, comprising much more skilled forms of practical support and adjustment to operating procedures that are underpinned by advisory body milieus that respect the capacity and right of people with intellectual disability to participate and foster supportive relationships with other members and secretariat members.” (Frawley & Bigby 2011, p36)*

3.3 NDIS

In the context of the modern Australian disability policy landscape, the change designed to address the disempowerment and transfer choice and control to the people with disabilities, was largely inherent in the move from block funding service providers for outputs, to funding Scheme participants (people with disabilities) as individuals to purchase supports to achieve goals in their individual plans. The change with the NDIS was not isolated:

> *“These changes in the disability policy landscape are also the culmination of a much broader, international paradigm shift within social services toward personalisation and individualisation.” (Meltzer, Davy 2019, 2)*

The transfer of power in relation to disabilities manifests in choice and control. It was a key tenet of the recommendations made by the Productivity Commission (2011, 30-32) and later became the subject of an inquiry in its own right with the Report “Introducing Competition and Informed User Choice into Human Services: Identifying Sectors for Reform” (Productivity Commission 2016)[4].

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[4] I also submitted a public submission to this Inquiry https://www.pc.gov.au/__data/assets/pdf_file/0005/204908/sub206-human-services-identifying-reform.pdf (Burrows 2016)

In the disability sector, the tenet of choice and control was incorporated into the legislation as a principle. The principles of the *National Disability Insurance Scheme Act 2013* (the Act) are listed in Chapter 1, Part 2 and include:

> ***3 Objects of the Act***
> *The objects of this Act are to…*
> *(e) enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports*
>
> ***4 General principles guiding actions under this Act***
> *…*
> *(4) People with disability should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports.*
>
> ***31 Principles relating to plans***
> *The preparation, review and replacement of a participant's plan, and the management of the funding for supports under a participant's plan, should so far as is reasonably practicable:*
> *…*
> *(g) be underpinned by the right of the participant to exercise control over his or her own life; and…*
> *(i) maximise the choice and independence of the participant…*
> (Office of Parliamentary Counsel 2018)

To ensure these principles are enacted in the everyday operations of the NDIS, the government has embedded them in the Practice Standards and Quality Indicators (NDIS Quality and Safeguards Commission 2021). They are included in the Core Module which must be addressed by each provider wishing to deliver NDIS supports to participants and upon being registered, must be audited against the Standards by an independent quality auditor.

Specifically, the Standards call for involvement in governance at both the individual and organisational levels. At an individual level the input is required to decision-making that impacts the individual:

> *“Outcome: Each participant is supported by the provider to make informed choices, exercise control and maximise their independence relating to the supports provided.*
>
> *To achieve this outcome, the following indicators should be demonstrated:*
>
> *• Active decision-making and individual choice is supported for each participant including the timely provision of information using the language, mode of communication and terms that the participant is most likely to understand.*
>
> *• Each participant’s right to the dignity of risk in decision-making is supported… (NDIS Quality and Safeguards Commission 2021, p6)*

And at the organisational level:

> *Outcome: Each participant’s support is overseen by robust governance and operational management systems relevant (proportionate) to the size, and scale of the provider and the scope and complexity of supports delivered.*
>
> *To achieve this outcome, the following indicators should be demonstrated:*
>
> *• Opportunities are provided by the governing body for people with disability to contribute to the governance of the organisation and have input into the development of organisational policy and processes relevant to the provision of supports and the protection of participant rights… (National Quality and Safeguards Commission 2021, p7)*

With this latter requirement there is no single means identified to comply, which leaves it to the provider to satisfy the Commission in the first instance, and subsequent quality auditors, that the means chosen to involve people with disability in the governance of the organisation are fit for purpose, are effective, are not superficial or tokenistic.

Terminology is a critical element in having a meaningful discourse. What is evident in the literature reviewed, and in the contemporary service provision landscape, is a confusion about terminology (McLaughlin 2008, Abraham 2015). For instance, the UN Convention refers to the rights of the person with a disability. In the NDIS legislation that person becomes a “participant” in the Scheme. And in general discourse a range of nouns are used, each with its own connotations. These connotations are different for different people – both those within the sector and those external to it. So it begs the question, when is a person a consumer, a client, a customer, or a citizen? Or as per the NDIS vernacular; a participant? Can that person be one and all of these things, depending on their actions, where they sit in the Scheme, or even on their perspective?

Notwithstanding the well-established “sovereignty of the consumer” concept in the field of economics, for the purpose of this thesis a more pragmatic definition will be used, based on the commonly applied vernacular in relation to the Scheme. In the context of the NDIS, the Participant is the recipient of services and supports. They are the consumer and a fundamental element of the Scheme is the drive for consumer sovereignty.

So the consumer can be hereby broadly defined as a person who consumes, or uses, something for themselves. A consumer may exhibit behaviours, or act, so as to perform an economic function, like purchasing a service for themselves or for someone else (customer). A consumer may be a partner in a professional relationship (client) like a patient receiving clinical care (Swinscoe 2010, Abraham 2015). Or a consumer may be acting to contribute ideas so as to advocate for others with similar conditions, or simply for the betterment of the greater community as a whole (citizen) (Farrell 2000, p32). But of note here, is that all other definitions (customer, client, citizen) have a component of consumer also. In laypersons’ terms, a person can be a consumer of telecommunications services and products, but may choose to be a customer of Optus, for example.

Citizenship, is probably the most extended version of a consumer - an empowered state, one which, as Simon Duffy states, encompasses seven keys:

1. *Purpose – set our own direction*
2. *Freedom – Take charge of our own life*
3. *Money – have enough to live on*
4. *Home – have a place where we belong*
5. *Help – get real help from other people*
6. *Life – get stuck in and make a difference*
7. *Love – find friendship, love and family (Duffy, Perez 2014)*

Where these are combined with rightsand participation, you have active citizenship (Duffy 2018).

Stainton (2017) points out that citizenship, being the range of formal recognitions and the instruments needed to implement those recognitions (2017), are not in themselves enough. It actually takes inclusion, and the will of a community, to not exclude and to not treat people as “cognitive foreigners” (2017).

For the purpose of this literature review, it will be acknowledged that broader functions like those of customer or client may be performed, but the base function for addressing the research question in relation to people with a disability is that of consumer. In this manner, it does not matter when an author ascribes a different function to the cohort e.g. a citizen purchasing services as an individual (Gooding 2016, p42) as we can assume that author is also discussing the base concept of the consumer. This is important when we consider that

> *“…sometimes user participation – not control – in decision making is the end goal.” (Litva 2009, p89)*

By having a clear understanding of the different roles that a consumer can have, it becomes easier to consider the role people with disabilities take in differing governance models. From the legislated school governing councils in the UK (Farrell 2000) to the policy-led NHS community control (Department of Health 2005; Litva 2009) and the semi-regulated environment of the NDIS and associated

National Standards for Disability Services (Department of Social Services 2013), the role of the consumer in governance is increasingly being mandated.

Consumer choice and control is central to the NDIS reforms, but it must not just relate to choice of services and access to individualised budgets. It must go further if it is to truly empower people and to lift them from a consumer level to one more akin to citizenship on par with non-disabled people. The choice must also be able to be exercised in relation to power, e.g., in relation to someone whom a person with a disability has a relationship with, and how much power that person is prepared to share with the person from whom they are purchasing a service (Meltzer, Davy 2019, 10). According to Meltzer and Davy

> *"Thriving and flourishing relationships matter for successful policy implementation, and they matter for the quality of life enjoyed by the people affected by policy." (Meltzer and Davy 2019, 3)*

The power of relationships has been raised as pivotal in determining an effective and efficient quality and safeguard regime for the NDIS. Local commentator Dr Leighton Jay (2019) has published a call to action to embrace informal supports and recognise "friends" for their legitimate contributions to the lives of people with disabilities. Jay's provocative article titled "Why we need to use the F-word" supports the assertions made by Meltzer and Davy about the importance of intangible assets like relationships (Jay 2019).

More recent studies have also picked up on the flaws in the benevolent assumptions underpinning the NDIS. Or as Wiesel et al (2023) put it, the "neoliberal imaginary" that is Australia's NDIS. These authors posit that two processes have been underway that have contributed to the empowerment of people with disabilities. The first is mainstreaming, which relates to the transition of people from specialised care or spaces to those of mainstream access for people of all abilities (Wiesel et al, 2023 p617). They argue that this move has been nuanced by changes over time from a focus on "normalisation, through to integration, inclusion and most recently personalisation." (Wiesel et al 2023, p619). These researchers show the natural symbiosis as well as tensions with the other important assumption of choice and control, which they see as one that "encapsulates calls for greater personal autonomy for people with disability in choices and decisions in all aspects of their lives." (Wiesel et al, 2023 p620).

The benevolence of the assumptions becomes challenged when one considers the neoliberal imaginary may have both perverse design flaws as well as unintended consequences. Wiesel et al (2023, p620) suggest that neoliberalism thinking may be driven more by the desire to save costs and use existing mainstream services (e.g. schools) rather than investing in specialised services (e.g. special education schools). They also argue that choice and control may only be an outcome enjoyed by those people who have strong supports and who live in welcoming communities (Wiesel et al 2023, p621), although they suggest the evidence of the impact of choice and control, especially in relation to individualised funding, may still be scant. That evidence is growing however with studies emerging in niche areas of the disability sector, or within defined cohorts, such as psychosocial disabilities (Hamilton et al, 2023) and rural areas (Wakely et al, 2022).

The moves towards mainstream services and choice and control are well intended, but don't always take into account everyone's needs or desires. There is evidence that some people prefer the "old ways" and had a sense of belonging with the institutions and their like friends in those institutions (Wisel et al 2023, p623). When it came time to exercise the choice and control there were surprising phenomena at play, including factors unrelated to the disability (e.g. decisions on preference for a larger pool, or good coffee for example) (Wiesel et al 2023, p624) and an inertia that impeded people looking for new options, fueled by a comfort with existing supports (Wiesel et al 2023, p625).

The important conclusion that these authors found was that the benevolent assumption that people with disabilities should be able to access mainstream services through choice and control over their funding, and not be bound by somewhat inferior specialised services, was somewhat flawed if considered as dichotomous. That actually:

> *"In the neoliberal imaginary, "mainstreaming" is imagined as the building of a bridge from an island of specialist services in which people with intellectual disability are trapped, to a separate mainstream service "mainland", desired*

> *but out of reach. Our analysis demonstrates that in practice, mainstream and specialist services are deeply intertwined, with specialist services offered within mainstream services and vice versa." (Wiesel et al, 2023, p629)*

The neoliberal imaginary talked about by Wiesel et al (2023) is heavily premised on the assumption that markets are both efficient and dependable. However the experience is proving far from that in Australia. In fact the market is proving to be thin in remote areas, having gaps and even failures, that are all requiring the government to invest in stewardship (Cesta, 2023, p175). Cesta describes this stewardship in terms of monitoring the markets, facilitating actions to influence the markets, and commissioning to nurture the markets (2023, p176).

Cesta makes the pertinent point that if Australia is to comply with its obligations under the *Covenant on the Rights of Persons with Disabilities (2007)*, then it must relax its obsession with neoliberalism and accept that markets require support from non-market mechanisms, and that in rural areas for example, a level of block funding is both appropriate and recommended (Cesta, 2023, p177).

Cesta presses this point home in regard to rural markets in particular and notes the Australian Government has moved to address this market shortfall with its release of a specific Rural and Remote Strategy[5] (Cesta, 2023, p176). This additional focus is deemed necessary in rural and remote areas of Australia due to the limited range of providers available, and hence the limitations to market operability. The impacts of these thin markets were explored by Wakely et al (2022) in an interpretive study involving seven people with disabilities living in different parts of rural New South Wales. The study found a number of impacting factors:

1. lack of local providers
2. additional burden of travel (time and cost)
3. burden of self-advocacy to continue explaining circumstances
4. time delays in provision of equipment
5. inconsistency in contacts with bureaucracy

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[5] NDIS, *National Disability Insurance Agency Rural and Remote Strategy 2016-2019* (February 2016)

Whilst some of these factors may have been prevalent in metropolitan areas also, they seem to have been amplified in rural areas due to the isolation. Like other studies, Wakely et al found that people with disabilities who had an existing skillset and were able to deal with the complexity of self-management were able to find more flexibility in choice and control (Wakely et al, 2022, p654). That is, they were more empowered to effect decision-making that impacted them, whereas those who were not able to read the language, or manage their own plans, were at the mercy of the bureaucratic system with all its shortcomings and intricacies. Or, as a generalisation:

> *"Personalisation schemes put an unprecedented emphasis on individuals to navigate care systems and advocate for their own needs and rights… As such, they pose significant potential to result in disproportionate benefits to higher socio-economic groups, entrenching or expanding social gradients in health." (Hamilton et al, 2023, p2)*

One final point made by the Wakely et al study related to the perception of the person first and foremost, a theme already discussed in this Literature Review. Participants in the Wakely et al study reported that participants felt they were placed under the umbrella of a particular disability and found this frustrating.

> *"Seeing people as whole, complex persons instead of their "disability" at the NDIS system level requires a shift in power dynamics to understand the person in a wider and more comprehensive context." (2022, p655)*

How choice and control manifests was a theme also explored by Hamilton et al (2023) in relation to psychosocial supports. This study found up to 10 market related impediments to the NDIS being effective at empowering people with disabilities. These included the following:

1. rigidity of the Scheme
2. complexity of information and procedures
3. lack of information and clarity – opacity
4. systemic disorganisation and inconsistencies
5. powerlessness in relation to the NDIS and its bureaucrats
6. poor understanding of psychosocial disability

7. limited available options
8. lack of accommodations to support choice and control
9. the impact of anxiety
10. dissociation and other effects of past trauma (Hamilton et al, 2023, pp7-16)

Not surprisingly almost all of the flaws noted by rural participants were also raised by the psychosocial disability cohort. However in addition to these flaws, this cohort also noted that dealing with the NDIS and experiencing each of the above could actually create another layer of trauma which in itself has become referred to as “moral injury” which further disempowers people with disabilities from exercising choice and control (Hamilton et al, 2023, p18)

It is fair to say that the literature is in agreement that the intention of the NDIS, and other like neoliberal, individualised schemes, are well intentioned and aim to empower people with disabilities through increasing access to mainstream services and through increased choice and control. Yet the literature is also in agreement that this is not always the case in reality. That the causal link between the Scheme and empowerment is not actually solid, but rather exists for some but not others and can be ethereal for all, depending on the circumstance.

What then is empowerment? Obviously it is a precursor to self-determination, which may be ascribed the measurement outcome function. But what then constitutes the input to that outcome? It is clearly more than simply being consulted; there must be a function of being actively involved in the decision-making (Ranson 1989, p17; Farrell 2000, p32). Indeed there must be a responsibility associated with the function and a consequence, both individual and public, of not exercising that responsibility with accountability (Wright 2015, p66).

The individual consequence is quite obvious – to forego access to valuable resources and/or services. The public consequence is less obvious, but more insidious. It relates to the ongoing application of resources without success. No doubt this is how many feel in the Aboriginal Affairs sector as we observed the 35th year since the Royal Commission into Aboriginal Deaths in Custody, which was appointed in 1987 and delivered its now archived report to government in 1991 (https://www.austlii.edu.au/au/other/IndigLRes/rciadic/). Since this time, incarceration rates, as a percentage of total prisoner population, have increased from 1 in 7 just prior to the Royal Commission to nearly 1 in 3 by 2014 (Creative Spirits 2022). It was also a topic (the costs of doing nothing) covered by the Productivity Commission in its inquiry into disability services (Productivity Commission 2011, 7). By 2021 the Sydney Morning Herald was similarly reporting a comparison of statistics from the Australian Bureau of Statistics saying at the time of the handing down of the Royal Commission Report in 1991 the Indigenous representation amongst incarcerated individuals was 14%. It is now 30%. (Gooley 2021). Nothing is getting better, indeed Creative Spirits intimates it is getting worse year by year (2022). The projected cost of the overincarceration of Aboriginal and Torres Strait Islanders in Australia's prison systems is $7.9 billion per annum (Creative Spirits 2022). Surely this speaks to the insidious cost of applying resources without success.

The last research question is the one that leads to the majority of recommendations from this research. The literature is almost unanimous in its call for more research to verify the participation of consumers in service design (Timberlake 2014, p912-3). Likewise there is support in the literature to determine where the current mandated provisions for consumer involvement in governance is failing (Gilchrist et al. 2019, Timberlake 2014, p913; Alam 2009, p287-9; Dahlberg 2009, p270; Wright 2014, p66-68; Litva 2008, p89-90). These failings are described later in the Chapter.

Whilst the thesis has been exploring this theme in the research, the rollout of the NDIS social reform in Australia has progressed. As successive investments have been made in capacity building the sector, it seems the Australian Government has taken a similar stance to that of British Columbia, with evidence now of mandated levels of representation in governance structures to attract certain funding. In this instance, the Australian Government has mandated that eligible organisations for funding for the Information, Linkages and Capacity Building funding round (2018-19) would need to meet the conditions for "Disabled Peoples and Families Organisations" which were as follows:

- *"Actively demonstrate their commitment to the Social Model of Disability, which seeks to remove barriers for people with disability to access mainstream services and live an ordinary life.*
- *Are run by and for people with disability and/or their families.*
- *Are led and controlled by people with disability and/or their families with a minimum membership of 50% of people with a disability and/or their families making up the organisation's board, staff, volunteers or members."* (previously available https://www.communitygrants.gov.au/grants/ilc-readiness-grant-round-2018-19).

In this instance, the government supported placing a high priority on the involvement of people with disabilities and with the lived experience of disabilities, being directly involved in the governance of organisations that would deliver activities to build the capacity of the sector to engage directly with people with disabilities.

Indeed the National Disability Insurance Agency (NDIA), the government bureaucracy charged with administering the NDIS, has been subject to scrutiny over its own governance and the involvement of people with a lived experience. As the year transitioned from 2016 to 2017, the Board was given a shake-up with four Board directors retired from office and four new appointments made. The criticism came from the perceived "commercialisation" of the Board, with the government wanting progress and results. In fact, criticism went beyond the mere Board structure, to argue that "control" actually rested with the management:

> *"…While disability advocates are right to say the board should have lived experience of disability, the reality is that the most important decisions about the NDIS never get near the NDIA board. Nugent [the Chairperson] and her colleagues are handed a fait accompli on almost every lever needed to effectively manage the roll out of the NDIS." (Bo'sher 2017)*

What was also widely reported at the time was the lack of representation of the lived experience on the NDIA Board (Every Australian Counts 2017). Importantly it can be reported that by 2023 the NDIA comprises 50% people with disabilities on its Board, with the appointment of Kurt Fearnley, a celebrated Paralympian, as the Chairperson.

3.4 Success and failure – the commentary

Whilst the literature review has for the most part pointed to highly developed conceptual frameworks that are embraced in policy design, it also points to systemic failure to achieve outcomes for the key stakeholder; the person with a disability. To be effective, the consumer governance framework must be both a good idea and also be executed well. It seems the latter has not always been the priority in public policy, as forensic analysis of experiences in the NHS in the UK have concluded for example (Clarke 2007, Litva 2009).

The literature all points to a building momentum that recognises the value of vulnerable people, as consumers, participating in the design, implementation and use of services and products. Academic literature and government policy adopts the consumer as a central stakeholder in service design, whether the consumer is partaking in the role as a consumer, client, customer or citizen. Indeed it has evolved from a spectrum type framework like the ladder proposed by Arnstein, through more pragmatic versions like the Shand and Arnberg (1996) public participation continuum presented as an unofficial background paper to the Oraganisation for Economic Development and Cooperation (OECD), through matrices and into maps (Bishop 2002, p14-29). Yet the literature suggests consumers still feel very much on the outer. As Clarke (2007) notes in relation to the UK Health system:

> *"The tension between needs and choice (or control) appears to have been resolved in favour of a presumption that needs are objective conditions and that choice is about the means selected to meet such needs." (Clarke 2007, 428)*

Key flaws obviously exist in the design of the consumer participation. The matter of choice and control in relation to power and its centrality in relationships has already been raised. As discussed by Meltzer and Davy (2019), there are many obstacles facing consumers when exercising choice and control, especially when you consider that the NDIS seeks to empower people through insurance principles and market forces.

The literature points to a number of issues that can be impediments to people with disability exercising choice and control, or failings as described earlier in the chapter. These include:

1. Access to information and ability to determine what is possible – too little or too much information, including reports of being overwhelmed with information – to guide decision-making (Alum 2009, p284; Timberlake 2014, p913)
2. Diminished value of skillset of consumers in comparison to professional skills, and a sense of subservience of the lived experience to university trained technical skills (Wright 2015, p67; Farrell 2000, p35)
3. Diminished value of consumers as a stereotype of social standing and/or financial means – including at times a sense of welfare dependency (Wright 2015, p67)
4. Access to viable and dynamic markets to exercise choice and control, especially from those areas (e.g. remote areas) where the market has been deemed "thin" (Alam 2009, p288)
5. Resources sufficient to influence market-type decisions i.e. spending power (Alam 2009, p289; Gooding 2016, p41)
6. The will to move from a purely consumer base to act as customers and exercise economic power in decision-making (Timberlake 2014, p905)
7. The will to break the inertia from the assessment-type status-quo and risk trying something new, exercising choices that may be different to the traditional system-generated solutions – like independent individual living options over the group homes that are ubiquitous today (Alam 2009, p289; Dahlberg 2009, p270; Timberlake 2014, p905)
8. Complacency and a tendency to revert to technical solutions and/or "packages of care" rather than individualised and tailored care (Alam 2009, p287; O'Brien 2015)

9. The will to genuinely engage consumers in decision-making and persist with that engagement (Janamian 2016, pS14, Timberlake 2014, p913)
10. A framework that requires, monitors and enforces genuine engagement of consumers (Wright 2015, p66; Litva 2009, p89-90)

Many of these issues are present in the Australian context also and were raised during interviews by research participants. Some of the issues, like the absence of market forces, are well known by the NDIS and there is ongoing work to address these. “Thin markets”, raised by Alam in point 4 above, is a circumstance where there is a severely limited range of suppliers, making it difficult for people to exercise choice in purchasing services, or even to access services in the first place. This is a term now synonymous with remote Australia and one to which significant resources will need to be applied to address if the promise of choice and control is upheld for all Australians with a disability. As the Regional Australia Institute identifies:

> “…the NDIS poses a unique set of challenges for those living in regional and remote Australia. Geographical remoteness may inhibit the intended goals of consumer choice and business growth.” (Regional Australia Institute 2019, p2)

It appears a start is being made, with the Department of Social Services and the National Disability Insurance Agency working together to address the issue with a consultation project *NDIS Thin Markets* to identify solutions to both limited markets and non-existent markets (Department of Social Services 2019).

People have spoken about access to information and have raised that at times they can be overwhelmed with too much. They have also reported at times the information is too scant to make an informed decision (Alum 2009, p284; Timberlake 2014, p913).

Sometimes the consumer’s voice is not forthcoming, or is diminished, because the professional skills are deemed superior and carry more weight in decision-making (Wright 2015, p67; Farrell 2000, p35). This can certainly be the case in therapy where the industry is trying hard to move from a therapist/client type relationship to a therapist+client type relationship – i.e. moving from one dominated by a professional power imbalance, to one which is based on mutual respect and valuing each other's contributions. Following on from this relational impediment, there can also be stigma that impacts consumers. They may feel a diminished value as a stereotype of social standing and/or financial means (Wright 2015, p67).

As raised above with thin markets, the literature identifies access to viable and dynamic markets as essential to exercise choice and control (Alam 2009, p288). As is the case in remote Australia, the dynamic and viable markets may be predicated on the number of people actually wanting to access services, and having enough resources (or purchasing power) to actually influence market-type decisions (Alam 2009, p289; Gooding 2016, p41, Malbon et al. 2019, p7). This impediment has led to some wonderful innovations in pooled funding arrangements to maximise purchasing power. An example is the on-country program run by the Machado Joseph Disease (MJD) Foundation in the Northern Territory of Australia (MJD Foundation 2020). This program allows multiple people with disability to share their funding supports to enable camping trips to special places on the land which allows the participants to enjoy a continued connection to their land. This would not be possible if each participant had to arrange and pay for the travel and care individually.

The Regional Australia Institute summarises both the opportunities and challenges for the NDIS, and for delivering choice and control for people with disabilities living in remote areas, as follows:

OPPORTUNITIES

- innovative approaches to care
- entrepreneurialism
- redefining 'choice'
- local approaches to care provision
- flexibility and person-led delivery
- community-building
- community leadership

CHALLENGES

- pricing
- workforce development
- geographical distance
- establishing consumer 'choice'
- community capacity building
- establishing local buy-in
- participants, providers and communities navigating new system and bureaucratic processes

(Regional Australia Institute 2019, p12)

In any move to choice, where a consumer had no choice prior, there can be a level of inertia to overcome. To change the behaviours of a consumer and start exhibiting behaviours of a customer can be daunting for many (Timberlake 2014, p905). Using that economic power to actually change spending habits and exercise economic power in accessing services can often take time and be traumatic for people with disabilities. Anecdotal evidence from people with disabilities transitioning to the NDIS suggests many people just want to maintain their current level of access to supports from one system to the new Scheme.

The pigeon-hole effect can be lasting with people with disabilities. This is the effect that comes from a diagnosis of a specific type of disability – from that point on to be pigeon holed as someone with cerebral palsy, or autism, or angelman syndrome, or even a combination of them. The will to break from this assessment-type status quo, one which can determine the level of resources a person with a disability might receive, can be difficult for many (Alam 2009, p289; Dahlberg 2009, p270; Timberlake 2014, p905).

People with disabilities can at times be complacent and, taking into account all of the issues already raised, can revert to technical solutions. This happens when they revert to a therapist/client relationship for example, and accept the technical solution offered by the therapist based on their professional expertise, rather than trusting in their holistic lived experience and seeking a solution that is truly individualised and tailored. (Alam 2009, p287; O'Brien 2015) This phenomenon can be exacerbated when service provider behaviour also changes to respond to efficiencies demanded in a market-type system. Reducing what service types are offered, and in what format, can further reduce a person with disability's access to services. (Malbon et al. 2019, p7)

Following this, complacency can easily ensue as people become dominated and disempowered. This can quickly become the case when the will to co-design is not there and service providers revert to offering their typical services and not ones that are tailored or individualised. Then the will to genuinely engage consumers in decision-making is actually not present (Janamian 2016, pS14, Timberlake 2014, p913), despite the policy rhetoric (Butcher et al. 2019, p76).

A more specific study into Occupational Therapy and the importance of garnering people's narratives, has found similar flaws in co-design approaches. Franitis (2005) found that whilst a person with a disability may intend to tell their story, they may focus on what they think the therapist wants to hear and leave out what they feel may be most important. They do this because of the power differential described previously. In addition to this, the therapist may be guilty of preferring quick assessment-type interventions, rather than qualitative narrative-based interventions in consideration of time and price (Franitis 2005, p578).

There is an ongoing debate around how to ensure people's voices are heard in the process of accessing services. It is a question that is asked directly in the interviews and is discussed in the Findings Qualitative chapter (Chapter 6). Whether or not one agrees, there is certainly debate in the literature about the benefits of an imposed framework that requires, monitors and reinforces genuine engagement of consumers (Wright 2015, p66; Litva 2009, p89-90). What British Columbia has adopted in Canada, may not be right for the NDIS in Australia for example.

These findings from the literature review were reinforced and supported by the finding of the independent review of the NDIS Act in 2019 by Mr David Tune AO PSM. As published by the government on Department of Social Services website:

> *"Feedback to the review found that some participants:*
>
> - *found the transition to the NDIS confusing and frustrating, with some people saying they 'missed' the supports offered under state and territory systems, particularly active case management*
> - *are frustrated about delays and lack of transparency around how the NDIA makes decisions*
> - *want to have more support to become informed and effective consumers*
> - *feel the NDIS is too complex and difficult to navigate*
> - *feel they are not recognised as the experts in their disability*

- *feel NDIA staff do not understand disability or appreciate the challenges people with disability face as part of everyday life" (Department of Social Services 2020)*

The impediments to choice and control that are listed above are drawn from academic literature and numerous case studies across US, New Zealand, UK and Australia. There is considerable overlap of the impediments identified from cohorts of people that are completely independent from each other, aside from the fact they are in relation to vulnerable people acting as consumers. In addressing these flaws, it should be remembered that not all consumers want to exercise choice and control. Some have an emotional bond to what is and what was, and some may be overwhelmed by the reality of their newfound obligation, especially if it means choosing ahead of professional expertise like medical advice. (Timberlake 2014, p904-5)

These impediments at an individual level can also accumulate to have an impact at a societal level. Malbon et al. point to some systemic failures that can be brought about by the functions of choice and control. These include the widening gap between socio-economic groups, given the ability of higher income persons to navigate the system and achieve their goals (2019, p3). Or the increasing gender disparity as women become further marginalised (2019, p7) and vulnerable people (intellectual disability and/or members of culturally and linguistically diverse backgrounds) languish with unmet need (2019, p5).

3.5 The way forward

The literature review has so far established that people with disability continue to feel disempowered, yet acknowledge the journey has been long to date and seems to be gathering momentum with an increased focus on co-design in systems offering choice and control. However as the Tune Review (Department of Social Services 2020) acknowledges, there remain shortcomings with the NDIS and the criticism can appear fierce at times (Every Australian Counts 2020). The reason for this is the inverse correlation between co-design and success of the innovation:

> *"…co-designing a service innovation will trigger a heightened sense of power because it can partially control and affect the innovation. This will then be a means of creating a stronger sense of psychological ownership, which in turn fosters a sense of engagement as the consumer becomes attached to the innovation and incorporates it into his/her perception of self. This chain of effects (co-designing, power, ownership, engagement) will then lead to higher valuation of the innovation and greater intention to spread positive WOM to other consumers. However, the same chain of effects will trigger a higher perception of service failure when the firm responsible for executing the innovation fails to deliver its intended benefits to the market." (Sembada 2018, p11)*

Sembada (2018) talks of the impact of the psychological contract once breached by the innovation failing. Those people who had not contributed to the co-design would be less impacted than those who had (2018, p11). This seems to be the prevailing sentiment of those participants in the NDIS who feel the promise of choice and control is not being met, despite their efforts to engage.

The gap that seems to be missing in the research is an agreed consumer governance framework. That is, a governance framework that is based on co-design principles and that seeks to incorporate input from consumers in making decisions that impact upon them. One that establishes a set of definitions, stratifies engagement, measures empowerment, and verifies self-determination as an outcome. This was the finding of research into decision-making in hospitals (Murray 2015), care of depression (McCusker et al. 2013) and palliative care (McConigley 2013). The latter study was specific to the use of impact statements, but maintained a lack of framework in relation to engagement with consumers in this regard.

These flaws and gaps in co-design will need to be considered if we are to address the sense of superficiality, or incompleteness, raised by most researchers. A contributing factor was the diversity of consumers and the difficulty in involving all views. This was well summarised by Litva et al. as:

> *"…(it) remains highly problematic until it is recognised that different users will take different role perspectives and desire different types of involvement in different aspects of the policy. Thus large, all-encompassing strategies of user involvement may only appeal to a limited range of users, and this could impact significantly on their use and usefulness." (2009, p 89-90)*

And it was the phenomenon that Malbon et al. (2019) referred to in finding that the impartiality of services may not lead to universal access, and cited Hart's inverse care law (Hart 1971) in relation to it. Hart's inverse care law states that the availability of good medical or social care tends to vary inversely with the need of the population served (Hart 1971). This is certainly true in Australia, with the Commonwealth administering the Distribution Priority Area program to support the distribution of medical workforce to service patients in areas of low supply (Australian Government Department of Health 2022). In relation to this thesis, the inverse care law applies in that just because the NDIS offers choice and control to everyone it still depends on each person's personal circumstances, including where they live, as to how much choice and control they are able to assume.

In addition to these flaws in assumptions, there may also be a gap in our understanding of outcomes. This is certainly the view of Dahlberg, Todres and Galvin who suggest without considering the existential benefits of lifeworld care, including the key components of vulnerability and freedom as well as vitality, movement and peace, one will never move beyond the simple paradigms of patient-led or person-centred care (2009, p270). However whilst they raise a compelling argument in the case of an Alzheimer's patient, it may be more important for us to concentrate on the practical and present rather than the abstract and existential. Lest the gap become wider on all the Indigenous social improvement metrics and the NDIS reforms forever remain in perpetual rollout and at the whim of bipartisan support and a fickle budget surplus.

This literature review has identified consumer engagement frameworks that have been developed, from Arnstein's Ladder to the IAP2 Public Participation Spectrum, to the newly released People with Disabilities "Connect With Me" resources. However what still appears to be missing is a framework that guides organisations on where and when to involve consumers, and to what level, in decision-making. Which policies are business as usual for example, and which policies have an impact on consumers' lives and would benefit from having their input and guidance? Which decisions are transactional and which ones, like recruitment decisions, are actually values laden, with the potential to impact people lives?

In relation to the Research Question, the literature that is summarised in this chapter tends to support the inclusion of people with disabilities in decision-making and in broader governance where that governance contributes to outcomes for those people. The literature supports the ongoing active investment in developing the skills of people with disabilities to be able to contribute to governance. And the literature also supports the involvement of people with disabilities, as a consumer cohort, to input to decision-making in relation to service planning, design and implementation through a mode of co-design.

The literature also identified some shortfalls. The lack of consistent approaches to co-design, including when consumers should expect to be involved in decision-making. The literature identified a varied nomenclature in the co-design community of practice. It also identified a level of confusion with nomenclature amongst the service users – people with disabilities and their carers.

Specific to the Research Objectives, needs arising from the literature findings can be summarised as follows:

1. Develop a shared understanding of what empowerment is, and what its relationship is to self-determination

The legislation provided the clearest guide to defining empowerment, through the Objects of the NDIS Act 2013 and the Guiding Principles that follow. The concept of self-determination was more prevalent in the ATSIC Act 1989 and in literature associated with Indigenous Affairs, and may also be a communal objective rather than just an individual one.

The literature agrees there are impediments to people with disabilities being involved in both decision-making at the individual level, and in governance at the organisational/policy level. And that as a society we should be working to address those impediments and to support people with disabilities to overcome them. The literature also concurs that co-design is a growing phenomenon in public policy and that engaging with the public, the consumer, or just the end user, is becoming a very mainstream practice. Not only for better business results and better value for money today, but for the broader empowerment of that cohort and their betterment to be able to contribute independently to society into the future.

2. Determine, from the perspective of people with disabilities, whether or not they are empowered to express their self-determination as intended by legislated service standards and as enshrined in the United Nations Convention on the Rights of People with Disabilities (UN 2007)

The NDIS Act 2013 references the UN Convention 2007 in its Objects which is an explicit desire of the Australian Government to meet the expectations of the Covenant. However the broader literature does not evaluate whether or not the Australian Government has achieved that objective. Continuous papers like those published by the Australian Institute of Health and Welfare and the Australian Bureau of Statistics give data on wellbeing, but do not subjectively evaluate a sense of empowerment from that data.

Interestingly the revised National Closing the Gap Agreement includes four priority reform areas. Of these four, one is dedicated to formal partnerships and shared decision-making (Productivity Commission 2022). The target of this reform is that:

> *“There will be formal partnership arrangements to support Closing the Gap in place between Aboriginal and Torres Strait Islander people and governments in place in each state and territory enshrining agreed joint decision-making roles and responsibilities and where Aboriginal and Torres Strait Islander people have chosen their own representatives.” (Productivity Commission 2022)*

The following outcomes and outputs are expected:

> *“Output indicators*
>
> - *Partnerships reviewed (new or existing) meeting the ‘strong partnership elements’*
> - *Number of partnerships by function, such as decision-making or strategic*
>
> *Outcome indicators*
>
> - *Proportion of Aboriginal and Torres Strait Islander people reporting they are able to have a say in their community on issues important to them*
> - *Proportion of Aboriginal and Torres Strait Islander people reporting improvements in their communities” (Productivity Commission 2022)*

Within these four priority reform areas, the National Closing the Gap Agreement now has 17 targets. And these targets now incorporate a target in relation to empowerment, although it is extrapolated from digital inclusion as the target, to decision-making as the outcome. Target 17 in the National Closing the Gap Agreement states:

> *“Aboriginal and Torres Strait Islander people have access to information and services enabling participation in informed decision-making regarding their own lives.” (Australian Government 2020)*

With the target associated with the outcome:

> *“By 2026, Aboriginal and Torres Strait Islander people have equal levels of digital inclusion” (Australian Government 2020)*

Adding a further layer of complexity to the extrapolation, the Productivity Commission points out that data is not available on levels of digital inclusion for the non-Aboriginal population, so a comparison is not able to be made at this stage (Productivity Commission 2022). At least this is an attempt by government to access some meaningful indication of increasing empowerment of otherwise vulnerable and marginalised people. The Australian Government may want to monitor the implementation of this target with a view to transposing it to the disability sector.

3. Delineate between popularly used concepts in the literature including consumer, client, customer and citizen

The literature gives very little guidance on popularly used terms. Whilst the language is becoming more specific in the co-design community of practice, the terms for the individuals participating in the process is still varied. The legislation refers to “ Participant” and the co-design literature refers to “consumers” with an aim to empower as “citizens”. This remains an area for the research to explore.

4. Determine the success of commonly used governance frameworks that increase choice and control in decision-making for people with disabilities and identify preferred governance frameworks for different decision-making environments

The literature identifies an evolution of commonly used participation and co-design frameworks and suggests an increasing sophistication of the models as they are increasingly used. The literature certainly supports a growing community of interest in the co-design field, although there is limited critical evaluation of co-design being linked to formal governance. The literature also does not identify the success or otherwise of any individual model. This is an area for the research to explore.

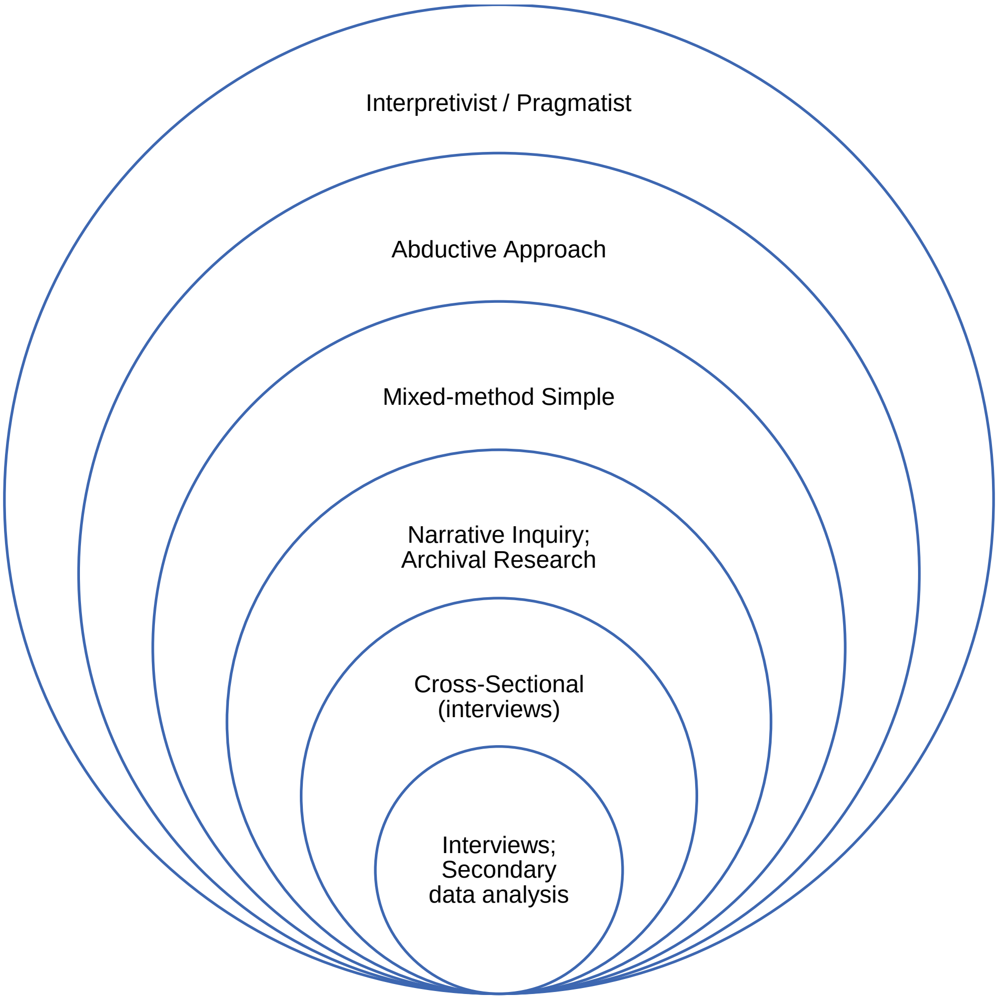
This literature review, whilst not undertaken as a systematic literature review on governance frameworks, was conducted on a sectional basis addressing four identified issues deemed relevant to the research objectives in contemporary Australia; they being: empowerment, co-design, the NDIS, and the subsequent media commentary and evolving research. It is evident from the literature review that there is a discord between expectation and reality with regard to choice and control being experienced by people with disability. It does not in itself necessitate that this thesis becomes an investigation into a problematised question, but it does mean that a solution(s) is warranted if found. Whether at the individual level, organisational level, or national policy level, people with disabilities are wanting involvement in decisions that impact them. The question becomes what level of involvement in which decisions in what timeframe. And what is right for one person may not be right for another – such is the nature of individualised choice and control.

4. METHODOLOGY

4.1 Overview

The primary research for this thesis was conducted from 2018-2021, with the surveys being conducted from 2018-2020 and the interviews being conducted from 2019-2021. The ethics approval for the investigation was granted by the Curtin University Human Research Ethics Committee (HREC) on 7 August 2018. The registered approval code from the Committee is HRE 2018-0653.

To answer the Research Question I chose to use a mixed method that involved the gathering of both quantitative data and qualitative data. In graphical terms, the methodology can be represented as a "Research Onion" in the following manner.



In brief, and with more explanation to follow, an outline of each layer of the onion is as follows:

1. Interpretevist / Pragmatist

   A commonly used approach when studying a qualitative field using interviews – whereby you gather different peoples' views which may lead to separate meanings based on different people's social constructions (Saunders et al 2016, p188)

2. Abductive Approach

   The researcher has started by observing the similarity between the sayings "Nothing About Us Without Us" and "Do it With Us, not For Us" and has then gathered data to suggest why this may be the case. He has then formulated a view that disempowerment does exist in different vulnerable cohorts, and specially the disability cohort, which has then led to further investigation of how governance approaches may assist with addressing the disempowerment (Pearson et al 2016, p148)

3. Mixed Method-Simple

   A simple mixed method research design was used to collect quantitative data from surveys which could then correlate with findings from more detailed qualitative data from interviews (Pearson et al 2016, p170)

4. Narrative Inquiry / Archival Research

   A literature review was undertaken in conjunction with an examination of legislation and regulation as well as a summary of contemporary media reporting. This helped to identify the gaps in the research and identify what had worked well in the past, what was touted for the future, and where the anticipated problems lay.

5. Cross-Sectional Interviews

   The interviews were conducted over a two to three year timeframe, butt for each interviewee, the interview was conducted at a certain time and lasted for up to one hour at that time. It provided a window into their views at a specific point in time and even though the full complement of interviews from all cohorts lasted up to three years, it is still a small window in a Scheme that has now been running for over a decade and for a movement that has been ongoing since the turn of last century. For this reason it is deemed a snapshot in time, rather than an ongoing or longitudinal study (Pearson et al 2016, p200).

6. Interviews; secondary data analysis

   Some of the interviews led the researcher to follow up on further research, for example the investigation into Duffy's seven keys of Citizenship (Duffy et al 2014). The interviews were semi-structured and this allowed a more free flowing discourse that led to further data being gathered that was not strictly in response to the set questions that are contained in the Appendices to this thesis. The literature presented data that was considered in light of the findings and a secondary analysis of some of this data was undertaken (Wakely et al 2022; Hamilton et al 2023).

In conducting analysis of the qualitative data, a thematic approach was used in line with the abductive reasoning. The researcher stated three propositions that were likely, and the data was interrogated accordingly. The themes were evident to the researcher early in the interviewing process and manual tags and highlights were made in the notes to allow follow-up. This was then cross-referenced to a degree using the NVivo data management tool.

In conducting the research I adopted an interpretivist philosophy which is most common for qualitative studies as it allows me to "make sense of the subjective and socially constructed meanings expressed about the phenomenon being studied" (Saunders et al 2016, p168). Within this overarching philosophy I used an abductive approach (Saunders et al. 2016, p146-148) to explore governance frameworks that empower people with disabilities in accessing community care services. The abductive approach was natural given my prominence as an industry practitioner, meaning there was also evidence of pivoting from deductive to inductive inquiry.

In one instance the data would lead me to hypothesise - a deductive approach. An example of this was the continued feedback that people with disabilities did not feel as empowered as service providers assumed. In another instance the feedback would lead to a theory and would get to the point where I sought data to further test and explore – an inductive approach. Combining in this manner is described as an abductive approach (Saunders et al. 2016, 148). What this means is that I was not only reading literature and assessing existing sources of data but was also working with people with disabilities and their parents and carers and was listening to their stories in day-to-day practice. I was also gaining insights to industry perspectives in professional association reports and media commentary. This included presenting a preliminary framework to an industry conference in Adelaide in 2018 for example. Feedback and input was constant throughout the research period, which is expected in an applied field of study such as a professional doctorate. As I continued to process the ongoing input, I questioned further.

The research data collected from surveys and questionnaires informed the research from the perspective of a person with a disability and more broadly from the perspective of people with a lived experience of disability; parents of children with a disability for example. This data has then been applied to address the broader research objectives, including via triangulation with carers and other significant people in the lives of people with disabilities, and those who work in the service provision industry (e.g. accommodation, care, and therapy sectors). The research has also sought the views of peak representation and advocacy bodies; both individual and systemic.

The research was conducted in two parts – surveys that provided both quantitative and qualitative data; and interviews with questionnaires that provided qualitative data. The surveys were anonymous, and whilst there were some open questions allowing comments to be made, there were none made that could identify their author. So there is no way of knowing if some of the respondents also participated in interviews, although I understand from speaking with people in the interviews that there were at least some who undertook both. It was certainly envisaged in the research plan to have a level of transfer from the survey cohort to consent to conduct more in-depth interviews.

The quantitative data that was collected was largely nominal (e.g. contextual data), and ordinal (e.g. demographic data). The data collection technique was via surveys that were conducted using Qualtrics. Some of the survey data was based on Likert scale responses which involved numerical data where the difference between two data values was not distinguished in a relative sense, so forms interval data. The questionnaire data also involved numerical data with relative values, so ratio data was also involved. The survey also involved demographic data which included categorical data. As such this represents descriptive (nominal) data.

The questionnaire used in the interviews was more involved and therefore included further investigation of affiliations and supports which resulted in descriptive data. The qualitative data for the most part was primary and both structured and unstructured. Interview questions were structured, but led to many stories which resulted in foundational quotes. Foundational because they formed a substantial argument to progress the research. The interviews were transcribed from audio files using artificial intelligence software in the first instance, and then manually proofed for accuracy.

The quantitative data was collected, in essence, to inform and verify the qualitative data, and to give me some exposure to surveys and statistics. The qualitative data was always going to be the core of the research, given it was essentially a social inquiry, studying people’s lived experience. And this is the preferred way to study the lived experience as it allows me to seek explanation – to dig deeper – especially when the research participant may be from a marginalized or silenced cohort of society (Liamputtong 2016, xi-xiii). The use of a mixed methods approach in this manner is referred to as a concurrent triangulation design (Saunders et al. 2016, p173).

In addition to the data collected from interviews and questionnaires, there was also information gathered from industry forums including the Therapy Focus Parent

Reference Group at a very local level, and the National Disability Services Annual CEO Meeting at a national level. I was also active at industry forums throughout the research period, including contributions to the WA State Disability Strategy and presentations at NDIS Forums, as well as participating in regional Aboriginal community-controlled research forums.

The research targeted numerous providers who specialise in targeted services (e.g. cerebral palsy, multiple sclerosis, neuro muscular disorders, autism etc.) and interviews were conducted with people with varying diagnoses, including comorbidities, and also differing levels of functionality. This was done purposefully to cover a range of different realities.

4.2 Quantitative – Surveys

The research undertaken as part of this investigation was designed as a mixed methods approach. The major component was the qualitative research using interviews. The minor, or supplementary, component was the quantitative research using surveys. This latter component was undertaken to compare results to themes identified in the qualitative research.

In conducting the quantitative research, two surveys were issued with participant cohort targets of people with disabilities and carers of people with disabilities. The two surveys expected to gain responses from 50 unique participants each.

Surveys were designed by me with guidance from the Principal Investigator. The final drafts were each then tested for appropriateness by two independent people who were representative of the respective participant cohorts. Final changes were made, especially with regard to the technical pitch of the language, and the surveys were published in April 2019.

Due to the nature of the surveys being deemed secondary to the interviews, and the market segmentation already inherent in the design, with four different cohorts targeted with interviews and two with surveys, no further segmentation was built into the research. Therefore demographic questions and epidemiological questions were not included. The focus of the questions was clearly on decision-making and access to supports. It was hoped that by keeping this focus clear from the start that more people might undertake and complete the surveys.

The surveys were launched using Qualtrics software. This meant the results could be stored on a Curtin University database and individuals' responses could be kept confidential from me. No effort was made to trace uniform resource locators (URLs), or web addresses. Raw data has been stored as output files on the Curtin University research database and is available if requested. The data is in a deidentified (and aggregated) format.

The surveys were promoted via Facebook interest groups over the period May to December 2019. The following details the groups and the dates the surveys were posted. Dates for posts promoting the People with Disabilities survey are in green and posts promoting the Carers of People with Disabilities survey are in purple.

Facebook Group	May 19	Jun 19	Jul 19	Aug 19	Sep 19	Oct 19	Nov 19	Dec 19
Disability Community of Practice Australia	29	23		16	17	30	17 25	9 20
NDIS Service Providers Discussion	30			16	17	30	25	20 20
Voice of the NDIS							17	9
NDIS Grassroots Discussion*								
Accessible Australia		23		16	17			9**
Friends of Kalparrin Families	29	23		16	17	30	17 25	9 20

* This Group blocked the posts due to its policy on "no research"
** As noted above, this thread resulted in a complaint to the ethics office due to incorrect ethics number attached to the survey post, lack of participant information statement and the nature of the implied consent. The correct ethics number and the information statement was supplied the following day, 10 December, and both surveys were changed to include a new question that overtly asked for consent prior to answering further questions.

This table shows that in total, there were 17 posts with links to the people with disabilities survey and 14 posts with links to the carers of people with disabilities survey. There was a noticeable increase in survey response after each post and although there was some evidence of snowballing, where research participants encouraged other participants to engage, there was significantly less than anticipated during the research design and candidacy.

Surveys were published on Qualtrics and were accessed via a weblink. The weblink was used by me to enable access by people anywhere, anytime via the internet. The weblink was typically published in Facebook groups that had a community of interest around disabilities. The following groups were approached and agreed to participate:

- Voices of the NDIS (VOICES OF THE NDIS | Facebook)
- Accessible Australia (Accessible Australia | Facebook)
- Friends of Kalparrin Families (Friends of Kalparrin Families | Facebook)
- NDIS – National Disability Insurance Scheme Australia (NDIS Discussion Australia | Facebook)
- Care and Support Sector Community of Practice – Australia (Care and Support Sector Community of Practice - Australia | Facebook)
- NDIS Providers Forum (NDIS Providers Forum | Facebook)
- NDIS Service Providers Discussion (NDIS Service Providers Discussion | Facebook)
- NDIS Grassroots Discussion (NDIS Grassroots Discussion | Facebook)

To show the dynamic nature of the field of research, some of the groups mentioned above changed during the period. They changed names, they changed rules around content of posts, and one even changed from direct post to vetted posts where the administrators reserved the right to block and cease a post.

The Facebook Groups were all closed groups. Whilst open to the public to join, with varying eligibility criteria, they were all deemed closed groups for the purpose of research. So the research participants were limited to those people who had already engaged in one of these groups and were possibly not indicative of the broader society. This is raised in the limitations section of the recommendations.

In one instance I posted an invitation to participate in the surveys, with a link to the surveys. The post was a heavily reduced post after it was agreed with the Chief Investigator to reduce the content of posts to maintain reader interest. The rationale for shorter posts was based on the Twitter platform where posts initially had a maximum 140 characters. The short version post omitted the Information Statement (Appendix 7) as an attachment. An aggrieved group member noted the omission and explored further, only to find the preface to the survey also referenced the wrong ethics number. This resulted in a complaint to the University's Ethics Office. The complaint was satisfactorily addressed within 48 hours with the Preface to the Survey being changed to reflect the correct ethics number (HRE 2018-0653) and the Information Statement posted to the Group pages where it had been omitted. Interestingly the complainant also went on to be a participant in the interviews in the person with a disability cohort and divulged their complaint to me during the interview, noting it had been resolved.

Both surveys were created in November 2018 and were published shortly afterwards. They were continuously promoted via 31 unique Facebook posts until they were finalised in March 2020. The data in Qualtrics was accessed by a specialist data engineer who was procured to assist with analysis. The engineer, Jenny Lalor, regularly assists doctoral students at Curtin University and was accessed via contacts at the John Curtin Institute of Public Policy. The final close-off was determined at the point in time when the complaint referred to above had been resolved, the Pandemic had been declared, the Milestone 2[6] presentation had been scheduled, and I with my supervisor and data engineer, had come to agreement that the surveys had reached research saturation point. A total of 43 participants completed the People with Disabilities Survey whereas only 35 participants completed the Carers of People with Disabilities Survey. Whilst both surveys had a higher number start the survey, only completed numbers were considered in the analysis.

The decision to close the surveys at the end of 2019 was based on the numbers of participants who had started the surveys. Once this number had exceeded 50 for both surveys, they were closed and weblinks were deactivated. In total the People with Disabilities Survey had 72 respondents start the survey and the Carers of People with Disabilities Survey had 56 respondents start the survey.

The preference at the start of the research was to have 50 survey participants in each survey, to enable some statistical rigour. Although these numbers were not achieved in terms of respondents who completed the surveys, there are still relevant trends that can be reported from the data. This was the purpose of the quantitative component of the research; to supply data that corroborated the themes identified in the qualitative research.

As stated previously, the quantitative data was designed to be supplementary in the research and was not deemed critical to the findings unless it constituted a substantial contradiction of qualitative investigation findings. Therefore the survey analysis was undertaken on the 43 and 35 cohorts of respondents who completed the surveys, respectively. However no detailed statistical analysis was undertaken as findings were either self-evident in the compare and contrast analysis, or the response rates lacked the validity to justify the in-depth statistical analysis.

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[6] Since 2016 Curtin University has implemented a system to monitor the progress of doctoral students. It consists of three Milestone presentations. The first Milestone is deemed the traditional Candidacy presentation as the starting proposal. Milestone 2 is completed when a substantial amount of research has been conducted and involves the presentation of a substantive Chapter. Milestone 3 constitutes the final presentation and defence of thesis to a peer panel. Once all three milestones have been completed a student becomes eligible for submission of thesis and ultimately graduation if successful.

The surveys were aligned in the questions, with the same themes explored. Questions only differed in relation to eligibility of funded supports and establishing the level of self-care a person with a disability administers. As such the People with a Disabilities Survey had 25 questions; two more than the Carers of People with Disabilities Survey.

With the relatively similar number of questions, all-in multiple-choice format, and with only seven of the questions allowing free text, the estimate of time for completion as stated to participants in the promotion of the surveys was 15-20 minutes.

The surveys, with all questions and survey flows, have been included at the end of the thesis as appendices. Two surveys (see Appendix 1 and 2) were designed that were focussed on two major cohorts:

i. People with disabilities – Appendix 1
ii. Carers of people with disabilities – Appendix 2

The surveys both had an introduction that explained the purpose of the research and had links to further information. They also had details of the ethics approval for the research.

The Survey for People with Disabilities had 25 questions and the Survey for Carers of People with Disabilities had 23 questions. Each survey had intuitive navigation built into them to ensure people's responses guided the questions asked. For example if someone decided not to provide consent to undertake the survey at question 1, the survey would accept that response and direct them to the final page thanking them for their participation, rather than proceeding to ask further questions.

4.3 Qualitative – Interviews

I chose to interview four different cohorts. To do this, four different questionnaires were designed which were specific to each cohort (see Appendices 3, 4, 5 and 6). The cohorts were as follows:

i. People with Disabilities (n 5/10) – Appendix 3

ii. Carers of People with Disabilities (n 11/10) – Appendix 4
iii. Organisations providing services to People with Disabilities (n 10/10) – Appendix 5
iv. Peak / Advocacy Bodies representing the interests of People with Disabilities (n 5/5) – Appendix 6

In the list of cohorts above there are numbers at the end of each description. These numbers represent the number of interviews (n I) conducted in relation to the number of planned interviews (n P) stated as (n I / n P).

In recording the data, I ascribed codes to each research participant. The codes were kept in a MS Excel file on the secure research drive in the Curtin University database. The codes were ascribed by firstly segmenting participants into the cohorts above and then into chronological order according to when the interview took place. This means there are participants in the first cohort with numbers 1.1, 1.2 1.3, 1.4 and 1.5 and so on for other cohorts. Where the number reached ten and above, the coding changed to 2.9, 2.11, 2.12 and so on. This was only on the basis that Excel does not record the last digit of a number if that number is 0. Hence 2.10 would be 2.1 which duplicates the existing participant code 2.1.

Unfortunately, for reasons described earlier, the number of research participants in the primary cohort, people with disabilities, was lower than originally hoped. However it was deemed enough to garner views of that cohort, and in turn when considered alongside the views of carers, provide an insight into the views of the broader cohort of people with a lived experience of disability. An additional interview was conducted in the carers' cohort to ensure that of all views garnered in the research, there were more from the perspective of the lived experience, than there were from the broader service and support sectors. Whilst I do not claim a saturation level had been reached, there was a sense that themes had already emerged from the interviews undertaken and I could draw valid conclusions without the need to prolong the study, especially given the limitations already discussed. I certainly felt confident from both lived experience cohorts that I had garnered the views of a diverse sample, with both physical and intellectual disabilities, and people with low and high support needs represented.

I used professional contacts to attract participants from the service providers and peak bodies, with all participants known to me in a professional capacity to some degree. The research participants in the carers' cohort were largely from the Therapy Focus Parent Reference Group who had also worked (as consumer representatives) with me, although some were also identified through industry forums (e.g. the Statewide Disability Strategy consultations) and via Facebook Groups and were previously unknown to me. Of the People with Disability cohort, approximately half were known to me and the other half unknown.

The interviews were conducted both in-person and over the phone. They were booked in advance with an email sent confirming the date and time. The email also included the Information Statement and the Informed Consent Form. By far the majority of consent forms were completed and returned. Only two were not. In both these instances I ensured the participants gave verbal consent and that this was recorded at the time.

Interviews were recorded using an Olympus digital voice recorder (Model WS-853). Immediately following the interview, the recording was uploaded as an MP3 File to Otter.ai (Otter), which is a subscription-based transcription service. Otter converted the voice files to text which could then be transferred to MS Word files. These were then saved as deidentified files in the Curtin University research drive, with details of the file (e.g. participant name and date) stored in a secure research key file. The Otter files were deidentified, with only a date stamp as a file name.

Following conversion to text, I then proofed each transcript in MS Word. Typically the conversion process took up to five minutes for Otter to complete. On average the proofing process took me two hours to complete, with some files taking in excess of four hours due to length and quality of recording.

Otter was able to convert voice recordings to text in a very efficient manner, which as the name suggests, is using artificial intelligence to continuously improve. However it was prone to systemic limitations (e.g. call quality) and idiosyncratic limitations (e.g. localised acronyms). Given the service operates out of San Francisco in the

United States, most of the data that is being anaylsed and converted is from an American context which would have little knowledge of terms like NDIS as used in Australia. Corrections during the proofing period included the following:

- Hairy – became Harry
- Angry Care – became Anglicare
- India – became NDIS
- Carbonara – became Kununurra

In so far as general conversation was concerned, the accuracy of converted text was really dependent on call quality and the level of static and/or reverberation on the phone line or in the room. A direct interview in a closed room was very accurate and had little change compared to an interview conducted in a café in the middle of a shopping centre. Another interesting quirk of the service was the echo phenomenon whereby text could be repeated up to three times, especially at the start of sentences. Generally speaking the in-person interviews resulted in better recordings and hence more accurate conversions to text transcriptions.

As I proofed each transcription, themes were manually collated in a thesis journal. For the main, themes were identified by me in a few ways:

1. as themes reiterated from the literature and/or industry forums
2. as themes raised by multiple participants
3. as themes that raised new ideas/concepts
4. as themes that had a potentially broader impact

All themes identified had a direct connection to the Research Question and/or Objectives.

Arguably this was a very subjective process that involved me listening to the interview and making notes of the interview and then cross checking those notes with notes made from the transcript proofing process. This resulted in 111 themes being identified from 31 interviews. These themes, in addition to notes taken at the time of the interview, were used initially to determine the findings and to test the Research Question.

In addition to this manual analysis, I used NVivo to identify more accurately the responses to each theme. When using NVivo the search criteria were associated with the questions asked in the interviews, which were directly related to the Research Questions. A combination of Codes and Cases were used. The Codes were reserved for the question relating to function in society (i.e. consumer, client, customer, citizen). The Cases were reserved for more detailed analysis including exploration of level of control in decision-making; level of control of planning; examples of mandated involvement of the lived experience. Admittedly most analysis was restricted to frequency of themes raised using different permutations of enquiry.

For the question about level of control in planning, which used a Likert scale, I reverted to manual collation of results. This seemed more appropriate as numbers were low and the responses were embedded in broader conversation, often having to be prompted from the participants.

This hybrid approach was required due to the semi-structured nature of the interviews. As participants became comfortable with the interviews, and realised they did understand the subject topic, they typically became far more conversational. This meant they often jumped ahead in the interview and answered subsequent questions without the interviewer stopping them. Analysis therefore by question number was not easy, and given the differences between questionnaires for each cohort, was not deemed the best method. This also made it more difficult to apply direct comparisons in NVivo.

In addition to the formal surveys and interviews, I also attended numerous forums and focus groups. True to the applied nature of a Doctor of Business Administration, I also had a practitioner role in the disability sector. During the period of research, I attended the following events in an active role (e.g. presenter / panel member):

- Better Boards Australasia National Conference (August 2018)
- NDIS State Forum (March 2018)
- National Disability Services WA State Committee (2016-2018; 2019-2020)
- Associations Forum National Conference (July 2017)
- National Disability Services CEO Breakfast (May 2017)

I also attended many events as an active participant, whether as a community representative, service provider representative, or as someone with a lived experience of disability (father to a child with a diagnosed disability). An example of events included:

- Kimberley Aboriginal Health Research Alliance Forum (2022)
- Kimberley Connections Disability Forum (November 2020)
- WA Government Statewide Disability Planning – Kimberley region (April 2019)
- First People's Disability Network (2019)
- NDS CEO Annual Meeting (2011-18)

Events attended became increasingly localised towards the end of the research due to my regional location as well as the restrictions imposed by the Covid-19 pandemic, especially from 2020-22.

In addition to events attended, I had an active role in managing a disability service. This involved interactions with people with disabilities, as well as their carers. One primary role was the coordination of the Parent Reference Group for Therapy Focus. After moving to Broome in 2019, I also interacted with people with a disability whilst managing a health service. This experience was important because it highlighted to me the similarities and differences between the disability and health sectors and identified many of the gaps that exist between the sectors.

This experience has been included in the research both formally, as cited references, and as discussion. Whilst the research and its analysis has been kept empirical, I have incorporated this experience at times in the interpretation of the data.

5. FINDINGS - QUANTITATIVE RESEARCH

5.1 Survey Analysis

Given the questions between the surveys were strongly aligned, the analysis has been undertaken by comparing responses to each question. This comparison of responses to each question is provided below. Tables in Green relate to People with Disabilities and are numbered in the PWD 1 type format indicating the question relates to the People with Disabilities cohort and the question number is 1. Tables in Purple relate to People Caring for People with Disabilities and are numbered in the CPWD 1 type format

As noted above, amendments were made to the survey in December following a complaint to the ethics office. The amendments involved the inclusion of a new first question that explicitly asked for consent to continue, rather than relying on implied consent.

The relatively small responses for consent being given is due entirely to the fact it was only asked in the last month of surveying. No comparison is made for this reason.

PWD 1

Do you give your informed consent to proceed with this survey?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	2	4.7	100.0	100.0
Missing	System	41	95.3		
Total		43	100.0		

CPDW 1

Do you give your informed consent to proceed with this survey?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	4	11.4	100.0	100.0
Missing	System	31	88.6		
Total		35	100.0		

The age cohorts for both surveys was similar, with both recording the bulk of responses from people either 26-45 years or 46-65 years. These age cohorts accounted for 74.4% of responses from the People with Disabilities survey and 85.7% for the Carers of People with Disabilities survey.

There were less people in the younger age cohorts in the Carers' cohort than the People with Disabilities' cohort, and whilst this may have been due to the caring function, which can be typically undertaken by parents of younger children, the difference is not large enough to consider further.

The age distribution does give confidence that both surveys were undertaken by people from a range of ages.

PDW 2

Age group

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Under 16 years	1	2.3	2.3	2.3
	16-25 years	5	11.6	11.6	14.0
	26-45 years	17	39.5	39.5	53.5
	46-65 years	15	34.9	34.9	88.4
	Over 65 years	5	11.6	11.6	100.0
	Total	43	100.0	100.0	

CPDW 2

Age group

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	16-25 years	1	2.9	2.9	2.9
	26-45 years	14	40.0	41.2	44.1
	46-65 years	16	45.7	47.1	91.2
	Over 65 years	3	8.6	8.8	100.0
	Total	34	97.1	100.0	
Missing	System	1	2.9		
Total		35	100.0		

The results for the gender question were more revealing than for age. Both surveys had a much higher response rate from female participants than from males. The results were 76.7% and 68.6% respectively for the People with Disabilities’ survey and the Carers of People with Disabilities’ survey.

The People with Disabilities’ survey had a higher response from males (16.3%) than did the Carers of People with Disabilities’ survey (5.7%). The latter survey had a higher level of missing data, from participants who did not answer the question, even though the option was provided to “prefer not to say”. That option was chosen by only one participant in each survey.

The difference in response rates by gender may be explained by prevalence of disabilities, as they are fairly even at the whole of population level. The difference is more likely to be explained by the profile of people accessing the Facebook groups where the surveys were promoted.

PWD 3

Gender

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Female	33	76.7	78.6	78.6
	Male	7	16.3	16.7	95.2
	Other	1	2.3	2.4	97.6
	Prefer not to say	1	2.3	2.4	100.0
	Total	42	97.7	100.0	
Missing	Not required to answer	1	2.3		
Total		43	100.0		

CPWD 3

Gender

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Female	24	68.6	88.9	88.9
	Male	2	5.7	7.4	96.3
	Prefer not to say	1	2.9	3.7	100.0
	Total	27	77.1	100.0	
Missing	System	8	22.9		
Total		35	100.0		

The next series of questions in both surveys differ slightly as they establish the status of the person in relation to disabilities, as well as eligibility to funded supports. These questions are discussed below for each survey.

5.2 People with disabilities' survey

Of the participants that responded, over 70% were eligible to receive funded supports.

Surprisingly almost 20% of respondents were not eligible to receive funded supports for a disability. This may be because the disability is health related and not yet transferred to the disability sector (e.g. amputee from prolonged onset of diabetes type 2) or due to psychosocial conditions that are either undiagnosed or not able to be catered for in the disability funding regimes. Or it may be because the respondent has not yet gained eligibility to the NDIS or undertaken the necessary registration and planning requirements.

Unfortunately there are four respondents, almost 10%, who don't know if they are eligible for funded supports. Hopefully once the NDIS has established itself and built the capacity and capabilities of the planners and functional assessors, the eligibility of many people, and their different disabilities and other conditions, will become clearer.

PWD 4

Are you eligible to receive funded supports due to a disability?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	30	69.8	71.4	71.4
	No	8	18.6	19.0	90.5
	Don't know	4	9.3	9.5	100.0
	Total	42	97.7	100.0	
Missing	Not required to answer	1	2.3		
Total		43	100.0		

Responses to the next question are mixed, with just over 50% giving a definitive answer of either yes or no, with the remainder stating they are not required to answer or not providing a response. There is no clear reason for this, other than possibly participants not having 100% confidence in the integrity of the research, or there still being a high degree of confusion about whether or not supports received are funded and by whom.

PWD 5

If yes, do you actually receive any form of funded support?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	22	51.2	95.7	95.7
	No	1	2.3	4.3	100.0
	Total	23	53.5	100.0	
Missing	Not required to answer	13	30.2		
	System	7	16.3		
	Total	20	46.5		
Total		43	100.0		

The following question retains a high degree of non-response (35%), although it has a higher definitive response rate. The findings are interesting in the valid responses in that it shows the participant cohort is relatively able and probably high functioning. Only three respondents did not care for themselves. Of the total respondents, over 50% cared for themselves at least some of the time, with nearly 40% caring for themselves all or most of the time.

PWD 6

Do you care for yourself?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes, all of the time	6	14.0	22.2	22.2
	Yes, most of the time	11	25.6	40.7	63.0
	Yes, some of the time	7	16.3	25.9	88.9
	No	3	7.0	11.1	100.0
	Total	27	62.8	100.0	
Missing	Not required to answer	1	2.3		
	System	15	34.9		
	Total	16	37.2		
Total		43	100.0		

For those people with a disability who had identified a primary carer, the highest category of carer was the paid carer, followed by partner/spouse. These two categories made up 85% of responses. It should be noted that only 21 responses were received to the question, from a participant cohort of 43, so the data is indicative only.

PWD 7

If not, do you have a person who cares for you?

		Count	Column N %
Primary carer	Q7_7 Partner/spouse	8	38.1%
	Q7_1 Parent/Grandparent	4	19.0%
	Q7_6 Unpaid Carer	1	4.8%
	Q7_2 Paid Carer	10	47.6%
	Q7_3 Guardian	1	4.8%
	Q7_4 Friend	1	4.8%

	Q7_5 Other	2	9.5%
	Total	21	

5.3 Carers of people with disabilities' survey

For those people who care for people with disabilities, the highest category was the parent/grandparent which accounted for nearly 60% of respondents. The next highest was "other" which had seven responses.

CPDW 4

What is your role in relationship to the person with a disability?

		Count	Column N %
Role in relationship to person with a disability	Q4_1 Parent / Grandparent	16	59.3%
	Q4_2 Guardian	1	3.7%
	Q4_3 Unpaid Carer	4	14.8%
	Q4_6 Paid Carer	2	7.4%
	Q4_4 Friend	1	3.7%
	Q4_5 Other	7	25.9%
	Total	27	

The table following shows the "other" responses were spread across seven different categories.

CPWD 4 (other)

Other role in relationship to the person with a disability

		Frequency	Percent
Valid	Auditor	1	2.9
	CEO service provider	1	2.9
	Child	1	2.9
	Foster mum	1	2.9

	No answer given	1	2.9
	Person with a disability	1	2.9
	Support coordinator	1	2.9
	Total	7	20.0
Missing		28	80.0
Total		35	100.0

The data for the carers survey has more definitive responses, with only seven, or 20%, of the 35 not giving an indication. The data shows the vast majority, nearly 70%, did receive a funded support.

CPWD 5

Does the person with a disability receive any form of funded support?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	24	68.6	85.7	85.7
	No	4	11.4	14.3	100.0
	Total	28	80.0	100.0	
Missing	System	7	20.0		
Total		35	100.0		

The following question again has a high degree of missing data. Whilst 54% of respondents stated the person with a disability used funding to purchase services from an external provider, the remaining 46% of data was missing, with 11% stating they are not required to answer. The latter point may allude to a lack of confidence in the research, but is probably more suggestive of a cynicism of the NDIS and government supports for people with disabilities. The only pertinent observation from the data is that no respondents actually stated “No” as a response.

CPWD 6

Does the person with a disability use a funded support to purchase services from a service provider external to that person's immediate family (whether an organization or individual)?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	19	54.3	100.0	100.0
Missing	Not required to answer	4	11.4		
	System	12	34.3		
	Total	16	45.7		
Total		35	100.0		

From now on, the survey questions come into alignment again with direct comparisons again able to be made.

With regard to having input to the amount or type of funded support received, there is a large difference between people with disabilities who responded and carers who responded. Nearly 50% of people with disabilities do feel they have a say in their funded supports, which compares to only 20% of carers of people with disabilities.

Both surveys still suffer from a large amount of missing data with 40% and 50% respectively choosing to not answer definitively.

PWD 8

Do you have any say in the amount or type of funded support you receive?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	20	46.5	76.9	76.9
	No	6	14.0	23.1	100.0
	Total	26	60.5	100.0	
Missing	Not required to answer	1	2.3		

	System	16	37.2		
	Total	17	39.5		
Total		43	100.0		

CPWD 7

Does the person with a disability have any say in the amount or type of funded support they receive?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	7	20.0	41.2	41.2
	No	10	28.6	58.8	100.0
	Total	17	48.6	100.0	
Missing	Not required to answer	4	11.4		
	System	14	40.0		
	Total	18	51.4		
Total		35	100.0		

The degree of missing data remains high, with 45% and just over 50% respectively. Interestingly the carers survey has a larger percentage of missing data, with again over 10% of respondents claiming they are not required to answer.

The responses show participants are very mixed in their perceptions of control. There is almost an even spread of low input and high input responses. The only trend emerging is that the people with disabilities’ survey had a higher number of respondents feeling they have a high degree of input, whereas only one person who cared for people with disabilities felt that level of control.

PWD 9

How would you rate the level of involvement you have to determine the amount of funded supports you receive?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Low	4	9.3	16.7	16.7
	2	6	14.0	25.0	41.7
	3	2	4.7	8.3	50.0
	4	6	14.0	25.0	75.0
	High	6	14.0	25.0	100.0
	Total	24	55.8	100.0	
Missing	Not required to answer	1	2.3		
	System	18	41.9		
	Total	19	44.2		
Total		43	100.0		

CPWD 8

How would you rate the level of input the person with a disability has regarding funded supports they receive?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Low	5	14.3	29.4	29.4
	2	4	11.4	23.5	52.9
	3	3	8.6	17.6	70.6
	4	4	11.4	23.5	94.1
	High	1	2.9	5.9	100.0
	Total	17	48.6	100.0	
Missing	Not required to answer	4	11.4		
	System	14	40.0		
	Total	18	51.4		
Total		35	100.0		

The following questions are not directly aligned, but are asking the same type of question from a 1st person and 3rd person narrative. The level of valid data is slightly higher at 60% and 50% respectively.

The data is very interesting in that it shows both cohorts feel they are having a large say in the type of funded supports received, with both surveys only having small responses to “not at all”.

The survey questions are seemingly contradictory because one would think if the person with a disability is having a large say in the supports they receive, then they are in control and other people would not have a large input. But the survey cohorts were most likely different persons, so the data is not interdependent. Nor are the responses necessarily mutually exclusive in that just because one person feels they have a lot of input does not exclude another person perceiving they also have a lot of input – it may just be input from a different perspective.

PWD 10

How much say do you have in decisions about the type of funded supports you receive?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	A lot	7	16.3	28.0	28.0
	Some	8	18.6	32.0	60.0
	A little bit	7	16.3	28.0	88.0
	Not at all	3	7.0	12.0	100.0
	Total	25	58.1	100.0	
Missing	Not required to answer	1	2.3		
	System	17	39.5		
	Total	18	41.9		
Total		43	100.0		

CPWD 9

To what level do you participate in decision making on behalf of the person with a disability when making decisions about funded supports they receive?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Wholly	11	31.4	61.1	61.1
	Partially	4	11.4	22.2	83.3
	Slightly	1	2.9	5.6	88.9
	Not at all	2	5.7	11.1	100.0
	Total	18	51.4	100.0	
Missing	Not required to answer	4	11.4		
	System	13	37.1		
	Total	17	48.6		
Total		35	100.0		

The sense of empowerment felt by people with disabilities in choosing who delivers supports is confirmed in the following question with nearly 70% of valid responses recording a high degree of involvement and only 20% recording “a little bit” or “not at all”.

PWD 11

Are you involved in choosing who delivers the funded supports you receive?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Not at all	2	4.7	8.0	8.0
	A little bit	3	7.0	12.0	20.0
	Some	3	7.0	12.0	32.0
	A lot	17	39.5	68.0	100.0
	Total	25	58.1	100.0	
Missing	Not required to answer	1	2.3		

	System	17	39.5		
	Total	18	41.9		
Total		43	100.0		

Just under 60% of participants responded in both surveys, with both giving 14 negative responses. With the difference in numbers of respondents, this meant that responses for yes and no for people with disabilities was much closer than that for carers, where more than twice as many respondents stated they did not receive support to enable a contribution to decisions.

Even though 11 people with disability stated they did access a support, or resource, to enable participation in decision making, none of them stated what that was. On the other hand only six carers of people with disability stated they accessed a resource and each of those detailed in the subsequent question what that resource was. The highest response was “trusted support person, e.g. therapist”.

PWD 12

Are you provided with support to enable you to contribute to decisions on matters that affect you?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	11	25.6	44.0	44.0
	No	14	32.6	56.0	100.0
	Total	25	58.1	100.0	
Missing	Not required to answer	1	2.3		
	System	17	39.5		
	Total	18	41.9		
Total		43	100.0		

PWD 13

If yes, what type of support?

		Count	Column N %
Support received to assist in decision making	Q13_1 Translator and/or interpreter	0	0.0%
	Q13_2 Communication aids	0	0.0%
	Q13_3 Trusted support person (eg therapist)	0	0.0%
	Q13_4 Other	0	0.0%
	Total	0	

CPWD 10

Is the person with a disability provided with a resource to enable them to participate in decision making on matters that impact upon them?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	6	17.1	30.0	30.0
	No	14	40.0	70.0	100.0
	Total	20	57.1	100.0	
Missing	System	15	42.9		
Total		35	100.0		

CPWD 11

If so, what sort of resource?

		Count	Column N %
Resource provided with for participation in decision making	Q11_1 Translator and/or interpreter	1	16.7%
	Q11_2 Trusted support person (eg therapist)	4	66.7%
	Q11_3 Communication Aid	2	33.3%
	Q11_4 Other	1	16.7%

	Total	6	

With valid data only just over 55% for both surveys, it is difficult to draw conclusions, however of those who did respond, both surveys recorded a majority of positive “yes” responses, with 67% and 80% of valid responses respectively. In this survey it is evident that carers recorded a slightly more empowered stance than did people with disabilities.

PWD 14

Are you able to participate in decision-making by the service provider that delivers services to you?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	16	37.2	66.7	66.7
	No	8	18.6	33.3	100.0
	Total	24	55.8	100.0	
Missing	Not required to answer	1	2.3		
	System	18	41.9		
	Total	19	44.2		
Total		43	100.0		

CPWD 12

Are you, or the person that you care for, able to participate in decision-making with the service provider?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	16	45.7	80.0	80.0
	No	3	8.6	15.0	95.0
	Don't know	1	2.9	5.0	100.0
	Total	20	57.1	100.0	

Missing	System	15	42.9		
Total		35	100.0		

Where respondents did provide a text response, the involvement in decision-making was largely reported at the individual planning level (77% and 75% respectively), with the remainder in the whole-of-organisation governance-type roles. Of these only one person with a disability contributed at the Board of Management (Director) level, compared to three carers of people with a disability.

PWD 15

If yes, what form does the participation take?

		Count	Column N %
Form of participation in decision making	Q15_1 Board of Management	1	7.7%
	Q15_2 Reference Group	0	0.0%
	Q15_3 Advisory Committee	1	7.7%
	Q15_4 Focus Group	1	7.7%
	Q15_5 Individual Planning Meeting	10	76.9%
	Q15_6 Micro-Board	0	0.0%
	Q15_7 Other	2	15.4%
	Total	13	

CPWD 13

If yes, what form does the participation take?

		Count	Column N %
Type of participation in decision making	Q13_1 Board of Management	3	25.0%
	Q13_2 Reference Group	1	8.3%
	Q13_3 Advisory Committee	1	8.3%
	Q13_4 Focus Group	1	8.3%

	Q13_5 Individual Planning Meeting	9	75.0%
	Q13_6 Micro Board	0	0.0%
	Q13_8 Other	2	16.7%
	Total	12	

A minimal response was received for the following question, with only one person with a disability indicating their form of participation constitutes self-management of their plan. This response rate could be due to no other form of participation, or more likely due to confusion over what the question was actually asking in relation to governance.

PWD 15 (other)

Form of other participation

		Frequency	Percent
Valid	No answer given	1	2.3
	Self manage	1	2.3
	Total	2	4.7
Missing		41	95.3
Total		43	100.0

CPWD 15 (other)

Other form of the participation

	Frequency	Percent
Missing	35	100.0

Where respondents chose all the aspects of participation they are involved with (not governance related), and where responses were not either or, a large number of people indicated their involvement was related to making decisions. A higher proportion of carers also stated they participated by advising and advocating. This is not surprising as many would expect that is a core duty of a primary carer.

PWD 16

Please indicate what this participation involves?

		Count	Column N %
Participation involves:	Q16_1 Making decisions	10	71.4%
	Q16_2 Advising	4	28.6%
	Q16_3 Advocating	3	21.4%
	Q16_4 Other	3	21.4%
	Total	14	

CPWD 14

Does the participation involve?

		Count	Column N %
Participation involves:	Q14_1 Making decisions	10	71.4%
	Q14_2 Advising	8	57.1%
	Q14_3 Advocating	10	71.4%
	Q14_4 Other	0	0.0%
	Total	14	

The responses of “other” by people with disabilities is spread across three different responses as per below.

PWD 16 (other)

Other participation

		Frequency	Percent
Valid	answering questions... but from a position of being unaware of possibilities.	1	2.3
	No answer given	1	2.3

	Some input -face-to-face with area manager, who is constrained by whatever funds are seemingly arbitrarily applied by NDIS.	1	2.3
	Total	3	7.0
Missing		40	93.0
Total		43	100.0

Survey questions specific to carers are below.

More than twice the number of carers felt they could not participate in a governance framework, with only four that felt they could. Although of 10 responses to the efficacy of the governance frameworks, the responses were split 50% to 50% yes and no.

CPWD 15

Are you able to participate in a governance framework that contributes to decision-making that impacts upon the person with a disability whom you care for?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	4	11.4	28.6	28.6
	No	10	28.6	71.4	100.0
	Total	14	40.0	100.0	
Missing	System	21	60.0		
Total		35	100.0		

CPWD 16

Do you think the governance framework is effective at improving decision-making by incorporating your views?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	5	14.3	50.0	50.0

	No	5	14.3	50.0	100.0
	Total	10	28.6	100.0	
Missing	System	25	71.4		
Total		35	100.0		

Both surveys received just less than 50% valid responses from participants for the following question regarding their position in relation to decision making. However both returned similar results for those who did respond, with the highest response being recorded for the term “client” and the lowest for “citizen”.

Both surveys only show a modest response for the term “customer” with 25% and 12% respectively. Whilst this number is higher for the cohort of people with disabilities, it is certainly not as high as some service providers might want, with their emphasis on marketing to customers who are now exhibiting choice and control and wielding economic power. Whether this changes over time is still to be seen, but results from the survey, although from low numbers of respondents, should be cross-referenced with results from the qualitative data which actually show a similar trend.

PWD 17

Word that best describes your current position with regard to decision-making for funded supports

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Consumer	6	14.0	30.0	30.0
	Client	8	18.6	40.0	70.0
	Customer	5	11.6	25.0	95.0
	Citizen	1	2.3	5.0	100.0
	Total	20	46.5	100.0	
Missing	Not required to answer	1	2.3		
	System	22	51.2		
	Total	23	53.5		

Total	43	100.0		

CPWD 17

Which word do you think best describes the current position of the person with a disability that you care for with regard to decision-making in relation to funded supports that they receive:

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Consumer	5	14.3	29.4	29.4
	Client	9	25.7	52.9	82.4
	Customer	2	5.7	11.8	94.1
	Citizen	1	2.9	5.9	100.0
	Total	17	48.6	100.0	
Missing	System	18	51.4		
Total		35	100.0		

Participants were asked to free-text to explain why they chose that particular response. These responses are detailed below. From the responses received, there seems to be a degree of frustration and a sense of disenfranchisement from the "system". Interestingly only one participant went to the effort of defining the terms in their response. This is something I chose not to do in asking the question, because the premise of the proposition is that there is mixed understandings of the terms that are now being used interchangeably. Hence the recommendation that the sector work to define the roles and develop a shared understanding of them in relation to decision-making and governance.

PWD 17 (why)

Why this word describes your current position with regard to decision-making for funded supports

		Frequency	Percent
Valid	Because I am	1	2.3
	Because I am the person using these supports.	1	2.3
	Business transaction with health system	1	2.3
	I am a RECIPIENT who can only make suggestions. NDIS somehow can determine my requirements after one short meeting.	1	2.3
	I purchase and use the services/equipment - nothing more	1	2.3
	Nowhere near enough info regarding what is available and how allocations are spent.	1	2.3
	Total	6	14.0
Missing		37	86.0
Total		43	100.0

CPWD 17 (why)

Why does this describes the current position of the person that you care for with regard to decision-making in relation to funded supports that they receive?

		Frequency	Percent
Valid	Citizen a member of a particular country and who has rights because of being born there or because of being given rights because of citizenship so that seems not the right fit. Client a person who uses the services of a professional such as a lawyer. A customer is usually a person who buys goods/services from a shop. Consumer is typically a person who purchases goods and services for personal use	1	2.9
	I see client as some who pays for services in a professional or medical area	1	2.9

	PWD designated word	1	2.9
	They can research services and utilise choice and control in selecting funded supports	1	2.9
	We purchase services from various providers of our choice & are advocates for the mainstream services our son accesses to evolve in their ability to better support young children with disabilities	1	2.9
	Total	5	14.3
Missing		30	85.7
Total		35	100.0

Survey questions specific to people with disabilities are below.

The responses show clearly that only one person of 43 total is involved in governance of a service provider. That one individual that is involved believes the governance is clear.

This result could be due to the fact that very few people are actually involved in governance. Given the slight majority (54%) of missing data, there is possibly still an element of confusion about what governance actually is.

PWD 18

If you receive supports from a service provider, are you involved in that organisation's governance?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	1	2.3	5.3	5.3
	No	18	41.9	94.7	100.0
	Total	19	44.2	100.0	
Missing	Not required to answer	1	2.3		
	System	23	53.5		
	Total	24	55.8		

Total	43	100.0		

PWD 19

If yes, do you think the governance framework you are involved with is clear in the expectations of involvement it requires from you?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	1	2.3	100.0	100.0
Missing	Not required to answer	19	44.2		
	System	23	53.5		
	Total	42	97.7		
Total		43	100.0		

For those participants that went on to describe their involvement in governance more broadly, the results were different between the cohorts. More people with disabilities were involved with advocacy organisations than any other, whereas more carers were involved with service providers. People with disabilities, whilst having a slightly lower number of respondents, were spread better across the range of responses, meaning they were more broadly represented in the governance of different agencies.

PWD 20

Are you involved with the governance of any of the following?

		Count	Column N %
Involved with the governance of:	Q20_1 Advocacy Organisation	6	50.0%
	Q20_2 Service Provider	2	16.7%
	Q20_3 Peak Representation Body	3	25.0%
	Q20_4 Local Government	1	8.3%
	Q20_5 Health Department (or similar)	2	16.7%
	Q20_6 Consumer Rights Group	1	8.3%
	Q20_8 Other	1	8.3%

	Q20_10 No	3	25.0%
	Total	12	

CPWD 18

Is the governance framework you are involved with associated with?

		Count	Column N %
Governance framework is associated with:	Q18_1 Advocacy Organisation	0	0.0%
	Q18_2 Service Provider	13	92.9%
	Q18_3 Peak Representative Body	1	7.1%
	Q18_4 Local Government	0	0.0%
	Q18_5 Health Department (or similar)	1	7.1%
	Q18_6 Consumer Rights Group	0	0.0%
	Q18_8 Other	1	7.1%
	Total	14	

The following comments offered by people with disabilities shows an example of governance representation. It also gives a good example of the cynicism that is evident in the participant cohort towards systems and bureaucracies.

PWD 20 (other)

Other group involved with the governance of

		Frequency	Percent
Valid	I’m an ex alderman from Devonport City Council Tasmania	1	2.3
Missing		42	97.7
Total		43	100.0

General comment re governance involvement

		Frequency	Percent

Valid	The entire process, from NDIS down, is shrouded in bureaucratese and obfuscation.	1	2.3
Missing		42	97.7
Total		43	100.0

The response for the following question is disappointing, with approximately 45% of participants responding in each survey. This is possibly due to fatigue in the survey following the more complex questions on governance. This was a risk raised by the user testing group in the design phase.

Of those who did respond, the surveys returned similar responses. More people are reporting some confidence in their level of understanding of the NDIS than low or none. Although both surveys would have a normal bell curve, with the average response somewhere midway in the scale.

Both surveys only had 11.6% and 11.4% respectively recording a high degree of understanding of the NDIS.

PWD 21

How would you rate your level of understanding of the NDIS?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	2	3	7.0	15.8	15.8
	3	8	18.6	42.1	57.9
	4	3	7.0	15.8	73.7
	High	5	11.6	26.3	100.0
	Total	19	44.2	100.0	
Missing	Not required to answer	1	2.3		
	System	23	53.5		
	Total	24	55.8		

Total		43	100.0		

CPWD 19

How would you rate your level of understanding of the National Disability Insurance Scheme?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Low	2	5.7	12.5	12.5
	2	1	2.9	6.3	18.8
	3	9	25.7	56.3	75.0
	High	4	11.4	25.0	100.0
	Total	16	45.7	100.0	
Missing	System	19	54.3		
Total		35	100.0		

Again, the level of valid responses to the following question is low, with 40% or less possible participants contributing valid data.

Of those who did respond, the Carers' cohort respondents appeared slightly more optimistic about the level of choice and control they would have once transitioned to the NDIS. The People with Disabilities' survey returned a higher "less" response than "more". Both surveys returned the smallest response for "same", which means people who did respond are at least discerning between what they access now and what they expect to access in the future.

PWD 22

Level of choice and control over the type and amount of funded supports available once you are a participant in the NDIS?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	More	5	11.6	31.3	31.3
	Less	7	16.3	43.8	75.0
	Same	4	9.3	25.0	100.0

	Total	16	37.2	100.0	
Missing	Not required to answer	1	2.3		
	System	26	60.5		
	Total	27	62.8		
Total		43	100.0		

CPWD 20

Will the person you care for have more or less choice and control over the type and amount of funded supports available once they are a participant in the NDIS?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	More	6	17.1	42.9	42.9
	Less	5	14.3	35.7	78.6
	Same	3	8.6	21.4	100.0
	Total	14	40.0	100.0	
Missing	System	21	60.0		
Total		35	100.0		

The question relating to obstacles and/or impediments to exercising choice and control has generated a widespread and diverse range of responses for both surveys.

The top five responses for people with disabilities was:

- Lack of information
- Knowledge of planners
- Understanding of personal circumstances
- Funding process
- Quality of planners

The top five responses for people caring for people with disabilities was:

- Quality of providers
- Quality of supports
- Quality of planners
- Knowledge of planners
- Understanding of personal circumstances

Three of the same responses appear in both surveys. Of these three common responses, two are directly related to the planners that are employed by the NDIS. This response resonates with findings in the qualitative study.

If something can be changed that would directly impact the efficacy and efficiency of the NDIS, it would be the capacity and capability of the planners. This theme will be raised in the conclusion of this thesis and will feature in the recommendations for further research.

PWD 23

What are the major obstacles to you exercising choice and control over funded supports you receive? (tick all appropriate)

		Count	Column N %
Obstacles to exercising choice and control over supports:	Q23_1 Lack of information	11	61.1%
	Q23_2 Too much information	0	0.0%
	Q23_3 Lack of choice	8	44.4%
	Q23_4 Too much choice	0	0.0%
	Q23_5 Quality of planners	9	50.0%
	Q23_6 Knowledge of planners	10	55.6%
	Q23_7 Lack of providers	7	38.9%
	Q23_8 Quality of providers	5	27.8%
	Q23_9 Capacity of providers	4	22.2%
	Q23_10 Quantity of supports	5	27.8%
	Q23_11 Understanding of personal circumstances	10	55.6%
	Q23_12 Funds	6	33.3%
	Q23_13 Funding process	10	55.6%
	Q23_14 Other	2	11.1%

	Total	18	

CPWD 21

What are the major obstacles to you exercising choice and control over funded supports you receive? (tick all appropriate)

		Count	Column N %
Impediments to people with a disability exercising choice over supports received	Q21_1 Lack of information	7	43.8%
	Q21_2 Too much information	5	31.3%
	Q21_3 Lack of choice	7	43.8%
	Q21_4 Too much choice	1	6.3%
	Q21_5 Quality of planners	11	68.8%
	Q21_6 Knowledge of planners	11	68.8%
	Q21_7 Lack of providers	5	31.3%
	Q21_8 Quality of providers	14	87.5%
	Q21_9 Capacity of providers	10	62.5%
	Q21_16 Quality of supports	12	75.0%
	Q21_10 Quantity of supports	5	31.3%
	Q21_11 Understanding of personal circumstances	11	68.8%
	Q21_12 Funds	10	62.5%
	Q21_13 Funding process	10	62.5%
	Q21_14 Other	2	12.5%
	Total	16	

Again, there is an apparent level of cynicism evident in the People with Disabilities participant cohort.

PWD 23 (other)

Other major obstacles to you exercising choice and control over funded supports you receive?

		Frequency	Percent
Valid	Compared to State system, the NDIS is WAY more difficult to get needed equipment approved. It also takes much longer. Payments meant to assist with things like transportation are a joke.	1	2.3
	I cannot use a phone so I need to access face to face and in a lot of cases this is not possible	1	2.3
	Total	2	4.7
Missing		41	95.3
Total		43	100.0

CPWD 21 (other)

Other major impediment to people with disabilities exercising choice and control over supports they receive

		Frequency	Percent
Valid	many children with disabilities have parents with disabilities who are not supported in the process. This group require adequate time for clear and open communication to be heard and understood to ensure the person they are caring for receives the plan they need.	1	2.9
	The information is too hard to filter through. We don't have the time or energy to sort through it all.	1	2.9
	Total	2	5.7
Missing		33	94.3
Total		35	100.0

Whether or not the following question could be seen as an indicator of empowerment is arguable, but it is interesting that people with a disability have more confidence in their ability to complain about their funded supports than do carers. The difference in the ratio is 3:1 compared to 1:1.

PWD 24

Do you have the ability to complain about the funded supports you receive?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	14	32.6	73.7	73.7
	No	5	11.6	26.3	100.0
	Total	19	44.2	100.0	
Missing	Not required to answer	1	2.3		
	System	23	53.5		
	Total	24	55.8		
Total		43	100.0		

CPWD 22

Do you believe people with disabilities have the opportunity to complain about the funded supports they receive?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	8	22.9	50.0	50.0
	No	8	22.9	50.0	100.0
	Total	16	45.7	100.0	
Missing	System	19	54.3		
Total		35	100.0		

Unfortunately for both cohorts, the confidence that the complaint once made will be heard, is low for both cohorts. Only 15% of valid responses for people with disabilities and only 6% of carers believe their voice will be heard.

This again lends itself to a high degree of disenfranchisement and cynicism in the system and the bureaucracy that runs it.

PWD 25

If you complain about the funded supports you receive, will your complaint be heard and responded to appropriately?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	3	7.0	15.8	15.8
	No	13	30.2	68.4	84.2
	Maybe	3	7.0	15.8	100.0
	Total	19	44.2	100.0	
Missing	Not required to answer	1	2.3		
	System	23	53.5		
	Total	24	55.8		
Total		43	100.0		

CPWD 23

If a person with a disability complains about the funded supports they receive, will their complaint be heard and responded to appropriately?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	1	2.9	6.3	6.3
	No	9	25.7	56.3	62.5
	Maybe	6	17.1	37.5	100.0
	Total	16	45.7	100.0	
Missing	System	19	54.3		
Total		35	100.0		

5.4 Summary

The Quantitative data, whilst collected first and hence presented first, was only ever intended to be supplementary to the Qualitative data. For the most part it is consistent with views expressed in interviews which are summarised in the next Chapter.

The quantitative data may appear inconclusive due to the low numbers of participants who completed the surveys, or answered each question, but there are certainly results that do support the propositions stated in the Introduction Chapter. Again, these are:

1. The transfer of power intended by contemporary social policies is well intended, but incomplete in practice;
2. Those transferring power believe the transfer is further progressed than those receiving the power; and
3. The transfer of power to the person with a disability is unique and different in each individual case.

Whilst a big assumption to make, it could be that the participants who did not complete the questions were either not informed on the subject matter (i.e. governance), or were disinterested due to frustration with the broader systemic changes that were impacting upon them. These were themes raised by people in the qualitative study that follows. Some of the research participants who were interviewed stated they had also completed the survey and expressed some dissatisfaction with it due to lack of explanation (e.g. definitions for consumer, client, customer and citizen) and stating a preference to discuss the topic to do it justice, rather than giving closed answer type survey responses.

In addition to this, there was evidence in the surveys of highly empowered participants giving very direct responses, and highly disempowered people also giving direct responses, with the missing data likely the participants in the grey area or feeling a level of ambiguity. This was a finding of questions relating to funded supports, with people either knowing they received funded supports, or knowing they did not. It was the large middle group who seemed unsure.

Another interesting finding was that people with disabilities, who did respond to questions about funded supports for example, appeared much more empowered than carers of people with disabilities. This may just be a reflection of the data being certain for that cohort, but it could be that all of the missing data was actually missing because people were unsure and therefore the data is not credited to the lower empowered type fields. The same phenomenon could be at play in responses for decision-making and accessing supports to make decisions. Those empowered people who were certain gave direct responses, yet those who were unsure or felt disempowered may have chosen not to answer – hence the large missing data results. Whilst only an assumption from this data, it was one that had some validity when cross referenced to interview responses.

As with the findings in the Qualitative study, it was clear from the Quantitative data that research participants were responding for the most part on an individual basis; that is, on governance as it related decision-making about their individual plans and circumstances. Whilst there was evidence of involvement in broader governance mechanisms, like Boards of Management, the response rate for types of decision-making being “Individual Planning Meeting” were either 75% or above for both the people with disabilities and the carer of people with disabilities cohorts.

As questions changed from individual decision-making to broader organisational governance, it was clear that less participants responded. It was also clear that participants became less decisive, with equal numbers of people feeling empowered and disempowered of those who responded. The increase in missing data supports the assumption that people may not have understood the concepts like “governance” and simply chose not to respond. This was also raised as a definition lacking by participants who were also interviewed.

It was not a surprise to see some results were aligned with findings from the literature review. All of the impediments/obstacles that were mentioned in both participant cohorts were identified by researchers in the literature. As a reminder, some of those impediments to choice and control (empowerment) were seen to be:

- lack of information
- knowledge of planners
- understanding of personal circumstances

As an extension of this line of query, the questions exploring empowerment in making a complaint revealed that most participants knew they could make a compliant, but few had any confidence that the complaint would result in action. This together with the high missing data could suggest there is a high level of disenfranchisement with the new NDIS “system” and suggests a level of disempowerment in being heard.

The quantitative data does have some direct relevance to broader findings in the thesis. For example, it supports the proposition that people with disabilities, and their carers, are less empowered than service providers believe and associate more with terms like consumer and client than they do with customer and citizen. Furthermore the data suggests that the NDIS has not yet delivered an increase in choice and control (taken to represent a form of empowerment) with a majority of respondents for both participant cohorts reporting the same or less choice and control than what they had prior to the NDIS. It also supports clear findings from the interviews that relate to the quality of planners for example. This is a theme explored in the Conclusion Chapter (Chapter 7) and is the basis of a recommendation in the Recommendations Chapter (Chapter 8).

6. FINDINGS – QUALITATIVE RESEARCH

The qualitative findings from the research are initially presented in cohort arrangement. This is due to the different questionnaires and different sequencing of questions used for each. Given the questionnaires were broadly designed to explore the Research Question and associated Objectives, the themes raised in each cohort can be summarised and then compared and contrasted with each other.

I have not presented the data in a like-for-like question format as the responses to the questions often differed. For example when a person with a disability responded to Question 5 – identifying the level of control they had over decision making, they responded from a personal perspective and took into account the supporting factors they had. When people caring for people with disabilities responded to the same question they often chose to provide two responses to designate without and with support responses. The latter score was always higher than the initial score. The organisations and peak body/advocate cohorts were not asked this question.

Another reason why the data was not presented in a like-for-like question format was because the semi-structured nature of the interviews also meant participants did not always stick to the script, but often answered subsequent questions out of order. Once discussion was free flowing, I encouraged participants to keep going to gain as much spontaneous input as possible. I would then ask the participant later in the interview if they had any further information to add if I felt they had already addressed the question in prior discussion. This meant responses were often out-of-sequence with the interview question numbers.

As a general observation, I found that people with the lived experience of disability tended to respond from an individual perspective. They would answer questions for the most part from an individual decision-making perspective e.g. decisions about access to everyday supports. People from an organisational background would be more likely to answer questions from a broader governance perspective e.g. suggestions how to involve people systematically in decision making, or decisions about recruitment or policy change for example.

It became evident to me early in the interviewing process that there were a number of themes that were being raised in different contexts and using different language, but which were essentially the same. An example was the concern that choice and control was limited to what was available from a menu of choices that the government offered, rather than truly tailored and individualised options. Or that people were only able to make choices within the remit of what they knew was possible, which was restrictive on choice when what they may have most benefitted from was a support they are not yet aware of, or may not be eligible for, or able to access. Knowing this, I began identifying the themes manually from the notes I took in interviews, using a simple colour coding with highlighters. These themes were further explored during the transcription process and both validated and added to as transcriptions were completed.

Due to this somewhat subjective process of identifying both key and common themes as people were speaking and again when transcribing the spoken words, I chose to also use the NVivo software to apply a more objective approach to analysing responses. This allowed me to count numbers of key words for example to garner some measure of the prevalence of issues.

The processes were kept separate in the following chapter to recognise the separate nature of the analysis – one subjective and the other objective. They were not integrated at the time as they were undertaken as separate pieces of work at different times. The NVivo work was undertaken at a specific point in time once all interviews had concluded. However the manual (thematic) analysis was ongoing from point of interview to transcription, and even later as I reflected on the notes in my research journal. Whilst presentation in this manner may lead to some duplication of themes, it serves to reiterate these in doing so. It also shows the complementary nature of the two approaches to analysis, noting the data (the interviews) were the same for both.

This stage of the chapter is divided into three parts. The first part is the analysis that was undertaken using the manual thematic analysis during the interview phase and onwards. The second part relates the NVivo software analysis that was undertaken at the conclusion of the transcription phase. And the third part compares and contrasts the themes from both analyses and between the cohorts.

6.1 Part 1 – Manual Analysis

6.1.1 People with Disabilities

Five interviews were conducted in the People with Disabilities cohort, of a planned 10. The people interviewed had varied disabilities, including both physical and intellectual, and in some cases had multiple disabilities. There were also circumstances of comorbidities with health conditions, which were not necessarily causal of the disability, but were still a factor.

Interviews were held on the following dates: 26/11/2019, 11/12/2019, 13/12/2019, 10/5/2021 and 20/11/2021. They ranged in length from 16 minutes and 22 seconds to 52 minutes and 7 seconds, with a rounded average of 35 minutes.

Before looking at the themes, some of the main issues raised in this cohort were as follows:

1. **The person with a disability is one in the same as the person (holistically) and cannot be separated**

The call from people with disabilities is to be seen holistically as a person first and foremost. The disability does not define the person, but rather they are a unique individual with hopes and dreams and all the complexities of any person living a life. To try and segment their lives for the bits that fit into a disability, or should be funded by disability supports, can be very artificial. The example given in this interview was the supports for clothes washing. It was difficult for the person with a disability to separate their own washing from that of other family members as the family washing was usually done together and separated into whites and colours. Likewise with shared items like tablecloths for example.

Another issue raised was the impact of the support work on the other members of the household, and the opinions and biases that may form:

> *"…we've got two teenagers. We don't want them to think there's people who just come along and do the dishes and wash their clothes for them. They have to do it for themselves. And so we sort of Yes, we cut back on some of the support workers coming in for that reason." (Research Participant 1.1)*

2. Choice and control comes with responsibilities – especially when employing Support Workers directly

There was acknowledgement by at least one person with a disability that choosing to self-manage their NDIS Plan came with responsibilities. By choosing to self-manage, the responsibility for employment of staff rests with the person with a disability. As an employer, the person with a disability effectively assumes responsibility for all those complex considerations related to health and safety of employees, taxation, public liability and professional indemnity implications and not the least the payroll duties to perform as well. Self-managing a sizeable disability support package from the NDIS appears to have some similarities to running a small business. If you do not self-manage, and instead place administrative control of the NDIS Plan with a service provider or with the National Disability Services Agency, then you do not assume these extra responsibilities as you would if they were the employer (or purchaser from an employer). The trade-off is less control. Hence the summary that with more choice and control (self-management) comes more responsibilities.

Another associated issue is how much the home needs to resemble a workplace. One participant acknowledged, in relation to safety:

> *"So I don't have posters up in my house." (Research Participant 1.1)*

3. To exercise choice and control is to compromise – you never get everything you want

Even when apparently in full control of decisions, one is actually not. As one research participant pointed out, when rostering at Christmas time, you are better off compromising to get what you want, rather than demanding everything, which may see your valued carer begrudge you for making them work and miss their own family obligations.

> *"So one of the things that I've learned over time is that the people that come into my home to provide me support they have lives as well. And they will work with me around holiday times like Christmas and things like that. You know, if they know that I can be flexible back with them. So yes, I have lots of control. But I'm also like, there are times when you have to compromise and that's just, that's normal, that's okay. (Research Participant 1.1)*

On a broader scale this issue was also raised by multiple participants in relation to the available marketplace and what the government has termed "thin markets", especially in relation to some rural and remote areas.

4. Choice and control in context – spontaneity v schedule and routine

A tension was identified when discussing sharing the personal aspects of one's life with a carer. Whilst spontaneous intimacy was desired by one person, they needed to be mindful of the presence of a carer and that sometimes routine needed to prevail.

5. Tension with guidelines and the need to make decisions compliant with them – e.g. moving funds between different supports as needed

There was a prevailing frustration with the rigidity of the NDIS. It was a Scheme designed to personalise supports and individualise payments for them. People were challenged to dream and to articulate their aspirations in a Plan and then design the reasonable and necessary supports to achieve those dreams. In reality people are seeing "cookie cutter" plans with "drop-down menus" for choice and little flexibility to move funds between different support categories.

One participant likened choice and control to the ability to manoeuvre funds within the NDIS plan structure:

> *"Because you can't change money between back and forth daily activities to health and welfare or whatever… that extra little bit of flexibility would be a huge, huge improvement. (Research Participant 1.2)*

6. Empowerment drain – where carers feel empowered by working with people more vulnerable than themselves

This was raised by only one participant, but relevant to all in the context of dichotomous empowerment. In this instance the person with a disability was describing carers they had worked with who were motivated by working with someone less able than themselves. The vulnerability of the person with a disability made the carer feel better about themselves as if empowering themselves by further disempowering the person they cared for.

> *"…that's why I moved on from the previous support worker, because she was a bit of a control freak. She felt empowered over vulnerable people I think… I think because normally we don't stand up for ourselves. And even for me, it's taken me years to learn to be assertive." Research Participant 1.2)*

7. Defining as consumers with a lived experience of disability rather than people with disabilities who are consumers

People with disabilities have argued the person must come first. Hence the protocol to refer to "person with a disability" rather than "disabled person". In the same way, people with a disability should be considered as people who are consumers first and foremost, rather than disabled consumers. Some participants referred to this in interviews, especially the impact it had on pricing for equipment. Whilst equipment could be bespoke and/or specialised for people with disabilities, it did not justify the mark-up in price for what was otherwise a normal consumable product. An example often talked about in relation to this point in the broader sector is the child's car seat. A quality product that meets Australian safety standards from a reputable supplier should cost around $300 in the marketplace. A similar product with additional lumbar supports to cater for reduced core strength in a child with cerebral palsy (for example) can cost in excess of $3,000.

This issue has another interesting aspect when the acronym is considered. The protocol above emphasises the person first and foremost, yet when using acronyms it has been perfectly fine to refer to “PWD” instead of writing people with a disability, although there are signs this is changing. However in Aboriginal Affairs the protocol states you must not refer to “ATSI” people, but rather Aboriginal and Torres Strait Islander people as to do so may be considered dehumanising for some.

8. Limitations of an NDIS Plan – when capturing someone’s whole of life dreams and aspirations

There was a sense from research participants that the concept of the NDIS was positive, but to encapsulate someone’s entire life in an NDIS Plan, inclusive of dreams and aspirations, was to trivialise what life is.

> *“Because normal adults don’t go through their life with goals and strategies for everything. It’s a very abnormal and artificial way…” (Research Participant 1.3)*

It was acknowledged that not all of someone’s life was funded by the NDIS. It was also acknowledged that NDIS Planners may not have the skills to grasp someone’s aspirations and support them in planning for them, especially where there are cognitive difficulties and/or cultural and language barriers.

9. The power of the collective over the individual – service providers having louder voice than people with disabilities

There was a prevailing sense from all participants that even the most empowered person with a disability is less powerful than a service provider. That the individual in the Scheme is simply not as important as the provider that may be providing supports to hundreds, even thousands of other participants. This created an imbalance of empowerment, at least in perception.

Relevant to this issue are the responses to the question about collective naming. Some participants stated they were customers because that is what they are called by service providers. They have to purchase services from a marketplace and that is what, they are told, customers do. One participant summarised the essence of this shared issue as:

> *"We are not the people with economic power in the system, even though a good part of the system is specifically constructed to make us think we are the people with economic power." (Participant 1.3)*

10. Lack of evidence of change through appeals – all must fight their individual battles

To this cohort the system appears slow to change. Rather than being responsive and learning from mistakes, the Scheme changes when the CEO or delegate makes a change, or when the Board adopts Review recommendations, or when legislation changes. All of these events are few and infrequent. The suggestion from one participant was a Scheme that changes in line with rulings from the Administrative Appeals Tribunal. When an appeal is upheld and a decision is overturned, the rules should be changed to reflect the decision, so that other participants can be saved the task of appealing.

11. Limitations of research – how to access the views of those most marginalised – cognitive impairment, poverty, language barriers, cultural divides

A number of participants noted their personal circumstance enabled them to participate in the research. They had the time, the communication and technology, the wherewithal to contribute. They had the education and language comprehension to contribute. Most noted the difficulty with accessing views in research from those most marginalised, especially people from culturally diverse backgrounds from a non-English speaking background with intellectual disabilities living in poverty (for example).

> *"It's the people that you can't get in research because they can't communicate or what have you that are really badly disadvantaged by the system."*
> *(Research Participant 1.3)*

12. The person with a disability is also a member of a family / household and therefore some decision-making is a shared process

Whilst the NDIS is premised on a very personalised approach to planning, with individualised supports and payments, many people with disabilities actually live in a shared context. They are part of broader family units themselves and their decisions must take account of the needs of others. Some of those family members may also have disabilities. Therefore choice and control in decision-making may need to be shared with a substantial other at times, as happens in any other successful and lasting relationship. In relation to home modifications, one participant stated:

> *"…what would actually work because it has to work as a household as well. So I think it's a bit of joint decision-making when it comes to certain aspects of the plan." (Research Participant 1.4)*

13. A/B → A+B journey is not yet complete with many specialists believing they are the experts in a person's life

In the westernised medical world there has long been a perception that the doctor knows best, that there is a hierarchy of knowledge and expertise with the specialist at the top and the patient at the bottom. This is represented as the A/B model of care. In the disability sector there is a strong push to transition to person-centred practice where the person is central to decision-making in all aspects of their care and are considered a true partner in that care, hence A+B. However many research participants stated this transition was not yet complete and many people in the system – from NDIS Planners to therapists, all considered themselves more expert than the person with a disability. As stated by one participant:

> *"Who is the expert? The specialist, or the person with a disability who lives it / uses it every day?" (Participant 1.4)*

14. In governance, the person designated with the skillset of a lived experience of disability must provide more than just a reality check – they must actually perform the role of a director and discharge duties expected by legislation

There was acknowledgement from numerous research participants that to perform as a director on a Board of Management today, you must be able to discharge your duties. You must fulfil the requirements of the duties prescribed in Sections 180-185 of the *Corporations Act 2001* for example. Duties that include showing due diligence in making informed decisions, acting in good faith, acting in favour of the company, as well as other sections in the legislation that require directors to avoid conflicts of interest and trading insolvent. And in most instances where the entity is not-for-profit in nature, directors must also meet the requirements specified in the Governance Principles of the *Australian Charities and Not-for-Profits Commission Act 2012*. Acknowledging this increasing complexity, one participant stated:

> *“Now, I mean, the governance level of boards has just gotten to a level where you’d need to have the multi-skilling of, you know, talent to get them to a level of governance that you need; it’s come a long way and has changed so much.” (Research Participant 1.4)*

Participating in the governance of an organisation and being a director of a contemporary service provider was deemed a high level ask. It required knowledge and skills and preferably some relevant expertise. Whilst the lived experience was valued, it was recognised that more was needed. Just being a reality checker and giving opinions of what would and wouldn’t work wasn’t enough in this day and age.

> *“…it’s about understanding that my needs are not the only needs that are out there.” (Research Participant 1.4)*

Participants also noted that to discharge one’s duties one had to be of sound mind. Whilst there was no definition for this in the *Corporations Act 2001*, to think a person with a profound intellectual disability would be able to consistently apply the cognitive rigour required to show due diligence would be unreasonable. Herein lies the importance of such resources that the *Count Me In* project is producing - resources that support organisations to match the right lived experience skills with the level of decision-making required on different Boards.

6.1.2 Carers of People with Disabilities

Eleven interviews were held with carers. The people they cared for varied from young children to adults and from diverse disabilities, both high functioning on the cusp of disability (e.g. Asperger’s Syndrome) and low functioning with profound disability and high dependence. In most instances the people were parents of the person they cared for, including one foster carer. In another instance the person was a social trainer and professional carer.

Interviews were held on the following dates: 18/4/2019, 17/6/2019, 1/7/2019, 9/8/2019, 10/9/2019, 20/9/2019, 29/7/2020, 21/10/2020, 12/11/2020, 21/10/2021, and 6/11/2021. They ranged in length from 27 minutes and 19 seconds to 1 hour and 11 minutes and 15 seconds, with a rounded average of 47 minutes.

As an overview, the main themes raised in this cohort were as follows:

1. Perverse outcome of insurance funding – once disclosed, it could cost more

Whilst the NDIS was generally perceived by carers as a positive development, there was some cynicism about how the marketplace responded to funded supports. In this instance a parent of a child with a disability likened the supply of equipment to a car repair – once the repairer knows the insurance company is paying, the cost doubles. This dynamic could mean inflated prices and additional costs from the disability portfolio. In the view of at least one parent, this has impacted their openness about the source of funding:

> *"I'm just a standard parent with a child with a condition that I'm looking to, I guess, perfect. That's where I might just starting holding back a little bit in terms of who's paying for what. Because that might get a bit of bang (for buck)". (Research Participant 2.1)*

2. Choice and control is about understanding what the alternatives are

A recurring theme from this broader lived experience cohort was the sense that your choices are limited to what you already know. And being able to discern what your alternatives might be and what your opportunity costs are, are important to ensure best use of limited resources to achieve one's goals.

3. Thin markets impact ability to choose

Thin markets exist in the disability marketplace. They are prevalent in rural and remote areas, but can also exist in metropolitan areas. They are markets which have limited suppliers, and limited scope of supply of either a product or service. They are such an issue that government has commissioned a project to explore them and how to respond to them (see https://engage.dss.gov.au/ndis-thin-markets-project/). The impact of thin markets on people with disability is immense. It often means people are assessed and granted a large package with detailed supports and sizeable funding, only to find half the package unspent at the end-of year review. Research participants in country areas reported some instances this has resulted in reduced packages for subsequent years.

4. Relationship between parent's effort and child's funding (versus actual need)

There was a strong sense by research participants in this cohort that funding was commensurate with the ability of a parent to advocate and lobby for their child. The concern was that parents who were informed were generally articulate and able to structure their child's needs in the format of an NDIS Plan, using the NDIS support language, and were thus able to attract higher levels of funding.

> *"I think about the people who are new to the system, who probably get nothing because they don't know how the system works. They don't know what to say or how to prepare for the NDIS meetings….Some people will walk away with the most incredible plans and some people will walk away with nothing. It should be the system sharing what is available, rather than fighting for what you can get." (Research Participant 2.4)*

These comments were not related to the "squeaky wheel" phenomenon, but rather a comment on the inequalities in the system and the propensity for the Scheme to further disempower those who are already marginalised.

5. Quality is determined by the planner on the day

There was a strong sense from research participants that the Scheme is heavily reliant on planners to do their jobs well. The quality of the Plan they ended up with was most heavily determined by the planner they were allocated on the day of their NDIS meeting.

> *"I don't think we have any control. I think it depends on who you get on the day… what background and knowledge they have, as to what type of plan you come out with." (Research Participant 2.4)*

Unfortunately the feeling was also that good planners were few and far between. There was also a sense that measures being implemented by the Scheme to address the knowledge and expertise of planners is contributing to the "cookie cutter" and "drop-down menu" phenomena. In effect, systemising planning, including the use of artificial intelligence, is moving away from the personalisation promised at the outset of the Scheme.

6. Not all disabilities are equal – still struggling to quantify supports for intellectual disability and psychosocial needs

There was generally a shared understanding between participants that disability needs are very different. Physical disabilities are often diagnosed early in life, even at birth, and needs are very tangible and measurable. By contrast, intellectual disabilities are often less obvious, diagnosed much later in life and supports are often intangible and somewhat ethereal. The feeling from participants was that the Scheme was responding well to those with physical disabilities, but there were still too many unknowns with intellectual disabilities and the psychosocial support industry was still in its infancy – at least in regard to servicing people with disabilities.

Another aspect of this issue is the difference in focus of the supports. Traditional disability supports recognise that disability is for the most part for life, and are based on an actuarial basis to invest early and offset the lifelong (future) costs of those supports. Psychosocial supports on the other hand are based on a recovery model that assumes the condition is not necessarily permanent and that a person can indeed recover and regain their independence. There remains a strong feeling amongst people with the lived experience of disability that this difference in approach has not been properly reconciled and mental health conditions are still not well catered for in the planning process of the NDIS.

7. You must focus on negatives to determine eligibility prior to accessing supports to build positives

This was a vexed issue for participants, especially those who were parents of a child with a disability. The journey to access supports starts with a diagnosis. This diagnosis can then have the effect of pigeon-holing and stigmatising the child for life. But it is the necessary evil required to determine eligibility to the NDIS and to then access supports in a funded package. The supports are needed to support and improve life with a view to usually increase independence and live life to its full potential. But to get there you must first focus on proving you (or your child) are low functioning, dependent, less than able, to prove eligibility. Some parents even felt the need to emphasise the negatives, and the impacts of those negatives, to ensure eligibility and best access to supports.

8. Power of customer is diluted when you must declare funds available prior to provider prescribing (e.g. equipment)

Similar to the issue raised by the people with disability cohort, the feeling was that once suppliers knew the government was paying for supports, the price would increase. And having to declare how much money was available prior to the item (e.g. equipment) being prescribed, meant invariably the item would cost as much as the funds that were nominated as available.- One participant used an interesting analogy with retail shopping to make the point real:

> *"Because every time we contact a provider they want to know how much money you have to spend. I'm not telling you that – you tell me how much it's going to cost… Every time I go into Myer I don't tell the shop assistant how much money is in my bank account so that she can sell me her most expensive clothes. I tell you what I want. I want a dress. You show me your dresses. I decide if I can afford them. It's really frustrating." (Research Participant 2.7)*

9. Terminology, language, and access to portal are all barriers

Many research participants spoke of the difficulty in accessing the NDIS portal. The modern two-factor authentication using MyGov ID, followed by the need for a My Gov account, and the computer, internet, and IT skills on hand to navigate the portal are all assumed pre-requisites by government. And to many people they are definitely not, and for some are simply unattainable.

The language used in the NDIS planning process is alien to some people. When asked about dreams and aspirations, people want to communicate in their own language, yet at some time the NDIS planner will require that to be “chunked-down” to NDIS Support category language. And specific terminology for different supports can be so industry specific as to exclude even the smartest person. In the words of one parent of a child with a disability:

> *“…just have no words to describe the frustration level, and confusion level, of this stuff. And I consider myself to be a relatively intelligent person.” (Participant 2.11)*

Which clearly resonates with this other parent of a child with a disability:

> *“Just trying to get your head around the terminology and what it all means. It’s hard enough for me and I’m an intelligent woman with two degrees.” (Participant 2.7)*

And from another participant who also worked in the sector:

> *“I think just even navigating the NDIS portal and trying to get access to the plan. I know I have difficulty with it. And I’m very competent and have been working in that industry for such a long time.” (Research Participant 2.12)*

Clearly this in not the view of just one person!

10. Negative medical terminology and assumptions (e.g. never walk, talk – vegetable for life)

Many parents have expressed negative experiences at time of diagnosis, both in hospital at time of birth, and later. Some communication from medical staff has been delivered with emotional detachment and with a sense of finality that leaves the parent demoralised – as in the example above where a parent on a Reference Group I worked with recounted how she was told by the Paediatrician at birth that their child would never walk or talk and would ostensibly be a vegetable for life. In some cases the messages have been the inspiration to seek out supports and ensure their child is given every chance in life to live to their full potential. Others have had a lasting impact of disempowerment for both child and parent.

> *"…they've always called us a miracle that he survived because his prognosis was a …vegetable. And for quite a long time I couldn't say that without bursting into tears. But that's how they speak." (Research Participant 2.9)*

11. Carers will change and even parents will pass away – need for independence

There was a sense of pragmatism shared by a number of research participants from this cohort, some of whom were already mature aged. There was a sense that gaining a level of independence was a natural aim as at some point the parent will no longer be alive to care for their child, or that carers inevitably move on with their life, or at least their employment. This was not a negative issue, but a reflection on a reality of change that needs to be managed and can further complicate decision-making and the level of control people with a disability can exercise.

12. Sense of progress made is akin to carrying the torch for those who went before

One research participant reflected that the NDIS reforms, and all the promise they offered, was a tribute to those who had advocated long and hard in the past for a fair go for people with disabilities. That there was a moral obligation on those benefiting today to see the changes were sustained and improved. And to do that required people with disabilities to remain engaged, to participate and to actively contribute to the reforms.

13. Delineating between disability specific purpose and general purpose – e.g. for equipment – can be difficult

A practical issue that most carers and parents faced was the access to items that could be deemed not reasonable and necessary, or not specific to the disability. A common example was an iPad which was used by many children with communication difficulties. However an iPad can be used to play games as well, or for parents to do shopping and other activities. The NDIS still seems to have many grey areas and decisions seem to be inconsistent, at least anecdotally.

14. Link between education and therapy – NDIS Plan relativities

Systemisation is not always a bad thing. In the case of links between therapy and education, it makes sense for an Individual Education Plan (IEP) to be linked to a Therapy Service Plan (TSP) and vice-versa, and for the teacher and therapist to be working with the child and with the parent to progress both educational and real-life goals for the child. However this is not always the case and is not mandatory in any educational sector unfortunately.

> *"…That plan covers all of that. But anything that sort of intersects to health or education, then help; there is no plan! And I suppose education is covered within the school system under an individual education plan." (Research Participant 2.6)*[7]

15. Too much choice can be emotionally draining and overwhelming

This was a reflection of early years, especially at the time immediately following diagnosis of a disability. It is also an issue raised in the literature (Alum 2009, p284; Timberlake 2914, p913) as a common obstacle to empowerment. It is interesting because the focus is usually on not enough choice (thin markets), but there is evidence in the research that too much choice can be a problem also.

16. Added impost of country living – specialist appointments in city, cost of travel and accommodation

In addition to the thin markets experienced in many country areas, there is an added burden of accessing services when they must be accessed. This is especially relevant with the assessments required for a diagnosis and hence eligibility to the NDIS. Participants based in country areas spoke of the costs of travelling to the city, getting accommodation (often for young siblings also) and the medical bills involved with assessments that were not yet covered by an NDIS package.

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[7] In 2011 I submitted a recommendation to a Western Australian Parliamentary Inquiry to see Individual Education Plans linked with Therapy Service Plans for children with disabilities.

> *"So it's flights, it's accommodation, getting an appointment, and most of them want to see you for the first part of the assessment on one day, and then come back in a few weeks for the second part. And I say to them, I'm sorry, you've got to do it within the school holidays or within a week, you can't always get those appointments, because it works on the assumption that you live in that town." (Research Participant 2.11)*

17. Exercising choice and control can be restricted to what you know – how can you choose what you don't know?

This was an issue raised by many participants that really became a theme interrelated with the specialist relationship and power imbalance prevalent in the disability sector. To understand what they don't know, and to make an informed decision knowing what alternatives are available, a person with a lived experience of disability must rely on specialist knowledge to fill their gaps in knowledge, or run the risk of making a less than adequate decision.

> *"That's quite a hard question. Because I don't know what I don't know. Right? So while I might think I've got control, I only have control within the remit of my knowledge of that disability, and of my child's unique presentation within that disability." (Research Participant 2.11)*

18. Legal nuances in decision-making – e.g. in relation to guardianship and administration

Disempowerment is not always the aim, but sometimes legal processes require powers to be transferred from individuals to others so as to protect people. This is common for people with disabilities, especially where cognition is an issue. Where the laws have determined it appropriate, a guardian or administrator may be appointed to safeguard a person's welfare. This means another person is legally empowered to make decisions on behalf of another person. The effect can be disempowerment of someone, but it is where society has deemed it in the best interests of someone to do so. In context, this may actually be an empowerment function, albeit somewhat paradoxically.

19. Decision-making is complex – and can be a trigger for unregulated emotions

One of the research participants was a Social Trainer by profession and she made the point that decision-making is actually a complex social skill – one that must be taught at a basic level and continuously reinforced to enable more complex decisions to be made, e.g., from what choice of clothes to wear in the morning, to questions of sexuality and intimacy later in life.

As such, decision making can trigger emotional responses. And these responses can be very unregulated. Whilst the NDIS appears a very positive reform to give people choice and control, it may not be desired by all and might be a trigger for further trauma for some. While decision-making at a governance level may be idealistic, it should not be assumed as ideal for everyone.

6.1.3 Organisations that Provide Services to People with Disabilities

Ten interviews were held with people who worked in organisations that provided community care services to people with disabilities. Invariably every person interviewed was a Chief Executive Officer of a service organisation. Some of those organisations were targeted to a specific disability, while others were general. Given the changes associated with the NDIS insurance agenda, each of the organisations was on a path to appeal to a broader market segment, whilst maintaining specialisation to a core cohort of people, whether that was a diagnostic group (e.g. autism) or an age group (e.g. paediatrics). Of those interviewed, some held numerous other roles as directors and committee members of peak organisations or advocacy bodies, or even as Board members of other service provider organisations, but were interviewed in the capacity of a senior management worker representing a service organisation.

Interviews were held on the following dates: 28/6/2019, 27/8/2019, 5/9/2019, 23/9/2019, 4/12/2019, 10/12/2019, 17/12/2019, 30/12/2019, 9/1/2020, and 24/1/2020. They ranged in length from 31 minutes and 14 seconds to 52 minutes and 59 seconds, with a rounded average of 42 minutes.

As a general observation, there was a nuanced difference between traditional service provider / advocacy organisations and those that had evolved as peer-led organisations. The latter were adamant that consumers should be involved in all aspects of decision-making and that this was a right that should be enshrined in all levels of policy, including the organisation's Constitution.

As an overview, the main themes raised in this cohort were as follows:

1. Involvement of People with Disabilities on recruitment panels

Involvement of people with disabilities in governance can be at many levels. It can be ongoing, as in membership to the Board of Management, or it can be time-limited and purpose specific, such as on a recruitment panel. The latter was seen as a good way to introduce people with disability to involvement in organisational decision-making. Participants also felt it was a key decision area to ensure the voice of the consumer is heard in choosing the people who will ultimately serve them.

> *"I think the area that seems to be called better in this day is the selection of staff. I think that there's always room for improvement and there's always room for being, you know, more open and with more control and say for the person with disabilities." (Research Participant 3.3)*

2. Acknowledgement of citizen theory – reference to literature

A number of participants mentioned specific citizenship models they are working to, to structure the involvement of people with disabilities. The Duffy "Seven Keys of Citizenship" (Duffy et al. 2014) was used as an example.

3. Choice and control is evident, but limited

As raised by other cohorts, there was a prevailing sense that the NDIS has become over-systemised and that decision-making is restricted to menu options. This is seen as an impediment to choice and control. It also relates to the sense of disempowerment from not knowing what the possibilities are – as raised by other cohorts. One participant stated:

> *"How do you plan for something you don't know about? When you're not aware of what the possibilities are?" (Participant 3.5)*

Another participant likened this issue to Henry Ford's comment about customer needs when building a car – he stated that if customers were asked what they needed, they would have said faster horses *(Participant 3.4).*

4. Need for co-design and for purposeful investment in co-design

There was a very strong sense from research participants that involving people with disabilities in decisions that impacted them would lead to better outcomes for them. And this in turn would result in a better business achieving better business outcomes (increasing customer base, increased revenue, more staff). However participants also recognised it was hard work which needed to be sustained. One participant stated:

> *"I think we've got to develop more capacity when we're doing design work to really get people with disabilities as decision-makers in the final say of things." (Participant 3.5)*

There was also a reality raised by another participant who was cognisant that the business needed to serve a number of people with disabilities:

> *"I think people with disabilities should always have input into what would make their service better. And I think there also needs to be a level of understanding that that's got to be done in the context of managing a business for 300 to 400 other people." (Participant 3.7)*

5. Important to balance passion v intellect when inviting the lived experience into governance

Knowing that the decision-makers have an interest in the business is important. That's why it's desirable to have the lived experience on the Board of Directors, because there is no stronger interest than a vested interest – or insights to such. But when the passion behind that interest is not well regulated, and drowns out the interest of others, the input can become detrimental.

6. Get people involved before things turn sour!

A frustration was expressed that had important implications for the recommendations. The sense from one participant is that people with disabilities are called for advice when something has gone wrong – to fix a problem. The preference was for people with disabilities to be involved from the start – to prevent problems occurring and to generally improve decision-making by making it more aligned with the values and desires of the service beneficiaries. As stated by one participant:

> *"It's so much easier to do good and innovative things when you've got a courageous Board, which we have. And you've actually got some balance sheet and you're not just on life support." (Research Participant 3.6)*

7. Collective input from the lived experience – panel approach with diverse backgrounds and experiences

This research participant cohort had numerous suggestions to improve the involvement of people with disabilities in organisational decision-making – and ultimately to empower them in decision-making that enabled them to access community services. These suggestions ranged from co-design models to panel involvement, recruitment advice to Constitutional recognition.

Most participants in this cohort mentioned the diversity of people with disabilities – not just because of the diversity of disabilities, but because they are also diverse people, just as society is diverse. Having one person with a disability involved will garner an individual's perspective, but would be well complemented by having panels of many people with disability to advise. An example from one participant was the panel structure operated by the Ability First Federation. With over 1,000 members, the Federation can garner views of diverse subject-matter experts in different areas of business. Whilst organisations may not fully comprehend the perspective of a person with a disability, another person with a disability may not understand / agree also.[8]

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[8] This model of pooled advice is being used in other sectors to great effect. The Violet Vines Marshman Centre for Rural Health Research at La Trobe University has just embarked on a similar process to establish a Rural Health Consumer Panel

8. Individual decisions do not always aggregate to inform organisational decisions

An extension of the tendency for people with disabilities to first consider decision-making in the context of decisions that impacted themselves as individuals, rather than organisational governance-type decisions, was the feeling that those individual decisions did not always aggregate together to form intuitive organisational decisions.

9. Consumer representation must overcome the inherent self-interest

Whilst research participants in this cohort were overwhelmingly supportive of consumer involvement, there was acknowledgement that self-interest is ever present and conflicts of interest need to be managed. There is also a need to ensure consumers are making decisions based on the organisation’s needs, and the collective consumers, rather than on their personal opinion in relation to their own needs aka the “reality checker”. This term is used for someone who assumes a role of testing the assumptions and decisions of a group (eg a Board) against what the consumer group would face in real life. They themselves assume they have already “walked a thousand miles in the shoes of a person with a disability”, so understand the unique tests of reality and are qualified to comment and advise. Whilst this can be valuable, the group dynamic can lend itself to the role acting to the detriment of others by diminishing the value of the views of others as unqualified.

10. Remuneration for consumer input – to pay or not to pay?

The payment for service, or compensation for effort, was raised by a number of participants in this cohort. There was broad acknowledgement that the views of consumers are valuable and desired, but are provided with a cost. That cost may just be reimbursement for travel and child care, or may be more substantial to actually recognise the intellectual property. As with Directors’ pay, there are a range

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and is now (2022) actively recruiting people in regional areas to contribute their views and experience. More information on this initiative can be accessed from ruralpanel@latrobe.edu.au.

of attitudes in the sector, although growing recognition that payment attracts a higher level of professional commitment.

11. Appetite for genuine and authentic empowerment – not just tokenism

In accessing the consumer voice, participants felt the organisation needed to be genuine. It needed to commit to hearing that voice, even if it didn't like what was said. And it needed to act on the information conveyed by that voice – it was not good enough to listen and do nothing.

> *"Funny enough, we're just having a chat this morning about empowerment. I think there's an appetite to look more broadly at this issue, but ensuring we do it in an authentic way with integrity, not just tokenism… an important contribution people with disabilities can make…but making sure we do it right. And we do it well. And it's not seen as tokenistic." (Research Participant 3.7)*

12. Change from relational to transactional model under NDIS

A number of participants in this cohort were lamenting the transition from a State-funded sector to the nationally-funded NDIS model. They felt much hard work had been undertaken over decades to foster relationships and build trust in the sector. With the advent of the NDIS, the "relational model" had been usurped by the upstart NDIS with all its promises of choice and control, when in reality the NDIS only delivered "cookie-cutter" plans with supports from "drop-down menus" in what many participants felt was a more "transactional model".

Certainly the operational environment changed with the transition from State to Federal systems. Payments that had previously been made in advance for a block of care to a number of people with disabilities, was changed to individual payments paid in arrears on a claim for service for each item of support – hence the transactional nature of the model. The cashflow implications for service providers was huge in the transition to the NDIS model and may go some way to explaining the views of participants in this cohort.

13. Customer connotations may start to commoditise people and their needs

Many research participants explained why they chose the collective name that they chose. In doing so there were some words of caution expressed and in this instance the caution was directed at the perverse outcome of giving economic power to vulnerable people resulting in their services being depersonalised and commoditised. The warning was to remember the service was still a human service and was servicing real people with real names.

> *"Customers is just a bit odd. It commoditises people. And I think it's just another form of branding and logo. And they're really, you know, Fred Smith, who just happens to have a disability and needs some support. We have a relationship with Fred and call him a customer." (Research Participant 3.7)*

14. Need for an ethical framework for decision-making aligned with people's values

An extension of involving people with disabilities in decision-making is the establishment of an ethical decision-making framework. One participant felt this was a way of guiding when and where consumers should be consulted.

> *"And if you've got good consultation from people about the big things that are important, which is, what are their values? How do we do things around here? How do we demonstrate we respect people, and align with their vision and values? And then use that as an ethical framework for decision-making – taking into account what families want." (Research Participant 3.9)*

However, this participant's views were somewhat countered by another's views, who felt:

> *"When I talk about leadership development, good governance and fiscal sustainability needs experts in any industry. And as long as the purpose and mission are understood by these experts, stakeholder interest will by nature be taken into account." (Participant 3.4)*

15. Diversity of disability is but a subset of the diversity of society – you can't have every single person or situation represented

This issue was raised by nearly every participant in this cohort. There was broad acknowledgement that people with disabilities are diverse not just because of the disabilities they have, and combinations thereof, but because people themselves are diverse in the society that we live in.

Having an individual appointed as a Director on a Board of Management is a possibility, but it should never be assumed that that person speaks on behalf of all people with disabilities, or indeed represents the views of all people with disabilities. The life experiences of someone with a sensory deficit is very different to someone with cerebral palsy and mobility challenges, to someone with autism, to someone with intellectual disabilities and cognitive impairment. They may have insights for each other, but have very different daily challenges they must overcome that are quite specific to their own disability-related circumstances.

16. Changing nature of mandates for representation – alongside gender, community control

The policy agenda is changing in the disability field, with government increasingly adopting ratio mandates. During the period of the research it was acknowledged in interviews that a funding program was changed to introduce specific grant opportunities that had an eligibility requirement for 50% of the governing Board to be people with lived experience of disability. The assertion was that this was done to ensure support for peer-to-peer led entities that would champion the voice of the person with a disability and would empower that voice on the policy agenda.

17. Super-users – people not expert in disability, but expert in using systems to support people with disabilities

This is a practical suggestion that acknowledges the difficulties people with disabilities are having accessing the NDIS portal and navigating their way through the planning and access to supports. Rather than just having experts in disability, there was recognition that having experts in the systems used to access disability supports may be of benefit. They could work to build the capacity of all stakeholder users, and provide valuable feedback to the portal owner, the National Disability Insurance Agency (NDIA).

18. **Invest time to get people creative – to take licence to do things differently**

A strong view was offered by one participant in this cohort that people needed room, space and time to become creative – to be given licence to do things differently. In their words:

> *“Invest time to get people creative – You don’t just want people to reiterate the issues you’ve got. You want them to be creative to find the solutions of the future.” (Participant 3.5)*

19. **Involvement of people with disabilities in governance should be a desired outcome rather than a requirement – intrinsic motivation**

This was a majority view held by participants in this cohort – that a culture that embraces inclusion as a value is far more powerful and will effect far greater change, than a government mandated requirement that it was felt would be complied with only as far as a “tick in the box”.

20. **Disability can create an interdependency with the carer – where it forms part of the carer’s identity as well as the person with a disability**

This was an issue that was shared by members of the lived experience cohort. Where carers have cared so long and with such whole-of-life intensity, when a change occurs (e.g. child moves out of house), the carer finds it difficult to adjust. The carer realises that caring has become part of their own identity, just as the disability is part of the identity of the person they care for.

6.1.4 Peak / Advocacy Organisations

Five interviews were held with people who were representatives of either Peak and/or Advocacy Bodies in the sector. These agencies were chosen for their breadth of expertise; from large industry collectives, designated sector peak, cultural diversity representative, private consultancy, to peer-to-per specialist support. People interviewed were either the Chief Executive Officer, State Manager or similar senior officer in the organisation.

Interviews were held on the following dates: 3/7/2019, 12/7/2019, 27/8/2019, 2/9/2019, 16/1/2020. They ranged in length from 36 minutes and 32 seconds to 56 minutes and 5 seconds, with a rounded average of 42 minutes.

As an overview, the main themes raised in this cohort were as follows:

1. **Perseverance is required – co-design can be hard!**

Recognised by all other cohorts, working with people is hard work and once committed, you must persevere. The commitment must be genuine and the engagement must be authentic. As one participant stated:

> *"Everybody wants to involve the lived experience, but when it comes to operationalising, it all becomes too hard. We must persevere!" (Participant 4.5)*

2. **Omnipresent paternalism, at all levels**

This issue was raised in different ways by different participants, but essentially all felt that there was a prevailing sense of paternalism in the sector. That the thinking by all stakeholders was the need to "protect" those poor disadvantaged people. This was an issue also raised by people with disabilities, with one participant in that cohort stating:

> *"…we are defined as intrinsically vulnerable and not able to consent which is offensive and wrong!" (Participant 1.3)*

If not to the extent of paternalism, there was a notion of power imbalance, whereby people with disabilities are deemed to be more disadvantaged than other stakeholders:

> *"When you're coming from a position of power, the relationship changes. When working with people in disadvantaged communities you must compensate for that power imbalance, or risk ending up with something that does not serve anyone's needs." (Participant 4.1)*

3. **Practicalities of governance and requirement for directors to discharge their duties**

Again this issue was raised by different cohorts. It acknowledges that the involvement of people with disabilities in the organisational governance must be more than idealistic, and must meet the minimum standards set by both the *Corporations Act 2001* and the *Australian Charities and Not-for-Profit Commission Act 2012.*

4. Governance is not for everyone! Some happier to stick to their knitting and make personal decisions

This issue was raised by a number of participants in this cohort. Also raised by other cohorts, these participants added that sometimes it's OK to operate without the voice of the lived experience at the highest level, as long as you always remain open to it being there. It may just be the wrong time for everyone to be involved, or that nobody has the burning desire to contribute at that level and are happy making decisions that impact themselves personally. Forcing someone onto a Board for the sake of having the lived experience present may just put that person in a vulnerable position and cause undue stress on them. One participant stated very clearly:

> *"Not everyone wants to be on the Board." (Participant 4.2)*

5. Remuneration for involvement should go beyond pay and include recognition and training

Payment for service was considered by the organisations' cohort also. In addition, this cohort felt payment was only part of the issue and that recognising contributions, both internally and externally was also a strong motivating factor that encourages involvement and empowers. Also, training in governance, to continuously build capacity in the organisation, or even by preparing people with disability to take on leadership roles in other government, organisations and/or companies in society would be beneficial in the long term and would contribute to broader empowerment of people with disabilities.

6. Cultural change required to incentivise broader involvement of the lived experience - mandated requirements have limited benefit

As stated by the organisations' cohort, this cohort also felt that cultural change was preferred to just having mandated requirements (e.g. ratios of people with disability on Boards). That is, the inclusion of people with disabilities should be celebrated for the positives it achieves, and not just as a mandated requirement.

7. Investment in strategies to support the lived experience in governance – suggestions for intensive personal supports to develop capabilities

An issue shared with other cohorts, participants in this cohort felt strongly that long term benefits from including people with disabilities in governance at the organisational level would be best sustained through concerted and ongoing investment. Suggested techniques included: mentoring, buddying, pre and post meeting debriefs, interpreters, and use of advisory committees as a bridge for experience. The essence of the theme was that appointment in itself was not the end, but the appointee needed ongoing support to perform in the appointment.

8. Tension between assertively promoting the lived experience versus meritocracy

This issue was raised more as a philosophical reflection rather than a concern. The intention is to include the voice of the lived experience on the Board, but how to do this can be a challenge, especially when you are also emphasising an order of merit. For this reason the issue relates to issues raised by other cohorts around the role needing to fulfil legislative requirements (having the merit for the role) and be more than a "reality checker" (just a representative of the end-user group).

9. Managing the omnipresent unconscious bias

Notwithstanding the above, the "reality checker" role can also be extremely valuable. It is the role that can remind the collective that unconscious bias is at play at all times in all of us. It is the voice that can remind us of that paternalism that is also perceived by many to be omnipresent in the disability sector.

10. Carrots and sticks – the desire for an inclusive society and the organisation as a microcosm of that society

This is an extension of the culture of inclusion issue mentioned previously. But shared with the lived experience cohort, the inclusion of people with disabilities should not just be for internal purposes, but also to share best practice examples of inclusion in governance to mainstream organisations and to extol the virtues of inclusion in governance so that it becomes normalised in the broader society.

11. The lived experience beyond decision-making and embedded in the way an organisation thinks, designs and evaluates

An extension of the involvement of people with disabilities in decision-making is to say organisations should aim for seamless involvement in all aspects of business life. This would mean the inclusion of the voice of the lived experience is factored into the way an organisation thinks, designs and evaluates what it does. It would become part of the culture of the organisation; a defining strand of its DNA.

12. Acknowledge limitations of empowerment within the realm of highly complex needs – but seek involvement to the extent of capability versus assume no capability

A practical and somewhat grounding issue arose from a participant reminding me that there may be limits to what one can expect a person with profound disabilities to contribute. In doing this however, one should not assume that no involvement is possible. Even if someone is non-verbal and immobile, there may still be ways of communicating preferences using communication aids and assistive technology for example.

13. Plans need to take account of disability needs, but also cultural and language nuances

In Australia there is a large Aboriginal population that is serviced by the NDIS. This population has cultural nuances that differ to the majority of other Australians. Aboriginal people can use a more collective decision-making process, as opposed to the individualised approach used by the NDIS.

Language used in the NDIS is very tailored to English speaking people. Definitions often have a legal meaning as well as a layperson meaning. And specific language is used within support categories to trigger allocations of resources. For many people, regardless of having a disability or not, this language is difficult to comprehend. Most people would find it difficult to define the role of an Occupational Therapist for example, or be able to explain what augmented assistive technology does. And when dealing with people from a culturally and linguistically diverse background, these difficulties can be compounded.

> *"That people just feeling not right. For our clients, whether they be Aboriginal families or CALD families. They don't understand the system and how it works. They don't necessarily understand what needs to happen… they didn't understand what the planners were talking about. To know who and what the agency did." (Research Participant 4.5)*

14. Growing sense that benevolence is a passing fad – and deemed paternalistic going forward

The NDIS has brought change to the disability sector, and some of that is positive change. It has elevated the right of people with disability to choose who provides services to them. To be able to choose from a marketplace. To not have to rely on the charitable contributions of benevolent benefactors as had been the case for at least the past century. To access services and products that meets their needs, rather than what a good person or cause was prepared to donate. And a word of caution for those organisations that rely on their benevolent work to define their purpose and reinforce their value to their followers, whether they be faith believers or club members, expectations have risen and quality standards have been defined. Benevolence is no longer seen as a positive just because it is donated. In some instances it is seen negatively, and certainly can represent the old and oppressive system to some people with disabilities. Hence the word "captured" which is often used in conversation by people with disabilities when describing their relationship with established charities.

6.2 Part 2 – NVivo Analysis

The NVivo analysis concentrated for the main part on keyword searches that identified in the first instance frequency of terms used in interviews. It was also used to determine common themes between the participants in a cohort.

Generally speaking the research participants from the “People with Disability” cohort gave less references to governance than did participants from the “Organisations caring for People with Disabilities” or the “Peak Bodies representing Organisations and/or Advocates for People with Disabilities”. As stated earlier in the chapter, the language used by People with Disabilities, and to a lesser degree their carers and parents, was more individualised and lay. They tended to describe scenarios that impacted them in their daily lives, using everyday language to do so. Participants in the other cohorts used industry language and spoke of concepts that were more abstract, as they may appear to be in the policy context for example.

To ensure the analysis allowed for some flexibility in language used, the searches incorporated broader terms. NVivo allows this to be done using a series of search categories as follows:

1. Exact e.g. talk
2. Stemmed words e.g. talking
3. Synonyms e.g. speak
4. Specialisations e.g. whisper
5. Generalisations e.g. communicate

The following is a summary of the findings presented as before, by cohort.

6.2.1 People with Disabilities

Cases that were examined for this cohort included the following:

Search	Type	Participant #	Incidence #
Choice and Control	Exact	4	18
Decision	Stemmed	5	18
Decision	Generalisations	5	78
Level of Control	Exact	4	10

NDIS	Exact	3	17
Self-managed	Exact	4	35
Goal 1	Exact	5	14
Goal 2	Generalisations	5	135
Supports	Exact	3	4
Accommodation	Exact	0	0
Personal Care	Exact	5	39
Equipment	Exact	4	8
Therapy	Exact	4	9

There is a clear difference between the search with an “Exact” return and with a “Generalisations” return. The returns for the decision query increased almost fivefold and for the goal query the responses increased by almost tenfold.

When talking about choice and control, people with disabilities in the most part were referring to flexibility. Having the flexibility to choose options that met their lifestyle. Whether that be in relation to employing support staff, or purchasing equipment. One participant explained choice and control in the following manner:

> *“It is interesting. I guess that's the thing I've learned is it's not so much about the money as it is about, I mean, you know, it is about money, but it is much about the supports and mechanisms and infrastructure around that allow them choice and control and people to evolve into debt if I need to as well.”*
> *(Research Participant 1.1)*

In this instance the participant was explaining that although the concept of choice and control is most usually associated with the NDIS Plan and the ability to make choices about how money is spent, it is and should be about so much more than that.

The searches around decision-making resulted in returns with all respondents commenting at some point about decision-making. As stated previously, in most instances the responses were in relation to decisions about daily life, rather than more abstract governance related decision-making. An example to explain this was the response from a participant explaining an important decision they had made was in relation to cessation of night-time support work. It was appropriate when they were younger and single, but now married they felt it was impacting the ability of the couple to be spontaneously intimate. The participant explained this was:

> *"that nuanced thing about choice and control that we don't often go in to." (Research Participant 1.1)*

However there were also examples of responses looking at the broader policy agenda:

> *"I want to continue to develop my goal of Getting disability on the agenda of decision makers making integration a goal for Australia as because places like Deloitte have written reports on the economic benefits of employing people with a disability. And it's never been properly implemented because of the culture in our society. So I'm pushing at the edges for change." (Research Participant 1.2)*

By opening the query up to generalisations, the returns included discussions around opportunities and options. These can be broadly related to the inputs of decision-making. There were also at least two participants who talked about the concept of prioritisation, or "importance". This is an example of consideration of the outputs from decision-making. And the responses also included at least three examples of outcomes assessment – what can be taken as the results of decision-making. In other words the participant was saying the decision-making was not the end in itself, but the means to the end, which was the desired lifestyle outcome. So there was evidence of consideration of inputs, outputs and outcomes when the search query was broadened for decision-making.

Level of control was discussed explicitly with four of the five participants. The same four participants gave examples of how they exercised control in decision-making, including insights to the complexities of decision-making. An example of this was in relation to purchasing a wheelchair. Whilst the specialists in the rehabilitation unit at the hospital were recommending an electric wheelchair, best for the role it needed to perform, the participant chose a manual wheelchair. Reasons given were the ability to manoeuvre independently, fit with the existing vehicle, and fit for family routines (e.g. holidays). Another participant pointed out the need for changing levels of control. The example given was in relation to changing functional independence:

> *"The mantra of choice and control really suits me because I have a brain injury and flexibility is so important, because every day is different when you live with a brain injury. Some days, I can pull my shoes on and others… I can't." (Research Participant 1.2)*

Having control was acknowledged by each responding participant as important and that those who might not be well informed, or have access to internet, or have full cognition, may not be able to have full control. And having control meant to be literate and able to plan. One participant explained the impact of services on spontaneity in their lives. Another stated they felt it was artificial to plan everything in life:

> *"Because normal adults don't really actually go through their life with goals and strategies over time for everything. It's a very abnormal and artificial way to apply what I hate to." (Research Participant 1.3)*

Only three of the participants spoke specifically about the NDIS. Responses were varied and ranged from how the NDIS impacted their personal access to services, to broader conceptual applications of NDIS and success or not in achieving the mantra of choice and control for people with disabilities. There was also reference to the impact on governance of a service provider by one participant who was also a director of a company delivering services.

The concept of self-management was explored by four of the participants. Issues raised were mainly in relation to self-management of NDIS plans, but acknowledgement also that shared management had a place, especially for financial expertise when large sums of money were involved, or where cognition was low. Interestingly there was also an element of aspiration whereby a participant not only talked of self-management of plan funds, but also the desire to retire as a self-funded retiree; an aspiration surely shared by many fellow Australians. All five participants talked of goals in their planning. Whilst this was not necessarily linked back to self-management or a level of empowerment, and certainly not to governance itself, they all acknowledged the role goals had in planning for their own supports. Participants raised goal setting at different levels (e.g. life goals versus daily task goals) and expressed some frustration with the language used by NDIS and the need to be conversant with the NDIS terminology in order to plan effectively for funded supports from the NDIS.

Goal setting was explored in relation to the provision of supports. Most participants were able to discuss the supports they received which were funded by government sources (all NDIS). Of those explored, only accommodation was not discussed. Of the others (therapy, equipment, personal care), participants were able to discuss how they accessed the supports and what level of control they had in managing the supports (e.g. purchasing, employing).

6.2.2 People caring for People with Disabilities

Carers actually used a mixture of language, having some sense of industry language as well as a strong affiliation with everyday language as it relates the daily life of the person they are caring for.

Cases that were examined for this cohort included the following:

Search	Type	Participant #	Incidence #
Governance	Stemmed	6	14
Decision	Stemmed	11	51
Decision	Generalisations	11	281
Level of Control	Exact	10	55
NDIS	Exact	11	64
Self-managed	Exact	1	2
Goal 1	Exact	10	52
Goal 2	Generalisations	11	311
Supports	Exact	9	20
Accommodation	Exact	5	15
Personal Care	Exact	7	18
Equipment	Exact	7	24
Therapy	Exact	8	81

As with the People with Disabilities cohort, the Carers cohort discussed choice and control in relation to accessing services, planning, purchasing and also in relation to personal circumstances. In relation to the latter a participant acknowledged that living in Broome (a small and remote town) resulted in a smaller marketplace which in turn restricted choices, but it was their choice to live there in the first place.

As it was a Carer cohort, the concept of surrogate decision-making was also raised and although not explicitly acknowledged by each participant, the interplay of person with disability and carer was discussed. One participant noted that just their presence in the room effected how her child responded to the planner's questions, looking for prompts and fillers from the parent which was not the case when they were alone and had to respond themselves, which they did with increasing confidence as time went on.

Another participant actually had a formal Guardian appointment which had a special range of circumstances whereby in some ways the surrogate decision-making was legally mandated. The participant explained it was important that their child had a sense of ownership over decisions, so they had come to an agreement over who was responsible for which decisions:

> *"…he makes big decisions about you know, what, when he wants some money from but I do the process, Guardian, so I make decisions around his health and services that he accesses." (Research Participant 2.12)*

Decision-making was discussed by all eleven participants. When the query was expanded from exact matches to generalised responses, the response increased fivefold. Likewise the discussions about Goals was held with all eleven participants and when the search was broadened to generalisations, the responses increased over sixfold. As with the People with Disabilities cohort, when the query was broadened it found instances of options and opportunities and prioritisation of importance. In other words, a range of considerations of inputs, outputs and outcomes in decision-making.

A rather sensitive issue raised by participants, and explored in depth by one participant, was the relationship between diagnosis and eligibility. That participant asserted that there is a tension in society whereby parents are reticent to explore developmental delays with their children because although it may answer their queries and address their concerns for their child, as well as enable access to funds and resources for support, it also meant their child would be labelled and pigeon-holed for life as a person with a disability, and with all the stigmas that may or may not be attached. It was as if this was a primary decision that parents had to make prior to the person with a disability making any subsequent and secondary decisions.

Most participants explained how they worked in partnership with the person they cared for to make decisions. Most articulated how they balanced information with making an informed decision, and owning that decision after being made. One participant explained the process as follows:

> *"I try and present as much information as I think he can follow, and get him to choose from simple options. So all in all, we put in about five or six, because he can't cope with too much information, he just shuts down." (Research Participant 2.12)*

This description is supported by another participant who was also a Social Trainer by profession. That participant raised the fact that decision-making itself is a high order social skill which requires a complex set of steps to be taken in order, with cognitive processing at each step, for a valid result to be achieved.

As with the People with Disabilities cohort, whilst most discussion was centred around decision-making for the individual, there were some responses that covered decision-making in relation to organisational priorities and policy input. Some carers were in governance positions both with service providers and with government. For the most part these were in advisory roles, with some being actual decision-making roles (e.g. directorships of public companies).

Setting goals was discussed overtly by 10 of the 11 participants and when extended to include general language, by all 11 of the participants. As with the People with Disabilities cohort, there was discussion on how the goals were subject to language constraints and that to comply with the NDIS planning framework you needed to hone your skills in bureaucratic language. You also need to speak that shared language in common with not only the NDIS Planner, but also the service provider and possibly a fund manager/support coordinator also. One participant explained their journey as follows:

> *"So his goals are really on living independently. So I'm just setting up his plan now just give some specific things, telling me. He's going to live independently in his own unit. His goals are to have a week holiday, planned and funded holiday. He's got a lot of health conditions, mental health and health conditions as well as disability. So to manage his health conditions, with support as needed." (Research Participant 2.12)*

After changing providers, the carer reported the following:

> *"So the new provider is not happy with the set goals. So his plans, but to be going back to NDIS with a change of circumstances and they want specific goals around cooking, maintaining his unit, keeping it clean, those sorts of things. So really, we are looking at breaking it down a whole lot more." (Research Provider 2.12)*

This example essentially speaks to the need to break down goal setting to achievable levels. This was an issue raised by most participants. The mantra of the NDIS is choice and control for people with disabilities to live the life they want to. But how we plan for the reasonable and necessary supports is a different matter and requires planning and decision-making at a more granular level – however understanding about that level of granularity is not consistent across the sector.

Of the Supports raised, all four categories were raised by about half the cohort or more. Therapy had the most responses and this may have been a result of the majority of participants also being parents of children. Therapy is a common support accessed by children, whereas accommodation is a more common support accessed by adults. The assumption is therapy as an early intervention can increase self-management and independence across the lifespan, and children are dependent on their parents in the early years for things like accommodation. An interesting aspect of supports raised by participants was the access to informal supports that are not necessarily funded. The example given by one participant was the neighbour who took their child to see movies at the cinema. The feeling was that although the intention of the NDIS was to acknowledge these informal supports and encourage them, the planning process (format and timeframes) has become more scripted and lends itself to detail funded supports over unfunded supports.

6.2.3 Organisations caring for People with Disabilities

This cohort was made up of predominantly Chief Executive Officers of service provider organisations in Western Australia. As executives of varying experience, they all had some industry knowledge of governance and of different models of governance that can impact control over decision-making. As such interviews involved a different set of questions and analysis on NVivo involved a different set of search criteria.

Cases that were examined for this cohort included the following:

Search	Type	Participant #	Incidence #
Governance	Exact	10	56
Governance Structure	Stemmed	10	120
Board of Directors	Exact	10	158
Decision-making	Stemmed	10	42
Input to decisions	Stemmed	10	112
Benefits of increased input	Stemmed	9	31
Advantages	Synonyms	10	100
Mandated level of involvement	Exact	10	89
Common practice	Stemmed	8	27
Common practice	Synonyms	10	329

It is evident from the results table above that the language used is more industry specific and the responses were on the whole, more complete. That is, most participants were aware of the language used and responded to the questions using the same language. Whereas the People with Disabilities cohort returned 5 of 13 queries with a full response rate, and the Carers cohort retuned 4 of 11 queries with a full response rate, this cohort returned eight of 10 queries with a full response rate. And of the two queries that were less than 100% response, the lowest was 80%. It should be noted that this cohort had questions very closely aligned with accepted industry terms and responses tended to use the same terminology.

When considering “governance”, participants described their own organisation, then its governance and structures used, and then explained what role people with disabilities had in the governance of the organisation. In responding to the questions, participants described a number of different mechanisms to engage with people with disabilities, from direct appointments to the Board, to advisory roles, to broader consumer engagement functions. Interestingly the language used was different across the responses, ranging from “people with disabilities” to “people with lived experience” to “service recipients”. Responses also involved a range of terms from “consumer” to “client” to “customer”. This was the subject of a specific question which will be discussed later in the chapter.

Participants in this cohort noted that governance was not a term easily translated into everyday language. One participant noted that governance considerations were stronger in relation to one’s personal circumstances:

> *“I think what we're very good at is really looking at involving people in decisions that impact on them directly. … it's not about governance. But it's really about, you know, day to day decisions. And their involvement in planning, for example, their involvement in making decisions about, you know, a whole range of aspects of their lives.” (Research Participant 3.1)*

When considering the governance structure itself, participants in most instances described informal mechanisms for involving people with a lived experience of disability. Interestingly a number of participants noted that due to the requirements of directors of companies to discharge their fiduciary and other duties, the focus for them was on people with a lived experience of disability (e.g. parents, carers) rather than specifically on people with disabilities themselves.

In addition to direct appointment to the Board of Directors, all participants were able to describe a mechanism for involvement. These ranged from advisory committees, to more specific issues committees, to more generic consumer engagement forums. There was broader acknowledgement that co-design was a skill that was improving for service providers and was being used more extensively in design, delivery and evaluation of services.

> *"I think where things are improving, is particularly around the area of co-design." (Research Participant 3.1)*

And this from another:

> *"I think nowadays, certainly from the organization's perspective… it's just simply the fact that our clients are part of the decision making process, the planning process, the evaluation process of what happens to them when they interact with us." (Research Participant 3.2)*

When talking of the governance structure, there was a discussion on whether positions needed to be mandated. One participant noted that many organisations are moving away from direct representation, indeed away from membership based organisations, and are becoming service providers governed by a skills-based Board. The involvement of the lived experience of disability is being mandated through the policy environment. This was described by one participant as follows:

> *"It's written in our governance policies, we will, we aim, and we have representation of people with disability as well as Aboriginal Australians on our Board. But it's not mandated in the Constitution. We don't have to, we just, we create. We have two candidates with the same skills and the same capabilities. And one of them was an Aboriginal Australian or person with disability and the other person wasn't, then the person with disability would get the role." (Research Participant 3.11)*

When discussing the Board of Directors itself, all participants were able to articulate the structure of the Board and the process to appoint members. There was no discussion around paid roles, although some participants did specify their roles were voluntary. In all instances the organisations represented were constituted and registered legal entities. As such they had requirements to be met for those discharging director duties. In the words of one participant, the implication of this for a disability service provider was:

> *“In many ways it reflects the needs of being able to involve people in decision making around governance structures. Obviously, when you're working with people with complex needs, who may be nonverbal who've got significant cognitive disability, it is really, really very challenging.” (Research Participant 3.1)*

In a similar way, with regard to decision-making in everyday life decisions, the same participant explained:

> *“I think there is still a huge amount of work to be done around supported decision making, and skilling staff to be able to work with people in the way that they have some confidence that people are really able to make a clear decision about what their preferences are. And that's not something that can happen without a commitment.” (Research Participant 3.1)*

The comment about the ongoing commitment is a theme that many participants talked to – the level of intensity required to engage with people with disabilities and the need to commit to it in the long term – and as a result is raised in the Conclusion (Chapter 7) and Recommendations (Chapter 8) chapters.

Having input to decision-making raised a number of interesting points. One of these was the desire to garner a collective input, rather than just individual viewpoints. A number of participants raised that no single person with a disability can represent the views of every person with a disability. A vision impaired person has a very different experience to a person with mobility restrictions to a person with an intellectual disability. Most saw it as a maturing of governance when organisations moved beyond the appointment of a single person to a Board and sought more comprehensive mechanisms to engage with the collective voice:

> *“I think it goes back to having genuine representation and input from the collective as opposed to having a few outspoken individuals that have got the loudest voice, who were just representing themselves.” (Research Participant 3.11)*

Again, the responsibility for discharging one's duties as a director, was raised. Probably underpinned by an increasing focus on good governance by the Australian Securities and Investments Commission, the Australian Charities and Not-for-profits Commission, and as required by Standard six (Service Management) of the National Disability Service Standards (DSS 2013) administered by the National Disability Quality and Safeguards Commission, the requirement to effectively discharge one's duties was paramount and is probably becoming more complex over time:

> *"The thing for me is that just because you have a disability doesn't necessarily mean to say that you are able to provide the level of input into running a multi million dollar organization that has responsibility for a huge number of people's lives." (Research Participant 3.2)*

There was also an acknowledgement by most participants that change is happening and more people with disability are being involved, in one way or another, in decision-making and broader governance. With these comments came a word of caution that the change must be done in a measured way. That the reasons for change must be well understood, the risks assessed, and the agency for change shared. That the system being changed, for all its faults, is not actually a bad system.

When asked about government mandates for involvement of people with disability on the Board, most participants thought involvement could be achieved by other mechanisms like advisory groups or reference groups. This was in stark contrast to the responses given by the people with disabilities cohort when the issue came up in the semi-structured discussion part of interviews (i.e. not all interviewees were asked the question directly). The feeling was that rather than use a "sticks" method alone, the government should use a "carrots" method where it created a culture of inclusion and intrinsic desire to involve people with disabilities in governance. Where it was seen as an obvious and desirable practice. When contemplating being forced to appoint people to the Board the following response was received:

> *"I like mandates and quotas and things as a general philosophy. But I think it's very dangerous. And I wouldn't support this any more than having consumer*

> *driven menus in a restaurant or non-medical staff dictating clinical outcomes in hospital." (Research Participant 3.4)*

A suggestion made by most participants was the need for diversity on advisory groups. To avoid a focus on individuals' circumstances and to ensure the macro issues are considered. One participant worded it as follows:

> *"…they should probably mandate that there needs to be a diverse range of people, from super users, to people that care, to the people that work in the sector." (Research Participant 3.11)*

The benefits of involving people with disabilities in governance, at least in an advisory format, was recognised universally by this cohort. Really the only difference of opinion lay in how much involvement, and thereby how much level of control over decision-making that has whole of organisation impact. The benefits identified were associated with service efficacy verification. That is, having service users involved in their own service planning and delivery gives a much better chance of actually delivering a service that the user actually needs and wants, and benefits from.

6.2.4 Peak bodies representing Organisations and/or Advocates for People with Disabilities

In some ways this cohort represented the most sophisticated responses. The focus was on the macro elements of decision-making, with a strong understanding of the policy environment and in many ways an impartial view of how the policy is being implemented. There was empathy for service providers, but a strong will to be true to the needs of people with disabilities. And with this came recognition of the diverse needs of people with disabilities. Not just for the disabilities they had, but for all the other life factors that impacted them also – from gender, sexuality, race, religion, linguistic background, level of education etc.

Cases that were examined for this cohort included the following:

Search	Type	Participant #	Incidence #
Governance	Exact	5	18

Governance Structure	Stemmed	5	38
Board of Directors	Exact	5	59
Decision-making	Stemmed	5	23
Input to decisions	Stemmed	5	60
Benefits of increased input	Stemmed	5	23
Advantages	Synonyms	5	38
Mandated level of involvement	Exact	4	31
Common practice	Stemmed	4	16

Whilst other cohorts had distinguished between governance at an individual level (e.g. decision-making in relation to one’s NDIS Plan) and governance at an organisational level (e.g. as a member of the Board of Directors), this cohort introduced other levels of governance. Both government policy but also program governance, for input to discreet and specific projects. Whilst some Organisation cohort participants had raised the one-off project involvement, the Peak cohort was more inclined to establish ongoing involvement. One example given was the standing pool of over 1,000 people with a lived experience who could be called upon to volunteer and form focus groups on projects of interest as they arose. This pool of people was seen as a resource for one peak body and its member organisations, but was hoped in time could be a resource for government and the broader public, especially if fees were to be paid.

When considering the governance structures, the Peak cohort had similar views to the Organisation cohort, with a strong grasp of legal implications associated with contemporary governance, the majority of respondents felt that involving people with disabilities could be achieved through a number of mechanisms and appointment to the Board of Directors was but one.

> *”…you can actually have appropriate engagement without actually designing a system that's being led by your customers. It can't be run by your customers, because it's actually a business. You've got business obligations from governance, right through to on the ground delivery.” (Research Participant 4.1)*

At least one participant noted that if appointment to the Board was the desired mechanism, then the organisation needed to take the additional steps to support that person on the Board to ensure they could discharge their duties – support through training, buddy systems etc.

One interesting point raised by a participant in the Peaks' cohort related to the expectation that people want to be involved. This chapter has already noted that "governance is not for everyone" and this cohort delivered a similar message:

> *"…but when it comes to contributing to the decision making of the organization, people are busy people and have other things to do. So it needs to be the right sort of opportunity for each person. There's lots of different ways that people can be involved and they involve different amounts of time and different levels of skills and understanding." (Research Participant 4.2)*

But one comment went slightly deeper. It raised the point that some people may want to be involved, but do not wish to disclose their disability to warrant their eligibility. The example given was for people with mental health conditions. And the requirement to disclose may in itself exclude a group of people from governance opportunities.

When discussing the Board of Directors specifically, this cohort was strongly advocating for skills, and building capacity of people with disabilities to be able to have the skills to meaningfully contribute to the Board. As for mandating involvement, the cohort advocated for a carrots and sticks approach. Probably less opinionated than the People with Disabilities who felt it should be mandated, and less opinionated than Organisations who felt it should not be mandated. This cohort felt there was need to nudge the commitment to include and involve, and some mandating may be required, but for the most part the government should nurture a sense of benefit from including, which may be incentivised through access to training programs for example. Another suggestion was to encourage the broader application of requirements for Disability Access and Inclusion Plans[9].

The Peaks' cohort was characterised by a sense of optimism. Whilst all cohorts thought the engagement of people with disabilities had increased and was "moving in the right direction", there was a sense that momentum was building when speaking with members of the Peaks' cohort. The NDIS was seen as a good thing that was well intentioned and, given time, was delivering on its promise to transfer choice and control to people with disabilities. One participant summed it up well with the following comment:

> *"I think one of the things that's really important, has been the introduction of the NDIS. And it's been important because there is, at least in theory, and to a certain extent in practice, has given greater power to people with disability largely through them having their decision making done independently of service providers, and also, through their being given some of the levers of control through access to mapping. And also some of the support roles that have been created around that like Local Area Coordinators, and Support Coordinators. Which does give (them) more power." (Research Participant 4.1)*

The cynicism expressed by this cohort was in relation to ongoing commitment, especially by service providers. Examples were cited of providers embarking on consumer engagement journeys only to revert to consultation. Examples of organisations consulting with people with disabilities, not to hear new ideas, but to have their existing plans verified.

> *"the organization quite often thinks that's a great idea, but "they" don't understand. We're not going to do that, or we haven't got time to look at that. This is our focus." (Research Participant 4.2)*

When looking to the why of the inclusion of people with disabilities, this cohort was similar to others in that it recognised benefits of services better reflecting the needs of the consumer. This was articulated by one participant as:

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[9] The Disability Services Act 1993 (WA) requires local governments and certain government agencies to develop Disability Access and Inclusion Plans. These plans have standard requirements that relate to employees, customers, built environment etc.

> *"When you're accountable to people, and you're very close, and they're close to the decision making, then you're actually dealing with very real issues as they are happening as opposed to being removed in structures that are bureaucratic. That makes sense." (Research Participant 4.3)*

When asked for examples of where engagement is done well, this cohort was able to cite numerous examples of consumer-led organisations. In Western Australia the names of People with Disabilities WA, WA Individualised Services, Avivo and My Place were all mentioned in this vein. In addition, Bankwest was mentioned for its long-term commitment to consumer engagement. And Optus Perth Stadium was mentioned as a large-scale procurement and planning project that engaged well. Whilst the Organisations' cohort tended to mention projects their own organisations were working on as examples, the Peaks' cohort went broader in their responses.

6.3 Part 3 – Contrasts and Comparisons

Part 3 of the Qualitative Section of this Chapter looks at the themes raised by the different cohorts and attempts to synthesise them into issues in common and issues in contrast. These lists are important as they inform the recommendations made in a subsequent chapter. They are listed below.

6.3.1 Issues in common across cohorts

In listing the issues raised by different cohorts it becomes evident that many issues are seen similarly. Broadly speaking, the main issues that resonate across cohorts are:

1. Involving people with disabilities in organisational governance is perceived positively and should result in better business outcomes through happier beneficiaries (service recipients)
2. Working with people is hard and the journey of co-design requires commitment and persistence

3. Co-design in the disability sector is in its infancy and is done best by peer-to-peer type organisations where the lived experience is more prevalent
4. Involvement of People with Disabilities on Boards of Management (Directors) on the whole is not done well and appears tokenistic in many instances; involvement of People with Disabilities on Reference Groups is done much better and is deemed a more genuine mechanism as a representation of broader consumer interests
5. Involvement in governance can be achieved at different levels and to varying degrees, without the need for everyone to be Board Directors. Examples given included recruitment panels, advisory committees, focus groups, special interest panels, and project steering groups
6. If People with Disabilities are appointed to Boards, they still need to discharge their legal and regulatory duties (e.g. duty of care, due diligence, act in good faith, mitigate conflicts of interest etc)
7. Involving People with Disabilities in Board-level governance is becoming increasingly complex as organisations themselves grow (in terms of both revenue and clients served) and as the regulatory regimes become more sophisticated
8. When involving People with Disabilities in governance, offer them ongoing supports and training to ensure they remain connected and active, and able to contribute in a way that adds value
9. There is diversity in disability just as there is diversity in society – involving people with disabilities is a model approach that simplifies a more complex problem, but does not in itself solve that problem
10. The NDIS has served to highlight the fiscal dynamics of disability supports and has heightened the need for transparency around cost and performance
11. The NDIS process and the language used is not user-friendly and needs to improve

6.3.2 Issues in contrast across cohorts

In listing the issues raised by different cohorts it also becomes evident that many issues are seen differently. Broadly speaking, the main issues that do not resonate across cohorts are as follows:

1. Whilst all cohorts thought having a culture of inclusion was the ultimate aim, people with disabilities felt the regulatory mandates were still important and required to ensure organisations complied and appointed people with disabilities to their Boards of Management
2. Most cohorts dismissed the "reality checker" function of a consumer representative, but the People with Disabilities cohort and their advocates also raised the positive grounding and practical focus that the "reality checker" function played in governance
3. Organisations supporting People with Disabilities almost unanimously saw their service recipients as "Customers" whilst People with Disabilities saw themselves as "Consumers". People with Disabilities acknowledged the sector wanted to see them as "Customers" and that this might be the design aim of the NDIS, but if considering the control over decision-making today, then "Consumer" for them is the more appropriate term
4. People with Disabilities acknowledged that they play a role in an economic marketplace, but wanted to be considered as people first and foremost, with holistic wants and needs in their lives, their families, and their communities – something not always recognised by other cohorts
5. Governance was not well understood, or even desired, by all. There was a difference in opinion about who needs who more, and whose purpose the involvement of People with Disabilities in organisational governance actually serves
6. Organisations supporting People with Disabilities saw themselves as customer-focussed and person-centred, yet many People with Disabilities and Carers saw themselves as subservient to the powers of these providers
7. If considering what skills are required on a "Skills-based Board", People with Disabilities and Carers would contend that "the lived experience" is a legitimate skillset, whereas other cohorts might consider "Law" and "Accounting" as skills, but not "the lived experience" – at least not of itself as a skill
8. Some People with Disabilities may further assert that the lived experience alone is not enough, and the representation should be from someone who actually has a disability

9. Whilst not necessarily a contrast between cohorts, the issue of whether or not the input from the lived experience should be paid for or not was not explored, but may need to be considered – feedback suggests a nominal honorarium to recognise out-of-pocket expenses like child care and travel was the common practice at the moment, but not a professional market rate of payment
10. Whilst supported decision-making was discussed by numerous participants across numerous cohorts, the issue of decision-making by legally appointed Guardians was only raised by the Carers cohort, and then only by a carer who was an appointed Guardian

The findings of the research have been outlined in this chapter. From the quantitative surveys that were conducted initially, to the qualitative interviews that formed the basis of the investigation. These findings have been drawn either empirically from raw data for the Quantitative investigation, or using an interpretivist and therefore subjective approach, to then apply the NVivo software to search empirically, for the Qualitative data. The data has then been summarised according to what I felt was relevant to the research and to answering the Research Question and addressing the Objectives.

More data is available and no doubt more findings can be detailed from that data. But for the purpose of this thesis, and this chapter, the data presented is authentic, accurate and can be reproduced from archived data files if required. Whether or not the data is replicable is another question and one should consider the limitations described in the following chapter to ascertain this. I expect to a large degree, it is.

7. CONCLUSION

This research was conducted in a mixed-methods manner. It utilised a quantitative approach using surveys and it utilised a qualitative approach using interviews. In short, the surveys resulted in a high take-up, but a fairly low level of completion. One might conjecture that this was due to the generally low level of understanding in relation to what governance actually is.

Whilst not evident from the surveys alone, the interviewees provided feedback that at first research participants were unsure of the subject of governance, until prompted to speak more broadly about decision-making. The ability to prompt was not available in the surveys. This finding was actually anticipated and not a surprise. The concept of governance is quite ethereal and whilst not misunderstood, is often misattributed and associated with the better-known concept of government in everyday life.

The fact that the term governance was not well known, and even possibly intimidated some people, is noteworthy. The implications extend to other terms that are used, including consumer, client, customer and citizen. But also terms like choice and control, and reasonable and necessary. Without an operating context, and application in a person's day-to-day life, they take on a bureaucratic meaning that only serves to disempower rather than achieve the intended outcome of empowering people with disabilities. Indeed some people with a lived experience of disability noted in the interviews that language itself was a hindrance to achieving outcomes and dealing with the NDIS requires learning a second language.

> *"I have two degrees and still don't understand NDIS terminology." (Research Participant 2.7)*

Apart from a couple of interviewees who had extensive governance experience, the remainder of people with disability and people with the lived experience of disability were providing responses in relation to governance aspects of their own NDIS Plans. Responses were about the level of control they felt they had over decision-making in relation to their own plan funding and choice of supports. Those participants in the organisation cohort and the peaks and advocates cohort were more inclined to respond from an organisational governance perspective, with comments about choice and control in relation to managing organisations, inputting to policy, and even guiding the NDIS itself.

In answering the Research Question “Which governance frameworks are effective at empowering people with disabilities to access care services in the community?”, I have undertaken a number of actions through the literature review, the research, and the collation of the findings. These actions include:

1. Delineate between people with disabilities and the broader cohort of people with a lived experience of disabilities, including those with family experience of disability and carers’ experience of disability for example
2. Outline common governance models that incorporate either or both of the above
3. Overview the evolution of engagement and participation frameworks
4. Describe co-design methodology and its application in today’s service industries
5. Detail the mandatory requirements now in place in quality standards to support co-design

This process leads to the conclusion that there is no one single right way. Or even one preferred method or framework. It leads to the conclusion that governance matters, and understanding governance is important, including the language used in governance. That it doesn’t matter which mechanism is used, or which framework is adopted, as they all have different and valid purposes and uses depending on the context – somewhat akin to Vroom’s situational leadership theory (1976). What is important is making the effort to hear the voice of people with disabilities at the governance level – both individually and organisationally, and indeed at the policy level feeding into government. That it is important to stretch beyond the voice of the lived experience to hear directly from people with disability. And that once the voice is present at the governance level, then that governance body commits to engaging continuously with people with disabilities, and those with a lived experience, via a participation framework, and/or as required by the *National Standards for Disability Services* (2013).

The interviews, which did allow explanation and a degree of conversation which tended to ease people's minds and make them comfortable to contribute, produced rich data from which many conclusions can be drawn, especially when considered in light of the literature review. For ease of understanding, these conclusions will be presented in line with the research objectives:

1. Develop a shared understanding of what empowerment is, and what its relationship is to self-determination

The research did raise the concept of empowerment and discussed the duality of it. For someone to be empowered could lead to someone else being disempowered for example. It was a concept that operates not in isolation, but in the context of relationships - relationships to funders, service providers, carers, family members and people in the broader community. Indeed, the tendency for many people to look after their own self-interests, at the expense of others' interests was raised – a tendency which empowers the person appointed to the Board for example, but disempowers others whose interests are not catered for.

> *"Difficulty for consumers to look past self-interest and input more broadly."*
> *(Research Participant 3.7)*

It was also a concept that could flex for any one person on any one day. In some decisions people felt it imperative that they were empowered and in control. For other decisions, they felt they could be informed of the decision and spend their time on better things. This didn't mean they were a consumer or a customer per se, it meant that they could be both and more depending on what the decision was, and how it impacted them. Even the most empowered person faced decisions that required very little input, if any, from them. This was not disempowering necessarily. It was empowering when they had the choice of what role to play for each decision to me made. This was where self-determination was felt most.

To this end, self-determination is a not necessarily a dichotomous bottom or top of ladder consideration. It is having the ability to choose which function to fulfil for which decision, knowing the impact the decision will have on your life. It is about having the right to be a consumer, client, customer and citizen all together in a single day depending what decision you want to make (or have made for you). And it is about government and the community care sector acknowledging this and being flexible enough to. cater for all choices a person with disability make. They are not all customers as providers seem to assume, and they are not all customers in all decisions made on any one day.

2. **Determine, from the perspective of people with disabilities, whether or not they are empowered to express their self-determination as intended by legislated service standards and as enshrined in the United Nations Convention on the Rights of People with Disabilities (UN 2007)**

From the perspective of people with disabilities, and from those with a lived experience of disability, the level of empowerment is improving. A common sentiment was "…we might not be there yet, but as a society we're moving in the right direction. The NDIS is a step forward." Most people in Australia appreciated the scale of the undertaking with the transition to the NDIS. It was touted as the second biggest social reform in history, second only to the introduction of Medicare with its Medibank origins from 1973 and Medicare as we know it today from 1984 (Biggs 2004).

There was an expectation when speaking with people that it would take time for the new Scheme to settle in, just as it did with Medicare. That it would take time for it to be embedded in social culture as the safety net it was designed to be. Indeed the financing of the NDIS, with the introduction of the additional 0.5% Medicare levy only being enacted from July 2019 – some six years after the legislated start of the Scheme, needs to settle into the Federal budgetary rhythm and into the public psyche. With the public now directly paying for it with a higher levy contribution from their tax returns, as well as a number of parallel programs focussing on individualised funding for person-centred outcomes (think Commonwealth Home Care Packages), there is building momentum for an NDIS to stay.

From the perspective of people with a disability, do they feel empowered as intended? I would say the answer is no. I would say this based on the level of cynicism still felt – as portrayed by the quantitative surveys with respondents having little confidence their complaints will be followed-up in a timely manner. And as portrayed in the qualitative interviews whereby people responded with different scores in relation to control over decision-making based on the perspective of person with a disability, and then on the carer of the person with a disability. But can they see an increase in empowerment since the inception of the NDIS? The answer would be yes. Do they feel there is a transfer of power from a system, and from the established service providers? Again the answer is yes. And I would say that most are also optimistic that the empowerment will grow in the future as markets reorient and provide more choice, as planners become more proficient in their roles, and as people's own confidence grows to take charge of their lives.

> *"I've become a little more savvy about it and understand the process… the power to understand an alternative." (Research Participant 2.1)*

In relation to the original Research Question "Which governance frameworks are effective at empowering people with disabilities to access care services in the community?" the short answer is consumer governance frameworks. Used with lower case script as there is no established proper noun, or convention, around this type of governance. It is a term coined by me to recognise the growing movement of including the voice of the consumer in the governance.

Consumer Governance Framework (now coined) is the proper noun for frameworks (structures, policies, processes, engagements) that actively seek to involve the user group (the vulnerable, the lived experience, the marginalised, or even just the consumer) in decision-making. It encompasses co-design and all of the other co-production components. It is parallel to both Corporate Governance and Clinical Governance and can be incorporated into both – as the voice of the consumer is incorporated in a planned manner. And it is the evolution of the work of such respected people as Arnstein, Rocha, Hart and Vroom to contribute participation theory as a core component of Citizenship Theory (Duffy 2014).

From looking at comments made in interviews, especially from the lived experience of disability cohorts, I can synthesise the governance frameworks that are effective at empowering people with disabilities to access community care services are those that:

1. Consider the scope of the impact of decisions
2. In particular, consider who is impacted by decisions
3. Differentiate between decisions at the individual level and at the collective (organisational/population) level
4. Differentiate the need for input from the perspective of a person with a disability, or from someone with a lived experience of disability
5. Consider if the perspective of the lived experience needs to be involved in the decision-making
6. Consider at what level and in what time to involve people with a lived experience
7. Consider how much control the person with a lived experience has over the decision-making
8. Effectively defines the involvement expected of all in decision-making
9. Communicates expectations of control in decision-making
10. Checks that communication has been received and reflects the shared understanding of control in decision-making
11. Evaluates the ongoing involvement in governance to measure satisfaction with level of involvement
12. Make changes as necessary to ensure ongoing supports for the inclusion of the views of the lived experience

The governance frameworks that are effective are those that use the range of participation techniques described in this thesis - from including the lived experience as a mandated position on the Board, to having Advisory Committees and panels of specialists, or peer led Boards for example. The governance frameworks that do not work are those that are superficial and/or where there is no real commitment to listen to the voice of the lived experience. Where perseverance is deemed too hard or costly. Or where people with a lived experience are tasked with providing menial input only. Ultimately the success of Consumer Governance is based on the value society places on the perspective of the lived experience. Perceptions of that value must be genuine. People in power must reach out to be inquisitive and encouraging. They must be open to suggestions and views when offered. And people with disabilities must be courageous to continue offering their insights and contributions. As one participant put it:

> *"…appetite to look at empowerment – but authentically and with integrity – not just tokenism." (Research Participant 3.7)*

3. Delineate between popularly used concepts in the literature including consumer, client, customer and citizen

Is there a delineation in the literature? In short, yes! From the early participation models of Arnstein (1969), Hart (1992), and Rocha (1997) there was an acknowledgement that the more informed and empowered someone was, the higher up the functional empowerment ladder they would be and the different role they would play – with consumers at the bottom rung of the ladder and citizens on the top rung of the ladder.

In looking at each of the roles in the literature, there appeared a common theme that it was not about the title alone, but about the function of that title. That people could indeed undertake multiple roles in any one day, and if they chose to undertake that role then they were empowered. Interestingly there was further comment that even when one makes a decision to undertake a role (e.g. citizen), it is important for the community to respond to that decision and be welcoming of the person in that role. This was raised in the literature (Litva 2009, p89) and also in the research:

"It takes a village to raise a child…" (Research Participant 2.6)

True empowerment is not just about the person with a disability voicing their opinions, it is about society being prepared to listen and act on those opinions. It is not just about the NDIS investing in supports to build the skills and confidence of a person with disability to be job ready. It is about society being prepared to employ that person and continue investing to get the best out of them.

And as for the research itself, without even defining the terms, there was a distinct difference between responses provided by People with Disabilities who lent towards the term consumer, and by Organisations that Support People with Disabilities who lent towards the term customer. Interestingly the Carers had mixed responses, but when prompted they explained their lean towards customer was more an external projection that was being described – an expectation of how one should behave, rather than a reflection of what they saw as daily reality, which was more akin to the term consumer. This seemed a reflection of the expectations being espoused by the NDIS, whereas when nudged in the conversation most people admitted that it was somewhat idealistic and their everyday reality was less empowered.

The exploration of neoliberalism in the literature review shows that government policy, like the NDIS reform, is leaning to a free-market approach where people can choose services individually, for themselves. This would assume a role beyond that of consumer, of either client or customer. However, the literature also showed limitations to neoliberalism – the limits of the markets themselves, and the limits of empowerment from just exercising the right to purchase, without genuine reciprocity of respect and without an investment in the capacity building of the community to continuously encourage that empowered involvement from people with disabilities. An interesting provocation arose from the research which I think summarises this latter point:

> *"Invest time to get people creative. You don't just want people to reiterate the issues you've got – you want them to be creative to find the solutions of the future." (Research Participant 3.5)*

Feedback from participants suggests of all the questions in the research, this one about terminology was deemed the most difficult and the most interesting. It sparked many management discussions in organisations and it instigated much reflection on the part of people with a lived experience. This is the question that made people think about the NDIS and all that this social reform has promised. The transfer of choice and control from the “system” to the “people” is a great idea that still needs to be executed properly – with their involvement. This is the reason for making recommendations in the following chapter – to take the learnings from the research and provide practical guidance on how to involve people in both decision-making and in broader governance.

In the Recommendations section of this thesis there are suggested definitions for each of these terms. The main finding is that there are multiple terms being used, they are undefined and are being used interchangeably, and they are definitely causing confusion. Even in writing this thesis it has been difficult to not refer to “consumers” as a broader cohort that includes aspects of the other cohorts. And the economists of the world will no doubt shun the idea of another definition for “customer”. This thesis is not trying to reinvent the wheel, but is trying to bring some awareness to the meaning of language used, and to diffuse the confusion around terminology, and with that, expectations. I believe this will result in increased participation and engagement of people with disabilities in not only their own lives, but also the society that they live, work and play in. Language itself has been a barrier to the transference of choice and control in decision-making and needs to be simplified and made consistent for all. Understanding the language used is key to managing expectations around how much control the person with a disability is likely to have in decision-making. And managing expectations is key to successful engagement and participation.

4. **Determine the success of commonly used governance frameworks that increase choice and control in decision-making for people with disabilities and identify preferred governance frameworks for different decision-making environments.**

In the broader context of vulnerable people there are definitely models of governance that are successful for delivering social programs. The network of 140+ community controlled Aboriginal health services in Australia is an example. As is the Federation of Ethnic Communities’ Councils. However in relation to people with disabilities there is no single, universally adopted governance model or framework in practice. Some providers are for-profit and some are not-for-profit. Some are aligned in Federated models (e.g. National Disability Services; and Ability First) and some are incorporated associations operating at a very localised level within a State. And each State has its own version of a Ministerial Council or other such Advisory Forum. Whilst there did not appear to be a distinct Disability Consumers' Forum, there is evidence of Health Consumers' Forums in each State and within these entities, a growing understanding that the needs of people with disability, at least as they relate to health, also need to be advocated for. Listening to the voice of the patient is key in Clinical Governance and should be the case for providers in disability care also.

The ongoing journey by government to appoint the right balance between lived experience and commercial acumen to properly manage and guide the still-fledgling NDIS has been evident from the start. Parents with children with disabilities (Bruce Bonyhady) have given way to businesspeople from the commercial world (Helen Nugent) who have now given way again to Paralympians (Kurt Fearnley) in charge of the NDIS Board. I would hope as the Scheme settles within government and within the population's psyche, just as Medicare has, it will establish the broader governance mechanisms to involve people with disabilities. In doing so itself, it can also lead by example for organisations to follow suit. This will be needed to transform a very transactional Scheme at present, into the relational Scheme it needs to be.

So whilst a single unified governance framework was not evident across the nation, there were certainly examples of frameworks being used – some very progressively. However there were definitely models and methods a plenty. From co-design toolkits to governance capacity building programs to a national consumer advisory panel (Ability First).

This thesis titled "Creating NDIS Impact - Getting the Right Mix of Choice and Control in Australia's Disability Sector" asked the research question "which governance frameworks are effective at empowering people with disabilities to access care services in the community?” The question was answered throughout the research. The governance frameworks that are effective at empowering people with disabilities are those which have the following qualities and can be said to be:

- Principle-led and ethical
- Inclusive by want, not by requirement
- Genuine and authentic
- Flexible to people’s skills and desires to be involved at different levels
- Adaptive to people’s needs
- Resourced with supports as needed
- Catering for diverse needs of different types of disabilities; and
- Accountable and responsive to the user group (to people with disabilities)

Any number of the governance frameworks discussed in both the Literature Review and in the Qualitative Findings can reflect these qualities. The important things are commitment:

> *“…truly embedded in how the organisation thinks, designs and evaluates” (Research Participant 4.4)*

And perseverance, that is - once chosen, an organisation must persist with it:

> *“Everybody wants to involve the lived experience, but when it comes to operationalising it, it all becomes too hard – must persevere!”*
> *(Research Participant 4.5)*

And whether it relates to the individual level, the organisational level, or the national policy level, the successful governance model will be one that appreciates the different lens brought to the matter by a person with a disability, or a person with a lived experience of disability. It is a governance framework that appreciates:

> *“It’s more of a Rubik’s Cube in the hands of a person with a disability than a tick box in the hands of a bureaucrat. It’s a dynamic process.”*
> *(Research Participant 3.3)*

At the individual level, the successful governance framework is one that listens to the person with a disability, inquires about their willingness and ability to be involved in decision-making, and one that adjusts appropriately to their desired input. Ultimately it is one that recognises that the person with a disability has valid input to governance, and that we should try to elicit that input from someone we value and who we appreciate has insight that we do not have:

> *"Who is the expert? The specialist, or the person with a disability who lives it / uses it every day." (Research Participant 1.4)*

And as with the discussion of the PWD acronym, the successful governance framework for empowering people with a disability are the frameworks that see people first, and don't ascribe labels or pigeonholes:

> *"People with disabilities are pigeon-holed as consumers with a lived experience, not as people who are consumers." (Research Participant 1.2)*

So with the principles front and centre in one's thinking, and with due consideration for what is unique and important for the individual, the following governance frameworks, as discussed in the Literature Review, all have a place as verified successful frameworks for empowering people with disabilities as consumers of community care services:

1. Representative Board / Skills Based Board
2. An Advisory Committee
3. An expert panel of advisors
4. A pooled panel of advisors
5. An ex-officio Board member
6. An appointed Board member
7. A two-tiered Board
8. A peer-led Board

In listing these common governance frameworks, there is an obvious graduation from advisory functions to more outright involvement in, and even ownership of, the decision outcomes and the possibly legal entity itself.

In addition to the frameworks that can be used to engage people with disabilities, there are also some logistical matters that can be addressed to support the involvement of consumers in governance. Supports may include some of the following, as suggested by Voice at the Table (VATT 2022) and further by the Australian Institute of Family Studies (Frawley 2020):

- Using Plain Simple English in written papers
- Allowing enough time for discussion
- Providing a travel reimbursement to cover out-of-pocket expenses
- Paying a sitting fee to acknowledge and value unique contributions
- Accessing a support person / sign language interpreter
- Defining language
- Removing barriers to access

The crucial aspect of this research has been to show the importance of involving the person with a disability in decisions that impact upon them. Whether this is co-designing their own services and supports, or whether it is involving people with a lived experience of disability in organisation governance, there should be a desire to increase the level of consumer participation through the ladders of empowerment rungs, and to genuinely codesign the services and supports, recognising the person with the lived experience also brings specialist knowledge and valuable insights.

When looking back to the proposition that I formed prior to the research. Or the itch that I wanted to scratch by embarking on the research:

1. The transfer of power intended by contemporary social policies is well intended, but incomplete in practice;
2. Those transferring power believe the transfer is further progressed than those receiving the power; and
3. The transfer of power to the person with a disability is unique and different in each individual case.

The following would be my conclusion. There is most definitely a gap between the idealistic Objectives in the UN Convention, the NDIS Legislation and the Disability Standards and what actually happens in practice – and impacts people's everyday lives. The transfer of power is happening, but slowly. The real power still rests with the "System" and not with the people accessing it. The transfer of power is happening, but there is a discernible gap between what the "System" thinks and what people with disability think. It is not as advanced; people do not see themselves as empowered customers, but rather as consumers on the up (maybe). And the transfer of power process is different for everyone. Some people are highly motivated and informed and some people are struggling to make ends meet. Of concern with this latter point is the tendency for neoliberal-type reforms like the NDIS to further empower the active and informed, and disempower the disadvantaged and marginalised. Poor people with limited internet access and from a non-English speaking background are going to find the NDIS difficult to navigate!

This chapter has summarised key aspects of the research as it relates to the research question. In the following chapter, this thesis puts forward recommendations to consider different types and levels of engagement for different decisions. It also recommends further research to determine consistency across co-design frameworks, to ensure we don’t continue to flounder with one-size fits all approaches. Or worse still, we don’t properly explain the rationale for empowering a vulnerable person, the level of power we are transferring, and the manner in which that power will be used ongoing. This is the purpose of the author including a proposed model in the Recommendations Chapter (Chapter 8); one that addresses for both the consumer and the service provider (or other party trying to engage with the view of the person with a disability and/or lived experience) the level of choice and control being transferred to the consumer. A model that considers choice and control according to the perceived complexity of the decision as well as the impact the decision is deemed to have on the person.

8. RECOMMENDATIONS

The findings of the research establish there are numerous governance frameworks, with differing mechanisms to garner participation from people with disabilities and from the broader lived experience cohort. However, the findings also establish that the frameworks are used to varying degrees in the sector and are not always used effectively, or persevered with to a point where the voice of the lived experience is heard and valued as perceived by the speaker of that voice and the listener of that voice.

The following recommendations are offered as a means to further embed the effective governance frameworks in the community care sector. They should be read as generic, unless a particular cohort, or target, is specified. The recommendations for the most part are based on the findings of this research, but in presenting the recommendations, they may also incorporate my own ideas and/or models as solutions for implementation. They also form a summary of the research in a manner, in that they explain what needs to be done to move forward from the issues raised by research participants – what needs to be done to empower people with disabilities as consumers of care services.

8.1 Involve the consumer

Regardless of the framework chosen, or the level of control a consumer has within it, make the effort to involve them in decision-making and in the broader governance of organisations that deliver community care services that they access. The more input consumers have, the more likely that services will be delivered that people need and want and that the effort of the organisation will result in positive outcomes for consumers, and the greater the impact for people with disabilities as consumers.

8.2 Commit to co-design

The message was delivered many times over from each of the participant cohorts: working with consumers is hard work! Engaging with people is difficult. Co-design requires effort and investment. But to be effective you must be sincere, you must commit, and you must persevere. Once you have embarked on this journey, you can do more damage from superficial engagement than if you had done nothing. So do it, do it genuinely, and keep doing it. And always remember that not engaging is also a genuine stance and warranted in some circumstances – not everyone wants to be consulted on absolutely everything and there is an expectation that managers make decisions they are expected to, and paid to, make. This is the challenge of finding the balance of choice and control in decision-making, as the thesis title suggests.

8.3 Co-design at all levels

Different people have different skills and different appetites and different timeframes. Be flexible with co-design and enable both ongoing and time limited opportunities. Develop the capacity of those people with disability involved so that they build confidence and skills in broader governance – from the project to the organisation (in time). And possibly to the policy level with whole of population impact in time.

8.4 Listen to the expertise of the person with the disability

Person-centred practice is not a passing fad. It is not a measure of an organisation's success, or a KPI for a funder. It is not a concept to sycophantically espouse at a conference. It is a fundamental acceptance that the purpose is serving a person with a disability in a way that meets their needs in a sustainable manner, according to them. It is a profound belief that the person with a disability has expertise in their daily living that is both relevant and valuable.

8.5 Simplify the process and the language

The research has established there are clear barriers in place right now for people with disabilities to access the NDIS, to develop a plan, to access supports, and to acquit the funding and evaluate those supports. Not only is the loop not closed, but for some it never opened.

This is something that needs to be stopped right now. The Australian Government, operator of the National Disability Insurance Scheme, its portal and its Agency, needs to review the portal access process and ensure "the reasonable person off the street" can reasonably access it within a reasonable timeframe and with reasonable effort. This includes access to the internet and ability to navigate the internet and the portal.

The Australian Government also needs to review its use of language – from legislation to regulation to guidelines and all other aspects of engagement with people with disabilities. It should look to use Easy English and benchmark itself as an Accessible Information Service (see Scope Easy Read) It should also encourage other organisations, especially service providers, to do the same. NDIS Planners should be trained in the use of Easy English and their job performance should be linked to NDIS Participant feedback.

Furthermore the NDIS should standardise the supports for access to translating and interpreting services for people with a non-English speaking background. Access to the Translating and Interpreting Service (TIS) should be encouraged in all aspects of planning and review and additional funds should be allowed for in the person's NDIS Plan, if translating and interpreting services are deemed reasonable and necessary. And this should be the case to ensure everyone can at least access the Scheme as a "reasonable person on the street", using that legal standard to ensure equity of access.

8.6 Define the language

It is clearly evident from the findings of this research that different cohorts are on different pages, and using different language. The legislation uses the term "participant" and yet service provider organisations tend to use the term "customer". While some people with the lived experience saw themselves as customers, they did not do so with the locus of control being internal. It was always because that was the function the NDIS planning process, and the marketplace, was projecting upon them. The majority saw themselves as "consumers", with very little bargaining power and at the mercy of the quality of planners and the inertia of an established service system.

It is evident to me that language is being used in a non-standardised way. It is also evident that language is being used interchangeably. This was confirmed by me when presenting at the Australasian Better Boards Conference in Adelaide in 2018 when by a show of hands, the audience gave split responses to the preferred nomenclature they were using at that time.

Definitions are important, but consistency of use is critical. Given the level of interchangeability of terms and errant substitution going on in general discourse, some definitions may assist. The following is a very rudimentary start:

- Consumer – Someone who consumes a product or service
- Client – A consumer who has a professional relationship with a provider, with some expectation of discretion and/or confidentiality
- Customer – A consumer with economic bargaining power who instigates transactions and purchases products and/or services
- Citizen – A consumer who performs the functions of client and customer and who is able to make informed decisions on those functions, with a level of control over the independence of those decisions and some ability to advocate beyond those decisions
- Participant – A term defined by Part 4, Clause 9 of the *National Disability Insurance Scheme Act 2013*

Note that the act of performing a transaction may be involved with each of the terms, but is only the defining characteristic of the customer. A Citizen is deemed to have all the characteristics of a customer and a client with the higher level of empowerment associated with being fully informed and able to make decisions, including the decision not to decide or be involved. Once a shared understanding has been created, consistency of use in the right context would be a move for the better.

These terms are not synonyms, but they are not mutually exclusive cohort descriptions either. The definitions are trying to ascertain that the function of consumer is the baseline, and with further empowerment (choice and control), the consumer is able to exercise other functions in addition to that of consuming. The recommendation is to define these cohorts in alignment with the functions being exercised, raise awareness of the differences between each definition and then request consistency in adherence to the definitions in conversation and commentary. See the Glossary at Appendix 8 for a more comprehensive list of definitions.

There are other aspects of language which remain problematic. The term "reasonable and necessary" is such an important term in the legislation as it basically determines the access threshold test. Yet there is only guidance in the legislation as to what the term represents. The Australian Government needs to continuously update the *Operational Guidelines* to ensure the language is defined and that there is a shared understanding of those definitions, especially between NDIS participants and the NDIS planners.

The language is important as a critical element of the NDIS is empowerment of people with disabilities to be able to exercise choice and control. Whilst some people may choose to participate as a consumer, they should at least be made aware of possibilities to exercise further choice and control and be able to act as clients, customers and/or citizens if they wish to. And that there are subtle differences between these terms, a point made clear in the literature by Abraham (2015).

8.7 Clarify what power people are going to have in co-design

The *IAP2 Spectrum* was introduced in the Literature Review. It sets out different levels of functional involvement members can have in decision-making. It is a good tool for organisations to use as they consider what level of involvement they are going to give to people with disabilities. It is a good way to frame the conversation as a service provider organisation when courageously transferring power to consumers as individuals so that they may be empowered.

The IAP2 Spectrum is here:

IAP2 Spectrum accessed from (accessed from https://iap2.org.au/wp-content/uploads/2020/01/2018_IAP2_Spectrum.pdf)

The level of power the consumer has in the process increases from left to right. An advancement on the IAP2 Spectrum is a Decision-Making Framework that was developed by me in conjunction with a colleague at Therapy Focus, Penelope Wakefield. The framework seeks to:

> *"…position people to have choice, control and be involved in matters that affect them and their life either directly or indirectly and to participate in service delivery and management decisions." (Fisher et al. 2018, p49)*

The framework was first presented at the Australasian Better Boards Conference in Adelaide in 2018 https://betterboards.net/conference-2018/conference-downloads/ (Burrows 2018). The framework is essentially an evolutionary adaptation of Arnstein's ladder (1969), as well as the IAP2 Spectrum (https://iap2.org.au/resources/spectrum/), forming both into a more three dimensional matrix-like framework. The framework is structured this way in recognition of the tendency for most people to actually fill the role of consumer, customer, client and citizen multiple times in any one day, depending on the decision being made.

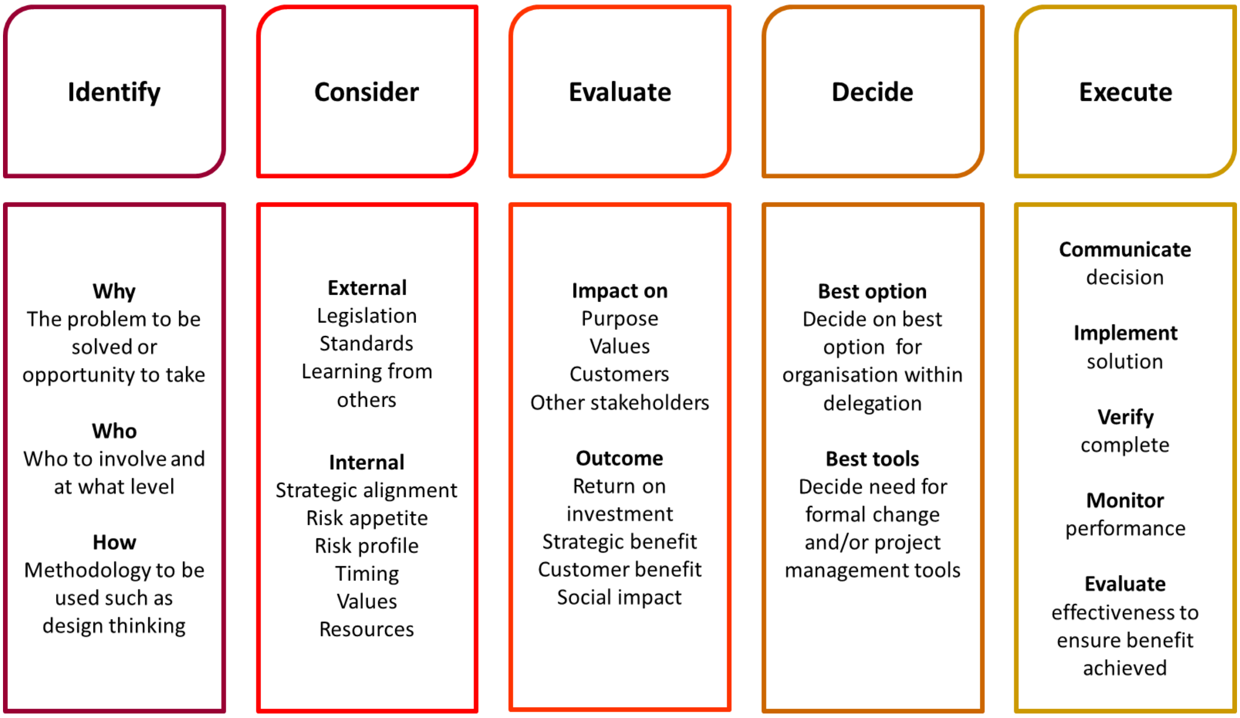
The reason for including this suggested framework is simple. It is to remind people in power that we must strive at all times to include the voice of the lived experience. That we must be flexible in involving that voice – from the times it is quiet and indirect, to the times it is loud and decisive. We must persevere and rather than wait for the voice to come to us, we must anticipate how to maximise that voice at each point. Herein lies the value of the Wakefield-Burrows Framework as it allows the user to identify the anticipated level of decision-making for the people with a lived experience, and to tailor engagement strategies to maximise input at each level – whether that be a consumer happy to just use the service, or an informed citizen wanting to use the service and participate actively in its governance.

This Wakefield-Burrows Framework will be beneficial going forward because it is designed to help define relationships from which real engagement can be built. At this time in the evolution of the NDIS it is critical that we concentrate back on relationships. That we build the trust in the Scheme between the different stakeholders. Whether or not this leads to the adoption of a single consistent governance model, as that being promoted by Disability Assembly WA (Bartnik et al. 2022, p18) is still to be seen. But at least it will help us focus back on the purpose – on the human element of the industry, on the people with disabilities and their lives – not just the commodities they consume.

This Wakefield-Burrows Framework was presented at the same Better Boards Conference referred to above, with a general acknowledgement by the audience in the room that the Framework would assist in deciding if co-design was appropriate in different circumstances, and if so, what level of power different people would have in the process. It should be acknowledged in this Framework that the process of co-design may need to start from the outset, with people with disabilities involved even in deciding what level of power people with disabilities should have in the co-design process, rather than being brought into the process after the fact and being told what role they will contribute.

Given mistakes witnessed by the researcher in his professional life working with organisations, including as a presenter at the Governance Institute, a means to better involve consumers in organisational governance was sought. One that went beyond the criticism of "rubber stamping" decisions. The Framework is offered here as a means to assist organisations decide what level of power they wish to transfer to their service user group, based on what level of decision-making they expect them to exercise. And to be able to adjust that level of power, in union with that cohort as an act of co-design, so that the engagement is real, dynamic, and appropriate. It is hoped by doing this the engagement will remain genuine and impactful for both the person with a disability, person with broader lived experience of disability, and for the organisation itself.

The Wakefield-Burrows Decision Making Framework is here:



Identify	**Consider**	**Evaluate**	**Decide**	**Execute**
Why The problem to be solved or opportunity to take **Who** Who to involve and at what level **How** Methodology to be used such as design thinking	**External** Legislation Standards Learning from others **Internal** Strategic alignment Risk appetite Risk profile Timing Values Resources	**Impact on** Purpose Values Customers Other stakeholders **Outcome** Return on investment Strategic benefit Customer benefit Social impact	**Best option** Decide on best option for organisation within delegation **Best tools** Decide need for formal change and/or project management tools	**Communicate** decision **Implement** solution **Verify** complete **Monitor** performance **Evaluate** effectiveness to ensure benefit achieved

Whilst this Framework can be used by anyone, it is particularly useful in an organisational setting, where a decision has to be made that impacts numerous people (e.g. service users, or consumers). It is akin to a broader procurement plan for high value purchases, with many of the same considerations. You wouldn't use it for small decisions that only impact yourself. Or if you do, you probably do all stages simultaneously. This is certainly what you do in procurement when making a simple purchase on credit card for example.

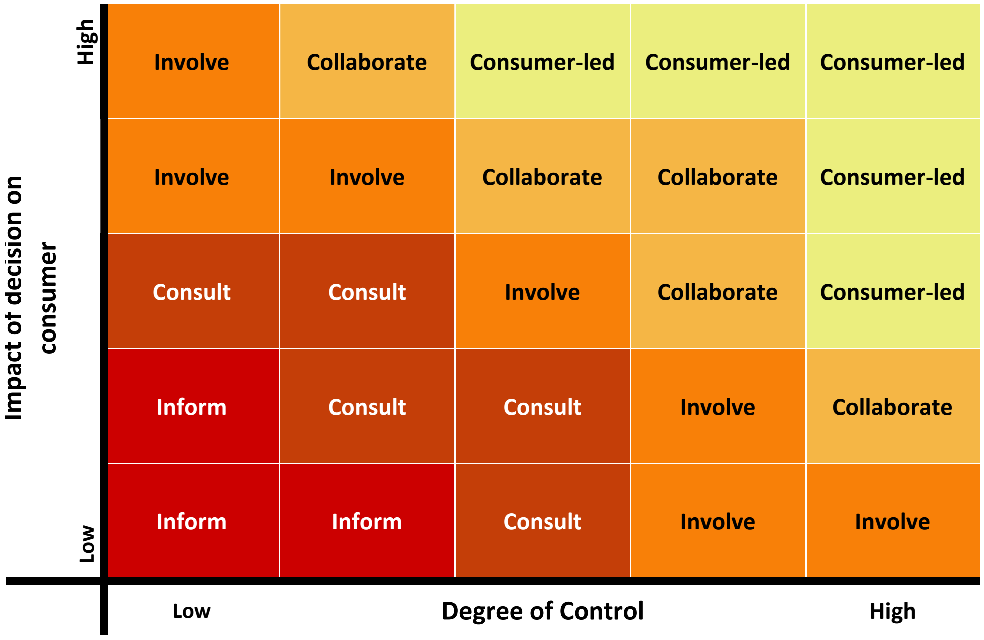
When applied in an organisational setting, the Framework allows you to identify the need for the decision, who will be impacted, and how the decision might be made. You will consider the legislative and regulatory environment and the risks involved in making a decision. You will evaluate the impact on various stakeholders and expected outcomes of making a decision. And you will decide then on how to make the decision. Whether it is a delegated decision by someone with the delegated power to make the decision, or one that requires more input from other stakeholders. This could include consumers, but equally it could include specialists. Finally, you execute the decision and communicate it and then monitor and evaluate it.

The important aspect of this Framework is that you consider who is involved in decision-making and what level of control they should have in the process right from the start, noting the point earlier that even this issue may need to be the subject of co-design. That is, people with disabilities (or consumers more broadly) may need to be involved from the “Identify” stage and not brought in only at the “Evaluate” stage when impacts are being considered. In using this Framework, it becomes important to know the impact the decision will have on stakeholders, particularly on stakeholders that represent the “user group”, or in this context – people with disabilities. This group can be constituted of consumers, clients, customers, citizens or any version of downstream user. The important question to ask is what function do they predominantly perform, and how much control over the decision do we want these stakeholders to have? In considering this question, it would be prudent to also ask what level of control do the user group already expect to have? This is especially important to manage expectations and ensure the stakeholders are aware of the level of control they will have in the process. It is entirely appropriate that for different decisions there is a different level of control afforded the stakeholders. The important thing is to ensure people are aware of the level of control they can expect if participating. Using this framework helps to determine that level of control and to explain it. This in turn fosters alignment of expectations, building understanding and trust between users and providers and ultimately between people with disabilities and the Scheme they are trying to access.

It is timely at this point to raise a contemporary example where expectations were not properly managed. The example involved a UK government department seeking the public’s assistance in naming a new polar research vessel. In this instance the government officials did not use an appropriate public participation tool and did not anticipate the power being vested in the public in choosing the name. Hence when someone suggested Boaty McBoatface, the public opinion ran hot and the poll was decisively won. A lesson in what happens when you let the internet decide (Rogers 2016). Had a Framework like the Wakefield-Burrows Framework been used, the department may have realised the naming of the vessel was not deemed critical by the public and the decision-making may be prone to whimsical and comical influences (Mitchell 2018). The UK Government eventually over-ruled the public decision and named the vessel the RSS Sir David Attenborough, however it retained the Boaty McBoatface moniker for a small, unmanned submarine vessel. Public backlash was minimal, with the name almost reaching pop culture status as if winning the poll was the victory in itself. There is now a website Boaty McBoatface – The changing face of democracy dedicated to the exploits of the vessel (and the theme of public decision-making) and the Royal Mint has produced a commemorative 50 pence coin to celebrate the icon that Boaty McBoatface has become.

To avoid scenarios like this and to assist at each decision-making point, especially the first stage of "Identify", the following Supplementary Framework can help determine the level of empowerment of the user group in decision-making, just as the IAP2 Spectrum does in public participation. When applying the Wakefield-Burrows Framework it assists in the "Identify" stage by enabling you to consider the function the user group will perform, and in identifying the function, you are able to better match the level of control being transferred to the user group in the decision-making process.

Engagement and Influence Matrix



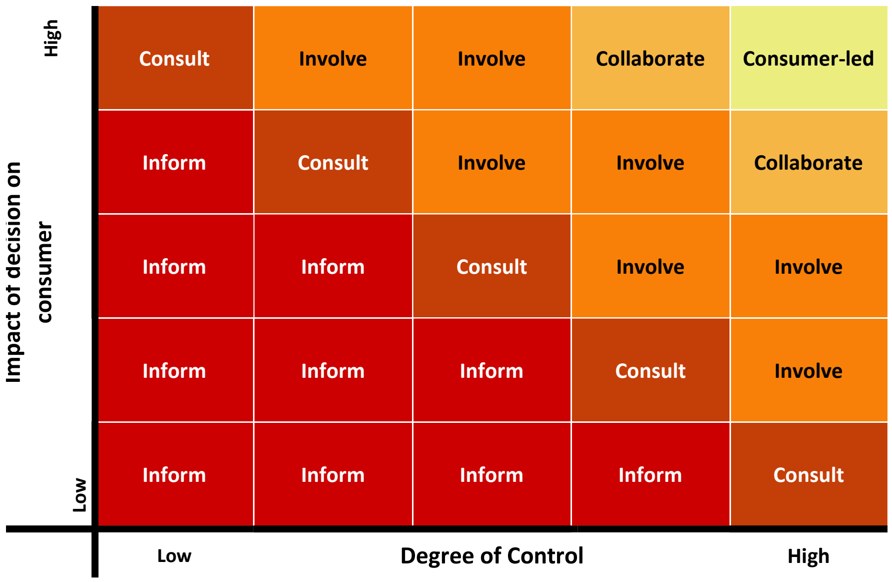
Involve	Collaborate	Consumer-led	Consumer-led	Consumer-led
Involve	Involve	Collaborate	Collaborate	Consumer-led
Consult	Consult	Involve	Collaborate	Consumer-led
Inform	Consult	Consult	Involve	Collaborate
Inform	Inform	Consult	Involve	Involve

This Supplementary Framework benefits from being structured in a familiar matrix format, with the IAP2 Spectrum language designating points on the matrices. The general term "empower” from the Spectrum detailed earlier has been changed to “consumer-led”, in keeping with the thesis language. In this instance the axes are depicting the degree of control the user group should exhibit on the “X” axis, and the impact of the decision on the “Y” axis. When acting on the recommendation above to define the language and agree on the different terms, the language can then be applied to this Supplementary Framework, starting with the Consumer, Client, Customer and Citizen delineations and then an overall assessment of how that delineation fits with the complexity of the decision being made.

Making the decision as to where a consumer fits on this matrix is a decision ultimately made by the organisation/person making the decision to engage with the consumer. However in making the decision it is important to manage expectations of all parties and the best way to do this is to involve all parties in the decision-making right from the start. Some consumers want all the power, and some want none of it…

Below are thematic representations for each of the defined cohorts: consumer, client, customer and citizen. They are thematic because they show a gradual decrease in the tendency to inform and an increase in the tendency to enable consumer-led decision making as you move from consumer and approach citizen cohorts. That is, the level of empowerment increases as more decisions are made by citizens, as you would expect by climbing the rungs on Arnstein’s Ladder, or moving along the IAP2 Spectrum from left to right.

Consumer



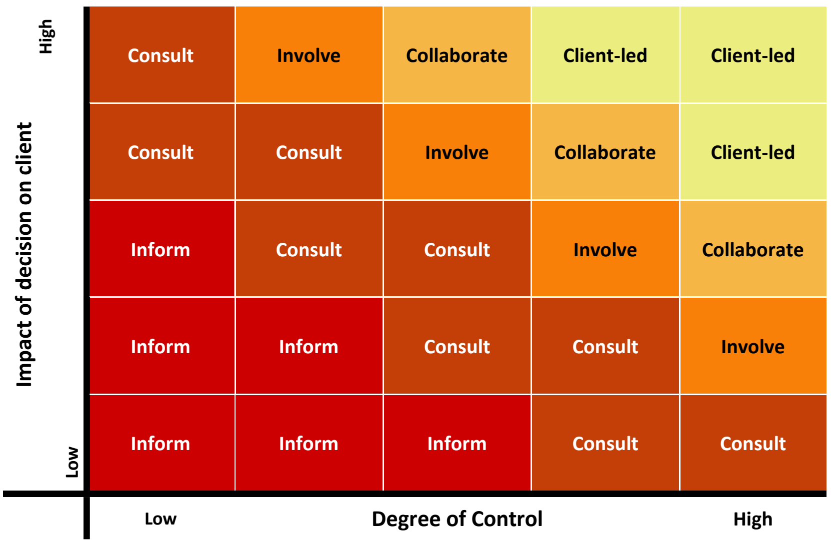
Impact of decision on consumer

High	Consult	Involve	Involve	Collaborate	Consumer-led
	Inform	Consult	Involve	Involve	Collaborate
	Inform	Inform	Consult	Involve	Involve
	Inform	Inform	Inform	Consult	Involve
Low	Inform	Inform	Inform	Inform	Consult
	Low		Degree of Control		High

Consumers often have a low degree of control over decisions and are typically involved at Reference Group level. The function they perform is to simply consume something. They are more often informed of decisions than actually in control of them.

An example of a decision where the user group is assumed to be a consumer group, and is simply informed of the decision with little input or ability to change the outcome, would be a decision involving access to the local swimming pool. The access would be determined by local government opening hours for the facility, access to the bus for transport, access to the support worker for care, and other timeframes with less flexibility, such as mealtimes.
This is not to say the user group would not have more input to decisions to access the swimming pool as a desired activity, as opposed to other activities like accessing the gym, or going to a movie, but once chosen the control over the decision of what time the pool is accessed is likely to be less.

Client



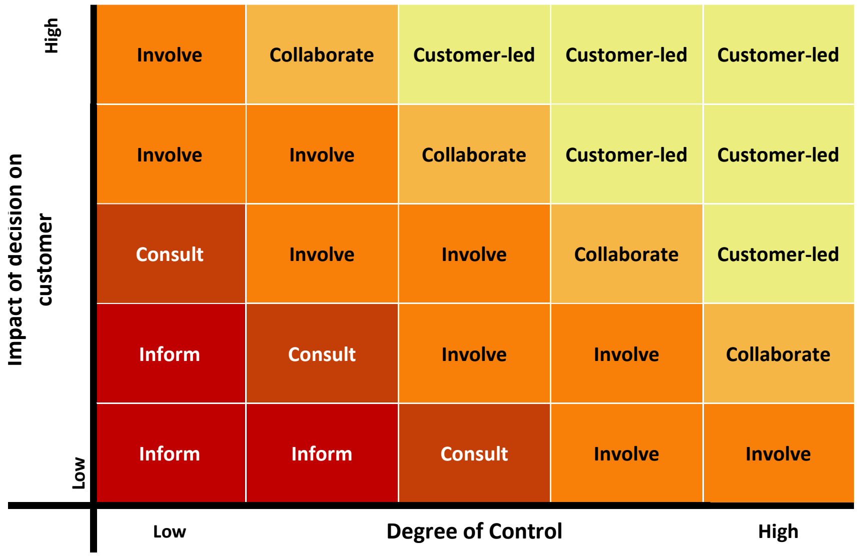
Consult	Involve	Collaborate	Client-led	Client-led
Consult	Consult	Involve	Collaborate	Client-led
Inform	Consult	Consult	Involve	Collaborate
Inform	Inform	Consult	Consult	Involve
Inform	Inform	Inform	Consult	Consult

Clients have a higher degree of control over decisions as they have a professional relationship with the organisation. A higher degree of trust and an assumption the client has more information to contribute as a service user. The client is typically afforded more control than a consumer. Note there is still a higher degree of direct decision making (and resultant informing) than client-led decision-making. That is, the matrix is still predominantly red, with only a partial section of yellow.

An example of a decision where the user group is deemed client level is a decision involving rostering of support staff. That is when the person with a disability accesses the physiotherapist – on a Tuesday or a Wednesday. There is some transference of control in the decision-making to enable the user group to satisfy its own needs amongst competing priorities.

The client-led decision differs only slightly from the customer-led decision where the user group can exhibit similar functions as the client, but also exercise a degree of economic power, or choice, in the decision-making. Using the same example, this may involve the person with a disability not only making a rostering decision and choosing which day the therapy is accessed, but also which physiotherapist they want to work with. That is, control over the staffing. And by making a decision to pay more (exercising economic power), they can access a nigher level of expertise in a more experienced physiotherapist. In the interviews with people with disabilities, the choice of support staff was deemed an integral part of choice and control and was highly valued by those people. These staff were coming into their homes and interacting with their families, and they needed to be able to trust them and to have a rapport with them, and if they felt uncomfortable, they felt they needed the ability to choose another worker who they could have the trusting relationship with.

Customer

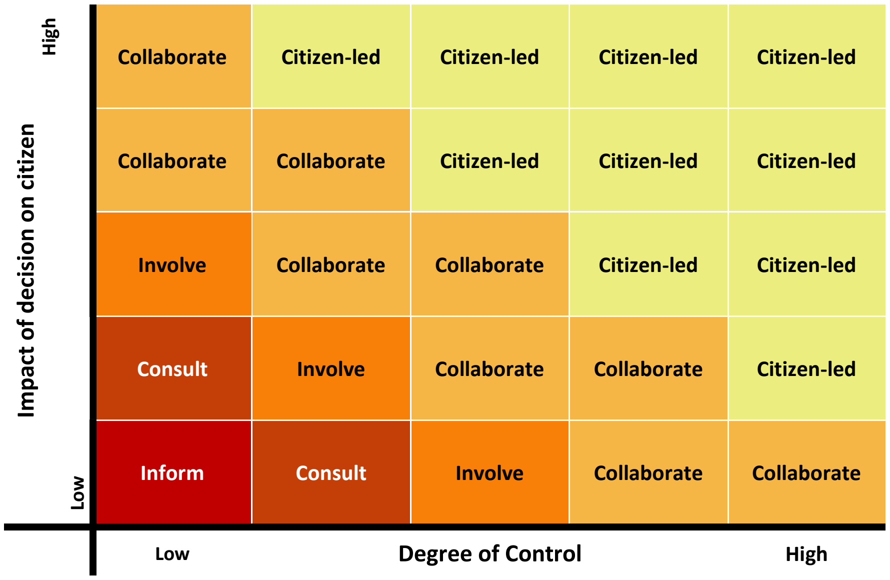


Involve	Collaborate	Customer-led	Customer-led	Customer-led
Involve	Involve	Collaborate	Customer-led	Customer-led
Consult	Involve	Involve	Collaborate	Customer-led
Inform	Consult	Involve	Involve	Collaborate
Inform	Inform	Consult	Involve	Involve

Customers are similar to Clients but also exercise economic power by making decisions about whether or not to purchase. This affords them more control over decisions. Note customers have an even spread of delegated decisions made by the organisation and decisions where they have a lead or at least supporting role. That is, there is an equal amount of red and yellow in this matrix.

In addition to the example above, another example of a decision that may be made by customers is one regarding whether to live in a group home or to live in supported individual living arrangements. That is, whether they want to purchase accommodation supports from an existing provider that manages a housing stock of usually large functional houses that they share with maybe two or three other people with disabilities, and care supports are centralised and shared between them. Or whether they choose to live independently in a house chosen from the open residential market (rented or bought) and supports are purchased individually as required and bespoke only to the person's own needs. Indeed this very example is becoming evident as the NDIS rolls out across the nation, with many disability service providers facing pressure on their revenue streams as much of their group home housing stock lies vacant, with people choosing the more individualised options and having no lock-in type contracts as they may have previously experienced.

Citizen

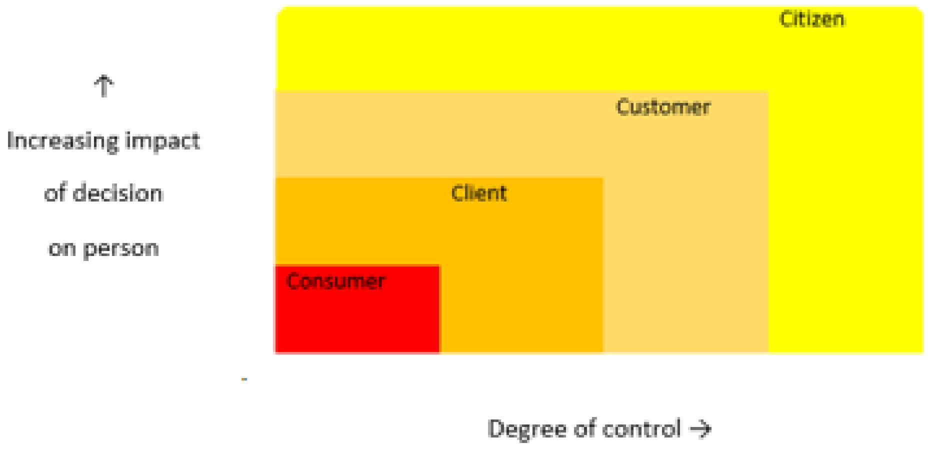


Impact of decision on citizen	Low		Degree of Control		High
High	Collaborate	Citizen-led	Citizen-led	Citizen-led	Citizen-led
	Collaborate	Collaborate	Citizen-led	Citizen-led	Citizen-led
	Involve	Collaborate	Collaborate	Citizen-led	Citizen-led
	Consult	Involve	Collaborate	Collaborate	Citizen-led
Low	Inform	Consult	Involve	Collaborate	Collaborate

A decision made by all cohorts in the NDIS is whether they will allow the National Disability Insurance Agency to manage their plans ("Agency manage"), or pay a service provider planner ("Plan manage"), or whether they self-mange ("Self manage"). It is likely those people in the citizen-led decision-making cohort would choose to self-manage their NDIS plans and those in the consumer-led cohort would choose the Agency to manage their NDIS plan and the associated funding.

When working with people who are informed, have access, and are able to contribute, the Supplementary Framework enables a more citizen-led approach whereby a large degree of empowerment is transferred to the users and they lead the decision-making. This lead can be at a macro level involving whole of system changes – like representatives chosen to represent on the Ministerial Advisory Council for example, or at an organisational level through being appointed as a lived-experience representative on a Board of Directors, to a micro level and having control over the majority of decisions that impact upon themselves. It can involve large decisions that impact on the broader consumer cohort (including all of the consumer, client and customer cohorts also). This matrix typically has more yellow than red, and a sense of more empowerment than disempowerment. Having said that, there is always room for a decision to be made by just informing the citizen – usually a menial matter, or one that has regulated requirements for example. Just as consumers have some scope for making their own decisions, and not always being informed of the outcome.

Whilst the cohorts of people described are not always subsets of each other, they often are. For ease of illustration then, this can be depicted as per below:



This Supplementary Framework has been tested and used in a service provider context (Therapy Focus) and has been the subject of a presentation to a national conference audience (Australasian Better Boards Conference 2018). This means the organising committee of the conference saw its legitimacy in abstract form and approved its presentation to the conference participants. Whilst not an endorsement in and of itself, it was acknowledgement of an approach worthy of promotion and exploration. Probably also an acknowledgement that nobody has got this engagement perfectly right and it remains a challenge for most.

8.8 Application to broader vulnerable and/or marginalised cohorts

Whilst this research was specific to people with disabilities and those with a lived experience of disabilities, the recommendations may also be relevant to other population groups, including women, people from culturally and linguistically diverse (CALD) backgrounds, older people, and Aboriginal people. It was the latter who were the focus of the research question initially, with me first learning the mantra "do it with us, not for us" when working in Aboriginal Affairs before learning the parallel mantra "nothing about us, without us" when working in the Disability sector. And this is the essence of the strategic intent expressed in the *National Closing the Gap Agreement (2020)* discussed in the literature review.

Comments made about government mandated ratios, that is a regulated level of representation by a marginalised and/or vulnerable cohort of people in governance (e.g. number of women on the Board of Directors equals >50% of total) were just as relevant to other cohorts as they were to people with disabilities, and this was recognised by many of the research participants. One research participant stated:

> *"Regulation only gets you just past GO!" (Participant 3.5)*

There emerged a consensus in the interviews which saw a preference for a combined approach where mandated ratios of consumer involvement (sticks) should be complemented by intrinsic motivation through a culture of inclusion and incentives to build that culture (carrots). This approach would surely be as relevant in the women on ASX200 boards debate, the gender pay gap movement, the non-executive directors on Aboriginal community-controlled boards discussion, and the student representative on University Council practice.

Another permutation of this recommendation was a suggestion to broaden the use of the Disability Access and Inclusion Plan (DAIP) requirement from local government to the broader service provider network. The same could be done for Reconciliation Action Plans in the Indigenous Affairs sector. Both formats of planning have structured components that mandate a level of effort and engagement – from the people employed, to the customers engaged with, to the built environment where you work from. It would be fair to say that both offer good, structured engagement tools that are very underutilised in society today.

8.9 Investment to support inclusion

The research showed numerous views that involving the consumer in the business would result in better practice which in turn would lead to better outcomes for the consumer beneficiaries that in turn would lead to a healthier business. To achieve this, organisations need to be prepared to invest to support broader inclusion of consumers in their business. Not only with a transfer of delegation according to a structured and defined Framework (refer above), but also with additional supports like mentoring, buddying, pre and post-meeting debriefing, and possibly even interpreters if language barriers, or transport if mobility barriers, or ICT if communication barriers. The investment should be sincere and should be sustained. The benefit becomes how the culture of the organisation changes when those involved see the sustained efforts of all to include people with disabilities in the business. And the detriment can also be when the effort is not genuine or sustained and when more damage is actually done through flawed co-design (Evans 2015).

This support can also come at the systemic level, with such sectoral investments as the 100 Women movement, the Emerging Leaders on Aged and Community Care Boards, and the People on Boards project. The latter was an example where a peer led organisation, People with Disabilities WA, was funded to develop a toolkit (2019B) and reference guide (2019A) to support organisations to engage with and appoint people with disabilities to their Boards of Management. Not only was the toolkit and resource guide an excellent end product and a great resource for the sector, but the process of developing it was upheld as a gold standard example of co-design in practice.

8.10 Lead by Example

Most service provider organisations, and certainly peak and advocacy organisations, have an objective to be a steward of the sector and a shining light for inclusion. It is one thing to adopt these recommendations and to operate as an inclusive business where people with disabilities are genuinely engaged and have power over decisions being made. It is another thing to project that sensibility onto the broader community and to show the benefits of broader inclusion in the community (Bartnik et al 2022). One research participant stated:

> *"The provider's role is not just to supply a product or service, but to transform community perceptions." (Participant 3.3)*

That participant went on to explain the Autism Association of Western Australia was a cultural development organisation prior to it being a service provider. The same is true of the iconic Central Australian Aboriginal Congress which, as its name suggests, was a cultural advocacy body before it was the major health service it is today. In support of this, another research participant reminded me that:

> *"…it takes a village to raise a child." (Participant 2.6)*

The relevance of this statement is multifaceted, but it reminds that a person does not live in isolation of the society around them, that their decisions are intrinsically linked to those people they interact with, and that they have a role as a person first and foremost, and as a person with a disability also. Similarly, service organisations in community care have a humane role first and foremost, and a specific service provider role secondarily.

8.11 Persevere with hard-to-reach persons

As with any human service, there are people in need who are hard to reach. In fact it is usually the people most in need who are the hardest to reach. Whether this be due to functional impairment caused by a disability, or socio-economic circumstances, language and/or cultural barriers, widespread trauma in the community, or just distance and isolation. It is for these people that the "system" should try extra hard to reach. There must be recognition of the additional work required to reach these people and some compensation for making the effort to connect them to the "system". In turn there should also be a moderation in place for providers only wishing to service those people with a disability who are engaged and informed.

8.12 Support someone to make decisions to the best of their ability

In line with the UN Convention (2007) and the Objectives of the NDIS (2013), one must assume the person with disability has intent and has a level of agency to express that intent. This means in making a decision, the first step is to establish how much input the person with a disability actually has and how much will they have to contribute. Supported and surrogate models of decision-making are supplementary to the person themselves making a decision. As best as possible one should persevere and present information for the person with a disability and gauge how responsive that person is to the information:

> *"I try and present as much information as I think he can follow and get him to choose from simple options… he can't cope with too much information, he just shuts down." (Research Participant 2.12)*

8.13 Find the right balance

As service providers become larger and more business focussed, there is a tendency for them to move away from association legislation towards company legislation. In doing this they often change their membership structure from a broadly inclusive type of membership to a very narrow and contained membership base; often being the directors themselves. This facilitates running a sophisticated modern business but can serve to lessen the input of the voice of the lived experience. It's important that when changes are made to legal entities and their Constitutions, that a balance is found between skills and representation of the service recipient cohort i.e. people with disabilities. This was a key difference in the views of people with disabilities and the representatives of service providers in the research. People with Disabilities still see it as necessary to have a seat at the table!

9. LIMITATIONS

This Chapter outlines some of the challenges faced during the research and some of the known limitations to the findings. Whilst all data is valid, and is available for inspection, the nature of the NDIS reforms and the continuing rollout of the Scheme over time means that people's views may have changed. Certainly, there was evidence during the period of research that people were becoming more confident with the new Scheme and its nuances. So the point should be made, that the study was a point in time study and the views expressed in interviews and responses in surveys may be different if asked again at a future point. The data may not be able to be replicated. However, I am confident the themes raised will stand the test of time.

The research was conducted using a snowball technique, which is common in qualitative studies. However the snowballing that occurred was minimal in that only three participants actually introduced me to further participants. This could have been due to the emphasis on individualism with the NDIS reforms, or it could be attributed to the Covid-19 Pandemic. However further research would benefit from supplementing the snowball approach with an endorsement and introduction by either a peak body (preferably) or a service provider.

Access to research participants was largely through closed Facebook groups. The groups were focussed on communities of interest with reference to disabilities and disability supports. Whilst these groups are open to different cohorts of people who meet the eligibility criteria for membership (e.g. carer, service provider, person with a disability), they are not necessarily reflective of the broader society.

The research that was conducted resulted in less participants than expected. Whilst the responses to surveys were high in the quantitative component, the completion rates were low which impacted the validity of the data. The quotas for interviews were met for the Organisations and Peaks/Advocates cohorts, exceeded for the Carers cohort, but fell short for the People with Disabilities cohort. Given the essence of this thesis is enabling the voice of people with disabilities, and empowering that voice, it is disappointing that the research failed to attract greater numbers of participants. I can speculate as to why – because of the Covid pandemic, or governance being an ethereal and complex matter, or the NDIS being about action and not more research, and the snowball approach not being aligned with the individualistic essence of the NDIS; but regardless it was disappointing to only reach half the nominated interview numbers of people with disabilities. In saying this I was pleased that of the 31 interviews that were undertaken, over half were from the lived experience of disability cohort. And of the people interviewed in this cohort, both people with disabilities and the carers, there was a good range of people with low and high support needs, and a range on disabilities represented, including intellectual disability. It is also worth noting that all of the surveys were conducted by people from the lived experience of disabilities cohorts.

The main concern, raised by research participants during interview, is how to hear the voice of those most disadvantaged. How to hear the views of those from a low socio-economic background with complex disability needs, including cognitive impairment. Or to hear from those from a culturally diverse background with English as a second language. Even with perseverance, it is difficult to access these people in the first instance as they often do not have the means or inclination to engage with support groups on Facebook for example, and are already disengaged from a system they perceive as not caring for them, so not necessarily willing to tell someone who they already perceive is part of a system that is suppressing them.

The research was conducted largely in Western Australia, with some participants residing in different parts of Australia. There were no confirmed international participants, although the deidentified nature of the surveys meant it was not impossible for international input. However further research may benefit from a broader approach, and possibly from a comparison of other countries who are at different stages of reform. If researching further, it would also be beneficial to consider approaches in different cultural contexts. Some interesting themes to be explored in the international context would include:

- Deregulated model of managing an insurance Scheme such as the NDIS, where the people with disability take the lead role in managing the Scheme in partnership with industry

- Collective decision-making in a more socialist context and funding models that can pool individual funding packages for economies of scale and broader community benefit
- Societies that are well advanced (e.g. Norway, Holland) in the co-design approach for planning, design and implementation of human services
- Organisations that are well advanced in person-centred practice (e.g. Buurtzorg Nederland)
- The formation of co-ops where staff and clients have a level of shared ownership and commensurate input to governance as owners
- Empowerment of people with disabilities in third world countries, where the prevalence may be higher, the total numbers of people with disabilities is known to be high, and the capacity of societies to care may be lower, but attitudes may also be more open and flexible without a century of charitable indoctrination

The focus on governance was possibly restrictive. Many participants expressed their concern at understanding what the purpose of the research was. When I explained it was about choice and control in decision-making, the conversation eased and people contributed freely. This may have been why participants disengaged with the surveys and there was a low completion rate. When governance was broken down this way it encouraged participation, but possibly lost some of the focus on the broader lens of governance. People often tended to focus on individual decision-making that impacted their daily lives, rather than broader governance mechanisms that may empower them in the longer term to access community supports – which was actually the topic of the research question. Drawing a link back from the individual level to the organisational level was difficult with regard to determining how the causality of empowerment at one level led to empowerment at another level. It may be worthwhile considering expanding the study from organisational governance (structured type involvement) to include all manner of consumer input, including at an individual level, for example client feedback mechanisms – as simple as compliments and complaints.

During the period of research, I changed employment and transitioned from the disability sector to the health sector. I also moved from the city of Perth to the town of Broome in Western Australia. These changes, together with the Covid-19 Pandemic that was declared on 11 March 2020 by the World Health Organisation, had a major impact on the research.

The change in employment had an impact because it meant I did not have direct access to potential research participants, nor the mechanism for introduction to that cohort. There were restrictions applied when arriving in Broome, with the Chairperson of the Western Australian Aboriginal Health Ethics Committee (WAAHEC) stating to an established stakeholder group (the Kimberley Aboriginal Health Planning Forum) that this research needed WAAHEC ethics approval to undertake research in the Kimberley region. I confirmed with the Chief Investigator (my DBA supervisor) that it did not, given the primary target cohort was not Aboriginal and had not changed from the participant cohort approved by the Ethics Committee. However due to obvious sensitivities, I minimized local research in Broome and made efforts to ensure Aboriginal people were not targeted in the research.

Given the proposed research participant recruitment method was snowballing (Liamputtong 2016, p17), the lack of access to local community was stifling. Furthermore the pandemic had an ethereal effect making people less sociable in a human contact sense. Given this thesis is most definitely human research, there was surely an impact here also, albeit hard to define. I'm sure many aspects of the impact of the Covid-19 pandemic will be studied in years to come.

The Covid-19 Pandemic had an effect on both the research and me. Once the Pandemic was declared, the mood changed significantly in the population, with most people concentrating initially on survival. Borders were closed to the local government level which restricted travel significantly and people were encouraged to stay at home unless travel was deemed necessary. There were also restrictions on the number of house guests that people could have. Whilst these measures did not make the research impossible, they certainly dampened people's enthusiasm to participate and refer. The Snowball methodology that was planned to extend the reach of the research, was certainly limited. The individualism that underpins the NDIS reforms was probably already reducing people's willingness to share their contacts, or extend their own social capital and trust, and the Pandemic compounded that further with restrictions and isolation.

As reported in the Methodology Chapter (Chapter 4), the majority of interviews were held pre-pandemic. In fact only seven of the 31 interviews were held after the Covid-19 Pandemic was declared on 11 March 2020. Two interviews with Persons with Disabilities and five interviews with carers were held during the Pandemic. All interviews for Service Organisations and Peak/Advocacy Organisations had been completed and no further interviews in these cohorts were held after March 11, 2020.

Whether or not the Pandemic had a further effect on earlier participants is largely unknown. Certainly it appeared from the interviews that people were living through the Pandemic and were responding with an increasingly different lens. But there were not any direct responses that referenced a different approach to decision-making because of the Pandemic. There was reference to different services being accessed during that period (2020-2021) with a rise in telehealth services for example.

Whilst the Pandemic did have an effect on access to research participants, the interviews that were held seemed to flow freely and there was no discernible difference between those held prior to March 2020 and those held afterwards. Possible nuances may be the subject of further research in the years following the Pandemic. Notwithstanding the Pandemic, access to research participants was difficult, especially in relation to People with Disabilities.

The methodology varied during the research period and it was noted earlier, less interviews were conducted than planned in the research design approved at Candidacy. The part-time nature of the study meant it was conducted over a longer period than usual. The doctoral study started in 2016 with Doctor of Business Administration coursework. Ethics approval was granted in 2018. Research started from 2019 and writing continued until the latter part of 2023. Even the literature changed over this period with initial readings from 2016 combined with contemporary media inclusions as late as 2023.

During this time the NDIS continued to rollout, both in numbers and in geography. People's lives also changed, with some subjects of questions changing from childhood to adulthood for example. Whilst not a longitudinal study in itself, there were aspects of longitudinal study as parents described the long-term changes in their children, and the increased independence they saw as goals were attained as their children grew up. Another example of a longitudinal impact was the change in government policy to introduce independent assessments as a checking measure to ensure supports prescribed in NDIS plans were both reasonable and necessary as per the legislation and accompanying guidelines, and value for money. At least one research participant noted this development in her interview and stated it was a disempowering experience.

In addition to the research limitations, there were technical limitations. The social media phenomenon is evolving quickly and the need to communicate in short posts does not always suit academic purposes. Finding the balance between effective communication on Facebook and full disclosure of purpose and ethics was difficult.

The use of artificial intelligence in the transcription service, whilst providing immeasurable benefit in efficiencies, was not perfect. Language recognition may have been impacted by lingual accents but was certainly impacted by technical language and acronyms specific to the industry. I certainly would recommend the use of this artificial intelligence software but would caution that the user must always proof the transcriptions generated.

These limitations are declared in honesty and with transparency. They do not detract from the validity of the research, and many were anticipated during the research design. The research did verify governance frameworks that are effective at empowering people with disabilities to access community care services. And the thesis makes valuable recommendations that can assist practitioners in the industry to further efforts to co-design services with people with disabilities and enable them to participate in decision-making on matters that impact their lives.

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11. APPENDICES

11.1 Appendix 1

Curtin University

People with Disabilities Survey

Start of Block: Default

Q1
Do you give your informed consent to proceed with this survey?

○ Yes

○ No

Q2 Please indicate your age

○ Under 16 years

○ 16-25 years

○ 26-45 years

○ 46-65 years

○ Over 65 years

Q3 Please indicate your gender

○ Female

○ Male

○ Other ____

○ Prefer not to say

Q4 Are you eligible to receive funded supports due to a disability?

○ Yes

○ No

○ Don't know

Q5 If yes, do you actually receive any form of funded support?

○ Yes

○ No

○ Don't know

Q6 Do you care for yourself?

○ No

○ Yes, some of the time

○ Yes, most of the time

○ Yes, all of the time

Q7 If you receive some care from another person, who would you describe as your primary carer?

☐ Partner/spouse

☐ Parent/Grandparent

☐ Unpaid Carer

☐ Paid Carer

☐ Guardian

☐ Friend

☐ Other ____

Q8 Do you have any say in the amount or type of funded support you receive?

○ Yes

○ No

○ Don't know

Q9 On a scale of 1 to 5 (low to high), how would you rate the level of involvement you have to determine the amount of funded supports you receive?

○ 1

○ 2

○ 3

○ 4

○ 5

○ Not applicable

Q10 How much say do you have to decisions about the type of funded supports you receive?

○ Not at all

○ A little bit

○ Some

○ A lot

Q11 Are you involved in choosing who delivers the funded supports you receive?

○ Not at all

○ A little bit

○ Some

○ A lot

Q12 Are you provided with support to enable you to contribute to decisions on matters that affect you?

- ○ Yes
- ○ No
- ○ Don't know

Q13 If yes, what type of support?

- ☐ Translator and/or interpreter
- ☐ Communication aids
- ☐ Trusted support person (eg therapist)
- ☐ Other ____
- ☐ Not applicable

Q13 Are you able to participate in decision-making by the service provider that delivers services to you?

- ○ Yes
- ○ No
- ○ Don't know

Q15 If yes, what form does the participation take?

- ☐ Board of Management
- ☐ Reference Group
- ☐ Advisory Committee
- ☐ Focus Group
- ☐ Individual Planning Meeting
- ☐ Micro-Board
- ☐ Other ____
- ☐ Not applicable

Q16 Please indicate what this participation involves:

- ☐ Making decisions
- ☐ Advising
- ☐ Advocating
- ☐ Other ____
- ☐ Not applicable

Q17 Which word do you think best describes your current position with regard to decision-making for funded supports that you receive

○ Consumer

○ Client

○ Customer

○ Citizen

○ Why? ____

Q18
If you receive supports from a service provider, are you involved in that organisation's governance?

(Note: in the context of this and some of the following questions 'Governance' refers to the processes, activities and relationships of the organisation that make sure that decision-making is informed and transparent and that the organisation is effectively and properly run)

○ Yes

○ No

○ Don't know

Q19 If yes, do you think the governance framework you are involved with is clear in the expectations of involvement it requires from you?

○ Yes

○ No

○ Don't know

○ Not applicable

Q20 Are you involved with the governance of any of the following?

- ☐ Advocacy Organisation
- ☐ Service Provider
- ☐ Peak Representation Body
- ☐ Local Government
- ☐ Health Department (or similar)
- ☐ Consumer Rights Group
- ☐ Don't know
- ☐ Other ____
- ☐ Not applicable

Q21 On a scale of 1 to 5 (low to high), how would you rate your level of understanding of the National Disability Insurance Scheme?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5

Q22 Do you believe you will have more or less choice and control over the type and amount of funded supports available once your are a participant in the National Disability Insurance Scheme?

- ○ More
- ○ Same
- ○ Less
- ○ Don't know

Q23 In your opinion, what are the major obstacles to you exercising choice and control over funded supports you receive? (tick all appropriate)

- ☐ Lack of information
- ☐ Too much information
- ☐ Lack of choice
- ☐ Too much choice
- ☐ Quality of planners
- ☐ Knowledge of planners
- ☐ Lack of providers
- ☐ Quality of providers
- ☐ Capacity of providers
- ☐ Quantity of supports
- ☐ Understanding of personal circumstances
- ☐ Funds
- ☐ Funding process
- ☐ Other ____

Q24 In your opinion, do you have the ability to complain about the funded supports you receive?

- ○ Yes
- ○ No
- ○ Don't know

Q25 If you complain about the funded supports you receive, do you believe your complaint will be heard and responded to appropriately?

- ○ Yes
- ○ No
- ○ Maybe

Q26 *This completes the survey thank you.*
Please click Next page to submit your answers, or click Previous page to return to survey.

End of Block: Default

11.2 Appendix 2

Curtin University

People Caring for People with Disabilities Survey

Start of Block: Default Question Block

Q1 Do you give your informed consent to proceed with this survey?

- ○ Yes
- ○ No

Q2 Please indicate your age

- ○ Under 16 years
- ○ 16-25 years
- ○ 26-45 years
- ○ 46-65 years
- ○ Over 65 years

Q3 Please indicate your gender

- ○ Female
- ○ Male
- ○ Other ____
- ○ Prefer not to say

Q4 What is your role in relation to the person with a disability?

- ☐ Parent / Grandparent
- ☐ Guardian
- ☐ Unpaid Carer
- ☐ Paid Carer
- ☐ Friend
- ☐ Other, please specify

____

Q5 Does the person with a disability receive any form of funded support?

- ○ Yes
- ○ No
- ○ Don't know

Q6 Does the person with a disability use a funded support to purchase services from a service provider external to that person's immediate family (whether an organization or individual)?

- ○ Yes
- ○ No
- ○ Don't know

Q7 Does the person with a disability have any say in the amount or type of funded support they receive?

○ Yes

○ No

○ Don't know

○ Not applicable

Q8 On a scale of 1 to 5 (low to high), how would you rate the level of input the person with a disability has regarding funded supports they receive?

○ 1

○ 2

○ 3

○ 4

○ 5

○ Not applicable

Q9 To what level do you participate in decision making on behalf of the person with a disability when making decisions about funded supports they receive?

○ Not at all

○ Slightly

○ Partially

○ Wholly

○ Not applicable

Q10 Is the person with a disability provided with a resource to enable them to participate in decision making on matters that impact upon them?

○ Yes

○ No

○ Don't know

Q11 If so, what sort of resource?

☐ Translator and/or interpreter

☐ Trusted support person (eg therapist)

☐ Communication Aid

☐ Other ____

☐ Not applicable

Q12 Are you, or the the person with a disability that you care for, able to participate in decision-making with the service provider that delivers services to the person you care for?

○ Yes

○ No

○ Don't know

Q13 If so, what form does the participation take?

- ☐ Board of Management
- ☐ Reference Group
- ☐ Advisory Committee
- ☐ Focus Group
- ☐ Individual Planning Meeting
- ☐ Micro Board
- ☐ Don't Know
- ☐ Other ______________________________
- ☐ Not applicable

Q14 Dos the participation involve:

- ☐ Making decisions
- ☐ Advising
- ☐ Advocating
- ☐ Don't know
- ☐ Other ______________________________
- ☐ Not applicable

Q15
Are you able to participate in a governance framework that contributes to decision-making that impacts upon the person with a disability whom you care for?

(Note: in the context of this and some of the following questions 'Governance' refers to the processes, activities and relationships of the organisation that make sure the organisation is effectively and properly run)

○ Yes

○ No

○ Don't know

Q16 Do you think the governance framework is effective at improving decision-making by incorporating your views?

○ Yes

○ No

○ Don't know

○ Not applicable

Q17 Which word do you think best describes the current position of the person with a disability that you care for with regard to decision-making in relation to funded supports that they receive (please explain your answer in the box below):

○ Consumer

○ Client

○ Customer

○ Citizen ____

Q18 Is the governance framework you are involved with associated with

- ○ Advocacy Organisation
- ○ Service Provider
- ○ Peak Representative Body
- ○ Local Government

Q19 On a scale of 1 to 5 (low to high), how would you rate your level of understanding of the National Disability Insurance Scheme?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5

Q20 Do you believe the person you care for will have more or less choice and control over the type and amount of funded supports available once they are a participant in the National Disability Insurance Scheme?

- ○ Less
- ○ Same
- ○ More
- ○ Don't know

Q21 In your opinion, what are the major impediments to people with disabilities exercising choice and control over supports they receive? (tick all appropriate)

☐ Lack of information

☐ Too much information

☐ Lack of choice

☐ Too much choice

☐ Quality of planners

☐ Knowledge of planners

☐ Lack of providers

☐ Quality of providers

☐ Capacity of providers

☐ Quality of supports

☐ Quantity of supports

☐ Understanding of personal circumstances

☐ Funds

☐ Funding process

☐ Other ____

Q22 In your opinion, do you believe people with disabilities have the opportunity to complain about the funded supports they receive?

○ Yes

○ No

○ Don't know

Q23 If a person with a disability complains about the funded supports they receive, do you believe their complaint will be heard and responded to appropriately?

○ Yes

○ No

○ Maybe

Q24

This completes the survey thank you.
Please click Next page to submit your answers, or click Previous page to return to survey.

End of Block: Default Question Block

11.3 Appendix 3

Interview People with Disabilities

Purpose

1. To gauge how much control over decisions you feel you have
2. To describe what could be done to improve how much control you have over decisions

Question 1

Briefly describe your funded supports

Prompt Accommodation
Care
Therapy
Equipment

Question 2

Do you receive funded supports from a service provider?

Question 3

Does the government pay for those funded supports?

Prompt NDIS?
Other?

Question 4

Do you have a plan that describes your goals and strategies and identifies supports to achieve those goals?

Question 5

On a scale of 1 to 10 (1 being lowest and 10 being highest), what level of control did you have over the planning for your funded supports?

Question 6

Were you able to choose who provided the funded supports?

Question 7

Do you make your own decisions, or do your family members/carers make them for you (or with you)?

Question 8

Which word do you think best describes your current position with regard to decision-making in relation to funded supports that you receive:

☐ Consumer
☐ Customer
☐ Client
☐ Citizen

Why?

____

____

____

Question 9

Are you involved in any organisation?

Prompt If so, at what level?

Question 10

Any further comments?

11.4 Appendix 4

People caring for people with disabilities

Interview

Purpose

1. To gauge how much control over decisions you feel a person with a disability has
2. To describe what could be done to improve how much control people with disabilities have over decisions

Question 1

Briefly describe the funded supports accessed by the person you care for

Prompt Accommodation
Care
Therapy
Equipment

Question 2

Do they receive funded supports from a service provider?

Question 3

Does the government pay for those funded supports?

Prompt NDIS?
Other?

Question 4

Does the person you care for have a plan that describes their goals and strategies and identifies supports to achieve those goals?

Question 5

On a scale of 1 to 10 (1 being lowest and 10 being highest), what level of control did they have over the planning for their funded supports?

Question 6

Were they able to choose who provided the funded supports?

Question 7

Do they make their own decisions, or do you or family members/carers make them for them (or with them)?

Question 8

Which word do you think best describes their current position with regard to decision-making in relation to funded supports that they receive:

☐ Consumer
☐ Customer
☐ Client
☐ Citizen

Why?

____
____
____

Question 9

Are they involved in any organisation?

Prompt If so, at what level?

Question 10

Any further comments?

11.5 Appendix 5

Organisations caring for people with disabilities
Interview

Question 1

Briefly describe the role of your organisation in supporting people with disabilities

Prompt Relationship
Support function
Legal status / funding source

Question 2

Describe the organisation's governance structure

Prompt Board and management
Elected / appointed
Skills-based / representative

Question 3

Do people with disabilities have a say in the governance of your organisation?

Prompt How?
Mandated by rules / Invited?

Question 4

Do people with disabilities have input to decisions made by your organisation?

Prompt How?
Structured / Impromptu?

Question 5

What do you see as the advantages of people with disabilities having input to decisions that impact upon them?

Prompt For self
For organisation

Question 6

Do you think it is common practice for organisations to involve people with disabilities in decision-making?

Prompt In broader governance structures

Question 7

Can you give an example where you think the involvement of people with disabilities in decision making is done well?

Question 8

Which word do you think best describes the current position of people with disability who access your organisation’s services, with regard to decision-making in relation to funded supports that you deliver:

- ☐ Consumer
- ☐ Customer
- ☐ Client
- ☐ Citizen

Why?

More specifically in relation to access to community care:

Question 9

Do you think people with disability have the appropriate level of input to decision-making on matters in relation to access to community care?

Prompt Planning
Consuming
Purchasing

Question 10

Do you think people with disability would benefit from having increased input to decision-making on matters in relation to access to community care?

Prompt At what level?
Individual / organisational?
Program / policy?

Question 11

Do you think government should mandate a level of involvement of people with disabilities in decision-making on matters in relation to access to community care?

Prompt How?
Regulation framework?

Question 12

Any further comments?

11.6 Appendix 6

Peak bodies representing organisations and/or advocates for people with disabilities

Interview

Question 1

Briefly describe the role of your organisation in supporting people with disabilities

Prompt Relationship

Support function

Legal status / funding source

Question 2

Describe the organisation's governance structure

Prompt Board and management

Elected / appointed

Skills-based / representative

Question 3

Do people with disabilities have a say in the governance of your organisation?

Prompt How?

Mandated by rules / Invited?

Question 4

Do people with disabilities have input to decisions made by your organisation?

Prompt How?

Structured / Impromptu?

Question 5

What do you see as the advantages of people with disabilities having input to decisions that impact upon them?

Prompt For self
For organisation

Question 6

Do you think it is common practice for organisations to involve people with disabilities in decision-making?

Prompt In broader governance structures

Question 7

Can you give an example where you think the involvement of people with disabilities in decision making is done well?

Question 8

Which word do you think best describes the current position of most people with disabilities with regard to decision-making in relation to funded supports that you receive:

☐ Consumer	☐ Client
☐ Customer	☐ Citizen

Why?

More specifically in relation to access to community care:

Question 9

Do you think people with disability have the appropriate level of input to decision-making on matters in relation to access to community care?

Prompt Planning
Consuming
Purchasing

Question 10

Do you think people with disability would benefit from having increased input to decision-making on matters in relation to access to community care?

Prompt At what level?
Individual / organisational?
Program / policy?

Question 11

Do you think government should mandate a level of involvement of people with disabilities in decision-making on matters in relation to access to community care?

Prompt How?
Regulation framework?

Question 12

Any further comments?

11.7 Appendix 7

PARTICIPANT INFORMATION STATEMENT

HREC Project Number:	HRE2018-0653
Project Title:	*An investigation of governance frameworks that empower people with disabilities to access community care services*
Chief Investigator:	*Professor John Phillimore, Executive Director, John Curtin Institute of Public Policy*
Student researcher:	*Matthew Burrows*
Version Number:	*2.0*
Version Date:	*180827*

What is the Project About?

The research is being conducted at a time Australia is introducing a National Disability Insurance Scheme. The aim of this reform is to transfer choice and control to people living with a disability. This research is exploring some of the themes arising from this aim.

As part of his Doctor of Business Administration (DBA) at Curtin University, Matthew Burrows is conducting research into governance frameworks that empower people with disabilities to access community care services. The aim of his research is to identify ways that service providers can organize themselves to allow people living with disabilities to have input to decisions that impact on them.

The study will involve a survey and semi-structured interview (and possibly a follow up interview) with a number of stakeholders. These include:

Interviews with:	People living with disabilities
	People caring for people living with disabilities
	Organisations providing care services for people living with disabilities
	Peak bodies advocating for and/or representing people living with disabilities
Surveys with:	People living with disabilities
	People caring for people living with disabilities

Who is doing the Research?

- The project is being conducted by Matthew Burrows. The results of this research project will be used by Matthew Burrows to obtain a Doctor of Business Administration at Curtin University and is funded by the Australian Government.
- I note that the researcher, Matthew Burrows, was employed by a service provider (Therapy Focus) in the disability sector, but I understand he is no longer employed there and that this research is separate to that employment and is not governed in any way by that employer.
- I further understand that Matthew Burrows will not use any information I provide to him for commercial gain, and will not transfer any information from the research to the service provider that he works for. I understand my participation will be anonymous to that service provider. If I am a client of that service provider, my participation will not be noted in any way by that service provider in case notes or any other manner.
- There will be no costs to you and you will not be paid for participating in this project.

Why am I being asked to take part and what will I have to do?

- You are invited to take part in this research because you either have a lived experience of disability, or you work in some form of support capacity to support someone who has a lived experience of disability.
- Your involvement will take the form of either participation in a semi-structured interview or an online survey
- If you participate in an interview it will be conducted at a place and time suitable to both you and the researcher. If you participate in an online survey it will be at an internet point accessible to you.
- The questions asked in both interviews and surveys will be focused on your experience working with organisations delivering community care services, and specifically about your perceptions of your control over decision-making.
- The online survey should take no more than 15 minutes to complete. All interviews are expected to last between 20-30 minutes.
- There will be no cost to the participant other than your time to be involved.
- For interviews, the researcher will make a digital audio recording so he can concentrate on what you have to say and not distract himself with taking notes. After the interview he will make a full written copy of the recording.

Are there any benefits' to being in the research project?

- There is no direct benefit to you for participating in this research. However you may increase your understanding of governance and the way organisations structure themselves. You may also clarify your role in exercising choice and control in accessing community care services.
- Sometimes, people appreciate the opportunity to discuss their opinions/ feelings.
- The researcher hopes this research will identify some barriers to empowerment for people with disabilities and will assist with solutions to overcome some of those barriers.

Are there any risks, side-effects, discomforts or inconveniences from being in the research project?

- There are no foreseeable risks from this research project. If you feel distressed from any conversation or any sentiment raised in the process of the research please raise it with the researcher, Matt Burrows, in the first instance.
- We have been careful to make sure that the questions in the survey do not cause you any distress. But, if you feel anxious about any of the questions you do not need to answer them. If the questions cause any concerns or upset you, the researcher may refer you to a counsellor with your consent.

Who will have access to my information?

- The information collected in this research will be re-identifiable (coded). This means that the researcher will collect data that can identify you, but will then remove identifying information on any data or sample and replace it with a code when he analyses the data. Only the research team have access to the code to match your name if it is necessary to do so. Any information collected will be treated as confidential and used only in this project unless otherwise specified. The following people will have access to the information we collect in this research: the research team and, in the event of an audit or investigation, staff from the Curtin University Office of Research and Development
- Electronic data will be stored on a Curtin University database and will be password-protected. Hard copy data (including audio tapes) will be in locked storage.
- The information collected in this study will be kept under secure conditions at Curtin University for 7 years after the research is published and then it will be destroyed.
- The results of this research may be presented at conferences or published in professional journals. You will not be identified in any results that are published or presented.

Will you tell me the results of the research?

- You will not receive direct feedback from the research, however your input will be included in the analysis and results in a de-identified manner.

Do I have to take part in the research project?

- Taking part in a research project is voluntary. It is your choice to take part or not. You do not have to agree if you do not want to. If you decide to take part and then change your mind, that is okay, you can withdraw from the project. If you choose not to take part or start and then stop the study, it will not affect your relationship with the University, staff or colleagues.
- If you are completing an online survey you can withdraw your *participation* prior to submitting your responses. You can do this by simply closing the browser. However, as data are anonymous you cannot withdraw your *data* after the responses have been submitted.

What happens next and who can I contact about the research?

- You can contact Matt Burrows as the principal researcher. Matt can be contacted by email at matthew.burrows@postgrad.curtin.edu.au
- You can contact the Chief Investigator, Professor John Phillimore, by phone (08) 9266 2849 or by email J.Phillimore@curtin.edu.au
- If you decide to take part in this research we will ask you to sign the consent form. By signing it is telling us that you understand what you have read and what has been discussed. Signing the consent indicates that you agree to be in the research project and have your health information used as described. Please take your time and ask any questions you have before you decide what to do. You will be given a copy of this information and the consent form to keep.
- If you complete the online survey, at the start of the questionnaire available via the link provided, there is a checkbox to indicate you have understood the information provided here in the information sheet.

Curtin University Human Research Ethics Committee (HREC) has approved this study (HREC number HRE2018-0653). Should you wish to discuss the study with someone not directly involved, in particular, any matters concerning the conduct of the study or your rights as a participant, or you wish to make a confidential complaint, you may contact the Ethics Officer on (08) 9266 9223 or the Manager, Research Integrity on (08) 9266 7093 or email hrec@curtin.edu.au.

11.8 Appendix 8

GLOSSARY

The research found that people often have different perspectives and one concept may mean something different to someone else with a different perspective. These definitions are supplied therefore in an attempt to develop a shared understanding of commonly used terms that are often interchanged in daily discourse.

The following words are used throughout the thesis with these meanings:

- Advocate – A person or organisation that has a primary function of advocating for the rights of a person(s) with a disability
- Carer – Someone who performs the role of caring for a Person with a Disability
- Charity – An Organisation whose purpose is deemed benevolent and is registered with the Australian Charities and Not-for-profits Commission (ACNC)
- Choice and Control – The function whereby a Consumer can effect influence on either choice and/or control in decision-making on matters that affect them
- Client – A Consumer who has a professional relationship with a provider, with some expectation of discretion and/or confidentiality
- Consumer – Someone who consumes a product or service
- Customer – A Consumer with economic bargaining power who instigates transactions and purchases products and/or services
- Citizen – A Consumer who performs the functions of client and customer and who is able to make informed decisions on those functions, with a level of control over the independence of those decisions and some ability to advocate beyond those decisions
- Lived Experience – A cohort of people with day-to-day living experience of a disability, whether that be a Person with a Disability (first-hand) or a Carer or Support Person (second-hand)

- Participant – A term defined by Part 4, Clause 9 of the *National Disability Insurance Scheme Act 2013*
- Patient – A Person accessing health services from a recognised health professional/provider
- Peak Body – An Organisation whose primary role is to represent the views of a number of Persons/Organisations with some common interest and/or purpose
- Person – A person first and foremost; and possibly a person with a disability (or other attribute) secondarily
- Person with a Disability – Someone with a disability that has a substantial impedance on their ability to function independently; and possibly, but not always, a Participant
- Organisation – A legal entity with defined Objects that relate its Purpose which is registered either as an Association under State/Territory law, or as a company under Commonwealth law
- Reasonable and Necessary – A requirement prescribed by the *National Disability Insurance Scheme Act 2013* for supports to be deemed related to the disability, not a day-to-day living cost generic to any other Person (eg groceries), and which represents value for money
- Service Provider – A person/organisation with a primary purpose to provide services to a consumer