# VULNERABILITY AND POWER TO SHAPE THE FUTURE

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by

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# ABSTRACT

Shaping ones own future is a powerful, life-affirming act.  For people with disability, their families, friends and allies, shaping the future has historically been a difficult, often adversarial process which has relied on negative images and stereotypes of vulnerability, abuse and neglect at the hands of an unresponsive "system".  Current reforms, the National Disability Insurance Scheme in particular, offer an opportunity for a more collaborative, positive and  citizen-led approach to creating a good life.

This project has used Causal Layered Analysis and Sense-Making processes to explore the ways in which we define and respond to our own vulnerability, the mental images we generate as part of that response, and what that means in terms of power to influence the future.

Findings suggest that while vulnerability and power to shape the future can and do co-exist, there are significant tensions between the community being both answer to inclusion and a dangerous place. There are invisible assumptions of poverty and low expectations for the future that will need to be examined and re-constructed if the National Disability Insurance Scheme is to be all it promises.
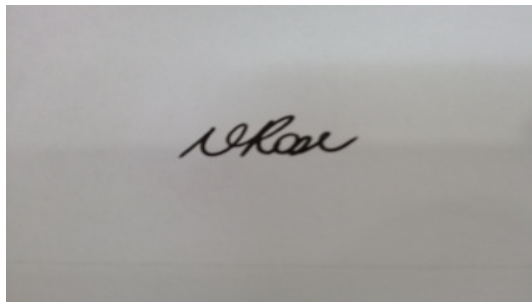
# KEYWORDS

Causal Layered Analysis, Futures Studies, People with Disability, Personal Agency, Power, Sense-Making, Vulnerability

# STATEMENT OF ORIGINAL AUTHORSHIP

The work submitted in this thesis is original, except as acknowledged in the text. The material herein has not been submitted, either in whole or in part, for a degree at this or any other university.

Signature:

Date:            1 August 2017

# AUTHOR'S PREFACE

This research comes in the 32$^{nd}$ year of a professional career focused heavily on social justice for people who are disadvantaged by a complex combination of impairment, poverty and lack of opportunity to influence their own future.



Using a panel of Indigenous art in the Kimberley region of Northern Australia as a metaphor, my own story is revealed to me in layers, without the need to attribute time or place or names of the characters. When I work hard to find meaning and coherence in the images that appear, answers elude me. When I pause and reflect with softened gaze, the panel takes on a three-dimensional quality and reveals many stories. I stop seeking coherence and chronology, letting the past, present and future emerge intertwined as I observe.

One of my earliest memories is as a 4-year-old waiting for my father to find me in front of the picture theatre of a small country town. It was a town of two industries and violence between workers over industrial strife was apparently common. On this occasion, a man was being speared headfirst into the concrete a very short distance from where I stood in new white shoes and lacey socks.

Less than ten years later I was a regular visitor to our local member of parliament, in a different but similar town, asking why industrial strikes were allowed given they cause families such financial hardship and loss of dignity (and why didn't he do something). In times of extended striking, wives and children of striking men

would sit on a blanket in front of the supermarket and the wives of non-striking men would discreetly place a small bag of groceries on their blanket, without making eye contact or engaging anyone in conversation.  Members of my own family were on both sides of the divide and I found the silence and loss of human dignity painful.  I have always had a sense that vulnerability to violence and indignity has both structural and individual dimensions, but that it is amplified where a person experiences impairment, poverty or abuse of power.

It was an easy decision to enrol in an allied health degree, and my early introduction to the ideas of "normalisation" from Wolf Wolfensberger (1972) further confirmed my early view that life is a struggle for the "vulnerable" and exposes them to violence and exclusion.  After ten years as an allied health clinician I became acutely uncomfortable with professionals exercising power *over* their clients rather than *for* them and changed career path.  I became actively involved in developing disability enterprise wage systems that included people with and without disability on an equal basis.  I agitated against the common practice in the disability employment sector of paying workers with disability on the basis of productivity, while their able-bodied peers were paid on the basis of competency.  I struggled to find like-minded peers and was frustrated by the unwillingness of people with disability to assert the most basic of rights in the workplace or community.  I subsequently engaged in some research to better understand the personal barriers to visioning and dreaming by women with an intellectual impairment and discovered the powerful, negative impact of the social and service system context in which they lived and worked.  Within days, I left my job and joined National Disability Services (then known as ACROD) to pursue systems advocacy more directly.

Unconsciously, as a long-term practitioner in the field of disability policy and practice, I have been part of defining and perpetuating prevailing discourses that may ultimately limit the range of futures people with disability imagine and create for themselves.  My observation is that many of the disability discourses are underpinned by assumptions of scarcity, susceptibility to exploitation and abuse, of needing safeguards and, above all, of vulnerability of people with disability.   I have, many times, been complicit in reflecting and amplifying images of abuse and neglect, of shops, schools, workplaces and public places rendered inaccessible and uninviting to people with disability, in attempts to influence public policy.

As an individual, however, it is evident that my path shifted sharply when I could no longer tolerate the prevailing discourse or find allies in my resistance.  I also lacked the skills to process and integrate what I experienced.  It is at this point in my life, facing my own future with options and optimism, that I reflect on the challenges ahead for people with disability and their families as they enter the National Disability Insurance Scheme (NDIS).  There is a significant gap between the dominant disability discourses and the expectation that people will imagine and choose from a range of choices and navigate their way to a better future.    An exploration of this divide that engages with people with disability, their families and service providers may well help us better understand how the NDIS will play out over the next decade or so. This is the territory in which I locate my research.

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# Chapter 1: Introduction

> *Individual choice and control* is a concept locked in a dominant discourse that silences creative and expansive possibilities. (Giri, 2012 p7)

The implied promise of the National Disability Insurance Scheme (NDIS), a national social insurance-based policy reform, is that people will have the opportunity to exercise greater choice and control than they have had in the past and, by doing so, open up a broad range of possible futures for themselves.  The lure of social and economic participation is presented as incentive to leap from current reality to an uncertain but possibly better future.

As a practitioner for 30 years in the field of disability policy and practice, I have been part of defining and perpetuating a discourse that may ultimately limit the range of futures people with disability imagine and create for themselves.  My observation is that the dominant discourse has been one of scarcity, susceptibility to exploitation and abuse, of needing safeguards and, above all, of vulnerability of people with disability.  I have, many times, been complicit in reflecting and amplifying images of abuse and neglect, and of shops, schools, workplaces and public places rendered inaccessible and uninviting to people with disability, in attempts to influence public policy in *their best interests*.

As a researcher, I am inspired by the possibility of people with disability imagining and shaping their own future.  To date, however, choice and control have been rationally and politically defined rather than understood in the context of relationship and personal agency.  There is currently insufficient research on the connection between vulnerability and capacity to anticipate and shape the future to be confident that the promise of individual choice and control will become the reality for people.

## 1.1 Context

### 1.1.1 Policy Context—the National Disability Insurance Scheme

The policy context for this research is the NDIS. The emergence of the NDIS, a major social policy reform with the principle of maximising choice and personal control over the future for individuals and their families at its centre, provides both opportunity and imperative to explore the relationship between perceptions of vulnerability and power to influence the future.

Since its endorsement by the Council of Australian Governments, the NDIS has had bipartisan political support, the legislative and funding base established, and extensive pilot programs in most states to test and refine implementation. Whether the NDIS has responded comprehensively to concerns of academics and advocates is not yet clear. Concerns expressed by Dr Eric Leipoldt in his submission to the Productivity Commission Inquiry into a National Long-term Disability Care and Support Scheme (Leipoldt, 2011) were two-fold: that economic considerations would be a major barrier to individual choice and control being realised, and that the scheme itself was based on market ideology rather than a body of research:

> A market-based approach based on cost-effectiveness and efficiency is not coherent with processes and aims of social inclusion and cannot therefore achieve them. Social inclusion is not built on contractual arrangements, cost-effectiveness, efficiency and competition. (Leipoldt, 2011, p. 2)

A review of research literature in both the disability and futures fields suggests there may be more significant constraints to change under the NDIS than the introduction of a market ideology. These include the extensive use of negative imagery of disability in influencing public policy and a discourse heavily dominated by constructs of vulnerability and powerlessness. While there is research that identifies self-determination and self-direction as important aspects of effective service models (Epstein-Frisch, 2006), critique on the way vulnerable people are depicted (Clendinnen, 1998) and the impact of vulnerability (Milojević, 2013; Robinson, 2012) there is little research on the relationship between vulnerability and the individual's ability to imagine and create a future for themselves.

Leipoldt (2011) went further in his criticism of the framing of the NDIS, echoing the work of Lakoff (2004). Lakoff suggests that once people have a frame,

they only accept facts that fit that frame. The NDIS to date has largely been framed in economic terms; that is, that investment in services and supports is primarily justified by the offsets to government from people entering or re-entering the workforce and paying income tax. This logic was effective as a driver for the NDIS but reflects a "balance sheet" approach to human service provision which needs to be interrogated further from the perspective of good policy (Chapple, 2013). The "balance sheet" approach is attractive in that it demonstrates the power of investing in human services, specifically the financial return on welfare expenditure. It fails, however, to acknowledge the social capital or human equity built as a result of social service investment. Many participants involved in the current research were well versed in the language of "cost savings" when people get jobs and "spending only for reasonable and necessary supports". There was, however, no reference in participants comments to social capital, capacity building or value to community by investing in social services.

Lakoff (2004) highlights the importance of changing such narratives as they support the "strict father" frame which dominates Western politics; that is, that if people don't succeed it's because they're lazy and need to be disciplined. Such a frame comes with assumptions that the world is a dangerous place. According to Lakoff (2004), this frame includes an authority figure (male) there to protect people in a dangerous world, with responsibility for teaching "his children" right from wrong; he requires obedience from his children and has a strong belief that those who are disciplined succeed and will become prosperous and self-reliant. This link between morality and prosperity is of concern, as it not only reflects outdated disability discourse but feeds the concept of the "deserving poor". It also potentially frames welfare expenditure as "wasteful".

If major public policy reform reflects our beliefs, through government, about how resources should be allocated and the role of the individual in shaping those decisions (Schissler Manning, 2003) then we need a better understanding of the capacity of individuals to make and give effect to those decisions in the NDIS context. A review of similar reforms in countries such as Canada, Sweden and the United Kingdom (UK) (Chenoweth & Clements, 2009) suggests that a more individualised approach to administering funding for supports and individual control over that funding produces better outcomes. For example, evaluation of personalised

approaches to social care for approximately 1000 service users in the UK showed little difference in cost of support ($280 versus $300 for conventional funding arrangements), but significant differences in perception of control over individuals' daily lives (IBSEN, 2008). These evaluation reports remain silent, however, on the issue of people with disability imagining and shaping their own future. While self-determination is seen as both a right and responsibility (Moseley, 2005), there is no reference to the impact of vulnerability on perceptions or experience of self-determination.

If anticipating and shaping the future under the NDIS requires the generation of images of a future not yet experienced, as suggested by Fred Polak (1961), then the proliferation of negative images during the political campaign for the NDIS may prove to be unhelpful. We need a better understanding of whether people with disability, their families and service providers are able to generate positive images of the future. An exploration of images generated as people consider the future would also provide an indication of perceived self-determination and empowerment over the future; that is, their capacity and expectation giving effect to choices made.

The idea of using imagery to open up a range of futures would be challenging and innovative for the disability field, given the bias toward negative image generation. It would also connect the discipline of futures studies to the pressing issues of system, policy and practice reform in our social service systems.

### 1.1.2 Futures Studies

Academics in the disability field (Kendrick, 1994) argue that the future of people with disability will remain limited by the tacit theories and untested assumptions about vulnerability that prevail in our social structures, social policy and disability discourse (Robinson & Chenoweth, 2012). The use of images could render the theories and assumptions of all stakeholders visible and available for examination. Unexamined, such images and assumptions may overly prescribe or bias us toward certain "closed" futures. Given the NDIS offers the promise of more expansive or "open" futures, tools and methodologies from the field of futures studies are used in this research.

While futures thinking has been evident since the predictions of the future by the first oracles, the beginnings of our modern conceptualisation of future studies can

be traced to the work of Toffler (1970) and Polak (1961) and their focus on rate of change and images respectively (Bell, 1997; Masini, 1994). Futures studies have extended focus from the temporal dimension to include spatial (Hicks, 2006) and spiritual dimensions (Sarkar, 1991). In addition to this shift has been an expanding interest in the concept of choice between a range of alternative futures and the concept of emergent futures—those that are unlikely to occur but would have great impact if they did (Dator, 1990). The concepts of choice and emergence invite questions about the relative contribution of structure versus personal agency in shaping the future. These questions, raised in the context of futures studies, are critical to this research—particularly to the examination of critical and collective empowerment.

Masini (1994) argues that the **only** place we can influence reality is in the future, but that such efforts give rise to tension between knowledge of reality and the desire and fear associated with an unknown future. Sarkar (1991) refers to variations in the level of reality, in perceptions of reality and in the quality of the images that emerge as part of experiencing each layer. Lived experience is highly regarded in the disability field as a source of information (Thibodaux, 2005). Understanding the impact of the images and perceptions of reality as part of that experience, be they constraining or liberating, may signal how the NDIS may unfold.

Dervin (1999) suggests that the place of tension between perception of reality and the desire and fear associated with an unknown future is a rich source of possibility—the place where meaning can be made of chaos and uncertainty. Bussey (Bussey, 2011) opens his article on Microvita and Transformative Information with a quote that confirms this place of tension is a rich field for study: "it was the sense that the whole universe was alive, and that everything was connected to everything by threads of meaning" (Pullman, 2000), p. 473).

Masini (1994) also refers to French futurist Gaston Berger's framing of futures thinking as bringing together the knowledge of past and present with the capacity to imagine and the will to act as useful. Gaining insight into how people with disability and their families and service providers interpret their past and present experience and their level of agency over the future is the subject of this research. While the NDIS brings promise of choice and control over lived experience, Godet (2006) reminds us

that the willingness to act and to take responsibility for the impact of our actions on the future is also a choice.

### 1.1.3 Using CLA to Unpack Multiple Futures

Inayatullah (2015), in reflecting on 14 years of practice using his Causal Layered Analysis (CLA) methodology (described later in Chapter 3), says:

> CLA has increasingly focused not just on the mapping of the external world but also on the mapping of the self. The intent has been double. First, to ensure that practitioners of foresight and/or of critical futures research are aware of their own worldviews and myths. Second, for those in workshops—whether young students, civil society leaders, government policy-makers or corporate executives—to explore their own double binds and to use CLA as a way to transform their own life stories. (Inayatullah, 2015, p. 13)

Inayatullah (2015) was significantly influenced by the work of Jungian psychotherapists Hal and Sidra Stone (1989). The central premise of their work was that we are all born vulnerable and that our personality develops as a product of how we protect that vulnerable inner-child. A multitude of selves develop in response to our experience of being rewarded or punished for certain behaviours as we grow. They refer to our primary selves or ego as the window through which we see the world, selves that are invisible to us unless we discover the range of disowned selves that obscure the ego. Inayatullah (2015) associates this discovery with the process of revealing and deconstructing current reality that is necessary to open up future possibility.

Over 30 years of practice, CLA has become both theory and process for transformation. Developed in the 1980s as a four-layered process for mapping the external world—the discourses, the worldviews, assumptions and underlying myths, metaphors and images—CLA has become a valuable tool for mapping self-transformation. By revealing the multiple layers of self and exposing the vulnerable self the path is opened for individuals to not only see but integrate their multiple selves.

Given the focus of this research is on whether vulnerability can co-exist with the power to anticipate and shape the future, CLA has been used as both theory and process for this research. Inayatullah (2015) deliberately situated CLA in the work of

Hal and Sidra Stone in order to challenge a single view of reality; he wanted to open up the idea of multiple possible futures by introducing multiple lenses (or selves) through which reality—past, present and future—could be viewed. Not only does such a process allow an objective view of multiple layers but it allows the complexities and contradictions to be viewed and examined. In the disability sector such contradictions and dualities are readily apparent, for example the community as welcoming and inclusive versus the community as dangerous.

It is Inayatullah's (2015) view that the opportunity to examine such double-binds and discern whether they are helpful or constraining is an essential part of anticipating and shaping one's future:

> The challenge, as with all foresight work, is to move from fragmentation to the preferred future, the integrated way forward. By identifying the issues (the internal research question) and the double binds that restrict their solutions, individuals create alternative maps of their consciousness and then move toward a new metaphor, a new life narrative, and consequently an alternative future. (Inayatullah, 2015, p. 14)

### 1.1.4 The Concepts of Vulnerability and Power

The concept of vulnerability has been explored in the literature with regard to its origins (Alwang, 2001; Bankoff, 2003; Stone, 1989) and its manifestations (Brown, 2013). Bussey (2014c) suggests that vulnerability is what keeps us in relationship with others and connected to what matters in our lives. He also suggests that this identity of vulnerability reflects a culture created by patterns and interpretations of past experiences, which make their way into discourse and constrain our ability to dream a different future (Bussey, 2014b).

Perhaps surprisingly, the language of vulnerability is less evident in the conversation of people with disability and their families than in the discourses of policymakers and advocates. Similarly, the language of abuse, neglect, poverty and socio-economic disadvantage is rare in the conversation of people with disability and their families. The use of CLA in this research is expected to offer insight into why this connection is hidden or absent for people with disability and their families. If, as Bussey (2014c) suggests, vulnerability keeps us connected to what matters in our lives, its absence may prove to be a constraint to imagining and shaping the future. If

a vision or range of possible futures is important for taking action today, a lack of acknowledgement of vulnerability may also constrain choice-making today.

Subsequent sections of this thesis focus on the nature of power and what it takes to imagine and create alternative futures. While vulnerability is less a feature of conversation for people with disability and their families than it is for other stakeholders, power is more readily acknowledged as significant across stakeholder groups.

Choice and control, as described in the NDIS, are suggestive of empowerment of people with disability. However, the discourses across all stakeholder groups included in this research reveal a clear perception that power resides with structure rather than with the individual or collective. This research has explored how power plays out across the stakeholder groups and its role in shaping futures for people with disability.

The target group for this research was people who have a physical and/or sensory disability, have a family member or friend with a disability (including people with a physical and/or sensory disability), people who work with people with disability (either directly or indirectly, such as through management or policy development roles), and advocates and others who identify as being from the disability sector and can be reached through a certified disability service provider agency. A small number of certified disability organisations were invited to distribute an invitation to their service users, staff and other stakeholders. The invitation was to attend a CLA-based workshop with the option of participating in a one-on-one interview.

## 1.2   The Research Subject

The policy framework for the NDIS reveals a potential contradiction between: (a) people with disability as vulnerable and in need of protection (Commision, 2011; Council, 2009) and (b) people as capable of making and giving effect to their own decisions about their future (www.ndis.gov.au). It is important to better understand the tension between these positions as it reflects the tension between personal agency and structure that is inherent in all social service systems. There has been some urgency to this research, as being able to shape one's own future is a key outcome

expected from the scheme, with the transition occuring between 2016 and 2019 (www.ndis.gov.au(NDIA).

The NDIS is a social insurance scheme, approved by the Council of Australian Governments on 7 December 2012, and will replace the current state-based funding system by 2019.  It is a significant social reform, similar in scale to the Medicare reform introduced in 1975.  It offers the opportunity for individuals to manage their own disability funding, based on a plan which documents personal goals and agreed, costed supports and equipment.   The stated goal of the NDIS at a scheme level is to maximise the social and economic participation of people with disability, with individual choice and control over what, where and when supports are provided central to system design (www.ndis.gov.au). As stated on the Every Australian Counts website:

> The National Disability Insurance Scheme (NDIS) is transforming the way disability supports are funded and delivered. The NDIS puts people with disability at the centre of the system for the first time—allowing them to determine their own future and receive funding which matches their needs and aspirations. (everyaustraliancounts.com.au)

The national Every Australian Counts organisation campaigned successfully for full implementation of the NDIS, largely based on an economic rather than social policy argument.   While vulnerability associated with lack of access to support services was a feature of many stories used early in the campaign it was not ultimately a dominant part of the discourse.  The more dominant messages in the campaign were the cost savings to government and community through income taxes paid by people with disability and their carers entering or re-entering the workforce as a result of having their disability support needs met.  The tension between social and economic drivers of the NDIS remains unresolved.

The above quote also positions "determining one's own future" as dependent upon receipt of funding, further amplifying the tension between personal agency and structure; the individual may be encouraged to make choices, but the power to give effect to those choices is linked to funding, and thus resides with the funder and funded service provider organisations.

For people with disability and their families, this dynamic represents a repeat of past experience and does little to address the disempowerment and vulnerability

associated with being reliant on others to have disability support needs met. Given perceptions of past experience and anticipation of the future have potential to either inspire or constrain present behaviour (Bussey, 2014a; (S. M. Inayatullah, I, 2015), research to explore the impact of vulnerability on power to anticipate and shape one's own future is both timely and necessary.

## 1.3   Research Questions

The purpose of this research was to explore the relationship between vulnerability and power to influence the future, using a futures studies frame, in the policy context of the NDIS.  Specifically, this project explored the following research questions (RQs):

RQ1:   How do stakeholders interpret "reality" with regard to disability, vulnerability and power to influence the future?

RQ2:   How does power play out across stakeholder groups when considering the future for people with disability?

RQ3:   How does the opportunity to deconstruct "reality" for people with disability open the path to multiple futures?

Leading authors in the disability field, such as Wolfensberger (1972), Kendrick (1994) and Robinson and Chenoweth (2012), locate vulnerability in the historical view of people with disability as less than human; therefore, not worthy of the respect and protections against abuse and neglect afforded other human beings.  Stories and perspectives submitted to the *Shut Out* report (National People with Disabilites and Carer Council, 2009) and the Productivity Commission report on long-term disability care and support (2011), confirmed many people with disability and their families perceive the experience of having a disability, in the absence of adequate supports, as negative.

Gestalt psychotherapists Hal and Sidra Stone (1989) and vulnerability researcher Brene Brown (2013) frame vulnerability in quite different terms.  Both describe vulnerability as part of the human condition—often disowned but always present.  Brene Brown (2009) describes vulnerability as the source of courage, while Hal and Sidra Stone describe the vulnerable self as one of many selves that need to be examined if we are to understand the subconscious myths and metaphors that shape our experience.

For people with disability, Wolfensberger (1972) has a less benevolent description of vulnerability—that which is associated with exploitation and harm by a system and community that define people in terms of "the other".  Clapton and Fitzgerald (1997) similarly describe people with disability as marginalised even by

the marginalised.  In both cases people with disability are seen as subject to the power exercised by a system that defines people by their impairment rather than other attributes.

The NDIS discourse to date has failed to address vulnerability or acknowledge its potential impact on choice-making or the ability to give effect to decisions made. This research aims to examine the way people understand the constructs of disability, vulnerability and power to anticipate and shape the future.  It is anticipated that by revealing and allowing stakeholders the opportunity to reflect on the patterns and connectivities between the concepts of vulnerability, disability and agency over the future—if indeed they exist—it may be possible to unlock an otherwise constrained set of alternative futures for people with disability.

Workshops and one-on-one interviews were undertaken with people with disability, family members, service providers and interested others from the disability sector, using CLA and a sense-making process as both theory and process

The implied promise of the NDIS, a national social insurance-based policy reform, is that people will have the opportunity to exercise greater choice and control than they have had in the past and, by doing so, open up a broad range of possible futures for themselves.  The NDIS narrative, however, positions "determining one's own future" as dependent upon receipt of funding, amplifying the tension between personal agency and structure, inherent in all social service systems.  The individual may be encouraged to make choices, but the power to give effect to those choices is linked to funding and thus resides largely with the funder and funded service provider organisations.

The broader context for the NDIS policy reform is a disability sector whose discourses range from disability as a personal tragedy to disability as a social construct, and a history of social change driven by images of vulnerability to poverty, harm and exploitation.

There is currently insufficient research on the connection between vulnerability and being able to imagine and shape one's future to know whether disability discourse and past social change efforts will enable or constrain transformation.  There is, however, sufficient research to suggest that the ability to generate positive images of a

future not yet experienced is an important element of transformation at both individual and societal levels (Boulding, 1995).

## 1.4   Emerging Questions

Both literature review and the author's policy and practice experience gives rise to a range of questions to be explored in this research

1.  Given the impact of disability and vulnerability discourses on both service system and individual identity, how readily will people adjust to the reframing of future possibility offered by the NDIS?

2.  Will stories of lived experiences of navigating the service system sit awkwardly with promises of choice and control offered by the NDIS?

3.  If power is contextual then what shifts in power relations will flow from NDIS, as a new context, for the various stakeholders—people with disability, their families, their service providers?

4.  Is it possible for the vulnerability associated with disability, projected or denied, to co-exist with power to shape the future?

5.  Will people be able to generate the positive images of the future needed to imagine something other than what they have experienced?

6.  Will people be able to not only imagine alternative futures but make and give effect to those decisions that will bring such imaginings to life?

# Chapter 2: Literature Review

## 2.1 Theoretical Considerations: Mapping Disability, Vulnerability and the Power to Shape the Future

Given the context for this research was the implementation of a major disability policy reform, the literature review commences with an exploration of how disability is understood, both in the context of lived experience and the dominant discourses evident in the literature, policy and practice. The shift from disability defined as personal tragedy (an unfortunate chance event) to social construct (externally generated by an inaccessible community) has been largely academic, with people with disability arguing such discourses objectify and constrain the experience of disability (Murphy, 1990; Oliver, 1990). Similarly, the shift from minimal choice and control pre-NDIS to the promise of empowerment and choice post-NDIS is likely to yield a mixed experience as the transition occurs. How do people with disability, their families and service providers adjust to the external reframing of their position in the social service system under the NDIS? How do they reconcile past experience with future promise?

Vulnerability, whether openly acknowledged or denied, has been a common element of discourse and lived experience for people with disability and their families, and was a key message in the early stages of the campaign for reform. The next section of the literature review explores the nature and impact of vulnerability in an attempt to understand its relationship with anticipating and shaping one's own future. The disability literature and the stories of lived experience of people with disability and their families suggest the NDIS narrative of powerful self-determination and social change driven by individuals and their families may sit awkwardly with stories of vulnerability to poverty, harm and exploitation that have successfully driven social change. To what extent does vulnerability associated with impairment co-exist with power to anticipate and shape the future? Do the negative images of vulnerability generated as part of the social change movement in the disability sector motivate or constrain the imagination and creation of multiple possible futures? How relevant is the generation of images in creating futures not yet experienced anyway?

There have been enough stories of lived experience in the Productivity Commission Inquiry and associated public submissions to understand that power for people with disability and their families is contextual. A powerful disability advocate in one context can find themselves powerless in another, for example on admission to a health facility. The third section of this chapter therefore examines the nature of power in the disability sector—both power *to* and power *over*. How do people with disability and their families generate and use power to get what they need from a complex, rationed service system and at what personal cost?

The final sections of this chapter aim to better understand the implications of how we view the constructs of power and vulnerability in the disability context for the individual and collective transformation promised by the NDIS. To what extent do the negative images of disability generated early in the NDIS campaign support or constrain people making and giving effect to decisions about an uncertain future?

## 2.2   Section 1: Disability Discourses

The NDIS narrative reframes what it is to have a disability and what it takes to obtain supports that meet individual needs. Eligibility is determined by impairment (both diagnostic and functional), context (existing social and physical supports) and, until recently, aspiration (dreams for the future). To obtain supports required, individuals need to engage with a state-controlled planning process in the expectation of receiving a prescribed amount of funding to pay for "reasonable and necessary" supports. Underpinning this process is the expectation that people will not only make choices, within specified parameters, but have power (control) to give effect to those choices.

While the NDIS exists largely because of the stories of lived experience of people with disability and their families, the voice of people with disability is largely absent from the current NDIS narrative. For more than 30 years, people with disability have challenged the dominant disability discourses as poor substitutes for an "insider" perspective (Kumari Campbell, 2009; Murphy, 1990; Oliver, 1990) and it appears the NDIS is no exception.

Paul Abberley (Abberley, 2002) describes discourse as a set of interrelated concepts being employed in an attempt to understand the social world and ultimately to govern paths of action that seem to be open to us. Ivana Milojević (2015) suggests

the impact is much deeper, reflecting worldviews at both the individual and societal level, which tell a deeper story about human experience. Oliver (1990), in the context of social service delivery, goes further to argue that not only do definitions and language drive practice but they shape how people with disability view themselves and what's possible.

Discourse has the potential to both open up and close down possibility for action (Barnes, 2002). Bourdieu (Bourdieu, 1991) agrees, arguing that language and the stories we tell ourselves and each other about who we are have a significant role in upholding and legitimising power structures in any given context. Such stories also reflect an optimistic or negative outlook on the future.

The examination of disability discourses in this section was used as a context for considering perceptions of current and future reality by a range of stakeholders. Discourse has become a critical element of futures-based work, both for its potential to reveal hidden assumptions, worldviews and identities that constrain future possibility and as a tool for reframing one's story (Milojevic, 2015). For the disability sector, as the NDIS unfolds, revealing and retelling the story will be critical for transformation at both the individual and societal level.

This section commences with a reflection on normality discourse and its associated story of "othering". The "othering" or marginalisation of people with disability and their families, made visible through the *Shut Out* report (National People with Disabilites and Carer Council, 2009) and Productivity Commission report (2011), provided a strong catalyst for the NDIS. However, some of the manifestations of "othering"—singularising, classifying and separating—are still clearly evident in the policies and processes of the NDIS and could be argued to be a source of vulnerability rather than its remedy.

### 2.2.1 Normality Discourse

> How societies divide "normal" and "abnormal" bodies is central to the production and sustenance of what it means to be human in society. It defines access to nations and communities. It determines choice and participation in civic life. It determines what constitutes "rational" men and women and who should have the right to be part of society and who should not. (Meekosha & Shuttleworth, 2009, p. 65)

The concept of "normal" emerged early in the nineteenth century, in parallel to the concepts of "abnormal" and "corporeal deviance" (Shakespeare, 2014; Thomson, 2009). Disability was assigned to the darker side of this dichotomy, as evidenced by the rise of asylums of the late nineteenth and early twentieth centuries, which were focused on protecting the "normal" from exposure to the "deviant", rather than providing care or sanctuary. While there was evidence of classification of deviancy, there was no evidence that such classification was used as the basis for intervention or care. The earlier work by medical psychologist, Edouard Seguin, in the mid-1600s (Simpson, 1999) on defining idiocy, may have informed the vocabulary of that period in time, but his approach to improving function through muscular, sensory and intellectual training was not adopted as a feature of institutional care.

Clapton and Fitzgerald (1997) describe the story of people with disability in recent history as the story of "otherness", a story of marginalisation, even by those who are themselves marginalised. As they argue here, this can lead to layers of marginalisation in which degrees of otherness come into operation:

> Bodily difference has for centuries determined social structures by defining certain bodies as the norm, and defining those which fall outside the norm as 'Other'; with the degree of 'Otherness' being defined by the degree of variation from the norm. In doing this, we have created an artificial 'paradigm of humanity' into which some of us fit neatly, and others fit very badly. Life outside the paradigm of humanity is likely to be characterized by isolation and abuse. The story we have recorded of the lives of people with disability is a story of life lived on the margins. For people with disability, their history is largely a history of silence. The lives of people with disability have not only been constructed as 'Other', but frequently as 'the Other' of 'the Other'. People with disability are marginalized even by those who are themselves marginalized. (Clapton & Fitzgerald, 1997, p. 32)

Clapton and Fitzgerald (1997) captured well the ground-breaking work of Wolf Wolfensberger (1972), who introduced the disability sector to the concept of "othering" and its manifestation for people with disability as being treated as less than human. While his early responses were to prosecute cases of abuse and exploitation in the 1960s and 1970s, his remedy of "normalisation" and its more recent framing of "normalisation" as social role valorisation have profoundly influenced both critical thinking and practice in the disability field internationally.

### 2.2.2 Moral Model Discourse

As focus on the economic benefits of people being supported to participate in the social and economic life of the community increased, so too did notions of the "deserving poor" become a feature of the moral discourse.

In parallel to the emergence of the normal/abnormal dichotomy, was the emergence of the *moral model,* which had its origins in religious mythology. Disability was viewed as a sin requiring concealment of the individual to avoid shame (Scheerenberger, 1983). More recently, but perhaps just as significant in shaping the lives of people with disability in the Western world, is the *moral underclass discourse,* which justifies exclusion from society on the basis of moral and behavioural delinquency (Levitas, 1998). While it has largely been overshadowed by the social model, which positions disability as a social construct, its impact can be seen in notions of the deserving poor which have quietly influenced our social and economic policy.

### 2.2.3 The Medical Model Discourse

Just as the moral discourse has continued to show up in public policy, so too has the medical model of understanding and responding to the needs of people with disability. Despite much criticism by disability studies academics, practitioners and advocates, another model still implicit in both our education system and social service system is the *medical model* of disability. This model frames disability as the result of individual pathology and rests the responsibility for remedy with the individual rather than with society in general (Bury, 1996).

The medical model locates disability in an institutional context, where health professionals have power *over* individuals through surveillance and the capacity to give or withdraw human contact and life-giving support, similar to the experience of prisoners in correctional facilities (Foucault, 1997). In these contexts, the rhythms and routines of daily life, access to visitors, food, medication and recreational activities, and the freedom to be independently mobile, are often constrained or managed by authorities in the best interest of individuals and families (disability) or of society (prisons).

According to Oliver (1990) and Chenoweth (L. Chenoweth, 2006) this paradigm has almost single-handedly driven the specialised service system for people

with disability, resulting in people's lives being shaped by professionals rather than being self-determined. Norwich (Norwich, 2007) asserts that the marginalisation of people with disability has not only been apparent over time but across cultures, defying opportunities for reform.

A recent analysis of the literature relating to abuse and neglect of people with intellectual disabilities in residential settings indicates that, even where choice and control is shared with individuals, it focuses on day-to-day decisions rather than significant life decisions about who to live with and preferences for support (Robinson, 2012). The authors conclude that not only do such arrangements fail to support meaningful choice and control by people with disability and those close to them, but contribute to the conditions where abuse and neglect occurs.

While widely criticised by academics as outdated, the medical model has significantly impacted on the lived experience of people with disability and their families and remains a dominant driver of social service provision in Australia. With the positioning of professionals, particularly medical professionals, as the primary source of authority, persistence of the medical model is a significant threat to transformation both individually and collectively.

### 2.2.4 Educational Discourse

The experience and impact of exclusion of people with disability is nowhere more evident than in our educational institutions. The internalisation of labels and negative images of the future in the formative years actively promotes identities of passive recipient and "other" (Milojević, 2013; Peters, 2010). Many of our educational institutions still view students as "vessels to be filled" and pathologise those unwilling or unable to conform. The processes for gaining support for participation still largely rely on documented diagnosis and assessment of levels of impairment rather than exploration of optimal learning conditions for the individual. All such processes are a legacy of the medical model.

Dan Goodley (Goodley, 2011) draws on the ideas of Michel Foucault in suggesting that the ongoing practice of labelling children as impaired in the education system not only describes but constructs children as objects. Tremain (Tremain, 2005) is careful to point out the distinction between Foucault's notion of disciplinary power, which can be productive, for example, providing access to support services,

and his conception of sovereign power which is oppressive. Notwithstanding the benefits of diagnosis in accessing support, labelling is considered to be one of many ways professionals in the disability field, both in and out of institutional settings, disempower and alienate people with disability (Robinson and Chenoweth, 2012).

Freire (1993) describes language as a cultural/political act when used with awareness and intention to transform reality at a personal and societal level. His pedagogical framework, *conscientisation,* was based on "learning to perceive social, political and economic contradictions, and to take action against the oppressive elements of reality" (Freire, 1993). While Freire's seminal research was with illiterate peasants in Brazil, there are parallels both to the oppression of people with disability through language and potential for greater agency through education.

## 2.2.5 The Social Model Discourse

Social models of disability are distinguishable from the medical model in that the basic determinant of disability is viewed as social rather than biological. Proponents have successfully shifted attention away from individual experience of impairment to the societal constraints of physical access, language, culture and discriminatory discourse (Barnes, 2002). The social approaches also shifted the discourse from disability as a "personal tragedy" to being a consequence of barriers created by society. This shift has largely informed the collective view that people with disability are socially oppressed, victims of communities that fall short of accommodating their members. For some this gives rise to anger which propels them to transformative action, for others it amplifies marginalisation and "otherness". Either way, the shift to a social model of disability and its attention to disabling environments opened the path for discrimination legislation and a focus on rights (Shakespeare, 2014). The rights-based model, which conceptualises disability as a socio-political construct, has subsequently emerged. While this model has equipped activists to adopt the strategies of influence used by other social movements, it still relies on perpetuation of an identity based on belonging to a minority group (Clapton, 1997).

It is debatable whether the identity of an oppressed minority is an essential ingredient for effective social movements. Shakespeare (2014) suggests that the social model has not consistently been a driver of progress for the disability movement in Western countries and may, in fact, create as many problems as it

solves. Specifically, he considers the swing from disability as a "personal tragedy" to the extreme view of disability as a consequence of "social oppression" as oversimplifying the complexity of lived experience with disability. Vehmas (Vehmas, 2012) also cautions against oversimplifying:

> The human world is an interpreted, construed world. Yet it would be intellectually and politically disastrous to conclude that impairments are not primarily or even secondarily physical facts and that nothing exists until it is spoken or written about. (p. 299)

While potentially a useful response to the "othering" and "marginalisation" phenomena, this discourse risks perpetuating rather than addressing the need for people to identify as part of a minority group. The shift from disability as an individual problem to a social construct has been an important platform for rights-based action and policy reform, including the NDIS. It is not yet clear whether this discourse ultimately enhances or constrains an individual's perception and experience of self-determination.

### 2.2.6 Cultural Disability Discourse

The cultural disability discourse is a variation on the social model, with recognition of the impact of individual impairment. Davis, for example, describes disability as "not so much the lack of a sense or the presence of a physical or mental impairment as it is the reception and construction of that difference" (Davis, 2002, p. 50). It involves consideration of disability as a construct from multiple perspectives—gender, peace, globalisation, policy and many more.

Fiona Kumari-Campbell (2009) and Helen Meekosha (Meekosha, 2008) also move away from a binary conceptualisation of disability, arguing instead for an understanding of power relations associated with imagery, symbolism and the politics of incapacity. Kumari-Campbell defines *ableism* as a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then, is cast as a diminished state of being human (Kumari-Campbell, 2009).

Perhaps the greatest contribution of this discourse is that, as the name suggests, it invites viewing and conceptualizing disability from a range of cultural perspectives,

including those that challenge the stereotypes. Meekosha (2008), in her keynote address to a disability studies conference at Lancaster University in the UK, argued for analysis of the power relations between the global north and the global south which produce and profit from disability. She challenged the dominant paradigms in disability studies by drawing attention to the impact of colonisation and violence perpetrated in the non-industrialised regions of the world on the experience of disability. She points to the issues of health care, education and employment in undeveloped countries as receiving very little scholarly attention and reminds readers of the role of global politics in keeping poor nations poor. In Australia, people with disability are more likely to experience poverty, poor health outcomes, homelessness and incarceration in association with having a disability (French, 2007).

### 2.2.7 Citizenship Discourse

Barnes et al. (2002) describe citizenship as one of the central organising features of Western political discourse and it is implicit in the purpose of the NDIS—to maximise social and economic participation in society. It is a useful framework in which to consider the denial of social, political and civil rights to people with disability. These include the right to vote, the right to have basic needs met, the right to safety and sense of wellbeing. Denial of these rights is to take away the power citizens have to shape or reshape their current and future reality at both personal and societal levels.

Jensen and Phillips (Jensen, 1996) define citizenship as a dynamic relationship between three dimensions—rights and responsibilities, access and belonging. Max-Neef (Max-Neef, 1992) provides a more comprehensive framework of human need to consider including the right to education, access to health and housing services, and social and economic security. Rioux (Rioux, 2002) suggests people with disability lack both the right and capacity to give effect to these rights and ultimately trade rights for charity. Examples of such compromise at an individual level may include joining a designated, segregated school or sporting group, or co-habiting with strangers with disability.

The reframing of intervention from professionals working "with" rather than "for" people with disability noted in the literature suggests greater equality than actually exists. It suggests a level of autonomy in decision-making and opportunity to

make "risky" choices that is misleading (Apsis, 1999). Apsis (1999) suggests that most of the decisions made by people with intellectual impairment are of a minor nature and rarely challenge the comfort and convenience of the service provider. She also reminds us that the rhetoric around working with individuals in *partnership* is also reflected in the funding relationship between government and non-government agencies. While language of partnership is often used, there is little doubt as to who holds the balance of power in the relationship (Shakespeare, 2014; Kumari-Campbell, 2009).

The last 12 months of NDIS transition (2016–2017) has seen a further, unexpected change in narrative. The National Disability Insurance Agency (NDIA) has struggled to manage the volume of people presenting, choosing to remove discussion on personal aspirations as part of the initial planning process. The remaining areas of focus—existing supports and level of need—potentially reduce individual planning to a funding administration/resource allocation process, rather than the promised tool for individual transformation.

That there has been minimal resistance to this change reported in the media or through consumer networks and peak bodies is surprising. It may be a reflection of cynicism that the NDIS was ever about genuine transformation or it may be that, collectively, we need to develop a new story to underpin the NDIS. In doing so, we need to address a fundamental dilemma—the NDIS assumes the individual is capable of re-imagining their future.

Table 1 provides a summary of the disability discourses found throughout the literature review.

**Table 1**: Summary of discourses

| Discourse | Key Elements |
| --- | --- |
| Normality | • Division of normal and abnormal at its core<br>• Response based on protecting the "normal" from the deviant<br>• Beginnings of "othering" |
| Moral model | • Religious origins<br>• Disability requiring concealment<br>• Emergence of "deserving poor" |
| Medical model | • Disability the result of individual pathology<br>• Health professionals with power *over* individuals "in their best interests"<br>• Dominant driver of modern service system |
| Educational | • Students as passive recipients "vessels to be filled"<br>• Support dependent on diagnosis and level of impairment assessed by experts<br>• Often primary experience of exclusion for people with disability |
| Social model | • Disability seen as social rather than biological<br>• Shift from disability as personal tragedy to societal responsibility<br>• Generates expectations that public policy and infrastructure will be accessible and inclusive |
| Cultural | • Invites viewing disability from multiple perspectives including gender, power, politics<br>• Global perspective<br>• Provides context for understanding poverty and poor health and other socio-economic outcomes |
| Citizenship | • Equates citizenship with social and economic participation<br>• Raises issue of rights being traded for charity<br>• Denial of rights denies capacity to shape current and future reality |

## 2.3    Section 2:  Vulnerability

Common to disability discourses, described in the previous section of this chapter, is the duality of individual attributes versus external factors as causative. Vulnerability discourses depict this same duality. Such discourses shape the debate and worldview from which the NDIS has emerged.

This section examines the relative impact of vulnerability as an individual attribute versus externally imposed phenomena. An exploration of vulnerability denied or projected follows, along with consideration of the implications of vulnerability on capacity to re-imagine the future.

Vulnerability is a term widely used by a range of policy, research and practice fields (Gorur, 2015). Thus, Gorur (2015) notes:

> How the abstract concept of vulnerability is understood, conceptualised and measured is of serious consequence to policy development, to those classified as 'vulnerable' and to those who are not. For example, if vulnerability is seen as an individual attribute, the target of intervention is the individual, and policy remedies might include attempts to increase the skills, capacities or outcomes of individuals. If, on the other hand, vulnerability is seen as the consequence of a complex, inter-related set of circumstances external to the individual, the targets of policy interventions might involve those external factors that are deemed to cause vulnerability. (p. 3)

Vulnerability of individuals with disability to abuse and neglect, and the failure of the system to keep people safe, were both drivers of the NDIS campaign. The scheme itself, however, focuses heavily on remedy through funded external supports, aids and equipment. Safeguards in the NDIS are about service quality and administrative appeal, with little focus on strengthening individual skill and confidence to navigate systems and the community as a safeguard.

Some definitions of vulnerability focus on the risk caused by various social, economic and political factors (Alwang, 2001; Bankoff, 2003), while others focus on the outcome or consequences of vulnerability, such as poverty, violence or homelessness. The main difference between the two approaches is that one focuses on external causes of vulnerability, while the other locates vulnerability as an individual attribute. Such differences not only drive different policy responses but different ways of measuring their impact. Income variance or risk of poverty is a

convenient benchmark but it fails to account for the complexity of causative factors (beyond economic factors) or the diversity in the individual experience of vulnerability (Gorur, 2015).

As outlined in the previous section, multiple discourses are evident in the literature, in public policy and in the stories of lived experience by people with disability and their families. These discourses reflect a range of assumptions and worldviews about the nature of disability, the power dynamics associated with it and the capacity for transformation. They also carry assumptions and worldviews, often hidden, about the nature of vulnerability associated with having a disability.

Some of the discourses focus on the tension between disability as individually (internally) or socially (externally) constructed, while others reflect broader gender, political and cultural considerations. Accordingly, the source and nature of vulnerability as part of such discourse is also contentious. Shakespeare (2014) gives voice to this tension:

> There is deep resistance in the disability studies field to seeing people with disability as vulnerable. On the positive side, this thinking reflects the assumption that rather than individualizing problems, they should be seen as arising in particular contexts, which create vulnerability. On the negative side, there is a resistance to giving due weight to impairment, or to recognizing the real differences between, for example, people with learning difficulties and non-disabled people. (p. 232)

Robinson and Chenoweth (2012) argue the consequences of vulnerability, suggesting that people with disability are more likely to be living in residential institutions and that rates of abuse and violence are higher than in community settings. Even in community settings, people with disability are more likely to be living in outer suburbs where housing is cheaper, public transport less available and social isolation more likely. Risk of financial or sexual exploitation, theft and violence is also higher and likelihood of prosecution lower, though these risks are mitigated by the presence of enduring relationships with family, friends and neighbours (Gravell, 2012). Gravell (2012) suggests strengthened protection and support from community service providers, safer public spaces and greater civic mindedness in the community can mitigate the risk of harm to people with disability.

For people not living in residential (custodial) living arrangements, vulnerability is associated with poverty and the many barriers to accessing training, jobs and home ownership. People with disability are more likely to be unemployed, to be living in poverty, to be assaulted, have poorer health outcomes and to be homeless than people without a disability (French, 2007). The resistance amongst academics to seeing people with disability as vulnerable, as noted by Shakespeare (2014), is perhaps why the construct is so poorly understood in the public policy context. Investment in social service provision is considered the responsibility of the state towards its most vulnerable citizens, yet funded external supports, aids and equipment are the primary intervention. There is little investment in the community development and individual capacity building needed to strengthen safeguards against harm.

Both past and present disability service provision has required eligible individuals to demonstrate sufficient deficit to qualify for services. Access to services is based in some part on diagnosis, age and level of support need and in significant part on availability of resources. Individuals are required to demonstrate their vulnerability, in full knowledge that resources are limited and provided at the discretion of the state and the service providers they fund. The NDIS differs in that it is referred to as an entitlement-based system, meaning eligibility and a sufficient level of need should reasonably be expected to qualify one for supports.

While there is little reference in either the academic literature or in the everyday narrative of the disability sector to vulnerability it is likely that vulnerability to harm is a combination of individual and contextual factors. While the individual experience of vulnerability varies from one person to the next, it is the perception of vulnerability that informs policy and program design. The NDIS is an example of a policy response that assumes funded supports are the best way to address the disadvantage associated with impairment. It doesn't directly address the poverty experienced by many people with disability, nor does it address the structural barriers to training, employment or finding a home. It does, however, attempt to target supports to the individual and family in such a way that they can participate in the social and economic life of the community in order to achieve a good life.

At an individual level the work of gestalt psychotherapists Hal and Sidra Stone (Stone, 1989) suggests that vulnerability, whether we acknowledge or deny it, is a major driver of our identity, our behaviour, our relationships and our experience of

life. The need to protect the "vulnerable little person" of our childhood is seen as the trigger for the development of various identities we inhabit over our lifetime, and failure to integrate these identities as a common source of pathology. Our level of awareness of these identities, and the degree to which we have control over them, is considered to be dependent upon whether we embrace or deny the vulnerable state from which they originated (Stone, 1989). Throughout this research evidence of people—those with disability, their families and their service providers—denying or projecting vulnerability is apparent.

Milojević (2013) suggests the point in time at which identity is established is also the point at which "othering", a source of vulnerability to violence, occurs. It is the point at which separation of self from others extends at the group level. The extent to which "othering" ultimately occurs depends on the perceived degree of difference between self and others (Milojević, 2013). Clapton and Fitzgerald (Clapton, 1997) describe people with disability as the "other" of the "other", defining "otherness" by the degree of variation from the norm. This is highly significant, as access to services is determined by level of support need; that is, the degree of variation from the norm.

Brene Brown (2013) and Hal and Sidra Stone (1989) suggest that projection of vulnerability onto others—that is, suspending and redirecting our own vulnerability—may be a means of protecting the vulnerable self. People with disability or other disadvantage, such as poverty, mental health issues and homelessness, are obvious targets for such projection. Levinas, as cited in Davis (2004) suggests that projecting vulnerability, or labelling others as vulnerable, may protect us from needing to acknowledge and deal with our own vulnerability, but that it also limits genuine compassion and acts as a barrier to collaboration.

While the literature suggests vulnerability is one of the defining characteristics of being human (Brown, 2013; Stone, 1989) it is not perceived so generously in our social service system or in our community more broadly. Images of vulnerability, such as those associated with abuse, neglect and victimhood, are still used in the media, in professional development and in human service design as a lever for influence and as the basis of demand for social service delivery (Kevin Cocks, personal communication, 15 June 2015) Such images help shape the motivation, behaviour and identity of people who work in the disability sector, and may enable

and strengthen the separation between service user and the professional who takes "care" of them (Oliver, 1990).

As the implementation of the NDIS proceeds, an examination of the perspectives on vulnerability by the various stakeholders is timely. While images of abuse and neglect at the hands of institutional custodians generated in the media have been a strong driver for the NDIS, the metaphor of "life's a struggle" and the worldview of people with disability as "child-like and vulnerable" are hardly compatible with the NDIS promise that individual choice-making and control of financial decisions will be commonplace. Similarly, the enduring expectation that the state *takes care* of its most vulnerable citizens is at odds with the concept of individuals being capable, confident and empowered enough to manage their own affairs. The worldview that services will always need to balance the needs of individuals with the need for financial sustainability, compromising if necessary, challenges the underlying narrative of services as totally altruistic.

## 2.4   Section 3:  Power to Influence

In order to understand the relationship between vulnerability and power in the disability context it is important to understand how power has played out historically for people with disability.

One of the great thinkers on power, Foucault (1972), was interested in the way power plays out in society, shaping our social institutions and worldviews along the way. He was interested not only in the overt use of coercive power by individuals but in the structures that constrain individuals, even when they appear to be neutral and independent. He was one of the first to identify the power of discourse in enabling or constraining individuals (Merquior, 1991). He was most interested, however, in the idea that power is ever present, not inherently good or bad, but a phenomenon to be examined and understood.

Panopticon, a central concept of Foucault's (1995) philosophy has relevance to the disability sector, particularly with regard to institutional settings of care which are still in evidence, though on a smaller scale, today. With origins in the prison system, panopticon refers to the combination of architectural design and optic effect that allows for constant surveillance of every inmate by an anonymous custodian. It is

about seeing without being seen and is a powerful force for discipline without requiring physical force.

This particular type of power is asymmetrical and not benign. It is not only about *security* and *safety* for individuals through constant observation but of moulding, shaping and "normalising" the behaviour of those being observed (Holmes, 2001). Foucault (1995) describes disciplinary power as distinct from domination, in that it separates, analyses and deconstructs individuals until sufficient singularities are delineated. While there are direct parallels in the use of disciplinary power in disability and mental health custodial and residential care facilities, the same pattern of separation, analysis and deconstruction can be seen in the assessment processes undertaken as part of accessing social service supports.

In contrast, academic and disability advocate Wolf Wolfensberger (1972) sought *normalisation* for people with disability by harnessing the power of individual status that comes when people have valued roles in society, such as neighbour, friend or customer; that is, when people have roles that "include" rather than "otherise" marginalised people. His philosophy of social role valorisation remains a central concept in contemporary service provision, particularly for people with an intellectual disability.

Mental health facilities and residential facilities for people with disability have drawn heavily on prison design and methods for therapeutic and security purposes. While modern facilities have become less overtly institutional, and now justify electronic surveillance methods as part of workplace health and safety obligations and technological advancement, the unequal power between observer and observed requires examination. In acknowledging the disciplinary power of custodial/residential facilities, Foucault (1995) expected that intellectuals (professionals) would do their work with consciousness. He expected they would reflect on the nature of this power both in dominant discourses and in the course of direct service delivery where it has the potential to infringe upon the rights and dignity of vulnerable people (Holmes, 2001).

Two classic social psychology experiments, the Stanford Prison experiment conducted in 1971 and the Milgram experiment in 1963, suggest that reflection on the rights and dignity of individuals does not naturally occur where disciplinary power is

dominant. Both experiments aimed to examine how far people would go in obeying an instruction when it involved harming another person in a hierarchical context. The results raised ethical questions about the conduct of the experiments and the potential for abuse of power and authority in institutional settings. A replication of the Milgram experiment 15 years later by Burger (1992) yielded almost identical results. Marsland, Oakes and White (2007) argue that where there are imbalances of power at any level within the social service system there is a risk that power will be used inappropriately, increasing the risk of abuse. Wardhaugh and Wilding (1993), in their work on the corruption of care, cite a range of conditions which create vulnerability in people who use social services, including isolation, neutralisation of normal moral concerns, management failure and the organisation being closed to scrutiny.

In his writings on disciplinary power Foucault borrowed from the concept of hegemony offered by Antonio Gramsci (Dylan, 2011). Hegemony refers to domination and control of knowledge and ideas by a ruling group through interplay between political society, which rules by force, and a civil society, which rules through consent. The catalyst for power that plays out between the two is wielded by universities, religious and other institutions who actively cultivate and perpetuate consent (Hoare, 1971).

The hegemonic power dynamic in the disability context begins with individuals from marginalised groups developing a loyalty to the authority that replaces independent thought and action. Decisions and actions are then driven by the dominant ideology or worldview, rather than by independent consideration. Eric Leipoldt (2011), in his submission to the Productivity Commission Inquiry into long-term disability care and support, raised concern over the inclusion of market ideology as an element of disability policy reform, considering it incompatible with social or individual transformation. For Leipoldt (2011), the inclusion of market ideology gives rise to significant tensions between the state's obligation to provide for its most vulnerable citizens (as opposed to leaving market forces to dominate) and the need for economic constraint. The result of this tension as the NDIS unfolds is a precarious balance between government regulation and price setting, and providing encouragement and incentive for new entrants into the "market". David McNally (McNally, 1993) argues that such tension in the social services will always lead to inequity and an imbalance of power.

The power of hegemony comes with the agreement that the dominant group has authority—moral, economic and political—and the associated ideas and concepts are accepted passively, without question. In the case of people with disability and their families, the power wielded by government (and service providers by proxy) as funder, benefactor and protector is assumed. The opposite position—that of receiver of funds, benefits and protection—comes with agreement to comply with bureaucratic requirements that include labelling, form-filling and proof of disability.

In a world where paid work has such highly valued status, power resides with those who are *able* to work and make the greatest (altruistic) contribution to society through income taxes. Those not able to work or who are on the receiving end of such benevolence are expected to be grateful and obedient, rather than share the valued status of those in paid work. In the absence of questioning, the benefactor may also be assumed to act in a fair and neutral way, to carry burdensome responsibility for fair distribution of limited resources, and to always be acting in the best interest of the individual.

Dissonance is inevitable in the face of large numbers of people with significant needs for support who receive no support at all, or when inconsistency is noted in levels of support offered based on diagnosis, level of need and geographical location. Such dissonance is evident in the story of people with disability, who observe differences in access to services based on type of impairment (with resources perceived as more readily available to people with physical disability, visual impairment or autism spectrum disorders than intellectual disability) and geographical location (less services and power to choose services in regional and rural areas) which may drive confrontation and, perhaps more often observed, discouragement. Both Gramsci, cited in Hoare and Smith (1971) and Foucault (19950 argue that this invisible power dynamic must be made visible and be critically examined before social change is possible.

The disability studies literature draws heavily on Foucault to explain the power of discourse for those in control to oppress those receiving services (Ritzer, 2000). The power of the voice of people with disability, which is beyond discourse, is perhaps better explored through the work of Bourdieu (Bourdieu, 1984). Bourdieu assumes that all human experience is shaped as individuals engage with their life in

the world around them, with effectiveness determined by how well they can acquire and utilise resources to have their needs met (Thibodaux, 2005).

Bourdieu (1977) sees power as culturally generated and reinforced through socialised norms that direct thinking and behaviour. His theory has a number of key concepts, the first of which is *habitus*—a combination of personal, physical, social and environmental factors which exist as a product of the individual's social position, perception of themselves and symbolic mastery Bourdieu (1977) describes habitus as neither a result of free will, nor determined by structures, but the product of the interplay between the two over time. As such, lived experience both shapes and is shaped by the perception of lived experience.

The second concept fundamental to Bourdieu's (1977) theory is that of "capital"—economic (material), cultural (knowing the rules, language, behaviours needed to fit in) and social (networks, who you know)—all of which are translated into symbolic capital which individuals carry with them into various social "fields". At an individual level, this sense of "social order" prescribes ones "place" in society and drives self-exclusion behaviours (Bourdieu, 1977). At a societal level, such translation occurs through everyday language and our education system, and leads to an unconscious acceptance of social differences. These various forms of capital play a central role in power relationships within society, providing a non-economic means of dominating and distinguishing oneself from others (Gaventa, 2003). Bourdieu (1977) cites this shift of capital from material to symbolic as the hidden cause of inequality.

The concept of "fields" is also fundamental to Habitus. "Fields" are the various social and institutional arenas where people demonstrate and compete for capital. A field may be a network, a workplace, a sporting event, a religious gathering or a school. The individual's experience of power will vary, not only according to the field they are occupying at a point in time but on a range of other contextual factors (Bourdieu, 1977). Individuals occupy different positions and experience power— domination or resistance—in each field differently based on the capital they bring (Moncrieffe, 2006). Some fields are inherently more powerful than others and some are more future-oriented than others (Gaventa, 2003).

In acknowledging the bias created by one's own beliefs and assumptions, Bourdieu (1977) proposed the need for self-critical reflection as part of an active sense-making process, such as CLA, which is used as the primary method in this research. Navarro (Navarro, 2006) suggests such reflection is a critical element of social change as it makes sources of power and the subsequent asymmetries in power visible.

Complimenting Bourdieu's construct of the social field, Adam Kahane (2012), author and social change practitioner, offers an additional perspective on power. He offers a perspective that positions power as a counterpoint to love, drawing on the work of Dr Martin Luther King (cited in Kahane, 2012) and Eric Fromm (1956) which defines love as striving for unity or connection. Kahane draws on a quote from Dr Martin Luther King:

> Power without love is reckless and abusive, and love without power is sentimental and anemic. Power at its best is love implementing the demands of justice, and justice at its best is power correcting everything that stands against love. (Dr Martin Luther King Jnr, 1967, as cited in Kahane, 2012)

Kahane (2012) describes both power and love as having a positive, generative aspect and a negative, degenerative aspect. He suggests that each bring out the best and most positive attributes in the other, and that the work of social change requires a constant balancing and adjustment of the two aspects. Using examples from his dialogue-based social change work in South Africa, Guatemala, India and with Canadian First Nations people, Kahane suggests that a strong relationship (love) without progress toward goals can be countered by strengthening the focus on action (power to influence). Gain or process (power) at the expense of a relationship (love) is best countered by activities that strengthen connection between the core stakeholders.

Kahane's (2012) reference to love in Fromm's terms—a quest for unity and belonging—is similar in meaning to the quest of the "vulnerable self" described by Hal and Sidra Stone (1989). Both frame vulnerability and desire for belonging as qualities present in all human beings, whether or not it is visible to them. Rather than being associated with lived experience of disability or disadvantage, vulnerability is considered part of the human condition, whether it is embraced or denied. In the

framing of Kahane, vulnerability or the quest for belonging is potentially the counterpart to the power to influence.

In providing a more critical examination of power than offered by Kahane (2012), Karlberg (Karlberg, 2005) distinguishes between two main types of power, power *to* and power *over*, describing the latter as most central to the Western discourse of power and a measure of capacity to achieve outcomes. He suggests that power as domination is central to the discourse of a range of social movements and underpins conflict and violence, arguing the need to intervene and change the discourse. This is apparent for the disability studies literature, with power exercised by those in control of service systems and institutions receiving significant attention (Robinson & Chenoweth, 2012). Power *to* has received much less attention in the literature (Karlberg, 2005), but is most relevant to the central questions of this research.

Erwin Laszlo (1989) and Kenneth Boulding (1990) have confirmed the need for a more integrated approach to power discourse, one based on assumptions of reciprocity, mutuality and interdependence. It is acknowledgement of this interdependence between individuals, families and community, and increasing focus on power *to* in the literature, that underpins this research.

## 2.5    Section 4:  Anticipating and Shaping the Future

Irrespective of how power plays out across social fields, the requirement to imagine and plan for an uncertain future is central to the role of both government and citizen. The NDIS policy reform promises individuals and families the opportunity for choice and control over services and supports, linking these to the promise of social and economic participation as a proxy for a better life. The NDIS narrative contains assumptions that people will be able to make and give effect to their choices, within the limitations of decision-making capacity and resources provided. The impact of past experience of power imbalance and inequitable resource distribution by the service system is not present in the narrative, nor is an understanding of what else it takes to anticipate and shape one's own future—the subject of this section.

Elise Boulding (1995) described Fred Polak as one of the first thinkers to visualise a wholly different future:

According to Polak, the human capacity to create mental images of the "totally other"—that which has never been experienced or recorded—is the key dynamic of history. At every level of awareness, from the individual to the macrosocietal, imagery is continuously generated about the "not yet". Such imagery inspires our intentions, which then move us purposefully forward. Through their daily choices of action, individuals, families, enterprises, communities, and nations move toward what they imagine to be a desirable tomorrow. (E. Boulding, 1995, p. 95)

The concept of citizens collectively anticipating and shaping their own future is well represented in the literature. Anticipatory democracy, a term coined by Alvin Toffler (1970) in *Future Shock,* provides both the framework and tools for engaging citizens collectively to inform public policy (Bezold, 2010). While the NDIS exists, at least in part because citizens, particularly people with disability and their families and friends engaged with it on a national scale, the imagery generated during this engagement centred around negative experiences of having a disability (Kevin Cocks, 15 June, 2015). According to Polak (1961), when negative imagery is associated with pessimism and a sense of helplessness, players remain bound by the present, with no social dynamic for change available to them. There is insufficient reference in either futures or disability research literature to understand whether the negative imagery used in leveraging change for the NDIS may ultimately constrain the future for people with disability and their families.

Miller and Poli (2010) define anticipation as thinking about "later than now"—a pre-requisite for understanding the present and an important element of the discipline of futures studies. It is an activity, however, that requires tolerance of ambiguity and a willingness to embrace creativity in how we imagine and prepare for the future (Miller, 2010). Inayatullah (1998) expands on the need for tolerance of ambiguity in preparing for the future, drawing on complexity theory to explain:

The future is patterned and chaotic: that is, it can be known and yet unknown, or explained but not accurately predicted. This 'both-and' perspective is especially useful in reconciling classical dichotomies such as agency (individuals can influence the future) and structure (structures define individuals and what is possible). (Inayatullah, 1998, p. 5)

Bussey (2014a) suggests that our actions today are the manifestation of our assumptions about the future, and that thinking about the future offers us a chance to rethink our potentiality, opening up a range of possible futures. In outlining a series of first principles of futures work he asserts that futures work is always about opening up future possibility, perhaps as remedy to the sense of powerlessness that comes when our sense of identity is entwined with the present moment.

Several authors (E. Boulding, 1988; Hutchinson, 2005; Polak, 1961; Slaughter, 1986) suggest our formation of mental images is both a deep reflection of our culture and central to our capacity to create the future one prefers. Educational academics suggest that imaging the future is a capacity that needs to be taught (Hicks, 2006; Hutchinson, 2005; Milojević, 2005; Reardon, 1988) and E. Boulding (E. Boulding, 1988) reminds us that lived experience is just one of the raw materials needed to imagine a different future. Hutchinson (Hutchinson, 2005) argues our education system is ultimately responsible for determining whether this ability is fully developed or constrained, and for designating some images as highly valued while others are marginalised and not seen. He joins Reardon (Reardon, 1988) and E. Boulding (E. Boulding, 1988) in their calls for building our capacity for reflective, imaginative conversation and new metaphors if we are to change prevailing paradigms.

## 2.6    Section 5:  The Future for People with Disability

> Despite the fact that approximately one in five of the world's population lives with disability there is still a significant gap in the literature, in imagining disability futures based upon the human rights of people with disability, and especially the rights we have to develop as full human beings. Not only have futures projects largely ignored disability or failed to explore its social and political dimensions but we would suggest that the diverse community of people with disabilities, their carers and families have largely not attempted imagining the future in this way. In part, this is because of the current situation of people with disabilities. (Goggin, 2005 p69)

Futurists and others suggest that the impact of images and language, either positive or negative, associated with an individual or group of individuals is powerful (E Boulding, 1995; Karlberg, 2005; Polak, 1961). According to Oliver (1990), in the disability field, the language and act of defining people with disability not only drives

practice but directly informs the way people view themselves. If, as Wolfensberger (1972) asserts, socially valued roles enhance the perception of competency and value in an otherwise socially de-valued person then the perception of self-determination is also likely to be consequential, in both social and economic contexts.

Inayatullah (2007), in referring to a speech to Queensland Advocacy Incorporated in 2002, proposed three foundational approaches to the future for people with disability for consideration.

The first was the future as given; that is, the unquestioned, taken for granted future which must be responded to (Inayatullah, 2007). Such a future is assumed to be driven by technology, with personal agency limited to those in control of the technology. For people with disability, technology is often seen as the way to overcome limitations of impairment, such as in the form of augmentative communication and environmental control devices. The locus of power for change is external to both individual and group.

Inayatullah (2007) described the second approach as *transcendental* or driven by higher forms, beyond our control. In the disability sector this is likely to relate to government policy or service system design determining future experience.

The third approach he described, perhaps more relevant given the purpose of this research, was the *contested* future (Inayatullah, 2007). This is a version of the future that is open to challenge and reframing by those who will live it. It is preferred in that it allows a measure of personal agency not allowed for in the given or transcendental futures. It is a future that can be shaped and reshaped and will inform the decisions of today. It is the future implied in the campaign and early design of the NDIS. While the NDIS implies the promise of a future that is open for people with disability, Goggin and Newell (2005) remind us: "The future construction of the disabled body and mind is largely a symptom of the power relations of disability" (Goggin & Newell, 2005, p. 69).

While disability discourses have shifted over time and varied with regard to perception of impairment as a personal tragedy or social construct, they remain reflective of worldviews grounded in deficit, exploitation and an ungenerous society. They fail to generate anything other than negative, pessimistic images of the future.

The literature on the nature of power (Bourdieu, 1984) suggests that such worldviews become part of the capital we bring as we engage with society. The concept of *habitus*—a propensity to think, feel or act in a certain way—Bourdieu (1984) describes as neither a result of free will, nor determined by structures, but the product of the interplay between the two over time. As such, lived experience both shapes and is shaped by the perception of lived experience.

Foucault (1972) also notes that power is a phenomenon not locked in by structure or agency but subject to change over the course of time. While he first describes the power of structures to constrain, even when they appeared neutral or independent, he also describes the way power can shift with a change in perspective. He proposes the need to examine and understand this dynamic.

If, as Goggin and Newell (2005) suggest, the future construction of the disabled body and mind is largely a symptom of the power relations of disability, and these power relations are not fixed but open to change, as suggested by Foucault (1995) and Bourdieu (1977), then this research is well-timed. The NDIS is potentially a strong social policy response to the negative experiences of disability—social and economic exclusion. To unlock its potential for transformation at both a social and individual level further examination of the constructs of disability, vulnerability and the power to shape the future is important and is therefore the subject of this research.

## 2.7   Summary

Table 2 summarises the key discourses found over the course of this literature review.

**Table 2**     Summary of key discourses

| Author | Worldview | Implications for disability |
| --- | --- | --- |
| Wolfensberger (1972) | People without valued roles in society are exploited and treated as less than human | Lack of valued roles (institutionalisation) increases vulnerability |
| Foucault (1972) | Those with power to label, hold the power | Power *over* individuals through surveillance and the giving and withdrawal of support |
| Oliver (1990) | Discourses objectify | Invited critical reflection on disability discourse as constraint; emphasised the power of lived experience |

| Author | Worldview | Implications for disability |
|---|---|---|
| Bourdieu (1991) | Human experience is shaped as individuals engage with their life | That impairment need not be a defining attribute, nor a constraint for shaping the future |
| Chenoweth (2006) | Medical model pathologises and constrains individuals | People's lives being shaped by professionals rather than being self-determined |
| Shakespeare (2014) | Social model discourse oversimplifies experience of impairment | Deep resistance in the disability field to acknowledging vulnerability associated with impairment |
| Gorur (2015) | Whether vulnerability is seen as an individual attribute or externally imposed impacts on policy response | Questioned vulnerability as cause or consequence for people with disability |
| Stone & Stone (1989) | Multiple "selves" emerge in order to protect the original "vulnerable" self of one's childhood | Vulnerability can be projected or denied depending on context |
| E. Boulding (1995) | Generation of images of a future not yet experienced is pre-requisite for creating that future | That imagining (and imaging) the future is a necessary element of determining one's own future |
| Kahane (2012) | Power is a counterpoint to love (quest for unity) and that each brings out the positive/generative aspects of the other | That it is possible for vulnerability to co-exist with power to shape one's own future |

## 2.8 Conclusion

The literature review reveals multiple discourses that have not only shaped the service system in Australia but people's view of themselves—both individually and collectively. Reflection on current practice in the social service system suggests that, while some critique on discourses has occurred in the academic field, understanding of the impact of language and culture in everyday service design and delivery is limited.

The literature is clear on the importance of acknowledging vulnerability and the relative impact of whether we attribute it to individual or systemic causes; no such

clarity is evident in practice. In working with people with disability, their families and service providers a greater degree of ambivalence about vulnerability is evident. Stone and Stone's (1989) framing of vulnerability in terms of multiple selves, which emerge in response to the vulnerable self of childhood, is considered a useful framing for this research.

With regard to exercising power, both literature and practice reveal significant resistance to power *over*—that is, exploitation and harm—and that this resistance may be a constraint to exercising power *to* shape one's future. The following chapter provides an outline of the methodology and methods through which data was gathered to better understand the tensions emerging as part of the relationship between vulnerability and power to shape the future.

# Chapter 3: Methodology

The literature review has provided the theoretical context in which this research is located and given rise to the research questions. This chapter outlines the methodology and methods through which data were gathered and interpreted to better understand the tensions emerging from the story so far. CLA (Inayatullah, 2015) and sense-making (Dervin, 2008) provide both theory and method.

A review of research literature in both the disability and futures fields suggests there may be more significant constraints to change under the NDIS than the introduction of a market ideology. While the NDIS is a social insurance scheme relying on a combination of regulation, price setting and supply and demand economics to stimulate choice for people with disability, McNally (1993) argues there will always be inequity in outcomes for those receiving social services in a market-based environment. Of perhaps greater significance is the extensive use of negative imagery of disability, over many years, to influence public policy and discourses heavily dominated by constructs of vulnerability and powerlessness. While there is research that identifies self-determination and self-direction as important aspects of effective, contemporary service provision (Epstein-Frisch, 2006), critique on the way vulnerable people are depicted (Clendinnen, 1998) and on the impact of vulnerability (Milojević, 2013; Robinson, 2012), there is little research on the relationship between vulnerability and the individual's ability to imagine and create a future for themselves.

The purpose of this research is to explore the relationship between vulnerability and power to influence the future, using a futures studies frame, in the policy context of the NDIS. Specifically this project has aimed to explore the following research questions:

RQ1: How do stakeholders interpret "reality" with regard to disability, vulnerability and power to influence the future?

RQ2: How does power play out across stakeholder groups when considering the future for people with disability?

RQ3 How does the opportunity to deconstruct "reality" for people with disability open the path to multiple futures?

The first question was explored in a small, mixed stakeholder group workshop format where people were invited to choose from a range of images and/or generate words, phrases or examples of what each of the three constructs mean to them. The images and text were used to populate a CLA matrix, with the three constructs— disability, vulnerability and power—to influence the future at the top of each column, and the four levels of litany, social cause, worldview and image/metaphor at the beginning of each row.

The second question was explored both through the CLA workshops and the one-on-one interviews with stakeholders based on Dervin's (2008) sense-making interview protocols. Both CLA and sense-making were used in the data analysis. The researcher's perspective was included as part of both methods.

The third question was examined on reflection of both sets of data by the researcher. It was anticipated that by revealing and allowing participants the opportunity to reflect on the patterns and connectivities between the constructs of vulnerability, disability and agency over the future, if indeed they exist, it may be possible to unlock an otherwise constrained set of alternative futures for people with disability.

## 3.1 Using CLA

To unpack multiple layers of a story for interpretation, CLA (Inayatullah, 1998) around the central themes of disability, vulnerability and power to influence the future was used both as method and theory:

> As method, it [Causal Layered Analysis] allows for specific contexts to be opened up to layered analysis while as theory, it offers an account of social space that links context to epistemological and ontological assumptions about the real, in a systematic way. (Bussey, 2014a, p. 46)

CLA is based on Inayatullah's (2015) theory that how we see ourselves, the stories we tell and the myths we inhabit are pre-conditions for our thoughts and actions in a given context (Milojević, 2015). As a method, it potentially exposes the hidden assumptions that drive culture and determines whether futures are open or closed:

> CLA enables more awareness of how futures discourse influences the present and how present actions influence emerging futures. By linking narratives

and assumptions to actions, CLA assists in the development of higher-level mindfulness about what we do and why we do it. CLA also helps identify 'used' and 'default' futures, continuations, essentially, of past discourses about the future, which may no longer be valuable or relevant to current or emerging issues. By doing so, CLA creates new spaces wherein preferable and more innovative futures visions and strategies can take hold. (Milojević 2015, p. 535)

CLA is a layered process of examining first the litany or most visible level of a story; that is, the version seen in the media, reflecting the most superficial, often emotive, view of people with disability with stories of hardship and exploitation or, alternatively, inspiration at overcoming seemingly insurmountable obstacles. This is followed by a second level, which is about interpretation or analysis of social causes, historical and political context and is often accompanied by blame of whatever part of the system is responsible. This may include the social service system as a whole, service providers or individual workers charged with keeping people free from harm. The third is a deeper layer, which invites examination of the impact of structure, discourse and worldview on the phenomenon being studied. In the context of this research, the third layer may be about the academic, rights-based or ethicists' view on the experience of disability. The fourth and deepest layer consists of analysis of the collective story—at myth or metaphor level—that drives the phenomenon, often unseen and unexamined (S. Inayatullah, 2015). While the reader is encouraged to explore the multiple layers, and include spatial and temporal dimensions of the phenomenon, there is no suggestion of one layer being superior to the others. Dator (1990) in review of Inayatullah's work (2004), described CLA as:

A very sophisticated way to categorise different views of and concerns about the futures, and then use them to help groups think about the futures far more effectively than they could by using any one of "layers" alone, as most theory/methods do. (Jacket, Inayatullah, 2004)

Bussey (2014a) describes CLA as a useful process for situating the individual at the causal centre of a subjective universe, with a diverse range of possible futures to choose from. In the current research, CLA was used as a workshop process and as a tool for analysis of the paradigms and constructs that emerged from the workshops and interviews (Hoffman, 2012).

## 3.2   Using sense-making

This research acknowledges, however, that people also construct their own knowledge and understanding of the world by intuiting, sensing, experiencing and reflecting on these experiences (Bussey, 2014c; Maturana, 1992; Senge, 1992).  What counts as "truth" to carers or policymakers or academics is a reflection of one's own life experiences and the meaning made of those experiences.  A complementary process, sense-making (Dervin, 2008), was used to frame and interpret the narrative generated through one-on-one interviews with people at the heart of this inquiry.  While workshops were likely to reveal images, examples and some narrative in response to the stimulus questions and interaction between group members, the interviews were expected to provide a more considered, personal perspective on the issues discussed.

Kesson, Traugh and Perez (2006) argue that narrative is most useful when deconstructed to reveal the deeper layers of meaning and least useful when it is accepted without critical examination.  According to Kesson et al. (2006) habitual perception obstructs a clear view of one's own story and acts as a barrier to re-imagining the future.  Rather than being of lesser value because of the emotional content and response, White (White, 2010) asserts that stories told by "knowers"— that is, people with lived experience of the content—are highly valuable.  Gathering oral accounts of individual perspectives is also considered particularly valuable. Portelli (Portelli, 2006) makes the case for oral rather than written accounts on the basis they provide richer information about emotional responses to ideas and experiences, comfort and familiarity with content, levels of anxiety about parts of the story, and how long the storyteller lingers over particular parts of the story, thus directing attention to certain aspects.

Narrative is considered important, not only as a means of inquiry but as material for sense-making, bringing together not only a record of human experience, but the physical and metaphysical realms (Hendry, 2010). Narrative offers a structure for organising our knowledge and experience and is both a method and reminder of the question at the centre of the inquiry: "To be open to what is not yet imagined, however, requires the deconstruction of habitual patterns of perception and action" (Kesson, 2006) p. 1864.

Sense-making (Dervin, 2008), described by its author as a post-constructivist approach, was used specifically to frame the interview process and as a basis for exploring how individuals make sense of their experiences. Sense-making refers to the internal and external behaviour people engage in to make sense of their world and is based on two primary assumptions: that reality is neither constant nor complete; and that information is the product of a subjective experience, rather than being an objective entity which can be transmitted from one person to another (Dervin, 1983): "Sense-Making thrusts itself between chaos and order, structure and person, facts and illusions, external worlds and inner, universals and particulars. Sense-Making posits reality as ordered in part, chaotic in part, evolving in part" (Dervin, 1999), p.730).

Patricia Kelly (2004) describes both CLA and sense-making as relatively new concepts and methodologies: "They are complementary at the theoretical level because they (1) welcome input from other methodological frameworks, (2) have a critical meta-dimension, (3) have a complex appreciation of time, and (4) have a deep concern for the planet" (Kelly, 2004, p. 184).

CLA (S. Inayatullah, 2015) and sense-making (Dervin, 1999) together provided a strong theoretical and methodological basis for this research, as they both support active participation and the reflection of ideas and images generated during data collection. They also both explicitly address power issues and assumptions. Both approaches view individuals in terms of mind, body, heart and spirit dimensions, are able to move freely from past to present to future and back, with capacity for abstraction, dreaming and ambition beyond time and space, and both approaches allow participants to explore and make meaning of their own experiences (Kelly, 2006).

As Inayatullah (Inayatullah, 2017) cautions, CLA may not be an effective process if people are unable or unwilling to acknowledge and explore the worldviews of others. The effectiveness of CLA as a process was monitored throughout this research.

## 3.3   Data Collection Methods

The primary methods of data collection were the facilitation of four CLA workshops, which included a range of stakeholders from the disability sector (people with

disability, family members and service providers), using a standard template on a whiteboard and floor as illustrated in Table 3.

**Table 3.** CLA framework

|  | **Disability** | **Vulnerability** | **Power to shape future** |
|---|---|---|---|
| **Litany** |  |  |  |
| **Social Cause** |  |  |  |
| **Worldview** |  |  |  |
| **Metaphor** |  |  |  |

The CLA workshops explored the central themes of disability, vulnerability and power, with participants invited to reflect on the ideas, images and worldviews as they became visible.

By using CLA as a workshop process, people with disability and other key stakeholders had the opportunity to express and reflect on their own experiences and assumptions relating to disability, vulnerability and power to influence the future. Each key area was addressed through a separate CLA process in a single workshop, with participants invited to reflect on any patterns or connections observed, and how power plays out across stakeholders and over time. For example, Shevaller (2011) suggests the metaphor level of CLA can make visible the application of power through imposing metaphors on others.

Both CLA and sense-making were also used to analyse each of the paradigms and constructs made visible through the workshops and interviews. While CLA does not argue for any particular *truth*, analysis using CLA seeks to explore how various stakeholders frame the future and, in doing so, privilege certain perspectives (Hoffman, 2012).

For one-on-one interviews, Dervin's (2008) sense-making interview protocols, with 8–12 workshop participants subsequent to each workshop, were used with the following indicative questions:

1. Tell me a story or give me an example that reflects your experience of how power plays out for people with a disability.

2. What was your personal experience in that story?

3. What gave you power to influence/shape the future in that example/story?

4. What impact did being able to influence have on the issue?

5. What impact did being able to influence/shape the future have on you (or others) as a result?

6. Given the impact, would you use your power to influence/shape the future again?

7. If so, is there anything you would do differently next time?

Dervin's (2008)protocols emerged from the field of media and communications, seeking to understand how people make meaning of situations. The process relies on interviews comprising neutral questions (without use of nouns) that tap into the four intersecting parts of the target experience/situation. The interview starts by asking for a description of the situation or experience itself, then explores what questions or uncertainties or struggles ensued, what learnings or conclusions ensued and what acted as the *bridge* in between (Dervin, 1999).

## 3.4   Target Group

The target participant group was people who have a physical and/or sensory disability, have a family member or friend with a disability, people who work with people with disability (either directly or indirectly, such as through management or policy development roles), advocates and others that identify as being from the disability sector and can be reached through a certified disability agency in Queensland.

A small number of certified disability organisations were invited to distribute an invitation to their service users, staff and other stakeholders. Participants had the option of contacting either their service or the researcher directly and were accepted on a first-in, first-served basis (3–4 workshops of 20 people maximum) to their preferred workshop event. Invitations were distributed through the regular communication mechanisms used by each organisation (e.g. newsletter, direct email, client consultative committee).

## 3.5 Location

The workshops and interviews were conducted in Queensland at appropriate, accessible and comfortable venues, including a community hall meeting room, coffee shops and service training facilities.

## 3.6 Duration

Participants attended a single, 3-hour workshop, with interviews taking approximately 1.5 hours each.

## 3.7 Analysis

The purpose of this research was to examine the underlying assumptions, worldviews and imagery that become visible when multiple stakeholders engage with the constructs of vulnerability, disability and agency over the future through a workshop and interview process. Data were gathered through small, multi-stakeholder groups engaged in a workshop structured around CLA across the three constructs, and a number of one-on-one interviews using Dervin's (2008) sense-making protocols.

The data from the CLA workshops were first organised in CLA table-form (including observations made by the researcher during data gathering) by group location or interview subject. Sample comments and quotes are provided in Appendix I.

The data from the one-on-one interviews were first organised into a table in accordance with the seven sense-making protocols that follow:

1.   Tell me a story or give me an example that reflects your experience of how power to influence the future plays out for people with a disability. (MAP IN TIME STEPS)

2.   What was your personal experience in that story? (IDENTIFY ANYTHING THAT CAUSED UNCERTAINTY, CONFUSION, GAP IN UNDERSTANDING—LEARNING REQUIRED)

3.   What gave you power to influence/shape the future in that example/story? (WHAT PRODUCED AN OUTCOME—I.E. INFLUENCED GETTING AN OUTCOME)

4. What impact did being able to influence have on the issue? (WHAT WAS THE OUTCOME?)

5. What impact did being able to influence/shape the future have on you (or others) as a result? (WHAT DIFFERENCE DID IT MAKE—SELF OR OTHERS?)

6. Given the impact, would you use your power to influence/shape the future again? (WILL IT CHANGE YOUR BEHAVIOUR IN FUTURE YES/NO?)

7. If so, is there anything you would do differently next time? (HOW WILL IT CHANGE YOUR BEHAVIOUR IN THE FUTURE?)

A sample of an interview is provided in Appendix II.

Ethical approval was granted for this research by the University of Sunshine Coast (approval number S14650, September 2015).

## 3.8 Summary

There is little research on the relationship between vulnerability and the individual's ability to imagine and create a future for themselves; however, there is some research that acknowledges that people also construct their own knowledge and understanding of the world by intuiting, sensing, experiencing and reflecting on these experiences. Habitual perception, however, obstructs a clear view of one's own story. For the purposes of this research, individual and family stories provide a useful structure for organizing our knowledge and experience.

## 3.9 Conclusions

CLA and sense-making, as complementary processes, were considered useful both for structuring the workshops and interviews, and in the analysis of the data that emerged. Together they provided comprehensive tools for exploring the central research questions:

RQ1: How do stakeholders interpret "reality" with regard to disability, vulnerability and power to influence the future?

RQ2:    How does power play out across stakeholder groups when considering the future for people with disability?

RQ3:    How does the opportunity to deconstruct "reality" for people with disability open the path to multiple futures?

The following chapter provides an outline of demographic data of participants and the findings from both CLA and Sense-Making data collection methods.

# Chapter 4: Results

Having established the theoretical basis for this inquiry—that is, to explore the relationship between vulnerability and power to influence the future, using a futures studies frame, in the policy context of the NDIS—a range of data were gathered through workshops and interviews. The findings detailed in this chapter are critical for advancing the specific research questions:

RQ1: How do stakeholders interpret "reality" with regard to disability, vulnerability and power to influence the future?

RQ2: How does power play out across stakeholder groups when considering the future for people with disability?

RQ3: How does the opportunity to deconstruct "reality" for people with disability open the path to multiple futures?

This chapter is organised into three parts, starting with demographics of participants and followed by the two methods of data collection, CLA workshops and sense-making interviews. Each of the two method sections are further divided into purpose, process, findings and the researcher's perspective. Data consolidated across all four CLA workshops are included in the text of this chapter, with individual quotes organised by stakeholder group provided in Appendix I. Key lessons from all ten sense-making interviews are included in the text, while a single, more detailed, sample can be found in Appendix II.

## 4.1 Demographics

Data were gathered from a total of 47 participants, 44 of whom attended workshops and 10 of whom participated in one-on-one interviews (see Table 4). Six of the interviewees also participated in a workshop. The workshops were conducted in accessible training or meeting rooms arranged by participating disability organisations. The interviews were conducted at the workshop venue or at a local coffee shop, depending on the individual's preference. Participating organisations included:

- Community Connections Inc., Townsville (1 workshop and interviews).

- ALARA QLD Limited, Ipswich (2 workshops and interviews).

- FSG Australia, Gold Coast (1 workshop and interviews).

**Table 4** Stakeholder distribution

| Stakeholder group | Workshop | Interview |
|---|---|---|
| Person with a disability only | 2 | 1 |
| Family member only | 21 | 2 |
| Service provider only | 12 | 4 |
| Both person with disability and service provider | 0 | 2 |
| Both person with disability and family member | 6 | 0 |
| Both family member and service provider | 3 | 1 |
| **Total** | **44** | **10** |

### 4.1.1 Gender

Of the 47 participants who were involved in the workshops and interviews, 39 were female (83%) and 8 were male (17%). Of the workshop participants 37 were female (84%) and 7 were male (16%), while 9 of the 10 interviewees were female (90%) and 1 was male (10%).

### 4.1.2 Age

Of the 47 participants, 6 (13%) were 60+ years old, 7 (15%) were 50+ years old, 24 (51%) were 40+ years old, 7 (15%) were 30+ years old, and 3 (6%) were 20+ years old.

### 4.1.3 Ethnicity

None of the participants identified as Aboriginal or Torres Strait Islander people and none required language or communication support.

### 4.1.4 Disability

Eight out of the 44 workshop participants had a disability (18%) and 3 out of 10 interviewees had a disability (30%). All participants with a disability had physical impairment as their primary impairment.

### 4.2    CLA Workshops

### 4.2.1 Purpose

The purpose of the CLA workshops was to explore the central themes of disability, vulnerability and power, with participants invited to reflect on the ideas, images and worldviews as they became visible.

By using CLA as a workshop process, people with disability and other key stakeholders had the opportunity to express and reflect on their own experiences and assumptions relating to disability, vulnerability and their power to influence the future.

### 4.2.2 Process

The CLA framework was offered graphically on a whiteboard (see Figure 1) and a large table surface, alongside a scattered arrangement of images, text, paper and pens for people to choose from and then speak to as they wished. The framework and process was first explained in terms of the research purpose and ultimately how to best support people with disability to imagine and create multiple possible futures for themselves. People were invited to participate on the basis of their shared interest in the future for people with disability under the NDIS.

**Figure 1**    Sample whiteboard CLA in progress



Each layer of the CLA was unpacked, as in Figure 1, for each construct (disability, vulnerability and power to shape the future), starting with litany, followed by social cause, worldview and metaphor/image.  The process was dynamic, with some participants choosing to move between the layers (within columns) and between constructs (within rows) to add, refine or change ideas and images as the discussions progressed.  For all four workshops and across all stakeholder groups, participants became comfortable with both the language and the process of CLA and required no clarification of the process or framework as the session progressed, as in Figure 2. There was only one occasion where a participant expressed a desire to remove a comment on the basis that it made her look like a bad parent.  Without intervention by the researcher, the group counselled her on the power of such a heart-felt example from lived experience and she consented happily to reinstate the comment.

**Figure 2**    Sample tabletop CLA in progress
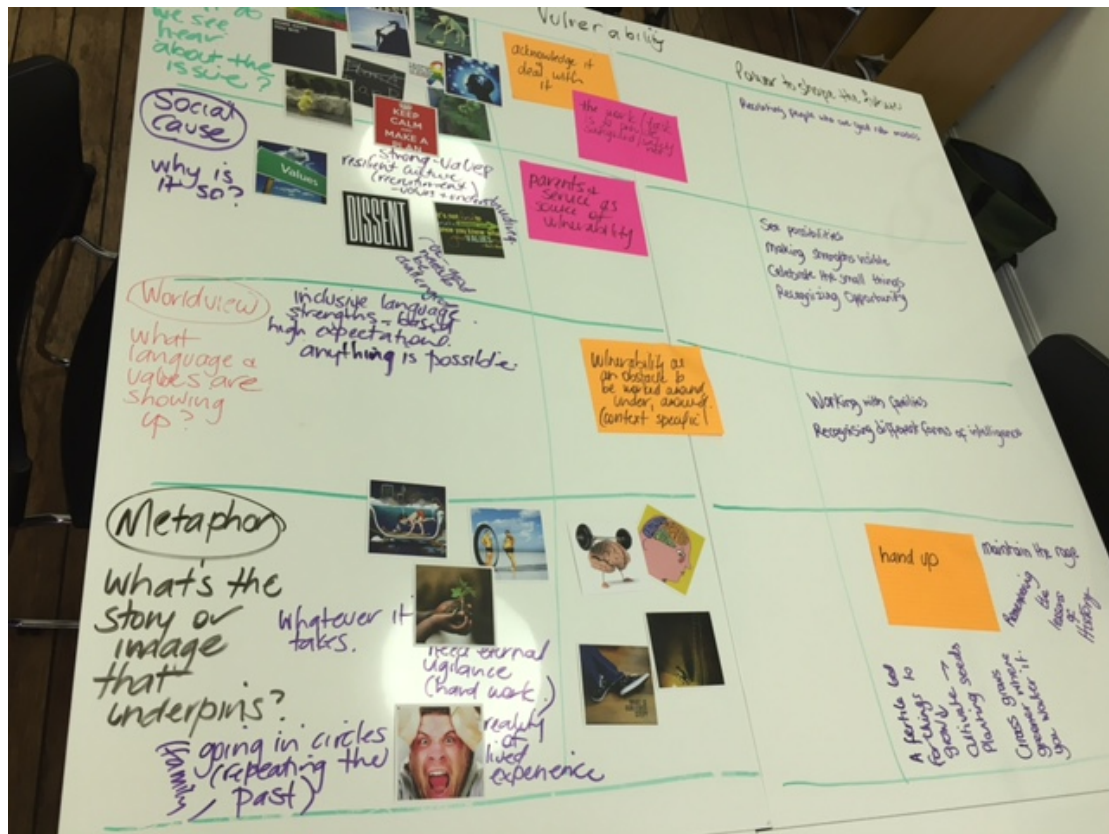


### 4.2.3 Findings

The text, images and comments from participants have been summarised in

Table 5, with detail grouped according to stakeholder group in Appendix I. While the voice of people with disability and family members was strong and clear, it should be noted that only 18% of workshop participants were people with disability.

**Table 5** CLA on Stakeholder understandings of disability, vulnerability and the future

|  | **Disability** | **Vulnerability** | **Futures** |
|---|---|---|---|
| **Litany** | Be grateful<br>Keep expectations low<br>You're on your own | There's no vulnerability here<br>Inclusive communities are the answer | There's no optimism here<br>The future is uncertain<br>Negative past constrains the future |
| **Social Cause** | Inequality in valued status and access to resources<br>System works for providers not people<br>No privacy in the service system | Inaccessible transport and affordable living arrangements<br>Insufficient support creates vulnerability | Access to supports as measure of success<br>Funding always linked to political cycle—uncertain |
| **World-view** | People with disability need protection<br>Systems are untrustworthy | Knowledge is power<br>Community is dangerous<br>Invisible is vulnerable<br>Surveillance is dangerous | Uncertainty is negative<br>Choice is overwhelming and risky<br>Choice is an illusion |
| **Metaphor** | Eternal child<br>Life's a struggle | There will never be enough<br>Butterfly trapped in a cocoon | Life is a compromise<br>Dreaming is for children |

*CLA on disability*

At the level of litany**,** there were many common words and images used to describe the experience of having a disability, which suggested that negative experiences held people back from thinking about the future. While participants were generally positive about the prospect of NDIS commencing in Queensland, comments such as "there's no optimism here I'm afraid" indicated a lack of confidence that the reform would bring a brighter future for them.

During interviews, individuals with disability made reference to a lack of privacy and constantly being under surveillance. One individual referred to distracting herself to avoid thinking about her future, stating she considered her parents' need for peace of mind as being more important than her own preferences and privacy. She also said "I can have the lifestyle I want or I can have my needs met. I can't have both", indicating expectations that dignity and choice need to be compromised in order to access sufficient support.

At the litany level, family member participants consistently expressed concern about the future for their adult child as they age and ultimately die. For many family member participants, being able to secure safe, affordable, long-term living arrangements with access to support as needed was their greatest concern. While some expressed a preference for siblings to pick up the responsibility when they could no longer care for their adult child, many expressed the view that this might not occur or shouldn't have to be the case.

Concern about ageing was closely associated with reports of being physically and mentally tired from always pushing to have the family's needs met: "It doesn't matter how hard I push or how angry I get—nothing changes." Parents also reported being conflicted between the need to be strong and vulnerable at the same time; that is, strong to be an effective advocate and vulnerable in order to qualify for access to specialised supports and services, with several parents expressing comments such as "so what mask do I need to wear today to get what we need?" Family member participants were readily able to identify the tension between being an advocate and being dependent on maintaining good relationships with service providers to get access to services. The aspiration to be a smart navigator of the system was evident; that is, being well informed, compliant and visible to the service system.

At the level of social cause there were several references across all groups with regard to inequality in valued status and access to resources as a consequence. The inequality referred to related to a "hierarchy of disability with differentiation between people with physical impairment (preferred), intellectual disability (less preferred) and difficult behaviours (most problematic) with regard to inclusion in the community and living away from home. Distinction was also made between impairments acquired at or around birth and those acquired later in life, with the suggestion that people born with an impairment and their families had lower expectations for their future than those with acquired impairment.

In explorations of worldview, there was a suggestion by one group that people with disability are broken, need to be cared for and kept safe, giving rise to the assumption demonstrated that it's the state's responsibility to do so. There was no awareness expressed regarding the incongruence of this statement and the expectation of self-determination expressed earlier by the group. There was, however, awareness of this incongruence expressed through one-on-one interviews, where preferred lifestyle had been compromised for the lifestyle of a congregated living arrangement in order to have personal care needs met.

At the social cause level, family member participants cited scarcity of supports, particularly public housing and suitable alternatives, as the cause for their concern, exacerbated by lack of information from services and community. The options discussed in workshops focused on congregated models of living, including nursing home and retirement living models, without regard to age appropriateness. There was no awareness or reflection on the tension between parents seeking a safe, protected place to live away from the family home and the assertion that family are the only enduring, trustworthy relationships. There was no discussion around the experience of abuse and neglect in congregate living arrangements as outlined in the literature, for example Robinson and Chenoweth (2012), or the Productivity Commission report (2011). The comment "family are the only ones who care—because we have to" was consistently noted across workshops and interviews.

With regard to the metaphors associated with the lived experience of disability, the "eternal child" emerged strongly in the context of requirement for care and protection rather than playfulness. "Life's a struggle", "life's a revolving door" and "life as many people in a bathtub" were also strong metaphors emerging from the

workshops, particularly from service providers and people with disability as stakeholders. One parent described her experience as being like planning a trip to Italy with her family but ending up in Outer Mongolia with "food I didn't like, no public transport and my family being angry with me because they didn't want to be there". Later in the workshop she asked to retract the example because it made her sound like a bad mother. Other participants encouraged her to leave it in because it resonated so well with them; she agreed.

The metaphor offered during an interview "I'm a butterfly in a cocoon, unable to get out" was also powerfully expressed. On reflection, the interviewee noted that she would die if anyone helped her out—she would need to fight her way out on her own to be strong enough to survive.

*CLA on vulnerability*

At a litany level, vulnerability was expressed as both part of the human condition, to be acknowledged and dealt with, and as potential for physical, financial, emotional and sexual exploitation, requiring care and protection.

Individuals described vulnerability in terms of having insufficient support or lacking privacy, while family members spoke of fear that others would have power *over* their family member with disability. Family members did not speak of their own vulnerability in the same terms, rather they spoke of it with respect to being unheard and invisible in a system that is there to provide support. While service providers spoke of vulnerability that comes with being human, they also referred to some service providers as making people with disability more vulnerable through their service model, for example accommodation services that close during the day to reduce staffing requirements.

With regard to social cause, most participants referred to the "othering" of people with disability and their families that occurs in the community, particularly by the media, and the importance of specialised services acting as safety nets for people and their families. While there was some reference to the need for skills in keeping oneself safe, many referred to the value of enduring family relationships as the most important safeguard against harm. While some participants referred to vulnerability being associated with being alone, some people with disability indicated that never being alone was problematic also.

The underpinning worldviews that emerged included the view that the community is a dangerous, unreliable place—the idea that connecting with others means they potentially have power over the individual, and that needing assistance means loss of pride and dignity.

The need for masks both to protect and project vulnerability as required to get services was a strong metaphor that emerged. The image of a bathtub full of people spoke clearly of ambivalence, with too many people being just as problematic as too few. However, the strongest image was that of a butterfly struggling in vain to get out of a cocoon in the knowledge that to receive assistance from outside would potentially cause death.

*CLA on power to influence*

At a litany level, participants appeared to locate power for delivering better outcomes through the NDIS in the hands of service providers and the community.

Service providers appeared to be the most optimistic of participants, suggesting their power lay in creating an environment where individual strengths and abilities would become visible to the community as a platform for inclusion. People with disability appeared less optimistic, with one person reflecting that she had "used up her dreaming as a kid". Both people with disability and family members expressed various forms of the comment: "there's no optimism here".

With regard to social cause, several family members reported being old and feeling tired—too busy reacting and surviving in the present to worry about the future. Structural barriers, such as poor public transport and lack of funding, were raised as obstacles to achieving one's goals, as was the general sense of disconnection from community experienced by people with disability and their families. Service providers commented that the disability service system is driven by crisis rather than planning, thus is not future-focused.

The worldviews that emerged in exploring power to shape the future referred to choice as overwhelming and risky, systems as inherently corrupt and not to be trusted, and choice as an illusion.

The underpinning metaphors and images that emerged in exploring power to shape the future included images of revolving doors, of a dog cleaning up his own poo with a dustpan and a young girl dancing to her own music, which captured one

participant's angst over seeing her daughter as potentially self-determining yet oblivious to the danger in the world around her (see Figure 3).

**Figure 3**   Sample images and metaphors



## 4.3   Sense-Making Interviews

### 4.3.1 Purpose

A complementary process, sense-making (Dervin, 2008), was used to generate narrative to explore how individuals made sense of their experiences.  Sense-making refers to the internal and external behaviour people engage in to make sense of their world. It is based on the assumption that reality is neither constant nor complete and that information is the product of a subjective experience.  While workshops revealed images, examples and some narrative in response to the stimulus questions and interaction between group members, the interviews provided more considered,

personal perspectives on the issues discussed.  It should be noted that 30% of the interviewees were people with a disability and that these participants had physical impairment only.

### 4.3.2 Process

Ten people were interviewed, seven of whom also participated in a workshop.  All interviews were conducted in a quiet, hospitable space, such as a coffee shop or staff lunch room.  Allowing for individual and contextual differences, the interviews followed the following indicative questions:

1. Tell me a story or give me an example that reflects your experience of how power plays out for people with a disability.

2. What was your personal experience in that story?

3. What gave you power to influence/shape the future in that example/story?

4. What impact did being able to influence have on the issue?

5. What impact did being able to influence/shape the future have on you (or others) as a result?

6. Given the impact, would you use your power to influence/shape the future again?

7. If so, is there anything you would do differently next time?

### 4.3.3 Findings

Six of the 10 interviews were based on individual advocacy efforts on behalf of another person, one related to self-advocacy and three related to attempts to influence on behalf of the broader disability sector (collective).  Key lessons from the interviews were as follows:

- that the power to influence outcomes in one domain doesn't necessary transfer to other domains, for example "it doesn't matter what positional power you have as a person with a disability.  It's gone the second you walk through the doors of a hospital"

- that social capital (reputation, qualifications, networks) built in one context (e.g. professional life) does not necessarily transfer to other contexts (e.g. self-advocacy)

- that people will give away their power to influence in order to reduce the pain felt by family members, for example "my parents' need for peace of mind is greater than my own preferences and privacy"

- that small wins in trying to influence, whether on behalf of self, other or the collective, rapidly build confidence and willingness to influence again

- that influence often comes at a personal cost (financial, physical, emotional, reputational, relationship)—that is the cost of advocacy

- that the cost (risk) of advocacy can effectively be shared to reduce impact on individuals

- that fear and fearlessness in attempting to influence on behalf of self, others or the collective can co-exist

- that significant success in attempting to influence the future can become a life-long pattern

- that there is no level of chaos and complexity in one's life that cannot potentially be the platform from which people anticipate and shape the future.


Perhaps the most important learning was that potential vulnerability (due to impairment) can and does co-exist with significant power to influence the future both in the individual and collective domains.

## 4.4 Researcher Perspective

Across stakeholder groups the following observations were made.

For family member participants, having a family member with a disability significantly influenced the prosperity, health and wellbeing of the family and their aspirations for the future. A few participants spoke of persisting grief, vigilance and the reluctance to think about the future that occurs when you have a family member with disability. All spoke of the ambivalence that comes with their engagement with

the service system, acknowledging the need to learn how to navigate the system effectively to get a good outcome. Several people spoke of the need to work out which mask (or similar metaphor) was needed at any given time in order to secure the resources needed. Some participants referred to the need to work out whether to be stoic or angry or compliant at particular points in time. Overall, people with disability and family member participants appeared to disown their unique individual selves and associated talents, challenges and dreams in the process.

It was observed by the researcher that service provider participants, including those with a family member with disability, experienced tension between their desire to support people to be self-determining and working in a risk-averse, compliance-driven service system.

The participants with disability varied considerably in their positional power but spoke of the persisting disadvantage and disempowerment that is associated with having a disability for many people. Like some of the family member participants, they also spoke of the need to learn how to "play" the system to get supports required and the compromises to lifestyle and identity required. During interviews people with disability referred to their power base as fragile and dependent on the context, for example being a powerful advocate is no guarantee of being empowered in the health system as a patient. All participants were circumspect about their own dreams for the future, with some references to dreams being a childhood activity.

## 4.5    Sense-Making in CLA Workshops

A range of sources of anxiety associated with uncertainty were noted for participants across all stakeholder groups. Knowledge of how to navigate the service system and relationships with key people were considered critical. Relevant knowledge included: decision-makers; points of influence, for example being on management committees of non-government organisations; and awareness of funding-round schedules. The knowledge gained was apparently used to inform behaviour; that is, timing of when to speak up and whether to amplify or understate problems, and whether to adopt a conciliatory or feisty tone.

Relationships appeared to be a particular source of anxiety, particularly with regard to the tension between having a voice and not compromising service levels.

Additional tensions were noted between the idea of an inclusive, welcoming community as being the way forward for people with disability and their family, yet considered dangerous and a potential source of harm for the innocent. Similarly, the service system was seen as both necessary for success but untrustworthy. People with existing funding packages appeared fearful that they may lose their entitlement under the new system and were unsure of whether it would be best to speak up or stay quiet to get the best outcome.

The most common response to fear and anxiety, where it was evident across the workshops, was for people to attend all available opportunities to increase their knowledge about the NDIS, irrespective of cost. Knowledge and its potential to reduce uncertainty was considered the best source of power over the future. Unfortunately for some, the price of such power was exhaustion and fear for the future always being present.

## 4.6   Summary

- There were significantly more women in the participant group than men; however, the pattern was similar across workshops and interviews.

- CLA served the purpose well as a structure for the workshops.

- All stakeholders appeared comfortable with the language and process of CLA.

- Participants were observed to move freely between the four layers of CLA and between the three constructs of disability, vulnerability and power to shape the future.

- People appeared to readily acknowledge alternative worldviews and were willing to consider and explore the perspectives of others.

- The use of sense-making for interviews provided an effective balance of structure and flexibility to allow for free-flowing conversation.

- Sense-making interviews invited reflection and appeared to reveal more of the story to the story-teller as they told it.

- The use of image cards was effective. People readily chose images to share with the group and were willing to explore the images chosen by others.

A full analysis of findings is provided in the next chapter.

## 4.7  Conclusion

CLA and sense-making were both considered to be effective tools for exploring the research questions and for use with the target population. Both tools served the purpose of creating transformative space. While many people had strongly held perspectives, the degree of certainty with which those perspectives were held was observed to soften over time during the course of the workshop or interview.

In combination, the two methodologies allowed for both deeper reflection that comes with sharing a story continuously, and the chance to inform and be informed by the perspectives of others in a group setting. The themes that emerged were both similar and complementary.

# Chapter 5: Analysis

This chapter addresses the central constructs of disability, vulnerability and power to influence the future using individual stakeholder perspectives generated through the CLA workshops and sense-making interview processes. Both CLA and sense-making are applied as tools of analysis across all data. In consideration of this analysis, it should be noted that this research was limited to people with a physical disability for ethical reasons. A total of 18% of workshop participants and 30% of interviewees were people with a physical disability. Given participants self-selected with knowledge of the purpose and process of this research, there was no expectation that people with disability included in the study were typical of all people with disability, or all people with a physical impairment.

## 5.1    The Impact of Discourse

### 5.1.1 On Having a Disability

While there appeared to be a dominant view of disability as a social construct—that is, the community and service system is the source of disablement and therefore must be the solution—it comes at the expense of individual agency and power to shape the future.

The literature review relating to discourse outlined the evolution of disability discourses in chronological order. This research demonstrates that the discourses not only overlap with regard to key elements but lack integration. Whether this is because of a lack of critical reflection or because structure has failed to keep up with successive discourses, the result is that elements of multiple discourses were evident across all stakeholder groups and constructs of disability, vulnerability and power to shape the future. If, as suggested by Barnes et al. (2002), discourse has the potential to either open up or close down the future, this lack of integration of discourses from the time of custodial care and protection in the early 1900s to the current worldview with disability as a social construct could be problematic.

Perhaps the clearest example of a lack of integration in disability discourses was in the enthusiasm for congregate living arrangements noted in some workshops (from parent participants) that reflect the earlier moral and medical discourse. Seeing

disability in terms of personal tragedy or individual pathology was evident in comments such as "the community tolerates people at best. It's not inclusion or real participation", "I feel real fear and heavy responsibility for the safety of my [adult] child" and "we say it can happen to anyone but the reality is the responsibility is worn by the family". Comments such as "the community thinks disability is contagious" and "society keeps people with disability out of sight" provided the strongest evidence of the moral and medical models persisting at a time when the NDIS is providing images and expectations that individuals and families will be powerfully shaping their own future. While participants did not readily identify the incongruence between such statements and the promise of social and economic participation under the NDIS, the impact was evident in those who aspired to congregate living arrangements and activities. There was no reference to or acknowledgement of the abuse and neglect of people with disability in institutional settings in Australia (and in particular Queensland), as highlighted in various enquiries over the past 20 years.

Also unexpected was the contradiction between the community being considered a dangerous place and willingness to actively seek congregate living arrangements for adults with disability.

### 5.1.2 On Self

While there were comments such as "some people are naturally risk-takers and some aren't" there was otherwise no acknowledgement of individual variation in personality, gender, culture, lifestyle choices or personal aspirations as being significant to identity. This applied across all stakeholder groups.

Other than referring to themselves as "getting older" or "tired of being angry" and a strong desire for their adult child with disability to be "taken care of" before they die, parents did not express any other plan or dream for the future. It was the researcher's observation that most parents resisted or at least had difficulty imagining a life other than the one they had already experienced.

One person spoke of making the deliberate choice to defer her own lifestyle preferences in order to give her aging parents peace of mind. On reflection about her own preferences and expectations for the future, she noted that loss of privacy was the greatest loss, but also said "I used up all my dreaming when I was young".

Comments from workshop participants such as "I have to be practical" and "there's a limit to dreams that can be achieved" were frequently noted.

At the social cause level, there were no responses at any level of discussion in workshops or interviews that referenced the need to strengthen skills or capacity to make decisions or be self-determining. There was strong focus on the need for the service system to be responsive and for supports to be adequate.

Discussion of metaphors and images revealed a range of conflicting statements and images, from "anything is possible" to the assumptions that the vulnerability that co-exists with disability means choices relating to the future are limited. Tensions were also noted between "reading the system to get what you need" and being "master of one's own universe". Being "master of one's own universe requires a strong identity, strong sense of who you are and what you stand for and I'm not".

In Bourdieu's (1977) framing, individuals navigate social "fields" of ideas and concepts in an ongoing way, using identities. Each of these identities has characteristics that allow them safe passage but advantage is dependent on context. Some identities may be misaligned with the values of other identities and, judging by the responses of participants in this research, may require behaviour that causes discomfort. Examples include the need to amplify deficit of a family member with disability or the need for an individual to compromise their own lifestyle preferences for peace of mind of a parent. The presence of multiple identities used to navigate the social service system was clearly evident in the participant group, particularly as "masks" worn by people with disability and their families in order to have their support needs met. The descriptions of "masks" being utilised drew parallels with references to the selves that develop in response to the vulnerable self of one's childhood, as described by Hal and Sidra Stone (1989). Even during the course of workshops and interviews, code switching, as described by Gramsci in Hoare and Smith (1971), was noted as people moved between the identities of angry parent, compliant service user and capable board member, indicative of hegemony.

Both Bourdieu (1977) and Gramsci (Dylan, 2011) describe these identities as being made up of ideas and concepts the individual didn't knowingly create; that is, they are given by society rather than generated by choice. This gives rise to the question about who is the authentic self? While participants in this research readily

identified the need to adopt masks (identities) for the purpose of navigating the social service system and accessing services and supports, reference to authentic self was notably absent. Bourdieu's (1977) concept of habitus is useful in that it accommodates the notion of authentic self, surrounded by imposed ideas and concepts which often render the authentic self invisible.

### 5.1.3 On Community Inclusion

Perhaps of greatest concern were the unexamined assumptions about the community being dangerous and unreliable, particularly given the NDIS value proposition, which includes the community stepping forward to provide supports both informally and through mainstream services and facilities. Of more significance at an individual level was the contradiction between families desperately seeking congregated living arrangements in the community, yet expressing fears that the community is dangerous and not to be trusted. This tension appeared to reflect untested assumptions about the value of community, the value of congregate living arrangements or any alternatives other than public housing. No discussion was noted around individuals' ideas or preferences for a home.

The beliefs around these opposing positions were held, at least at the outset of dialogue, with a high degree of certainty and suggest that the concept of choice and control as used by the NDIA requires further exploration. Data yielded in this research indicate further contradictions with regard to choice as liberating or overwhelming, and control as an illusion.

The narrative around the NDIS focuses on participation in the social and economic life of the community and an assumption that the community will welcome such engagement. Responses in both workshops and interviews suggest a lack of clarity around definition of "community" and a general lack of trust that the community will welcome such engagement. There are tensions between the idealised view of "everything is possible" and "the community is willing to embrace difference" and the reality of inadequate housing options, and high levels of unemployment and associated disadvantage for people with disability.

Tensions were also apparent in the promise of individual choice and control in a disability support system that, while better resourced, seems just as bureaucratic as the old one.

### 5.1.4 On Othering

The Clapton and Fitzgerald (1997) reference to otherness as a story of marginalisation even by those who are themselves marginalised was confirmed by reports from participants that level of access to resources and valued status more broadly was driven by the type of disability, ranging from physical disability (preferred) to intellectual impairment (less preferred) to people with challenging behaviours (least preferred). Such comments suggest that value is determined by how well the system responds, rather than contributions or strengths of the individuals themselves. Some participant comments reflected the moral underclass discourse, which justifies exclusion from society on the basis of moral and behavioural delinquency (Levitas, 1998). While there were no references to exclusion of people on the basis of behaviour, there were references to "class distinctions" and the view of participants that people with challenging behaviours have less favourable access to services and supports. Meekosha and Shuttleworth (2009) note the way societies divide "normal" and "abnormal" as being central to what it is to be human, and the critical determinant of choice and participation in civic life.

Dan Goodley (2011), drawing on the ideas of Michel Foucault, suggests that in an educational context the practice of labelling people as impaired constructs them as objects. While such labelling has and continues to be a pre-requisite for access to specialised supports and services in Australia, Tremain (Tremain, 2005) distinguishes between Foucault's notion of disciplinary power, which is productive (allowing access to services and supports), and his conception of sovereign power, which is oppressive and disempowering. There has been little critical reflection on this in recent literature or policy documents.

The medical model, which defines disability as a result of individual pathology and the responsibility for remedy with the individual rather than society (Bury, 1996; Shakespeare, 2014), was also clearly evident in participant responses. The element of discourse that describes power *over* individuals (to give or withdraw support) by professionals was also evident in participants' comments. They described a range of behaviours to influence the outcome of such engagement, with clear tension between getting a good outcome and maintaining relationships (and long-term potential for having needs met) in the process. The element of the medical model discourse

relating to being under surveillance was also reflected in comments and images from workshops and interviews.

Disability as a social construct was clearly evident in the narrative of participants, but in the context of causing disadvantage and exclusion rather than as a platform for transformation.  For most participants, including service providers, the struggle for individuals to influence (endure) their own current situation was enough, leaving little energy or desire to shift the collective experience of people with disability and their families.  As Shakespeare (2014) suggests, it is debatable whether the identity of the oppressed minority is an essential ingredient of effective social movements.  He suggests the social model has not consistently been a driver of social change and the findings of this research support this view.  The call from Kumari-Campbell (2009) and Meekosha (2008) for further exploration of the understanding of power relations associated with the imagery and symbolism of incapacity is also validated by the findings of this research.

Perhaps, as asserted by Shakespeare (2014), we have gone too far.  While the social model discourse is contemporary and defensible, it assumes that the people who live it have integrated the former discourses of personal tragedy.  Without integration we have moved to a place where not only is disability a personal tragedy but we have located the source of solution as external to individuals and families—that of disabling environments and policy.  While locating responsibility for change with policymakers, the designers of buildings and homes, and institutions may be reasonable, perhaps in doing so we have further disempowered people with disability and their families as creators of their own future.  For those participants who had experienced success in influencing both individual and collective circumstances, there was little confidence that this power would generalise to all circumstances.  For example, one person indicated that his power, both positional and through advocacy successes, was surrendered when he walked through the doors of the health system.

There was little evidence in workshop responses of citizenship and rights-based discourses.  Given the purpose of current reforms is to maximise social and economic participation in society, this should be of concern.  Barnes et al. (2002) suggest that denial of basic rights—the right to vote, the right to have basic needs met, the right to safety and sense of wellbeing—takes away the power of citizens to shape or reshape their current and future reality.

Bourdieu (Bourdieu, 1991) reminds us of the power of the language we use and the stories we tell ourselves in legitimising power structures. While the language of the NDIS has been about individual choice and control, that language did not show up in participant responses. Choice and control were referred to in rhetorical terms and by one participant as "an illusion". The more dominant narrative relating to influence that emerged from both workshops and interviews was that of needing to "read the situation and work out which identity to play".

If, as described by Paul Abberley (Abberley, 2002) discourse is our attempt to understand the social world and ultimately govern our path of action, then the discourse revealed in both workshops and interviews suggests we are caught between deep discouragement and cynicism about the benevolence of community and a desperate need for inclusion and shared responsibility for people with disability having a good life.

## 5.2    The Nature of Vulnerability

Gorur (2015) suggests that how we define vulnerability is of significant consequence. The findings of this research suggest that the way we understand vulnerability is not only relevant to the subject but at the heart of how people perceive their experience and think about their future. Feedback from participants indicates that while people espouse vulnerability as part of the human condition, as suggested by Brene Brown (2013), the vulnerability associated with impairment is a powerful driver of behaviour and how people view the future.

Less visible to participants was the vulnerability evident in the denial of self they described in choosing "masks" that would serve them best as they deal with the service system to have needs met. For most, the vulnerability related to others having power *over* them, for example physical, sexual, emotional or financial exploitation. For others the vulnerability was in the context of exposure to harm in an unreliable, potentially dangerous community.

With regard to their own vulnerability, it was noted that family member participants readily articulated using a range of "selves" that would best serve their purpose in accessing supports for their family member. The researcher noted shifts in many participants between identities described by Hal and Sidra Stone (1989) as emerging in response to their own vulnerable selves, including but not limited to the

tired, discouraged self, the feisty advocate self, the protective mother, the angry citizen and so on.

The literature suggests poverty as a reasonable measure of vulnerability (Gorur, 2015) however, poverty was not raised in either workshops or interviews as a source or manifestation of vulnerability. Fear of violence or homelessness, while not verbalised, was implied in the narrative and observed by the researcher. While participants had a strong focus on transition to living arrangements outside of the family home in the workshops, there was no reference to evidence—either anecdotal or in the literature—relating to abuse and neglect while in institutional (congregate) living arrangements as a consideration.

The presence of enduring family relationships in a person's life was considered a major protective factor, as suggested by Gravell (2012); however, there was no reference to other protective factors such as involvement with disability service providers, safer public spaces or greater civic mindedness in communities as suggested in the literature.

It was noted by the researcher during workshops and interviews that participants were more comfortable discussing vulnerability in a collective social context than as an individual circumstance. According to Shakespeare (2014), this phenomenon risks giving too little weight to impairment as a source of difference and denial of opportunity for appropriate supports for responding to need. It also potentially denies a critical element of the individual's past experience and fears for the future.

## 5.3   The Power to Influence

There was a perception common to all stakeholder groups in the workshops that our societal structures constrain rather than enable people with disability and their families, even when they appear to be neutral and independent. There was, however, little awareness of constraint by the narrative itself as suggested by Merquior (1991). Foucault (1972) cautioned against seeking to define patterns in how power plays out and, indeed, the application of power reported by research participants tended to be reactive and without clear pattern. Reference to power over people with disability and their families was frequent, usually associated with stories or images of individual exploitation. The idea of power to influence was readily discussed in association with

getting access to services and supports in the past or present but not in the context of anticipating and shaping one's experience in the future.

Bourdieu's (1977) construct of habitus provided a useful reference point for stories, images and metaphors, suggesting ambivalence and contradiction in the experience of disability, vulnerability and power to influence the future depending on context. Family members especially were well versed in the cultural and social capital needed to get a good outcome in the disability service system and of their place in the "social order"; however, reports of their experience influencing the system indicated it did not guarantee success.

The self-critical reflection Bourdieu (1977) considered important for making sense of experiences was not noted amongst workshop participants. Navarro (2006) highlighted the absence of self-critical reflection as problematic in terms of social change, as self-critical reflection renders visible sources and asymmetries in power.

An impression that emerged for the researcher on completion of the workshops and interviews was that participants across all stakeholder groups work so hard to resist power *over* that their power *to* is also diminished. The suggestion by Laszlo (1989) and K. Boulding (1990) of a more integrated approach to power discourse— one based on reciprocity, mutuality and interdependence—would find a useful place in this discussion.

## 5.4 Anticipating and Shaping the Future

Across stakeholder groups there was wide variation in feedback, with some service providers projecting an abundance worldview (anything is possible, we have everything we need) and the majority who projected a deficit/poverty worldview.

Tension emerged when a parent described the experience of having a child with disability using negative images, then later wanted to retract the comments because it sounded like she was a bad parent. Others encouraged her to leave the description as it resonated well for the rest of the group and "felt honest".

Tension also emerged between participants (all groups) wanting to "maintain the rage" by remembering the experiences of the past (negative images) and focusing attention on positive images of the future. Minimal awareness of the impact of where people choose to focus their attention was noted.

Not only was the prevailing worldview demonstrated by the majority of workshop participants deficit-based, but the degree of certainty in those beliefs and assumptions was high. While the degree of certainty was noted by the researcher to soften over time, as the underlying layers became visible, it appeared to be an obstacle to imagining alternative possibilities for life in the future.

CLA provided both the theory and tools for exploring the constructs of disability, vulnerability and power to shape the future across all three stakeholder groups in both workshop and interview settings. Sense-making as a tool provided a clear structure for the interview but benefited from the addition of CLA for analysis.

Primary benefits of the CLA process include the gradual revealing of layers of belief and assumptions about current reality and the emerging opportunity to examine and ultimately reconstruct reality. The deconstruction process was non-confrontational and, while significant emotional responses were evoked, these were accommodated and to, at least some extent, integrated with each successive layer. CLA created a space where the softening of viewpoints occurred over time, allowing more flexibility on what counts as truth. Occasionally participants would repeat a similar, softer version of an earlier statement having had time to reflect and listen to other participants' viewpoints.

The use of images to stimulate discussion and represent perspectives at every layer (litany, social cause, worldview and metaphor) was particularly useful with this population as it removed the need for literacy or confidence in a group setting. Many participants chose images as the starting point for expressing themselves, including those who were well experienced at presenting in a group setting.

It is the researcher's observation that people will develop confidence in reflecting on their own and others' experiences, be able to process and integrate conflicting beliefs, assumptions and experiences over time and use the experience as a platform for opening up a range of possible futures. Such a process is potentially an antidote to the fear and resistance which appears to have surfaced as we move towards the NDIS.

Workshop participants readily chose images over words to describe their experiences, assumptions and aspirations for the future, reflecting Fred Polak's (1961) view that the generation of imagery is the key dynamic of history. Polak also

suggests that when the images are associated with pessimism and a sense of helplessness, as seen in the workshops, players remain bound by the present, with no social dynamic for the change available to them. The data gathered, especially those through the workshops, suggest this may be true. The source of negative images did not appear to be related to the negative imagery used in leveraging support for the NDIS, as suggested in the prologue of this thesis, rather they were a reflection of lived experience and perception.

Rather than a high level of tolerance for ambiguity, suggested by Miller and Poli (2010), as a pre-requisite for anticipating the future, the data and researcher observations revealed significant duality and tension between strongly held positions. For example, service providers operate with a mandate to provide individuals with choice and control within the constraint of a highly risk-managed, compliance-driven funding arrangement. Family members espouse enduring family relationships as the only protection against harm, yet are seeking congregated care-based living arrangements in a community they regard as unreliable and potentially dangerous. People with disability themselves are caught between aspirations for a decent life and lifestyle, yet accept poor-quality supports and living arrangements. The "both-and" perspective (that both conditions may co-exist) suggested by Inayatullah (2015) to reconcile such tensions was not apparent in the data collection.

On the whole, the capacity for reflective, imaginative conversation and new metaphors was somewhat limited in the workshops. Perhaps of most concern was the lack of perception evidenced through narrative or image, that people with disability, their families, or service providers are self-determining. As Wolfensberger (1972) suggests, perceptions of social value are associated with self-determination; as such, these findings are significant.

On a positive note, the literature suggests a way forward in futures work. Bussey (2014a) suggests that opening up future possibility is an antidote to the sense of powerlessness that comes when our sense of identity is entwined with the present moment. Hutchinson (2005), Hicks (2006), Milojević (2005) and Reardon (1988) remind us that lived experience is just one of the raw materials needed to imagine a different future and that imagining the future is a capacity that can be taught. The opportunity to strengthen reflective capacity, particularly in the face of poorly

integrated discourse around disability, vulnerability and power to shape the future, also offers a way forward.

It is the experience of the researcher that strengthening reflective capacity not only softens the degree of certainty with which limiting beliefs are held but reveals potential for opening up the future to a range of possibilities.

## 5.5    Summary

The following points summarise the key findings of this stage of the research process:

- Numerous tensions and contradictions were noted in the comments of participants as data gathering unfolded.

- The strongest ambivalence was noted with regard to community, which was considered both a source of possibility and a source of danger.

- A lack of optimism for the future was associated with the idea that dreaming is "for children".

- Feedback suggested that people value knowledge needed to navigate the system to access resources more highly than self-determination.

- People stated they were willing to adopt whatever mask (identity) needed to get what they or their family member needed.

- The discourse of disability as a social construct was used to explain disadvantage and exclusion, rather than as a platform for transformation.

- While some people had experienced success with attempts to influence their circumstances they had little expectation that this power would generalise to other contexts.

- Choice was considered by some to be an illusion.

- Vulnerability appeared to be a powerful driver of behaviour, though it was not always visible.

- Vulnerability was mostly understood in terms of power *over*, in the form of physical, sexual, emotional or financial exploitation at the hands of a potentially "dangerous" community.

- While the literature suggests poverty as a measure of vulnerability it was not raised as a source or manifestation of vulnerability.

- Fear of harm and homelessness were not verbalised but were implied in the narrative.

- The importance of enduring family relationships as a protective factor was raised, but there was no mention of other protective factors such as involvement with services, safer public spaces or greater civic mindedness.

- People appeared more comfortable discussing vulnerability in the collective, rather than individual, context.

- With regard to power, people with disability and their families were familiar with the idea of building social capital to help get good outcomes from the system, but had little expectation that it guaranteed success.

## 5.6   Conclusion

The data collected using both methodologies were consistent with experiences since the beginning of the transition to the NDIS: that people have difficulty being optimistic and are somewhat resistant to re-imagining the future.   Persistent worldviews that "life is about compromise" sit awkwardly with NDIS principles of "choice and control".

Perhaps of most concern was the impression that emerged that people work so hard to resist power *over* that power *to* is also diminished.  The next and final chapter of this thesis provides consideration of the broader implications of this research for the next stages of NDIS implementation.

# Chapter 6: Conclusions

## 6.1 Main Aims of the Research

The aim of this research was to examine the paradigms and constructs that became visible when multiple stakeholders engaged with the concepts of vulnerability, disability and agency over the future through a workshop and interview process. It was anticipated that by allowing stakeholders the opportunity to reflect on the patterns and connectivities between the concepts of vulnerability, disability and agency over the future, if indeed they exist, it may be possible to unlock an otherwise constrained set of alternative futures for people with disability.

In considering the implications of feedback, images and stories generated by this research, the impact of the researcher's power must not be overlooked. However, throughout this research the voice of people with disability was strong and clear, remaining at the centre of every research question.

## 6.2 Research Questions and Findings

The literature review provided the context in which this research was located and gave rise to the research questions. Each question and the associated findings are discussed below.

### 6.2.1 RQ1: How do Stakeholders Interpret "Reality" with Regard to Disability, Vulnerability and Power to Influence the Future?

Elements of multiple disability discourses were visible across all stakeholder groups, indicating a lack of integration of each discourse over time. Impairment was seen as static rather than contextual, and as personal tragedy rather than a social construct. Physical access and lack of specialised supports were mentioned as constraints; however, other aspects of the social model discourse, such as language, culture and discrimination, were not evident in the discussions. There was no reference to entitlement or rights as might be expected of a citizenship discourse, and the assertion by Rioux (2002) that people with disability lack both capacity to give effect to these rights and ultimately trade rights for charity is well demonstrated by the comment from one woman with a disability: "it's a trade-off—dignity and choice for charity; lifestyle for having needs met and I can't have both". The metaphor of the "perpetual

child" for adults with disability was strong, as was the experience of "otherness" as described by Clapton and Fitzgerald (1997) and Milojević (2013).

The lack of integration in disability discourses was reflected in the unexamined contradictions and tensions visible in the data across all stakeholder groups. Service providers operate with a mandate to provide individuals with choice and control within the constraint of a highly risk-managed, compliance-driven funding arrangement. Family members espouse enduring family relationships as the only real protection against harm, yet are actively seeking congregated care-based living arrangements in a community they regard as unreliable and potentially dangerous. People with disability themselves are caught between aspirations for a decent life and lifestyle, yet accept poor-quality supports and living arrangements.

Similarly, participants demonstrated ambivalence with regard to vulnerability, on the one hand referring to vulnerability as part of the human condition and, on the other, a source of fear and resistance. For the most-part, vulnerability was not acknowledged other than in the context of masks that project or protect vulnerability for the purpose of accessing resources. While there was no reflection on the nature of vulnerability associated with disability, the data indicated a perception of vulnerability as an individual attribute rather than the consequence of a complex, inter-related set of external circumstances. In contrast, consequences of vulnerability, such as poverty and disposition to harm, were implied but not explicit. Perhaps as a consequence there was also no mention of interventions that might reduce vulnerability, such as opportunities to build skills and confidence and improve outcomes as suggested by Gorur (2015).

Most consistently, the medical model discourse showed itself amongst family members, with perceptions that they ultimately bear responsibility, rather than disability being a responsibility of society in general, evident in comments such as "I feel real fear and heavy responsibility for the safety of my [adult] son." While there were references to siblings taking up the responsibility, most frequently parents were seeking alternative living arrangements for the future. The constraints of specialised, institutional living arrangements were neither acknowledged nor explored during data collection.

The interplay between vulnerability and power to influence the future was evident in references by several participants to the use of masks to either protect or project vulnerability to suit the context; that is, to maximise access to supports. Hal and Sidra Stone (1989) suggest that suspending or redirecting our own vulnerability may be a means of protecting the "vulnerable self". Levinas, as cited in Davis (2004) suggests that it not only protects us from dealing with our own vulnerability but that it limits collaboration and acts as a barrier to collaboration.

Shadows of the moral model and its construct of the "deserving poor" were also noted in reference to the hierarchy of disability, based primarily on type of impairment, when it comes to accessing supports. People with physical disability were considered most likely to receive supports, people with an intellectual disability were less likely to receive supports and people with challenging behaviours were least likely to receive supports. This belief was articulated by a number of participants, across all stakeholder groups, and requires further exploration.

The discourse that was conspicuously absent was an economic discourse. The greatest leverage for the NDIS as a policy reform came from the economic argument—not only the savings in welfare spend when people are participating socially and economically in their community, but the return on investment when people with disability and their carers enter or re-enter the labour market and pay tax. While activists largely argued on the basis of entitlement to participate socially and economically in society as a human right, it was the actuarial and economic argument that was most persuasive politically.

There was little or no reference to poverty (or associated homelessness, marginalisation or poor health outcomes) as a source of vulnerability or as the reason for relying on the state to provide services and housing. Likewise, the possibility of increasing income as a means of increasing lifestyle choice, financial security, peace of mind or personal wellbeing was not raised by workshop or interview participants.

With regard to power to shape the future at a system level, the most notable finding was a lack of optimism. Stakeholders were generally positive about the NDIS being more equitable, better resourced and a fairer means of distributing those resources; however, participants were not necessarily positive about the future. Reluctance was noted across all participants to imagine (or re-imagine) the future and

the construct of an extended present, as initially described by E. Boulding (1988) and later by Slaughter (1995).

Persistent views that systems are inherently untrustworthy and that too much choice is overwhelming anyway, while acknowledged as unhelpful, were evident in the data. These views also indicate, as suggested by Inayatullah (2015), that people see the future as *given* rather than *created*. While a lack of a sense of self-determination and power to shape the future was evident across all stakeholder groups in the workshops, the lack of critical reflection on how long-held beliefs can be limiting was also considered significant. Perhaps most significant was the degree of certainty people had regarding beliefs about how the world works and the current reality for people with disability and their families.

A more positive experience and higher general expectations of being able to influence the future were noted in the one-on-one interviews undertaken as part of this research. Six of the 10 interviews were based on individual advocacy efforts on behalf of another person, one related to self-advocacy and three related to attempts to influence on behalf of the broader disability sector (collective). The following lessons emerged from the narrative:

- that power to influence outcomes in one domain, for example in the context of advocacy for others, does not necessarily transfer to other contexts (e.g. self-advocacy)

- that social capital (reputation, qualifications, networks) built in one context (e.g. professional life) does not necessarily transfer to other contexts (e.g. self-advocacy)

- that people will give away their power to influence in order to reduce the pain felt by family members

- that small wins in trying to influence, whether on behalf of self, other or the collective, rapidly build confidence and willingness to influence again

- that influence often comes at a personal cost (financial, physical, emotional, reputational, relationship)—that is the cost of advocacy

- that the cost (risk) of advocacy can effectively be shared to reduce impact on individuals

- that fear and fearlessness in attempting to influence on behalf of self, others or the collective can co-exist

- that significant success in attempting to influence the future can become a life-long pattern

- that there is no level of chaos and complexity in one's life that cannot potentially be the platform from which people anticipate and shape the future.

Perhaps the most important learning was that potential vulnerability (due to impairment) can and does co-exist with significant power to influence the future both in the individual and collective domains.

With regard to the way power plays out across the social service system and community, Bourdieu's (1977) reference to networks of habitus (individuals surrounded by ideas and concepts) is useful. Power is not inherent in any one place but executed when labels are applied to parts of the network influencing their behaviour toward each other in positive and/or negative ways. The labelling of people as service users rather than citizens, as welfare recipients rather than workers, and allowing disability to be their central defining characteristic, is likely to have a lasting negative impact. The findings of this research suggest that critical reflection on how people interpret "reality" with regard to disability and how power plays out across stakeholder groups requires further attention.

It was the researcher's observation that strongly held beliefs and assumptions softened over time, rendering them at least partly visible and potentially able to be examined as a means of individual and collective empowerment.

A high level of self-reflection (perhaps inspired by the sense-making interview questions) was also evident in the interview responses which provided more positive experiences of influence. These findings suggest that while dominant discourses around disability and vulnerability may have shaped our service system and, indeed, influenced how people with disability view themselves, their negative impact on expectations of influence is not universal.

### 6.2.2 RQ2: How does Power Play out across Stakeholder Groups when Considering the Future for People with Disability?

There were no direct references to the use of coercive power over people with disability or their families by individuals in this research; however, the power of "independent, neutral" structures to constrain individuals with disability, their families and their service providers was evident throughout the data gathering process. One interviewee, a family member, said that she "worked so hard not to exercise power *over* her son [with disability]" that she had "lost her power *to* influence effectively on his behalf".

Foucault (1997) refers to examinations in schools and workplaces as examples of how such power is exercised in less obvious, but potentially more damaging, ways than custodial care. The entry and assessment processes of the NDIS—both the process and stakeholders' perceptions—are examples relevant to the context of this research.

In spite of the shift from funding delivery through service providers to funding provided directly to individuals and families, the voice of service providers has been privileged in policy development and preparation for the NDIS. The greatest investment in preparation for the future has been for the service system itself—both for the administration (NDIA) and delivery (non-government service providers) components of the system. This investment has focused on innovation in service design, reconfiguration of accounting systems to accommodate individual funding packages rather than block grants, and investment by service providers to retain market share. Relatively little investment has been provided directly to people with disability, their families or consumer advocacy agencies to prepare for their future. Very little investment has occurred to inform people with disability who are not existing service users, or the school, business or broader communities. Marginalised parts of the population, such as people from non-English-speaking backgrounds and people living in rural and remote parts of Australia, have also been largely excluded from NDIS preparation activities.

Participants appeared to locate power for delivering better outcomes through the NDIS as being in the hands of service providers and the community, but expressed ambivalence about community benevolence with comments such as "the community is dangerous and unreliable". While service providers were the most optimistic of

participants and reported their role as building on the strengths of individuals with disability to support community inclusion, people with disability and families were less optimistic. This appears to be related to structural barriers to inclusion, such as poor public transport and lack of affordable housing, as well as to fatigue and lack of hope. A general assumption across all stakeholder groups that the "system" is driven by crisis rather than planning was also dominant.

Empowerment of people with disability, their families and other stakeholders is implied as a goal in the NDIS policy reform. While empowerment is understood as manifesting in "choice and control" there is little reference to the prevailing beliefs and assumptions that underpin the constructs of choice and control. Given the NDIS is a funding administration scheme, one assumption is that financial resources and the supports they purchase will empower individuals to live a decent life. However, the level of funding is capped and the products and services that may be purchased are limited by the NDIA to those considered "reasonable and necessary". The individual budget for supports is determined with consideration of need and context—existing networks. Goals and aspirations have been removed from the entry-level planning process in the interest of expediency. Appeals processes relating to funding decisions are primarily internal to the NDIA; the invitation to dream, to explore a wide range of alternative futures, or to appeal institutional decisions is not part of this disability reform, potentially limiting its capacity to deliver on the promise of individual and societal transformation.

### 6.2.3 RQ3: How does the opportunity to deconstruct "reality" for people with disability open the path to multiple futures?

Overall, the demonstration of reflective, imaginative conversation to open the path to multiple futures was limited in the workshops. Perhaps of most concern was the lack of perception evidenced through narrative or image, that people with disability, their families or service providers are self-determining, evidenced by comments such as "choice is an illusion. There is no choice." Given the researcher observed a significant softening of viewpoint or degree of certainty in position in most participants over the 2–3-hour workshop it is considered likely that this capacity may develop over time. Most participants appeared to enjoy the use of images as part of the CLA process, with many appearing to prefer the images to articulating their perspective, irrespective of whether their perspective was positive or negative.

## 6.3    The Need to Find a New Narrative

The archetypal story structure, as reflected in Joseph Campbell's hero's journey (Campbell, Cousineau and Brown, 1990), starts with a protagonist with a quest or striving (dream), followed by a range of obstacles to achievement of the quest (tension), followed ultimately by a reversal.

In reference to the hero's journey, media-based futures commentator Douglas Rushkoff (2013), in his book *Present Shock*, asserts the driver of the reversal holds the greatest power to influence.  He suggests this power to influence comes because the audience of a well-told story will agree to compromise or sacrifice in order to experience the reversal they've come to expect at the end of the story.   The observations made during data collection suggest that this is the case across all stakeholder groups in the context of the current disability policy reform.  The various alterations to the entry and planning process for the NDIS mean significant compromise to the aspirational focus on the future initially promised, to which there has been no apparent resistance; without a dream, there is no quest to anchor the story.

Douglas Rushkoff's (2013) book is based on the construct of present shock, with reference in name to Toffler's *Future Shock* (1970).  While Toffler's central theme was about resistance to rate of change, Rushkoff alludes to present shock as a manifestation of this resistance—the future collapsing in on itself, as seen in "reality" TV, satirical cartoons and popular series where there is no hero's journey.   The protagonist remains locked in a perpetual storyline that lacks quest, tension or reversal (outcome).   The characters themselves are locked in a perpetual state, with no apparent quest, no expectations of conquering challenges and no expectation of an end to the story.  The characters appear frozen in time rather than traversing time.

The general narrative emerging from this research follows a similar pattern. Metaphors of the "perpetual child" and "life as a revolving door" speak clearly to this conclusion.  While the NDIS could potentially provide the platform for altering this pattern, data suggest the pattern is more dominant than the hero's journey archetype. People with disability and their families who participated in this research tended to draw their power (defined as having access to supports) from navigating (either defensively or fiercely) the system to have their needs met; that is, from resistance to

not having needs met, rather than being inspired by a dream or quest. Similarly, there was little expectation of overcoming obstacles (though there was no shortage of obstacles in the system noted) and no expectation of reversal of fortune or attainment of quest. There was little sense of traversing time or being engaged in a journey, but a strong sense of being frozen (stuck) in the moment.

The original narrative around the NDIS was indeed the story of the hero's journey—an effectively crafted narrative around unmet need, systemic and attitudinal barriers and the promise of social and economic participation (and a good life) for all as an outcome. While there are many stories of positive outcomes for individuals and families who have already engaged with the NDIS in transition sites, the collective narrative around early experiences of NDIS implementation has been disjointed and disconnected. While this pattern is a reflection of the implementation schedule for the NDIS it makes it challenging to compare the experience of stakeholders with the original narrative. Perhaps the lack of resistance to the NDIS collapsing into an administrative reform can be explained by Rushkoff's (2013) suggestion that people are willing to compromise in the interests of a promised reversal (outcome). Perhaps also the lack of resistance to removing the element of aspiration noted from peak body commentary is a reflection of being locked into the extended present described by E. Boulding (1988) and later Slaughter (1995). Perhaps for all stakeholders, agreeing to changes to the initial NDIS planning process that deny the imperative to imagine a range of possible futures locks us all into an extended present.

The current period of policy reform provides an ideal opportunity for transformation; however, this research suggests we have not yet created the conditions where used futures will make way for multiple futures. The narrative revealed in the research indicates a high degree of duality—conflicting beliefs and assumptions about personal agency, structure and power to shape one's own future, not yet visible to the players.

The narrative does, however, reveal that individuals, families and service providers are willing to engage in the work of exploring the lenses through which they are operating when given the opportunity. Research findings also reveal a softening of the degree of certainty in which a particular position was held over the period of the workshop or conversation.

Whether policy change results in social transformation and, more significantly, individual transformation may depend on our ability as a society to create spaces for deconstructing current reality for people with disability and their families, in order for the future to be reimagined. It may also depend on our ability to re-engage individuals and families in the hero's journey.

## 6.4 The Need for Integration

One of the researcher's strongest observations was the lack of integration of personal identity noted during data collection. While participants were able to articulate the use of different selves (angry, vulnerable, powerful, weak) to serve a purpose or influence access to resources, the impact on personal and collective identity was not visible to them. Individuals and families appeared to define themselves by their disability or in relation to the person with a disability. There was no reference to other attributes, such as gender, talents, role, culture or lifestyle preferences, as elements of identity.

Milojević (2013) suggests that the "othering" that occurs as identity is established is a source of vulnerability to violence. She describes it as the basis for separation of self from others, which affects not only the individual but extends at a group level. Milojević (2013) and Clapton and Fitzgerald (1997) define otherness as difference between self and others and the degree of variation from the norm, respectively. This phenomenon was evident in the research findings across all stakeholder groups and needs further exploration.

The perceived impact of "othering" was also evident in references to the hierarchy of disability with regard to effectiveness in accessing resources, across all stakeholder groups. Kevin Cocks (personal communication 15 June, 2015) suggests that images of vulnerability, such as those associated with abuse, neglect and victimhood, are still used in media, professional development and human service design as a lever for influence and as the basis of demand for social service delivery. Oliver (1990) suggests that such images, in turn, shape the identity and behaviour of people who work in the disability sector and may enable and strengthen the separation between individuals and the professional who takes "care" of them.

While images of abuse and neglect at the hands of institutional custodians generated in the media were a strong driver for the NDIS they were not discussed in

the context of decision-making about the future by any of the participants. Rather, there was a clear expectation that the state would continue to take care of its most vulnerable, particularly with regard to availability of public housing. The tension between such expectations and the NDIS promise of individual choice-making and financial control was not visible to participants.

## 6.5 Reframing

The researcher observed that participants have largely accepted the language and framing of disability issues that have become associated with the NDIS: "Framing is about getting language that fits your worldview. It is not just language. The ideas are primary—and the language carries those ideas, evokes those ideas" (George Lakoff, 2004, p. 4). Lakoff (2004) suggests that once people have a frame, they only accept facts that fit that frame.

The NDIS to date has largely been framed in economic terms; that is, that investment in services and supports is primarily justified by the offsets to government from people entering or re-entering the workforce and paying income tax. This logic was effective as a driver for the NDIS but reflects a "balance sheet" approach to human service provision, which needs to be interrogated further from the perspective of good policy (Chapple, 2013). The "balance sheet" approach is attractive in that it demonstrates the power of investing in human services, specifically the financial return on welfare expenditure; however, it fails to acknowledge the social capital or human equity built as a result of social service investment. Many participants were well versed in the language of "cost savings" when people get jobs and "spending only for reasonable and necessary supports". There was no reference to social capital, capacity building or value to community by investing in social services.

Lakoff (2004) highlights the importance of changing such narratives, as they support the "strict father" frame which dominates Western politics, which is that if people don't succeed it's because they're lazy and need to be disciplined. Such a frame is at odds with the Convention on Human Rights for Persons with Disability (UN, 2006) and comes with assumptions that the world is a dangerous place. According to Lakoff (2004) this frame includes an authority figure (male) there to protect people in a dangerous world, with responsibility for teaching "his children" right from wrong; he requires obedience from his children and has a strong belief that

those who are disciplined succeed and will become prosperous and self-reliant. This link between morality and prosperity is of concern as it not only reflects outdated disability discourse but feeds the concept of the "deserving poor". It also potentially frames welfare expenditure as "wasteful".

## 6.6    Readiness for the Future Under the NDIS

Barriers to generating new narratives revealed in the research include risk-aversion, poorly examined constructs of choice and control, a heavy emphasis on planning rather than dreaming, the perception of service providers as the most powerful stakeholders, poor tolerance of ambiguity and lack of practice. The initial focus for planning in the NDIS policy documentation was on need (relating to functional capacity across 10 domains of daily living), context (relating to existing formal and informal support networks) and aspiration (dreams and goals for the future), in equal measure. Since transition has commenced, however, the element of aspiration has been removed from the planning process. In parallel, administrative processes for service providers have retained a strong focus on system compliance, a standard menu of funded supports and standardised reporting. While this may reduce uncertainty for both funder and individual it offers only closed futures for people who use services and their families.

Gaspar (Gaspar, 2011) suggests that thinking about the long term by way of various scenarios, particularly those that deal with qualitatively different options, brings greater freedom of choice and also influences our interpretation of the past: "In terms of diversity the freedom of future shaping can now be linked to the freedom of decision-making and actions, and they mutually strengthen each other" (Gaspar, 2011, p. 99). He also suggests that, while using scenarios in decision-making requires goals and objectives to be set, it is important to continue to reflect and explore current concepts and experiences rather than narrowing the focus of effort to developing plans. A tendency to focus on plans, to the exclusion of "dreaming", was observed by the researcher during data collection across all stakeholder groups.

Taken as a whole, the narrative evident in the data across all stakeholder categories indicates a disposition toward closed futures rather than the expansive possibilities hoped for with the NDIS. The NDIS, by letting go of the aspirational component of the planning framework, is in danger of producing more of the same,

albeit with greater reach and resources. To explore this possibility and the implications for societal (collective) transformation, the data are considered in the context of a range of possible futures for the disability sector using Dator's (Dator, 1990) four archetypal scenarios and the scenarios for the disability sector offered by Inayatullah (2007) to an audience of advocates in Queensland in 2002.

Dator's (1990) method uses four archetypes based on the assumption of continued growth, collapse, steady state and transformation respectively. Applying these states to the "market" narrative in the NDIS, the collective implications of each state can be considered in the context of the findings of this research.

### 6.6.1 Scenario 1:  Continued Growth Scenario: The Garden Grows Unevenly

The continued growth scenario occurs where popular backing for the NDIS remains strong and bipartisan political commitment to investing in future supports continues. With the outlook for the future positive, the disability support provider market continues to develop with new commercial and not-for-profit partnerships, hybrid service types and philanthropic support multiplying rapidly.  After some early challenges with managing the technology-based administrative functions associated with service provider registration and payment, the NDIS is able to step back and allow market forces to drive quality and reach in service provision.

The price of aids, equipment and technology starts to reduce, with increased competition making community participation and entry or re-entry to the workforce affordable.  More people with disability in the workforce comes at just the right time, as levels of people leaving the workforce for retirement reach an all-time high.

New service provider entrants into the market recognise the power of having people with disability in key positions and greater numbers of people with disability move into governance roles within government and the non-government sector as a result.  Having people with disability in such key roles becomes a significant value proposition and, initially, while small and focused on mission rather than profit and market share, those organisations flourish the most.

The greater willingness to employ and fully engage people with disability in the workforce and in governance roles brings strong return in terms of social and economic participation for those involved, but unfortunately the overall numbers of people affected are relatively low.

Other service providers try to improve market position and profit by narrowing the range of services offered, focusing on service locations and disability types that bring strong financial return.  As a result, growth patterns follow the hierarchical lines identified in this research, with people with a physical disability most favoured, followed by people with intellectual disability, with people with challenging behaviours finding it very difficult to secure services.  Family members call on their old patterns, using their skills in navigating the system, using whatever "mask" is needed to get access to services and supports.

On the whole, the continued growth scenario results in a flourishing but inequitable market, where the volume of service delivery is higher but the pattern of inequity and the angst for those who miss out continues.  Growth favours those who were already well placed to benefit but overall the pattern of vulnerability remains the same.

**6.6.2 Scenario 2:  Collapse Scenario: The Multi-Nationals Block out the Sun**

Growth in size and profile of the market starts to attract large multinationals, whose strong expectations of profit drive greater standardisation of service options and less responsiveness to individual needs.  Many services enter the aged care market at the same time, biasing the housing development market to large-scale residential living arrangements.  While there is an initial surge in uptake for these service offerings, ultimately people with disability reject these options, preferring one-off arrangements, located less obviously in their community of choice.  People with disability and their families step back from the market, preferring to work with small niche operators and collectives.

Those people with disability engaged with organisations as staff or directors during the initial growth phase become disenchanted with the relentless growth agendas of their organisations, fearing loss of identity and person-centredness historically associated with large services, ultimately disengaging from those organisations completely.

As large providers increase their investment in advertising and start to compete fiercely for their market share, concerns about quality of services offered grow and trust in the market dissipates.  A growing sense of competitiveness, suspicion about profit motive and cherry-picking leads to instability, as people with disability decide

to manage their own funds and pull back from the market. Support workers leave the familiar structure of organisations, preferring to work freelance for small collectives of people with disability and their families close to home. People tire of being defined by their disability, choosing other attributes and lifestyle preferences as a basis for aligning with other marginalised groups. The disability support market collapses. Many more people with disability have a package but cautiously navigate the market in search of suitable providers. Multi-nationals drive the agenda and the pattern of vulnerability deepens.

### 6.6.3 Scenario 3: Steady State Scenario: The Garden Make-Over Team Move In

The consequence of collapse is for the NDIA to assume greater control over the market, compelling service providers to become certified through a national quality system before being able to conduct business and establishing targets for employment of people with disability as a pre-requisite for registration as a provider.

As a result the large multi-nationals withdraw from the market, selling their large residential services to aged care providers, who revert to traditional models of care. These models of care ultimately prove unacceptable to people with disability. Many medium- to large-size organisations consolidate and re-engage with their client base to test their market offerings, compelled to refocus on individual needs and goals rather than offering a standardised product.

Some small service providers close their doors in reaction to market instability, but those that remain refocus their efforts on building good relationships with their client base and ensuring their services are on target. While very comfortable with using technology to assist mobility and in the self-management of funds, people otherwise pull back on their use of technology, trusting face-to-face communication and strong relationships, favouring small service providers.

The stronger NDIA presence also means greater transparency in market performance, and trust in the service system by current and potential customers starts to return. It ultimately, however, increases administration costs and does little in the way of transformation. The most vulnerable steer clear of the chaos, waiting in vain for the promise of the NDIS to come to life.

## 6.6.4 Scenario 4: Transformation Scenario: Permaculture Prevails

In spite of the flourishing market in disability support provision and the proliferation of large-scale residential options on offer, people with disability turn away from specialised supports and traditional service offerings, investing instead in technological advances. Early in the transition to the NDIS people with disability, their families and innovative service providers build partnerships with universities and social enterprises focused on technological solutions. These organisations learn early to engage people with disability in advisory and staff roles and enjoy ready access to the market.

While smart phone apps to locate accessible toilets and parking have been in use for some time, real-time information on disability friendly shops and businesses amplifies the purchasing power of people with disability and their families. Web-based platforms for hiring personal carers, bartering of goods and services, and critiquing specialised services play an important role. The areas of greatest growth are web-based platforms for training and education (strengthening pathways to employment), monitoring of health and wellbeing, and budget management and reporting for funding packages, all of which place the individual in a stronger position to plan and drive their own future.

One of the strongest areas of advancement is in augmentative and alternative communication systems, driven by a market that caters not only for disability but the thousands of people who speak languages other than English. Previous barriers to training, employment and civic engagement are greatly reduced and contribute significantly to stronger social and economic participation for people with disability.

The second most powerful area of advancement is in mobility aids and equipment, significantly reducing physical access barriers to both workplaces and the community. Occurring at the same time as regulation for all new buildings (residential and commercial) to be accessible, the barriers to living and working are dramatically reduced.

In revisiting the economic drivers of the NDIS, policy decision-makers decide that disability support expenditure should be tax deductible and the welfare spend slows dramatically. Unspent funds in the NDIS are used on supporting social enterprise and small business development, and research into genetics, robotics and

artificial intelligence to support the health and wellbeing of people with disability and their families. Politicians agree to a living wage rather than the old system of benefits and concessions, and poverty ceases to be a major contributor to disadvantage for people. The role of government shifts to administrator, while people with disability drive new policy initiatives and fill a broad range of governance and service development roles across the government and non-government sector. People with disability and their families feel less vulnerable and grow in confidence and empowerment, driving innovation and certainty in the market as a result.

Each of these archetypal scenarios is plausible and relevant, with elements already starting to become visible as transition to the full NDIS gets closer. The defining element of the transformation scenario, however, is the integration of the NDIS into a broader, national social and economic reform agenda.

These scenarios not only serve as prompts for thinking about the future, they ensure there are no assumptions that tomorrow will be like today and serve as a reminder that change is always possible.

## 6.7    Researcher as Researched

As a researcher, the opportunity to immerse oneself in the familiar territory of workshops and interviews with people with disability, their families and service providers and then step back to reflect on both the observed and observer has been a useful one. Less familiar was the experience of having one's own untested assumptions and worldviews revealed during the course of workshops, particularly those that related to the current service system. The researcher's long-held belief was that the current service system would be well served by having people with disability in positions of authority and more specifically positions of governance and oversight. The untested assumption was that of the current service system and associated bureaucracy as a given. As this worldview became visible, a range of alternative responses to need opened up.

This experience reinforced the need for the researcher to remain in the role of facilitator, rather than active participant. While not removing the effect of researcher bias, it at least acknowledged the presence and potential contamination of unchallenged "expert" perspectives being imposed on the conversation.

The duality observed in participants reflects the experience of dissonance described by the researcher that inspired this research. The lack of integration of selves—powerful, vulnerable, angry, desperate, assertive, timid—is similarly reflected in the author's preface. Preconceptions of the relative power of agency and structure, evident on reflection though not expressed, have given way to an understanding that neither are opening up the future for people with disability and their families.

Perhaps to expect a significant change in public policy to drive social and economic transformation is unreasonable. At its best, policy can create the conditions from which a person can fully engage in the social and economic life of the community. It is a reference point for government decision-making, drives investment in social service provision and access to resources and reveals the values of the community. It may make a contribution to social transformation and may potentially enable individual transformation, but remains constrained by economic drivers and political imperative.

Exploration of perceptions of vulnerability amongst stakeholder groups revealed contradictions around the central NDIS constructs of choice and control. Research findings indicate both the illusion of being in control (choosing which mask to wear to access supports) and denial of poverty and disadvantage (for example, rented public housing being the only option considered). Findings also indicate a willingness to be defined as vulnerable in order to receive supports and an absence of other defining characteristics relating to gender, role, talents, culture or lifestyle choices. Research findings also reveal tension amongst stakeholders, particularly parents and service providers, between exercising power *to* and power *over* people with disability.

The service system—that is, government program funders and non-government service providers—is, at its best a means of meeting individual and family needs for support—a platform from which people can imagine and create a good life for themselves. It remains caught, however, between managerialism—a focus on compliance and consistency—and the mission to deliver highly individualised services and supports.

If evidence of social transformation can only be seen in the lives of individuals and families, then this research suggests the NDIS transition is failing to deliver on its promise. Rather than transformation, without the promised focus on dreams and aspirations, it is more likely a transition from one administrative system to another. It may provide the enabling conditions for individual transformation but by chance rather than design.

## 6.8    Constraints of Research Design

As with any research, it is important to acknowledge the limitations of the research design.

### 6.8.1 Constraints of Limiting Impairment Type

The research design, by limiting the target group to people with physical and/or sensory impairment, may have perpetuated the hierarchy of influence mentioned in the workshop findings. Families and people with physical and sensory impairment are recognised as the most influential in terms of social change in the disability sector, and workshop findings indicate that this hierarchy is also reflected in the pattern of access to supports. To overcome such a limitation, it is recommended that future research include a broader range of impairment groups, with specific attention to people with an intellectual impairment who constitute the largest group of people who will access the NDIS. There were no observations made during the course of data gathering or analysis that support the researcher's ethical concerns about the appropriateness of using CLA with people with an intellectual impairment. The CLA process was readily framed to suit each audience and participants quickly became comfortable with both the language and processes. The use of images rather than text worked well in all groups and removes potential literacy barriers from the process.

### 6.8.2 Constraint of Sample Size

Sample size was small, with family members being the dominant stakeholder group represented. People with disability were the smallest stakeholder group represented. This was not unexpected, but it presents a significant limitation for this research. It was made clear during the introduction to each workshop that the views expressed by each participant were their own and that there was no expectation that any individual

represented the views of others. Findings and implications of this research should be considered accordingly.

### 6.8.3 Constraint of Sample Recruitment Process

While it was effective to recruit research participants through direct invitation from three disability service organisations in Townsville, the Gold Coast and Ipswich, it is likely that people self-selected on the basis of having a good relationship with the service provider and some capacity to participate in a group process. While not all participants were current service users, all were familiar with the specialised disability service system and had at least some knowledge (pre-conceptions) of the NDIS. Because the target group was limited to people with physical and/or sensory impairment, invitations were not distributed to all service users from each service and therefore the sample does not represent the broader range of people with disability living in the community.

### 6.8.4 Constraints of Data

Data were gathered to help inform our understanding of the relationship between vulnerability and power to influence the future. The dataset was not gathered to explain or make causal inferences between the two constructs. The data were not tested by the participants or any other group of stakeholders with regard to analysis, nor were supplementary data sought or used to verify findings.

### 6.9  Conclusion

### 6.9.1 Key Learnings

The following key learnings were uncovered by this research:

1. While discourses around disability and vulnerability have significantly shaped the service system and the way people view themselves, the way people choose to interact with their life experiences is what shapes identity and power to influence the future.

2. Capacity to reflect on perceptions of reality is more important than the nature of the experience.

3. The degree of certainty in perceptions of reality can soften over time, in the company of others and with sufficient space and tools to support reflection.

4. Having more control, in the context of an outdated service system, does not necessarily improve outcomes from that system.

5. Stepping back and deciding whether or not to engage (with an outdated service system) is a powerful act and at the heart of self-determination.

6. Optimism and the ability to generate positive images of a future not yet experienced is critical (and that CLA is a powerful tool for facilitating the process of dreaming).

7. Societal transformation is constrained by limits on individual transformation.

8. That vulnerability and power to shape the future can and do co-exist.

The best-case vision for the future of the NDIS implementation is one where people have the opportunity to learn and practice generating positive images of the future from an early age and the chance to experience options and consequences as they grow. It is one where leadership capacity in people with disability, their families and advocates is valued and all stakeholders remain vigilant about innovation dominating over compliance in the provision of disability supports.

Ultimately, the relationship between vulnerability and power to shape one's future is best understood by those with lived experience of disability and their families. People have undoubtedly been shaped by the dominant discourses and their experiences seeking and using specialised services; however, they need not be defined, nor their futures closed, as a result of these experiences.

While reconstruction of reality and the generation of multiple futures with participants was beyond the scope of this research, it would be a valuable next step for academics, policymakers and practitioners alike—ideally as collaborators. The NDIS transition provides both urgency and context. Futures studies theory and tools provides the means. The possibility of individual and social transformation provides the compelling reason why.

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# Appendix I

A summary of comments (see Table A1) and observations recorded by the researcher, by stakeholder group, during and immediately following the workshops and interviews is provided as follows:

**Table A1.** Summary of comments

| Topic | Stakeholder | Summary of comments and researcher notes |
|---|---|---|
| **The things we say over and over about how the external world is** | *Individual Perspective* | "It doesn't matter what positional power you have as a person with a disability. It's gone the second you walk through the doors of a hospital." |
| | | "It's not safe to be who you really are. You need to work out who you need to be to get what you want." (similar comments from family members in all groups) |
| | | "Life's a struggle." (similar comments from family members in all groups) |
| | | "Vulnerability comes from having to trust people." |
| | | "Vulnerability comes in the night time." |
| | *Family Member Perspective* | "We say it can happen to anyone but the reality is the responsibility is worn by the family." |
| | | "Parents are supposed to know everything and have the answers. I don't." |
| | | "You getting what you need means I miss out." |
| | | "You have to be powerful to get what you need but being powerful damages relationships [burns bridges]." |
| | | "The grieving never stops." |
| | | "My questions are never ending." |
| | | "Better to be born with disability then you have no expectations." |
| | | "A safe future depends on siblings being willing to be involved." |
| | | "People with disability are highly vulnerable to exploitation—physical, financial, emotional, sexual… having a safe, protected place to live is the most important thing." |
| | | "I feel real fear and heavy responsibility for the safety of my [adult] child." |
| | | "The system doesn't care." |
| | | "The community thinks disability is contagious." |
| | | "There's class distinction—if you have a disability you are |

| Topic | Stakeholder | Summary of comments and researcher notes |
|---|---|---|
| | | stuck in the lower classes." |
| | | "The media perpetuates the tragedy of disability and makes fear worse." |
| | | "Society keeps people with disability out of sight." |
| | | "The community is dangerous and unreliable." |
| | | "Language is important—it sticks." |
| | | "Ultimately, you're on your own." |
| | | "We have to work with the hand we are dealt." |
| | | "Some days you win and some days you lose." |
| | | "It's just the way it is." |
| | | "Disability means poverty, no choice." |
| | | "Asking for help means losing pride." |
| | | "Keep your expectations low—be realistic." |
| | | "You always need a plan B." |
| | | "Wanting connection for my daughter means opening her up to others having power over her." |
| | *Service Provider Perspective* | "There will always be unmet need." |
| | | "Services are the safety net." |
| | | "The system is driven by crisis not planning." |
| | | "Nothing will happen without staff with the right values." |
| | | "It's all about choice and control and that's what we give people." |
| | | "We need to keep expectations high." |
| | | "People with disability are often treated as child-like and in need of care and protection." |
| | | "You need to be in crisis to get what you need." |
| | | "The community isn't the all-welcoming, all-rosy place that's just waiting to embrace people. It takes work." |
| | | "The community tolerates people at best. It's not inclusion or real participation." (supported by family member participants) |
| | | "The service system and community won't be inclusive if they don't have to be." |
| | | "Poor public transport keeps people disconnected." |
| | | "There's a big gap between the words [rhetoric] and the reality." |
| | | "Some services actually increase vulnerability for people, for example, closing supported accommodation during the day so |

| Topic | Stakeholder | Summary of comments and researcher notes |
|---|---|---|
| | | they don't have to staff the centre." |
| | | "Some services restrict people and tie them in knots." |
| | | "People can over-rely on services and lose skills." |
| | | "Getting a service always means compromise or trade-offs." |
| | | "Choice matters." |
| | | "Too much choice causes overwhelm." |
| **The things we say over and over about how we feel about the world** | *Individual Perspective* | "It's a trade-off—dignity and choice for charity. Lifestyle for having needs met—I can't have both." |
| | | "We are always under scrutiny, there's no privacy anywhere" |
| | | "there's no optimism here I'm afraid." |
| | | "Bad experiences hold people back." |
| | | "I distract myself to avoid thinking about the future." |
| | | "My parents' need for peace of mind is greater than my own preferences and privacy." |
| | | "My needs were too great at the time. I had no choice." |
| | *Family Member Perspective* | "I'm tired, I'm getting old." |
| | | "It doesn't matter how hard I've pushed or how angry I've been. Nothing changes." |
| | | "Its only family who cares—they have to." |
| | | "When I look at the future I see nothing." |
| | | "Choice is an illusion. There is no choice." |
| | *Service Provider Perspective* | "There will never be enough." |
| | | "They [policymakers] will never get it right." |
| | | "There will always be unmet need." |

# Appendix II

**Sense-Making Interview (example)**

Interview with woman with a physical disability, 40+ years old:

*1. Tell me a story or give me an example that reflects your experience of how power plays out for people with a disability.*

Struggling with managing self-care living on my own. Funding for support reduced, dad suffering significant health problems and becoming increasingly concerned about me. Dad had a heart attack, requiring me to be less reliant on him and give him peace of mind. Funding department offered a placement at an institution and despite long-held reservations about this option, I accepted it on a trial basis. On return home after the trial, I continued to struggle to manage living independently without paid supports. Parents increasingly anxious. I moved back into institution. It is barely tolerable and not an acceptable living arrangement for me. I feel like a butterfly trapped in a cocoon but know I have to find my own way out as the butterfly fails to develop the strength it needs to survive if someone else helps it break free.

*2. What was your personal experience in that story? What challenged you?*

Having my own struggles affect dad's mental wellbeing given his health issues and concern about me.

*3. What gave you power to influence/shape the future in that example/story?*

Having an option that would relieve my parents of anxiety and give them peace of mind, knowing I was safe and getting the help I needed. Being able to surrender my own needs and preference for an independent life for him.

*4. What impact did being able to influence have on the issue?*

It helped alleviate his fear for me. Provided a short-term solution.

*5.   What impact did being able to influence/shape the future have on you (or others) as a result?*

Gave dad peace of mind but reduced choice, quality of life and happiness for me.


*6.   Given the impact, would you use your power to influence/shape the future again?*

Yes I will.


*7.   If so, is there anything you would do differently next time?*

I'd probably do the same again but I'm now in a living situation I'm not happy with.  I'd given up on my own dreams for the future (stopped having them when I was young).  I'm like the butterfly and need to work out how to get myself strong enough to get out.