

Stephanie Backhouse  
Student Number 31209551

ART 610 Community Development.  
Masters by Coursework Research Dissertation

**Who loses out in the NDIS? An analysis of the early rollout of the National Disability Insurance Scheme in Australia.**

I declare that this dissertation is my own account of my own research. It contains as its main content work which has not been previously submitted for a degree at any university.

Name:

Date: June 30th 2017

## *Abstract*

*The National Disability Insurance Scheme (NDIS) is heralded as the second biggest social reform since Medicare and is currently being rolled out across Australia. The NDIS individualised funding model promises a transformational change in service delivery for people with disability and claims to deliver increased autonomy to assist Australians with disability to achieve their goals and enjoy an ordinary life. This thesis is a timely analysis of the early rollout of the NDIS. A consideration of the disability service delivery and policy which precipitated the NDIS in Australia places this policy reform in context. Comparisons are drawn with the implementation of the current social care model in the United Kingdom. Particular reference is made to the work of Dr Simon Duffy, an advocate for individualised budgets and self directed supports and key critic of the present interpretation of the personalisation agenda in the UK.*

*Evaluations of the current NDIS model indicate significant opportunities for people with disability to build on existing social and financial capital. This thesis also explores the constraints which impact on these opportunities. I suggest that the original intent of the 'Every Australian Counts' campaign (a citizen led movement of disability activists and supporters lobbying for substantive equality through the implementation of the NDIS) is compromised by a political discourse of privatisation and marketisation. Structural barriers which continue to hinder full actualisation of citizenship rights are not adequately addressed in an individualised funding model with a focus on service delivery. Some groups of people with disability may be left behind in a user led system.*

## INTRODUCTION

The Western Australian Disability Services Act (1993) defines 'disability' as an intellectual, psychiatric, cognitive, neurological, sensory or physical impairment. In 2015, there were 4.3 million or 1 in 5 people with disability living in Australia, with one in 12 Australians reporting that they had experienced discrimination or unfair treatment because of their disability (Australian Bureau of Statistics, 2015). The current implementation of the Australian National Disability Insurance Scheme (NDIS) is heralded as the second biggest social reform since Medicare. It promises a transformational change in the model of service delivery for disabled Australians and claims to "support people with disability to live independently and to be included in the community as fully participating citizens" (Act, N.D.I.S., 2013, Part 2:4, 11(b)).

The focus of this thesis is a consideration of whether the NDIS provides adequate protection to ensure that Australians with disability are able to actualise their right as other members of Australian society to realise their potential for physical, social, emotional and intellectual development, as stated in the first general principle guiding actions under the NDIS Act 2013 (Act NDIS 2013, Chapter 1, Part 2/4). The thesis focuses on secondary research without any direct involvement of people with disability. Throughout the thesis, I refer variably to 'people with disability' and 'disabled people'. "People with disability" is the preferred usage in Australia as it references disability as secondary to personhood; 'disabled person' is the term widely used in the UK and references a person with an impairment who is systematically disabled by social and cultural processes.

Firstly, I will consider what is meant by active citizenship and attempt to define how social inclusion is addressed within the context of the NDIS. Implicit in this analysis is a consideration of the possibilities and constraints of a neoliberal discourse as it relates to social policy rooted in a social justice agenda. In order to contextualise this debate, I will track the history of disability services in Australia which precipitated the genesis of the NDIS. I map a journey from custodialism (the protective supervision of people with disability stemming from

an assumption of a lack of competence) to personalisation (a social care approach which advocates for an individual to have maximum choice and control over the services which they receive).

The thesis will draw heavily on policy and primary commentary driven by the personalisation agenda from the United Kingdom (UK), particularly on the work of Simon Duffy, cited as the 'architect' of personalisation (Slasberg, Beresford, Schofield and Harlow, 2013, p. 92). I will detail the content and intent of the NDIS, and compare and contrast these details with lessons learned from the strengths and limitations of disability policy reform in the UK. Finally, I will study evaluations of the early stages of the NDIS rollout and draw conclusions about whether the ideological driver of the NDIS is still aligned with the progressive agenda of the disability rights movement.

I will argue that the current NDIS individualised funding model has the capacity to implement change at an individual level but lacks the scope to drive broader societal change. I conclude that, while providing measurable benefits to those with existing social capital, the NDIS may unintentionally create inequalities between groups of people with disability. I challenge the power of the NDIS to provide not just consumer choice, but "real" choice for people with disability made through active, democratic and collective participation as citizens. I suggest that as the statutory body for the implementation of the NDIS, the National Disability Insurance Agency (NDIA) cannot instigate the radical practice required to challenge perception of disability at a systemic level but rather acts as 'gate keeper' to maintain the status quo through their management of strict eligibility criteria and resource allocation (Stevens et al., 2011, pp. 262-263).

## CHAPTER ONE

### **The Citizenship Agenda**

In 2005, a picture painted by disability advocates for those with lived experience of disability residing in Australia was bleak:

Compared with the rest of the Australian population, as Australians with disabilities, we are more likely to live in poverty. We are more likely to be physically, emotionally and sexually abused...We are more likely to experience difficulty obtaining education and employment, and more likely to experience difficulty in acquiring affordable accommodation. We are more likely to have problems accessing public buildings, basic information in ways we can understand, and public transport. We are less likely to own our own homes...We are less likely to get married and have children (Goggin & Newell, 2005, p. 19).

Goggin and Newell, the authors of “Disability in Australia: Exposing a social apartheid”, sought to unmask the entrenched discrimination which prevented people with disability from accessing their full citizenship rights.

The NDIS marks a movement away from old systems of paternalistic care and claims to deliver increased autonomy to people with disability to achieve their goals and enjoy an ordinary life (Australia. Department of Human Services, 2017a). The scheme proposes to support disabled people to transition from passive to active citizens through systems of choice and control, co-production and adequate resourcing to equalise power imbalances and facilitate access to participation and contribution in the economic, social and cultural life of their communities.

It is important at the outset of this thesis to explore what is meant by the terms ‘active citizenship’ and ‘social inclusion’, to identify how these concepts are used in the context of the NDIS and to consider the strengths and limitations of the current NDIS model to deliver on claiming the right to full citizenship.

### Social inclusion and active citizenship

In order to understand the broader definition of social inclusion and active citizenship, it is necessary to first grapple with the notion of citizenship itself, to which these terms are integrally linked. Citizenship is conferred by belonging to a nation state. It is a legal status which relates to a sense of national identity and grants the political, economic and social rights to participate in civil society (Preuss, 2003). Modern citizenship can be understood to include the rights necessary for individual freedom such as freedom of speech, property rights and the right to justice; the right to participate in the exercise of political power through holding office, voting and related activities and the social rights to meet human needs such as adequate minimum income, housing, education and healthcare (Preuss, 2003). Modern citizenship also includes the obligation to live the life of a good citizen to promote the welfare of the community . Broadly, modern citizenship can be understood in terms of the principle of equality of status:

Citizenship is a status bestowed on those who are full members of a community. All who possess the status are equal with respect to the rights and duties with which the status is endowed (Marshall 1964, p. 87).

However, many people with disability have historically experienced a strong sense of exclusion from ordinary life, “shut out” from the social, cultural and economic life of their communities:

There appears to be a common belief that people with a disability are not able to make a significant contribution to the community and that they are somehow not of equal value as human beings (Deane, 2009, p.11).

Citizenship is a contested notion: systemic disadvantage may make a legal principle of equality a formality rather than a reality. The attributes of belonging, contribution and autonomy which are intrinsic to citizenship, may be compromised. Exclusion is a process by which those without power are limited and controlled through oppressive processes and practices embedded in

language, institutions and behaviours. The consequences of powerlessness are manifested in a lack of equal opportunity for access and participation in society (Kenny, 2010, p. 23). British sociologist T. H. Marshall was the first to suggest that the pattern of social inequality could be altered through the equalisation of status conferred through the notion of citizenship (Marshall, 1964, p. 88). He was writing during the establishment of the post war welfare state and saw the granting of social rights as a reduction in the risk associated with capitalism for Britain's most disadvantaged citizens (Marshall, 1964, pp. 102-3).

The core concept of the social inclusion agenda is to "address power inequities in order to participate and contribute with equal autonomy" (Held, 1994, p. 47) in the economic, social, cultural and political life of the nation (Kenny, 2010, p. 24). Kenny (2010) states that participation in society, access to the resources required to facilitate this and control of one's own life are human rights (p. 25). These rights are enshrined in the Convention on the Rights of Persons with Disabilities (CRPD) which was ratified by Australia in 2006. The CRPD promotes equal enjoyment of human rights, respect of inherent dignity and effective participation in society on an equal basis with others (U.N., Division for Social Policy & Developmental Disability, 2006). It has served as the major catalyst in the movement towards an understanding of the active citizenship of people with disability and underpins the social model of disability. A social model of disability indicates that it is the barriers in the economic, legal and built environment and prevailing societal attitudes to disability which limit the capacity of people with disability to participate in society on an equal basis, not the individual's impairment (French, 2009, p. 20).

Whereas passive citizenship denotes the rights and duties conferred to an individual member from above, active citizenship defines the capacity to control one's own agenda, to decide on one's own needs and goals, to contribute to and participate in the life of the community and to receive the resources required to facilitate this (Kenny, 2010, p. 111). Citizens have rights **and** responsibilities which include following the law, respecting others, contributing and being productive (Sly & Tindall, 2016, p. 8). Goggin and Newell (2005) suggest that historically, the lived experiences of people with disability have not

fitted into accounts of liberal democracy and the sort of citizenship ideals on which they rest (p.196).

### Social inclusion and the NDIS

Inclusive social policy marks a shift from the disability policy of the past when people were congregated on the basis of disability, disconnected from the local community infrastructures and where the experience of exclusion, prejudice, ignorance, indifference, patriarchy, disempowerment and social isolation was prevalent (Nisbet, Hagner, Antal, Fox and LaPoint, 2006, p.73). Conversely, the NDIS (which was inspired by the aspirations of disabled people, their families and supporters with the intention of promoting autonomy and citizenship), can be implemented to work towards the full inclusion and participation of people with disability in the citizenry of their nation state.

The NDIS can be interpreted as providing the resources to create substantive equality (recognising the need to treat people differently to achieve equitable outcomes). It acknowledges the preexisting disadvantage that many people with disability are subject to by offering 'reasonable and necessary' resources "to lead an ordinary life" in their community (Australia. Department of Human Services, 2017a, p. 3) and by providing a level of choice and control by service users in the selection of supports and service providers which has previously been inaccessible in a service driven model.

Proof of citizenship is one of the eligibility criteria of the NDIS. Inclusion in the demos confers the right to the reasonable and necessary resources to assist eligible people with disability to participate in the social and economic community. Through an NDIS individualised funding model, person-centred planning (which focuses on the goals of the individual) provides the opportunity to define one's life as opposed to previous models of disability support which pigeon holed people in universal services. Individual budgets treat funding as an entitlement to be used flexibly to work towards one's own objectives; supported living asserts the rights of the disabled person to make their own choices about where and how they choose to live and independent living supports allow disabled people the opportunity to manage their own lives and

connect with the community on their own terms (Duffy, 2012, p.115). An intention of a person's individual plan is that it will include opportunities to develop skills that lead to greater independence, self-management and community inclusion and thus render NDIS participants more capable of claiming and contributing to their citizen rights and responsibilities.

Without doubt, increased resources will lead to positive outcomes for many NDIS participants but the anticipation of inclusion assumes a welcoming community which embraces diversity. Substantive citizenship may be compromised if civil society fails to present opportunities to participate or facilitate pathways to develop social value or increase self-esteem. It is well recognised that individualised funding must be accompanied by (non-individualised) programs that facilitate access and connection to supports (Bigby & Fyffe, 2009, p. 5). Under the NDIS, individualised funding is complemented by an Information, Linkages and Capacity building (ILC) component, which provides non-individualised grants to fund programs which promote people's increased connection in their communities (Australia. Department of Human Services., 2017b).

#### Factors that impact on the realisation of citizenship for people with disability

All members of a nation state possess a civil identity and as such, citizenship can confer a sense of solidarity or "social glue" where commonalities of citizenship may override diversity to create "a common national culture, common set of identities and a common value system" (Turner, 1997, p. 10). In their book "Disability in Australia: exposing a social apartheid", Goggin and Newell (2005) claim that disabled people have been subject to a form of social closure, in which alienation and stigmatisation force disabled people to be excluded from the group.

People with disability living in Australia endure an insidious, oppressive and deeply rooted system of being placed apart from others in society. In every sector of society...people with disabilities face discrimination, exclusion and 'othering'. (p.195)

Goggin and Newell's summary is an encapsulation of the social model of disability - that it is the societal barriers which prohibit individuals from achieving their citizenship rights. The service system within which supports are provided has changed since this book was written, but the service delivery system is only one factor in that exclusion. Despite the three decades of person centred rhetoric since the Disability Discrimination Act (1992), changes in culture and practice have only gone so far to impact on the claiming of full citizenry for Australians with disability (Kendrick, Ward & Chenoweth, 2017, p. 6).

The foundation of the Australian nation state is itself based on an exclusionary, eugenic ideology. The language and imagery of citizenship reflect a hegemonic normalcy which excludes people with disability. Meekosha and Dowse (1997) write, "The good citizen is embodied as male, white, active, fit and able in complete contrast to the unvalued, 'inactive', disabled other" (p. 50). There is a lack of positive, powerful portrayals of people with disability in government, business, media or sport in Australian society (Goggin & Newell, 2005). There is an overrepresentation of people with disability as welfare recipients, as consumers of support services and as those with long term health conditions or with experience of discrimination. People with disability are under-represented in the labour market, as home owners, students completing school or in rates of social and community participation (Australian Bureau of Statistics, 2015). People with disability are massively overrepresented in the justice system (Baldry, 2016). Those who experience negative community attitudes, who are seen to lack 'capacity' or who are not given the opportunity to communicate their opinion are less likely to be able to claim valued roles in civil society. Previous experience of marginalisation and cycles of rejection in unwelcoming communities may inhibit people with disability (and in particular, people with intellectual disability) from experiencing a sense of collective identity conferred by citizenship status.

#### The limitations of the current NDIS model

The NDIS bears the hallmarks of neoliberal social policy which requires individuals and communities to take responsibility for their own wellbeing rather than the state. In a neoliberal discourse, privatisation devolves responsibility for

social issues from the public to the private sector and more emphasis is placed on community and family to replace the formal support of state funded programs (Kenny, 2010, p. 56). Marketisation claims to create a more responsive workforce and competition between service providers purports to increase efficiencies and quality in service delivery (Kenny, 2010, p. 139). However, the assertion that an NDIS with foundations in neoliberal social policy can facilitate active citizenship may be compromised on several levels:

- The market is not neutral

There are Informational and power asymmetries between service professionals and service users (Needham, 2011, p. 9) and also between differently abled consumers in a market landscape which privileges competency, capacity and independence. Outcomes for those without strong social and financial resources, self advocacy or a network of advocacy around them may be compromised in their capacity to make the most of market opportunities (Power, Lord and deFranco, 2013, p. 240; Glendinning, 2008b, p. 456). For some NDIS participants, support is mediated by and dependent on paid carers who are primarily informed by a concept of duty of care rather than a promotion of citizenship rights (Meekosha & Dowse, 1997, p. 53).

- Consumer power may not always facilitate empowerment

The government retains overall command in terms of policy direction and fiscal management. NDIS participants are only 'quasi' consumers as the government is the actual purchaser of services. The government, as the purchaser, decides the nature and extent of service provision rather than the consumer of the service themselves (Dowse, 2009, p. 579).

- An individualised funding model does not itself address broader societal change

Individualised funding is only one component of a process to facilitate the active citizenship of people with disability. Poor access to mainstream

health and community services, transport, education and leisure opportunities, a lack of affordable housing and discriminatory community and institutional attitudes towards people with disabilities will impact on the capacity of an individualised funding model to bring about significant change (Bigby and Fyffe, 2009, p. 11). A social model of disability which focuses on reducing attitudinal, environmental and institutional barriers is at odds with the neoliberal values of individualism and self responsibility.

### What has been learnt from the UK experience to promote citizenship?

There are significant parallels between the NDIS and recent UK disability reform. Throughout this thesis, I draw heavily on the work of Simon Duffy, a leading contributor to the UK personalisation debate. Duffy proposed that direct payments (giving service users money directly to pay for their own care, rather than having care provided for them); person centred planning, self directed support (being in control of the support people need to live the life they choose) and individualised funding could improve quality of life for individuals and bring about economic efficiencies in service delivery (Duffy, Tyson & Stansfield, 2008). He described these individually tailored components of support as the ‘technologies of personalisation’ (Duffy, 2010, p. 256). Duffy proposed that these ‘technologies’ alone could not bring about social justice unless their application was underpinned by an ‘inclusive’ model of citizenship. He developed a citizenship theory of social justice to clarify the values which inspired the technologies of personalisation. The theory incorporates three key principles:

A fair society is one where all its members treat each other with respect, that is, as equal citizens.

A fair society ensures that the grounds for respect (the keys to citizenship) are so defined that everyone can achieve citizenship, and thus be respected as an equal.

A fair society organises itself so that everyone gets sufficient support to be able to achieve effective citizenship

(Duffy, 2010, pp. 261-263).

The theory refers to a moral, ethical citizenship which incorporates a sense of equal status or worth. Duffy stresses that the support required to achieve a sense of citizenship goes beyond the financial resources required to bridge the gap between lived experience and aspiration to active participation in civil society (Duffy & Williams, 2012, p. 24).

Iain Ferguson, Professor of Social Work and Social Policy at the University of the West of Scotland, points out that Duffy's Citizenship Theory does not address the disabling elements of the neoliberal political system in which the reforms were produced. Ferguson suggests that it is the neoliberal social and economic agenda which itself limits social justice. A failure to address the broader issue of redistribution within a capitalist framework or acknowledge the common experience of poverty and inequality among disabled people (Ferguson, 2012, p. 55), compromises the benign intent of Duffy's citizenship theory. In his critique of Duffy's work, Ferguson (2012) quotes Houston (2010):

Under neo-liberal welfare reforms, service users are in danger of mirroring the experience of sojourners from a distant era after leaving their habitation of bondage: liberated from years of slavery under the yoke of welfare paternalism but now stranded in the desert of atomistic individualism, weighed down by their newly found responsibility. (p. 55)

Ferguson argues that the roots of the Independent Living Movement were founded in collective responsibility and collective organisation, not individual empowerment (2012, p. 59). He adds that individualism confers the need for individuals to take responsibility for their own actions and manage the risks of their own behaviour. Ferguson suggests that this resonates more with the call to reduce welfare dependency than a promotion of social justice (2012: 60). He implies that a neoliberal policy agenda at a time of fiscal austerity may be more about mechanisms for cutting costs and as a consequence, reducing choice and control (2012, p. 69). In a UK context, Ferguson (2012) writes that personalisation has been coopted "by powerful forces whose notion of social justice are very different from the one's (Duffy) espouses" and it is the neoliberal

discourse in the UK which is now the main ideological driver of personalisation (p.57).

Simon Duffy has since acknowledged that austerity measures and complex, bureaucracy had impacted negatively on the promise of personalisation to promote citizenship in the UK (Duffy, 2011, p. 24). Duffy has made recommendations for the implementation of the NDIS based on his perception of the shortcomings of the UK experience of personalisation and I will study these in detail in Chapter 4.

In this chapter, I have explored the notion of substantive citizenship, reiterated the multiple disadvantages experienced by people with disability, highlighted the antagonisms of neoliberal social policy and suggested that in addition to an individualised funding model, it is imperative that the NDIS addresses broader systemic barriers which impede all Australians with disability from claiming their full citizenship rights.

The ILC component of the NDIS has been cited as the mainstay of the drive to increase access and inclusion in communities through personal and community capacity building. The 2017 Federal Budget secured future funding for the NDIS through a 0.5% increase in the Medicare Levy but it is significant that the original \$132 million allocation for the ILC component (which is only 0.6% of the total NDIS budget (Naufal, 2017)) has been reduced by a further \$12 million in the most recent 2017 Federal Budget. In addition, the ILC is a competitive grants based process which may impact on community development outcomes which are themselves collaborative by nature. Marshall (1964) suggested that redistribution of the scarce resources of a capitalist society to create a solidarity could reduce the level of conflict between social classes. Turner (1997) proposed that this could be interpreted through a Marxist lens to suggest that “the collapse of capitalism is contained by political reformism, which leaves the fundamental structure of class exploitation unchanged” (p. 11). A pessimistic perspective on the lack of significance attributed by the government to the importance of community development initiatives to address systemic barriers through the NDIS may parallel Turner’s cynicism about commitment to

fundamental structural change. The citizenship of people with disability in Australian society requires more than just their presence in the community.

My next chapter looks more closely at the development of disability policy and practice in Australia in order to place the work of this thesis in context.

## CHAPTER TWO

### **A historical overview of disability in Australia**

In the last chapter I looked broadly at the concept of citizenship and how the aspiration to social inclusion and active citizenry may be impacted by a neoliberal framework. Before continuing to look at more recent changes to disability policy in Australia and the UK, I will explore a brief history of disability policy and practice in Australia, and map a journey from custodialism to personalisation. This chapter describes only key Commonwealth initiatives in disability policy in Australia and does not explore the 'double disadvantage' of particular sub-groups of people with disabilities such as those from Aboriginal and Torres Strait Islander or non-English speaking background, or people with specific types of disability beyond their inclusion in the generic term, 'disability'.

In March 1964 in Perth Western Australia, Maurice Benn shot his son Bernard through the head and was found guilty of murder. Maurice Benn was a university professor, Bernard was 5 years old and had a diagnosis of 'mental retardation'. In court, his father pleaded that he was unable to contemplate a meaningful future for his son and envisaged institutionalisation as the child's only option. At the time, the murder was reported euphemistically as a "mercy killing" and Maurice Benn received widespread community support calling for his acquittal (Cocks, Fox, Brogan & Lee, 1996, pp. 84-6). The case highlighted significant contemporary issues: the devaluation of people with disability and the sense of 'burden' attached to a diagnosis, the lack of appropriate or effective services for people with disability and their families and inadequacy of public policy. In the 50 years since this event, there have been some key improvements in the socio-economic experiences of people with disability and their families but the sense of 'otherness' or "apartheid" remains (Corker & French, 1999, p. 96; Goggin & Newell, 2005, p. 18).

After white settlement, Australia adopted the attitudes to disability of paternalism and fear, approaches that were prevailing in England at that time. From the late 1800s, segregation for people with disability was commonplace. Eugenic theories underpinned the existence of large institutions where people who were

mentally ill, disabled, old or socially unacceptable lived “lives characterised by tedium, diminished status, deprivation and systematic abuse” (Jones, as cited in Duffy, 2010, p. 258). Parents of children with intellectual disability were encouraged to give up their children to institutions, with the advice that they did not have the capacity for education (Jenkinson, 2008, p. 2). After World War I the Australian government funded the Repatriation Commission to provide practical assistance for ex servicemen with disability to be reintegrated into the community. This work was expanded after World War II. The Commonwealth Rehabilitation Scheme 1948 (CRS) sought to increase the independence of returning disabled veterans and other pensioners with disability, with a focus on vocational education, training and employment (Goggin & Newell, 2005, p.64). CRS Australia continued to provide employment related services until 2015, when responsibility for these services moved to the private sector. Despite this shift, people with disability generally continued to be infantilised and seen to be in need of help, care and protection (Dean, 2003, p. 216).

From the 1950s, there emerged a strong volunteer movement of mostly parent led groups wishing to secure better opportunities for their disabled sons and daughters (Jenkinson, 2008, p. 2). Organisations such as the Crippled Children’s Association (now Novita), the Slow Learning Children’s Group (now ACTIV Foundation), the Spastic Welfare Association (now Cerebral Palsy Association) and Mentally Incurable Children’s Association (now Nulsen Disability Services) were formed after parents advocated for formal supports which distinguished children with disability from an inclusion in a broader categorisation of ‘insane’. These segregated institutions which accommodated, educated and provided day time activity for people with disability were predominant up until the 1970s. The institutions were still initially custodial in their intent and later, the focus lay on the extension of functionality through training and skill development as a way of improving or ‘normalising’ life for people with disability (Disability Services Commission, n.d.) The names of these organisations reflected the devalued roles of the service recipients. Over time, “crippled” and “spastic” became known as expressions of contempt and derision, “languages of disability constrained and evaluated people, under the guise of simply describing them” (Cocks et al., 1996, p. 282).

From the late 1960s onwards, the primary discourse of eugenics, segregation and lack of basic personal rights was challenged by social pressure to reform institutions. New discourses of deinstitutionalisation and normalisation reflected a wider cultural shift as the post war growth of human and civil rights movements across the world gained momentum and inspired the disability rights movement (Goggin & Newell, 2005, p. 64). The social injustice of institutionalisation was a key premise in the work of Wolf Wolfensberger, whose theory of normalisation in 1972 argued that damaging stereotypes socially constructed in response to human difference are reinforced by the practice of segregation (Wolfensberger, as cited in Duffy, 2010, p. 258). Wolfensberger reinforced the earlier work of Bengt Nirje, who advocated that people with disability should have the opportunity to experience, “patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society” (Nirje, 1969, p.19). Wolfensberger developed this theory during the 1970s & 1980s and reframed normalisation as the social role valorisation theory (SRV) which considered disability or “socially devalued people” within the context of a disabling social and cultural construct. Wolfensberger claimed that “devaluation is not something which is inherent in the person” (Wolfensberger, 1992, p. 2) but located within wider social values, ideas and contexts (Cocks et al, 1996, p. 284).

In 1976, the United Nations General Assembly adopted a resolution proclaiming 1981 as a special year to encourage the full integration and participation into society of the estimated 450 million people who had a physical or mental disability. The International Year of Disabled persons (IYDP) spearheaded a global disability rights movement which advocated self determination and representation. The movement highlighted the construct of systemic oppression and challenged the notion that disability was a private not a public problem. A focus of the IYDP was to highlight the societal barriers which hindered the inclusion of people with disability in mainstream society and maintained the inequality of life expectations. Following the IYDP, there were a number of initiatives implemented by the Australian government which had implications for the provision of services and supports for people with disability and which marked a shift from the exceptionalistic policies of segregation and institutionalisation to a more inclusive, community orientated approach. The

1986 Disability Services Act and later, the 1992 Federal Disability Discrimination Act enshrined disability as a human rights issue. These anti discrimination policies rooted responsibility for equal opportunity and access within the community and in a significant conceptual shift, disability rights advocacy was recognised as a program area to be funded under the Disability Services Act 1986 (People with Disability, n.d.).

In 2008, Australia ratified the Convention on the Rights of Persons with Disabilities (CRPD). The CRPD was developed in an effort to overcome the 'invisibility' of persons with a disability in international human rights law and practice (French, 2009, p.19). It clarifies the principles of nondiscrimination, inclusion, access and active participation as they relate to people with disability in a rights based approach driven by dignity and freedom. This brought about the recognition that people with disability, as every other citizen of Australia, had the right to live in the community, attend mainstream education, engage in paid work and participate in activities in their local community. Instead of an assumed lifelong dependency, the focus shifted to independence, productivity and contribution. Expectations were raised for individuals and for positive, inclusive community responses.

Following the ratification of the CRPD, Australia introduced the National Disability Agreement 2008 (NDA) policy framework designed to acknowledge and protect the basic rights of people with disabilities. The NDA built upon the existing Federal Disability Discrimination Act 1992 and was agreed to by all Australian states and territories to ensure a cooperative approach to supporting people with disability to achieve increased economic and social inclusion.

In late 2008, the Australian Government commissioned the National People with Disabilities and Carer Council to produce a consultation report to inform the National Disability Strategy. This incorporated the feedback of people with disability, their families, carers and service providers across Australia. In what came to be known as the "Shut Out" Report, many people with disability expressed their strong sense of exclusion from an ordinary life. The report suggested that systemic disadvantage precludes people with disability from experiencing their full range of citizenship rights and the gap between the

legislation and the lived experience of Australians with disability was a recurring feature of the submissions:

Virtually every Australian with disability encounters human rights violations at some point in their lives and very many experience it every day of their lives (Deane, 2009, p. 15).

Historically, people with disability were “shut in”, hidden away from mainstream society in institutions. Now, they felt “shut out”, excluded from the social, cultural and economic life of their communities as a result of the built environment and societal attitudes. The Shut Out Report called for a whole of government, whole of life approach as an important step in “closing the gap between the lived experience of people with disability and the rest of the Australian community” (Deane, 2009, p. 63).

In 2009, the Disability Investment Group (DIG) was assembled and commissioned by the government to explore innovative ways of supporting the disability sector based on private sector funding models. Socio-demographic and economic drivers affecting the demand for disability services were incorporated into the policy discussion. In December 2009 the Australian Government released the report, “The Way Forward: A new disability policy framework for Australia”. The report criticised existing policy as inequitable, inefficient and ineffective. The principal recommendation was for a feasibility study into a social insurance model for disability support in which early investment would aim to reduce total costs calculated over a lifetime (Disability Investment Group, 2009). The report considered how a national disability insurance scheme could be designed, administered, financed and implemented. Rather than the existing fragmented approach to funding, the scheme would support an Australia-wide rights based notion of entitlement, dependent upon eligibility. As an insurance model, the costs of meeting the essential lifetime needs arising from disability would be calculated and a premium or contribution would be required from each taxpayer (DIG, 2009, p. 6).

The focus had shifted from a concept of disability with relevance only to a specific disadvantaged minority to a community responsibility to uphold the

principles of equality and freedom embodied in the Australian ethos “a fair go”. The long-term costs to society of an increasingly large percentage of the population living with a disability were balanced against to an individual responsibility to safeguard against personal risk (DIG, 2009, p. 8). The DIG report removed disability services from the sphere of welfare and instead presented an economic proposal ‘to create incentives for private investment in disability’ (2009, p.1), fitting in with a contemporary political agenda which sought the privatisation of services to generate productivity and effective competitive service delivery.

“The Way Forward” supports the concept of normalisation (Brown and Smith 1992). The investment in people with disability to “fulfill their potential to participate and contribute to the community in the same way as other Australians” (DIG, 2009, p. 21) echoes the theories of Nirje and Wolfensberger, forty years earlier. These contemporary opportunities claim to dispel the historical representations of people with disability as those without the capacity to participate in mainstream society.

In February 2011, the Council of Australian Governments (COAG) signed a National Disability Strategy (NDS) 2010-2020, a 10-year plan to provide coordinated government services for people with disability in Australia. The NDS Strategy is rooted in the ideas of social justice and citizenship. It defines disability as a human rights issue and champions the values of equity and fairness in which each citizen has equal access to participation and decision making, services such as housing, health, education, opportunities for rewarding work and a liveable income. Inherent in this, is the notion that people with disability should also assume the same responsibilities as all members of society, according to their ability.

In July 2011, The Productivity Commission released the feasibility report for a national disability insurance scheme, as recommended by the DIG. The report’s findings echoed the criticisms of “The Way Forward” and found the existing disability support system to be “underfunded, unfair, fragmented, and inefficient” (Productivity Commission, 2011, p. 3), with little opportunity for choice or control. The Commission recommended the implementation of a National

Disability Insurance Scheme (NDIS), a national long-term care funding scheme based on self directed services and supports funded through individualised funding packages. At the same time, a strong campaign from the disability community “Every Australian Counts” lobbied government and sought to change public attitudes and awareness of the right of all Australians to aspire to the same opportunities.

In 2013, the National Disability Insurance Scheme (NDIS) Act was passed with bipartisan support to provide a framework for the objectives and principles of the NDIS. The legislation claims to offer individuals with disability increased control over the services and supports they receive and the flexibility to choose from a wide range of service providers leading to greater opportunities for independence and community participation (Reddihough, Meehan, Stott and Delacy, 2016, p. 69). July 1st 2016 marked the commencement of a national rollout of the NDIS. The general principles guiding actions under NDIS Act reference the recognition of rights “to realise (the potential of people with disability) for physical, social, emotional and intellectual development, to respect for their worth and dignity and to live free from abuse, neglect and exploitation, to pursue any grievance, and to determine their own best interests to the extent of their capacity” (Madden, McIlwraith and Brell, 2014, p. 6).

When we consider this chronological evolution of disability policy and practice, there appears to have been a transformative shift from disability as a construct of need and dependency characterised by fear, disgust and pity (Scotch, 2000, p. 6) to a society that is inclusive and enabling, providing equality and the opportunity for each person to fulfill their potential (Productivity Commission, 2011). From a theoretical perspective, people with disability were viewed initially as objects of charity. Later a medical model was applied to disability: the ‘problem’ was viewed as intrinsic to the individual, and thus disability could be ameliorated by altering the course of the disability itself or adapting the disadvantaged to their situation (Jenkinson, 2008, p. 6). Since the 1970s, the social model has underpinned the disability movement in Australia. Rather than addressing the welfare or health needs of the person with a disability, more focus has been placed on the physical, social and attitudinal barriers which

hinder active participation and contribution, for example, “by enacting laws that prohibit discrimination on the grounds of disability” (Roth, 2007, p.4).

Undoubtedly, expectations by, of and for people with disability and their families have changed. Activists, academics, politicians, artists, doctors, lawyers, sports people, celebrities and others are groups with representation by people with lived experience of disability. However, despite the legislation and policy rhetoric, service provision and community attitudes still continue to perpetuate practice of isolation, marginalisation and congregation on the basis of disability. “Promises, promises”, a book based on the stories of people with lived experience of disability suggested that,

The discourse of inclusion, citizenship and human rights is predominant. Policy makers have annexed the same language of rights by people with disability but on the whole, the comprehensive, interrelated and entrenched social and economic norms that constitute a disabling society have not been seriously examined or transformed (Clear, 2000, p.72).

Segregated settings where people with disability are educated, live, work and recreate continue to be commonplace (Deane, 2009). There are many people with disability who are now located in the community but their physical presence alone does not guarantee a sense of social connectedness and inclusion (Bigby & Ozanne, 2001, p.177). Many disabled children encounter negative stereotypes in mainstream high school which may contribute to their own identity development and perpetuate disability as a social construct (Corker & French, 1999, p. 93). According to data from the Survey of Disability, Ageing and Carers (SDAC) compiled in 2012 by the Australian Bureau of Statistics (ABS), there has been little change in the labour force participation rate for people with disability aged 15-64 years between 1993 (54.9%) and 2012 (52.8%). Conversely, over the same period, the participation rate for working-age people without disability increased from 76.9% in 1993 to 82.5% in 2012 (ABS, 2012). In 2015, almost one in 12 Australians with disability (281,100 people or 8.6%) reported they had experienced discrimination or unfair treatment because of their disability. The median gross income for a person with

disability aged 15 to 64 years was \$465 per week, less than half the \$950 per week income of a person without disability. Over one-third (35.1%) of women and over one-quarter (28.1%) of men aged 15 years and over had avoided situations because of their disability (ABS, 2015). The gap between legislative policy, rhetorical activity and the substantive material, social and cultural benefits to people with disability is apparent (Clear, 2000, p. 73).

Charity events which raise money for people with disability perpetuate their portrayal as passive recipients of care and welfare (Goggin & Newell, 2005, p. 24). Media events (eg cameos of paralympians) celebrate individuals overcoming the adversity and tragedy of disability in a personal triumph of resilience and application (Goggin & Newell, 2005, p. 34). The term 'supercrip', (reflecting ironically on the derisive and devaluing language of disability) has been coined by the disability community to highlight the stereotyping of inspirational models who achieve "despite" their disability. In this context, it is not society which disables someone by its reaction to limitations and difference, but the individual who either fails to "rise above" their misfortune or exhibit the personal strength and willpower to "achieve against all odds".

Prenatal testing is offered to all women in Australia as routine antenatal care as a way of identifying 'genetically defective' fetuses with termination of pregnancy as a possible outcome. There are two issues here: the first is a reflection on the status and value of people with disability and the second is the impact on society's acceptance of difference, should a 'screening out' of disability be possible. It is interesting to consider the parallels between this neo eugenics and the decision made by Maurice Benn in 1964.

The eligibility process and assessment for determination of funded services in the NDIS is based on proof of impairment and incapacity. Deficit is located within the individual and as such, the rhetoric of inclusion is juxtaposed with a discourse of need (Hallahan, 2015, p. 192; Goggin & Newell, 2005, p. 53). In a 2015 paper, Hallahan asks, "has policy reform recapitulated a historically evident notion of neediness and dependency?". The request for formal funded services must be balanced against an evident incapacity, which may indicate a return to a medical model of disability and potentially contributes to a

perpetuation of the cultural and social aspects of social exclusion (p.192). People who are deaf and are Auslan first language speakers or who are classified as being on the Autism spectrum may identify as being part of a linguistic or neurodiverse minority rather than as having a disability. For such people, NDIS eligibility processes create disability.

A consideration of the extent to which the NDIS seeks to challenge the social construct of disability and shift the Australian debate on diversity will be a question I return to throughout this thesis. Before looking at the NDIS in more detail however, in the next chapter I will examine social care provision in the UK, particularly over the last 10 years. The UK experience is relevant as it then becomes possible to draw comparisons with a similar model of disability support and consider recommendations based on lessons learned, as it applies to the implementation of the NDIS.

## CHAPTER THREE

### **The rise (and fall) in support for the personalisation agenda in the UK**

In the previous chapter, I outlined the chronological development of Australian disability policy and services from custodialism to personalisation. Prior to considering the NDIS in detail, I will look at the challenges arising during the implementation of the personalisation agenda in the United Kingdom (UK). Policy and primary commentary about the UK personalisation agenda will inform my understanding of the capacity of the NDIS to fulfil the commitment of the National Disability Strategy 2010-2020, for people with disability to participate as equal citizens. Simon Duffy's trajectory from advocate to critic of personalisation and his more recent statements about the specific failings of the personalisation model are relevant in understanding potential antagonisms inherent in the current model of the NDIS.

#### UK Reform Agenda

In 2008, social care gained unprecedented attention in the UK in politics and the media. The Social Care Minister Ivan Lewis urged councils to deliver on the opportunities presented "by the most profoundly important year in a generation" for the sector (Samuel, as cited in Beresford, 2008, p. 8). Lewis was referring to the 'transformation agenda' encapsulated by personalisation which marked a shift away from the paternalistic service driven policies of the past to a new person centred approach in disability services. The personalisation rhetoric promised personal autonomy and self determination, more closely aligned to the guiding principles of the United Nation's (UN) Convention on the Rights of Persons with Disabilities (CRPD) than anything that had preceded it (Power et al., 2013, p. 242).

The roots of personalisation were borne out of the UK's Independent Living Movement, a grass roots campaign which advocated for autonomous choice and control over the necessary support required to facilitate independent community living for people with disability. The Disability Living Allowance 1992 (DLA) and subsequent Community Care (Direct Payments) Act 1996 paved the

way for adults with physical disability to receive “cash for care” by providing direct payments to purchase community care services of their choice as an alternative to the existing “one size fits all” standardised services (Power et al., 2013, p. 209). The rationale was that direct payments could provide the individually tailored support disabled people wanted in order to live independently and to have access to mainstream community opportunities. From an ideological perspective, the claim was that supports that are ‘enabling’ could redress the societal barriers experienced by people with disability and facilitate their participation in the community on a level playing field with other citizens. In reality, there was little uptake amongst service users: the local authorities who administered the budgets were criticised for being bureaucratic and controlling. Funding levels failed to match expectations or needs (Beresford, 2008, p. 15) and a lack of information, thin markets and capacity for choice continued to present barriers for those who received payments (Glendinning, 2008b, p. 453).

The Disabled People’s Movement’s campaign for direct payments was aligned with the prevailing political discourse which included an increasingly individualist framework. Disabled people’s rights to autonomy and self determination resonated with the Conservative Government’s agenda of deregulation and privatisation. A lack of choice and control reflected the concerns of New Labour who highlighted the importance of social justice, equality of opportunity and the value of a free market economy to facilitate this (Morris, 2011, p. 3). A key focus of public policy was an emphasis on participation or ‘user involvement’ and ‘choice’ (Beresford, 2008, p. 15).

The concept of ‘personalisation’ was first popularised in 2004 by Charles Leadbeater (former advisor to British Labour Prime Minister Tony Blair) who defined it as,

putting users at the heart of services, enabling them to become participants in the design and delivery...services will be more effective by mobilising millions of people as co-producers of the public goods they value (Leadbeater 2004).

However, the argument has been made that ‘user involvement’ has become an ideological battleground. Leadbeater describes a modern citizenship where consumers become co-producers. Critics of the marketisation of social care saw consumerism as “a model that prioritises the individual over the community and ... privatises citizenship” (Needham, as cited in Glendinning, 2008b, p. 459). Government and disability advocates both employ the language of choice and control but with different origins and intent:

(The) government has effectively sat its ‘market-consumer’ discourse on the disabled movement’s ‘social rights discourse’, producing a powerful hybridisation but one riddled with tensions (Scourfield, 2005, p. 473).

#### ‘In Control’ and the model of personalisation

This ‘powerful hybridisation’ was manifested in strong government support of the personalisation model developed by the UK organisation ‘In Control’ and promoted by the then ‘In Control’ CEO, Simon Duffy. The ‘In Control’ project was set up in 2003 as a partnership between central and local government and some independent organisations working alongside disabled people to rework what they believed to be an outdated, poorly designed service system which failed to support the aspirations of its’ users to become active citizens.

From 2003 to 2005 ‘In Control’ worked with people with intellectual disability to develop a model of self-directed support. ‘In Control’ demonstrated that by including people in the design and delivery of their own support, significant improvements both in quality of life and in the efficiencies of service delivery could be evidenced (Duffy, Tyson & Stansfield, 2008). Duffy (2010) suggested that the rationing system by which resources were assigned to individuals and the professionally dominated process of planning and organising support in the existing care management model could be redressed by direct payments, self directed support, individual budgets and person centred planning, which he referred to as the ‘technologies of personalisation’ (p. 253). He envisaged that personalisation would have the capacity to “bring about social change and enhance the citizenship of disabled people” (p. 265). The work of ‘In Control’

attracted the interest of policy makers and in 2005, the Department of Health began its own research and development program to explore the concept of individual budgets in which consumers controlled decisions about the expenditure of money on services (Duffy et al., 2008).

The process of introducing the personalisation agenda in the UK was progressed by the Department of Health Concordant “Putting People First” (2008) which recommended a rollout of personal budgets for all people using disability services by 2011 (Power et al., 2013, p. 214). This protocol was populated with language which resonated with both disability advocates claiming social justice: (‘equality of citizenship’; ‘maximum choice, control and power’; ‘self determination’; ‘dignity’) and with the proponents of marketisation: (‘shared responsibility’; ‘third/private sector innovation’; ‘retail market model’; ‘a programme which is co-produced, co-developed, co-evaluated’; participation ‘as active and equal citizens, both economically and socially’) (HM Government, 2008). The support for this reform policy was continued under the Conservative coalition government in 2010. Personalisation sat comfortably within the government’s liberatory agenda. Personal choice and control was aligned with a dominant global discourse of increased freedom and control, individual responsibility and savings in public expenditure as a result of economic efficiencies (Boxall, Dowson & Beresford, 2009, p. 509).

The construction of personalisation as a modern, politically and ethically progressive discourse positioned its adoption as inevitable. Iain Ferguson, author of “Reclaiming Social Work: Challenging Neo-liberalism and Promoting Social Justice” quotes a document published by the Scottish government:

Increasing personalisation of services is both an unavoidable and desirable direction of travel for social work services. Unavoidable in the sense that both the population and policy makers expect it; desirable in the sense that it builds upon the capacity of individuals to find their own solutions and to self-care, rather than creating dependence on services (Scottish Executive, as cited in Ferguson, 2012, p. 61).

In this context, the debate around personalisation is seen as being not simply for or against a mode of service delivery but for or against the perpetuation of existing, oppressive services. As such, critics of personalisation could subsequently be labelled as paternalistic and conservative (Ferguson, 2012, p. 61).

The Individual Budgets Evaluation Network (IBSEN) summary report (2008a) was the first 'robust' study of the implementation and impact of personalisation in social care in the UK. The evaluation results were equivocal but indicated that Individual Budgets "have the potential to be more cost-effective than standard care and support arrangements" and that the cost-effectiveness advantages and sense of control experienced by individuals were greater for people with mental health problems and younger physically disabled people than for older people or people with learning disabilities (Glendinning et al., 2008a, p. 23). Evaluations of the work undertaken by 'In Control' reported that most benefits were gained by those with stronger self advocacy or with strong advocates around them and those that had existing care arrangements in place (Power et al., 2013, p. 238).

#### Disillusionment with the implementation of personalisation

In 2005, Simon Duffy had warned that Individual Budgets could not be taken out of context: they needed to be combined with supported decision making processes, support planning, flexibility in how funds are used and minimal bureaucracy alongside an important system wide shift around the mainstreaming of disability issues. He reiterated that their intent should be to genuinely empower people with disability in order to enjoy their full citizenship rights and control how resources are used, not implemented as a bureaucratic response to issues of service delivery or as a means for maximising cost savings (2005, p. 14).

By 2009, Simon Duffy had left 'In Control' in order to work independently of government. Duffy acknowledged that many individuals and families had experienced a greater degree of control, flexibility and quality of life as a result of system reforms (Duffy & Williams, 2012, p. 19) but he suggested that the lack

of a legal framework to support the reforms had led to inconsistencies in implementation. Duffy attributed the shortcomings of personalisation to increased bureaucracy around the assessment and planning processes which he felt had led to budget cuts and loss of autonomy. He suggested that an inflexibility around how individual budgets could be spent had contributed to a failure to shift power and control to people with disability (Duffy & Williams, 2012, p. 19). Duffy later redefined UK social policy as “zombie personalisation” (Duffy, as cited in Needham & Glasby, 2015, p. 273) in which marketisation had overridden the principles of social justice and the language of citizenship and community has been coopted for very different outcomes to the ones he had originally intended. His vision for personalisation had been one where people were able to exercise choice and control in a flexible system which facilitated active citizenship but in an article he wrote for The Guardian newspaper in 2014, Duffy describes the reality of personalisation as an excuse for abandonment, for unnecessary complexity and bureaucracy and a vindication for cost cutting (Duffy, 2014). In 2012, Duffy wrote that the austerity measures implemented under the guise of personalisation were the most direct attack on the rights of disabled people since the creation of the welfare state (Duffy, 2012, p. 19).

#### A critique of personalisation

Advocates of personalisation, such as Leadbeater, anticipated the ways in which the model could draw on the neoliberal discourse to bring about economic efficiencies and greater autonomy for service users through a non-paternalistic, non-hierarchical, less interventionist, individualised approach in a competitive market paradigm (Leadbeater, as cited in Mladenov, Owens & Cribb, 2015, p. 308). Conversely, for those who believe that a radical user led program of reform has been displaced by a neoliberal agenda which seeks to dismantle the welfare state, personalisation has been a subterfuge to,

implement a New Public Management philosophy designed to increase market reach and in the process, force individuals to take responsibility for their own (lack of) wellbeing” (Williams and Dickinson, 2015, p.151).

There is no doubt that UK reform strategies have had the transformative effect on some people's lives that the rhetoric of personalisation predicted. Individual, powerful stories have contributed to the perceived success of the personalisation agenda which has led to its adoption into the National Health Service as Personalised Health Budgets (Darzi, as cited in Needham & Glasby, 2015, p. 270). However, the degree of this success is highly contested. Services for people with disability may have shifted away from a paternalistic service driven system to more positive, inclusive person centred approaches, but there is a disappointment in the UK that the current personalisation agenda appears to have lost touch with its initial roots and values (Needham & Glasby, 2015, p. 273).

Needham suggests that there is "purposive ambiguity" around the definition of personalisation in order that "a wide range of divergent interests have been able to sign up to and advance it, without needing to reconcile internal tensions" (Needham, 2011, p. 55). Some of these tensions are listed below:

- An individualist framework espousing autonomy, self determination and choice and control can be seen as part of a wider political agenda of reducing public services and the role of the state which can lead to an undermining of collective responsibility and redistribution (Morris, 2011).
- Personalisation does not address existing structural disadvantage which restricts the individual's capacity for self-actualisation (Mladenov et al., 2015, p. 321).
- Service users take on the responsibility and risk formerly the remit of the state (Mladenov et al., 2015, p. 323).
- Individual consumers may be drawing on unequally distributed personal economic and social resources that, in turn, lead to or increase inequitable outcomes.(Glendinning, 2008b, p. 457).
- Increased market efficiencies may include the expectation of an increase in informal (unpaid) support.
- There are funding challenges for organisations to deliver services that are difficult to measure in a marketised framework based on 'unit cost' e.g. systemic advocacy; community development; innovative practice; peer

support and as such, the structures to help people to be heard are weakened (Dowse, 2009, p. 579).

- The widening of markets has the potential to deprofessionalise and deregulate disability support (Power et al., 2013, p. 243).
- Economies of scale in a competitive marketised environment may lead to large organisations offering (potentially poorer quality) services at lower prices with the potential for ‘cream-skimming’, especially where demand exceeds supply, and smaller organisations with no guaranteed funding, unable to compete (Glendinning, 2008b, p. 457).
- The introduction of social care as a for profit opportunity is a barrier to a socially transformative model (Beresford, 2008, p. 13).

### The impact of austerity

Critics suggest that personalisation has been used to legitimise the retrenchment of public service provision in the context of the post 2008 austerity measures (Mladenov et al., 2015; West, 2013, p. 646) and that the language of personalisation has been used to mask austerity as ‘improvement’, thus providing an ‘ideological cover for the most draconian of austerity measures’ (West, in Mladenov et al, 2015, p. 319). A 2011 study echoed these concerns:

... the popularity of personalisation as a policy approach was being used to offer political cover for service changes which were more about cutting budgets than about enhancing choice and control (Needham, 2011, p. 64).

A document produced by the UK Health & Social Care Consortium, Think Local, Act Personal (2011), acknowledged that the “current financial context and consequent reductions in public expenditure now present an even greater challenge (to social care support)” (p.1). The Think Local, Act Personal partnership agreement recommended a personalised approach where “the most significant efficiencies are likely to come through reducing people’s reliance on paid support” and that partners should consider “mobilising people’s own resources, skills and assets to meet their care and support needs, leaving

public funding to cover those that cannot be met from such means” (p. 5). Mladenov et al (2015) suggest that personalisation has been reduced to “a means for achieving more with less, which greatly undermines its usefulness for improving social justice” (p. 232).

### Evaluations of the personalisation model

The largest survey of people who use personal budgets was undertaken by ‘In Control’ and Lancaster University. The results of the online survey were released in 2014. The survey collated responses from over 4000 people in 26 different local authorities who received or who care for someone in receipt of a personal budget. The survey indicated that over 80% of budget holders felt that things were better or a lot better regarding their quality of life and being supported with dignity (Waters & Hatton, 2014, p. 30). The less positive feedback related to securing paid employment or volunteer work and making a difference to where and with whom they lived. The report confirms that there are people who are significantly benefiting from a more individualised approach to disability support however the authors reiterated that the results of the survey were not a nationally representative as the sample was self selecting and respondents only answered the questions presented. Those who are most marginalised may not be captured in these statistics.

A smaller study based on the Standards We Expect project was published in 2011. The project involved a consortium of people with disability and their supporters, practitioners and researchers and was undertaken over four years to explore ideas and experiences of person-centred support. The report identified key barriers of personalisation which included:

- the lack of a well-supported, skilled and well-trained workforce amidst greatly increasing demand.
- increasing reliance being placed on ‘informal’ or unpaid support such as family members.

- organisational barriers including increased bureaucratisation, tightening administrative controls and inflexible organisations
- a continuation of paternalistic and inflexible service provision
- service users' restricted access to mainstream policies and services, in particular as this related to travel and transport, education and continuing disability discrimination. People living in rural areas and from black and minority ethnic communities face additional barriers.
- a lack of capacity-building through ensuring accessible information, advice, guidance and advocacy.

Overall, the report summary cited two major interrelated problems: the chronic inadequacy of social care funding and the continued existence of outdated paternalistic attitudes at odds with person centred support (The Standards We Expect Consortium, 2011).

In a 2016 Centre for Welfare Reform presentation, Simon Duffy advised that between 2010 and 2014, UK social care had been cut by over 30% and that by 2014, 500,000 fewer people were receiving support. He anticipated that by 2020, the cuts would be even bigger (Duffy, 2016, Slide 3). A 2016 Independent Living Survey published by 'In Control' on behalf of the Independent Living Strategy group found that in the face of recent austerity measures, 48% of respondents reported that the choice and control they enjoyed over their support was poor or very poor (In Control, 2016). Instead of personalisation having the capacity to bring about social change and enhance the citizenship of people with disability (Duffy, 2010, p. 265), the implementation of the technologies of personalisation combined with tighter eligibility conditions in the context of post 2008 austerity measures in the UK, has limited budgets and reduced capacity for choice and control. There appears to be a significant disconnect between what personalisation promised and what now exists (Needham & Glasby, 2015, p. 273).

Lessons from the UK for Australian reform

In 2012, Duffy co-authored a paper reflecting on the lessons learned from the UK experience of personalisation and made ten recommendations about how the NDIS could get the best possible start (Duffy & Williams, 2012, p. 4). I have listed these key learning opportunities in table 1 below and then summarised the recommendations under 3 primary themes, choice and control, flexible implementation and accessible information.

Table 1: Duffy's recommendations for effective implementation of the NDIS

Duffy's recommendation for effective NDIS implementation	Primary theme
Make the entitlements real	Choice and control
Only define the essential parts of the system	Choice and control
Enable an ongoing process of social innovation	Flexible implementation
People need to know enough to be able to plan	Accessible information
Set clear and public rules that are easy to understand	Accessible information
Enable a pragmatic process for transition	Flexible implementation
Develop a system which is sensitive to time and outcomes	Flexible implementation
Do not put undue focus on the plan	Flexible implementation
Do not let any group dominate the process	Choice and control
If in doubt, focus on peer support	Choice and control

In the next chapter, I will look at the NDIS in more detail and consider the implementation of the scheme in the light of Duffy's recommendations. The three issues of choice and control, flexible implementation and accessible information will form the focus of my consideration.

## CHAPTER FOUR

### **The National Disability Insurance Scheme**

After examining the research and primary commentary driven by the UK's personalisation agenda in the previous chapter, I summarised the issues proposed by Simon Duffy in 2012 as essential to the successful implementation of the National Disability Insurance Scheme in Australia. In this chapter I will explore the genesis and actualisation of the NDIS and consider its implementation in the light of these 3 primary issues: choice and control, accessible information and flexible implementation.

#### The harbingers of reform

Australia ratified the Convention on the Rights of Persons with Disabilities (CRPD) in 2008. This signified a commitment by the Australian government to acknowledge and protect the rights of people with disability and, building on the existing Commonwealth Disability Discrimination Act 1992, to increase opportunities for all Australians to fully participate in the economic, social and cultural life of the nation. The 2010 implementation of the National Disability Strategy, underpinned by the principles of the CRPD was seen as an important step in closing the gap between the lived experience of Australians with disability and the rest of the community.

As discussed in Chapter 2, the primary recommendation of the 2009 Shut Out Report was to address systemic disadvantage and build more inclusive communities (Deane, 2009, p. 63). The 2009 DIG report illustrated a significant shift in focus from welfare to investment, and the first to introduce the language of the market as a means of facilitating this transformation. These two reports led to a 2011 Productivity Commission Inquiry Report on Disability Care and Supports. The report confirmed that a National Disability Insurance Scheme was not only feasible but would create social and economic benefits for all Australians (Productivity Commission, 2011, p. 3). The NDIS would be based on a national, entitlement model. Funding would no longer depend on where a disability was acquired, what the disability was or how much an individual

earned. People could access ‘reasonable and necessary’ personalised support instead of fitting in to a ‘one size fits all’ service driven model with significant rationing. Geographical inconsistencies with multiple systems operating across Australia would be replaced with a national, unified framework (PricewaterhouseCoopers, 2011, p.11).

The Productivity Commission’s recommendation for a national disability insurance scheme was based on the findings that the NDIS would provide significant benefits, including:

wellbeing gains to people with disabilities and informal carers; efficiency gains in the disability sector; savings to other government services; increased labour force participation, and the resulting fiscal gains (Productivity Commission, 2011, p.11).

A new language of disability, framed within the context of investment was evident in these reports. Investment in people with disability could maximise individual potential and reduce longer term care costs. Investment in their carers to reenter the workforce could facilitate their capacity to contribute as future tax payers. Investment in service provision offered business opportunities for the private sector. By comparison, existing disability policy had created a “growing, unfunded liability” (DIG, 2009, p.13).

Bruce Bonyhady, a founder of the NDIS and chairman of the National Disability Insurance Agency (NDIA), identified two key factors that came together to create bipartisan support for the NDIS. The first was the strong economic case for disability reform. The second was the National Disability Carer Alliance and their grassroots campaign Every Australian Counts which for the first time brought together people with disability, their families and carers, service providers and disability advocates with a single, unified claim for system reform (Bonyhady, 2010).

In a 2016 report undertaken by National Disability Services and Every Australian Counts, economic modelling predicted the potential scale of the

impact of the NDIS on the NSW Gross State Product when fully implemented. The Every Australian Counts Campaign Director reported,

The NDIS will not only make a huge difference to lives of 460,000 Australians with permanent and significant disability but will repay the taxpayer many times over. Once fully implemented the NDIS has the potential to increase GDP by \$22billion. We've heard a lot recently about potential budget blowout, this report shows again, the NDIS could actually be our golden ticket (National Disability Services, 2016, p.1).

### The Scheme

The National Disability Insurance Scheme Act was passed in 2013. This incorporated the recommendations of the Productivity Commission and received bilateral support.

The NDIS claims to address a substantive citizenship through the provision of autonomy and resources, to “support people with disability to live independently and to be included in the community as fully participating citizens” (Act, NDIS, 2013, Part 2:4:11b). The NDIS marks a significant shift in policy to provide people with disability the opportunity to “exercise choice and control in the pursuit of their goals and the planning and delivery of their supports” (Act, NDIS, 2013, Part 2:3 (1)(e)).

The NDIS first transitional phase was launched on July 1st 2013. On July 1st 2016, the Scheme moved from trial phase to full rollout around Australia. Full coverage for all Australians was projected to be completed by July 2019. It is estimated that 460,000 people will be eligible for NDIS funding, which equates to approximately 2% of the Australian population (Madden et al., 2014, p.15) but only a fraction of the estimated one in five people in Australia living with a disability (ABS, 2015). Access to the scheme is controlled by strict eligibility criteria which requires evidence of a permanent disability and significant functional impact which adversely affects one's capacity for social and economic participation (Act, NDIS, 2013, section 24).

For those people who are eligible, the NDIS funds 'reasonable and necessary' supports to assist them to live an 'ordinary life'. A funded individualised support package is based on the person's statement of goals, objectives and aspirations together with an assessment of their functional limitations and support needs (Australia. Department of Human Services 2017c). The types of supports that the NDIS may fund for participants include: daily personal activities; transport to enable participation in community, social, economic and daily life activities; workplace help to allow a participant to successfully get or keep employment in the open or supported labour market; help with household tasks to allow the participant to maintain their home environment; and therapeutic support, equipment, assistive technology and modifications to facilitate these processes (Australia. Department of Human Services., 2017c). A key focus of the NDIS is to increase social and economic participation in the community. This may include support to build skills and capability, with the intention that engagement in education, employment and community activities then becomes possible. In keeping with a social insurance model, the NDIS also funds early intervention for eligible participants, with a view to improve individual outcomes and thus reduce longer term costs (Act, NDIS, 2013, section 25). The NDIS is expected to be partly self-financing under the assumption that social investment in 'reasonable and necessary' funding packages will lead to greater workforce participation of both carers and people with a disability (Productivity Commission, 2011, p.12). Unlike previous disability models, people in receipt of NDIS funding have the opportunity to have significant input into the nature of their support and to identify the service provider of their choice.

Access, planning and payments are managed by an independent statutory organisation, the National Disability Insurance Agency. (In Western Australia, arrangements are different but are intended to be consistent with the NDIS to reflect a bilateral agreement with the Commonwealth, (Porter et al., as cited in Productivity Commission, 2017, p. 5). Funding for the NDIS is shared by Commonwealth, State and Territory Governments. The scheme will be funded in part by increasing the Medicare levy from 1.5 to 2%. When the NDIS is fully operational, projected costs are \$22.1 billion per year with further growth after

maturity expected to reach \$25 billion by 2022-23 (Australia. National Commission of Audit, 2017).

### Information, Linkages and Capacity building

A significant second part of the NDIS is the Information, Linkages and Capacity building (ILC) component which underpins the model of social insurance. The ILC is seen as an investment to reduce the lifetime costs of disability at both an individual and community level through a provision of community education, broad based interventions and capacity building (Australia. Department of Human Services, 2017d, p.1). Under the NDIS Act 2013, these more general functions are referred to as “developing and enhancing the disability sector... facilitating innovation, research and contemporary best practice in the sector; and building community awareness of disabilities and the social contributors to disabilities” (Act, NDIS, 2013, Section 8). The ILC claims to provide a bridging interface between the scheme and mainstream services by linking people with disability (or those supporting people with disability) to appropriate services, as well as building the capacity of the community and mainstream services to create greater inclusivity and accessibility of people with disability (Australia. Department of Human Services, 2017d, p. 4). A second expectation of the ILC is that it will support people with disability who are not eligible for, or currently not accessing, the NDIS by providing links to appropriate support in the community so that people need only move into the scheme when necessary.

NDIS funding is intended to meet people’s disability support needs. Other mainstream services, as experienced by all citizens, such as health care, aged care, education, transport and housing are not included (Productivity Commission, 2017, p.15). The two parts of the NDIS aim to complement each other: people who are not deemed eligible for access to funded support can utilise the ILC to connect to existing disability, community and mainstream supports; community education and building community capacity will deliver better mainstream responses to disability; and a focus on building capacity of people with disabilities over time may optimise outcomes, reduce Individual

Funded Packages (IFP) and thus ensure longer term financial sustainability (Productivity Commission, 2017, p.15).

ILC will begin to be rolled out in mid-2017 and when fully implemented by 2019-20 will have funding of around \$132 million in total, distributed through a competitive grants process (Australia. Department of Human Services, 2016, p. 5).

### Duffy's recommendations for the NDIS

Duffy made a series of recommendations in relation to the design and implementation of the NDIS based on the UK experience of personalisation. The discussion will now turn to the application of his findings to the NDIS.

Duffy stresses the importance of 'genuine' choice and control over the reasonable and necessary support required to advance one's life chances. This includes the use of the term 'entitlement' which helps to redress the imbalance of power between people and professionals in traditional funding systems (Duffy & Williams, 2012, p. 9). NDIS participants have the opportunity to make decisions around services received and providers used (Productivity Commission, 2017, p. 6). Consumer choice is an important source of personal power (Fawcett & Plath, 2012, p. 749) but there may be additional antagonisms around choice which limit an individual's capacity for autonomy. The concept of choice as a key organising principle in public policy is part of a global neoliberal discourse which shifts responsibility for social care from the public to private sphere, which preferences markets over states and individualism over collectivism (Clarke, Newman and Westmarland, 2008, p. 246). Clarke et al. suggest that 'real choice' may be limited to a marketised conception of choice, where actual capacity for exercising power and control is constrained by three components. Firstly, structural inequality privileges those with existing economic, social and cultural capital. Secondly, power asymmetries between consumers and service providers filter the views and experiences of service users through professional and bureaucratic processes. Thirdly, the market may not be able to respond to consumers' wishes (Clarke et al., 2008).

Dr Rhonda Galbally, Chair of the NDIS Independent Advisory Council suggests that choice and control becomes a meaningless mantra unless people with disability have a vision and aspiration to what is possible and the encouragement and support to realise those aspirations. She adds that people who have experienced years of disenfranchisement and isolation may have little capacity for aspiration (Galbally, 2016). Dr Galbally is also critical of the Government's lack of priority given to building inclusive communities (which was a central feature of the social justice agenda of the Every Australian Counts campaign). In the 2016 Sambell Oration, Galbally reports that "It was never envisaged that these individual packages provided by the NDIS would be given in a vacuum of an inaccessible, non-inclusive Australia". Significant expectation was placed on the capacity of the National Disability Strategy to reform mainstream systems to work in partnership with NDIS towards inclusion and active citizenship for all Australians. Dr Galbally voices her concern about the validity of this process in the Oration:

The fact that the National Disability Strategy has dropped off the radar has serious implications for the NDIS. It has loaded up the NDIS with either inadvertently taking on the impossible responsibility for ensuring that all systems become accessible and inclusive (impossible because the National Disability Insurance Agency does not have the authority or the resources), or the more likely scenario to emerge by default in the absence of an active National Disability Strategy: to have the NDIS overseeing the vast expansion of closed segregated services as the solution to a non-inclusive outside world (Galbally 2016, para. 11).

Despite decades of evidence that existing legislation had done little to change the structural barriers for people with disabilities, the support funded by an individual's NDIS plan does not seek to play any role in broader change in relation to the large scale barriers confronting people (Gibbs, 2013). The NDIS mechanism of individualised funding cannot alone remove the systematic obstacles to social inclusion, create universal access to mainstream services and facilities, alter discriminatory community attitudes towards people with disabilities, change organisational practices or redress low quality disability

support. Choice, as it relates to the individualised funding model of the NDIS, remains rooted in a conception of consumer choice rather than choices made through active, democratic and collective participation as citizens. The ILC has been promoted as a key component in addressing the systemic barriers in society. However, the level to which this has been funded (\$132 million (or 0.6%) from an NDIS annual projected cost of \$22 billion) indicates the Commonwealth government's lack of priority in addressing these barriers and questions any commitment towards a radical system change. Clarke et al (2008) suggest that the politics of choice are used as a rhetorical device to conceal other political intentions, "choice as a proxy for deeper processes of privatisation or marketisation" (p. 247). This interpretation could also be levied on the choice mechanism of the NDIS.

Duffy recommends early indicative signals about approximate levels of funding to assist with planning. He suggests that if there is not sufficient information provided to an individual to facilitate planning prior to professional planning involvement based on the costs of assisting people in similar circumstances, this would guarantee lower levels of citizen engagement, independence and creativity (Duffy et al, 2012, p.15). NDIS pricing guides are available to provide pricing limits and benchmarks but there is no indicative budget provided to people eligible for NDIS prior to the planning process. A 2017 NDS Report "How to get the NDIS on track" recommended that NDIS pricing should be more flexible for participants and service providers and that the inadequacy of some NDIS prices pose a substantial risk to the capacity of the disability support market to meet a growing demand for services (NDS, 2017, p. 11).

The NDIS Act 2013 states that supports should be 'reasonable and necessary' and provide 'value for money' (Madden et al, 2013, pp. 106-7). There is an inherent ambiguity about what constitutes reasonable and necessary support or what is represented by value for money.

According to Duffy, an obscure, complex system may lead to cynicism, dispute and increased reliance on judicial and political processes (Duffy & Williams, 2012, p. 20). There has been criticism that the NDIS has been rolled out without being fully developed. The Productivity Commission recommended that the

initial roll out of the NDIS should take place in 2014 but this was brought forward by the Labour government by one year. (It has been suggested that this was in order for Julia Gillard to promote the NDIS as part of her election platform (Naufal, 2016)). In the first quarter, the NDIA received over 2000 complaints about the NDIS MyPlace portal ICT system. A recent NSW State Government survey found 62% of people with a disability have still not heard about how to access the NDIS and 57% are unaware of when the program starts. There have been reports of plan inconsistencies, errors and delays, poor communication between participants and planners and financial distress for participants unable to access upfront funding. In the six months to December 2016, the National Disability Insurance Agency (NDIA) approved as many participant plans as it had in the preceding three years to comply with targets in inter-governmental agreements (NDS, 2017b, p. 5). A report from the Australian National Audit Office in 2016 concluded that the NDIS implementation is outpacing the preparatory work needed (NDS, 2017b, pp. 5-6). Rapid expansion of the NDIS has heightened pressure on the recruitment and development of a skilled workforce capable of responding to the aspirations of NDIS participants (NDS, 2015, p. 22). The current NDIS implementation targets are driving rapid high volume processing of individual's plans and the quality of the plans nationwide is inconsistent (NDS, 2017b, p. 6). Not all participants have the opportunity to comment on their plan before it is finalised leading to an outcome which does not necessarily reflect their needs and aspirations (NDS, 2017b, p. 7). This in turn impacts on the NDIS commitment to promote individual choice and control. Donnelley suggests that implementation which is politically driven has created errors and complexities which may threaten the viability of the NDIS (Connelley, 2016). This rapid rollout resonates with Scourfield's criticism of the personalisation agenda in the UK: that a market consumer discourse has overridden the social justice discourse.

Duffy advocates for an empowering, permissive, flexible system to enable people with disability to exercise their human rights. This, he suggests, will in turn, lead to a progressive and evolutionary change led by people with disability and their families. Where the state devolves responsibility to self directed support, innovations may develop through peer networks, family leadership groups, community led initiatives, community advocacy, micro enterprises and

new forms of managing personalised support (Duffy & Williams, 2012, pp. 12-14). There is a risk that sector development will flounder in the transition to the NDIS and smaller, potentially more innovative service providers will not be competitive in the uncertainty of the NDIS market (NDS, 2015, p. 6). Dr Ken Baker, the CEO of the National Disability Services identifies bureaucratic processes, financial instability within organisations, low prices and poor provider access to market information about patterns of supply and demand as barriers to the sustainability and effectiveness of the NDIS (NDS, 2015, p. 10) and its capacity to bring about evolutionary change.

The support plan is a central requirement of the NDIS. However, Duffy suggests that support plans may have little intrinsic value and just add to the bureaucratic process. He writes that being in control of an adequate budget and the flexibility to use the funds creatively would lead to more innovative outcomes than holding a person to account for fulfilling their plan (Duffy & Williams, 2012, p. 23). The NDIS support plan is generally valid for 12 months, although a plan can be reviewed at any time. Duffy suggests that it is expensive and inefficient to impose reviews on those who do not need them, or to apply inflexible rules to budgets which require amendment within a plan's annual lifetime (Duffy & Williams, 2012, p. 20).

Duffy also stresses the importance of validating funding allocations with reference to outcomes. A consideration of personal outcomes is addressed through the NDIS individual plan annual review process but Ken Baker (CEO NDS) suggests that in a broader context, it is of paramount importance that the NDIS recognises the value of investment in quality research:

The NDIS will not be true to its insurance principles if it fails to invest in research that tests the efficacy of various support interventions and service practices and stimulates innovation and the dissemination of knowledge across the service sector (Ken Baker NDS, 2015, p. 28)

The transformational NDIS agenda may be compromised unless there is clear evidence about what works. Baker suggests that the NDIA needs to share data,

fund research and support innovation or it risks embedding outdated practices across the disability sector (NDS, 2017a, p. 7).

Duffy suggests that a phased approach with a flexible interpretation of the rules is necessary for the Scheme's successful implementation (Duffy & Williams, 2012, p. 21) and that bureaucratic systems may stifle creativity and social innovation (Duffy & Williams, 2012, p. 24). A system which is predominantly predicated on a professional assessment of functional capacity with decisions regarding the level of support funded "in the hands of professionals using standardised tools" (Fawcett & Plath, 2012, p. 757) is not comfortably aligned with an autonomous individual in control of their own supports and services. Capacity for autonomy may also be impacted by the availability of formal advocacy support, which cannot be funded through an NDIS individual plan. Independent advocacy is critical to redress the relatively weak power of people with disability in relation to the service system (Kendrick, Ward & Chenoweth, 2017, p. 8).

Finally, Duffy recommends the stimulation of peer support as the "most reliable, valued and sustainable form of support" as a key to the successful implementation of the NDIS (Duffy & Williams, 2012, p. 24). It is important that this is not interpreted as an increase in the provision of informal (or unpaid) support but rather that the representation of people with disability in peer networks, as service providers, as board members, as policy makers and as active community citizens becomes unremarkable.

In the final chapter, I will use evidence collected through formal evaluations of the NDIS to test some of the suppositions I have extrapolated from my understanding of the primary commentary so far.

## CHAPTER FIVE

### **The early stages of the rollout of the NDIS**

I have previously described the National Disability Insurance Scheme and examined it, primarily, through the lens of the work done by Simon Duffy and his recommendations based on his experience of the implementation of the personalisation agenda in the UK. In Chapter 4, I summarised these recommendations as relating to three major issues: choice and control; accessible information and flexible implementation. A formal evaluation of the rollout of the NDIS to date has been undertaken by The National Institute of Labour Studies (NILS), at Flinders University. I will highlight the findings of this and other evaluations firstly in relation to Duffy's summarised issues, and then to illustrate my observations about the early rollout of the NDIS.

The NILS independent evaluation has been commissioned by the Australian Government Department of Social Services (DSS) to monitor and evaluate the experience of participants, their families and carers, service providers and their workforces in the trial sites of the Australian Capital Territory, Victoria, New South Wales, Northern Territory, South Australia and Tasmania. An initial report (based on wave 1 interviews) was released in 2015 (Australia. Department of Social Services 2015) and an intermediate report (wave 2 interviews), in 2016 (Mavromaras, Moskos & Mahuteau, 2016). The final report is due for release in late 2017.

#### Choice and control

Findings from the Initial and Intermediate Reports indicated that the NDIS was seen by people with disability, their families and carers and by Disability Service Providers as facilitating the opportunity to improve lives and increase social activities; to develop independent skills and experience new activities (Australia. DSS, 2015, p 4). Many of the first wave respondents in the Initial Report felt that

the well-being and quality of life of the NDIS participant had been enhanced through the support they were receiving as part of their NDIS plan. They referred in particular to an increased choice of funded provisions, choice in hours of support, and a choice of activities, an increase in the number of hours supported, increase the frequency of service provision, access to better equipment and a wider range of therapeutic or social activities (typically socialising with other people with disability) (Australia. DSS, 2015, p. 33). Both the quantitative and qualitative data for the Intermediate Report indicate that the majority of second wave respondents received increased supports as a result of becoming NDIS participants. Both data sources also indicate that most NDIS participants and their families and carers report that they have more input and choice over the type of supports they received, the timing of those supports, the location of their supports, and the choice of service provider (Mavromaras et al., 2016, p. 54).

From the perspective of choice and control, the Intermediate Report cites that about half of all NDIS participants receiving supports indicate that they are better off, about a third that they are about the same as before the NDIS, and about 15 per cent that their choice and control is negatively impacted by the NDIS (Mavromaras et al., 2016, p. xiii). Of this disadvantaged group, the qualitative data indicates that those who were unable to effectively advocate for services on their own behalf (Mavromaras et al., 2016, p. xi), “vulnerable” families, those unable to navigate the NDIA website to explore information about available services and providers, and those less able to articulate their support needs, are less likely to experience greater choice over their supports (Mavromaras et al., 2016, p. xiii).

Both wave 1 and wave 2 evaluations found that there was a strong association between perceived choice and control and disability type. People with mental health and psychosocial disability are more likely to report less choice and control over supports since becoming NDIS participants whereas people with physical and sensory disability experience the lowest levels of dissatisfaction (Mavromaras et al., 2016, p. 57). Those with intellectual disability and/or very high needs and those people who struggled to manage the new and sometimes

complex NDIS processes were less likely to have their individual choices acknowledged and respected (Mavromaras et al., 2016, p. 66).

Whereas at wave 2, respondents observed greater choice of some services and support and improved quality due to the existence of more registered NDIS providers (and therefore more competition) (Mavromaras et al., 2016, p. 42), exercising choice was constrained for those living in non-metropolitan locations with fewer service providers (p. xiii). In the Initial Report, NDIS participants living in regional areas had experienced minimal impact since the implementation of the NDIS, reportedly because service infrastructure, already comparatively underdeveloped, had remained unchanged (Australia. DSS, 2015, p. 34).

The quantitative data indicates that the 15 - 17% of NDIS participants who report that their choice and control over their supports is negatively impacted by the NDIS, are more likely to have experienced a decrease rather than an increase in the number of supports they receive since the implementation of the NDIS (Mavromaras et al., 2016, p.57). This reinforces the supposition that those who are unable to articulate their needs and do not have access to independent advocacy to ensure adequate support in their individual plan, will not be advantaged by the NDIS in its current form.

First and second wave respondents indicated that outcomes in relation to choice and flexibility were ameliorated for those fully self managing their funding (Australia. DSS, 2015, p. 65; Mavromaras et al., 2016, p. 59). The Initial Report indicated however, that uptake on those choosing to self manage funding for NDIS approved supports was low (Australia. DSS, 2015, p. 7) with perceived barriers around extra responsibility and bureaucracy (p. 75). This was reiterated in the Intermediate report with the additional concern that the NDIS provided insufficient safeguards to address the potential risk of fraud or mismanagement of funds by those undertaking self-management (Mavromaras et al., 2016, p. 59).

The Every Australian Counts (EAC) “2017 NDIS Report Card” echoed these findings. The results were collated from an online survey undertaken by 2,177 EAC supporters between November 2016 - January 2017. 71% of people with

disability and 61% of families and carers who responded to the EAC survey indicated satisfaction with their experience of the NDIS so far. 78% of people with disability and 74% of families and carers felt that they had the same or more support since the implementation of the NDIS. 64% of people with disability and 61% of families and carers felt that their life was the same or better than before the NDIS. The concern expressed by the EAC was that only half of the respondents felt they had had choice and control in the process and a quarter of respondents felt that they were disadvantaged by the NDIS (EAC, 2017). Also to be noted is that those with the capacity to respond to the EAC online survey are unlikely to be the cohort of those most disadvantaged in the NLS evaluation. Those most marginalised are potentially underrepresented in both data analyses, particularly if they do not access print or internet based information, are isolated and/or are not currently linked into service provision.

My discussion so far has focused on those who are eligible for NDIS. It is also important to consider those who do not meet the eligibility criteria. The qualitative data in the Intermediate Report uncovered concerns about the impact the NDIS would have on people with disability not eligible for the NDIS who have previously accessed disability support services. Some non-NDIS participants were reported to be receiving fewer services while others were falling through service gaps and getting no supports at all (Mavromaras et al., 2016, p. xvii). Services that were previously block funded which may have been accessed by a broad range of participants are now not available to those without individualised funding.

Duffy stressed that an entitlement which was rooted in respect for human rights and equal citizenship would facilitate genuine choice and control over the reasonable and necessary support required to participate on a level playing field (Duffy, 2013, p. 13). It is clear that there are many who will benefit from an increased sense of autonomy brought about through the implementation of the NDIS. However, the NLS evaluations and the EAC Report Card captured information about choice and control only as it relates to service provision. Consideration of the impact of the NDIS on a broader sense of choice and control as it relates to social inclusion was not a focus of the interviews. The fact that a significant number of people expressed a lack of choice and control and

disadvantage in their experience of the NDIS indicates strongly that the scheme is unable to deliver a sense of real entitlement, firstly because there are flaws in the implementation; secondly, because the human rights agenda out of which the concept of the NDIS was borne has been consumed within a scheme which preferences competitive service delivery; and thirdly, because the entitlement to which the NDIS rhetoric refers is linked to a neoliberal conditionality of individual responsibility which sits uncomfortably alongside a group which has historically been constituted as the “other”. I will revisit these ideas later in the chapter.

### Accessible Information

Duffy recommended that for the NDIS to be implemented optimally, people should have enough information to plan successfully and that bureaucracy be minimised (Duffy & Williams, 2012, p.20). The EAC survey listed the NDIS’s excessive bureaucracy as the primary issue in their claim that the Scheme did not meet expectations. The majority of both NDIS participants and families and carers felt they would have benefited from increased information during the planning process (EAC, 2017). The qualitative data in the NILS Initial and Intermediate Report also indicated that NDIS participants and carers felt they had insufficient information to choose their service providers confidently. Access to information was further compromised by the perceived challenges in navigating the NDIA website (Mavromaras et al., 2016, p. 65).

The Initial Report indicated that many participants typically limited their plan to retaining existing services and service providers (Australia. DSS, 2015, p.4), requesting more frequent and more intensive support rather than choosing different or more innovative types of support (p. 75). By wave 2, familiarity with NDIA processes appeared to reduce the sense of overwhelm experienced during participants initial planning process (Mavromaras et al., 2016, p. 4). NDIS staff appeared to be more familiar with these processes too, leading to more efficient communication among participants and the NDIA (Mavromaras et al., 2016, p. 58).

Reduced and low literacy among some NDIS participants combined with challenging, bureaucratic language used in NDIA documentation were cited as

raising communication barriers between NDIS participants and NDIA staff, leading to inequitable outcomes for those with more complex communication needs (Australia. DSS, 2015, p. 77). NDIA staff considered that participants and families who were confident, educated and able to articulate support needs had better outcomes than those with less capacity to understand the Scheme, including participants with intellectual disability (Mavromaras et al., 2016, p. 37).

NDIA staff reported challenges with respect to engaging with people from culturally and linguistically diverse or Aboriginal or Torres Strait Islander backgrounds. These included a lack of knowledge about the NDIS in some communities, communication barriers and fewer service options outside metropolitan and regional centres (Australia. DSS, 2015, p. 77). Staff reported that these challenges were exacerbated by the lack of available opportunities to engage meaningfully in an accelerated rollout (Australia. DSS, 2015, p. 7).

It seems inevitable that these inequities of outcomes will be widened in this current NDIS format if those people who are considered at risk of being left behind or under-serviced continue to be disadvantaged by a lack of access to information relevant to their circumstances.

#### Flexible implementation

Duffy recommended that transition to the NDIS should be pragmatic, less focus should be placed on the plan and that the NDIS should enable a flexible process capable of facilitating ongoing social innovation (Duffy & Williams, 2012, pp. 14-21).

The rapid launch of the NDIS meant that policies and procedures were not fully in place at the start of the trial to support the implementation of clear guidelines around eligibility and planning processes. NDIA staff described the sector as being slow to move from block to individualised funding in those areas where the NDIS has already rolled out. The transition to the NDIS was also adversely impacted by inadequate information technology processes for NDIA staff (Australia. DSS, 2015, p.7). and the failure of the MyPlace Portal to process NDIS payments claims in a timely fashion (NDS, 2017a, p.4). The scheme was

built on a co-design approach involving collaboration between participants, community, NDIS Planners and Agency partners, but use of co-design has diminished in the rapid rollout (NDS, 2017b, p. 12). During the trial phase, participants could have input into their draft plan before it was finalised. NDS reports that this practice has now largely ceased, leading to people receiving plans that do not reflect their goals and needs (NDS, 2017b, p. 7). The most common concerns from respondents about the transitioning processes in the Initial Report focused on the lack of responsiveness by the NDIA, the complex bureaucracy associated with both eligibility and planning processes and dissatisfaction with some NDIA staff members' disability-specific knowledge (Australia. DSS, 2015, p. 32).

Central focus is placed on the plan in the implementation of the Scheme. NDIS participants have input and choice around who, how and what is provided, but their choices are limited by rigid plan implementation based on close detailing of 'reasonable and necessary' supports approved under the NDIS. First wave respondents requested more discretion and flexibility in the implementation of the NDIS plan (Australia. DSS, 2015, p. 35). In the Intermediate Report, a number of factors were seen to be limiting access to disability supports including small numbers or low capacity of service providers in certain geographic areas, lengthy waiting lists for some providers or types of support, inflexibility of support hours by service providers, rigid structures in the NDIS claiming system and capped prices for certain types of support (Mavromaras et al., 2016, p. 31), all of which challenge the flexibility to fulfil individual aspiration. NDIA staff questioned the capacity of some NDIS participants to articulate their goals and aspirations and suggested that the scheme may have over-estimated the ability of NDIS participants and their supporters to undertake planning and negotiate plan implementation. Progress towards articulating or realising more ambitious objectives was not expected until later in an individual's NDIS planning cycle (Australia. DSS, 2015, p. 7).

It is anticipated that the additional funding and market competition provided under the NDIS will benefit both NDIS participants and the sector by generating more diverse service options, greater service flexibility and enhanced person-centred care (Australia. DSS, 2015, p. 6). However, in the Intermediate Report,

disability service providers and NDIA staff report that demand for disability supports has exceeded supply (Mavromaras et al., 2016, p. xii). This is reiterated in the NDS 2016 State of the Disability Sector Report which indicated that many disability service providers lack the internal financial capacity to invest in the service development required to meet the rapidly growing demand. Some disability support organisations report that they may not be able to cover the costs of supply for some supports at the maximum price set by NDIS. NDIA are committed to imposing a uniform pricing framework across most of Australia (NDS, 2017b, p. 11). The gap between supply and demand will be disparate across locations, across service types and across categories of disability. Risks include thin markets and regulation, financial viability for services and workforce availability (NDS, 2017a, p. 7).

The “Independent Review of the Readiness of NDIS for Transition to Full Scheme” commissioned by the Government in 2016 identified the growing gap between market demand and supply as an area of ‘high risk’ and recommended, “...both immediate and short term actions to strengthen mitigation and responses in relation to potential market failure or provider collapse” (Kruk, as cited in NDS, 2017b, p. 5).

NDS advise that supply gaps are already emerging particularly for people with very complex needs, for personal care and community participation supports (NDS, 2017a, p.3) and there is a danger that disability support organisations may cease to provide certain supports which they consider underfunded under current NDIA cost guidelines (Mavromaras et al., 2016, p.xii). These factors will have significant implications for flexibility and innovation, particularly in areas where markets were already thin and will further disadvantage those who are already marginalised.

In the final section of this thesis, I will outline my observations of the early rollout of the NDIS.

1. The market does not have the capacity to deliver ‘inclusion’

Firstly, individualised funding linked to individual outcomes does not directly address broader inclusive societal change. Secondly, inherent in the NDIS genesis is the premise that markets self manage and regulate (Productivity Commission, 2011). If the market fails, functions poorly or takes time to develop, this will impact outcomes for individual NDIS participants. Wave 2 responses from disability sector organisations reflected the challenges an expanding workforce creates including skills shortages, recruitment and retention of staff, decreased opportunities for professional development, an increase in the need for work which was unfunded (e.g. administrative tasks), an increase in the casual workforce and less well-paid work (Mavromaras et al., 2016, p. xii). Reported impacts included changing business models, increased merger and acquisition activity, entry of new providers, exits from the sector, and more competitive, less collaborative relationships between providers (Mavromaras et al., 2016, p. xii).

Since the 1980s, public sector reform has shifted the responsibility for social services previously provided by the state to a market model of resource allocation and service delivery, with an emphasis on consumer choice and competition between service providers (Dean, as cited in Purcal & Fisher, 2014, p.89). There is significant research which reiterates the incapacity of the free market to meet human needs in an equitable way. Instead of reducing social and economic inequalities, it serves to exacerbate them (Tesoriero & Ife, 2010, p. 6). The NILS evaluations reflect this paradigm: an individual may be empowered but a privatised consumer choice model of disability services may not be able to respond to the supports requested; those individuals without strong self advocacy or adequate advocacy support may be disadvantaged both in the planning process and once chosen services are received; and the quality and diversity of services available, particularly in those areas where the market is thin, may be so limited that consumer “choice” is in fact meaningless (Fawcett & Plath, 2012, pp. 754 -55). The three principal forms of structural disadvantage in Western society are generally considered to be class, gender and ethnicity (Tesoriero & Ife, 2010, p.72). The NILS evaluations reflect the double, triple and potentially quadruple disadvantage experienced by the 15% of NDIS participants who may have faced a decrease in supports since the introduction of the Scheme, who have not been able to actualise their right to employ choice

and control, or articulate their goals and dreams to benefit from the opportunity available to them. “Those people with disability who did not fully understand the approach to disability services or could not fully articulate their needs were considered at risk of being left behind or under-serviced under the new system (Australia. DSS, 2015, p. 47).

I suggest that the NILS evaluations clearly demonstrate that the market model of the NDIS heralds advantages in terms of efficiency, competition, personalised services and responsiveness for those with the capacity to successfully navigate the system. However, the NDIS market model fails to acknowledge that it operates within a political system in which structural disadvantage precludes all members of society from claiming their full citizenship rights.

## 2. The NDIS has created ‘tiered’ economies

Just as those most marginalised are the least likely to benefit from the NDIS, there is some justification from the responses to the NILS evaluation to indicate that smaller disability support organisations, previously operating under block funding models would not survive in the NDIS market model.

Financial viability is threatened by NDIA determined prices not matching the costs of service delivery (Australia. DSS, 2015, p. 6), and further impacted by increasing amounts of unfunded work (including administrative tasks to comply with NDIA regulations), and having less funding available for fixed costs (e.g. property maintenance) or staff training and development (Australia. DSS, 2015, p. 5). Workforce stakeholders in wave 2 interviews argued that the sustainability of some service providers, in particular smaller ones, could be at risk.

Many organisations were reported to be currently operating at a loss under the Scheme (Mavromaras et al., 2016, p. 44). In rural areas, the volume of business that providers may legitimately expect to receive was also feared to be insufficient to sustain smaller providers (Australia. DSS, 2015, p. 80). Increased merger and acquisition activity had been occurring in the trial sites at wave 2, with larger organisations taking over the operations of some smaller providers.

At wave 2, NDIA staff reported that in some of the trial sites there were reports of new large providers coming from interstate.

Stakeholders were concerned that competition between providers might force disability service providers to reduce their operating costs and thus reduce quality of care (Australia. DSS, 2015, p. 6). The provision of certain services may cease which were considered underfunded under current NDIA cost guidelines (Mavromaras et al., 2016, p. 12). The emergence of new labour-for-hire services for people self managing their NDIS funding led to concerns about safeguards for participants and workers in a deregulated market (Mavromaras et al., 2016, p.45). The Initial Report captured the concern expressed by existing providers that after the trial phase, for-profit organisations would enter the disability sector to target the profitable supports or 'pick the easy clients'. This would leave existing disability service providers to manage the more difficult and challenging clients (Australia. DSS, 2015, p. 38). In wave 2 interviews, respondents felt that the Scheme had adversely changed the dynamic within a previously collaborative sector with increased competition for staff and clients now occurring (Mavromaras et al., 2016, p. 45).

I suggest that there is the potential for a tiered economy to evolve within the service delivery market which could potentially exclude smaller organisations. The concern is that larger organisations may lack an equal capacity for innovative service delivery and participants will experience limitations in the range of options available with a potential reduction of choice dependent on geographical area and profitability of support. Kendrick et al (2017) suggest that historically, innovation and change in outcomes for people with disability has been driven by smaller initiatives working in ethical partnership with disabled people and their families rather than by the established service sector (p.11).

I have already illustrated that a tiered economy may be operating amongst scheme participants, with greater opportunity available for those with existing financial and social capital. The social insurance model of the NDIS aims to optimise the social and economic independence of people with disability, manifested by increasing the participation and contribution of NDIS participants and their carers, particularly in the workforce. However, according to wave 1

respondents, for the four fifths of NDIS participants who were not already employed, there was limited support in this area with providers struggling to find inclusive employment opportunities, and not actively supporting NDIS participants in taking the next steps once a work activity/experience had ended (Australia. DSS, 2015, p.35). The Intermediate Report indicated that increased economic participation amongst people with disability was considered a long-term process. Time was needed to change cultural beliefs amongst employers about the employability of people with disability and to develop an individual's employability skills. The Report reflected the feedback from services and participants that more needed to be done to develop effective guidance, supports and linkages to employers in order to open up labour market opportunities for people with disability (Mavromaras et al., 2016, p. xvi).

### 3. The NDIS has conflated service delivery and social inclusion

Although I agree that the systemic change required to bring about a significant recalibration of the number of people with disability in the workforce cannot be a quick fix, I suggest that the NDIS in its current format is incapable of delivering such an outcome. The NDIS has conflated service delivery and social inclusion in its market model and the expectation is that the NDIS in isolation will have the capacity to bring about the social change required to transform societal barriers which inhibit inclusion.

The Every Australian Counts campaign, based upon social justice values and aspiration and underpinned by the social model of disability, was an important contributor to the actualisation of the NDIS. However, I argue that the central policy goal to integrate people with disability into the conventional Australian economy and society through a neoliberal paradigm emphasising individualism, entrepreneurship, material accumulation and the free market may be an anathema to a serially disadvantaged and excluded minority. Kendrick et al. (2017) question how people without capacity or supportive networks will protect their personhood and aspirations from a market driven service sector with competing agendas that might not have their best interests at heart (p. 7).

I referred earlier in this thesis to Simon Duffy's distancing himself from his work with the UK government once he recognised that in the implementation of personalisation, marketisation had overridden the principles of social justice. The NDIS bears the hallmarks of a neoliberal social and economic paradigm as an ameliorative measure which does not tackle the root causes of exclusion within society. The rhetoric of the NDIA goals may be rooted in the human rights agenda but the conflated nature of the scheme itself impedes the realisation of structural change.

The current NDIS model does not have the capacity to challenge broader social issues. The interfaces between the NDIS and mainstream services such as health, education, transport, child protection, justice and mental health are still being negotiated. However, NDS suggest that much of the current interaction between the NDIS and mainstream service systems is driven by skepticism around cost-shifting (NDS 2017c). It is important that the Government recognises that it continues to have a responsibility to address the social inequalities experienced by people with disability in addition to the practical benefits gained through the NDIS. In its current format, I suggest that the structure of NDIS is heavily biased towards service delivery and the 0.6% of the NDIS budget allocated to build community awareness and capacity building of mainstream services to promote more inclusive attitudes and practice is woefully inadequate.

4. The intentional premise behind the NDIS is no longer driven by a human rights agenda

The financial sustainability of the NDIS is of critical importance. I referred in Chapter 4 to the statement by the EAC's Campaign Director about the economic modelling in NSW which forecast the significant positive impact the NDIS would have on the Gross State Product, to the extent that he identified the NDIS as Australia's "golden ticket" (National Disability Services, 2016, p.1). The poor outcomes cited in the NIDS evaluations regarding economic participation of people with disability, the workforce challenges for service providers and the cost of the average plan exceeding the initial modelling done by the Productivity Commission (by up to 30% on early performance data (Australia. NCOA 2017,

para. 7)) suggests that the financial viability of the scheme in its current format is in jeopardy.

The NDIS is not immune from scrutiny in a time of austerity. In the UK, market based competition has helped legitimise welfare state retrenchment (Owens & Mladenov, 2016). The NDIS may be at risk from future 'efficiencies' in an attempt to curb liabilities for the tax payer which could include eligibility 'creep', co-payments, funding caps, pricing restraint and reducing the level of support in individual plans (Nexia Edwards Marshall NT 2016, p. 4) .

A skeptical analysis of the ongoing commitment of the Australian Government to fund the fiscally risky NDIS may point to an underlying intentional premise whose foundation lies in the need to find new sources of growth and employment in an Australian post manufacturing and post mining boom rather than in a social justice agenda which liberates participants from paternalistic control through increased individual autonomy (Miller & Hayward, 2017, p. 143). The responsibility for significant social change has been lain at the feet of individuals and service providers with additional support provided through the NDIS non participant expenses such as ILC. The ILC competitive grants process (which replaces existing advocacy and information services) claims to address 'community awareness' and 'capacity building'. These may be examples of 'weasel words': deliberately ambiguous public language with no specific meaning (Watson, 2003, p. 53) which absolve Government from a commitment to deliver on the early human rights agenda of the Every Australian Counts campaign. The NILS evaluations clearly indicate that marginalised groups continue to be excluded. The individualising focus of the NDIS risks obscuring structural inequities and exacerbates the problems of powerlessness, inequality and injustice. In the current NDIS model, marketisation has been the unexpected consequence of the human rights struggle against paternalism (Morris 2011).

I recognise that there are challenges associated with NILS evaluations. There are variations in implementation in each of the trial sites, and the NDIS is still in an organic process during the early stages of implementation. However, I suggest that the results of the early implementation serve to show that the NDIS

provides only a veneer of inclusivity and is in fact, contributing to the formation of new hierarchies and growing inequalities through a redefinition of disability which separates those who have the social and financial capital to maximise on the clear advantages of the scheme and those who are unable to overcome the individual and structural barriers that contribute to their ongoing exclusion.

If autonomy is defined as the capacity of people to “have the power to define themselves as opposed to being defined by others” (Bhattacharyya 2004), the NDIS cannot provide a “real” entitlement unless existing structural disadvantage which restricts the capacity for self-actualisation is adequately addressed. Major structural inequalities associated with restricted autonomy such as exclusive communities, attitudinal barriers, geographical inequality, poverty and ill health will continue to impact on quality of life and living standards experienced by the majority of disabled Australians, irrespective of the benefits that an individualised funding model may bring. There are significant challenges faced by consumers in a market landscape which privileges competency, capacity and independence. These are exacerbated for those without strong self advocacy or a network of advocacy around them or those for whom aspiration for a different life is compromised by past and ongoing experience of disadvantage and rejection. Where disability is rebranded as investment, the value placed on a person with disability may be more about their status as commodity in the evolution of a new market based around inclusion than about a recalibration of society’s acceptance of diversity.

## Conclusion

Primarily, this thesis considers the first general principle guiding actions under the NDIS Act 2013, “People with disability have the same right as other members of Australian society to realise their potential for physical, social, emotional and intellectual development” and whether this can be successfully actualised through the implementation of the current NDIS model. In the first two chapters, I explore what it means to be a citizen and how the claiming of full citizenship by people with disability has historically been impacted by ongoing exclusion. I outline a timeline of disability services and policy leading up to the NDIS in Australia, which tracks a progressive claiming of rights from custodialism to personalisation. I suggest that the NDIS does not have the capacity to deliver on the promise of full citizenship for all. I highlight the antagonisms of neoliberal social policy and propose that marketisation compromises a social justice agenda and inhibits an inclusive model of citizenship through a preferencing of existing capacity and a lack of acknowledgement of systemic barriers. Chapters 3 and 4 consider recent changes in social care policy in the UK and draw comparisons with the rollout of the NDIS in Australia. I suggest that the lessons learned from a personalisation agenda implemented during a period of austerity in the UK indicate that an individualist framework has been used to vindicate cost cutting and increased bureaucracy. I suggest that Duffy’s primary recommendations pertaining to ‘real’ choice and control, flexible implementation and accessible information are not heeded by the current NDIS model and that, in the longer term, this will impact on the sustainability of the NDIS and on individual outcomes for NDIS participants. A detailed analysis of the initial and intermediate NLS evaluations of the early rollout of the NDIS reflects an increase in a sense of autonomy experienced by many NDIS participants but also confirms the negative repercussions for those people with disability who are the most disadvantaged and least able to articulate or actualise their aspirations. Complex bureaucracy, a lack of market readiness and capacity, a competitive rather than collaborative service sector and an accelerated NDIS rollout have and will impact on the

delivery of promised outcomes. The primary focus on service delivery inhibits the capacity of the Scheme to invest in the machinery to redress the systemic barriers to social inclusion.

For these reasons, I suggest that the current model of the NDIS is flawed and does not provide adequate protection to ensure that *all* Australians with disability are able to actualise their right to realise their potential for physical, social, emotional and intellectual development.

In the forward to Duffy's 2016 paper, 'Citizenship and the Welfare State', O'Brien suggests that, "Without deep roots, welfare reform becomes little more than disconnected tinkering to impose a succession of politically fashionable ideas" (Duffy, 2016, p. 6). Duffy (2011) claims that these deep roots are embedded in the social model of disability, the independent living movement, social role valorisation, inclusion and the values which inspired his Citizenship Theory (p. 11). He suggests an increase in local control, a strengthening of social rights, a promotion of collective action and provision of a universal basic income could positively impact on the capacity of the welfare state to support the full citizenship of people with disability (Duffy, 2016).

Recommendations for local control, social rights and collective action are reflected in the NDIS Independent Advisory Council briefing paper which identified the positive contribution of Disabled Persons User Led Organisations (DPULO) in the UK as a key strategy to build capacity of both people with disability and the system. The paper acknowledged the unique value of user led organisations in advocacy and peer support, facilitating co-production, changing societal perceptions and expectations, shifting power balances and supporting systemic transformation (Australia. DHS, 2015, p.23). Future research could explore the prevalence and impact of user led organisations in a post NDIS Australian landscape. Conversely, future research could explore what constitutes 'ability' or 'skill' within a market driven system. Inherent in this is a consideration of the extent to which 'disability' when represented as the other to 'skill', locks disabled people out of a capitalist mode of production.

## REFERENCES

- Act, N. D. I. S. (2013). *National Disability Insurance Scheme Act 2013*. Australian Government, Canberra.
- Australia, Bureau of Statistics. (2012). *Survey of Disability, Ageing and Carers (SDAC)*. Retrieved from: <http://www.abs.gov.au/ausstats/abs@.nsf/0/C7C72D7706E9BED0CA257DE2000BDC60?OpenDocument>
- Australian Bureau of Statistics. (2015). *Disability, Ageing and Carers, Australia: Summary of Findings* (cat #4430.0). Retrieved from: <http://www.abs.gov.au/ausstats/abs@.nsf/0/56C41FE7A67110C8CA257FA3001D080B?OpenDocument>
- Australia. Department of Human Services. (2015, September). *Capacity Building for People with Disability, their Families and Carers*. Retrieved from: <https://www.ndis.gov.au/medias/IAC-advice-on-Capacity-Building-PDF-?context=bWFzdGVyfHJvb3R8NTg5MDU2fGFwcGxpY2F0aW9uL3BkZnxoZWYvaGFILzgzOTc4NjQ1MjU4NTQucGRmfDE3NDEzNWlwZDM5ODUxNjRkNTA5M2FhMjQ3ZGY4YzI2MDg3OWQ4MGVjOGI2NWYwYjNjMDc2MTEzZDIiOTViNjA>
- Australia. Department of Human Services. (2016, November). *ILC Commissioning Framework*. Retrieved from <https://www.ndis.gov.au/medias/documents/hf4/ha1/8799111970846/ILC-Commissioning-Framework-PDF-3MB-.pdf>
- Australia. Department of Human Services. (2017a). *My NDIS Pathway - a guide to being an NDIS participant*. Retrieved from: <https://www.ndis.gov.au/html/sites/default/files/My-NDIS%20-Pathway.pdf>
- Australia. Department of Human Services. (2017b). *Information, linkages and capacity building*. Retrieved from: <https://www.ndis.gov.au/communities/ilc-home.html>
- Australia. Department of Human Services. (2017c). *What are reasonable and necessary supports?*. Retrieved from: <https://www.ndis.gov.au/participants/reasonable-and-necessary-supports.html>
- Australia. Department of Human Services. (2017d). *Information, Linkages and Capacity Building Policy Framework*. Retrieved from: <https://www.ndis.gov.au/html/sites/default/files/ILC-Policy-Framework.pdf>
- Australia. Department of Social Services. (2015, December). *NDIS Evaluation Initial Report*. Retrieved from: <https://www.dss.gov.au/disability-and-carers/programs-services/for-people-with-disability/national-disability-insurance-scheme/ndis-evaluation-initial-report>
- Australia. National Commission of Audit. (2017). *9.2 The National Disability Insurance Scheme*. Retrieved from: <http://www.ncoa.gov.au/report/appendix-vol-1/9-2-national-disability-insurance-scheme.html>
- Baldry, E. (2016, 18 April). How the justice system fails people with disability—and how to fix it. *Australian Broadcasting Corporation* Retrieved from: <http://>

[www.abc.net.au/radionational/programs/ockhamsrazor/australian-justice-system-disability-indigenous/7326240](http://www.abc.net.au/radionational/programs/ockhamsrazor/australian-justice-system-disability-indigenous/7326240)

- Bhattacharyya, J. (2004). Theorising community development. *Journal of the Community Development Society*, 34(2), 5-34. Retrieved from: <http://libproxy.murdoch.edu.au/login?url=http://0-search.proquest.com.prospero.murdoch.edu.au/docview/224653788?accountid=12629>
- Beresford, P. (2008). Whose personalisation? *Soundings*, (40), 8+. Retrieved from <http://go.galegroup.com.libproxy.murdoch.edu.au/ps/i.do?p=AONE&sw=w&u=murdoch&v=2.1&it=r&id=GALE%7CA191189541&asid=452537ff264318fff35e8906aabc05c3>
- Bigby, C., & Ozanne, E. (2001). Shifts in the model of service delivery in Intellectual Disability in Victoria. *Journal of Intellectual and Developmental Disability* Vol 26/2 pp. 177-190
- Bigby, C., and Fyffe, C. (2009). An overview of issues in the implementation of individualised funding, in Bigby, C. and Fyffe, C. (ed), *Proceedings of the Third Annual Roundtable on Intellectual Disability Policy: Achieving their own lives: The implementation of individualised funding for people with intellectual disability*, Oct 24 2008, pp. 40-45. Melbourne, Vic: La Trobe University. Retrieved from: <http://arrow.latrobe.edu.au:8080/vital/access/manager/Repository/latrobe:32297.jsessionid=D2D40BFAB91A7ECB8B397DBE95D785F5>
- Bonyhady, B. (2010, 21 October). *Reforming Disability Policy: From Charity and Welfare to Social Insurance and Investment, 2010 Oswald Barnett Oration*. Retrieved from: [http://apo.org.au/files/Resource/barnett\\_oration.pdf](http://apo.org.au/files/Resource/barnett_oration.pdf)
- Boxall, K., Dowson, S., & Beresford, P. (2009). Selling individual budgets, choice and control: local and global influences on UK social care policy for people with learning difficulties. *Policy & politics*, 37(4), 499-515.
- Brown, H. and Smith, H. (1992). *Normalisation: A Reader for the Nineties*, London: Routledge.
- Clarke, J., Newman, J. and Westmarland, L. (2007). The Antagonisms of Choice: New Labour and the reform of public services. *Social Policy & Society* 7:2, 245–253 doi: 10.1017/S1474746407004198
- Clear, M. (Ed.). (2000). *Promises Promises: Disability and terms of inclusion..* Leichardt, NSW: Federation Press.
- Cocks E., Fox C., Brogan M. & Lee M. (eds). (1996). *Under Blue Skies : the social construction of intellectual disability in Western Australia*. Perth: Edith Cowan University
- Connelley, F. (2016). The NDIS in 2016: A tough year in disability *Fundraising & Philanthropy Australasia*. Retrieved from: <http://www.fpmagazine.com.au/347588-347588/>
- Corker, M., & French, S. (1999). *Disability discourse*. Philadelphia, Pa;Buckingham;;: Open University Press.

- Dean, H. (2003). Welfare, Identity and the Life Course in *Social Policy* Ed. Baldock, J., Manning, N., and Vickerstaff, S. Oxford University Press
- Deane, K. (2009). Shut out: the experience of people with disabilities and their families in Australia. *National People with Disabilities and Carers Council. Canberra: Canprint*. Retrieved from [https://www.dss.gov.au/sites/default/files/documents/05\\_2012/nds\\_report.pdf](https://www.dss.gov.au/sites/default/files/documents/05_2012/nds_report.pdf)
- Disability Investment Group (DIG). (2009). The Way Forward - A New Disability Policy Framework for Australia *Commonwealth of Australia Policy, vol. 34, no. 3*, pp. 469–488. Retrieved from [https://www.dss.gov.au/sites/default/files/documents/05\\_2012/dig\\_report\\_19oct09.pdf](https://www.dss.gov.au/sites/default/files/documents/05_2012/dig_report_19oct09.pdf)
- Disability Services Commission (DSC) *1940s-1950s – Birth of the associations* Retrieved from <http://www.disability.wa.gov.au/understanding-disability1/understanding-disability/history-of-disability-services/1940s-1950s--birth-of-the-associations/>
- Dowse, L. (2009). “Some people are never going to be able to do that”. Challenges for people with intellectual disability in the 21st century, *Disability & Society, 24:5*, (2009) 571-584,  
DOI10.1080/09687590903010933
- Duffy, S. (2005). Individual budgets: transforming the allocation of resources for care. *Journal of Integrated Care, 13(1)*, 8-16.
- Duffy, S. (2010). ‘The citizenship theory of social justice: exploring the meaning of personalisation for social workers’. *Journal of Social Work Practice, 24(3)*, 253-267. Retrieved from <http://www.tandfonline-com.libproxy.murdoch.edu.au/doi/full/10.1080/02650533.2010.500118>
- Duffy, S. (2011). *A fair society and the limits of personalisation*. The Centre for Welfare Reform, Sheffield. Retrieved from <http://www.centreforwelfarereform.org/uploads/attachment/261/a-fair-society-and-the-limits-of-personalisation.pdf>
- Duffy, S. (2012). The limits of personalisation. *Tizard Learning Disability Review, 17(3)*, 111-123.
- Duffy, S. (2013). *Designing NDIS: An international perspective on individual funding systems*. The Centre for Welfare Reform. Retrieved from: <http://www.centreforwelfarereform.org/library/by-az/designing-ndis.html>
- Duffy, S. (2014, January 30). Personalisation was supposed to empower vulnerable citizens. It failed. *The Guardian*. Retrieved from <https://www.theguardian.com/public-leaders-network/2014/jan/30/personalisation-social-care-support-bureaucracy-service-failure>
- Duffy, S. (2016). *Social Care Reform - The Way Forward* (Slides). Retrieved from: <http://www.centreforwelfarereform.org/library/by-az/social-care-reform-the-way-forward.html>
- Duffy, S., & O'Brien, J. (2016). *Citizenship and the Welfare State*. Retrieved from: <http://www.centreforwelfarereform.org/uploads/attachment/487/citizenship-and-the-welfare-state.pdf>

- Duffy, S., Tyson, A., & Stansfield, J., (2008). *An Introduction to In Control*. Retrieved from [https://www.academia.edu/5853374/An\\_Introduction\\_to\\_In\\_Control](https://www.academia.edu/5853374/An_Introduction_to_In_Control)
- Duffy, S., & Williams, R. (2012). *The Road to NDIS: Lessons from England about Assessment and Planning*. Julia Farr Association, Purple Orange, Unley, SA. Retrieved from [http://www.purpleorange.org.au/files/7613/5415/5343/The\\_Road\\_to\\_NDIS\\_Lessons\\_from\\_England\\_about\\_Assessment\\_and\\_Planning.pdf](http://www.purpleorange.org.au/files/7613/5415/5343/The_Road_to_NDIS_Lessons_from_England_about_Assessment_and_Planning.pdf)
- Every Australian Counts (EAC). (2017, May). *NDIS Report Card*. Retrieved from: <http://www.everyaustraliancounts.com.au/ndis-report-card/>
- Fawcett, B., & Plath, D. (2014). A national disability insurance scheme: What social work has to offer. *The British Journal of Social Work*, 44(3), 747-762.
- Ferguson, I. (2012). Personalisation, social justice and social work: a reply to Simon Duffy. *Journal of social work practice*, 26(1), 55-73. DOI: 10.1080/02650533.2011.623771
- French, P. (2009). Accommodating Human Rights: A human rights perspective on housing, and housing and support, for persons with disability. *Sydney: People with Disabilities Australia*. Retrieved from: <http://www.pwd.org.au/documents/pubs/AccommodatingHumanRights2003.pdf>
- Galbally, R. (2016). *Working for Lives of Common Dignity*. Sambell Oration. Retrieved from: <http://www.centreforwelfarereform.org/library/by-az/working-for-lives-of-common-dignity.html>
- Gibbs, E. (2013, September 30). Equal but different. Ramp Up. *Australian Broadcasting Corporation*. Retrieved from <http://www.abc.net.au/rampup/articles/2013/09/30/3857116.htm>
- Glendinning, C., Challis, D., Fernez, J., Jacobs, S., Jones, K., Knapp, M., ... Wilberforce, M. (2008a) *Evaluation of the Individual Budgets Pilot Programme: Summary report*. Retrieved from [https://pure.york.ac.uk/portal/en/publications/evaluation-of-the-individual-budgets-pilot-programme-summary-report\(a48b45d7-21b9-442b-9ad2-edab6874ca04\).html](https://pure.york.ac.uk/portal/en/publications/evaluation-of-the-individual-budgets-pilot-programme-summary-report(a48b45d7-21b9-442b-9ad2-edab6874ca04).html)
- Glendinning, C. (2008b). Increasing choice and control for older and disabled people: a critical review of new developments in England. *Social Policy & Administration*, 42(5), 451-469.
- Goggin, G., & Newell, C. (2005). *Disability in Australia: Exposing a Social Apartheid*. Sydney: UNSW Press.
- Hallahan, L. (2015). Disability Policy in Australia: a triumph of the 'scripto inferior' on impotence and neediness?. *Australia Journal of Social Issues Vol 50 No 2*. pp. 191-208 DOI: 10.1002/j.1839-4655.2015.tb00344.x
- Held, D. (1994). "Inequalities of power, problems of democracy" in David Miliband (ed) *Reinventing the Left*. (pp 47 - 59). Cambridge: UK Polity Press.
- HM Government. (2007 December). *Putting People First: A shared vision and commitment to the transformation of Adult Social Care*. Retrieved from <http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/>

[prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_081119.pdf](http://prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_081119.pdf)

- In Control. (2016). *Independent Living Survey*. Retrieved from: <http://www.in-control.org.uk/media/243039/independent%20living%20survey%202016%20v2.pdf>
- Jenkinson, S. (2008). *Disability: Local, National and International Trends* Retrieved from Western Australia, Disability Service Commission website: [Disability: Local, national and international trends](#)
- Kendrick, M., Ward, M., & Chenoweth, L. (2017). Australia's national disability insurance scheme: looking back to shape the future, *Disability & Society*, DOI: 10.1080/09687599.2017.1322493
- Kenny, S. (2010). *Developing communities for the future*. 3rd Ed. Australia. Cengage Learning.
- Leadbeater, C. (2004). *Personalisation through participation: A new script for public services*. London: Demos. Retrieved from: <https://charlesleadbeater.net/2004/01/personalisation-through-participation-new-script-for-public-services/>
- Madden, B., McIlwraith, J., & Brell, R., (2014). *The national disability insurance scheme handbook*. Chatswood, NSW: LexisNexis Butterworths.
- Marshall, T. H. (1964). "Citizenship and social class" Ch IV in T. H. Marshall. *Class, citizenship and social development: essays*. (pp. 65 - 122). Garden City, New York: Doubleday
- Mavromaras, K., Moskos, M., & Mahuteau, S. (2016). *Evaluation of the NDIS, Intermediate Report*. Australia. Department of Social Security. Retrieved from <https://www.dss.gov.au/disability-and-carers/programs-services/for-people-with-disability/national-disability-insurance-scheme/ndis-evaluation-intermediate-report>
- Meekosha, H., & Dowse, L. (1997). Enabling citizenship: Gender, disability and citizenship in Australia. *Feminist review*, 57(1), 49-72.
- Miller, Paval & Hayward, David (2017). Social policy 'generosity' at a time of fiscal austerity: The strange case of Australia's National Disability Insurance Scheme *Critical Social Policy* 2017, Vol. 37(1): 128–147
- Mladenov, T., Owens, J., & Cribb, A. (2015). Personalisation in disability services and healthcare: A critical comparative analysis. *Critical Social Policy*, 35(3), 307-326.
- Morris, J. (2011). *Disability Policy* Retrieved from <http://www.disability.co.uk/sites/default/files/resources/Disability%20policy%20equality%20summary%20by%20Jenny%20Morris.pdf>
- National Disability Services. (2015). *State of the Disability Sector Report 2015*. Retrieved from <https://disabilitysectorreport.nds.org.au>
- National Disability Services. (2016). *Economic Benefits of the NDIS in New South Wales* Retrieved from <https://www.nds.org.au/policy/reports>

- National Disability Services. (2017a, January). *2017 Federal Budget Submission*. Retrieved from: [https://www.nds.org.au/images/news/NDS\\_Federal\\_Budget\\_Submission\\_2017.pdf](https://www.nds.org.au/images/news/NDS_Federal_Budget_Submission_2017.pdf)
- National Disability Services. (2017b, May). *How to get the NDIS back on track*. Retrieved from: <https://www.nds.org.au/news/how-to-get-the-ndis-on-track-nds-paper-released>
- National Disability Services. (2017c, March). *National Disability Insurance Scheme (NDIS) Costs: Submission to the Productivity Commission*. Retrieved from: <https://www.google.com.au/url?sa=t&rct=j&q=&esrc=s&source=web&cd=8&ved=0ahUKEwjR8L3EnOXUAhVGE7wKHdsTA0wQFghRMAc&url=https%3A%2F%2Fwww.nds.org.au%2Fpdf-file%2F052bb005-fe17-e711-8231-0050568e2189&usg=AFQjCNF05anqmr65S9FcrTnhlzWGMhyV5Q>
- National Disability Strategy (NDS) 2010-2020. Retrieved from: <https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/national-disability-strategy-2010-2020>
- Naufal, R. (2016, August 16). Shitstorm: A short history of NDIS Implementation. *Disability Services Consulting*. Retrieved from: <http://www.disabilityservicesconsulting.com.au/resources/shitstorm/>
- Naufal, R. (2017, January 15). *ILC: Kneecapping the NDIS*. Retrieved from <http://www.disabilityservicesconsulting.com.au/resources/ilc-kneecapping-the-ndis>
- Needham, C. (2011). Personalization: From Story-line to Practice. *Social policy & administration*, 45(1), 54-68. DOI: 10.1111/j.1467-9515.2010.00753.x
- Needham, C., & Glasby, J. (2015). 'Personalisation - love it or hate it?' *Journal of Integrated Care Vol 23/5* pp 268-276. Retrieved from : <http://www.emeraldinsight.com/doi/abs/10.1108/JICA-08-2015-0034>
- Nexia Edwards Marshall NT. (2016, November). *The National Disability Insurance Scheme. Is it financially sustainable?* Retrieved from <http://nexiaemnt.com.au/wp-content/uploads/2016/12/Darwin-NDIS-Scheme-November-2016.pdf>
- Nirje, B. (1969). The normalization principle and its human management implications. In R. Kugel, & W. Wolfensberger (Eds.), *Changing patterns in residential services for the mentally retarded*. Washington, D.C.: President's Committee on Mental Retardation. in SRV-VRS: The International Social Role Valorization Journal, Vol. 1(2) - 1994. Retrieved from: <https://pdfs.semanticscholar.org/9e0a/660fd410944d0938603af5ca250988d15f60.pdf>
- Nisbet, J., Hagner, D., Antal, P., Fox, S., LaPoint, N. (2006). Community-Centred Strategies for Supporting Persons with Disabilities *Journal of the Community Development Society Vol 37 No. 3*
- People with Disability (pwd). (n.d.). *History of Disability Rights Movement in Australia*. Retrieved from <http://www.pwd.org.au/student-section/history-of-disability-rights-movement-in-australia.html>
- Power, A., Lord, J., deFranco, A. (2013). *Active citizenship and disability: implementing the personalisation of support*. New York: Cambridge University Press

- Preuss, U. K. (2003). *The ambiguous meaning of citizenship*. Chicago, IL: The University of Chicago Law School-The Center for Comparative Constitutionalism.
- PricewaterhouseCoopers (PwC). (2011). *Disability Expectations: Investing in a better life, a stronger Australia*. Retrieved from: <http://www.pwc.com.au/industry/government/publications/disability-in-australia.htm>
- Productivity Commission. (2011). *Disability Care and Support: Executive Summary, Report no. 54, Canberra*. Retrieved from: <http://www.pc.gov.au/inquiries/completed/disability-support/report/disability-support-executive-summary.pdf>
- Productivity Commission. (2017, February). *National Disability Insurance Scheme (NDIS) Costs Issues Paper, Canberra*. Retrieved from: <http://www.pc.gov.au/inquiries/current/ndis-costs/issues/ndis-costs-issues.pdf>
- Purcal, C., Fisher, K. R., & Laragy, C. (2014). Analysing choice in Australian individual funding disability policies. *Australian Journal of Public Administration*, 73(1), 88-102.
- Reddihough, D. S., Meehan, E., Stott, N. S., & Delacy, M. J. (2016). The National Disability Insurance Scheme: a time for real change in Australia. *Developmental Medicine & Child Neurology*, 58(S2), 66-70.
- Roth, L. (2007). *Government policy and services to support and include people with disabilities*. NSW Parliamentary Library Research Service. Retrieved from <https://pdfs.semanticscholar.org/9a76/4afcfb403e58fa3022f9ccfa2d5879ba3e8a.pdf>
- Scotch, R. K. (2000). Disability policy: An eclectic overview. *Journal of Disability Policy Studies*, 11(1), 6-11. doi:10.1177/104420730001100104
- Scourfield, P. (2005). Implementing the Community Care (Direct Payments) Act: will the supply of personal assistants meet the demand and at what price?. *Journal of Social Policy* 34 /3 469-488
- Slasberg, C. Beresford, P & Schofield, P. (2012). 'Can personal budgets really deliver better outcomes for all at no cost?' *Disability and Society Vol 22;7* p1029 -34.10.1080/09687599.2012.736671
- Slasberg, C., Beresford, P., Schofield, P., & Harlow, E. (2013). The increasing evidence of how self-directed support is failing to deliver personal budgets and personalisation. *Research, Policy and Planning*, 30(2), 91-105.
- Sly, S., & Tindall, B. (2016). *A guide for providers of support*. Centre for Welfare Reform. Retrieved from: <http://www.centreforwelfarereform.org/uploads/attachment/527/citizenship-a-guide-for-providers-of-support.pdf>
- Stevens, M., C. Glendinning, S. Jacobs, N. Moran, D. Challis, J. Manthorpe, J. Fernandez, K. Jones, M. Knapp, A. Netten and M. Wilberforce. (2011). Assessing the role of increasing choice in English social care services. *Journal of Social Policy* 40(2): 257-74
- Tesoriero, F., & Ife, J. W. 1946- (James William). (2010). *Community development: Community-based alternatives in an age of globalisation* (4th ed.). Frenchs Forest, N.S.W: Pearson Australia.

- The Standards We Expect Consortium. (2011, May 18). *Transforming social care: sustaining person-centred support*. Joseph Rowntree Foundation. Retrieved from: <https://www.jrf.org.uk/report/transforming-social-care-sustaining-person-centred-support>
- Think Local Act Personal. (2011). *Next steps for transforming adult social care*. Retrieved from: [http://www.thinklocalactpersonal.org.uk/assets/Resources/Personalisation/TLAP/THINK\\_LOCAL\\_ACT\\_PERSONAL\\_5\\_4\\_11.pdf](http://www.thinklocalactpersonal.org.uk/assets/Resources/Personalisation/TLAP/THINK_LOCAL_ACT_PERSONAL_5_4_11.pdf)
- Turner, Bryan, S. (1997). Citizenship Studies: A general theory. *Citizenship Studies*, 1 (1) 5 - 18
- United Nations *The International Year of Disabled Persons 1981* Retrieved from <http://www.un.org/esa/socdev/enable/disidydp.htm>
- United Nations, Division for Social Policy and Development Disability. (2006). *Convention on the Rights of Persons with Disabilities*. Retrieved from: <http://www.un-documents.net/a61r106.htm>
- Waters, J. & Hatton, C. (2014). *Third National Personal Budget Survey (POET 2014)*. Retrieved from <http://www.in-control.org.uk/media/168205/third%20national%20personal%20budget%20survey%20oct2014.pdf>
- Watson, D. (2004). *Death sentence: The decay of public language*. Random House Australia.
- West, K. (2013). The grip of personalization in adult social care: Between managerial domination and fantasy. *Critical Social Policy*, 33(4), 638-657. 10.1177/0261018313481563
- Williams, I., & Dickinson, H. (2015). Going It Alone or Playing to the Crowd? A Critique of Individual Budgets and the Personalisation of Health Care in the English National Health Service. *Australian Journal of Public Administration* vol. 75, no. 2, pp. 149–158 doi:10.1111/1467-8500.12155
- Wolfensberger, W. (1992). *A brief introduction to Social Role Valorization as a high-order concept for structuring human services*. (2nd (rev.) ed.). Syracuse, NY: Training Institute for Human Service Planning, Leadership and Change Agency (Syracuse University).