Delivering on its promise? Better but not good enough.

An analysis of Victoria’s individualised funding program for people with disabilities from a capabilities and human rights based perspective.

A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy

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Declaration

I certify that except where due acknowledgement has been made, the work is that of the author alone; the work has not been submitted previously, in whole or in part, to qualify for any other academic award; the content of the thesis is the result of work which has been carried out since the official commencement date of the approved research program; any editorial work, paid or unpaid, carried out by a third party is acknowledged; and, ethics procedures and guidelines have been followed.

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Abstract

Australia has followed international trends in individualising disability support funding as a means of offering greater choice and self-direction in how funds are used to purchase services (Laragy, Fisher, Purcal & Jenkinson, 2015). This approach is shaped by contemporary disability legislation and policy which is increasingly informed by a human rights narrative and commitment. This commitment in Victoria was formalised in 2006 in the Charter of Human Rights and Responsibilities, and nationally in 2008 when Australia ratified the United Nations Convention on the Rights of Persons with Disabilities.

As well as promising increased choice and control, proponents of individualised support funding argue for the economic benefits of these arrangements, particularly as demographic changes place increased pressure on social support and care budgets (Productivity Commission, 2011). Australia’s National Disability Insurance Scheme (NDIS) is based on individualised packages. When fully implemented in 2019/20 the NDIS will have an expected 460,000 participants at a projected estimated annual cost of $22.1 billion (National Commission of Audit, 2014). The NDIS was created following the Productivity Commission’s 2011 public inquiry into Australia’s disability support and service system. The inquiry found the system to be ‘underfunded, unfair, fragmented and inefficient’ (p.2) and recommended a new scheme designed to offer greater certainty and choice to people with disabilities eligible for support funding.

Despite enthusiastic and bipartisan support, debates continue regarding core ideological and practical elements of individualised funding reforms. These relate to the theoretical tensions between the neoliberal individualism of personalisation and consumerist narratives and the collective citizenship roots of disability rights values. It has been argued that in appropriating core rights based concepts, such as user involvement, and self-determination, neoliberal governments facing funding challenges have ‘corrupted’ these ideas to promote policies which potentially limit rather than
expand individual freedoms, reduce capacity for collective representation, and shift focus from the social reforms required to address disadvantage (Morris, 2011, p.3; Meekosha, 2000). Research showing the negative impact of inadequate resourcing, unmet need, and barriers to real choice in funding and services, add weight to such claims (Lymbery, 2014; West, 2013). There are fears that uncritical implementation will threaten the fundamental person centred innovations which originally drove personalisation reform (Duffy, 2012a, 2012b).

This research is located amidst these dichotomous debates. There is great emotional and economic investment in the NDIS and it is therefore critical that concerns and lessons from the local and international experience are not glossed over but are instead used to inform critical thinking about policy and implementation (van Toorn & Soldatic, 2015; Duffy & Williams, 2012).

This study aimed to contribute by exploring the example of Victoria’s Individualised Support Package (ISP) program from the perspectives of people using ISPs and service providers. The primary research interest was to understand if, how, for whom, and under what conditions the ISP program delivered on its human rights promise of greater choice and self-determination, and where it did not. I have explored the nature and location of mechanisms influencing the freedom to choose and how the interplay of these shaped individual capacities to engage with and benefit from this system.

To answer these questions, I analysed data from in depth semi structured interviews with eleven ISP holders, five family carers, two support workers, two ISP planners and seven senior managers and co-ordinators from six different service providers. The perspectives of services providers offered an important adjunct to those of funds holders, offering insight into the cultural, financial and workforce challenges they faced in the paradigm shift toward individualised approaches.

This interpretive study was located in a contemporary disability studies framework and guided by a constructionist epistemology. I used an emergent capabilities and rights based framework to analyse the mixed and contingent findings. This conceptual framework encouraged analysis beyond reported outcomes to examine the choices.
participants were actually free to make, the real opportunities available to them, and the processes and mechanisms influencing these conditions.

The findings suggest that linking people with individualised resources does not produce choice in the absence of the social relations and structural conditions in which it can flourish. The relationship between individualised resources and meaningful opportunities was shown to be complex and contingent, shaped by a network of interdependent mechanisms and relationships which acted to expand or constrain participants’ freedom to choose. The concept of conversion, drawn from the capabilities framework, explained these dynamics and the conditions required for the transformation of otherwise latent formal and natural resources into valued choices.

Conversion factors related to fundamental program and design elements, personal and social characteristics, service approaches, and structural and contextual factors. A key finding was that current ISP resourcing and planning typically underfunded and underplayed the factors responsible for conversion itself leaving the potential of critical resources latent or underutilised. In particular, there was insufficient recognition of the relational nature of choice and self-determination in everyday lives and the implications of this for funding, planning, and services. Instead, the operational costs of the thinking, linking and bridging work required for self-determination were frequently shifted to individuals, family carers, and services so that these groups ultimately bore the burden of government cost cutting measures.

These findings have implications for assessment and planning and the degree to which individualised funding programs recognise and resource sources of conversion and the relationships and mechanisms therein. The need for a paradigm shift away from deficit based processes to those which build on personal and social capitals and the multiplying effects of these in people’s lives as well as the broader community is a central implication.

Related to this, the findings also highlighted the importance of relational service approaches built on trust and collaboration. These characteristics build partnerships between services and the community to create innovative and inclusive pathways and enable change.
Whilst the mixed findings reflected existing dichotomies in the literature, a capabilities lens and the dynamic of conversion were used to offer a fresh way of understanding participants’ mixed experiences and to resolve tensions that exist between policy and practice. This approach goes beyond studying outcomes and by analysing the conditions in which individualised funding can expand real opportunities and the freedom to choose, the social justice impact of such reforms can be more clearly measured and understood.
Chapter One

Introduction

1.1 Introduction

Individualised funding and self-directed support models aim to offer people with disabilities and their family carers greater choice, control and flexibility in their funding arrangements and how they variously purchase and use services. These models are in contrast to traditional models which funded services and where service users were obliged to access a predefined set of service options. The primary aim of individualised funding arrangements is that the person will know how much funding they have and will decide how they choose to use it, in relation to their needs and goals (Duffy, 2010). Individualised funding is one of a set of person centred mechanisms designed to promote the rights of people with disabilities, to operationalise key social model principles, to promote self-determination and social inclusion, and, in doing so, to challenge traditional paternalistic and welfarist funding and service frameworks (Productivity Commission, 2011; Duffy, 2010).

Australia's ratification of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2008 and Victoria’s Charter of Human Rights and Responsibilities have together created a climate in which there is greater public scrutiny regarding how public authorities bearing duty to people receiving services comply with their human rights obligations. In Australia, federal and state disability legislation, policy and program objectives reflect this strong human rights narrative and aspiration.

Individualised funding frameworks are a key mechanism in the shift toward the personalisation of social support and care services in developed countries. Personalisation refers to the positioning of the person at the centre of their funding and support systems, a significant contrast to previous service centred models (Leadbetter,
Whilst promoting individual choice and autonomy, personalisation reform also reflects governments’ concerns for cost management in the global context of an aging population, rising prevalence of disability, and increasing and competing demands on the public social support and care purse (Productivity Commission, 2011).

Thus, the notion of personalisation houses the dual and sometimes competing claims and ideals of the disability rights movement on the one hand and neo liberal motivations relating to individual consumerism and economic efficiencies through free market forces on the other (Mladenov, Owens & Cribbs, 2015; Needham, 2011). The potential for conflict between these competing ideologies and the consequences for people with disabilities informs vigorous contemporary debate which to date remains unresolved (Dodd, 2012; West, 2013). A key concern has been that the ‘elasticity’ and broad scope of the personalisation narrative has allowed ‘divergent interests’ to ‘sign up and advance it’ without addressing these central tensions (Needham, 2011, p. 55). Commentators are concerned that approaches like individualised funding are being embraced in the absence of more thoughtful implementation and comprehensive evidence of their impact particularly in the context of austerity measures and rationed social support resources (Duffy, 2011; Boxall, Dowson & Beresford, 2009). The scope and limits of personalisation therefore remain ambiguous and contentious at one level and publicly embraced and endorsed at another (Mladenov et al, 2015).

This thesis seeks to make a modest contribution to the evidence informing these debates by undertaking an empirical study in one state in Australia and amongst a small group of people with disabilities, their supporters, and service providers. Understanding the diverse context of individualised funding across Australia is important in framing the present research and is outlined below.

Australia has had various forms of individualised funding in place since Western Australia introduced the Local Area Co-ordination (LAC) program for people with intellectual disabilities in 1988 (Bartnik & Chalmers, 2007). This program was later extended to people with other forms of disability. While the effectiveness of the program generated similar initiatives elsewhere, programs vary according to scope, eligibility criteria, extent of portability, and in relation to levels of control over funding administration and how funding can be used (Fisher et al, 2010). Since the Western
Australia program, multiple models have been operationalized across Australian states. The Victorian program of individualised funding is a particular type as is detailed below.

Victoria first implemented individualised funding in the early 1990s when flexible funding arrangements were made available to limited groups of people, primarily for attendant care services (VAGO, 2011). Futures for Young Adults legislation in 1996 was a significant step towards individualised funding in Victoria for 18 year olds leaving school (Laragy, 2004). The Victorian State Disability Plan 2002-2012 formalised individual choice as a driver for funding and service provision and identified flexible funding arrangements as a key mechanism for this. Support & Choice packages, as they were called, were introduced in 2004 with the program’s key principles claimed to be grounded in human rights and person centred approaches to funding, planning and services. Key objectives related to promoting choice, quality of life and social inclusion.

In 2008, the Victorian Department of Human Services (DHS) collapsed different flexible funding packages into the one program to introduce Individualised Support Packages (ISPs) (VAGO, 2011). This program is the focus of this study.

The DHS ISP guidelines (2014) describe the framework as being based on the principle that ‘people with a disability should be able to live and participate in the life of the Victorian community, with the same rights, responsibilities and opportunities as all other citizens of Victoria’ (DHS, 2014, p.1). It is intended to centre around key elements of self-directed planning, funding, and support. These were defined in the 2010 ISP guidelines as:

- Self-directed planning: personalised and directed by the person.
- Self-directed funding: based on person’s needs through a planning process to support design and purchase of flexible and responsive supports
- Self-directed support: a combination of formal and informal, public and private services co-ordinated to deliver the best outcome given the person’s circumstances

(DHS Support Your Way, 2010)
The ISP program will be described in more detail in Chapter Two. The following elaborates upon the emergent Victorian policy agenda from the introduction of the ISP program, 2008, onward.

The rights based policy context which informed individualised funding in Victoria continues to develop. The National Disability Strategy 2010-2020 (2011) and Victoria’s current State Disability Plan (2013-2016) continue to reflect an unambiguous commitment to the rights of people with disabilities. The right to choice, self-determination, and full participation in the social, economic and cultural life of the community are central to policy debate and documentation. These developments have taken place at a time of unprecedented change in how support funding and services are delivered in Australia.

The National Disability Insurance Scheme Act 2013 has further embedded individual funding architecture as a mainstream approach and within a universal and user rather than service led model (Productivity Commission, 2011). The National Disability Insurance Scheme (NDIS) has been described as an ‘epochal reform in Australian social policy’ with implications of significant import for disability and social policy more generally (Goggin & Wadiwel, 2014, n. pag.). Expectations of the NDIS are high and its success will be judged on both economic and social justice measures (Bigby, 2014). While campaigning and support for the NDIS united political opponents, its design and implementation are closely scrutinised as commentators debate the capacity of the reform to deliver on its potential and promise (Goggin & Wadiwel, 2014; Bigby, 2014; Duffy, 2013). NDIS pilot sites were launched for different target groups in 2013 just following the collection of data for this thesis. This may be seen as either a limitation (not reflecting NDIS practice) or as a benefit insofar as the study informs further development unencumbered by complexities post NDIS implementation. Details of the NDIS will be discussed in more detail further below and in Chapter Two.
1.2 Focus of this research

Despite the comprehensive uptake internationally and in Australia, as outlined above, there has been limited research, particularly in Australia, exploring the experience of individualised funding and service approaches from a human rights based perspective (Kirkman, 2010; Fisher et al, 2010). There is an urgency to understand this experience and its implications for the Australian context particularly given the launch of the NDIS and its continuing roll out. With Australia becoming signatory to the United Nations CRPD and its Optional Protocol in 2008, and with Victoria joining the Australian Capital Territory (ACT) in being the only two Australian states with a human rights act, the centrality of the human rights discourse remains vital in the Victorian context.

Internationally and locally, there is a need to better understand the relationship between individualised funding policy goals and human rights outcomes from the perspective of multiple key stakeholders and, particularly, from the perspective of those actively using funding and services and those delivering them. The Report of Audit of Disability Research in Australia (2014) recently reinforced the need for more policy research which is informed by the experiences of people with disabilities and or their family carers.

There is a need to examine how duty holders (i.e. those who have a duty to respect, protect and fulfil human rights) who are implementing individualised funding programs manage their obligations under the CRPD and the Victorian Charter of Rights and Responsibilities. This is with regards to not only negative protections but, importantly for social and economic participation, in relation to the progressive realisation of positive social, economic, and cultural rights. Negative rights refer to the political and legal rights which need to be protected by the state whilst positive rights, the socio-economic and cultural rights, are realised by duty holders acting proactively (Ife, 2010) Progressive realisation refers to the realisation over time of socio-economic and cultural rights with that progress being dependent and contingent upon the availability of resources (Chenwi, 2013).
This research therefore examines the Victorian Individual Support Package (ISP) framework as a vehicle for exploring the extent to which the rights based promises inherent in this and similar models are played out in the everyday lives of people using funding and services. The research has sought to understand if and how the social, economic, and cultural rights of people with disabilities and their families are being progressively realised as a result of engagement with individualised funding and service reform. Reflecting a human rights based analysis, the focus of this study is on the arrangements, conditions, processes and variables which either promote choice, autonomy, inclusion and other rights or, which alternatively, limit or constrain them.

The Victorian ISP model formalised in 2008 offers people with a disability three different funding arrangements, depending upon the level of control they choose to have over their funding (DHS, 2010). These include: i) to directly manage their own package; ii) to use a state wide financial intermediary services; or, iii) to use a registered disability service provider to deliver or purchase services on the person’s behalf.

The ISP is a portable package which is attached to the person with the aim of allowing them flexibility in the nature of their supports and choice of provider to reflect changing needs and goals. The package moves with them when they change providers. People eligible for funding under the Disability Act 2006 can make an application to go on the Disability Support Register. A notional offer of funding is made when an ISP matching the person’s application becomes available. If accepted, the person is offered the services of an ISP planner to develop a support plan and funding proposal or they can also do this with independent supports. The funding proposal is then returned to the relevant DHS regional office for approval or amendment based on funding guidelines and criteria (Disability Services, ISP Guidelines, 2010).

The Department of Human Services defined an ISP as follows:

...‘an allocation of funding to a person with a disability to purchase supports that will best meet their ongoing disability support needs and achieve their goals,’

(Disability Services, ISP Guidelines, 2010, p.3)

An ISP aims to enable a person to ‘direct the identification and implementation of supports that are most appropriate to their individual needs and circumstances’ and to
'exercise choice in obtaining support that will assist them to achieve their goals and pursue their own lifestyle’. The needs of family members or carers are also supposed to be considered when planning for an ISP to help ‘maintain the caring relationship.’ (Disability Services, ISP Guidelines, 2010, p.3)

Packages are allocated on the basis of the number of ISPs available to distribute. At the time of data collection there were allocated targets for four main funding levels, divided into 17 levels at approximately $5000 intervals for each level. Packages were allocated through eight DHS regional offices with each region providing packages based on the number of new packages they had to allocate (VAGO, 2011).

The banding arrangement aims to offer resources to people with a range of needs and operates in conjunction with a priority access system. This system also influences how resources are allocated. Priority status criteria apply to: children in facility based care and people at risk of harm to themselves or others; those moving from or avoiding facility based care; and, those with rapid degenerative conditions or in extreme situations (Disability Services, ISP Guidelines, 2010).

People’s access to and use of their individualised funds is determined to a large extent by a priori government policies, practices, criteria, rules and regulations. Previous reports have described these processes within the DHS bureaucracy as burdensome and ‘unnecessarily complex’, and that people applying and planning for an ISP are not treated consistently (VAGO, 2011, p.vii). These conditions contribute to inequity and are exacerbated by the fact that need exceeds supply.

As will be argued shortly, much of the academic debate around individualised funding has focused on how the implementation of these funding reforms, through new organisational and administrative arrangements, carries through on its promise of increased choice and control for funds holders. However, there has been limited analysis from a rights based perspective of the experiences of those using individualised support funding, the extent to which central rights promises are realised in everyday lives, and the factors contributing to this.
1.3 Developing the aims of the research

This research seeks to inform emerging policy and service provision in the area of individualised funding by exploring if and how the rights based aspirations through which such reforms are promoted matches the lived experience of people with disabilities and their families. The research is located in the example of the Victorian ISP framework. This research requires an understanding of the Victorian policy context and also a conceptualisation of human rights given these are the ‘promises’ being tested.

The following chapter will review the research from the disability studies, personalisation, and human rights literature to contextualise and frame the study and point to a methodology capable of addressing the research question.

The research interests for this thesis are set out below and will be refined into research questions and aims following the literature review in the next chapter.

- To what extent and in what ways does the Victorian individualised funding model achieve its human rights promise to people with disabilities?
- What are the experiences of people using individualised funding and of those providing support services and what are the factors contributing to the promotion of human rights within this policy and practice framework?

1.4 Structure of the thesis

The thesis is divided into nine chapters. This first chapter has briefly introduced the international and local policy context in which this research is located, the debates and knowledge gaps, the focus of the research, the research aims and questions, and some initial detail explaining the arrangements and aspirations of the Victorian ISP program.
Chapter Two will expand upon this introduction, further establishing the social and economic climate in which the personalisation of social support and care has come to dominate policy and service design in developed countries. The intersection of this reform with the international human rights framework, in particular the Convention on the Rights of People with Disabilities, will be discussed to explore common themes as well as the tensions in the competing ideologies driving the overarching personalisation narrative.

In establishing the dichotomies and debates in the literature, this chapter will outline theoretical and conceptual frameworks regarding models of disability and human rights in their relevance to the evolution of personalisation, individualised funding, and self-directed service approaches. The chapter traces the international disability rights movement and shows its contribution to contemporary understandings of disability as a human rights issue and people with disabilities as subjects and rights holders instead of as ‘objects’ and ‘problems’ (Quinn & Degener, 2002, p. 1). The relevance of the international human rights framework and particularly the CRPD is discussed in relation to obligations towards people with disabilities generally and in relation to experiences of individualised funding and support programs specifically.

The capabilities approach is also introduced and discussed here as a perspective which I retrospectively used to develop further meaning from the mixed and sometimes contradictory findings produced from the first phase of data analysis. Expanding upon a capabilities based understanding of human rights, as an analytic frame for assessing the impact of individualised funding, is one of the major contributions of this thesis (Vizard, Fukuda-Parr & Elson, 2012).

The second chapter also reviews the empirical research previously conducted in individualised funding and service programs to establish the particular gap in evidence from a human rights based perspective.

The third chapter introduces the relativist ontological and constructivist epistemological framework underpinning the interpretive study design I adopted in this research. It also discusses contemporary disability studies’ principles and important
concepts and developments in disability research as they relate to this study’s interests and focus.

The fourth chapter outlines the study design and methods in detail, showing an internal consistency in the philosophical assumptions underpinning the interpretive paradigm, the research questions, the sample frame, and the methods used to collect, analyse and interpret the data. Methodological alignment is critical to the trustworthiness or value of a qualitative study and refers to the congruence and ability of the overarching knowledge paradigm and methodological framework to respond to the research questions (Lincoln & Denzin, 2011; Creswell, 2007; Richards, 2002). Methods employed for ensuring trustworthiness of the research are also explained.

Chapter Five is the first findings chapter and presents findings regarding outcomes, benefits, and risks in the context of the Victorian ISP program, based on the experiences of people with disabilities, family carers, and support workers. This leads to Chapter Six which presents findings based on interviews conducted with disability service provider managers, program co-ordinators, and ISP planners. These findings offer data triangulation with the experiences of people using services and provide an organisational perspective on challenges for the disability sector in the transition from traditional service arrangements toward individualised approaches and the implementation of the NDIS. This chapter presents a managerial and practice account of the benefits, tensions, and challenges of these reforms.

Chapter Seven offers analysis of the arrangements, conditions and resource characteristics which enabled or constrained rights based experiences and outcomes related to choice and self-direction. This chapter identifies the contradictions and paradoxes contained in the findings, that there was benefit and cost, gain and risk, winners and losers.

The findings in Chapter Five to Seven are systematically discussed in Chapter Eight. This chapter introduces a capabilities based understanding of human rights as a more comprehensive vehicle for understanding the inequity of experience and outcomes.
identified in the data. In showing the synergies between capabilities and human rights based approaches, Chapter Eight offers a developed conceptual and practical framework for understanding this study's mixed and sometimes contradictory findings. Importantly, Chapter Eight expands on the principle of conversion, a central concept in the capabilities approach, as an explanatory vehicle for gaining deeper meaning from the findings and the complex relationship between individualised resources and the accomplishment of real choice and opportunity. This chapter discusses the dynamic of conversion in transforming the potential of otherwise latent resources into manifest and chosen opportunities and the mediating role of conversion factors across personal, socio-economic, and institutional spheres. Identifying this dynamic and the processes and relationships required for conversion in the ISP program is a key contribution of this study. This analysis has application beyond the Victorian context and offers some practical and conceptual resolution of the tensions described throughout the thesis.

Chapter Eight therefore builds on a growing body of research which is using the capabilities approach to extend human rights analysis in social and public policy development and evaluation. This conceptual lens complements human rights approaches by considering the practical substance and implications of policy aspirations and providing an additional mechanism for monitoring the conditions in which duty bearers can fulfil their positive rights obligations, as per the principle of progressive realisation (Nussbaum, 2012). It is argued that a capabilities informed approach offers a fresh perspective on the debates canvassed throughout this thesis and informs thinking regarding how individualised approaches can more equitably promote choice and self-determination within the broader context of collective citizenship values.

Chapter Eight also summarises the implications of this thesis for policy and practice and concludes by reinforcing the possibilities which a capabilities based understanding of human rights can offer individualised funding reform in Australia and internationally.

Chapter Nine concludes this thesis by briefing drawing together the key findings and arguments previously presented, reviewing limitations, and outlining implications for future research and evaluation, and for the NDIS.
Chapter Two

Competing discourses in contemporary individualised and self-directed funding and service frameworks

2.1 Introduction

The previous chapter introduced the key policy principles and objectives of Victoria's individualised funding and service framework. I explained the importance of exploring the heritage of ideas within disability studies and in relation to both individualised funding and human rights. The task of this chapter is to explore current understandings in these areas and show how they frame this study and inform its methodology.

This chapter will trace the significant shifts internationally and in Australia over the past 30 years in the provision of support funding and services to people with disabilities. These shifts reflect broader transformations to social support and care policy and practice during this period as reforms have sought to address new social needs in the context of significant demographic, economic and socio-cultural change (Ranci & Pavolini, 2015; Arksey & Kemp, 2008). Core demographic and social changes have included an aging population, increasing rate of disability, escalating medical care costs, and the decreasing number of informal carers due not only to an aging population but also to an increased rate of female participation in the workforce (Ranci & Pavolini, 2015; Productivity Commission, 2011).

Socio-cultural drivers shaping social support and care policy reform came from on the one hand powerful user groups such as the disability rights movement, and, on the other, the increasing influence of neoliberal ideology in public administration in the 1990s. These combined forces resulted in a distinct shift in how the delivery of public
services and responsibilities were thought about and administered, moving from a professional model toward marketization and greater flexibility (Ranci & Pavolini, 2015; Larbi, 1999).

Disability rights group were pivotal in driving this reform, operating from a platform of increased self-determination, choice and control, as reflected in the principles and articles of the UN CRPD. These demands required access to more devolved and flexible forms of support entitlements and services. As human rights aspirations were influencing policy direction, so too was there mounting pressure on limited government resources and administration capacities across developed countries due to escalating economic demands (Ranci & Pavolini, 2015). The convergence of these forces stimulated a ‘new culture of care’ (Ranci & Pavolini, 2015, p.274; Larbi, 1999). This new context demanded different ways of responding to on the one hand the community’s demand for social rights, and on other, pressures on governments to devolve the organisation of social services to the market (Larbi, 1999).

These changes and the employment of private sector strategies, such as marketization of public services, reframing service users as consumers, and an increased focus on outputs confront and challenge the relationship between the state, community, and the service sector (Larbi, 1999). In particular, the relationship between the family and the state is necessarily ‘recast’ (Ranci & Pavolini, 2015, p. 281), a theme which is explored throughout this thesis.

These factors have shaped the demographic, economic, social, and cultural imperatives driving social support and care policy platforms and agenda, as well as outcomes within which conceptions of disability rights and citizenship must also fit.

2.2 Competing drivers and blurred narratives

The provision of supports and services to people with a disability is one area where the tensions described above play out. These tensions are particularly highlighted given
contemporary understandings of disability as a human rights issue and, inherent in this, examination of the relationship between the rights and responsibilities of people with disabilities and the obligations of the state, as outlined in human rights instruments, to protect, promote and fulfil these rights. Australia is a signatory to the CRPD and is required to meet its human rights obligations at a time, arguably, of economic austerity with the demographic challenges described above looming large for generations to come (Productivity Commission, 2011).

Importantly, the state’s responsibilities do not stop at protecting citizens’ negative, or first generation, civil and political freedoms such as the right to life, the right not to suffer abuse, torture, inhuman or degrading treatment, or constraints to liberty and privacy. Human rights and the state’s obligations also extend to a progressive realisation of the positive or second generation economic, social and cultural rights such as the right to education, health, housing, and economic security (Chenwi, 2013; Ife, 2010).

The late 1990s saw a strong consumerist discourse echoing rights based principles, but also, as noted above, converged with neoliberal influences which were driving the reform and marketization of social support and care services. The convergence of ideas has led to a ‘hybrid’ discourse in which the concept of personalisation and self-directed care has come to mean many things and has assumed an ambiguity which has at times impeded sustained and critical evaluation (Mladenov et al, 2015, p.308; West, 2013; Needham, 2011). Some argue that whilst sharing the objectives of individual choice and autonomy, personalisation policy and practice distinguishes itself from a more holistic rights agenda in its emphasis on individualism, often at the expense of broader collective representation, shared accountabilities, and the structural reforms required to address the root causes of disadvantage and inequity (Dodd, 2013; Ferguson, 2007). O’Brien & Duffy (2013) contribute to this critique in describing personalisation as a ‘set of attractive practices’ which are stripped of meaning when these practices emphasise not the broad themes of ‘relationship, power and citizenship’, but rather organisational practices around providing support in more individually ‘personalised’ ways (p.7). Similarly, Dickinson, Needham & Sullivan (2015) point to accountability and quality
dilemmas in individualised funding contexts when risk as well as benefit is individualised. They question who is accountable for outcomes in arrangements where responsibility for decision making and spending of public moneys is transferred to the individual and identify the inherent risks of these scenarios. These include risks for those most vulnerable and least able to operate as the rational and autonomous actors assumed in the ‘logic of choice’ (Mol, 2008) which underpins individualised funding and support programs (Dickinson et al, 2015).

Internationally and within Australia, mechanisms such as individualised funding and self-directed and person centred approaches in planning and service delivery have been used to shift, to different degrees, the levers of control more closely toward people with disabilities and their supporters and, simultaneously, reduce the influence of professional and bureaucratic decision makers (Dozar et al, 2012; Arksey & Kemp, 2008). A key feature is that such arrangements explicitly individualise the ‘financial aspects of health and social care’ (Dickinson et al, 2015, p.418). Different systems and terms have been used, such as cash for care, care and counselling, and personal budgets however the overarching aim of this policy agenda has remained consistent (Arksey & Kemp, 2008). In Australia, individualised and person centred approaches for people with disabilities have been embedded in the new National Disability Insurance Scheme (NDIS). The NDIS has been established to provide Australians living with a significant and ongoing disability funding for long term care and support with a key aim being to provide individuals and their family carers with greater flexibility and control in how care supports are provided.

Whilst the international and local research identifies a range of positive outcomes for different stakeholders, United Kingdom (UK) critics in particular have warned about the rapid take up of personalisation and individualised funding approaches in the absence of stronger empirical data regarding their merits and implications and in the context of austerity measures (West, 2013). Boxall, Dowson & Beresford (2009) suggest that personalisation of social support and care has been promoted through the use of exemplars, but without due consideration of the risks of ‘wholesale implementation of personalised social care’ (p.508). They and others have warned about the speed of
uptake and that a rushed ‘bushfire approach’ to adopting individualised funding programs without a ‘coherent set of ideas and an accumulated body of knowledge’ jeopardises its potential and more accountable and transparent implementation (West, 2013; Boxall et al, 2009, p.508). Dickinson et al (2015) reflect these concerns in their exploration of accountability issues and dilemmas within individualised funding. They describe the implementation of these programs as ‘challenging and complex’ requiring ‘substantial changes across a wide range of different service systems and institutional boundaries’ (p.419). They emphasise the risks for individuals using funding and services as well as for formal and informal carers if these issues are not thoughtfully and adequately resolved.

There are also concerns for the impact of individualised funding and support arrangements on the conditions and welfare of support workers and questions about how the balance between service user empowerment, choice and control and workers’ rights to fair and safe working conditions can be best managed (NDS, 2014; Laragy, Ramcharan, Fisher, McCraw & Williams, 2013; Ungerson, 2004). Pressures arise from changing consumer demands regarding the quality and nature of support and the capacity of traditional service models and workforce capabilities to deliver flexible and multi-faceted services (NDS, 2014).

Drawing from the international and domestic experience, concerns relate to lack of regulation and accountability for a workforce which is already low paid, highly casualised, precarious, female dominated and vulnerable to the availability of people, such as newly arrived migrants, who may be willing to do the same work for less pay and poorer conditions (Dickinson et al, 2015; Ranci & Pavolini, 2015; Ungerson, 2004). As well as impacting on worker wellbeing, deterioration in workforce conditions can also lead to a drop in the quality of care services (Ranci & Pavolini, 2015).

At a relational level, studies have also highlighted issues for both service providers and service users as emotional, work, and life boundaries blur in the shift toward individualised home based care and support and changing employment arrangements (Ungerson & Yeandle, 2005). Boundaries and work life balance are further complicated in programs, such as some cash for care schemes in Europe, where relatives can be employed to provide care. Whilst such arrangements have benefits in terms of formally
acknowledging previously unpaid and informal care, studies have also highlighted tensions for relationships, privacy, and in managing the balance between ‘work and life’ when family members are employed in this way (Ungerson & Yeandle, 2005; Ungerson, 2004).

The ambiguity and breadth of concepts such as personalisation, entitlement, rights, and needs, further complicates understanding of the parameters of personalisation reforms and attempts to evaluate its impact (Lymbery, 2013; Foster et al, 2012; Needham, 2011; Kendrick, 2007). For example, are individualised funding approaches, as a key mechanism within personalisation reforms, really about citizenship and inclusion as promised in the policy? Or are they in reality confined to choice in day to day services? What is the impact on real choice when policy goals are constrained by economic pressures, funding cuts and resource rationing? Without clarity on terms, aims, and scope, it is difficult to measure success. Without clear terms for evaluation, the conflation of individualised funding rhetoric and reform with broader citizenship aspirations can continue unimpeded (O’Brien & Duffy, 2013, p.7). Citizenship and rights have been difficult to isolate and measure in lived experience and as a result have not been sufficiently explored, and certainly not at an empirical level in the Australian context.

2.3 Implications for the Australian context

Australia has had insufficient time to reflect more carefully on the ideological and practical tensions arising from the competing discourses described above and what this might mean for policy and practice as well as for the community. The NDIS launched trial sites in 2013 and its national rollout begins this year (2016) with full implementation expected in 2019/20 at a projected annual cost of $22.1 billion (National Commission of Audit, 2014). An estimated 460,000 people with disabilities are expected to participate in the scheme. There is significant financial and emotional investment in the success of the NDIS and far reaching implications for those providing and using services (van Toorn & Soldatic, 2015). Yet, at the time of this research, there has been limited robust empirical research in this area and particularly not in Australia.
Complicating efforts to gain a clearer empirical understanding of benefits and risks both globally and locally is the significant variation in programs across states and countries and the ‘multiple meanings’ attributed to underpinning policy language (Bigby & Fyffe, 2008, p.4). Individualised funding approaches have been implemented across different jurisdictions and diverse contexts with varying purposes, scope of choice, expectations, administrative options, and user group demographics (Fisher et al, 2010; Bigby & Fyffe, 2008; Laragy, 2004).

Some say it is necessary to step back from the ‘evangelical’ rush to individualised funding and support frameworks and explore instead the implications of the overarching but competing discourses (West, 2013, p. 647). Of importance is the need to investigate the impact of personalised approaches, including individualised funding and service models, on the rights and opportunities of those whose everyday lives and opportunities are shaped by such reform.

The problem alluded to above seems to emanate from the level at which the debate has taken place. At the time of this research, there have been a number of theoretical arguments about the potential of individualised funding to promote human rights but limited research based on the empirical experience. Further, the empirical evidence that exists has often been on the basis of quality of life or utilitarian measures. These frameworks, as will be discussed later in 2.6.1, can be limited in acknowledging the ‘dilemma of difference’ (Terzi, 2005) arising from the diverse needs and experiences of people with disabilities. The nature of these theoretical debates is outlined below.

A tranche of literature problematises the tensions inherent in the holistic intent of human rights and its citizenship claims, and the individualistic orientation of the personalisation and consumerist narratives (Mladenov et al, 2015; Lymbery, 2014; Dodd, 2013; West, 2013; Needham, 2011; Clarke, Smith, & Vidler, 2005). There are concerns that offering more individual choice in funding and services does not necessarily empower people individually or collectively if not in tandem with the structural reforms required to address disadvantage and inequity (Dodd, 2012). A conflict rests in the individualism of personalisation reforms through the pursuit of
individual choice and the inherent risks of this to the collective voice and representation which have traditionally driven social change (Mladenov et al., 2015; Clarke, Smith & Vidler, 2005).

Clarke, Newman, Smith, Vidler & Westmarland (2007) also explore the tensions in the ‘citizen consumer’ construct and the antagonisms of choice therein, identifying inequality, power and ‘public-ness’ as key ‘political conflicts’ challenging the central idea of choice as a key driver in public and social policy reform (p. 245). They also identify the multi layered meanings of choice in the neo liberal discourse as an impediment to greater clarity in analysis and evaluation of choice based social reform.

Clarke, Smith & Vidler (2005) sum up the ambiguities and tensions as follows:

> It is possible to see consumerist approaches to public service reform as a progressive challenge to producer domination and bureau-professional paternalism; or as a regressive individualised narrowing collective democratic engagement (and a front for marketization/ privatisation). (p.178)

Following the above are concerns regarding the ‘risk transfer’ from the state to the individual, as individuals and families take up new responsibilities for financial accountability and the management of services and staff (Dickinson et al., 2015 p.422). This ‘transfer’ carries not only the promise of greater choice and control but also the risk of failure and harm, particularly for those least able and resourced to operate as ‘expert’ consumers in a market model (Dickinson et al., 2015). Concerns regarding the potential for individualised and self-directed arrangements to exacerbate existing levels of inequality among people using services have been well documented (Slasbert & Hatton, 2011; Clarke et al., 2007).

Importantly, however, commentators do not discount the benefits of progressive reforms which have ‘emerged from user movements’ and which aim to offer people using funding and services greater choice and control (Lymbery, 2014, p. 307). Rather, it is the ambiguity and multiple meanings inherent in personalisation and its often
uncritical promotion by governments and other stakeholders which many argue make its analysis so complex (Lymbery, 2014; Needham, 2011).

In line with the above arguments, a key critique is that individualised funding reforms continue under a positive rights narrative regardless of the reality of shifting political and economic imperatives and the real costs of properly and equitably implementing such programs (Lymbery, 2014; West, 2013; Spall, Macdonald, & Zetlin, 2005). West (2012) argues that the ‘dream’ of personalisation continues to be promoted by governments who gloss over administrative and economic constraints as if the promise of choice and control were a reality for all rather than an aspiration for most. Reinforcing this argument, Lymbery (2014) argues that analysis of personalisation ‘must engage with the substantial complexities of policy, combined with the difficult financial circumstances within which it is being implemented’ (p.307).

Similarly, Ranci & Pavolini (2015) in an analysis of long term care reforms for elderly people (aged 65 and over) in eight European countries conclude that the trajectory of policy progress toward more universal entitlements in long term care since the early 1990s has been significantly influenced by the impact of the financial crisis which began in 2007. This has resulted in a gap between the initial vision of universal support care as a ‘social right’ and the practical experience of access to such care and the quality of its provision. It was found that a ‘restricted universalism’ (p.282) had developed across European jurisdictions in which although entitlements to eligible people have ‘increased or been maintained’, service provision has been narrowed and limited due to ‘financial constraints, budget ceiling or sustainability criteria’ (p. 282). Ranci Pavolini (2015) found that austerity measures had diverted policy attention toward the market and renewed emphasis and reliance on informal networks of care and support. Impacts on programs varied from mild to significant and included increased use of waiting lists for residential care in Sweden, and in Denmark, cuts to social care staff. In England, funding cuts to local authorities were expected to result in more than 1 million older people receiving no formally funded support between 2012-2014 (citing Seeleib-Kaiser, 2012). In Spain, Italy, and France, impacts included funding cuts, a slowing of the reform agenda, increased waiting times, tensions regarding means testing and reduction in
coverage. Critically, it was found that although the concept of universal care was framed as a ‘social right’ (p.282), the impact of the financial crisis was that not all those ‘in need’ received it. This study highlights the vulnerability of economic, social, and cultural rights in times of austerity given the overarching principle of progressive realisation to which they are subject.

It is the aim of the remainder of this chapter to frame the research and its research questions in an understanding grounded within these debates and intertwined concepts. The remainder of this chapter sets out key theoretical and conceptual frameworks and the local study context to inform an aligned methodological approach.

### 2.4 Disability and Human Rights

*Disability is a human rights issue! I repeat, disability is a human rights issue*

UN Special Rapporteur on Disability, Bengt Lindqvist (2000)

Lindqvist’s address to the 19th Congress of International Rehabilitation encapsulated the shift from an individualistic understanding of disability toward a social understanding of the phenomenon as one of human rights and social justice. Similarly, Sen (2004) links disability and human rights in his commentary on social justice, arguing that ‘overlooking or ignoring the plight of disabled people is not an option that an acceptable theory of justice can have’ (2004, p. 2). Both Lindqvist and Sen build on contemporary understandings of disability as a social, cultural, economic, and political phenomenon, and thus an issue of critical social justice and public concern.

Conceptualising disability as a human rights issue has evolved within the broader international human rights movement following the proclamation of the United Nations Declaration of Human Rights in 1948 (Rioux, 2011). This evolution has been formalised by a series of human rights instruments most significantly in the adoption of the Convention on the Rights of People with Disabilities on December 13, 2006. The
purpose of the CRPD is to provide states with a tool to ‘end the injustice, discrimination
and violation of rights’ experienced by people with disabilities (UN Enable, 2015). The
convention was opened for signature on March 30, 2007 and entered into force on May
3, 2008. More than 80 countries initially signed in a record breaking response (UN

At this time, a national human rights consultation was also being conducted across
Australia. It aimed to seek views on the protection and promotion of human rights as
part of a broader debate regarding the introduction of human rights legislation
nationally (NHRCC, 2009). The subsequent report released in 2009 recommended
Australia enact a national Human Rights Act however, despite this, Victoria and the
Australian Capital Territory remain the only two jurisdictions in Australia with their
own human rights legislation. These are the Victorian Charter of Human Rights and

A key aim of the CRPD and, later, its Optional Protocol, has been to practically reject
conceptions of people with disabilities as ‘the objects of charity, medical treatment and
social protection’ and to instead formalise the role of people with disabilities as rights
holders with a right to the ‘full and equal enjoyment of all human rights and
fundamental freedoms’ as well as respect for their ‘inherent dignity’ (Arbor, 2006, p. 1;
CRPD, Article 1). The CRPD is the first binding international human rights instrument to
focus exclusively on disability and in doing so has been hailed as a ‘critical milestone in
the development of international law on the rights of people with disabilities’ (Lord,
Suozzi & Taylor, 2010, p. 564). The convention represents the progressive efforts of the
international human rights and disability communities to develop awareness and
entrench a holistic, socially based, as opposed to medical, understanding of disability
(McCallum & Martin, 2012; Lord, Suozzi & Taylor, 2010). Importantly the CRPD
integrates and legally recognises positive as well as negative rights (Ribet, 2011; Lord et
al, 2010).

Whilst Lord et al (2010) observe that the CRPD has not fully resolved the long standing
tensions between medical and social models, they describe the CRPD nevertheless as a
progressive breakthrough for people with disabilities. Importantly, the CRPD also provides a practical framework for progressing objectives (Lord & Stein, 2013; UN CRPD, 2006) and in particular sets out practical steps for progressing positive rights. For example, in Article 24 on education, the convention sets out the state’s obligation to provide access to specific opportunities such as learning Braille and alternative script. This Article also discusses employment of teachers with disabilities who are, for example, qualified in sign language and Braille.

In Australia there is a ‘new urgency’ to developing the relationship between human rights and disability supports (Rioux, Basser & Jones, 2012, p.2). The CRPD’s key principles informed the National Disability Strategy 2010-2020, the aim of which is to ensure human rights principles are embedded into policies and programs affecting people with disability, their families and carers (National Disability Strategy, 2010-2020, p.9). The Victorian Disability Act 2006 was also informed by rights based principles prior to the CRPD with a focus on ‘whole-of-government, whole-of-community response to the rights and needs of people with a disability’. Replacing the Intellectually Disabled Person Services Act 1986 and the Disability Services Act 1991, the new Act aimed to exert stronger emphasis on measures for improved access, community participation, and social inclusion.

However, the practical application of human rights tools remains contentious as does the gap between aspiration and lived experience. Some argue that human rights treaties and disability legislation and strategy documents set ‘standards for aspiration’ rather than explicit rules for practice, not least since rights based approaches are very much an emergent, contextual and dynamic area of practice (Beitz, 2009, p. 43). Operationalising rights based policy principles in practice is thus a complex and contingent endeavour, seeking as it does to ground ‘standards for aspiration’ in diverse individual human contexts whilst also seeking to identify and address structural causes of socio-economic disadvantage (Yamin, 2008; Kirkemann-Bosen & Martin, 2007). In particular, operationalising rights based strategies around economic, social and cultural rights is particularly difficult given the proactive investment required and the
difficulties associated with monitoring and conceptualising abstract ideas into defined and measurable outcomes (Jacobs, 2009).

Inherent in a rights based approach is the aim of converting legislative objectives into ‘policies, practices, and practical realities’ (Australian Human Rights Commission, 2015). A rights approach to disability necessarily requires focused attention on barriers to self-determination, participation and inclusion and the creation of conditions in which people with disabilities are free to participate fully and equally (Rioux et al, 2012).

Correspondingly, a rights based approach assumes that it is the state's obligations as a primary duty bearer to ensure the resources and services required to respect, protect, and fulfil the rights of citizens. The implications of these duties in relation to individualised funding and service approaches will now be discussed.

The CRPD addresses the state's progressive realisation obligations in Article 4 (2) when it requires states to undertake ‘measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realisation of (economic, social and cultural) rights’. Importantly, although this principle recognises that the realisation of positive rights takes time, there is also the obligation on states to ensure ‘immediate and tangible’ steps to ensure progress toward realisation of rights as part of the longer term plan (Chenwi, 2013, p.744).

An important understanding within the progressive realisation principle relates to its intent that states do not stop at ensuring minimum level requirements or access in relation to rights. Rather it is intended to obligate states to go beyond ‘minimum’ toward higher levels of attainment (Chenwi, 2013).

However, as such rights are only measurable and quantifiable in their realisation over time, and are dependent on resources being made available by the state, the principle of ‘progressive realisation’, which allows for the state's discretion about the limits of their
maximum resources, is problematic (Chenwi, 2013). Many argue that the focus on improvement over time can allow underlying systemic, cultural and political causes of discrimination and rights violation to continue unchecked (Chenwi, 2013; London, 2008; Kirkemann - Boesen & Martin, 2007).

Further, measuring improvements requires data to be collected and subsequent claims to be made upon such data. In a rights based model, a state’s performance is based on the form and level of social, economic, and cultural rights its citizens are enjoying at any point in time and the state’s corresponding capacity to fulfil its obligations (Chenwi, 2013). Accountability within the system therefore relies on accurate and systemic data monitoring as well as rights holders making claims about improvement, or lack thereof, based on their experiences (Kirkemann-Boesen & Martin, 2007). Thus, the interface and dialogue between duty bearer and rights holder making claims is critical to developing shared rights based objectives (London, 2008). The capacity to engage in dialogue is a critical element of a rights based approach and depends upon the relative power and capacity of both parties to do so.

Measures based on resources committed to collective change in the circumstances of people with a disability are important however may indicate little about the rights experience of the individual. The lack of data based in individual rights experience complicates evaluation at this level.

Rights progress may be seen in people being better resourced to pursue their own aims and, as a result, changes in their living circumstances, education, employment, social relationships and housing situations. However, to accomplish this requires a mechanism through which the person is freed to pursue and resource their lives as they choose. The individualised planning framework is offered as a key contemporary vehicle through which this is supposed to take place.

Importantly then, personalised funding and service approaches, depend upon the individual consumer’s ability to engage in individualised forms of participation and representation via dialogue and negotiation with the state as a key duty bearer and
funder, and with service providers. It is unclear however, given the lack of research in the field from a rights based perspective, how these relationships might be developed and progressively nurtured within the context of individualised funding. This represents a major gap in our knowledge and a key area this research explores.

Following on from this, it has also been argued that current individualised funding approaches, in their lack of investment in independent community based advocacy, brokerage and related support infrastructure, run the risk of reinforcing tensions between individual rights and the collective representation required to press for the social and structural reforms needed to address disadvantage (Lord et al, 2010). These tensions, unfortunately beyond the direct scope of this project, have not been properly explored in the Australian context but remain an important and necessary focus for future research.

2.4.1 Tracing the lines: social and political responses to disability
The move towards a human rights approach in disability funding and service models has been informed by significant and emergent shifts in disability theory. Disability until the middle of the 20th century drew on traditional and individualised notions premised upon disability as a medical problem to be cured, treated, and/or rehabilitated (Barnes, 2007; Meekosha, 2000). Barnes (2007) observes that although there are historic accounts of disability activism dating back to the 19th century, the movement did not properly galvanise in the UK until the 1960s. At this time disability activists countered individualistic and personal tragedy conceptions of disability with conceptions of disability as a social construct.

In 1976 disabled activists Paul Hunt and Vic Finkelstein, as members of the Union of the Physically Impaired Against Segregation (UPIAS) in the UK, developed a ‘socio-political reinterpretation of disability’. This reinterpretation fundamentally distinguished between impairment as a biological condition and disability as a socially constructed phenomenon (Barnes, 2007, p. 205). This definition broke new ground in interpreting disability as something which is imposed on people ‘on top of’ an impairment ‘by a society which is intolerant of any form of biological flaw whether real or imagined’ (Barnes, 2007, citing UPIAS, 1976, p.npag.). The move to defining disability as a form of
social oppression rather than individual pathology reinforces disability as a human rights issue. Barnes (2007) defined disability as ‘on a par with other forms of unjustifiable discrimination and prejudice such as racism, sexism, heterosexism and homophobia’ (p.204).

Similarly, Meekosha (2000) views disability discourses through the prism of power and argues that the medical 'ensemble’ have successfully ‘promulgated a powerful discourse of disability’ (p.npag.). She describes this medical discourse as one of oppression which has subjected people with disabilities to two key forms of control. The first relates to medical control of bodies through the medicalised problematizing of difference, and the second to constraints and isolation imposed through institutions such as ‘asylums, hospitals and prisons’ (p.npag.). She further argues that despite discourses of equality and social participation, disability continues to be individualised through the medical domination of impairment categorisation.

Writing from a United States (US) perspective, Winter (2003) summarises the original objectives of the US disability rights movement as replacing ‘oppression with empowerment and marginalisation with full inclusion’ (p.2). The movement sought to do this by empowering people individually and collectively as well as by influencing legislation, policy and practice. Winter also usefully describes social movements, of which the disability movement is one, as happening in three phases. The first is about defining the problem, the second develops solutions, and the third phase is about dealing with the consequences or ‘aftermath’ of the solutions such as new policies and practices. It is argued that personalisation reform and its rapid take up by governments can be defined as fitting the second phase, as a proposed solution to a range of problems. It can then be argued that this research is located in the nexus between the second and third phases, between the development of solutions and exploring the consequences of their aftermath.

2.4.2 The influence of the social model
Michael Oliver’s book, *The Politics of Disablement*, published in 1990, served to summarise and formalise the paradigm shift which the disability movement had been advocating over the previous decades (Barnes, 2007; Abberley, 1992). With disability
defined as a social construction, the location and analysis of disability shifted to the environment, society and culture, and thus drew political and policy attention to questions about how to address these disabling elements as opposed to questions about how to change the individual (Corker & Shakespeare, 2002).

The social model had a significant impact on the political cohesiveness of the disability movement’s efforts, particularly in the UK, where it has been described as the ‘ideological litmus test of politics in Britain’ (Shakespeare & Watson, 2002, p. 3). Shakespeare & Watson (2002) described the power of its simplicity which can be taken up individually to free people from negative self-conceptions and collectively to provide a unified and strategic focus for advocacy.

The social model has played a central role in human rights discourse and the development of the CRPD in that it has offered a framework for understanding the external location of disadvantage and discrimination and the barriers faced by people with impairments in their efforts to engage with and access opportunities on a par with others (Albert & Hurst, n.d.). In this model, disability is understood as a socially constructed ‘web’ of discrimination and social, cultural, political, and economic barriers produced by ‘negative social attitudes and cultural assumptions’ as well as ‘policies, laws, structures and services which result in economic marginalisation and social exclusion’ (Albert & Hurst, n.d., p. 2).

However this argument has also attracted critique. Some claim a falseness in the rigid distinction between the biological and the social (Bickenback, 1993) and inadequate reference in the model to the complex interplay between impairment and disadvantage (Shakespeare, 2002; French, 1993; Morris, 1991). Shakespeare (2002) has further argued that the ‘strong’ social model has in fact ‘outlived its usefulness’ and has called for work to begin on a new approach to disability politics, based on a ‘materialist ontology of embodiment’ (p.10).

However, the social model continues to dominate contemporary legislative and policy thinking about disability (Wasserman, Asch, Blustein & Putnam, 2013). The impact of
social model thinking within the CRPD therefore represents the culmination of a story which started with social movements and the construction of new ideas for implementation over a period of nearly fifty years.

2.4.3 Toward self-directed policy and practice
The shift from professionally controlled funding and service models to frameworks in which people with disabilities can exert greater choice and control in their funding and service arrangements reflects the move from a theory of ‘personal tragedy’ (Oliver, 1990) based in dependency and individual deficit to a socially and human rights informed conceptualisation of people with disabilities as citizens and rights holders (Goodley, 2011; Basser, 2011; Barnes & Mercer, 2010).

The first principle of the CRPD outlines the right to dignity, individual autonomy and the ‘freedom to make one’s own choices’. These universal freedoms are enshrined in the international human rights framework and have direct implications for disability funding and service frameworks and their obligations therein. The key interest of this study, individualised support funding, represents one arrangement which seeks to link the CRPD’s first principle with the freedom to purchase services of choice as a mechanism and, hence, to challenge disadvantage in the pursuit of chosen ends. These policy and program reforms mark a significant shift from prior welfarist based models to ostensibly shift the locus of control to the person, framing and repositioning the individual as expert of their service system and lives (Rabiee & Glendinning, 2010; Laragy, 2010; Lord & Hutchinson, 2003; Dowson & Salisbury, 2001).

In locating rights based principles within a broader personalisation and consumerist agenda, contemporary social support and care reforms have elevated individual choice as a central device for managing inequities and inconsistent standards within the service system (Clarke et al, 2007). In promoting the principle of user choice within a consumerist frame, there is an increased emphasis on and faith in the market’s redistributive capacities, including the capacity to flexibly respond to shifting and diverse consumer needs and demands (Greve, 2010; Clarke, 2004).
In this way, principles of empowerment, participation, and autonomy overlap personalisation discourses to unify the two concepts in the public consciousness despite what many describe as some key ideological tensions (Mladenov et al, 2015; Dodd, 2012).

The rights of people with disabilities to full citizenship and the equal opportunities these require have been the basis of social and political action and the subsequent development of person centred and self-directed frameworks, supported by systemic advocacy and user led organisations (Rioux et al, 2012; Barnes, 2007). Ironically however the collective work of social movement activists, so necessary in influencing the development and adoption of international disability human rights tools, is not well mirrored in contemporary funding models in Australia. For example, NDIS documentation identifies that ‘systemic advocacy and legal review and representation will be funded outside of the NDIS’ (see http://www.ndis.gov.au/sites/default/files/ILC-Policy-Framework.pdf; http://www.ndis.gov.au/participants/making-decisions-about-support/ndap).

Commentators are concerned about the impact of cuts to disability advocacy groups in the early days of the NDIS and how this will impact representation for different groups and their access to funding and services (Macey, 2015; Williams, 2015, n.pag.). Late in 2015 the Commonwealth Government’s Department for Social Services (DSS) cut funding to key peak disability bodies in a tender process described by Williams (2015) as resulting in an ‘undignified spectacle of these groups having to pitch why their voice might be more important than the others.’

2.4.4 The personalisation push
Personalisation has been described as a ‘potent but highly contested and ambiguous idea’, depending on how it is interpreted and implemented, with the potential to just play at the edges in a ‘shallow’ form or, in its ‘deep’ manifestation, to ‘reorganise’ how public goods and services are created and delivered (Leadbetter, 2004, p. 19).

Personalisation reform refers to an overarching set of principles and agenda which seek to reinforce ideals of service user empowerment, participation and self-organisation in the public resources they use (Leadbetter, 2004). Duffy (2012) has described personalisation as a ‘range of interconnected innovations that were developed by
disabled people and their allies in order to promote active citizenship’ (p.119).
Individualised funding is one of these innovations and a key mechanism for devolving choice and responsibility to individuals and families within a framework linking self-direction with goals of equality and social citizenship. Personalisation is thus a persuasive narrative and has been a dominant public and social policy agenda in the UK over past 20 years (Mladenov et al, 2015; Needham, 2011) with Australian federal and state governments following suit.

Despite the overlap of choice and self-determination principles, there are critiques of tensions in the competing ideologies driving personalisation reform, in the quality and nature of its implementation, and in the conflicts produced by inadequate resourcing and investment in community supports and infrastructure. Tensions rest in the strain between the collective foundations of disability rights principles and the individualism of the choice and consumerist agenda driving personalisation and marketization of social support and care (O’Brien & Duffy, 2013; Ferguson, 2007; Burton and Kagan, 2006; Clarke, 2004). The ‘logic of choice’ (Mol, 2008) has been challenged in its application to health and social supports based on what many see as its flawed underlying assumption that all are equally able to operate as rational and autonomous consumers in a support and care market (Dickinson et al, 2015). Commentators also warn that these tensions are difficult to address as they are easily obscured within a personalisation narrative deceptive in what it promises given the economic realities in which it is mired. The location of these promises in a ‘broader discourse of transformation’ and ‘hope’, is, it is argued, too easily appropriated by managerial and neo liberal motives dominated by struggles to manage unmet need with shrinking budgets rather than ideals relating to empowerment and choice (West, 2013).

Needham (2011) expands on this theme, referring to the personalisation narrative as an ‘empty signifier’. This means that in its ambiguity, the term personalisation can be used to gloss over multiple and potentially conflicting ideas, values, and implications (Needham, 2011). Reflecting this claim, Lymbery (2012) also accuses the personalisation narrative as cloaking itself in the ‘rhetoric of liberation’ whilst simultaneously working as a ‘vehicle to deliver swingeing cuts’ (p. 187). O’Brien & Duffy
(2013) also caution that ‘good words’ used in the promotion of personalisation, such as ‘capacity, citizenship and empowerment’ are stripped of their meaning and become ‘empty or even harmful’ when mired in stories of ‘commerce and control’ (p.7).

It is thus contended that whilst greater choice and influence in services and life is generally a shared social policy and community ambition, the unproblematised way in which personalisation reforms have been implemented is of concern (Lymbery, 2012). Commentators have warned of the implications for equity if reforms such as individualised funding are implemented without more careful thought for design, adequate investment, and overarching reference to original person centred principles (Duffy, 2012a). In light of the global financial crisis, UK commentators in particular have pointed to the disconnect between the reality of austerity measures and shrinking social support budgets and the promotion of personalisation as a transformative agenda (West, 2013; Needham, 2011). Lack of adequate resourcing has been described as the singular most significant barrier to personalised approaches achieving their ‘autonomising potential’ (West, 2013, p.641).

A pressing consequence of these conditions is that those with least voice and capacity, with least capacity to navigate and benefit within an individualistic consumerist model, will be most negatively impacted (Lymbery, 2012). Lymbery has also suggested that many people requiring social supports may not actually want certain responsibilities associated with increased choice. When individualised packages are automatically given rather than an option, such as in the Victorian ISP model, a key choice, to participate or not, is effectively withdrawn. From a rights perspective, these conditions throw up significant challenges regarding the state’s obligations to progressively realise positive rights, particularly in the context of austerity measures (Foster et al, 2012).

Evaluation and research in this area is further challenged by the significant variation in programs, scope, and interpretation of individualised funding approaches across and within countries. These variations create ‘methodological challenges’ for measuring the various impacts of individualised and self-directed approaches, particularly from a rights perspective (Productivity Commission, 2011).
In summary, whether argued from a human rights or personalisation narrative, there are significant tensions between the two even if the notions of choice and autonomy are common. Individualised funding and person centred approaches seek to bring these narratives together in a policy and practice framework but may equally be contradictory in their implementation and outcomes as they are in their conception. These tensions are further complicated by economic shortfalls and competition for government spending.

It is amidst these debates and economically challenged times that individualised funding reform has continued to be developed across jurisdictions, including in Victoria with the Individualised Support Packages program in 2008. The next section reviews more closely the development of individualised funding policy internationally and in Victoria where this study is located.

2.5 Individualised approaches in historical perspective

Individualisation of support funding might be seen as stemming from the 1960s normalisation movement in Scandinavia and later in North America (Chappell, 1992). The normalisation movement originally aimed to offer people with intellectual disability everyday choices and living circumstances as close as possible to those enjoyed by the general community (Burton Smith, Morgan & Davidson, 2005). In 1983 Wolfensberger proposed a name change to social role valorisation (SRV) with SRV theory further developing original normalisation ideas (Kendrick, 2005; Wolfensberger, 1995). SRV theory seeks to counter social devaluation of people with disability by promoting opportunities and the ‘establishment’ and ‘enhancement’ of the ‘valued social roles’ of these groups (Kendrick, 2005; Thomas & Wolfensberger, 1999, p.125).

In the UK, Canada and the US, the independent living movement also pushed for deinstitutionalisation and user led organisations emerged to mobilise and support people in their efforts to live more autonomously in the community (Barnes, 2007). Centres for Independent Living in the UK were managed and controlled by people with disabilities and sought to realise the rights of people with disabilities to participate and
to exercise greater choice and control in their lives (Barnes, 2007). However, some argue that decision making power in many ways remained in the hands of administrators and professionals (Laragy, 2002, 2004).

The earliest documented versions of programs offering individualised or direct payments to people with disabilities occurred in the US in the 1970s when Vietnam veterans sought more flexible supports (Yeandle & Ungerson, 2007). During the same period, the Woodlands Parents Group in Canada organised to receive individual funding to assist in moving their children with learning disabilities from Woodlands, a residential institution, into the community with the support of community based services (Power, Lord & DeFranco, 2013). A key part of this plan was service brokerage as an independent function which would support the person and their family to buy and organise services with their individualised funding (Power et al, 2013).

Following this, also in Canada, individuals with developmental disabilities and their families were given the choice of managing their own individual budget in a program called Special Services at Home (SSAH) (Lord & Hutchinson, 2008). The earliest forms in the United States were referred to as cash for counselling programs. Individualised funding approaches have since become the dominant form in many US states and have been supported by legislative reforms in 2006 and 2007 which made provision for more Medicaid beneficiaries to have control over their own personal assistance services (Harrington, Ng, Kaye, & Newcomer, 2009, cited in Chenoweth & Clements, 2009, p. 9).

In the UK, the Independent Living Fund was established in the 1970s to offer ‘cash-for-care’ schemes with tight eligibility criteria (Laragy, David, & Moran, 2015). Subsequent to the NHS and Community Care Acts 1991 and 1993 in the UK, the Community Care (Direct Payments) Act 1996 offered people with all types of disabilities access to individualised funding (cash in lieu of direct services), allowing them to manage their own funds and directly employ personal assistants (Dickson & Glasby, 2010; Hudson & Henwood, 2008). Further legislation regarding the mandatory offer of direct payments to social care users was developed through the Health and Social Care Act 2001 and later by the Health and Community (Scotland) Act 2002 (Laragy, 2010).
An important development in the UK was the pioneering of self-directed support by In Control, an organisation for people with intellectual disabilities and their families formed in 2003 which aimed to offer an alternative system of assessing resource needs. This system aimed to offer more certainty to people using funding by ensuring they knew how much they were entitled to before they planned their supports. The model also aimed for reasonable and manageable costs and minimisation of inefficiency and waste (Duffy, 2005). The success of In Control led to individualised budgets being piloted for adults and older people receiving social care services from 2005 (Prime Minister’s Strategy Unit, 2005). These were replaced by Personal Budgets in 2008.

_Putting People First_, published by the Department of Health in 2007, described a vision for the ‘transformation of adult social care’ (LGA, 2015). Key principles were: prevention; early intervention and re-enablement; personalisation; and information, advice, and advocacy (DH, 2007).

Elsewhere in Europe, a variety of schemes developed in line with overarching reforms to welfare policy and provision designed to address ‘new social risks’ and driven by shifting demographic, economic, and socio-cultural drivers (Ranci & Pavolini, 2015, p.271 citing Bonoli, 2005; Arksey & Kemp, 2008; Ungerson & Yeandle, 2007). Individualised forms of funding and support, such as cash for care schemes, offered different levels of regulation regarding the degree to which people with disabilities and older people had choice in how they were able to manage and spend their funding, on which services and for what purposes (Arksey & Kemp, 2008). Ranci & Pavolini (2015) describe the shift toward a more universalistic and generous model of long term care and support as ‘major paradigmatic’ policy reforms (p.273), particularly for those countries which had previously relied heavily on informal supports and had provided benefits to less than 10% of eligible citizens aged 65 and over. These countries included Germany, France, Spain, Italy, and the Czech Republic.

In their international narrative review of cash for care schemes, Arksey & Kemp (2008) found that whilst social and economic drivers were diverse and varied between countries, interest in cash for care schemes was shared amongst countries regardless of
the dominant welfare and political orientation. Whilst design and implementation of programs varied across countries, as did the systems for financing them, and the level of regulation, Arksey & Kemp (2008) observed that the fundamental aims and assumptions of individualised approaches remain the same. As already discussed, these relate to structuring provision of funding and related service frameworks such that they are tailored more directly to individual needs and aspirations (Laragy & Ottoman, 2011; Fisher et al, 2010; Dickinson & Glasby, 2010; Stainton, 2009; Lord & Hutchinson, 2003). This is intended to allow greater flexibility and control regarding what supports are provided, how, by whom, and when. Central to these programs is the effort to progressively reduce bureaucratic involvement and shift the locus of choice and control from professionals and administrators to people with disabilities and their supporters (Dickinson et al, 2015; Lord & Hutchinson, 2003).

Key variations in individualised funding arrangements exist in funding administration options; level of funding portability; prescriptions regarding how and on what the funding can be spent; direct employment of staff or not; sector and workforce regulation; and whether and how family members can be employed (Cortis et al, 2013; COAG, 2012; Fisher et al, 2010; Chenoweth & Clements, 2009). Similarly, terminology varies across jurisdictions and in different countries depending on the program’s scope and intent e.g. cash for counselling, direct budgets, personal budgets, individualised funding (Dickinson et al, 2015; Laragy, 2010).

Market and competition mechanisms are seen as playing a central role in individualised funding approaches. They are trusted to redistribute resources more equitably and to promote greater choice for service users (Baxter, Glendinning & Greener, 2011). It is hoped that devolving service provision and responsibilities to the market will reduce ‘welfare paternalism’ (Cortis, Meagher, Chan, Davidson & Fattore, 2013, p.2) and transform ‘inflexible systems into ones that grant greater power to individuals’ (Dickinson et al, 2015, p.417).

Williams (2007) has summarised the literature to describe four key features required for effective forms of individualised funding. These include ‘genuine’ control over funds
by the person or their supporter; infrastructure documentation such that the intentions of the program and responsibilities of parties are well defined; planning and brokerage support; and support to manage funding and services (p. 16-17). Duffy & Williams (2012) have since elaborated upon these, drawing on the English experience to identify 10 central ‘lessons’ for assessment and planning in the lead up to the NDIS. These are grounded in the core principles of ‘personal control and choice’ and keeping the ‘advancement of people’s life chances, and associated human rights, at the heart’ of the system (p.4). In practice this means a system which is flexible and adaptable, clear and transparent, which defines only the ‘essential’ elements of the process, and, importantly, which enables social innovation (Duffy & Williams, 2012).

In Scandinavia, high levels of taxation combined with a commitment to social democracy and equality for all citizens combine to promote highly flexible and person centred funding models (van Toorn & Soldatic, 2015; Laragy, 2010). The Support and Service for Persons with Certain Functional Impairments Act, (1994) sets the legislative conditions for these principles to be implemented. In a study comparing the experience of flexible funding models in Australia, Sweden, England, and Scotland, Laragy (2010) found that Sweden was distinguished by the adequacy of its investment in the independence and self-direction of people with disabilities, underpinned by socially reinforced expectations of equity and social inclusion. Laragy also found that people were given high levels of discretion and autonomy in how they could spend their funding. The limited focus on formal planning processes was noted as being in stark contrast with other countries such as England and Australia where controls on planning and spending are more formalised (2010).

As reported in Chapter One, Australia’s first major engagement with individualised funding was in Western Australia in 1988 with the use of Local Area Co-ordinators to work with people with intellectual disabilities. Since this time, other states have also implemented initiatives using individualised funding and direct payments options (Laragy & Naughtin, 2009). Some of these have also included Local Area Co-ordination models including the ACT, Queensland, the Northern Territory and New South Wales (Bennett & Bijoux, 2009). The aim of Local Area Co-ordination is to work with both

2.5.1 Impact of Individualised Funding - Findings from the literature
A review of the literature shows that the international experience of individualised funding is mixed, dependent upon the lens through which the analysis has occurred, and which stakeholders are prioritised. The following views express this diversity. Where uptake of individualised budgets was optional and at the authority’s discretion as in the UK, uptake has been described as patchy and sometimes inequitable (Carr & Robbins, 2009). Implementation and administrative systems internationally and locally, have been described as ‘unnecessarily complex’ and inconsistent, particularly application processes (VAGO, 2011, p.vii; Laragy, 2010; Commission for Social Care Inspection, 2004). The lack of adequate investment in independent advocacy, independent community based supports, and slow to change bureaucratic controls have for some limited choice and reproduced inequity (Ferguson, 2007, 2010; Spall et al, 2005). A key and ongoing concern has related to difficulties accessing consistent, timely and reliable information and resources required for informed choice (Laragy et al, 2015; Clarke, Newman & Westmarland, 2008). Access to information is enshrined in the CRPD, is central to a model dependent on individual choice making, and has particular relevance for the most vulnerable and isolated (Baxter & Glendinning, 2011).

Other research has identified the following negative outcomes for service users: lack of support to take on employer like duties when directly employing staff and managing complex administrative arrangements; lack of funding parity, consistency and transparency; uneven uptake across diverse groups especially those with complex and
high support needs; lack of market diversity and service choice, including community based options; and, risks inherent in intimate employer employee relationships including particular issues associated with employing family members (Laragy & Ottman, 2011; Fisher et al, 2010; Ottman et al, 2009; Chenoweth & Clement, 2009; Bigby & Fyffe, 2009; Newman et al, 2008; Spall et al, 2005; Ungerson & Yeandle, 2005).

Claims of cost efficiencies produced by individualised funding have also been contested and described as ‘self-evidential’ (Needham, 2015, p.59) and ‘circular’ given such calculations do not include the administrative and personal support costs of managing and using individualised funds (Productivity Commission, p.15). There are also inherent difficulties in evaluating the cost benefits of individualised arrangements, such as cash for care schemes, given the significant variations in program design and contexts (Arksey & Kemp, 2008).

Accountability dilemmas have also been identified as responsibilities for funds management, choice, and outcomes shift from the state to the individual and family. Dickinson et al (2015) observe that such reforms involve changes to ‘structures, values, and practices’ (p. 419) and that these must be resolved if the potential of individualised funding arrangements is to be realised for all stakeholders. Unanswered questions include but are not limited to who holds the accountability and responsibility for spending public money, for outcomes achieved, and for the working conditions and wellbeing of paid staff (Dickinson et al, 2015).

Many studies have focused on implications for services and workers associated with the introduction of individualised and consumer centred funding models. Staff retention and workforce planning reform have been identified as priority areas for the integrity and quality of personalisation reforms in all sectors (Rubery, Hebson, Grimshaw, Carroll, Smith, Marchington & Ugarte, 2011). Focusing on the Australian context, Cortis et al (2013) have described the disability service industry as characterised by low pay, low status, under skilling, and high rates of casualization. They argue that these challenges pose threats to the capacity of provider organisations and workers to implement consumer centred policy goals and maintain quality standards whilst also
ensuring worker rights and wellbeing. Cortis et al (2013) summarise key challenges for the Australian industry and workforce in the context of individualised funding as relating to service continuity and job security; income security, opportunities to gain, use, and retain skills; occupational, health and safety; and, rights to voice and representation (p.2).

Similarly, other mainly international studies have also identified issues for staff relating to role change and job uncertainty, reduced professional development opportunities, reduced quality of supervision, and isolation from peers (NDS, 2014; Carr & Robbins, 2009; Stainton, 2009; Glendinning et al, 2000). The precarious nature of disability support worker conditions has also been identified as a risk which can be hidden in home and community based settings, as opposed to highly visible workplaces in service centres (NDS, 2014; Cortis et al, 2013). Related to these are risks and vulnerabilities for both service provider and service user associated with shifting and blurred role and relationship boundaries and the formation of strong emotional bonds. Issues arising relate to over attachment and over involvement potentially leading to overwork driven by an increased sense of obligation (Rubery & Urwin, 2011; Laragy et al, 2013).

Care, work, and life boundaries have been found to be further complicated in arrangements which allow the employment of relatives as carers, such as in Dutch, Austrian, Italian, German and Swedish programs (Arksey & Kemp, 2008; Ungerson & Yeandle, 2005; Ungerson, 2004). Whilst doing so legitimates and funds previously unpaid care work, there are also risks to family dynamics and relationships when family members are employed to provide care work (Ungerson & Yeandle, 2005). These include potential threats to autonomy, identity and privacy when boundaries between work and life are ‘dissolved’ and where such threats are not recognised and managed (Ungerson & Yeandle, 2005). There are also risks for employed family members associated with reduced social rights, low pay, and threats to employment prospects caused by time out of the mainstream workforce and the opportunities therein (Frericks, Jensen & Pfau-Effinger, 2014).
In addition to these workforce issues, challenges for providers in the transition from traditional and group to individualised arrangements have largely related to the costs and demands of implementing new and complex systems, difficulties associated with the ‘unbundling’ of block funding, and, concerns over ongoing service viability in the context of increased consumer choice and portability of funding (Chenoweth & Clements, 2009; NDS, 2009). Maintaining a flexible, responsive and skilled workforce in the face of growing and changing demand and competition from other industries, such as health and aged care, has also been identified as a risk by the disability sector (NDS, 2014).

Ideological concerns primarily relate to the ‘uneasy’ synthesis of market economy modelling and human rights values and rhetoric (Burton & Kagan, 2006, p 300), reflecting a wider political debate over the competing discourses of collective social reform and neo liberal individualism as outlined in Section 2.2 (Mladenov et al, 2015; Clapton, 2009; Spandler, 2004). It has been argued that individualised funding approaches may shift control and power to an extent but cannot, in isolation, address systemic and structural barriers such as funding shortfalls, discriminatory community attitudes, poor facilities and issues of access and participation (Shah and Priestly, 2011; Clapton, 2009; Bigby & Fyffe, 2009).

Despite these mixed findings, disability advocacy organisations and the community remain vocal in their support given the benefits they perceive as well as the comparison to previous highly problematic funding and service arrangements (Productivity Commission, 2011). Various studies have shown that individual funding mechanisms can in different contexts deliver a range of economic efficiencies for public authorities (Stainton, 2009; Stainton, 2006) and positive personal and social outcomes for individuals and their families such as greater choice, autonomy, flexibility, service quality and control over supports and activities (Laragy, 2010; Ottmann et al, 2009; Carr & Robbins, 2009; Chenoweth & Clements, 2009; Williams, 2007; Stainton & Boyce, 2004; Glendinning et al, 2000).
The Productivity Commission inquiry into a long-term disability care and support scheme for Australia also found that there was enough positive evidence to support individualised funding in its final recommendations (Productivity Commission, 2011).

2.5.2 The Australian Context and the NDIS
In Australia, the evolution in social attitudes toward disability has been documented in milestone reports and policy documents. The landmark Shut Out Report (National People with Disabilities and Carer Council, 2009) documented community consultations across Australia to inform the development of a National Disability Strategy (NDS). The NDS was intended to reflect the Australian Government’s commitment to social inclusion and enshrine the rights of citizens with disabilities to full participation in economic, social and cultural life (National People with Disabilities and Carer Council, 2009). The consultation attracted more than 750 submissions with over 2500 people attending the consultations. An analysis of the submissions identified multiple barriers to equality and the full participation of people with disabilities, key among these the ‘chaotic, underfunded, and fragmented disability service system’ (Bigby, 2014, p. 93).

The report highlighted critical areas for government and community reform and reflected arguments mounted over decades regarding the gap between the discourse of rights, choice and personalisation and the everyday reality of people’s lives. Meekosha (1999) pre-empted the Shut Out Report findings when, in 1999, she described Australia as a ‘war zone’ for many people with disabilities (p.1):

> At a time when citizenship is a catch-cry in public debate, disabled Australians are effectively denied many of the simple rights their fellows take as given.  
> Meekosha (1999)

Meekosha made the further point that although human rights are mandated once signed, it is through the actions of services and community interactions that rights are predominantly promoted or denied on a day to day basis.
Ten years later, the *Shut Out* Report echoed Meekosha’s misgivings, describing Australia’s disability service system as follows:

….broken and broke, chronically underfunded and under-resourced, crisis driven, struggling against a vast tide of unmet need. Services were unavailable or infrequent, unaffordable or of such poor quality as to be of little benefit. Respondents felt that more effort went into rationing services than improving them. (p.8)

Most importantly for this study, the subsequent Productivity Commission report recommended the adoption of individualised funding and a human rights framework as central platforms for policy and practice reform (Productivity Commission, 2011).

In line with this recommendation, a key purpose of the NDIS Act 2013 is to give effect to Australia’s international rights obligations under the CRPD (Part 2, Section 3). Goggin and Wadiwel (2014) point out that although there are other examples of rights based legislation at the national and state levels, it is a ‘powerful development’ to see a social support scheme explicitly committing to the social and economic participation rights of people with disabilities (p.n.pag.). As well as promoting a rights platform for people with disabilities, the NDIS has also been supported on the basis of arguments relating to the economic risks of both social exclusion and the financial unsustainability of the previous system (Bigby, 2014). Evaluation of the NDIS, therefore, will be based on economic as well as social justice and human rights gains (Bigby, 2014).

The NDIS was launched in July 2013 to bipartisan political support and is funded by a new 0.5% increase to the Medicare levy (National Disability Insurance Scheme Act 2013). The scheme offers lifetime entitlement and is intended to be nationally consistent. It is currently (2016) being trialled in seven sites across Australia with different target groups: in Tasmania for young people aged 15-24; in SA for children six and under; in Barwon, Victoria, the Hunter area, NSW, the ACT, WA, and the NT for adults up to age 65. It is to be progressively rolled out nationally from this year (2016) and expected to be fully implemented in 2019/20.
It is against this background of tension and debate, economic constraint, hope and concern, that the performance of contemporary and emerging individualised funding and self-directed frameworks needs to be measured. This study therefore has the potential to inform early implementation of the NDIS and to contribute through empirical research to the complex and important debates regarding how individualised funding programs can best work to promote and realise rights for people with disabilities.

2.5.3 Individualised Funding in Victoria

The Victorian Government’s 2009 policy statement, *Support Your Way*, outlined its vision for people with disabilities and the government’s philosophy and policy regarding self-directed approaches. This vision built upon the State Disability Plan (2002-2012) and was underpinned by two key documents, the Victorian Charter of Human Rights and Responsibilities 2006; and, the Victorian Disability Act 2006.

*Support Your Way* affirmed the rights, responsibilities and opportunities of Victorians with disabilities as citizens on a par with all others with access to the ‘social, educational and employment opportunities’ required to ‘actively participate and be included in their communities’ (p.4). To do this, the document emphasised the importance of ‘high quality person and family centred services which are based on self-directed principles’ (p.4). In addition, the vision also required better services and strong, accessible communities which would be more ‘welcoming and inclusive’.

*Support Your Way* outlines the central elements of the self-directed approach as self-directed planning, funding, and support based on the human rights principles of self-determination, choice, inclusion, transparency, accessibility and citizenship (DHS, 2009, p.2). Self-directed approaches were defined as those which locate the person at the centre of their service system and which enable the person to ‘identify, design and oversee the support and resources they require’ (p.7). This meant that supports and resources provided would be based on the person’s ‘needs, goals, lifestyle choices, and aspirations’ (p.7).
The aims of the Victorian ISP program typify the optimism of individualised funding objectives across jurisdictions. The above sections have reviewed arguments and perspectives which support or caution against the likelihood of such aspirations being consistently achieved for all. But there is little empirical data in Australia designed to systematically and empirically explore the relationship between these rights based goals and the everyday experience of people using individualised support funding and self-directed services.

This chapter now gives an overview of the capabilities approach in its relationship with human rights and its retrospective application to this research. The following section explains why a capabilities lens was applied to the findings in a second level of analysis to deepen understanding of the mixed findings developed from the first analysis. These findings reflected diversity of experience as well as pointing to the need for an extended conceptual framework through which to further meaning could be developed. It was clear that the study needed more discerning and probing research questions regarding the relationship between provision of individualised resources, self-determination and the real freedom to choose, not just in relation to everyday service decisions but also in relation to sustaining and meaningful lifestyles. The capabilities approach offered a useful set of interpretive ideas which could be used to progress this analysis and answer the emerging research questions more fully.

2.6 A capabilities based understanding of the human rights experience

This chapter has identified the lack of consolidated empirical research regarding the implementation of individual funding models and their social impact from a human rights based perspective. This is despite a need to test policy objectives grounded in universal human rights principles and particularly regarding the CRPD to which Australia is signatory (Fisher et al, 2010). These principles argue for autonomy, choice, self-determination, participation and inclusion as key criteria for and necessary components of citizenship. But research to date has been largely grounded in utilitarian economic, quality of life, and, basic social modelling perspectives. Although potentially
useful, these perspectives do not necessarily apply a social justice lens to important questions about the equity and fairness of processes or the system’s capacity to cater for diverse needs and context (see for example Fisher et al 2010; Glendinning et al, 2008; Chenoweth & Clement, 2009; Carr & Robbins, 2009; Stainton, 2009; Fisher & Campbell-McLean 2008).

2.6.1 The limits of utilitarianism
An emphasis on quality of life and utilitarian measures, defined by satisfaction or even happiness has been described by some as a key limitation of social policy evaluation (Bessant, 2014). A key critique is that such measures do not adequately explain the diverse voices, needs and aspirations of pluralistic populations (Bessant, 2014; Terzi, 2005). This failing poses particular risks for marginalised and minority groups such as people with disabilities where both individual and collective voice may be already diminished in the public sphere (Terzi, 2005). When policies are developed and evaluated on the basis of satisfaction of the general rather than on the basis of plural needs, abilities and contexts, the ‘dilemma of difference’ can be glossed over (Terzi, 2005). A consequence is that policy or program outcomes become the end rather than the means, and the needs and hopes of different groups and individuals are ‘neither acknowledged nor respected as ends in themselves’ (Bessant, 2014, p. 141).

Similar critiques have been applied to evaluation and analysis of individualised funding programs. For example, Duffy (2012) has argued that much research into individualised funding reforms, such as the IBSEN study (2008), has focused on expressed satisfaction with day to day utility or satisfaction in service decisions, but failed to fully explore the overarching achievement of citizenship as a key measure of policy and program success. He argues that such evaluations, based in concepts of individual utility, are insufficient frameworks for critical evaluation of innovative and emergent systems concerned with addressing diverse rather than uniform needs (Duffy, 2012). Duffy contends that individualised funding approaches are complex and emerging innovations and cannot be evaluated as ‘simple interventions’ to be applied in fixed and generic ways (p.117). Further, Duffy cites Mills (1962) in arguing that social value cannot be reduced to an
account of happiness or preference satisfaction because happiness in and of itself is a poor measure for determining whether an act is socially just or good.

The rationale for retrospectively introducing a capabilities approach to the analysis builds on these arguments and extends the original human rights framework to allow for a more nuanced understanding of participants’ diverse and contingent experiences of choice within the ISP framework.

The following section explores the key tenets of the capability approach in more detail, including its merit as an explanatory framework in this study and its synergies and alignment with both the human rights based approach and the social model of disability.

2.6.2 A shift toward a capabilities based analysis
It will now be argued that a capabilities lens, drawing on the work of Amartya Sen (1987, 1999a), Martha Nussbaum, (1999, 2000, 2006) and others, is a useful framework for better understanding the dynamics of choice, empowerment, and benefit within self-directed funding and service frameworks.

A key motivation for Amartya Sen in developing the capability approach to inform development policy and frameworks was to extend traditional economic rationalist and utilitarian measures of well-being and offer instead an alternative social justice framework for measuring equality. In this framework, the measure of effectiveness is freedom rather than wealth, income, or utility as represented by satisfaction or happiness (Nambiar, 2013). Rather than using equality of resources or outcomes as indicators of effective policy and programming, Sen argued that measurement also needs to focus on the extent to which social arrangements expand people’s freedom to choose lifestyles they value (Klein, 2015; Sen, 1995). Sen argued that assessing justice by simply equalising certain inputs or requiring similar outcomes glossed over diversity and the diverse ways in which people might be able to translate resources into chosen and meaningful outcomes. He also argued that such policy measures also failed to adequately account for individual agency and the adaptive preferences people typically
make in the face of the social, economic, and cultural constraints shaping their expectations and choices (Klein, 2015; Sen, 1995).

Sen developed the capabilities approach to emphasise that social arrangements should primarily aim to expand people’s substantive and process freedoms such that they are empowered and enabled to develop lives they value (Sen 1999b). Accordingly, policy, programs and institutions should be measured on how well they provide the capabilities, or the freedoms, people require to exercise real choice and self-determination (Terzi, 2005). A capabilities lens therefore shifts the analytic focus to the conditions and processes required for people to enjoy the substantive freedom to choose and be what is important to them. The approach posits that such freedoms are enabled or constrained by the socio-cultural and contextual arrangements shaping these conditions. The approach is thus a ‘normative framework for assessing inequality’ (Terzi, 2005, p.219) and does so by drawing attention to the relationship between the resources available to a person, their capabilities and opportunities, and the things they choose to do and become i.e. functionings.

Sen conceptualises capabilities as a ‘type of freedom’ and opportunity to which people have ‘real’ access (2012, p. xii). He describes capabilities as both substantive and process based. This is a critical distinction as it leads on to identifying who has the obligation for these different forms of freedoms or capabilities and how they may be promoted (Klein, 2015). Substantive freedoms are those people require to pursue lifestyles they value, for example, the freedom to be educated, to access good quality health care, to live where and with whom they choose, or to be in an intimate relationship. Process freedoms on the other hand are those processes and mechanisms which empower and enhance people’s sense of agency and self-determination (Klein, 2015). Examples of process freedoms include the opportunity to participate in individual and public decision making (Klein, 2015).

Sen argues that it is useful to understand capabilities as human rights essential to a flourishing life. They have correlate obligations which it is the duty of public authorities and institutions to provide (Sen, 2012). For example, the right to autonomy or
education can be understood as core capabilities. A capabilities perspective thus focuses on the enablement of these capabilities or opportunities as the measure of a socially just framework (Nussbaum, 2012).

There are a variety of interpretations and critiques of the capabilities approach. It has been described as informationally demanding and as a ‘set of ideas, concepts and methodological instructions’ which lack some clarity regarding what it ‘actually is how it should be interpreted and operationalised’ (Goerne, 2010, p.6). The terminology has also led to confusions and been described as ‘clumsy and unfortunate’ in the context of disability (Burchardt, 2004, p.738). It is also generally accepted that interpretation and application of the key concepts have over the decades been variable and diverse (Burchardt, 2004) with some claiming the framework has been misinterpreted in ways which are counter to Sen’s original intent (Klein, 2015).

The framework has also been critiqued as an overly individualistic account of freedom and choice however Sen and others have countered this allegation, arguing instead that the capabilities approach is inherently relational with firm social constructivist underpinnings (Terzi, 2005; Burchardt, 2004). They argue that rather than being individualistic, the concepts provide an analytic approach for understanding how social and contextual factors shape individual capabilities and opportunities (Smith & Seward, 2009; Sen, 2000; Robeyns, 2000, 2005; Sen, 2000). Reinforcing this point, Burchardt (2004) has emphasised the value of the framework in addressing disadvantage by focusing on the ‘social, economic and environmental barriers to equality’.

The capabilities framework is an alternative to, and departure from, traditional normative theories of justice and offers a ‘critically different conceptualisation of the purpose and principles of public policy’ (Orton, 2011). Despite concerns there has been a growing application of the approach in social policy development, analysis, and evaluation in developed countries and particularly from a human rights perspective (Elson et al, 2012; Goerne, 2010; Robeyns, 2005). Since the approach emerged for application in development work, Sen, Nussbaum and others have continued to develop

2.6.3 Capabilities and Functionings

In the capabilities approach, the distinction between two key concepts, capabilities and functionings, is critical. **Capabilities** are defined as what people *can* or have the freedom to do and **functionings** are the actualised states of being and doing they choose (Sen, 1979, 1999a). In other words, functionings are capabilities that are realised and can be understood as a subset of a capabilities set (Robeyns, 2014). Robeyns (2014) further clarifies capabilities as a person’s ‘real freedoms or opportunities to achieve functionings’ and thus the important distinction is ‘between the realised and the effectively possible, in other words, between achievements, on the one hand, and freedoms or opportunities, on the other’ (2014, p.npag.).

By making this distinction between what people actually do and what they have had the substantive and process freedom to do, a capabilities analysis draws attention to how real rather than notional freedoms are enabled or constrained within any given policy and program framework, by what mechanism, by whom and for whom (Nambiar, 2013; Clarke, 2005). Importantly for this research focus, a capabilities based lens shifts the evaluative space from equality of inputs and outcomes to instead focus on processual and procedural fairness and systemic capacity to respond to diversity. This includes understanding how conditions shape and enable access to and conversion of resources in to the real capabilities, freedoms or opportunities people value. This represents a vital departure from previous conceptualisations for measuring outcomes and reorganises how the collected data should be understood and interpreted.

This framework allows a more nuanced unpacking of the nature of individual choice and the factors which expand or constrain it. The conditions and processes which create these freedoms and opportunities come under greater scrutiny as do the roles and obligations of those responsible for creating and resourcing these conditions, such as the state, its delegates, and the market.
Like capabilities and functionings, the concept of conversion is a key element in the capabilities approach and has been used as a central device in the second phase of analysis. The dynamic of conversion and key principles are described below.

2.6.4 The concept of Conversion
Given that resources are taken up differently by diverse individuals, depending on the interplay of personal, socio-cultural, institutional and environmental factors, a central understanding in the capabilities approach is that resources, both formal and natural, are latent until such time a person is empowered to access and convert them into manifest and meaningful beings and doings (Vizard, Fukuda-Parr & Elson, 2012). Beings and doings here refers to what people are and do.

Conversion describes the critical relationship between latent resources and actualised freedoms and the characteristics of resources and processes which enable this process (Goerne, 2010). Although linked and interdependent in many ways, conversion factors are typically categorised as personal, social, cultural, institutional, and environmental (Goerne, 2010). Smith and Seward (2009) usefully explain conversion factors as the contextual mechanisms which allow people in different circumstances with different aspirations to convert the same resource into different capabilities for different outcomes. They go on to argue that any explanation must include these three elements i.e. commodities, conversion factors or mechanisms, and outcomes. This conceptualisation has significant implications for social policy and practice.

As identified earlier, this concept has been of significant analytic value in this study, explaining inconsistencies and inequities by drawing attention to the mediating influence of forces operating across different spheres of influence, many of which were well beyond what the person himself could control or shape. The mechanism has helped interpret the findings by examining more closely the mechanisms required for different participants to effectively benefit within the ISP framework, to engage with and convert their available resources into chosen and better lives. The discussion in Chapter Eight elaborates on the concept of conversion in direct relation to this study’s findings and discusses the nature of conversion factors within the ISP and service framework, as
suggested by the data, as necessary forces and variables in the conditions and opportunities required for choice and self-determination.

2.6.5 Synergies with human rights and the social model of disability

In prioritising issues of social justice, freedom, diversity and agency, as well as participatory processes, the capabilities approach is synergistic with applied human rights principles (Elson et al, 2012). It has been argued that the capabilities approach is important in conceptualising a holistic model of disability rights and is a rich adjunct to human rights and disability theorisation (Stein & Stein, 2007). The synergies between capabilities and the social model of disability have also been elaborated, countering claims that the two concepts are divergent (Burchardt, 2004). Like the social model, a capabilities lens conceives individual freedoms and well-being as socially constructed and is equally concerned with the structural, economic, and social barriers to citizenship (Elson et al, 2012; Burchardt, 2004). Stein and Stein (2007) have similarly drawn links and have employed both a capabilities perspective and the social model of disability in their development of a holistic disability rights model. Given its commonalities with the social model of disability and central human rights principles, I argue that that capabilities framework has much to offer disability policy analysis, particularly in relation to programs ostensibly promoting choice, self-determination, and ultimately citizenship.

Importantly, the framework as applied in this study continues to be informed by the principles of the CRPD, an understanding of rights as indivisible and interdependent, and of their promotion and realisation as necessarily a participatory process achieved through dialogue between rights holders and duty bearers.

It is also argued that a capabilities based understanding of human rights helps give substance to otherwise aspirational rights claims, particularly positive rights claims associated with social, economic, and cultural freedoms (Nussbaum, 2012). Both Sen (2012) and Nussbaum (2012) suggest that if we understand capabilities as valued human rights we can then interrogate more explicitly the obligations of duty holders charged to ensure provision of these capabilities or opportunities. Thus, to explore this
study’s findings through a capabilities lens potentially offers greater direction regarding the responsibilities of the state, services, and other duty holders in relation to people using self-directed funding and services.

This study follows other research which has incorporated a capabilities perspective to monitor and evaluate social and public policy, and legislation, from a rights based perspective (Kimberley et al, 2012; Gorecki & Kelly, 2011; Burchardt & Vizard, 2011; Burchardt, 2008; Stein & Stein, 2007). These studies have used the alignment between capabilities and human rights to illuminate in applied ways how rights based principles might be converted from policy aspirations to everyday practices and achievements. This is a key aim of this research. This potential is important and relevant to the challenges posed by this research, particularly in its emphasis on the positive obligations of the state, services, and other duty holders in relation to social and economic citizenship and inclusion (Nussbaum, 2011).

2.6.6 Applying a capabilities lens in this study
The first level of analysis produced findings which were limited in explaining the diverse and sometimes contradictory data beyond existing explanations. The original rights analysis reflected and confirmed what previous studies have shown about the risks and benefits of individualised funding approaches but left unanswered dichotomies present in the literature and contradictions in the data. The rights discourse and framework needed extension in order to offer a more complete explanatory framework to answer the emerging research questions. For example, how do individualised support frameworks enable the freedoms people with disabilities require to lead the lives they value? What level of agency did participants really have in this system, how was it constrained or enabled? What can the choices they made tell us about the opportunities available and about the framework’s capacity to support diversity and difference? It became apparent that in order to more fully understand people’s everyday experience of choice and self-determination within the ISP framework I would need to look beyond an outcome analysis of participants’ expressed satisfaction with outcomes or, alternately, their dissatisfaction. A more nuanced analysis was required.
Whilst increased choice and flexibility in everyday decisions were described and valued, closer examination revealed the highly relative nature of these choices, showing them to be better when compared to previous hardships and resource poor conditions. Whilst participants expressed satisfaction with service choices on a day to day basis, many still described lives and lifestyles on the margins of society, still excluded from the opportunities they required to participate socially and economically on their terms.

Incorporating a capabilities lens addressed to some extent the analytic limitations of this study. In particular, understanding that people’s diverse needs, capacities and contexts influence how they interact with policy and program frameworks and the degree to which they benefit or are disadvantaged, is critical for this study’s analysis (Smith & Seward, 2009).

Focusing on diversity encourages a differentiated and contingent understanding of how individualised processes and pathways produce different rights experiences and outcomes for different people in different circumstances (Smith & Seward, 2009; Terzi, 2005). A capabilities perspective therefore has the potential to explain data that exposes inconsistencies and inequities. Given the initial analysis in this research mirrored the debates in the existing literature, I moved toward a capabilities framework as a way of progressing the analysis and contributing to these debates.

As the analysis will show, it is diversity and difference rather than standardisation which must be central to debates regarding personalisation and individualised approaches if aspirations of choice, autonomy, and other rights are to be realised individually as well as collectively (Goerne, 2010). Applying a capabilities lens explicates in greater depth what the findings could tell us about the diverse everyday experience of rights in relation to engagement with individualised and self-directed reforms and about the dynamic of converting resources into valued choices. This expanded understanding of human rights as capabilities highlights issues of processual equity and access to opportunity as central to evaluation and helps explain the disabling impact of the inequities and inconsistencies the data exposed in relation to ISP processes and resource allocation.
It also identifies, I believe, the benefits of emergent study designs which give latitude for decision-making throughout the research process. Chapter Eight will further explain how a capabilities lens might disentangle the competing strands of personalisation and human rights to suggest an alternative framework for evaluating experience and outcomes. An ongoing theme will be exploration of the tensions between the individual and collective dimensions of rights as represented in the individual and community dichotomy and the extent to which the Victorian model addresses these tensions.

It is important to note here that had I originally planned to use a capabilities approach, I would have incorporated a stronger capabilities framework to structure the interviews and interview questions. I may have concentrated more specifically on the dynamic of conversion in the activation of otherwise latent resources into valued opportunities (Clark, 2005). But although it did not directly inform the construction of the methodology and the questions asked of participants, given the synergies and shared roots between a capabilities perspective, human rights, and social model thinking, adopting a capabilities analysis later in the project has not been a major limitation.

2.7 Summary

The emphasis in this chapter has been upon the theoretical frameworks relating to disability and human rights and how these intersect in individualised and self-directed frameworks as mechanisms for choice within broader personalisation reforms. The tensions inherent in the respective ideologies underpinning disability rights and the neoliberalism of personalisation have been described, particularly the impact these tensions can have in the implementation of social support and care policy reforms which combine key tenets of both. The chapter has outlined the evolution of self-directed funding and service approaches for people with disabilities in the broader context of global human rights scaffolding and neoliberal social and public policy reform shaped by a changing demographic and economic conditions. I have belatedly introduced a capabilities perspective and argued that it can enrich and extend, practically as well as conceptually, the human rights framework used. It is contended
that a capabilities based understanding of human rights offers some resolution to the contradictions and paradoxes demonstrated in my findings and which reflect the debates outlined in this chapter.

The following chapter outlines the research and disability philosophies that have informed this research and is followed by Chapter Four which outlines the research approach in detail. This approach will frame human rights as socially constructed and as given meaning and substance by being contextualised in the lives of people with disabilities using individual funding, the people supporting them, and those providing services. This method of interrogating the ‘gap’ between rights based policy and practice has aimed to identify where, how and for whom rights and opportunities are promoted and realised with the ISP funding context. How does the ISP funding and service model expand or constrain self-direction and choice in everyday lives; and, where should future investment and thinking need to focus in order to embed conversion mechanism in future program design.

Chapter Three

Study philosophies and a contemporary disabilities studies framework

3.1 Introduction

In Chapter Two it was argued that there are tensions, as well as common ground, between personalisation and human rights discourses. Whilst shared values remain uncontroversial, the processes, ideologies, and motivations driving either agenda are often at odds and contradictory. These tensions however are not publicly examined in the promotion of personalisation through key mechanisms, such as individualised funding. Reflecting these debates, the chapter showed how individualised funding, as a
reform which is promoted by both discourses in policy and practice, is seen as similarly producing a diverse range of outcomes, both 'good' and 'bad', of 'winners' and 'losers'. Although slowly growing, the empirical research exploring the lived experience of people with disability using individualised funding remains limited. Much is left to be discovered, particularly within a Victorian and Australian context and, more appositely given the centrality of the individualised funding approach during the study period, in the launch and piloting of the NDIS.

This chapter explains the ontological and epistemological assumptions of the constructivist interpretive paradigm in which this qualitative research is located. But first the chapter revisits the frameworks discussed in the previous chapter to firmly frame this study within contemporary disability studies and human rights theory. It will then go on to outline the study design and methodology which has been used to explore the competing theories around individualised funding as reflected in the experiences of those using funding as well as those providing services in the ISP framework. Their experiences and those of family carers have been thematically analysed from a rights and capabilities based perspective to explore the nexus between human rights (particularly choice and autonomy) and consumerism as represented through individualised funding frameworks.

3.2 Nature of the research problem

This research seeks to help resolve the conflicting empirical and theoretical debates by establishing a knowledge base drawing from the experiences of stakeholders engaged in one particular model, namely Victoria’s Individualised Support Package framework.

This research aims to explore if, where and under what circumstances Victoria’s system of individualised payments (ISP) meets its human rights and citizenship commitments in the lives of people with disabilities and their family carers, drawing on their experience as well as the perspectives of Disability Service Provider managers, ISP planners and support workers. The focus is on choice, autonomy, and self-
determination as key human rights principles as set out both in the CRPD to which Australia is signatory and as core concepts claimed by both human rights and personalisation discourses. The research aims to examine the personal, material and social challenges, resources and opportunities within the individualised funding framework which enable or limit the individual’s capacity to claim and exercise these rights and to pursue the lives they variously choose.

3.2.1 The Research Questions

Chapters One and Two framed the debates and competing ideologies which give rise to tensions within the design, implementation and experience of individualised funding and support models. The following overarching research questions were identified as addressing a gap in the literature and seek to explore, through lived experience, the tensions identified in the previous chapters.

1. To what extent and in what ways do individualised funding models promote, protect and ensure the human rights of people with disabilities, most particularly in relation to choice and autonomy?

2. What are the tensions, risks and opportunities from a human rights based perspective in the delivery and implementation of individualised funding in Victoria? How are they experienced by key stakeholders, (the person, their family carer, support workers and service managers)?

3. What are the key mechanisms that might be used to address current shortfalls and risks in meeting the personalisation and human rights based aspirations of Victorians with a disability, the Victorian Government and the NDIS?

3.2.2 Establishing a link between ontology, epistemology, and methods

A research paradigm guides and establishes how knowledge will be investigated and interpreted and ‘sets down the intent, motivation and expectations for the research’ (Mackenzie and Knipe, 2006, p. 1), thus underpinning the design process. Denzin and Lincoln (2011) define a knowledge paradigm as an ‘interpretive framework’ and as a ‘basic set of beliefs that guide action’ (p.91). This understanding reflects other definitions such as Creswell’s ‘worldview’ (2007).
Paradigms distinguish ‘first principles’, and encompass the key questions of ethics, epistemology, ontology and methodology (Denzin & Lincoln, 1990, p.91). The question of ethics pertains to the researcher's moral stance and values in the world, epistemology regards how the researcher will know or understand the world, ontology refers to the nature of reality, and methodology deals with the 'best means for gaining knowledge about the world' (p.91). These four terms are dynamically linked and must be aligned and made explicit in qualitative research in order to produce a coherent and rigorous contribution to the field of study. The epistemological and ontological assumptions of this study are described below in the context of a disability research paradigm.

3.2.3 A Contemporary Disability Research Paradigm

Earlier a distinction was made between individual and medicalised approaches to understanding disability and the social model approaches which developed from the 1960s onwards (Barnes, 2007). It was shown how, through disability activism, the social model approach came to be recognised within the CRPD. As part of the redefinition of disability, the disability movement also came to examine and critique traditional forms of research into and with people with disabilities, arguing for methodologies and participatory approaches which were socially focused, which empowered people with disabilities, and which centred on their priorities rather than those of third parties (Goodley, 2011).

This has been a move away from traditional research involving people with disabilities which has been situated in the uneven power relations between researcher and participant underpinned by, but not exclusive to, the domination of disability research by positivist, medical and individual models of disability (Goodley, 2011). In line with a social model approach, contemporary disability studies have increasingly aimed to influence social and cultural reform. When disability is socially located, as opposed to within the individual, and understood as a ‘cultural and political phenomenon’, the location of research must also shift to this space (Goodley, 2011, p.1). In doing so, contemporary disability research directly rejects the ‘personal tragedy’ view of disability (Goodley, 2011, p.1) and by definition assumes a social model and social relational conceptualisation of disability, critically theorising disability as produced by inequality, exclusion and oppression (Meekosha & Shuttleworth, 2009; Thomas, 2004a).
In line with this paradigm, social approaches to disability research also question whose interests are being served and which individuals and community will benefit from the research (Oliver & Barnes, 2012; Denzin & Lincoln, 2011; Goodley, 2011). Oliver (1992) described much disability research as a ’rip-off’ from which academic careers have benefitted but which has done little to influence the issues and policies contributing to the exclusion and oppression of people with disabilities. As implied above, this ’rip-off’ is not peculiar to positivist research but is also contained in much qualitative social research (Goodley, 2011). As recently as 2012, Oliver & Barnes have argued that if the aim of critical disability studies is social change, proponents have ‘yet to demonstrate their inclusivity or their usefulness in this endeavour’, with the endeavour referred to being that of communicating ideas in ways which can be used for the ’betterment of all’ (p.182).

In line with this argument, emancipatory research methods have developed, designed to address issues of participant ownership by embedding the interests and involvement of people with disabilities as co-researchers within the project design (Goodley, 2011; Lincoln et al, 2011; Barnes & Mercer 2010). Approaches such as action research and user led methods are examples.

Goodley (2011) has subsequently categorised contemporary disability research as either non-participatory, participatory or emancipatory, depending on key elements including ownership (’research by whom’), involvement (’research with whom’) and application (’research for whom’) (p.23). Importantly however, Goodley (2011) notes that none of these approaches should be privileged over the others and that each have its role in furthering contemporary disability research.

Whilst this research is not emancipatory, it does centre on the voice of people with disabilities and aims to inform policy and practice central to their needs and aspirations. To do so, the research also seeks the experiences and perceptions of other groups directly engaged with the ISP framework. Thus, the ontological interest of this research lies with the lived experience of those directly involved in using,
operationalising, delivering, or supporting others to use individualised funding to improve their lives.

This approach entails responsibilities and accountabilities for bringing to light people’s experiences as well as the ethical analysis and reporting of findings based in participants’ narratives. Erickson (2010) highlights these dual accountabilities below:

Many of us today consider privacy to be a human right, yet we can consider as complementary to privacy the right to have one’s daily life portrayed in ways that do not distort its conduct and intentions, nor silence its subjective experience. (Erickson, 2010, p.113).

This points to the role of qualitative social research in illuminating lived experience as a means of challenging practices which have traditionally silenced those with least voice and representation. Erickson maintains that silencing or ignoring such experience represents a form of human rights violation similar to more overt and intentional promulgation of ‘negative stereotyped portrayals’ of the ‘routine practices’ of different groups (2010, p.113). He refers to social research as lifting the ‘veil’ on everyday struggles and achievement so that they can be understood and interpreted to ‘tell about’ how people live (Erickson, 2010, p. 113). At its most powerful and when well executed, good qualitative social research can therefore play a role in furthering people’s rights and affirming human dignity by giving voice to those who might otherwise have none and representing the meanings they give to their actions (Erickson, 2010; Denzin, 2010). Such an approach accords with the principles of human rights adopted as a focus for this study.

But whilst research ambitions may have merit and integrity, there remain key epistemological issues about the extent to which voices deconstructed through the process of interview, transcription and analysis can be best and most ethically represented. These questions have implications for the research design and include ethical considerations regarding beneficence in terms of research benefits outweighing the risks to the person i.e. inconvenience, discomfort, and privacy (National Statement on Ethical Conduct in Human Research, 2007).
The next section explains the interpretive paradigm in which this research is located and the constructivist epistemology leading to the methodology and data collection methods.

3.2.4 A constructivist/interpretive paradigm
This study design is based on relativist ontological assumptions which posit that reality and experience are socially constructed, multiple, situated, created within social interactions and ascribed meaning through these interactions (Guba & Lincoln, 1994). These assumptions contrast those of a positivist ontology which seeks to establish a singular knowable truth (Guba & Lincoln, 1994). This understanding of the nature of reality and experience informs the study design, epistemological, methodological, and ethical considerations. Importantly, the epistemological assumptions here have determined how I have conceptualised my role as researcher and the role of participants as active in the production of knowledge (Mantzoukas, 2004).

The study draws on a social relational understanding of disability to reveal the diverse and socially constructed experiences of rights such as choice, and autonomy. It seeks to test these against the rights promise of the Victoria’s ISP framework as explained in Chapters One and Two (Support Your Way, 2009) but also with regard to other similar programs. In attending to the interdependence between personal experience and social, economic, and cultural barriers, the social relational model offers a framework for a detailed analysis of the forces operating to either promote and realise rights through everyday interactions or, conversely, to constrain them (Thomas, 2004).

The research thus employs a constructivist epistemology which understands that reality and therefore knowledge is produced in the active constructions of people ‘in and through forms of social action’ (Holstein & Gubrium, 2011, p. 341). The research requires, therefore, an emic account of meaning, based in the perspective of the insider, an understanding from the participant’s worldview and not a description of behaviour produced from an outside neutral position (Schwandt, 2007).
A relativist ontology is consistent with a contemporary framing of human rights not as objective universal truths but rather, as subjective experiences and practices which are realised in the transaction between a rights holder and duty bearer in a particular time, place and space (Brinkman, 2010; Fields, 2010). Although guided by universal ideals, the everyday experience of rights is found in the multiple and changing meanings people ascribe to their diverse situations (Brinkman, 2010). Illuminating this experience is the core task of this study.

3.2.5 Interpretive inquiry
My role, in this interpretive inquiry has been to engage with the lived experience of people with disabilities, family carers, support workers and managers of services, to understand their lived experience and to work iteratively between the different sets of data to interpret similarities and divergences. To do so I have used semi-structured interviews which allow flexibility to follow participants’ interests and pursue the meanings they give their experience. It has also been important to move beyond the individual case to understand its relevance to others and to the broader social and cultural context (Layder, 2006). This is based in an epistemological understanding of knowledge as a product of interactions between the researcher and participants as opposed to knowledge extracted as static measurable facts (Carter & Little, 2007). Importantly, interpretive inquiry also understands that the interview interaction represents only that version of experience which the participant is willing or able to offer in that particular time and place (Carter & Little, 2007). Qualitative methods typically include interviews, focus groups, fieldwork and observation and rely on a hermeneutic process of interpretation (Creswell, 2007). From these options I chose in depth semi-structured interviews as my key method for producing the data I needed to answer my research questions.

Rich situated description of the phenomenon, the participant, and the conditions in which these are located is critical for qualitative analysis to be trustworthy (Smith et al, 2013; Denzin, 2001). These considerations are discussed in more detail below and in Chapter Four in relation to what I did in this study to address research rigor.
3.2.6 The role of the interpretive researcher: responsibilities and challenges

Critical to the trustworthy nature of interpretive research is the dynamic and reflexive role of the interpretive researcher in the interview and analysis process (Carter & Little, 2007). Building rapport, empathy, and trust are critical phases in this process and need to be underpinned by what Lather (2006) describes as a position of ‘constitutive unknowingness’ and Erickson as ‘humility’ (2010).

The rigorous use and management of self in interpretive inquiry carries risks and responsibilities and presents what Larkin, Watts & Clifton (2006) describe as a ‘dilemma of reflexivity’ (p.107). The qualitative researcher requires mature levels of critical self-awareness, empathy and sensitivity in order to manage this complex set of interactions such that experience can naturally and authentically emerge (Larkin et al, 2006; Conroy, 2003). Disciplined reflexivity is also required in order to manage the productive tension between influencing and being influenced by the data as part of the hermeneutic circle (Conroy, 2003), as outlined above.

Management of self and the interpretive research relationship with the participant thus requires ongoing ethical consideration throughout the research process (Conroy, 2003). Key mechanisms for supporting these challenges in this research included regular academic supervision, reflexive note taking, and the constant review and reworking of the analysis to ensure its integrity and trustworthiness. The concept of trustworthiness, as a measure of research integrity and rigor will be elaborated upon in the following chapter on Study Design in Section 4.2.8. Further ethical considerations will also be discussed in more detail in the following chapter.

A central consideration of this research has been to explore participants’ experience within the individualised funding and service system, guided by the research questions regarding tensions and risks as well as mechanisms influencing the experience of choice and self-determination. Linking individual experience to systemic issues was thus a core part of this research however this relationship was not necessarily easily or naturally identified by participants themselves. It was therefore important to look at what the personal narratives were collectively saying about systemic and structural issues. This analytic process required the use of hermeneutics, as explained in the section below.
3.2.7 The hermeneutic circle

The hermeneutic circle is central to interpretive research and refers to the interdependence between the part and the whole. The concept is premised on the interpretive belief that the whole can only be understood through its parts and its parts can only be understood through the whole, whether these be at a minute textual level or at the level of being in and understanding the world (Smith et al, 2013; Schwandt, 2007; Conroy, 2003). The interpretive researcher enters the hermeneutic circle in order to engage and understand the participant’s experience. Importantly and as has been stressed above, the concept implies the impossibility of study which is ‘interpretation free’ (Denzin, 2001).

I engaged in the hermeneutic process across many dimensions of interaction throughout this research. This included during the recruitment process, interview phase, and later in working with and between the transcribed texts, policy analysis and other data sets. Such ‘hermeneutic-dialecticism’ has been described by Guba & Lincoln (1989) as a core assumption of constructivism and explained as a ‘comparing and contrasting’ meanings given by different groups about a ‘particular phenomenon’ in order to understand it. Following this, this interpretive research has required data gathering and analytic methods which could intercept and engage across different groups to better understand multiple experiences and meanings.

This epistemological positioning differentiates itself from essentialist and descriptive phenomenology such as that of Edmund Husserl which requires a more rigid bracketing of the researcher’s experience and prejudgements in order to isolate and understand a phenomenon devoid of context (Smith, 2006; Denzin, 2001). Instead, the interpretive approach in this research uses the researcher’s self- knowledge and personal biography as part of the data and meaning making process (Layder, 2005; Van Manen, 1990).

The interpretive circle extends to a double hermeneutic as the researcher in the interview and then later in the analysis and communication of research findings seeks to ‘make sense of the participant trying to make sense of what is happening to them’ (Smith et al, 2013, p3; Schwandt, 2007). The double hermeneutic was originally described by Giddens (1984) and acknowledges the influence of the researcher’s
interpretations in the participants’ world at all stages of the research process (Denzin, 2001).

The interpretive and hermeneutic frameworks for this study were not aligned with the more formulaic theory formation offered by Grounded Theory approaches (see Glaser and Strauss, 1967; Strauss & Corbin, 1994) although this would have been a reasonable approach given different research questions and aims. Rather, and particularly in addressing research question 2, my interest has been in progressing understanding of how people intimately construct the experience of rights at an everyday level, how these constructions are influenced by external forces, and how these constructions equate with the ISP policy promises. Thus, the analysis sought themes regarding meaningful behaviour and action grounded in the social experience of human rights and individualised funding, as understood and acted upon by participants in the research.

3.3 Summary

In this chapter I have linked the research questions and aims, drawn from the earlier literature review and described an internally consistent approach which is methodologically aligned in terms of ontology, epistemology and data collection methods. The research is located in an interpretive paradigm guided by a constructionist epistemology and sits firmly within a contemporary disability studies framework. The exploration of meaningful behaviour and action is at the heart of this research and implies the need to explore the views of different stakeholders involved with the receipt or delivery of ISPs and the related service framework. By demonstrating the links between ontology, epistemology and method I have presented an argument for adopting semi-structured interviews as the primary research tool in this interpretive inquiry. In the following chapter, I outline the study design and methodology in detail.
Chapter Four

The Study Design and Methods

4.1 Introduction

This chapter sets out the study design in detail and discusses the methodological procedures in terms of what was planned and what actually transpired. The reality and challenges of conducting research with people with disabilities introduced a number of hurdles which required adaptations. Formal ethics procedures and considerations regarding the rigor of the study are discussed toward the end of the chapter.

4.2 Methods – planned and actual

This study adopts an interpretive methodology to engage with the lived human rights experience of people with disabilities and their family carers in the context of Victoria’s individualised funding system. I used in depth semi structured interviews as the key method for understanding how participants experienced and realised choice, autonomy, self-determination, dignity and independence in different and diverse lives. Since individualised funding is the product of the social action of many parties, these interviews with service users and carers were supplemented by semi-structured interviews with those delivering services in different roles across the disability service system. Interviewing these different groups offered the multi-perspective account required to understand individual experience within the broader funding and service structure. This design offered the data required to: explore how actors sought to promote, protect and ensure human rights (Research question 1); explore tensions, risks and opportunities (Research question 2); and, to explore what mechanisms might
be used to address current shortfalls and risks in meeting the personalisation agenda (Research question 3).

The next section outlines the sample frame for each of the stakeholder groups and the ways in which the research tools sought to address each of the research questions in this study.

4.2.1 The participant sample

The sample frame is represented in Figure 4 below. The sample included people using funding and their family carers and three other groups representing key roles and functions in the broader framework. These included Chief Executive Officers and senior managers or co-ordinators of Disability Service Provider organisations and one resource agency (service providers); Individual Support Package planner/facilitators; and, disability support workers. These groups have been included based on their status as duty bearers and service providers in the ISP funding framework and pathway. These roles have been explained in Chapter One. How these roles are inhabited and executed can significantly expand or limit the opportunities and choices available to those they are serving. The values, assumptions, and practices brought to these roles have a significant bearing on the policy people with disabilities actually experience and the extent to which they are enabled to take up the potential opportunities within individualised funding and self-directed planning approaches. More will be said of the sampling strategy when exploring the methods.

Figure 4.1 The sample frame
4.2.2 Recruiting the primary participants – people with disabilities using an ISP
This sample was selected purposively and was not intended to be representative of the Victorian or Australian population of people with disabilities. Purposive sampling refers to the recruitment of participants based on their ability to offer data relevant to the research purpose and question (Patton, 1990). In other words, purposive sampling aims for homogeneity of certain characteristics in relation to the research questions. For this study and in the case of the primary participant group, it was the common experience of being an adult (18 and above) with a significant disability and being in receipt of a Victorian ISP which formed the key inclusion criteria. People fitting this category but who could not speak for themselves and who did not have formal or informal representation or support to assist with communication were excluded from participation due to the impracticalities this would pose. It is acknowledged this exclusion may be a limitation of this research as it excludes people who already have reduced voice.

My initial aim was to interview 12 people with disabilities who were using ISP packages with equal representation of the three different funding administration options (i.e. held by the disability service provider, held by MOIRA (the state financial intermediary), or direct payments), of metropolitan, regional and rural regions, and of physical and cognitive disability categories. However I was ultimately only able to recruit 11 funds
holders and there was not the even representation across different categories as I had initially aimed for. Although the research design did not aim at community representation, the research questions meant it was important that the sample contained diversity across the following characteristics and this was achieved although not as evenly as originally intended:

- gender;
- disability type – primary diagnosis of physical or cognitive impairment;
- ISP funding arrangement as outlined in Chapter One i.e. direct payment; provider administered; independent funding administrator; or, combination of these;
- geographic spread across DHS regions – metropolitan, rural, regional

The recruitment strategy depended heavily on the cooperation of Melbourne and regional Victorian disability service providers to assist in recruiting participants from their client data bases by distributing the research information and invitation to participate. This seemed an effective and expedient way of accessing people with an ISP living in the community covering regional, metropolitan and rural DHS regions. I approached more than 10 service providers with sites in metropolitan and regional Victoria during the first six months of 2011 based on either prior knowledge of their service and/ or recommendations from the disability services community regarding those providers likely to be interested in the research and its questions.

I approached large multi-site and multi service organisations offering a range of residential, work training, group based and individualised services as well as smaller more boutique services which had either transitioned from a traditional service structure to individualised only services, or which had been established to deliver only individualised services and programs.

I first approached services by phone to introduce myself and the research. If they were interested I then arranged to meet with the relevant senior manager and also emailed the Plain Language Statements designed for managers (Appendix E) and ISP
participants (Appendices A) in addition to the Easy Language version for ISP holders (Appendix B). Informed consent forms were also forwarded (see Appendix C).

I was granted initial meetings with seven managers. At these meetings, I outlined again my research project and sample criteria and asked the provider to distribute the information to the people they supported via case managers and other avenues such as internal newsletters and staff meetings. I also asked managers to consider whether they would be interviewed for this project.

Although all managers were interested and enthusiastic about co-operating, only some of the agencies actively sought and recruited participants on my behalf. I realised in retrospect that the senior managers I interviewed were not in daily contact with the case management staff who were in direct contact with potential participants. Although interested, it became apparent that many of the agencies I approached were either too busy to help recruit or perhaps took on a gatekeeping role and did not distribute my research information as broadly as I had hoped.

I have since reflected that it might have been more effective to request to speak with a middle level staff member in direct contact with the people using the service. It should also be noted here that the nature of individualised funding means that people are not as likely to physically present at the provider agency, unless they have remained in a group, but are instead in the community thus making it more difficult to access them for research purposes.

Providers sent information about my research and invitation to participate to people using their service who met the inclusion criteria. This included Plain Language and Easy Language versions (see Appendices A and B). Interested people then contacted me by phone or email to further discuss the aims of the research and what participation would involve. If still interested, I then emailed, mailed or faxed them the informed consent form to read before the interview (Appendix C). Interviews were arranged at a venue of the participant’s preference.
Ultimately 11 participants with disabilities were recruited from three agencies, two in metropolitan Melbourne and one in regional Victoria. This selection of services did not offer the broader geographic scope I was seeking resulting in fewer participants being recruited from rural areas than I had hoped and no participants from remote areas. There were also more females than males. This reduced the opportunity to examine issues for people and services in diverse contexts as well as identify potential gender differences. Table 4.1 shows characteristics of the sample group of participants with disabilities using an ISP.

<table>
<thead>
<tr>
<th>Participants</th>
<th>Gender</th>
<th>Age</th>
<th>Social and economic context</th>
<th>Primary self ascribed Disability</th>
<th>Funding administration</th>
<th>Package Amount and use</th>
<th>Region</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jill</td>
<td>F</td>
<td>52</td>
<td>Living alone in own home</td>
<td>Physical – spinal injury, incomplete paraplegia</td>
<td>Provider administered</td>
<td>$7500 ISP Community access; travel, domestic help</td>
<td>Metro N/W</td>
</tr>
<tr>
<td>Val</td>
<td>F</td>
<td>53</td>
<td>Living in respite care while waiting for place in a Community Residential Unit (CRU) Husband and daughter live separately</td>
<td>Physical, Multiple Sclerosis (MS)</td>
<td>MOIRA/Financial intermediary</td>
<td>$ ISP Not available at time of interview Community access; personal care; travel; physio; case management; counselling</td>
<td>Metro S</td>
</tr>
<tr>
<td>Kate</td>
<td>F</td>
<td>32</td>
<td>Living in a CRU. Family supports: mother</td>
<td>Physical/ Cognitive Cerebral Palsy (CP)</td>
<td>Provider administered</td>
<td>$ ISP Not available at time of interview 2 days day program; community access</td>
<td>Metro S/E</td>
</tr>
<tr>
<td>Name</td>
<td>Gender</td>
<td>Age</td>
<td>Living Situation</td>
<td>Disability</td>
<td>Support Type</td>
<td>Funding</td>
<td>Location</td>
</tr>
<tr>
<td>--------</td>
<td>--------</td>
<td>------</td>
<td>------------------</td>
<td>------------</td>
<td>--------------</td>
<td>---------</td>
<td>----------</td>
</tr>
<tr>
<td>Jess</td>
<td>F</td>
<td>Late 40s</td>
<td>Living alone in own home</td>
<td>Physical, MS</td>
<td>Provider administered</td>
<td>$ ISP Not available at time of interview</td>
<td>Metro S/E</td>
</tr>
<tr>
<td>Candice</td>
<td>F</td>
<td>48</td>
<td>Living in own home with 2 sons</td>
<td>Physical, MS</td>
<td>Direct Payments</td>
<td>$45,000 ISP Personal care, domestic help, some community access</td>
<td>Regional</td>
</tr>
<tr>
<td>Bill (married to Loris)</td>
<td>M</td>
<td>60s</td>
<td>Living at home with wife, Loris. Self-employed, part time.</td>
<td>ABI and complex physical impairments</td>
<td>Provider administered</td>
<td>$ ISP not available at time of interview</td>
<td>Metro S</td>
</tr>
<tr>
<td>Loris (married to Bill)</td>
<td>F</td>
<td>50s</td>
<td>Living at home with husband Bill. Supports Bill in his part time work</td>
<td>Cognitive/Physical</td>
<td>Provider administered</td>
<td>$ ISP not available at time of interview</td>
<td>Metro E</td>
</tr>
<tr>
<td>Therese</td>
<td>M</td>
<td>20</td>
<td>Living at home with mother Works part time at her DSP Deferred Arts degree</td>
<td>Physical CP</td>
<td>Provider administered</td>
<td>$38,000 ISP Personal care; emergency funding</td>
<td>Regional</td>
</tr>
<tr>
<td>Simon</td>
<td>M</td>
<td>Late 20s</td>
<td>Lives with mother, step father and siblings. Unemployed Studying part time at TAFE Waiting for place in new disability</td>
<td>Physical CP</td>
<td>Direct Payments</td>
<td>$72,000 ISP community access support aids, equipment and personal health products; Respite;</td>
<td>Metro E</td>
</tr>
</tbody>
</table>
The size of the sample of people with disabilities (n=11) is consistent with the literature regarding detailed interpretive analysis where interpretive detail and depth within and across cases is required rather than analytic breadth (Smith et al, 2013). Smith et al (2013) in discussing their approach to Interpretive Phenomenological Analysis (IPA), argue against a positivist mindset to sample size and the assumption that higher numbers indicate ‘better work’ (p.52). Instead, they argue that the number of participants should never be so great as to compromise the time, reflection and quality required of an interpretive phenomenological approach.

I have adapted elements of the IPA approach developed by Smith et al (2013) to conduct detailed analysis of the data and argue that, in conjunction with the further 16 participants drawn from other stakeholder groups, my overall sample size of 27 participants is adequate for the scope and intent of this research. More is said of rigour in the research design later in this chapter. I will also explain in more detail why and
how I adapted the IPA approach to suit the needs of the data and the parameters of this study in Section 4.4.

Details regarding the sampling strategy and characteristics of the remaining four participant groups are outlined below.

### 4.2.3 Family Carers
Family carers were included in the study on the basis that they were closely involved with the management of the primary participant’s ISP and their day to day supports. It was also based on the informed consent of the ISP holder i.e. the family member. Five family carers were interviewed as part of the interview with the primary participant. The participation of the family carer was established prior to the interview being conducted via telephone and assurance by the family carer that their family member wished them to be part of the interview. I checked this consent again when I met the participants at the interview.

Four family carers were parents and one was the sister of a man who had died one month before the interview. This family carer wanted to participate on the basis that she felt it was important to share her and her brother’s experience of individualised funding.

The characteristics of the five family carers (using pseudonyms) are represented in Table 4.2 below.

<table>
<thead>
<tr>
<th>Participants</th>
<th>Relative</th>
<th>Relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Andrew</td>
<td>Bess</td>
<td>Father</td>
</tr>
<tr>
<td>Dolores</td>
<td>Simon</td>
<td>Mother</td>
</tr>
<tr>
<td>Shirley</td>
<td>Kate</td>
<td>Mother</td>
</tr>
<tr>
<td>Sally</td>
<td>Therese</td>
<td>Mother</td>
</tr>
<tr>
<td>Nancy (also included in table 4.1)</td>
<td>Shane (deceased)</td>
<td>Sister</td>
</tr>
</tbody>
</table>
4.2.4 Disability Support Workers
I had initially hoped to run a focus group with support workers working with ISP package holders who were not participating in the study. This design aimed to capture views from a range of support workers across DHS regions who, I felt, may speak more openly if they knew I was not also interviewing one of their service users. However it soon became apparent, through discussions with agency staff, that given their working schedules, it would be difficult to draw together such a group. I also did not have the means to reimburse support workers for their time to participate in a focus group.

I therefore decided to interview support staff working with the study participants, if the person being supported gave consent. I only managed to recruit two support workers on this basis, given the logistics of daily shifts and timing of interviews. As with family carers, I was particular about checking for the consent of the person using the ISP before beginning the interview and in both cases it was clear that the support worker's participation was approved of and welcomed.

<table>
<thead>
<tr>
<th>Participants</th>
<th>Providing services to</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mandy</td>
<td>Bess and Andrew</td>
</tr>
<tr>
<td>Carol</td>
<td>Bill and Loris</td>
</tr>
</tbody>
</table>

4.2.5 Providers – CEOs, senior managers, and co-ordinators from disability service providers
CEOs and senior managers were invited to participate on the basis of their interest and experience in providing services to people using individualised funding.
Recommendations were sought from contacts within the disability sector. An information form specifically for providers was designed and distributed (see Appendix E). See Table 4.4 below for details regarding these participants.
4.2.6 ISP planner/facilitators

I recruited two ISP planner/facilitators through contacts I had established in the early round of recruitment phone calls and meetings. Both planners worked for service providers not represented in the senior manager category. The planners were given a research information outline and invitation and a telephone conversation was held to explain the research and determine their interest. Interviews were then arranged and conducted at their workplace. See Table 4.4 for details regarding these participants.

Table 4.4 Sample of Service providers (CEOs, Senior Managers, Co-ordinators) and ISP planners

<table>
<thead>
<tr>
<th>PARTICIPANT ROLE</th>
<th>SERVICE CHARACTERISTICS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Planner/facilitator A</td>
<td>Provider A</td>
</tr>
<tr>
<td>• Located in national multi-site organisation providing social services to different groups of people experiencing disadvantage. Disability services include supported accommodation, day programs, pre vocational and work training, respite care, and, ISP facilitation and planning.</td>
<td></td>
</tr>
<tr>
<td>• Metropolitan</td>
<td></td>
</tr>
<tr>
<td>Planner/facilitator B</td>
<td>Provider B</td>
</tr>
<tr>
<td>• An independent service providing service and support co-ordination, planning and facilitation, housing support and finance administration. Negotiates with on behalf of the person with care and service providers. The service does not employ or provide support worker staff.</td>
<td></td>
</tr>
<tr>
<td>• Metropolitan</td>
<td></td>
</tr>
<tr>
<td>Senior Manager 1</td>
<td>Provider C</td>
</tr>
<tr>
<td>• Personalised community based support for people with an intellectual disability including education and training in literacy and numeracy and a transition program for young adults.</td>
<td></td>
</tr>
<tr>
<td>• Large volunteer base to supplement paid hours</td>
<td></td>
</tr>
<tr>
<td>• Service is transitioning from a centred based service to a personalised model.</td>
<td></td>
</tr>
<tr>
<td>• Metropolitan</td>
<td></td>
</tr>
<tr>
<td>CEO 1</td>
<td>Provider D</td>
</tr>
<tr>
<td>• Large service providing residential and day services and individualised programs.</td>
<td></td>
</tr>
<tr>
<td>• Day programs are community based with an inclusion focus.</td>
<td></td>
</tr>
<tr>
<td>• Metropolitan</td>
<td></td>
</tr>
<tr>
<td>CEO 2 Senior Co-ordinator 2</td>
<td>Provider E</td>
</tr>
<tr>
<td>• A small community advisory, training and resource organisation</td>
<td></td>
</tr>
<tr>
<td>• Promotes ‘typical’ pathways in the community</td>
<td></td>
</tr>
<tr>
<td>• Metropolitan</td>
<td></td>
</tr>
<tr>
<td>CEO 3</td>
<td>Provider F</td>
</tr>
<tr>
<td>• Direct Support</td>
<td></td>
</tr>
<tr>
<td>• Service Coordination</td>
<td></td>
</tr>
<tr>
<td>• Person Centred Planning</td>
<td></td>
</tr>
<tr>
<td>• Regional</td>
<td></td>
</tr>
</tbody>
</table>
4.2.7  Focus and form of the semi-structured interviews
Semi structured interviews were the primary method of entering into and engaging with participants' subjective experience. Semi structured interviews allow for a conversation which, although guided by topic questions and the overall research aim, inductively follows the interests of the participant (Perakyla & Ruusuvuori, 2011). I was conscious of allowing the interview to guide rather than dictate the encounter and thus saw it as vehicle for delving and opening in contrast to a more structured interview approach which would seek instead to contain discussion to specific topics (Smith & Osborne, 2003; Layder, 2008).

Thus and in keeping with the emergent nature of this research, the original topic questions for each of the participant groups were starting points designed in the anticipation that they would be iteratively modified as interviews progressed, new lines of enquiry emerged, and as redundant questions based on inaccurate assumptions were eliminated. See Appendix F for the interview outlines for ISP holders and family carers and Appendix G for service providers and ISP planners.

This approach helped to develop rapport with participants as well as manage the tensions between the emotional and cognitive work going on in the interpretive participant researcher relationship (Smith & Osborne, 2003; Denzin, 2001). Developing relationship whilst at the same time managing the research process and boundaries was a challenge I frequently reflected on during interviews and following in supervision and in my research diary.

The general question topics for each of the participant groups are outlined below. They were designed to address the research aims whilst allowing space for conversations to touch on relevant but unanticipated areas. As noted above, the emergent nature of this research resulted in the schedules changing over time and in response to new knowledge and themes which were being iteratively developed. For example, I modified my questions asking why participants had chosen individualised funding when it became apparent that for most participants getting an ISP had not been a real ‘choice’. Rather, their previous funding arrangement had been automatically rolled into an ISP.
Understanding this was an important finding and informed the development of new questions.

I also learnt following the first few interviews that people were often preoccupied by their struggles with the DHS bureaucracy in the application, funding approval and planning processes. The need to discuss these struggles sometimes dominated the interview and I had to manage the tension between allowing participants to effectively debrief in this way before moving on to their current experience of individualised funding and outcomes achieved. These struggles are detailed in Chapter Five but are important to mention here as these early findings influenced my understanding of the relationship between DHS and people seeking support funding and thus my line of inquiry in subsequent interviews and reading of the literature.

(i) **Question topics for people with a disability receiving an ISP and family carers**

The focus of these interviews was to explore participants’ perceptions and experience of choice and autonomy within the individualised funding and service framework. Related to this were questions about the resources, supports and processes which expanded or limited their capacity to choose and be self-determining. These questions related mainly to their experience of the ISP framework and the services they were using but I also encouraged discussion of the nature and location of social and structural enablers and barriers beyond these systems.

I was particularly interested in experiences aligned or in tension with the rights outlined in Article 3 of the CRPD and as they are represented in the ISP policy literature. In other words, when I asked people about their experience of individualised funding and support services and what had influenced this, I was listening for and following up on examples related to the principles of choice, autonomy, independence, respect, dignity and equity. In particular, I was listening for examples of where these rights had been promoted, realised (research aim 1), limited or even violated through relationships and practices within the funding and service provision context (research aims 2 and 3).
I did not ask explicit questions about human rights given the language and meaning of rights can be so multiple and potentially vague (Ife, 2010). I sensed that such an approach would be likely to produce more generic practiced responses rather than the natural and more revealing stories which unfolded when I asked about what people enjoyed and wanted from life and how these goals were enabled.

I also tailored the nature and complexity of the questions and the level of discussion to the capacity of the participant. This was important given some participants had cognitive and communication impairments and were communicating with the assistance of their parent carer and/or support worker. So for example, whilst it was appropriate with some participants to discuss, at their initiation, their awareness and understanding of the human rights framework or the CRPD in particular, with others it was not. Instead, I relied on their stories and the meanings they attached to these to understand how individualised funding impacted their experience of rights on an everyday basis.

**Question topics:**

- Contextual information about the ISP such as length of time the participant has held the ISP, how it is administered, its value, and previous support funding (if any) prior to the ISP. Questions were also asked about services the participant used and their experience of these.

- Reasons for choosing an ISP and/or hopes for the ISP (note that in many cases, an ISP was not a choice) (research questions 1 and 2)
  - Needs and goals: *What is important to you in your life on a day to day basis and in the longer term?*
  - Enablers: *What you do require to progress your everyday and longer term goals? How does your ISP help with this? How do the services you use help with this?*
• Previous funding and service experiences: How has your experience with the ISP compared with previous funding which was not portable, individualised, or flexible? This question explored social participation, autonomy and self-direction in relation to funding and service choices. (research questions 1, 2, and 3)

• Experiences of funding and service administration, assessment and planning: What was your experience of applying for and planning the package i.e. completing a Disability Support Registration application, waiting, interactions with DHS and services, ISP planners? (research questions 1 and 2)

(ii) Question topics - Service provider senior managers
The interview with service provider senior managers focused on the following topic areas:
• The degree to which the human rights promises of Victoria’s ISP policy framework are realised in the lives of people with disabilities, their families and the community. Examples from their experience of both positive and negative or neutral cases were elicited (research question 1).
• Providers’ understanding of implementing a rights based approach and the enablers and barriers to this (research question 1)
• Local innovations relating to individualised approaches and goals of social inclusion and participation, independence, and self-determination (research question 2)
• Hopes and reservations in relation to changing agency roles and shifting boundaries in the move to individualised approaches and the proposed NDIS. Tensions for providers and potential impacts on people with disabilities and the broader community (research question 2)
• Organisational processes and broader systemic issues supporting or obstructing successful implementation of individualised approaches e.g. recruitment, workforce availability, staff working conditions (research questions 2 and 3)

(iii) Question topics - ISP planners/ facilitators
ISP planner/facilitators were interviewed in relation to the following broad topic areas:

- Potential and observed impact of individualised funding processes on people’s capacity to exercise, take up key human rights such as choice, dignity, independence and autonomy (research question 1).
- Description, experiences and views about the ISP planner/facilitator role in relation to individualised funding and the scope of their responsibilities with clients/users (research question 2 and 3)
- Factors enabling and limiting this capacity from the individual, organisational, community and policy perspectives (research questions 2 and 3)

4.2.8 Learning through the Recruitment Process

Although the recruitment process was difficult and extended beyond expected timelines, the initial conversations I had with service managers and the hurdles I encountered in establishing a sample offered significant early insights into funding and implementation issues troubling the ISP framework. This early ‘data’ offered insight into the diversity within the disability sector and the range of provider experiences and perspectives in the transition toward individualised funding and toward the proposed NDIS (initially introduced under the different name of ‘disability care Australia’ in July 2013). These insights into providers’ concerns and hopes as well as knowledge gaps challenged some of my initial assumptions about the program and developed my thinking about participant interviews and what I needed to explore to answer the research questions.

One of these assumptions was that people with a disability or their representative actively chose to have an ISP based on a desire for more choice, control and portability of funding. Whilst this may have been the case for many soon after the introduction of ISPS in 2008, the idea of choice was far less apparent by early 2012. Instead, providers and staff described how existing support funding was being automatically ‘rolled over’ and ‘rebadged’ into an ISP often without people being actively aware of the change. This was confirmed later by participants. Participants’ level of understanding of the change
to their funding, clarity of information and explanation provided, and understanding of implications for choice varied significantly among the participant group.

It also became apparent during the recruitment phase that ISP funding had been reined in, with spending in some regions limited to critical support needs at the expense of supports and activities linked to social participation. Provider staff also described increased waiting times on the Disability Support Register, (DSR). These issues have been revealed in reports such as the Victorian Auditor General’s Report (2011) and had already informed my thinking however having these realities confirmed in the field emphasised the importance of exploring them further. It also confirmed the importance of spending preparatory time in the field and becoming familiar with the context, as discussed in the qualitative research literature (Creswell, 2007).

I also learnt that it was very difficult to find people with ‘new’ packages to interview. I had originally hoped to recruit people who had been allocated their ISP within the previous six months and to reinterview again after nine months. However, I discovered that very few service providers were supporting people with new ISPs despite the fact that, officially, 360 new ISPs had been offered in the 2011/2012 financial year (VAGO, 2011). I extended the criteria to one year but even this proved too difficult and so, given the time constraints of this research, I abandoned any time criteria regarding how long the person had had their package. This in turn led me to alter my inclusion criteria and study design based on two interviews and focus instead on one interview with the possibility of a second interview later should the data analysis suggest and require it. This has not been required.

The above insights, gleaned through the recruitment process revealed the gap between what was explicitly and implicitly represented in the DHS literature at the time and what was occurring during this time of transition.

These early meetings and phone calls also highlighted the need to include interviews with ISP planner/facilitators in the study. My informal conversations with several planner/facilitators when I was recruiting ISP holders showed that people in these roles
were managing much of the tension and difficulty inherent in the transition toward individualised funding, managing people’s expectations and hopes whilst also working within an often constrained fiscal, policy, and organisational environment. Their role at the intersection of policy, funding, planning, and community required that I include their experience and perspectives in this research.

4.3 Conducting interviews

I organised the location and time of the interview based on participants’ preferences as long as it was deemed safe for all parties and accessible for the participant. Considerations of privacy, mobility issues, comfort, ease and minimal disruption for participants were important. In all but one case, participants in the ISP holder group (i.e. people with disabilities and their carers) chose to be interviewed in their home.

Home was also an ideal location from a research perspective in two key ways. Participants appeared at ease in their own home where they were emotionally and physically comfortable and thus the interview conversation appeared to flow more naturally. These conditions promoted the interpretive goal of understanding the person in context and allowed me to observe their everyday living environment, their level of comfort or otherwise, the accommodations that families had or and had not made for their adult child or that participants had or had not made for themselves. Conducting the interviews at home also meant that in the interviews involving support workers and family carers, I could observe first hand and in situ the dynamics of these relationships.

One participant chose to have her interview at her service provider’s office.

The interviews with managers and ISP planners all took place at their work.

4.3.1 Observations and field notes

I documented observation notes as soon after the interview as possible in order to record my impressions whilst still fresh. These notes recorded the following: my first impressions regarding the interview including areas for change in future interviews; descriptions of the physical setting; the mood (tense, easy, connected, happy, flat) and
nature of the relationships if it was a joint interview (supportive, conflicted, harmonious, creative); new lines of inquiry to pursue; and, issues which were unclear to me and needed following up and/or further reading. These field notes have proved invaluable in the analysis phase in that they refreshed me and returned me to the intangible, descriptive and emotional elements of the interview which I may have forgotten in the following analysis phase.

4.3.2 Informed consent and Confidentiality
A Plain Language Statement, including an Easy Language version, and a consent form (Appendices A, B, C) were sent to the participants in the ISP holder group prior to interview either by myself if the participant had contacted me with their address details or through the disability service provider who had assisted in recruitment, with the offer of clarification by telephone prior to the face to face meeting. This information was then further explained in person to check for understanding and willingness prior to signing of the consent form and beginning the interview.

Monitoring ongoing informed consent and capacity to participate as well as initial consent is important in emergent research with people with disabilities (Ramcharan & Sutcliffe, 2002). Sensitivity to participants’ well-being was an ongoing ethical concern in this study and to address this I checked for not only consent and willingness to participate but also understanding at key points during the interviews (Ramcharan, 2006).

Participants were reassured of their right to pause the interview, or withdraw at any time during the interview or study, without fear of prejudice or reprisal, if they chose or became uncomfortable or distressed. The potential for the interview to raise disturbing and upsetting memories was always present given the nature of some of the topics being discussed. Although several participants did become upset as they recalled certain experiences, these instances were manageable within the context of the interview. It was also clear that recounting these experiences, usually regarding interactions with the funding system, was important to the person. I made sure at all times that the person was comfortable and wanted to continue. I was also conscious of
the need to check participants’ physical comfort during the 60 or 90 minutes of interview time.

Where people could not communicate independently, their supporter spoke for them and I used visual prompts where appropriate. While speaking through a supporter potentially filters the interaction and communication between researcher and participant, it was important, where possible, to include people with significant communication impairments in this research so as to canvass the experience of those limited in speaking for themselves.

Interviewing participants together with their family carers had the added benefit of offering some insight into their interactions however I was also aware of the potential for risk and conflict of interest. These are discussed in more detail in the following section, in addition to measures I put in place to ensure as far as possible authentic representation.

4.3.3 Co-interviewing and shared experience – strengths and risks
In total, there were 27 participants across the four groups and 17 interviews. These were both individual and group interviews with the configurations of the group interviews for the participants with disability, family carers, and support workers detailed below:

- 4 interviews with ISP holder and their family carer
- 1 interview with married couple and their support worker
- 1 interview with ISP holder, family carer and support worker

As mentioned earlier, there was also an interview with a family carer whose brother had died not long before the interview.

In the four interviews where the interview included the parent carer, three required the parent carer to speak on behalf of their son or daughter to different degrees. In two of these the person with disability could not speak for themselves, in one the person could speak to a limited degree and in the fourth, the person conducted most of the interview.
independently with their parent in the room but only participating to clarify something or when I actively questioned them.

Co-interviewing offered a significant opportunity for experiencing and observing in a naturalistic way the texture and quality of interaction and communication in these relationships. People with communication impairment rely on others to support their communication and these others are predominantly family carers. Decision making around every day and more significant choices is thus usually a negotiated process between people. Joint interviews allowed me to intercept this dynamic and observe how choices are reflected upon and made, how ideas get communicated, how things get done, about their everyday practices, about how meaning is made. It allowed a glimpse into their shared reality in its convergence and in its tensions, particularly between competing needs and interests such as decisions about respite care or adult children moving from the family home into supported group accommodation when there is ambivalence on the part of the person.

Thus, observing interactions between parents and their adult children or between the triad of support worker, parent and person with disability offered much that independent, separate interviews might not. For example, a support worker or parent carer interviewed independently from the person she or he is supporting may ascribe to a range of human rights ideals which they may not enact in their everyday practice with the person.

At the same time, I was highly mindful of the risks of co-interviewing in the three cases where the family carer was speaking on behalf of their family member whilst also participating in the interview in their own right. A key risk was the potential for the carer’s views to dominate the interview at the cost of those of the ISP holder in a way which would not occur with an independent interpreter. During the interviews I sought to address this by checking with the person that their parent’s reflections accurately represented their experience however, due to their communication difficulties, this was not always fully effective. It has subsequently been important during analysis and repeated listening to the audio recording to tease out the boundaries between the different voices, representations and meanings whilst also respecting the overlap and convergence between the two.
I was also aware during the interviews and subsequent listening to the audio recordings of the competing tensions the family carer often managed, between their needs and those of other family members and those of the person for whom they were caring. These competing needs clearly had implications for how the ISP was used. Representing these tensions in the analysis was an important element of the research, as will be shown in the findings chapters (Chapters Five, Six, Seven).

The interview process described above ultimately offered rich benefits in terms of naturally intercepting and observing everyday relationships, in understanding interdependence and tensions, and how choice making can be mediated within and between family and support roles. However, co-interviewing in this way also risks a type of filtering of voice and experience.

4.3.4 Confidentiality, Recording, Data storage

With participants’ signed consent, all interviews were audio recorded using an unobtrusive Live Scribe pen which also allowed me to jot down notes and return to these notes with audio as required. However, as it transpired, I took very few notes during the interview as it tended to interrupt engagement and rapport with the participant and unnecessarily highlighted my researcher role.

I transcribed the audio recordings verbatim both manually and using Dragon Speaking Naturally voice recognition software. The latter was convenient at times but I found manually transcribing the audio allowed a greater immersion in the life of the interview and the conversation, taking me back to the place and time.

The recordings and transcripts were stored in a secure password protected computer at RMIT University. The paper copies of the transcripts and field notes have also been stored in the same secure facility. The data will be destroyed in five years from the end of the research. Documents will be shredded and soft data deleted from my personal and university drives in five years’ time as per the National Statement on Ethical Conduct in Human Research (National Statement, 2007).

To ensure anonymity to participants and organisations, all data has been de-identified using new identifiers to distinguish the transcripts. This thesis has and future
publications from this research will use pseudonyms and care has been taken to
disguise identity by association.

4.3.5 Formal ethics procedures
This research was approved by the RMIT Human Research Ethics Committee in
December 2011.

Research involving people has the potential to be intrusive and ethically contentious
(Cheek, 2010; Kellehear, 1996). This is even more so when working with people with
disabilities, a group known to be marginalised and disadvantaged (WHO, 2011) and
which is classified in the National Statement (2007) as a vulnerable group requiring
specific ethical considerations. There is a broad body of literature examining ethical
research with people with disabilities (see for example Goodley, 2011; Barnes and
Mercer, 2010; Ramcharan, 2006) acknowledging key tensions and risks.

My practice in this research has been informed by overarching research values of
respect, research merit, justice and beneficence, as outlined in the National Statement
2007, as well as interpretive principles such as reflexivity and reciprocity between the
research and participant, and self-critical awareness (Erickson, 2010). These values
and principles seek to manage the potentially uneven power relations which can exist
between the researcher and the researched or what Erikson describes as ‘researcher
privilege’ (2010). These principles have informed all aspects of the research process
including my interpersonal relations with participants, managing and confidentially
storing the data, and through the processes of analysis, interpretation and publication.

As argued in Chapter Two there was a strong emphasis on employing a research
method that minimised participants’ discomfort and inconvenience, reflected human
rights principles of dignity and respect and which, politically, through its findings would
maximise the benefits for people with disability. I feel the potential benefits of this
research outweigh its risks and that by adopting the approaches I have any potential
risks have been minimised.
4.4 Analysing the data

I began analysing the transcribed interview data and field notes using NVivo software for preliminary open coding. However I did not continue with this approach as it seemed in tension with the idiographic analysis I was attempting. I found the ease with which I could create new nodes, and the text fragmentation this encouraged, challenged my intent to understand in depth and in detail each participant’s narrative in its own right, particularly in the early analysis phase. Coding for themes took me laterally across the transcript and experience whereas what I needed to do was delve, in the first instance, ‘vertically’ into each transcript. Extracting parts, i.e. passages and quotes, detracted from understanding the whole and thus disrupted, for me, the hermeneutic circle described earlier. I felt important aspects of the individual experience and the links and meanings within were being lost. I have, however, since reflected that if I had been more experienced in using NVivo, I may have been more proficient in bending the software to my needs and purposes rather than being driven by the ease with which it allowed me to ‘chop up’ the data.

My dissatisfaction with this form of thematic coding led to further reading and a search for an approach which would more closely match my analytic aims and desire to delve more deeply into each participant’s narrative and experience as well as investigate themes and divergence across the sample. I adopted the analytic approach used in Interpretive Phenomenological Analysis (IPA) (Smith et al, 2013) as it offered these mechanisms and was more aligned with the demands of the study questions and goals. IPA usefully provided a systematic and idiographic approach to understanding and coding the meaning exemplified in the data, beginning with immersion in each individual transcript and descriptive coding before moving to develop major overarching themes for each transcript. The IPA approach offered a structured and interpretive approach which allowed for a progressive development of major themes within each transcript before then looking for shared and divergent themes across the body of transcripts (Larkin et al, 2006). This process helped link individual experiences of choice and self-determination with the collective experience and then in relation to the broader social and policy context. The analyses of the data from different groups
were then compared to identify policy and practice implications. This approach was used for the interviews with participants using ISPs and their family carers and supports workers. I used a similar but modified form of thematic analysis for the interviews with disability service providers and ISP planners.

While offering a systematic structure for analysis, IPA is not intended to be prescriptive but instead provides flexible guidelines which the researcher can adapt to suit their research objectives (Smith & Eatough, 2006). This was important as I proceeded with the analysis and adapted the process slightly to accommodate the larger than usual (for an IPA study) sample size and the project’s time parameters. Whilst I used the method’s process for analysis, as outlined below in Section 4.4.1, I did not pursue individual themes as deeply as I might have with a smaller sample of, for example, four or five. My process could be described as a meeting point between an idiographic and a thematic analysis, drawing on the best features of both to provide a systematic and detailed account of participants’ diverse contexts and experience. The adapted IPA approach allowed me to both categorise and explain the data as well as show the importance of understanding divergence and implications of this. As will be shown in the analysis of ISP holders’ and family carers’ experience in Chapter Five, unearthing diversity of experience prompted the second tier of analysis from a capabilities perspective and led to the concept of conversion as an important explanatory mechanism.

There is little in the personalisation and human rights literature which examines the subjective experience from an interpretive perspective despite the need for greater insight and understanding of the everyday experience of choice and self-determination in the context of individualised funding. The analytic approach used allowed for a bottom up or maybe more appropriately ‘inside out’ perspective of choice and autonomy within this funding program.

It should be noted that voice and representation are not the same and that my role as an interpretive researcher has not been to represent views verbatim but rather to interpret meaning in what people have told me. Whilst the person is the expert of their lives, I as the researcher have taken on the responsibility of the interpretative and analytic work. The ultimate research findings and argument will reflect participant
voices offered at a point in time, but will not be their voices and does not aim to be (Larkin et al, 2006). This double hermeneutic, as discussed above, produces unique research outcomes and findings, outcomes which could be different if conducted by a different researcher with a different history, purpose and lens and in a different historical context. However, the rigor of such research can be tested through a thorough description of the research design including, importantly, the analytic process.

I describe below the analytic process I used, drawing from the IPA framework (Larkin et al, 2006). After this I offer a worked example to demonstrate the process. In Section 4.2.8, I describe the criteria and strategies I employed to demonstrate methodological coherence, the plausibility of the interpretations, and the trustworthiness of the interpretive claims within the context of the study design and approach (Tracy, 2010; Yardley, 2000; Lincoln & Guba, 1985).

4.4.1 The Analytic Process

1. The first phase was descriptive refamiliarisation with the data whereby I read through each transcript many times to understood it in its own right. This phase was part of a scaffolding approach to theme development. During this first phase I looked initially for that which was of interest as well as that which related to the research question. These initial notes cut across a range of categories including descriptive, linguistic and conceptual (Smith et al, 2013). In my analysis, I looked particularly for anything the participant said relating to human rights principles of choice, autonomy, independence, respect, autonomy, dignity, equality (CRPD Art.3) or regarding individualised funding processes, as well as general themes relating to needs and aspirations. I began with the first interview I conducted, which was on reflection quite ‘thin’ so then followed Smith et al’s (2013) advice and moved next to one of the more complex and ‘thick’ or rich interviews. This first stage was about re-entering the participant’s reality and provided the first level of analysis from which future ultimate themes were developed. These initial first stage notes were written in the left hand column of the transcript.
2. The next step involved rereading each transcript to consolidate and cluster the initial notes into more descriptive, slightly higher level interpretations to form emergent themes for each transcript. These emergent themes were labelled and noted in the right hand column as single words or phrases or even questions to summarise the theme. This stage was more analytical and drew upon my interpretive capacity to make links and draw connections within the text. In this phase I worked hermeneutically within the transcripts, developing understanding by moving between the part and whole of the transcript. The emergent themes were linked to relevant sections and quotes.

3. The third stage of analysis conceptually clustered the emergent themes into overarching analytic categories, again for each transcript. The research aims and questions guided the development of these themes.

4. The fourth phase was to construct a table of the overarching themes for each transcript showing the emergent themes contributing to each of these and including supporting quotes from the transcript. An example of this process within the one transcript is shown in Table 4.5 below. This example shows how the clustered themes in one participant's transcript contributed to the overarching theme of Disabling Processes/Constraints to choice and control and contributed to similar themes in other transcripts to produce the superordinate or major theme of Relationships, Processes, and Systems.

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Table 4.5 Example of theme development for one transcript (Candice)

<table>
<thead>
<tr>
<th>Superordinate</th>
<th>Overarching</th>
<th>Emergent</th>
<th>Original Transcript</th>
</tr>
</thead>
<tbody>
<tr>
<td>R= researcher</td>
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| Relationships, processes, systems | Disabling processes/Constraints to choice and control | 1. Lack of information and explanation about how ISP can be used is a barrier to choice and optimising funding potential | R: When did you get your first disability funding?  
C: 2002 Home First.  
R: And it changed to ISP?  
C: Changed it to something else, they put it all together and then I think they took it apart again. I lost track.  
R: Did you say you wanted individualised funding?  
C: No, I didn’t even know about it until I actually rang. |
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<tr>
<td></td>
<td>- Inadequate and inaccessible information</td>
<td></td>
<td>C: A lot of people don’t know that the ISPs are about or anything. I hadn’t been told about the ISP.</td>
</tr>
<tr>
<td></td>
<td>Lack of understanding in new funding and service context</td>
<td>2. Anxiety and being unsure about how to use funding stops people using ISP in new and meaningful ways</td>
<td>C: A lot of people still don’t know that they can change things. They are a bit scared.</td>
</tr>
</tbody>
</table>
|  |  | 3. Have to fight for choice, feels as though there are few options | R: Do you use any hours to take you out to do things in the community.  
C: No, I have only just learnt that I can do that.  
C: So has been this huge learning curve for me. And to try and find out things has been quite difficult.  
C: I am learning I have more choice; no one has bothered to sell it as being a level of choice. I don’t feel as though I have any choices. The ones I have I have had to push for. |
|  | Effort and work involved in getting choice and control | 4. Approval and funding processes do not flex to fit changing needs, reduces person’s autonomy in funding use, is a barrier to | R: Did you know you could ask for a review?  
C: No, I have learnt all sorts of things. It has been a really steep learning curve….the more I am aware it’s like wow!  
C: They get put off [ISP holders re opting for Direct Payments option]  
C: … I say no to things, just too hard.  
R: But if you can use your hours for that? [swimming]  
C: Yes, I would do things. I would love to get back in the pool again.  
R: You could book a carer for an hour and a half.  
C: Yeah, I hadn’t really thought about that. I would be great, getting fit again. In response to idea that funding could be used |
5. Once each transcript was analysed using the above process, I then looked for patterns across the transcripts to reveal commonality of experience as well as interesting divergences which would then work together to illuminate the topic. A master table was then developed of the group’s superordinate or major themes including supporting emergent themes (Appendix H).

Smith et al (2013), in keeping with IPA’s ‘idiographic commitment’ (p. 100) encourage researchers to try to bracket learnings from the first transcript analysis in their work with subsequent transcripts. However, I found this difficult as my thinking and understanding were changed by each transcript analysis and rather than bracketing what I had learnt, I instead used it to interrogate potential themes in the next. Working
iteratively in this way was a form of constant comparison within and across the texts, similar to that used in Grounded Theory Method (see Glaser & Strauss, 1967, 1978)

4.4.2 The Second Tier of Analysis
After the initial analysis, my findings reflected arguments advanced by both proponents of individualised funding in its current form and of those cautioning against risks and unthoughtful implementation. For example, experiences and outcomes were unevenly distributed with some benefitting substantially whilst others experienced more minimal improvements in their level of choice and control and general circumstances.

Simply replicating these findings with some minor new contribution would not contribute to new knowledge or significantly meet my research aims. I needed a further level of analysis to make sense of the data and particularly the inconsistencies and inequities I had revealed. I needed a conceptual framework which might explain the shared as well as the diverse and sometimes contradictory experiences. In particular I was looking for concepts that were less to do with individual circumstances and more to do with a social relational understanding of disability, taking into account the interplay between the personal and the socio cultural and environmental context which shaped participants’ experience of choice and self-determination.

A subsequent review of the literature led me to explore the potential significance of the capabilities approach in helping me develop a more nuanced understanding of the mixed findings. In Chapter Two I introduced the capabilities approach, its origins, and its synergies with human rights and contemporary disability theory. I decided retrospectively following the first phase of analyse to use it to extend this study’s original human rights frame as a more comprehensive way of understanding the complex forces shaping choice and self-determination. I discuss the relevance of a capabilities based understanding of human rights and its particular application to this study in more detail in Chapter Eight.

By re-analysing the data from a capabilities based perspective and its central concept of conversion, I was able to explore, in a fresh way, the dynamic relationship between resources, processes, context and outcomes and identify what I term in the discussion
chapter of this thesis as ‘conversion factors’. These factors are effectively the mechanisms, relationships, and processes which carry the variables of both freedom and of constraint, of success and of failure. The details of the re-analysis of the data and the implications for policy and practice are explored in detail in the discussion chapter. The discussion of conversion factors and the conclusions drawn about it from my data constitute one of the central contributions to knowledge of this thesis.

4.4.3 Trustworthiness and Rigor

The validity and rigor measures by which conventional positivist research is tested have been discarded by most qualitative researchers as inappropriate for the assessment of trustworthiness, value or usefulness of qualitative research studies (Tracy, 2010; Shenton, 2004). When Lather (2006) asserts that ‘validity is far more that a technical issue solved via correct procedures’ (p.52) she is referring to the need to establish beyond such concrete measures more flexible and plural, yet also reliable, criteria for sound qualitative research.

Trustworthiness here refers to the recognition that the research is thorough and is worth paying attention to, worthy of basing changes to practice, behaviours or policy on (Tracy, 2010; Lincoln and Guba, 1985). Although some qualitative researchers have attempted to maintain the language of the positivist paradigm, others have argued for a redefinition of what rigor means for qualitative research (Shenton, 2004). Others have questioned the ability of any universal predetermined criteria to assess qualitative studies given the diversity of paradigmatic aims and approaches and the arguable absence of uniform qualitative research designs (Rolfe, 2006).

However there is a need in this research to demonstrate rigor in terms which can be generally accepted so that the study will be seen as credible and trustworthy, and thus useful in influencing policy and practice. Tracy (2010) confirms the importance of quality criteria as a pedagogical tool in guiding learning and practice and leading to excellence. She also argues that universal criteria and a ‘common language of excellence for qualitative research’ allow for research to be more effectively accepted and
communicated to more diverse audiences, including the influential and those not familiar or at ease with qualitative inquiry (p.849).

Clear criteria are also important to protect participants against potential risks in qualitative research. Erickson (2010) and others note the importance but also the challenges of doing good and respectful qualitative social research, of maintaining the balance between interpretation and propaganda (Goodley, 2011) or research which is overly self-referential in nature (Creswell, 2007). Or, the balance between affirming human dignity by honestly telling the ‘truth’ about meaning making in people’s lives (Erickson, 2010, p.113) and simply exploiting different groups of people in the interests of academic curiosity and career advancement (Oliver, 1992).

To demonstrate trustworthiness and rigor in this project I have referred to several models including Lincoln & Guba’s 1985 model of rigor, Yardley’s (2000) four point model and also incorporate, where relevant, Tracy’s eight ‘big tent’ criteria for qualitative research (2010). Tracy’s framework clearly overlaps but also in some criteria extends and enriches those of Lincoln & Guba and Yardley. These combined criteria, discussed in the section below, help establish on what basis readers can trust the interpretations and claims made by the researcher. The criteria rework positivist measures to accommodate the different ontological and epistemological underpinnings of qualitative inquiry and have been particularly helpful to me during this research.

I now demonstrate how key criteria for trustworthiness and rigor have been established in this study.

**Credibility**
Generating complex and rich data and exploring a phenomenon from multiple perspectives is a key way of addressing credibility. Thick description of context across levels is an important criterion for credible qualitative research. Thick rather than thin description locates this study in time and place and is important for readers to assess the relevance of findings for their own context (Tracy, 2010; Shenton, 2004). Policy analysis contributes significantly to explaining and describing the Victorian, Australian, and international policy and legislative framework in which this study occurs. Spending
many months visiting and speaking with agencies and individuals in the disability services sector and becoming familiar with the nature and culture of the individualised funding platform has also been important in developing thick description and establishing the credibility of this research (Shenton, 2004). Further, the research has also documented rich description of individual participants’ context and makes extensive use of quotations from the data to support emerging themes and demonstrate how interpretive claims have been informed by the data.

Further documented mechanisms for credibility have included regular supervision with my two RMIT supervisors and maintenance of a reflective journal recording memos, impressions, emerging questions and themes, challenges, and limitations. I have also kept notes documenting my decision making through the research process, including changes consistent with its emergent design, such as the decision not to proceed with focus groups and adjustments to the interview schedule as my learning developed and the need to interrogate certain areas of inquiry became apparent. These decisions and reflections have been discussed above.

Triangulation is another important method for achieving credibility and is a key criterion of rigor and trustworthiness (Tracy, 2010; Yardley, 2000). Triangulation can be achieved through exploring experiences of the same phenomenon from the perspective of different groups (i.e. data sources), through methodological diversity, by using more than one researcher, and/or the use of multiple theoretical or analytic frameworks (Creswell, 2007; Patton, 1990). This study demonstrates both data source and methodological triangulation in its inclusion of multiple participant groups and the use of semi structured interviews, policy analysis, and literature review and observation notes. In particular, interviewing different groups responsible for providing services, as duty bearers, as well as those using funding and services, as rights holders, has sought to understand the experience and intent of individualised funding policy from a range of perspectives, and to ensure ‘multivocality’.
Transferability and Resonance
This study addresses the two concepts of transferability and resonance by providing enough rich description regarding the study context, methodology, assumptions, and analysis, for readers to assess the usefulness of its claims in other contexts (Tracy, 2010; Lincoln & Guba, 1985). Providing thorough detail regarding the study design is also important should others wish to reproduce a study similar in some or all aspects. Interpretive research by its very nature about finding the universal in the particular as well as the particular in the universal (Larkin et al, 2006). If conducted and described well enough, the research should have a transferability, resonance and relevance across a variety of audiences emotionally, cognitively and theoretically (Smith et al, 2013; Tracy, 2010).

Dependability and Meaningful Coherence
To address issues of dependability and meaningful coherence, I have outlined in this and the previous chapter the paradigmatic assumptions underpinning this interpretive research and the methodological decisions stemming from these. I have also relied on my supervisors to examine the coherence between my questions, data collection methods, data archive, analysis and interpretive findings as a means of confirming methodological alignment and consistency of final claims.

Confirmability
To address confirmability I have demonstrated in the findings chapters the analytic process which links the original interview data with the major themes ultimately explicated. The interpretive analytic process I used, adopted from IPA methodology, offers a systematic framework for demonstrating such development. Also important to the concept of confirmability is to demonstrate self-reflexivity regarding the influence of personal bias in decision making during all phases of the research (Shenton, 2004; Miles & Huberman, 1994). Supervision has assisted in this process as has documentation of these sessions, my thoughts and impressions and key reasons for pursuing particular courses of action during the research. In keeping with the interpretive tradition, I have also striven to embed a high level of reflexivity in the writing of results, discussion and conclusion chapters.
4.5 Limitations

The limitations of this research project are outlined below.

- Service providers operating as gatekeepers in my recruitment strategy had the potential to skew the sample toward those with 'positive' stories who were eager to participate in research of this nature. However, as it eventuated, even when people had positive stories to tell, they were also keen to share the problems and limitations they had experienced.

- The sample does not offer a proportionate number of participants with intellectual disability in relation to the Victorian population. The difficulties I had in recruiting participants within the timeframe meant that I could not wait until the sample was more balanced.

- There were no rural and remote representatives due to recruitment difficulties.

- Participants were not drawn from as wide a spread of service providers or DHS regions as I had hoped. All participants were drawn from three agencies across two DHS regions. This was due to difficulties finding a larger and more diverse group of service providers able to assist in recruiting ISP holders.

- Introduction of a capabilities perspective at the analysis stage may be seen as a limitation given this conceptual framework did not inform the original design.

Having now set the theoretical, empirical and methodological context, the following three chapters present the findings.
Chapter Five

Better but not good enough: the experience of people with disabilities and family carers using individualised funding

5.1 Introduction

This and the following two chapters will present the findings of this study, detailing the experience of people using individualised funding, of their supporters, and of service providers. The analysis of participants’ experience, including data from the family carers involved, is from a rights and capabilities perspective as described in Chapter Four. During the analysis I sought to identify how formal programmatic and service resources, systems, and processes interacted with informal, personal and social resources to enable or constrain real opportunities for choice, self- direction, and social inclusion.

The analysis explored participants’ experiences in terms of impacts and outcomes of the ISP funding and service framework, given their expectations and the nature of resources and opportunities actually available to them. Understanding the relationship between aspirations, access to and use of available resources, and outcomes, relates to research questions 2 and 3 regarding tensions, risks, and opportunities, and the mechanisms used to address identified shortfalls and risks.

In distinguishing between these two domains i.e. what was achieved and what participants had the freedom and real choice to achieve, I sought to identify the enablers and constraints to the experience of choice, self-determination, and social inclusion as identified in research question 2.

What were the conditions and relationships which enabled or constrained self-determination and the lifestyles designed by participants for themselves rather than by
others? This relates to research questions 1 and 2 and the promotion, protection and ensuring of human rights. This analysis also distinguishes between meaningful self-direction not just in day to day service decisions but also and importantly in relation to significant lifestyle decisions such as where and with whom participants lived, how their days were organised, and with whom they associated. Related to this is the analysis of what constitutes real ‘choice’ and flexibility, particularly in a context of limited resources and opportunities.

This first findings chapter will focus on outcomes and impacts of engagement with the individualised funding and services framework, the second findings chapter on the perspectives of service providers, and the third will present a more detailed analysis of the factors expanding or restricting the potential of participants’ resources and their capacity to access and convert this potential in self-determining and meaningful ways.

This analysis uses a capabilities perspective, as outlined in Chapter Two, to better understand the meaning of people’s choices and achievements in light of the effective and real rather than notional opportunities to which they had reasonable access and which then contributed to what they had the freedom to do and be. As will be discussed in Chapter Eight, stepping back to interrogate the actual rather than rhetorical relationship between resources and outcomes within the ISP framework, and participants’ experience of rights therein is central to understanding how the potential of self-directed funding and service approaches is activated. This analysis will show how the interplay between factors across personal, social, institutional and environmental levels impacted on processes of choice and self-determination in everyday living as well as on costs and risks.

An interpretive analysis, adapted from the IPA approach described by Smith, Flowers & Larkin (2013) produced three superordinate or major themes, within which clustered themes naturally fell and in which the data can be best understood. These themes are linked and interdependent, form the basis of the findings chapters, and are listed below:

- **OUTCOMES/IMPACTS**: refers to positive and adverse outcomes identified by participants using individualised funding, including benefits and risks associated with being an ISP holder and family carer.
• RELATIONSHIPS, PROCESSES AND RESOURCES: refers to the influence on choice and self-determination of the formal and informal resources available to participants and the mechanisms, processes and relationships through which these were provided and accessed. The extent to which participants were able to activate the potential of these resources was influenced by both the distinct characteristics of the resources and the conditions in which they were available. This category also refers to the relationship and interplay between different types of resources and how these expanded or constrained choice and self-determination e.g. the relationship between formal support funding and family carer energy and time.

• CONTEXT: this has emerged as a cross cutting theme which refers to the socio-cultural and environmental conditions which influenced outcomes related to choice, self-determination, inclusion and other rights.

Not all data has been presented but rather, only those themes which illuminate the primary research question: To what extent and how do individualised funding programs protect and promote the rights of people with disabilities?

In three of the joint interviews, the parent or support worker was speaking for or assisting their family member or service user to communicate with the researcher. The family carers and support workers were also participating in the interviews in their own right.

Systematic analysis of the interviews with individuals holding ISPs, their family carers and support workers demonstrated a diverse, contingent, and uneven spread of impacts, benefits, risks, and costs. The analysis also revealed uneven capacities to engage and benefit from the self-directed framework given its informational, coordination, planning and choice making demands. It was found that positive outcomes consistently favoured those whose personal and social resources, related abilities, knowledge and experience equipped them to navigate and benefit within this choice based model. Those without these resources found it more difficult to benefit within this system.
The following section presents analysis of the data which yielded categories relating to the positive and negative impacts and outcomes participants experienced.

5.2 Impacts and Outcomes

The analysis of the data showed both positive and negative impacts, benefits and risks, and the transaction costs and trade-offs associated with transitioning to and using individualised funding. Transaction costs describes those potential or actual costs associated with the ISP model whilst trade-offs are those decisions which may have been categorised as ‘choices’ but which were in fact a compromise produced by significantly inadequate funding, service, or community options. Section 5.1.1 details the key positive outcomes reported by individuals and their family carers. These are on a spectrum relating to increased opportunities for independence and autonomy, social participation, and, respect and dignity. Section 5.1.2 shows adverse impacts, unexpected consequences, and the constrained outcomes produced when resources, supports and opportunities did not match participants’ expectations and goals. The following section, 5.1.3, extends upon these findings to detail the individualised nature of risk and the transaction costs experienced by individuals and family carers within the ISP program, given funding, service, and contextual limitations.

5.2.1 Positive Impacts, Outcomes and Benefits

Whilst the benefits and outcomes of individualised arrangements for individuals and family carers were interdependent, the findings have been organised into five categories for clarity. These are presented below and also summarised in Table 5.1.

(i) Self-direction and control

When conditions and relationships were such that participants were able to exert their preferences in everyday decisions they benefited from flexible funding and services arrangements. While there was great variance in the level of control and self-direction participants enjoyed, several exemplars demonstrated the benefits of greater control and innovation in how funding and services are used.
Importantly, the analysis showed that perceptions of self-direction and choice were largely related to what participants expected of their ISP and the alignment between their funding and service arrangements and their goals. The following three participant vignettes, although with very different levels of funding and support, demonstrate this principle.

Jade, a woman in her early 30’s with a mild cognitive impairment used her small but well targeted $10,000 ISP to live independently in social housing, a personal goal she had nursed for many years. Jade valued not being as reliant on her elderly parents for care, after years of feeling that she had imposed on them. She observed that, ‘I love that I have my own independence. I don’t have to say to mum I’m doing this or I’m doing that’.

Key to her independence was being able to employ the same workers each week, workers with whom she had developed strong relationships of trust over time. Although they only came for several hours each week, Jade decided how these hours would be used depending on her needs that week such as domestic, administrative, or community outings.

_I am so grateful for having the package, it helps my day to day living. And if I need more time I just ring up and say I need Kim for three hours and it comes out of my money._ Jade, ISP holder

The second example demonstrates how a comprehensive package of $72,000 put a young man and his mother more firmly in control of their lives. Simon, a man with complex physical impairments, had, under his previous block funded arrangement, been unhappily attending a day program for 10 years and was very limited in his capacity to participate in the broader community due to limited funding. However when allocated his ISP, Simon with the support of his mother, Dolores, converted his resources to support a community based lifestyle consistent with his interests and passions. This included regular day and evening outings with friends, TAFE maths and English study, authoring a memoir with the support of a paid worker, and tailored weekends away with friend and support staff. These weekends used funding which had previously been used for disability group camps which Simon had found restrictive.
Dolores emphasised the contrast between Simon’s and her own quality of life and choices with the ISP with their previous circumstances. She described how under his previous funding arrangement both she and Simon felt socially isolated with Simon ‘sitting at home all day with me’ when he wasn’t at his day program. In contrast, Simon’s life post ISP was defined by his interests and goals, as Dolores explained:

*If he sees something on TV, he tells me and we go. He gets to the footy, he’s a mad Richmond supporter so he goes regularly to that, he wants to go see Silverchair so we’re doing that. You need carers to do all this.* Dolores, family carer for Simon

In the third case study, Jess, a woman in her 40s with multiple sclerosis, was using her ISP to supplement her existing material and social assets to remain living in her own home and in her community, surrounded by and connected to family, friends, and familiar services. She used her funding for adaptions and equipment, travel, and support hours for personal and domestic care and community access. Her mother and friends remained heavily involved in supporting her.

As highlighted in these three examples, the flexibility and portability afforded by the ISP package, as well as its adequacy, was critical in promoting greater choice and the capacity to pursue meaningful goals. Equally important was that Jade, Simon and Jess were able to draw upon existing personal and social resources and supports to translate their funding and service arrangements into pathways toward activities and goals which gave their lives meaning. For example, Simon’s mother was instrumental in advocating for increased funding and then in working collaboratively with services to tailor his ISP resource to his needs such as converting group camp funds to personalised weekends away. In Jess’s example, her mother provided her evening meals six nights each week so that she could save her support hours for ‘fun things like shopping’ and staying connected with friends.

Also important were Simon and Jade’s level of clarity about their goals and how their funding contributed to achieving these. Jade was determined to maintain her independence in her new social housing arrangement and knew what she needed from her support services to ensure this. Simon was equally clear about his study and social
goals and his desire to pursue these in the mainstream community beyond disability
group programs.

For most participants, having choice in support staff was also critical in creating and
maintaining the meaningful opportunities and pathways they sought. Participants
consistently emphasised the importance of being able to select particular staff, including
different staff for different purposes and activities. Factors taken into consideration
included the quality of the existing relationship and mutual understandings, workers’
experience, skills, attributes, interests and, sometimes, gender. These and the following
examples highlight the relational rather than transactional underpinnings of many of
the positive service interactions participants described:

• single mother Candice particularly wanted male workers who could offer a male
  role model and presence for her sons
• Val preferred to go to galleries and movies with support workers with similar
  cultural and artistic interests with whom she could share the experience
• Simon employed a regular support worker with good literacy skills to help him
  write his memoirs, but others for supporting him when he went to the pub or to
  play cards
• Kate chose support workers interested in art to accompany her to art classes
• Bill, with highly complex and specialised care needs required workers who were
  familiar and skilled in his needs whom he could trust not to hurt or distress him,
  as had happened with contract agency staff who did not know him
• many female participants preferred female workers for personal care

A key benefit of having more choice and control was the capacity to ensure continuity of
service and within this the capacity to build relationships with support staff. A major
theme running through the data regarded the value participants placed on the
emotional and social support provided by support staff, including case managers and
staff in planning positions. Relationships developed over time and offered benefits well
beyond practical care and support. These benefits are exemplified when Jade describes
how trust in her workers and their understanding of her needs and context were critical
in managing the challenges of living independently and contributed to her sense of well-being, safety, and social connection:

*I've had Kim, for two years. I said to her, if you leave this place I will kill you. I have two support workers, Kim and Holly, and they’re both fantastic. They can read me now, they know when I’m not coping with things.* Jade, ISP holder

Similarly, most participants described one or more of their support workers as *a friend*. One participant, Jess, was the exception to this when she pointed out that she did not require either a friend like relationship or continuity with her support workers however did stress the importance of the ongoing relationship she had formed with a planner in her service.

**(ii)** Social participation, spontaneity and relationships

The data also revealed the importance of flexible use of the ISP and services to support opportunities for social participation, both spontaneous and planned. Enough funding to support reasonable levels of social participation, in line with personal interests and preferences, was a critical and determining factor in participants’ satisfaction with their ISP. For example, Shane’s package included enough funding for social activities, football club memberships, travel, and recreation, Bess’ package factored in support required for holidays, and Simon’s package included enough support and travel funding to maintain the social relationships and activities which he valued, including in the evenings and on weekends.

Participants expected their funding to extend beyond their home based personal care needs and enable the lives they envisaged for themselves in the community. This necessarily involved unplanned and spontaneous as well as structured activities. For example, Val described a key expectation as having the ability to ‘go where I want, when I want’.

Importantly however, adequate funding for social, cultural and economic participation didn’t simply involve the practical supports required to pursue these such as support hours, travel, and other costs. It also required time, funding, and opportunities for what one service provider described as the ‘linking and thinking’ work required to enable participation and greater autonomy. This involved taking the time to work with the
person to understand their preferences and to think more deeply and creatively about how to respond to these priorities in more inclusive and community based ways. Related to this was the importance of staff attitudes and willingness to do this planning and linking work as well as possession of related attributes, skills and knowledge. Having more choice and control over staff continuity built relationships and trust and provided a basis for this bridging work which was both person centred and community focused.

These relationships, informed by mutual understandings, were critical to supporting the emergent and dynamic work of choice and self-determination on a day to day basis. For example, support worker Mandy’s long and trusting association with Bess and her family over a period of eight years provided a strong basis for providing proactive and tailored practical supports as well as emotional support to both Andrew, her father, and Bess. As an example, at the time of the interview Mandy was planning the itinerary and making arrangements to travel with Bess (as her support staff) to Sydney for a holiday. Andrew had left these arrangements to Mandy.

Despite the critical importance of this linking and bridging work, the findings revealed a lack of acknowledgement in the assessment phase and subsequent lack of resourcing for the time and energy this work involved. As a result, the extra load of this work was often absorbed by family carers, friends and services. This finding regarding cost shifting to services and informal supports is further explored in the section detailing negative outcomes.

(iii) Independence
Outcomes associated with independence ranged from everyday acts of autonomous decision making and activity to long term achievements associated with being supported to leave the family home or being able to return or stay at home. Funding and services were used for modifications and support services or to purchase a place in supported accommodation.

Participants emphasised the relationship between being supported to live independently in a home of their choice and their sense of dignity, emotional wellbeing, and health. Being supported to live at home was also important in maintaining valued
social networks. For example, Nancy, primary carer for her brother Shane, described how his $70,000 package had enabled her to care for him at home as opposed to him being placed in a nursing home. This had allowed brother and sister to stay together in the home they had shared prior to his Acquired Brain Injury (ABI), close to family friends and the support and opportunities this network offered. Nancy stressed the importance of keeping life as ‘normal’ as possible for both of them and emphasised the relationship between being at home and Shane’s health:

_I doubt whether they [his friends] would have visited him if he was there [in the nursing home]. It was vital for him to be home. I say it all the time but he would have died straight away if he was in a nursing home._ Nancy, Family carer

Similarly, Andrew, Bess’s elderly father, emphasised the importance of ISP funding in keeping Bess at home and the family together. He observed that without Bess’s package and the network of care providers the package paid for, he would not have been able to support her living at home:

_Without [service provider’s] help and the carers I wouldn’t be able to manage Bess. I would have to put her into a home, you know a CRU._ Andrew, family carer

Participants also had the choice during the period of this study to increase control over their funding by taking up the Direct Payment option. This option paid funds to a bank account in the fund holder’s name, allowing them to manage and spend the funds more flexibly and with greater administrative control and independence. Interestingly however, only two participants (Nancy and Candice) took this option despite control and independence being important aspirations for all participants. Reasons offered for not taking up the Direct Payments option included perceptions of the time and administrative burden this would entail and related perceptions that they lacked the financial skills to take on the responsibility.

However both Nancy and Candice noted that taking up the Direct Payment option had not been difficult. A key benefit for them was what they described as reduced interference from DHS and increased control with service providers. Nancy for example believed that Direct Payments gave her more control over every day spending and
staffing decisions, important considerations for her given the complexity of Shane’s needs. For Nancy, the goal of keeping life ‘as normal as possible’ was critical and meant keeping government and services several steps removed from their everyday decision making.

(iv) **Dignity and respect**
The analysis showed that across the participant group increased choice created dignity and relational benefits. This aspect of choice manifested in a number of ways. In particular, participants described the right to choose how they were supported and by whom as central to their sense of dignity and self-determination. Flexible and portable funding contributed to this as did personalised and responsive services which could quickly and effectively respond to changing circumstances and preferences.

Being able to influence continuity of support staff was important to those participants who valued the opportunity to develop longer term relationships with services and individual workers. Related to this was the multi-dimensional role of support staff, providing not just ‘a pair of hands’ but also social connection and emotional support as well as sometimes support in service co-ordination and different forms of informal advocacy related to medical, legal, and funding matters.

The following quote exemplifies participants’ general expectations regarding the right to choose based on workers’ personal and social attributes and the dignity benefits flowing from this:

> And I want to choose who I go with, I want to go with people who are interested in that. I don’t want to go to horror movies because that is what they [the support worker] want. Val, ISP holder

Family carers also valued the dignity and relationship benefits of longer term support relationships and the emotional and social as well as practical benefits of working with support staff who understood both the person’s and the family's collective needs. In these examples, the data showed a highly co-operative and collaborative dynamic whereby trusted long term support staff used their initiative, based on experience of the person and care for them, to promote conditions for greater self-determination.
For example, after working with the family for eight years, Mandy, Bess’s support worker, was alert to Andrew’s needs as well as those of his daughter and had become an important emotional resource, supporting and sharing decision making with him about Bess’ day to day care and activities. So much so that if Mandy was unavailable for a shift, Andrew would sometimes save the community access component to be used at a later time. These hours contributed to a bank of saved hours which would be used for extra outings or holidays.

The social connections and friendships formed through service provision often lasted beyond the working relationship. For example, Val described how she sometimes socialised with previous workers and stayed connected through phone calls and exchanging birthday cards, saying: ‘I have people who aren’t with the agencies any more who ring up and say let’s go out.’

Working with familiar staff also reduced the indignity of poor or insensitive care from staff who, due to lack of understanding, training, and/or skill, failed to meet the person’s needs. For example, Dolores described her son’s experience with a new worker who was unprepared for his practical or social needs. In relaying the story, Dolores emphasises the risks of transactional service approaches and the corollary importance of relational approaches in which understanding the person is core to the service:

_They sent us out a gentleman who I didn’t realise at the time... had never even pushed a wheelchair. It was his first day on the job so I found out later he shook (she laughs). So I had to go out and shove him in the car and send them to the pub. Simon said he [the worker] got him two drinks and said nothing to him all night. We never saw the bloke again and I wasn’t impressed with that agency and I don’t think we ever used them again. At least the one we are with, they know us and we don’t get people sent out that you don’t know._ Dolores, parent carer

The data highlighted both overlap and tensions between the needs and well-being of the ISP holder and their family carer and how greater individual choice and control in service decisions had positive flow on implications for family carers. The following presents findings which expand on this theme.
Benefits for family carers

The findings repeatedly confirmed the interdependent nature of individual and family carer well-being and the role of flexible funding and services in supporting and strengthening these relationships. Family carers identified the benefits of flexible funding coupled with services which could sensitively accommodate carer as well as individual needs. Continuity and familiarity with the more nuanced workings of family relationships was shown to be critical in more holistic approaches.

For example, Bess’ support worker Mandy, showed that she understood and cared about Bess’ father Andrew's needs for respite and social support, integrating awareness of his needs as important considerations in her work with the family:

Because he [Andrew] needs respite too. He likes going to the local, to the pub. He likes seeing his mates and watching the footy. That’s really important. And even when I take Bess out every second Saturday Andrew goes up for a bet. It’s his time.

Mandy, support worker

As reflected above, being able to access services in the evenings and weekends, not only offered funds holders greater choice but allowed also family carers more flexibility in structuring respite time, outside of normal working hours.

Related to their need for respite, family carers also identified the importance of funding being adequate and flexible enough to allow a more reasonable balance between their carer roles and other family and social relationships. Dolores for example described how Simon’s increased independence, because of his ‘mega’ package, had significant benefits for the whole family, allowing them more time together as well as the opportunity for her to return to part time work.

In another example, adequate and flexible funding helped maintain a family carer’s social networks whilst managing her new caring role. Nancy and her brother shared the same friendship groups and because his package allowed him to return home, rather than remain in a nursing home, they could both maintain these friendships more easily, as she describes below:
We would be over there having dinner, we would have dinner parties and he would come along. He's not just my brother's friends, but they're my friends as well.

Nancy, family carer

The positive impacts and outcomes identified in the data have been summarised in Table 5.1 below and include increased choice and flexibility in decisions regarding social participation activities such as study, recreation, developing and maintaining social relationships, and volunteer work. Reduced dependence on family carers and friends for support was a related benefit of adequate funding and flexible services. Increased dignity gained through increased control was also identified as a result of decreased reliance on others to offer unpaid care. The table includes supporting examples and quotes. Importantly, the definition of positive outcome here is an alignment between what the participant’s goals, his/her expectations of what his/her ISP and services could support, and the reality of what could be achieved with their package, given their circumstances and other available supports and resources.
### Table 5.1 Positive outcomes for people with disabilities and their family carers using individualised funding and services

<table>
<thead>
<tr>
<th>Outcomes in line with expectations/ goals</th>
<th>Funding and service enablers</th>
<th>Examples from the text and quotes</th>
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</thead>
<tbody>
<tr>
<td>Independence and Autonomy</td>
<td>Adequate funding for individualised supports for critical, personal and domestic support, equipment and aids, travel funding for taxis and mileage.</td>
<td>'[If not for the ISP] I would be lost, I wouldn’t be here, I would still be at home.' Jade, ISP holder</td>
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<td>'I don’t go to town on it (taxis). I don’t go for joy rides around town in taxis. But to be able to get to and from appointments to be able to meet up with friends and that would only be once a month.' Val, ISP holder</td>
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<td></td>
<td>Choice and control in when and who provides the service, fitting in with personal daily rhythms and preferences</td>
<td>'If I do have issues, I just say no, I don’t think so. I can refuse and I am sure that they can refuse.' Val, ISP recipient</td>
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<td>'I was very strict. I didn’t accept, I didn’t even try to... near enough wasn’t good enough. If someone didn’t want to be here I didn’t want them in my house. I just rang and said sorry they’re not going to work out’ Nancy, family carer, DP user</td>
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<tr>
<td>Independence from funding bureaucracy 'interference' and disability services system</td>
<td>Enough funding to substitute formal for informal care</td>
<td>'I had emergency funding for carers to come and it felt great to be more independent. ...it’s hard to explain but I was paying for people to come in. It wasn’t that they were doing me a favour to look after me, like my mum. It was their job.' Therese, ISP holder</td>
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<td>'I love that I have my own independence. I don’t have to say to mum I’m doing this or I’m doing that’. Therese, ISP holder</td>
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<td></td>
<td>Direct Payments : 2 participants used DP and believed it offered more control over their funding</td>
<td>'We just wanted to live our lives as normal as possible and the less phone calls and people you have to bother to spend your own money, that seems more normal to me than sending off money to notify people that you just bought petrol or for his wheelchair car.' Nancy, family carer</td>
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<td>Social Participation and Relationships</td>
<td>It's easier. I find it's easier to manage where things are going and you know what's going on.' Candice, ISP holder</td>
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<tr>
<td>More spontaneous and regular participation in chosen activities</td>
<td>‘...then Kane [support worker] comes from 12.30 to 5.30 and they do different stuff then go out and have lunch and come back about 5.30 then another carer comes and gets him and takes him out to play poker at the local pub and gets home about 11pm.’ Dolores, family carer</td>
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<td>Flexible, responsive service providers, able to work at different times of day and evening.</td>
<td>‘And every second Saturday...Bess loves the football, and I might take her up to Leon’s and we have a bite to eat and watch the football. Claudia has taken her to Annie and Moonshadow.’ Mandy, Support worker</td>
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<td></td>
<td>‘He might just go away with one support worker and do his own thing for the weekend.’ Dolores, family carer</td>
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<td>Effective and reliable case management/co-ordination support</td>
<td>‘So a good CM is very important, very important. This one is very good, very on top of it.’ Dolores, family carer</td>
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<td>Banking, converting support work hours for different purpose.</td>
<td>‘We have a bank of hours. So we used some of that for Point Lonsdale [a weekend away].’ Andrew, family carer</td>
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<td>Sometimes if something happens I can use it differently, can say not this Friday but next Friday do double. Jill, ISP holder</td>
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<td>Funding which extends beyond basic personal care needs. Funding which is aligned with broader lifestyle goals and which recognises the time, planning and co-ordination required to achieve these: e.g. funding for taxis and mileage to overcome multiple public transport access barriers; for holidays, sports memberships, cinema passes, adequate support hours</td>
<td>Just that capacity to do that...normal...without the ability to go to a movie, the gallery, football, a café, whatever, I would feel that there were very limited options and life is uncomfortable enough as it is. Val, ISP holder</td>
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<tr>
<td>Flexible, responsive and organised service providers who prioritise the individual’s needs.</td>
<td>‘...I knew them and I was happy with them and he’s been involved with X through day placement for years, he’s been going on camps</td>
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Preferred workers who enrich social experiences, who can work proactively and who are interested in being with the person.

' preferred staff who wanted to be here.' Nancy, Family carer

'Yes and the perfect thing is that Bess likes going away with me and the other carer Claudia, she feels safe with us.' Mandy, Support worker

'Yes. They have been very good to me. I see a number of carers now who aren’t with me for various reasons.' Val, ISP holder

Choice to maintain and build continuous relationships with preferred staff leading to reciprocity and mutual regard in formal relationships.

'I know the carers love coming out with me on community access and that is why I try to get the carers who have been very loyal to me I like to take them out and give them a change and give them free movies or pay to go to lunch.' Val, ISP holder

'They treat us like individual people...’ Loris, ISP holder

Family Outcomes

• Respite, more time for work, leisure and other relationships
• Emotional support
• Able to support family member at home
• Shared care and responsibility
• Flexibility and independence

Individualised supports
Respite care
Camps
Day program
Family and friends like relationships with support workers

'He [support worker] can stay for the weekend while we go away and he takes him on camps. He is really good he is my lifesaver.' Dolores, family carer

'I find it’s easier [Direct Payments] to manage where things are going and you know what is going on. The less paperwork and the less people I have to deal with the better.' Nancy, family carer

'Without Service X’s help and the carers I wouldn’t be able to manage Bess. I would have to put her in a home, you know, a CRU.' Andrew, family carer

Dignity and Respect

• Dignity of choice as part of self-determination
• Developing long term relationships with support staff
• Shared and mutual concerns, shared problem solving
• Reciprocity
• Trust and safety
• Social connection

Dignity and respect as part of self-determination

for years. That is the only place that would take him out on camp....’ Dolores, family carer
5.2.2 Adverse impacts, risks and costs
The above analysis has presented the findings related to the benefits and positive impacts of individualised funding arrangements when supported by adequate funding levels which are aligned to lifestyle goals, person centred and flexible service approaches, and in the context of meaningful opportunities and choice. However the findings also pointed to the inconsistent and graded nature of such experiences and outcomes. Benefits were not evenly spread or available to all. There was inequity and inconsistency in resources, processes and approaches with the funding and service system shown to be limited in how it responded to and supported diverse needs and circumstances.

The following presents the findings showing adverse impacts and risks and the transaction costs of engagement in the ISP framework. The findings highlighted a range of constraints and barriers to self-direction and autonomy embedded within the funding and service framework. These barriers existed in the manifest impact of particular features and conditions as well as in the absence of enabling factors. These constraints are presented below and relate to: inadequate, inconsistent, and delayed funding; needs and deficit rather than goals and strengths based assessment and planning processes; lack of adequate time, resourcing and support for service brokerage and co-ordination, case management and planning; inconsistent service approaches lacking in innovation and person led focus; insufficient advocacy presence; and, limited access to tailored non-disability based and inclusive community services and opportunities.

These findings show participants’ experience of the ISP program as contingent and diverse, with risks and costs as well as benefits highly individualised within this system. In showing the importance of existing personal and social resources in optimising the potential of ISP funding, these findings also underline the equity risks for those with weak personal and social resources who are least able to navigate and negotiate within this system.

(i) Inadequacy
Inadequacy was a recurring theme, relating mainly to inadequate levels of support funding but also in relation to other resources such as accessible and affordable community based services and social networks and connections. In relation to funding levels, four of the participant group found their ISP to be significantly inadequate to
support what they believed were reasonable needs and aspirations regarding social inclusion and autonomy. These participants variously described their funding levels as ‘bare minimum’, as offering ‘very few choices’ and as not aligning with what they required for the better, more ordinary lives they envisaged. Their support funding focused primarily on their practical and personal support needs and failed to adequately support the level of social and community engagement they required. Their packages also failed to offer the level of independence they sought from family carers on a day to day basis.

Lack of adequate support funding meant that some participants, such as Kate and Therese, felt they did not have real choice regarding what they did each day, how they did it, when, with whom or where. These circumstances frustrated participants and contributed to their isolation from the mainstream. For example, Kate had no choice but to attend her day program at least three days a week due to inadequate funding for the five days of the individualised support she would have preferred. Kate’s mother, Shirley, described her package as minimal and as ‘offering very little scope for choice, really’.

Similarly, Therese, a young woman with cerebral palsy had few friends and went out socially very little as her package did not include enough hours to pay for the support workers she would need to assist her:

I don’t really have friends. I would rather have a carer there (when going out) but again I don’t have funding for that. Therese, ISP holder

For participants with already weak or fragile social networks, reducing opportunities and supports for social participation reinforced and perpetuated their sense of marginalisation and difference as well as impacting their sense of dignity and autonomy. For example, Bill and Loris, the married couple in the study, described their distress at not being able to do things that a ‘normal’ couple or ‘grown ups’ would do, because of funding inadequacy:

And Bill was crying to me because he couldn’t take me out for a night, or a movie. And we have been trying to go away for a weekend and we can’t, we can’t…… We are not kids, we are adults. We need to be like everyone else. Loris, ISP holder
Inadequate funding levels also impacted family carers’ choices and freedoms by failing to provide the support and respite they needed to pursue and maintain their own interests and lives. This had placed strain on their personal relationships with partners and other family members.

As well as impacting personal well-being and social participation, inadequate funding also reduced access to health services which would have promoted independence through increased functioning. Several participants had been recommended allied health services, such as physiotherapy, and occupational and speech therapies, but could not afford them. Shirley, Kate’s mother, spoke of the irony of the ISP not funding the therapies her daughter needed and which would reduce dependency on others. There was criticism from these participants of the way in which the policy framework relied on families to ‘exhaust community options’ which often did not exist. Shirley, Kate’s mother expressed this frustration as follows:

\[\ldots\ldots\text{but every avenue you go down there is a problem. You can get a few sessions [of physio] and if you go private it becomes very expensive. For people’s quality of life and health they need to be able to access these services regularly.}\]

(ii) Rationing and trade-offs

A further consequence of inadequate funding was that decisions about rationing scarce resources fell upon individuals and families to make in very private ways, highlighting the double-edged nature of ‘flexibility’ in these funding and service arrangements. Whilst flexibility expanded choice it was also a mechanism for individualising hard decisions about how limited funding should be used. The graded nature and benefits of flexibility depended on the level of formal and natural resources to which participants had access. For example, whilst Bess benefitted from saving her excess personal care hours to use instead for holiday support, Therese and Val’s ‘choices’ to use their community access hours for necessary personal care were less palatable and significantly impacted their opportunities to participate on their terms. Further, the private nature of these compromised choices and their consequences meant that they went undocumented in reviews and were not accounted for in planning or analysis of their support needs and costs. The following example from Val demonstrates the nature and consequences of resource rationing on social participation:
The other thing that we used to do, if I was using too many hours for personal care then I would knock out the community access day. I would just not go out for a couple of weeks. Val, ISP holder

(iii) Uncertainty
Uncertainty also dominated participants’ narratives to varying degrees, related to a limited sense of influence in funding decisions specifically and life generally and some anxiety regarding the extent to which their ISP funding could adequately cater for future and changing needs. The annual nature of the funding cycle and worries about ‘giving back’ what hadn’t been spent, contributed to uncertainty and anxiety about future needs and planning. Restrictions on how the ISP could be spent as well as uncertainty about the funding guidelines further reduced participants’ sense of autonomy in how the package was used.

Five participants spoke explicitly about their concerns for the future and their lack of clarity about how their ISP funding would respond to their changing social and impairment related needs. For example, Kate’s mother Shirley described the limits of funding which focused on current rather than future needs:

I think it is barely adequate. It doesn’t give Kate any scope to do anything. It is bare minimum. And it just doesn’t allow her any flexibility …… [The future] is not something you can plan for... so I think it really restricts her. Shirley, family carer

Similarly, Val described her lack of certainty around future funding as keeping her in a ‘holding pattern’. She described a lack of choices and uncertainty as contributing to a ‘taking one day at a time’ approach to life. A key concern was that her community access and related travel funding would be cut once she moved to a Community Residential Unit. This worried her given her friends and family were on the other side of the city and cuts to her community access hours would restrict her contact with them. She was very concerned about being ‘left destitute’ and isolated, restricted in her freedom to access not only social supports but also to much needed health services. Val was anxious about having to ‘fight’ ‘to maintain her current funding level:

…… And before I move into a residence I will be due for another review and I have a strong feeling that I will have to fight. It will be presented as a fait accompli that
there will be no support for community access hours. I also have taxi hours to get to
doctors’ appointments and I am sure they will say there will be none of that
available…. I have concerns that all of a sudden I will be left destitute and I won’t
be able to access physio or be able to afford transport to and from physio and
physio is the only thing that is keeping me physically OK. Val, ISP holder

Also contributing to uncertainty and limiting self-direction were long and unpredictable
waiting times for ISP funding decisions. Most participants were on the Disability
Support Register (DSR) for more than 12 months before they were allocated a notional
package. During this time were given no certainty regarding the timing or nature of the
outcome. For some, social, health, and economic circumstances deteriorated as they
waited.

The negative impact of inadequate and uncertain support funding was confirmed in the
interviews with ISP planners, support workers, and service managers. For example,
Planner A described the difficulties she had in gaining DHS approval for ISP packages
which extended beyond basic one to one support and mileage: ‘That’s all we can get
approval for at the moment. One to one support and mileage. That’s it.’ Planner A

This planner also criticised the deficit based lens with which DHS administrators in her
region would scrutinise and challenge her funding proposals for what she deemed to be
reasonable and necessary levels of support and community access:

......but sometimes they [DHS] might say, ‘why does this person have [in
their funding proposal] 6 hours community access per week? And it’s like,
‘well, how many hours do you go out into the community each week to do
things you want to do? Planner A

The above findings show the limits to self-direction, certainty, autonomy and social
participation imposed by inadequate and restrictive funding levels. In this analysis,
choice and flexibility are shown to have a dark underbelly when they enable difficult
and very private rationing decisions in the context of inadequate resources. These
descriptions exemplify the uncertainty and sense of maintenance some participants
described, in contrast to the flexibility, self-direction and flourishing suggested by ISP
policy.
Exacerbating the impact of scarce resources was the negative impact of bureaucratic and service inconsistency. The findings regarding this theme are presented below.

(iii) **Inconsistency and lack of transparency**
Participants’ experiences highlighted the adverse impact of inconsistency in DHS processes and decision making mechanisms as well as in service approaches and attitudes. Inconsistency produced an uneven playing field characterised by inequitable and uneven experiences and outcomes. Moreover inconsistency was often unexplained and participants had little opportunity or capacity to address it particularly in the context of individualised approaches.

For example, whilst some DHS regions funded reasonable levels of community access, as defined by the person, in the form of travel (mileage and taxi fares) and appropriate levels of support worker time, other regions were more likely to robustly question and reduce requested levels. Whilst some participants received funding for sporting club and recreational memberships, cinema passes and supported holidays, others did not. Further, it appeared that such inconsistency was well known amongst services and planners yet unaddressed. Interviews with providers confirmed systemic inter regional inconsistency and suggested that whilst it was partially due to the constraints of the funding model it also reflected significantly different staff attitudes and approaches toward funding for social participation. Such inconsistency and lack of transparency exacerbated an already uncertain and complex process for people seeking and using funding and services. The inequity produced by these circumstances was articulated by Carol, support worker to Bill and Loris:

*I am a loss to understand with all the people I work who have lots, the amount of funding some people seem to have, so much more than others.* Carol, Support Worker

Related to these experiences was the generally held perception that chance and luck played a big role in funding outcomes. For example, several participants referred to being ‘lucky’ in getting ‘enough’ funding to meet even their most basic needs. Where participants lived and which DHS region therefore decided on their proposal, played a role in either expanding or further constraining choice.
Planning experiences were also diverse and uneven. Because funding flexibility and scope was embedded in the nature of the plan, the planning process had significant impact on participants’ capacity for choice and self-direction later on. The process could be transactional and narrowly defined by a rigid interpretation of the ISP funding guidelines, such as Nancy’s experience (see Section 7.3.1 for further detail), or sensitive and personalised, based in a relational and holistic understanding of the person’s context and aspirations, such as was the case for Bess and Simon. Whilst some participants described the benefits of planning which was ‘global’ in nature, allowing for maximum flexibility, others felt restricted by tightly structured and overly defined plans.

When plans were too narrowly defined, participants were frustrated by not having enough discretion and autonomy in how they used their funding. Having to reapply to DHS for changes and approvals to spend funding on new or emerging needs not identified in the original plan added to frustrations, particularly when new approvals took time. For example, Candice’s garden was overgrown and a safety hazard but she could not use her funding for a gardening service because details of the service she wanted to use had not been itemised in her original plan. Similarly, Val had to seek approval for a new wheelchair battery because this had not been included in her funding proposal.

Poor planning experiences and lack of clear information also left some participants feeling unsupported and unsure of the scope of their individualised funding and their role and rights within it. This was particularly the case for those new to disability services and who lacked both content and process knowledge of the sector. Lack of clarity and understanding contributed to anxiety about how funding could be spent and limited confidence in pursuing certain options, resulting for some in lost opportunities. For example, Candice did not know that she could use her support funding to attend university lectures or to go swimming and had, as a result, not been doing either because they had become ‘too hard’. Similarly, lack of adequate planning support and information had initially left new family carer Nancy more concerned about contravening funding guidelines than about how she could optimise its potential. A consequence was that she had used her own money on items for which she later realised she could use his ISP.
There was also difficulty for some in obtaining consistent information about the ISP pathway and funding guidelines. Information was described variously as too much, overwhelming, complex, vague, and as lacking specificity to individual circumstances. Further, finding relevant information was difficult when participants were not quite sure what they needed. This quandary was described in the following account from Candice:

*One time I rang them [a national support service] because I didn’t know what I needed but knew I needed some help. They said well what do you need? I said well I need to know what is available to know what I need.* Candice, ISP holder

Reflecting inconsistency in ISP assessment and planning processes, the findings revealed similar inconsistency in service approaches, as presented below.

(v) Maintaining the status quo: limits to innovation and change

Some participants did not have the choice to leave disability based group programs for mainstream community based alternatives because of the limitations of their ISP, limited community based alternatives, and limited support from certain services. Whilst some participants were involved with services providing exclusively individualised approaches and had the funding to support this, other participants, such as Kate, remained engaged in group programs, despite their preference not to be.

Participants also described the challenges of seeking to create or find alternatives to traditional disability based options even when they had the funding and desire to do so. For example, two families described their failed attempts to develop alternative accommodation arrangements for their family member given their wish to avoid disability group housing and associated waiting period of many years. Both families had funds to contribute and ideas about how friendship based supported accommodation could be developed. However, lack of funding support and co-operation from the authorities, for reasons associated with cost, risk and occupational health and safety concerns, left these families feeling unsupported in their attempts to pursue more innovative and personalised housing solutions:
But they (DHS) wouldn’t supply funding for the sort of support you needed. No, you could buy a house but they wouldn’t match funding or anything like that. There was absolutely no leg up in this supposed queue. Shirley, family carer

In the absence of non-disability based options, ISPs were used for traditional services such as group homes and day programs. But for some, such as Kate, staying in such programs maintained the status quo rather than providing opportunities to expand her personal and social goals. There was an inherent paradox in these circumstances, given the ISP policy goals regarding choice and social participation, as noted by Kate’s mother Shirley below:

Just because you have a disability and you go to a day program doesn’t mean you are going to like the people you are spending time with or have anything in common with, other than what you are doing during the day. Shirley, family carer

Similarly, Kate and her mother’s experience of life in her CRU was that the structures and conservative and restrictive staff practices frequently limited rather than expanded her freedoms and opportunities. Kate and her mother were both concerned that Kate had become more socially isolated following her move to her CRU than when she was living at home due to cuts to her community access funding, service centric routines, and overly maternalistic staff attitudes combining to restrict rather than expand her choices.

Participants’ experiences point to a slow to change service sector underlined by a risk averse culture with concerns for financial viability sometimes overriding a more authentically person centred and community focused approach. The examples of families thwarted in their efforts to develop alternatives to traditional disability housing and day programs show the hurdles involved in creating more typical community based options. These were exacerbated by the fact that families often had limited knowledge of exemplars already operating in the community, from which they could learn.

There was also limited evidence in the data of innovative thinking and support regarding employment. Three participants had paid part time work (one self-employed selling confectionary) and four expressed a strong interest in employment but were not
involved in job preparation or seeking activities. Several participants had previously done light volunteer work such as phone counselling however this was sporadic.

Three participants were studying part time at TAFE or university with two participants using their ISP to support this. However Therese had been forced to defer her arts degree for one semester due to the funder’s inability to respond quickly and effectively when her support needs changed. This funding delay and lack of responsiveness to her changing needs was frustrating and impacted on Therese’s well-being and capacity to move forward as she emphasised:

Yes, and it [the degree] can take 8 years part time so that’s another year gone.
Therese, ISP holder.

This example is discussed in more detail further below.

For some, there was a significant gap between their goals and the flexible support services and processes they needed to progress these and what the funding and service system, and community, could offer. This gap was confirmed in interviews with service providers, to be discussed in the following chapter. The next section presents findings showing how lack of flexibility and responsiveness within the funding bureaucracy disempowered rather than enabled participants’ choice and control in accessing and using their ISP funding.

(vi) **Bureaucracy and disempowerment**
The analysis has so far revealed a series of constraints to choice and self-determination embedded within the funding pathway, produced by bureaucratic and organisationally centred practices seemingly at odds with person centred rhetoric and principles. Disempowering attitudes, practices and processes at the organisational, social and institutional levels often worked in opposition to the potential of individualised resources and services to promote and expand opportunities. These disablers were both explicit, in the form of overly complex or slow formal processes, and powerful in their absence, such as in the lack of enabling and helpful attitudes, practices and processes or availability of meaningful options. It was also clear from the data that the disempowering effect of these constraints varied depending upon participants’ capacity
to leverage other resources in their lives and to advocate and negotiate better conditions with DHS, services and in the community. As noted previously, lack of these resources disadvantaged those participants least able to defend against or negotiate disabling practices.

For some participants, accessing and engaging with the funding bureaucracy was adversarial and combative, described variously as a ‘fight’, ‘battle’ or ‘struggle’ and came at an emotional cost in addition to their daily routines and care loads, as reflected in Dolores’ experience below:

*You have to fight for everything. I’ve been to local members, I’ve been to Cheryl Garbutt years ago, I’ve been to everywhere to try and get an ISP package. Everything I do is a struggle and a fight………I get tears, I get angry, I get everything. It is so emotionally draining.* Dolores, family carer

Reinforcing the experience of separate rather than shared interests was the ‘othering’ language participants used to refer to the DHS bureaucracy, such as ‘them’ and ‘they.’

The shift to a self-directed platform did not, for some participants, appear to be accompanied, consistently, by a transition to improved person centred processes. The costs of navigating and engaging this complexity was absorbed by participants, as demonstrated in Andrew’s experience. He described navigating the system as ‘a lot of running around’ with sometimes limited outcomes:

*But it’s so complicated. It is for me because I’m not a young man. The thing is you have to apply for all these things and they knock you back.* Andrew, family carer

Related to these perceptions was the experience of the funding and support framework as fragmented and failing to link up in ways which would enhance and streamline participants’ real control over their funding resources. When funding came from different administrative ‘buckets’, with different guidelines, criteria, and waiting periods for each, participants’ capacity to meet their needs more autonomously and seamlessly was diminished. For example, Candice could not draw from her ISP to buy the motorised scooter she needed and which would have increased her independence and significantly reduced her support worker costs.
Other examples of non person-centred processes embedded in the funding bureaucracy and pathway included:

- annual funding cycles and the requirement to use a percentage of funding within the annual cycle to avoid the risk of it being taken back;
- lack of meaningful and review mechanisms;
- inconsistent and complex information provision which often did not meet participants’ needs;
- standardised time allocations for planning and developing funding proposals, regardless of the complexity of the person’s needs or circumstances;
- automatic ‘rebadging’ of previous support funding arrangements into individualised packages with, for some participants, inadequate communication or explanation of what this meant for them and implications of the change;
- lack of helpfulness in some staff attitudes and practices.

Some services also demonstrated non person-centred and sometimes disempowering practices. These were often manifest in what services did not do or the information they did not give as much as in what they did do or impart.

In several examples participants felt their needs were being commodified, their individuality not recognised, and their interests and needs taken as secondary to organisational, economic, and efficiency priorities. For example, Val reflected others’ experiences when she described feeling like a ‘scheduling dilemma’ at the hands of one of her providers:

_Sometimes I got assigned for a community access visit someone I was barely tolerating. …..I said excuse me I am not a scheduling dilemma. If my personal carer isn’t available for that (and normally they would tell me that)…… I am not a scheduling dilemma. I would like to be consulted_, Val, ISP holder.

Providers also commented on a disconnect between the self-direction rhetoric and aspects of the funding pathway as well as the embedded practices of some services. This data will be expanded upon in the following chapter however the following quote from Carol, Bill and Loris’ support worker, points to a lack of person focus in staff attitudes and exemplifies the above theme:
I suppose customer service is going out the window everywhere. But in this case it’s really hard and there is also sometimes cross communications and misunderstandings. No one is explaining back or even having the courtesy to say ‘is this what you are asking? ‘is this what you want?’ to make it clear. Carol, Support worker

The following examples summarise ways in which some service and individual staff practices disempowered and restricted participants’ choices and autonomy.

- failure to respond to requests for information or advice in timely and relevant ways;
- failure to send staff rosters to participants before shifts so that they would know who was coming and failing to advise of staff changes in advance;
- support worker incompetence, lack of preparation, and lack of knowledge of person’s physical and practical needs causing unnecessary pain and discomfort;
- ignoring requests for particular support workers based on participant preferences;
- providing inconsistent and complex information without consideration of literacy and comprehension needs;
- failure to encourage and support new opportunities and pathways beyond traditional disability services; and,
- failure to proactively and explicitly explain the new opportunities under the ISP, such as portability.

Related to the above were the risks and costs to individuals, family carers, and service providers which were highlighted in the analysis. These were shown to be produced by the combined pressures of inadequate and uncertain support funding, the new and different demands of individualised arrangements, and the challenges of operationalising choice in the context of a slow changing and sometimes cautious service sector and community. The analysis showed that in many cases available options lagged behind participants’ needs and expectations. The risks and costs associated with this set of dynamics are presented in the section below and are
significant in that they reflect how responsibility for converting resources into outcomes is often transferred in ways which inhibit the outcomes to which participants aspired as well as stressing critical natural resources necessary to these outcomes.

5.2.3 Cost shifting and transaction costs
A consequence of the funding, support, and opportunity gaps identified above was that the costs of these inefficiencies and inadequacies were often absorbed by individuals and their family carers on top of existing demands and workload. There was also evidence of some particularly person centred services absorbing costs in their unpaid support, case management and advocacy efforts. The analysis highlighted the extra and new challenges of self-direction particularly for those with limited resources and opportunities or with limited experience in choice making. The new demands were the corollary of the benefits of choice and included the thinking, planning, sourcing and coordinating work required to operationalise self-determination at home and in the community. This included building new local knowledge about services and developing skills and capabilities related to service, staff and relationship management. The data consistently revealed the cost shifting of economic efficiencies at government level to people using funding and to those services inclined to absorb such costs.

The data also showed that despite participants having diverse capacities for engaging and optimising opportunities within the ISP framework, most participants did not receive funding for case management as part of their ISP or chose not to use their limited funding package for these services. It was explained by a service provider that many service users were reluctant to use their resources for something they could not ‘see’, such as co-ordination and case management, given this would reduce funding for what they perceived as their more pressing practical needs. Thus, much of this secondary or articulation work was absorbed, unfunded, by carers and services. This clearly placed those without such active supports at a disadvantage.

For example, Therese’s mother described feeling alone and unsupported in her efforts to organise Therese’s university arrangements:

*I was pulling my hair out just getting it all together so that she could get there (to university). We would take one step forward and, two steps back. Every time we*
tried to do something, something went wrong. I was trying to do it all on my own.
Service X was useless as far as help, Sally, family carer.

There was also very limited evidence of participants accessing independent advocacy or information services which might have assisted in choice making, representation, and negotiating improved conditions. This finding highlights the limited nature of independent advice and information networks, free from funder or service interests, to which participants in this study appeared to have access.

Related to this, the analysis also suggested that participants’ decisions and choice making were often made in a vacuum and not always informed by a thorough assessment of information and options. This was complicated by for some by lack of accessible and consistent information as well as by the inadequate and rushed nature of the planning process and the fact that planning occurred prior to a final budget figure being approved. For participants who had not used flexible funding before and/or who had mainly used disability services and group programs, more time as well as more targeted and personalised support and planning was needed to support choice making.

But planning in the funding environment could also a challenge for those with long standing experience of disability and the service sector. For example, Shirley, Kate’s mother, described how unrealistic and unskilled planners failed to understand the challenges Kate faced when asked about what she wanted to do in the future. She felt inexperienced planners failed to understand how her daughter’s history and lack of experience in choice making impacted her capacity to forming realistic goals and plans in the community:

But it’s really hard and that’s one of the things that I get frustrated with the intake workers when they say, ‘What do you want to do with your life?’……And for people to make life changing decisions based on previous experiences, which you need, and you need considerable experience to know what you really want to do… it’s just so difficult. And I think that’s a major restriction in life, as well as the funding, is the lack of being able to individually and independently experience and explore the world around you. Shirley, Family carer

In contrast, other participants, such as Jess and Jade, used their experience, confidence and clarity about their needs and goals to optimise available information, resources and
opportunities. Similarly, those with strong social networks and community connections, such as Simon and Jill, were better equipped to build on these strengths and use their natural resources to leverage their formal resources in planning and pursuing choices.

In addition to reliance on individuals and families to do much of the 'heavy lifting' work of self-direction, restricted funding continued to assume that family carers would provide significant levels of personal support and care. The shift to individualised packages had not alleviated this pressure for most families. Several participants spoke of resenting the ongoing pressure and obligation on their family carer as well as the unwanted dependency on others it perpetuated. Val exemplified these concerns in relation to her worries about the burden of her care on her husband and daughter:

*I think the stress of being at home... Ultimately your family are relied on....it doesn’t matter how much the department says we will fund you. Ultimately the other agencies who you are relying on will say ‘oh sorry we can’t come up with workers for this particular shift’... we can’t say ‘well I really can’t. There is no other avenue (but family support).* Val, ISP holder

Similarly, Therese resented the impact on her mother who was also managing her own chronic health condition. She criticised DHS for exhausting family supports and putting the family system at risk before they would then contribute extra resources:

*They expect parents to be providing care and they only step in once the parents can’t do anymore. Which is really unfair.* Therese, ISP holder

At the same time, some participants were conflicted in their anxiety and uncertainty about how they would manage if they could not rely on family and friends when funding was inadequate to their needs, as the following quote demonstrates:

*But if I didn’t have the support of my husband it would have been extremely difficult to continue with the hours that I had.* Val, ISP holder

Also related to the theme of transaction costs was the blurred area of mediated choices, with family carer needs merging with those of the ISP holder to sometimes obscure the primary influence on decision making about ISP use. For example, moving to supported
accommodation reflected Kate’s desire for independence and her mother’s need for respite however there were moments during the interview where Kate’s ambivalence about the move was obvious, begging the question about what might have been a preferred alternative for her if different options had been available. The use of respite care was another more explicit example. Each participant who had used respite care expressed strong dislike for it and yet Dolores felt she had no choice but to use it for Simon in order to ensure she had time to herself, as she explains below:

….we’ve been there [respite service] 10 years, two nights a month. He doesn’t like going but that’s to keep me on holidays otherwise I cannot get away. Dolores, family carer

The analysis highlights this as an ambiguous area in relation to ISP use and raises questions about how such tensions, and family carer needs, can be best mediated and supported in the context of individualized funding arrangements. This area becomes more difficult to disentangle given the interdependence of needs and the private nature of family decision making processes.

The above findings highlight the risks of exhausting the natural resources and supports so necessary to maintaining and building social value in participants’ lives. It can be seen that the family unit and related resources are often over relied upon to fill funding and support gaps in a variety of ways, from personal support and care to the thinking, planning, co-ordinating and advocacy work so central to benefit in the self-directed framework. These risks fall more heavily on those least resourced and in the context of limited independent advocacy and information infrastructure.

The gap between the autonomy and self-direction promised by the ISP policy framework and people’s everyday lives, generated by lack of adequate funding, support, and opportunity, as seen in the above analysis, is further elaborated below to bring these findings into focus.
5.3 The gap between promise and practice

It can be seen that for this sample of participants, there was a gap for some between the choices and opportunities they hoped for and what their ISP package, services, and the community could provide.

There were several exceptions, such as Simon and Shane, however the findings show that ISP assessment and allocation was predominantly needs rather than strengths or goals based, as were the processes and mechanisms through which funding was provided. ISPs varied in their scope and structure and were predominantly focused on personal and practical impairment related needs. For most, their package did not adequately acknowledge or resource sustained social and economic participation and the supports, planning, advocacy, and innovation required for this. The analysis showed that there was not enough formal acknowledgement in assessment and planning, of the resources, both formal and informal, required to inform and operationalise choice and self-determination in everyday lives. Instead, lack of adequate funding and support for these tasks made implicit assumptions about these responsibilities being absorbed by unpaid supports. A consequence of these shortfalls and deficits was that whilst those who were well resourced and able to manage the new demands of the self-directed framework benefitted, others missed out. The opportunity to use the ISP for better lives was available to some but not all.

Thus, there was a gap between what ISP policy promised in terms of self-direction and social inclusion and what participants experienced in terms of opportunities to realise these goals. Figure 5.1 offers an heuristic summarising participant funding allocation and use from a rights and capabilities based perspective and highlights the gap found in the data between what many participants aspired to in terms of higher order accomplishments associated with citizenship and what the individualised funding program and services framework, given its fiscal and structural limitations, could provide.

The heuristic is interpretive in nature, based on participant narratives rather than numerical analysis and is based on an adapted Maslow’s hierarchy of needs (1943, 1954) to show levels of development and aspiration reflecting participants’ narratives.
in contrast with the limits of their support funding, as they described them. The left hand triangle shows what funding was allocated and used for in relation to needs and goals and is contrasted with the right side of the diagram which shows participants’ actual aspirations regarding good and better lives. These expectations incorporated but exceeded basic personal care needs and were associated with higher order social, cultural and economic life goals related to education, community belonging, social and economic inclusion, relationships and employment.

Importantly, the diagram also shows the activities, processes and relationships required to bridge the gap between resources and citizenship rights, typically provided by family and extended social networks as well as some services. As noted above, the risk highlighted here is that much of this work was unfunded and thus increasing expectations placed on these groups.
Figure 5.1 ISP funding availability and use compared with participants' goals and expectations
5.4 Summary and links with the literature

The analysis has identified both the benefits and adverse impacts of the ISP program and how these were diversely experienced by diverse people in diverse contexts. Through this analysis we can see how in the individualised funding model, risks and costs, as well as benefits, are personalised. It was also evident that benefits were graded, with some enjoying significantly improved opportunities whilst others enjoyed more modest improvements in their quality of life. Others continued to feel constrained within a 'holding pattern', unable to participate more fully and on their terms, despite individualised resources. Inadequate funding which failed to more holistically support goals and aspirations was a key barrier to greater choice. So too were traditional and established service approaches which were slow to respond to participants’ changing needs and expectations but which also lacked skill in supporting participants in developing the new capabilities required to benefit within the self-directed framework.

Further, the analysis identified how much of the critical work of operationalizing choice and self-determination in everyday lives was often unacknowledged and underfunded. When this was the case, the time and costs of this work were absorbed by the individual and their natural supports, adding to existing responsibilities. Some services also absorbed these costs. These mixed findings reflect the debates in the broader literature regarding the risks of individualised approaches when not appropriately resourced (Ferguson, 2012) and in the absence of the social and structural reforms required for collective reform and change (Dodd, 2012).

A conflict also exists in the disconnect between ISP policy intent regarding greater choice and self-direction in how funding is used and the series of constraints embedded in the machinery of the bureaucracy and service sector. These related to a relatively untransformed and cumbersome bureaucracy which in seeking to manage an underfunded program frequently reverted to deficit based and non-person centred systems. Similarly, transition toward self-directed approaches in the service sector appeared patchy, slow and inconsistent. Together these constraints acted to limit the notional potential of the ISP, services, and the community in real terms in everyday lives.
The analysis reflects concerns regarding the administrative and informational factors which act to impede the potential impact of greater self-direction in funding and services. These barriers included ambiguous funding guidelines which led to inconsistent interpretations and applications by funding administrators. In particular, variation regarding what constituted 'disability related' and what was necessary and reasonable for social participation resulted in inconsistent and inequitable approaches to assessment and planning. Struggling to access timely, consistent and accessible information about funding access and use featured as a barrier to informed choice making, again reflecting existing research (Laragy et al, 2015). The lack of access to independent advocacy and advisory services to support decision making also operated as a constraint to improved outcomes and more informed choice, reflecting similar claims the literature (Chenoweth & Clements, 2009; Williams, 2007).

In addition to the inconsistency and inequity built into the ISP framework, as evidenced by the mixed findings, the analysis also points to the flawed program logic linking individualised funding with the promotion of broader citizenship rights in a direct causal relationship. The analysis has shown how despite enabling greater choice and flexibility in service decisions, participants could still feel frustrated and on the margins of mainstream life due to funding which failed to support opportunities beyond personal care needs.

The findings also emphasised the interdependence of formal and natural resources available to an individual and the risks of overstressing personal and social resources when formal resources were insufficient. Much of the work of self-determination and inclusion was clearly located in and produced in the social relations and networks developed between people using services and those providing them, highlighting an interdependency necessary for the production of meaningful outcomes for both parties.

These resources were critical to supporting the often emergent and dynamic work required to support real autonomy and choice in everyday lives within this funding context. In this way, the findings consistently highlighted the multifaceted role and value of social capital as a resource, enabler and outcome in participants’ lives, reflecting both the social capital and capabilities literature (Migheli, 2011; Coleman, 1988). Social capital has been defined as the ‘by product of trust relations between people’ (Grix, 2002, p. 181). The findings reflect Coleman’s (1988) notion of social
capital as context specific with its production promoted or constrained by the structures and processes which defined participants’ activities, resources, and opportunities (Maloney, Smith & Stoker, 2000). The capabilities literature expands upon this, identifying social capital as a core social and cultural conversion factor (Migheli, 2011).

Whilst adequate funding was critical to supporting the conditions in which these relationships could flourish, other factors, such as choice of staff, a diversely skilled workforce, and staff continuity, were important in ensuring relationships in which dignity, choice, and autonomy were promoted. Further, access to diverse community options for participation was also shown to be a context specific factor critical to expansion of networks and therefore social capital.

Importantly, it was in these relationships and alliances that the thinking, co-ordinating, linking, and the ‘pulling together’ work of choice and participation took place. These findings highlight a form of co-production whereby relationships and processes grounded in values of equality and reciprocity allowed for power to be negotiated in order to pursue goals of meaning to the person (Needham & Carr, 2009).

Social relationships, connections and networks were the medium through which resources were able to be converted however, as the findings indicate, a central risk of underfunding and insufficient community based supports was that for some participants there was an over reliance on these resources. These findings reveal a deep paradox and highlight the risks associated with implementing individualising funding arrangements with insufficient resourcing for inclusion and participation, reflecting existing concerns in the literature (Lymbery, 2014; 2012).

The findings also revealed limitations in the capacity of the ISP framework and its systems to respond to diverse needs and contexts. The framework appeared to assume a level of capability without acknowledging diverse starting points, skill and capacity to navigate and benefit within the system. The absence of equalising supports and robust independent supports contributed to an uneven playing field in which some were advantaged in this system and others were not. For some, this dynamic further perpetuated existing disadvantage.
These findings reflect Duffy & Murray's (2013) ‘real wealth’ (p. 311) and Williams’ related citizenhood and capitals arguments (2013), both of which posit that funding and systems must build on the strengths found in individual, family, and community as the source of transformation in the personalisation process. Duffy and Murray (2013) have contended that too often such potentials are underdeveloped, particularly in marginalised groups. The study extends this to show that too often the personal and social capital in participants’ lives were fatigued rather than nurtured and built upon by appropriate resourcing and opportunities.

Therefore, this chapter has shown that the impact and potential benefits of the self-directed funding and service framework were not evenly distributed but were mediated through a spectrum of personal, systemic and contextual factors. It has pointed to the diverse experiences of participants depending upon their existing material and social resources, as well as personal attributes, experience, and capabilities. Thus, it is important to understand in more detail the factors and variables across levels which contributed to these mixed and sometimes controversial findings. Chapter Eight will present findings regarding the arrangements, variables, and resource characteristics which influenced conditions in which choice and self-direction were promoted, or constrained. The next chapter, presenting findings from interviews with disability service providers and ISP planners, will contribute to Chapter Eight.
Chapter Six

Findings from interviews with Disability Service Provider Managers, Co-ordinators and ISP planners

6.1 Introduction

This chapter presents the findings from interviews with three Chief Executive Officers, four senior managers or co-ordinators, and two ISP planner facilitators drawn from across six different disability service provider organisations. These findings offer provider perspectives at different levels of service provision as an alternative lens to those of ISP holders and their families. Managers and planners were asked about their organisational experience and approach to individualised services within the ISP framework and within this their thoughts regarding enablers and barriers to improved outcomes for service users as well as for services. They were also asked for their perspectives regarding the transition toward the NDIS and the reforms required to address shortfalls and risks at the sector, community, and structural levels for successful implementation (research questions 2 and 3).

As noted in the methodology chapter, the sample was purposefully selected from organisations self-reporting as experienced in and committed to individualised approaches as well as through word of mouth recommendations. These providers represented organisations ranging from large multi-site and multi service providers offering residential, group, work training and individualised services to smaller agencies providing only individually tailored services. There was also a small community education and advisory service resource information agency which specialises in supporting people and families to develop inclusive community based pathways. Participant and organisation characteristics were outlined in Chapter Four in Table 4.2.
Importantly, there were similarities between providers’ experiences regarding the benefits and risks of the ISP framework and those reflected in the experiences of individuals and family carers. They identified similar multi-level enablers and barriers to operationalising choice and self-determination.

However the providers contributed new perspectives on the role services and the community should play in the future and the changing nature of relationship and exchange services should be developing with different stakeholder groups. The findings fell into three key categories which have been defined here as key relationships or interfaces and points of transition and transfer where conditions either constrained or enabled service users in their access to valued opportunities and resources.

These interfaces or boundaries have been categorised as being: A) between the service and the individual; B) between the service and the community; and, C) between the service and the program and policy context, including the machinery of the bureaucracy as shown in Figure 6.1 below.

Figure 6.1 The interface and points of transfer between services and key stakeholders
Chapter Five dealt with the experience of people with disabilities and family carers with services and supports as well as with the community. This chapter offers the opportunity to triangulate these findings by offering a similar exploration of the service interface with both the individual and family (Interface A, Diagram 6.2) and with the community (Interface B, Figure 6.2). These two interfaces, A and B form the two substantive analysis and findings sections of this chapter. In a third section, Interface C, the policy and structural context for change, will be considered.

6.2 Interface A - The service and individual/ family interface

The analysis revealed a shared narrative between providers and planners regarding the need to reinterpret the role and function of services in people’s lives in the context of self-directed funding and services and an increased focus on community based approaches. Central to this change was both the nature and focus of the work as well as a shift in organisational and worker culture and attitudes, and the quality, nature, and power dynamics of the service and service user relationship.

The following four sub themes describe key factors identified in the provider interviews as influencing the disability sector’s capacity to effectively and more consistently transition toward self-directed approaches, in line with changing community and funder expectations.

6.2.1 From ‘client land’ to ‘person land’

All managers emphasised the need for a paradigm shift in how services conceived of their relationship with service users, as enablers and linkers, facilitating lives led in the community in line with the person’s self-defined goals and aspirations. To do these services needed to understand the person in their social context with the same rights to access and participation as other members of society. Providers highlighted that working with service users as ‘people’ in the community rather than as ‘clients’ of a service required a holistic approach involving understanding of the person’s history and aspirations, their social context, and their opportunities and resources. Developing a ‘person first’ culture necessarily involved, in practice, keeping the needs of the person ‘front and centre’ of everything a service does (CEO1).
Providers contrasted this orientation with the traditional service function of both creating and defining the services people with disabilities could access. This reorientation required a parallel shift in staff and organisational capacity and willingness to look outwards to the community, rather than inwards, and a corresponding shift in power relations. It also had implications for how service organisations planned and structured for the future and in relation to recruitment, workforce development and organisational culture.

This approach was exemplified by the following comment from CEO2:

_If we are working from the assumption that all people belong to the community then of course all opportunities should be open to people with disabilities and we should be dealing with them in typical ways and that's not to say people don’t need support ....... you add supports to a typical pathway – you don’t create a special one._ CEO2

Senior Manager 1 described this move toward ‘typical’ pathways as a move from ‘client land to person land’, representing an important change in status and corresponding shift in the contemporary purpose of disability service provision. This purpose was elaborated upon by CEO1 as follows:

_What are we here for? We support people to live an everyday life, every day. Not special, especially not, certainly not different, and not segregated every day. And to try and do that in natural ways that we all try and make connections and friendships and whatever. We all need support and we’ll receive support in different ways._ CEO1

Following this, there was consensus that in order to reorient itself, the sector would need to be able to demonstrate in practice and not just in rhetoric what moving on from a ‘charity’ to rights based model meant. This would involve countering traditional notions of ‘grateful’ service users which, it was stressed, were still evident across the sector. CEO1 reflected others when he elaborated upon this challenge in the quote below:

_...yeah they [service users] have got rights, they have got expectations that we need to try and meet and it creates a different power relationship to the more_
traditional one: [which is] ‘yeah they are clients of our service and they should be bloody well grateful for what they might receive’. And that’s an exaggerated statement but that’s the culture I have seen in the past but that’s not the way it should be and is not the way that it is [here]. CEO1

6.2.2 Individualised funding as tool
In line with the above findings, providers agreed that individualised funding was a critical ‘tool’ and ‘building block’ in enabling greater choice and control within a rights based approach. However it was also stressed that its potential, as a tool, would be limited in the absence of broader socio-cultural and structural change including community reforms and attitudinal change regarding the social inclusion of people with disabilities. These would be required in order to create the opportunities, relationships and more inclusive pathways people with disabilities needed to participate more fully. 

One manager encapsulated this idea by observing whilst important, funding could not do the ‘linking and thinking’ work required to create opportunities and bridge toward inclusion. Funding could not ‘buy’ the relationships and connections people required to participate and feel valued for their contribution. The following exemplifies this central idea:

....individualised funding is a really important building block, [but] it is not enough by itself .......... it does require the right culture and being driven by trying to do what people are really interested in and I think your experience will be if you can’t get that right then it doesn't really work. CEO1

Further, there was a risk in thinking that an individualised resource would be used to buy something new if overarching paradigms of thinking did not also change, including the expectations of people with disabilities and their families who needed to be encouraged and enabled to look beyond ‘traditional’ services:

The money [funding] is not enough because for years now where people in Canada have had individualised funding .......... people buy the same thing unless they are given assistance and capacity to think about something else because we are talking about a mindset shift after years of devaluation. Senior co-ordinator 2
Opinions varied over whether the person’s individual budget should be known before or after the planning process and how to manage these tensions i.e. should dollar limits or aspirations guide planning. Several providers believed the current model whereby people are required to develop their goals and a funding plan prior to budget approval and certainty was a barrier to informed and realistic planning. It was felt that this process in many ways set people up to fail because they did not know exactly what they had to ‘dream with’ and ‘what the goalposts’ are:

One of the challenges with the current DHS individual payment system, we say go dream about anything you want, have a wonderful dream. And they go well I have this fantastic $80,000 plan I would like implemented and then DHS go well sorry we only; have $10,000 available. CEO 2

The counter argument put by other providers however was that the money should be the ‘last piece in the equation’ and that people should be allowed to ‘dream first’ when developing their plan so that their budget did not limit their creativity:

IF is a tool, the last piece of the equation. You start with the person and work back from there.......IF is like a piece at the end, almost to help.’ CEO 2.

6.2.3 Culture, skills, and values
Culture change was identified as both a key enabler of sector transition and a product of seeing successful outcomes for people using individualised funding. Reinforcing this argument, a team leader observed that providing quality personalised service was ‘more a cultural thing than a skill thing’ with her team’s core values and ‘reasons for coming to work’ ultimately shaping the quality of support they offered service users. Another manager described this orientation as ‘being driven by trying to do what people are really interested in’. In practical terms, this was described as services being arranged around service users’ needs rather than around workers’ timetables and requirements. Flexibility, motivation, and commitment to the work were identified as key elements of the team culture required within a self-directed framework.

Managers also commented on the relationship between service culture and community change, explaining that service change would be influenced by changing community attitudes and expectations as positive examples of people living more autonomously
were observed and shared. But this also worked in reverse with sector resistance to change slowing community expectation and confidence in exploring new options.

Reflecting the ideas above, service providers described the leadership role they should take in encouraging service users to move beyond the status quo, to think beyond what they know and what they have done before (CEO2). Related to this was the distinction between person centred rhetoric and the reality of person centred approaches in practice. CEO3 explained this as follows:

\[\text{The plan is just a plan, exactly. Your approach has to be person centred; practices are much more important than a person centred plan in my world. You can train people how to write a plan but it doesn't change the attitude. \ldots... This can be a change which traditional services struggle with. CEO 3.}\]

Related to this theme was dissent regarding the place and value of diversity in the market. Whilst some felt it important that group programs remained in order to offer choice, one provider was outspoken in her belief that whilst disability group programs remained, the key principles driving personalisation were diluted and difficult to realise.

6.2.4 Funding the real cost of individualised service provision

The analysis also revealed provider concerns for financial viability, stemming from the real costs of personalised approaches, as a key barrier to transition. Several managers used the term ‘client capture’ to describe how some services continued with practices designed to maintain and delimit options rather than expand opportunities in the broader community. One of these practices was to not adequately explaining the potential of individualised and portable funding due to concerns about what new client choices might mean for their service. For example, a service manager noted the following:

\[\text{It is really interesting how much feedback we get from people when they say that their traditional day program says 'oh don't worry about that letter, just ignore that letter that says you can do something different, everything is fine, just continue on as we are'. To try and basically... still capture people. CEO 3}\]
This manager described this motivation as being about the building of *empire* rather than enabling individual service user goals and interests. For this manager, the practice of separating people with disabilities from mainstream society, in the form of *special* services, cut across ISP policy goals and intent regarding social inclusion and diversity. This theme was encapsulated by another manager as follows:

*If your world is narrowed to just a day service you’re not going to have any other friends, I think it creates a great vulnerability for people. So that’s what we’re trying to open people’s minds up to push against a paradigm... we’re still talking about people with disabilities not being included. And why? Because you’re excluding them.*  
**CEO 2**

However all providers were concerned about the risks of underfunding. It was argued that the DHS hourly rate of $37.30 failed to cover the full cost of quality person centred and self-directed services in the community. One manager described the rate as a ‘co-payment’ for the *real* cost of the service. But she, like other managers, pointed out that many services absorbed these costs because a strict business model and charging for every hour would penalise service users. It would eat into their packages leaving too little for direct services such as personal care and community access:

*So the co-ordinators tend to do a lot that is the case management function but that’s not recognised. That’s all built into that unit cost of $37.30 per hour you have to miraculously do everything in that..........We do everything within the $37.30. Not great, not viable on long term basis but we have made it viable because we have to. ...... It is a co-payment for what the service actually costs but if we took more the person loses hours.*  
**CEO 3**

This dilemma was described by CEO1 as the tension between doing this work properly and keeping the enterprise going. Inadequate funding at the individual level meant that the practice of doing unfunded work had become normalised across many services. Senior co-ordinator 1 described this practice as follows:

*It [support co-ordination] is not something that we are funded for, it’s something we do just by the nature of the organisation we run and relationships.*
Similarly, when referring to community liaison, this provider noted: ‘We do it, that’s one of those unfunded things that we seem to do’. These findings reflect those reported in Chapter Five regarding the way in which support staff and services stepped into the gap left by funding shortfalls. It was agreed among services that charging higher hourly rates and charging more rigorously for all hours worked were not realistic options given the limits of service users’ funding.

At an institutional level, managers also pointed to the cost shifting impact of DHS restructuring and downsizing in preparation for the NDIS and new State and Commonwealth responsibilities. The regional provider believed staff reductions in regional DHS offices had reduced efficiency and effectively shifted extra responsibility and work onto services.

... DHS cost shifting has been really apparent over the past 12 months particularly and with the job costs. It really does affect us. CEO 3

6.2.5 Ideological tensions

Whilst there were similarities in provider’s views regarding the key principles and enablers of self-directed approaches, the analysis also showed distinct ideological differences regarding how to get there. These are important to report given these often quite nuanced differences in service ideologies were not generally well articulated or understood by service users, despite the impact they would ultimately have on how services were delivered and outcomes.

A key point of difference concerned the benefits or risks of separate programs and accommodation arrangements for people with disabilities. Several managers criticised segregated services, such as day programs and group housing, arguing that there was no role for such services within an ‘ordinary’ or ‘typical’ pathways approach. These managers argued that such programs limited people’s expectations and capacity to build new connections and relationships beyond the disability community. This theme is demonstrated in the following quote:

People need to see themselves as people whose place belongs in a community. The community is not in day services, it is with their peers in the world, like everyone else. Senior co-ordinator 2
In contrast, the second category of thought argued there was a role for disability specific programs if they were in the context of choice and supporting individual interests and pathways. For example, CEO1 observed the following:

“You can go too far. It was right for the system to react negatively to group activities but to then swing to the point where you say we don’t want people to do anything in a group well how stupid is that because we all do things in groups.”

This section has described managers’ perceptions regarding the changing nature of their role as service providers, their relationships with service users, and the economic, structural, cultural, workforce, and procedural challenges associated with these transitions. The following section moves to managers’ attitudes and experience regarding their changing relationship with the community. It reveals significant downward pressure in terms of funding as well as constructing organisational mechanisms and delivery processes capable of meeting the anticipated outcomes of individualised funding.

6.3 Interface B - The service and community relationship

Providers agreed on the need for services to adopt a more progressive community development and externally oriented focus. This work involved building strong partnerships with the community and business sector with the aim of creating new opportunities and pathways whilst supporting people with disabilities to participate and connect with these new opportunities and networks. Providers also noted on the importance of building on community resources in creative ways given the reality of ongoing funding constraints.

Notably, managers observed that businesses were less interested in discussion about human rights than in discussion about the reciprocal benefits of making their business more accessible to people with disabilities. One manager noted that leading with a rights based argument risked making some business owners defensive. The more effective approach was for providers to build a relationship with businesses first, to ‘speak their [business] language’, and explicate the economic as well as social benefits of
increasing access to people with disabilities. The following passage reflects this approach:

_We have had much more success bizarrely enough than the rights path...economically what’s in it for them [the business] and then subtly introducing the rights angle. And they have stronger relationships and they say ‘oh yes of course this person deserves this opportunity’. We wouldn’t have been so successful if we had gone in with a heavy handed approach ‘you must do this to your building, you must make it accessible, and you must do this or that……And then we can also add in ‘Oh look at the difference you can make for this person as well..._ CEO 3

Related to this was the emphasis providers shared in building sustainable social capital in people’s lives. This involved strengthening existing natural networks and enabling new ones. To this effect, one manager observed that whilst meeting physical support needs remained an important focus for services, it was social capital which ‘made the difference’ in people’s lives and thus enabling and building social capital was a central service function. This understanding was evidenced in the following quotes:

_Social capital is where people get a life. It’s where people have the richness in relationships._ CEO1.

_It is through the richness of relationships both in the community with family, intimate relationships that sort of stuff, that brings a richness to a person._ Senior co-ordinator 1

To this end, several organisations discussed the use of social capital criteria and outcomes, such as community involvement, as a quantifiable measure of service performance. For example, Senior Manager 1 explained that staff in his organisation were asked questions regarding the ‘connections’ they were helping service users make, how they were drawing on the community, and what type of social capital they were trying to create. This manager described this work as central and as ‘something we have to do all the time’. This manager also described staff roles in this work as community developers, linkers and brokers. These conceptions and expectations had subsequent implications for organisational systems and the skills, attributes, willingness and knowledge of individual workers.
The following section presents findings regarding managers' views on the policy and practice factors influencing their capacity to deliver individualised services effectively and equitably.

6.4 Interface C: The policy and structural context

Managers and planners identified policy, implementation, and broader structural factors which mediated their and their staff’s capacity to work in more person centred, flexible and responsive ways with service users. Reflecting the experience of service users, problems related to: lack of leadership and vision in the government and disability sector; a slow, complex, and inconsistent bureaucracy; and, inadequate resourcing for better lives and the work required to enable self-determination and participation, resulting in cost shifting to services as a matter of practice. The following presents these findings in more detail.

6.4.1 Leadership and vision for cultural and structural change

Managers and planners pointed to deficits in leadership and vision at the government and sector levels as key barriers in the effective transition toward individualised approaches. Most providers believed that whilst the ISP policy framework offered direction and guidelines for change, there were problems with patchy implementation and there was a lack of clear top down and values led vision. It was felt there was a policy ambivalence which did not go far enough in structuring conditions for the outcomes intended.

Several providers also strongly felt that DHS had stepped back from taking a more directive role and had a sometimes unrealistic faith in the sector, the market, and the community to manage the diverse needs of people with disability and to drive the changes required. CEO2 argued that DHS misjudged the community’s energy and capacity for driving service change in the short term. This concern is reflected in the following observation from Senior Co-ordinator 2 from the same organisation:

Many people in the Department have said our role is to create the structures so that people can live the life they want ....... and they're saying that leadership has to come from families, individuals and service providers and they will respond to
that…. But the people I have spoken to have said it is not our role to decide for services how they are going to run their business. Senior co-ordinator 2

There was also a sense that the sector lacked capacity for innovation and change. Lack of ‘talent’ and too few exemplars of what quality innovative personalised services and organisations might look like meant that services had little to guide new practice, slowing down the transition with trickle down consequences for service users. Given these deficits there were concerns that the administrative shift to ISPs risked being little more than a ‘rebadging’ exercise for some services and some service users. This finding confirmed ISP holders’ experience, outlined in Chapter Five, showing very mixed service orientations. CEO 2 explained this concern:

There are not many people going out and getting their hands dirty, practicing it, making mistakes and figuring it out. And there are not many people willing to do that. You have to really work at the grass roots, you have to be in people’s lives.  

CEO 2

It was suggested however that active documentation and sharing of exemplars showing more innovative use of funding would promote sector reform, with improved outcomes for service users:

And once that is done other people could look and say that’s how you do it….. and produce some examples so some people can kick the tyres on them. How did you do that? That’s what it looked like before and this is what it looks like now? How did that piece work?  CEO 2

There were related concerns that given inconsistent leadership and patchy service capability that the introduction of the NDIS might not drive the level of reform anticipated. Some were also concerned that the NDIS might bolster traditional group services because service users would continue to buy what they knew and what was accessible if not exposed to alternate more personalised options. There was a concern that consumer choice within the NDIS would not necessarily equate with greater choice and self-determination if the market and service sector culture did not also transform in line with policy objectives. CEO 2 expressed the concern that although the NDIS might give people more funds and increase ‘the power of the consumer’ it would not necessarily ‘enhance quality of life or culture’ if these people were not also encouraged
to move out of what she called ‘segregated services’ and given options and support to do so.

6.4.2 Administrative inconsistency and funding inadequacy

Providers also confirmed participants’ experience of administrative and funding inconsistency and inadequacy. As with ISP holders and family carers, providers saw this inconsistency as stemming from pressure on inadequate resources as well as diverse interpretations of funding guidelines within and across DHS regional offices. Much appeared to depend on the DHS officer in the role on the day and their understanding of the real level of support people with disabilities required to enable self-determining lives. For example, Planner A described the difficulties she regularly encountered when seeking funding to support basic levels of participation:

We have certain arguments with DHS as the buckets have become tighter and the budget and the flow on effect of job cuts etc. . . . We have conversations where they ask why does this person need travel? Why can’t they just catch public transport? And you have to point out that the person lives in XX, 30 mins from YY and there is no public transport.

Funding inconsistency between regions was also apparent and appeared to be well known among planners, as demonstrated by the following quote:

Cos I came back from that training going ‘Did you know we’re not supposed to be doing supported holidays’ [and her colleagues said] ‘What are you talking about, I just had one approved last week. Planner A.

For both ISP planners, who operated at the interface between policy, funding and the community, there was ongoing stress involved in mediating and managing their consumers’ expectations of reasonable levels of funding and support within the reality of limited budgets and workload pressures. For example, Planner B stressed how difficult it was, in her region, to gain funding approval for anything other than personal care and mileage. She described the following to demonstrate her experience of the type of value judgements administrators made in their gatekeeping role:
...they [DHS] might say, why does this person have six hours of community access per week?'...and it is like, ‘well, how many hours do you go out into the community each week to do the things you want to do? planner B

One planner described the processes around funding approvals as not objective and as ‘very traumatising’ for planners and their clients.

Both ISP planners also described the challenges and tensions in preparing realistic funding proposals given what one described as the ‘changing goals posts’ of DHS approval processes. One planner described the nature of ISP funding guidelines as ‘wishy washy’ compared to the clearer guidelines for other funding programs such as for example, the Home and Community Care (HACC). It was felt that this, combined with diverse understandings of disability among decision makers, contributed to administrative inconsistency and subsequent inequity for people with disabilities.

Also reflecting participants’ experience, providers and ISP planners commented on the deficit based nature of ISP assessment processes, the focus on ‘what people can’t do, not what they can’ and the negative outcomes this produced for service users. Exemplifying this approach were accounts of people having to provide intimate details of impairment related care in order to prove their eligibility for adequate funding levels. The following demonstrates with an example:

-I don’t think there is much dignity in that funding proposal whatsoever, especially in the XX region where it is all deficit based. One of my consumers said when he was doing his DSR he had to put in great detail what his bowel care was and how demoralising that was to put down. planner B

Planners also raised conflict of interest as a key issue given their DHS funding base and location within host services. For Planner B, there was ongoing tension between drafting funding proposals which the funder would accept and developing a plan which represented her consumers’ goals and needs. She had been criticised by an administrator for what he had assessed as her overly ‘aspirational’ funding proposals. In expanding on these examples, this planner pointed to the gap between ISP policy aspiration and her experience of the dilemmas posed in its implementation:
So there is a challenge between what DHS says is an ISP and what it is to be used for and how we are meant to work with people in the XX region. We are told that we are not planners, we are facilitators and we don’t have a role we have a function... [laughing]...that was told to us. Planner B

Time and workload pressures produced by limited planning time, high caseloads, and deadlines also produced tensions between meeting organisational and funding demands and working in the best interests of the person. If targets were not met, there could be a flow on impact of reduced DHS referrals to the agency and further flow on impacts for staff employment. Planner B summarised these conflicts and pressures in the following account:

*I mean the massive discrepancy between what the department tells groups like Advocacy X and our consumers about what we do compared to what they tell us to do and the time limits that they give us to do it. At the moment we’ve got 26 referrals we need to have done by the 21 December. Um, and they gave them to us in October so that’s two months for 26 people to explore community options and do all this stuff that they tell Advocacy X and consumers that we do. But in the background they’re going ‘well, you need to get those funding proposals in to us. So it’s a completely messed up system really.* Planner B

*And also....We have to push them through as quickly as possible or we don’t have a job after December.* Planner B

This section has highlighted the impact of underfunding and related workflow pressures on services and how this contributes to the gap between ISP policy and practice. The following section presents providers’ reflections regarding the importance of community expectations in addressing some of these constraints and in shaping market and sector reform.

**6.4.3 Bottom up, consumer led change in the wake of the NDIS**

Most managers believed that over time and with the introduction of the NDIS there would ultimately be a slow but a gradual ‘bottom up’, consumer led sector transformation. This will be discussed further in Chapter Eight in the light of the findings regarding mediating factors identified in this research. Whilst expressing some caution, most managers were optimistic and buoyant about the opportunities the NDIS
would offer the sector and the community, believing that competition was a good thing and also that community expectations would eventually inform market responsiveness. These views clearly represented a faith in the market mechanisms to eventually improve service quality and responsiveness across the sector:

[in response to services’ anxiety about the NDIS] I say, how is it any different from how Coles deals with Aldi coming into the market place. The government shouldn’t prop that up, that’s called competition and that’s healthy for consumers. People have a right to have choice about their opportunities out there. My argument is that if you provide a good service which is actually responsive to what people want, they won’t leave you, they will stay with you, they will bring their friends. You need to think that it is customer service. You need to be aware of that. Ultimately I think traditional services won’t have a choice but to finally get that. People will vote with their feet and they’ll start choosing. CEO 1

Most managers were also optimistic that the market model would eventually benefit the most isolated and marginalised who, it was acknowledged, found it most difficult to ‘vote with their feet’ by leaving services which were not meeting their expectations. However, as has been evidenced in Chapter Five and will be further explored in the following chapters, the capacity to ‘exit’ or ‘vote with your feet’ is highly dependent upon a number of prior factors, opportunities and conditions. As will be argued later, it is also dependent upon the successful investment in the person to convert potentiality into chosen outcomes through provision of required resources in addition to funding such as advocacy if required, accessible and relevant information, and opportunities.

Related to the above and support for market mechanisms, there was an expectation that the NDIS would allow for and potentially support considerable service diversity. This would include a mix of for profit and not for profit organisations as well as a mix of large and more boutique providers which would each target different groups and needs. For example, one manager forecast that many for profit organisations would ‘pick off the easy work’ whilst the experienced community based not for profit organisations would continue to work with people with complex needs over the long term.

However all providers agreed that in order to benefit from market mechanisms and increased consumer choice in the NDIS there must be an emphasis on consumer rights
safeguards and robust independent complaints mechanisms to protect service users, as well as increased support for individual and systemic advocacy.

6.5 Summary

Analysis of the data produced from interviews with managers and planners has reflected in many ways the experience of service and funding users regarding constraints and enablers of choice and self-determination within the ISP framework. Providers reflected ISP holders’ positive experiences and hopes as well as their concerns regarding inadequate funding, deficit based approaches to assessment and funding, limited service and social innovation, and the risks associated with these shortfalls. Like individuals and family carers, providers identified access to choice and opportunity as either enabled or constrained by the nature of resources available and the processes, relationships and structures through which these were provided and managed. Themes in the data also highlighted issues regarding the cultural and structural challenges providers experienced in the ISP program and, projecting forward, in preparation for the NDIS. Central to each of these challenges was a re-orientation or reinterpretation of the role of services in the lives of people with disabilities and within the community. These findings fell into three overarching themes, each representing an interface or relationship requiring change and reorientation. These interfaces were used to compartmentalise this chapter between: 1) the service and individual; 2) the service and community; and, 3) the service and the policy and funding context.

This analysis highlights the utility of analysing a particular phenomenon or topic from different stakeholder perspectives. While the data shows a general consensus regarding the need for sector transformation, there was some divergence among providers regarding the extent to which services should restructure and evolve. These differences reflected different ideological positions about the role of disability specific group services and pathways to social inclusion for people with disabilities.

The following summarises key themes induced from the provider interviews showing critical factors in enhancing choice, autonomy, and inclusion at the three different levels described above:
• Culture, values and practices which are driven and shaped by the fundamental needs and goals of the person rather than those of the service and workers e.g. ‘person first’

• Community development focus – linking and bridging to existing community opportunities and resources as well as creating new pathways through building relationships with businesses and community organisations

• Relational approaches incorporating a focus on understanding the person in their broader social context and developing a working together approach to delivering personalised supports defined by the person’s life goals and not just their impairment related needs

• Willingness and capacity in services to do the relational ‘thinking, linking, and bridging’ work required to support people in operationalising choice and self-direction. This term refers to the co-ordination, case management, relationship building, creativity and innovation required in resource management and planning

• Adequate funding for the time, services and supports required for flourishing lives, beyond practical and critical care support

• A flexible and committed workforce interested and committed to shaping their practice around individual timeframes, interests, and needs

The following chapter presents the second tier of analysis from a capabilities based perspective and is followed by discussion of the study implications.
Chapter Seven

From Latent Resources to Manifest Outcomes:
The place of Conversion

7.1 Introduction
The previous two findings chapters have shown that individualised funding, in the form of the ISP, produces both benefit and risk, gain and cost. These findings reflect both sides of the academic debate concerning the implementation of individualised funding and competing claims regarding the impacts and consequences of this reform in social support and care. All participants in this study enjoyed some benefits in having portable and individualised funding and increased choice and flexibility in service decisions is unanimously valued. But a significant number of ISP holders continued with difficult lives on the margins of society, a long way from the human rights based ISP policy aspiration and ideals.

This chapter seeks to answer questions about these mixed experiences, why some benefit so well in this system and others do not. It will do so by reporting on a second tier of analysis of the data presented in the previous two chapters. This analysis as explained in Chapter Two draws on a capabilities framework and the methodological approach is described in Chapter Four (Section 4.2.7).

In the first section of the analysis I will present a vignette which draws from the data to exemplify and make visible the dynamic of conversion and the notion of conversion factors. In a capabilities framework this dynamic and these factors create relationships between resources and outcomes which convert the otherwise latent potential of available resources into meaningful action and outcomes. Their absence is likely to distinguish those who benefit and those who continue to struggle within the ISP system or at least, given resource constraints, those who can optimise their capabilities and opportunities as opposed to those who do not, and, cannot. To test this, the second section will draw upon previous analyses. The conversion factors in
these preliminary analyses will be presented in Table 7.1 which systematically reflects the nature of these conversion factors in the data.

Given the limited nature of this study it is unlikely that even a systematic analysis will yield a thorough categorisation of conversion factors. Despite these limitations, the final section of the chapter will elaborate upon the series of indicative conversion categories summarised in Table 7.1 that have been induced from the data and which will provide a focus for the discussion in Chapter Eight and a basis for further research.

7.2 Understanding Conversion Factors

In Figure 7.1 below I present a composite vignette as an heuristic drawing from the research data to demonstrate some of the conversion factors identified in the data operating across a range of levels. Discussion of these levels and how conversion can be understood will follow.
In this scenario, we see a range of positive and negative conversion factors, across personal, socio-cultural, institutional and environmental levels impacting Tom’s freedom to choose the terms of his participation, opportunities and future. Tom has made a choice about his education and the meaningful goal of achieving his degree (a functioning). His determination to do so is demonstrated by the three hour round trip he makes three times a week. At this point the resources that have been mobilised span personal, social and formal spheres and are outlined below:

- personal attributes such as his intellectual capacities and determination

Tom, 21, has significant physical impairments and has just completed the second year of his arts degree. He lives in a regional centre and makes the three hour round trip three days a week to get to university, leaving at 6am. His mother accompanies him to provide personal support during this time. Workers from a Melbourne based support agency have been assisting him with personal care at university and the Disability Liaison Unit provides scribing and study support. However, the Melbourne agency is closing and can no longer offer support. Further, his mother has a chronic health condition which is deteriorating and she does not feel well enough to continue to support Tom on the train. In these changed circumstances, Tom would like to use one of his long term local support workers, whom he knows well and trusts, to support him during travel and whilst at university. He likes that they know him well and can anticipate his needs and preferences. But he will need increased funding to pay for their travel given that his mother did this for free.

However, DHS cannot approve increased funding in time to start the new semester and can give no indication of when his new application will be processed. Amendments to existing plans are treated as notionally ‘new’ within the ISP system, and as such ISP holders return to a queue, otherwise known as the Disability Support Register. Tom cannot start the new semester without support and appeals to the Disability Ombudsman. But his appeal cannot be acted upon in the absence of a final DHS decision against which to appeal. Further, Tom would like to live in Melbourne closer to university but has been on a waiting list for a supported accommodation place for five years already with no sign of a place coming up. Consequently Tom has to defer his course and after six months still does not know when he might be able to return to university. He now spends a lot of time sitting at home watching TV or on Facebook. His funding for support hours is not enough for more than one outing each week. Without university he is feeling increasingly isolated. His mother has reduced her already low part time work hours to offer Tom physical and emotional support whilst he is at home waiting for a funding decision. One of Tom’s service providers has also taken up Tom’s cause and is advocating with a local MP. She is not paid to do this but is doing so out of her sense of justice.
• a network of university friends
• funds for transport through Access Travel Pass;
• funds for support through the ISP;
• a regional transport system;
• support relationships that are trusted, known, flexible, which anticipate his needs and preferences, and which have been shaped by a long term association;
• a progressive service provider the structure, policies and focus of which endorse the person centred approach he values;
• university supports through the Disability Liaison Unit including study support and scribing assistance
• emotional, moral, and practical support from his mother
• a service provider’s willingness and capacity to go above and beyond their role to advocate on his behalf for increased funding with the local MP

The above list indicates a number of capitals or assets including: Tom’s own personal resources; social capital and cultural resources in the form of family and friends, valued relationships, community networks, and as a university student; and, a number of service, program and institutional resources including his ISP package, funds for transport, and university supports relating to liaison support and scribing. There is also further socio-cultural capital in the trusted long term relationships Tom enjoys with his support staff and provider agency. Tom’s relationship with his mother is a central and sustaining capital in his life which acts to produce more capital through new opportunities and connections. All of these are important resources which, given the right mechanisms and conditions are activated to successfully convert Tom’s choice to undertake degree level study into a reality.

It is important to recognise here that the activation or ‘conversion’ of resources is contingent. For example, if Tom had been offered a place in a supported accommodation unit close the university, his resource needs would be very different due to reduced travel support needs and less dependency on his mother. In this situation different resources would be required such as those related to moving and settling into a new area and residence and payment for the CRU. However, the lack of supported accommodation places is a structural level constraint which has set up conditions in
which other resources need to be mobilised. These include not only increased ISP resourcing but ongoing and increased dependency on his mother’s resources, a dependency Tom does not want. There is clearly huge complexity in Tom’s situation and his systems of resources are interdependent and ‘fragile’ – pressure and change in one resource area will have a significant knock-on effect on everything else, as is observed in this vignette.

Changes in Tom’s circumstances produced new resource challenges and served to deactivate some of his resources and place increased stress on others. The following explains how negative rather than positive conversion factors related to what and how resources are delivered constrained Tom’s freedom and right to choose.

We saw in the vignette how the under resourced ISP funding system, labouring under a bank of unmet need, could not respond to Tom’s changing context and needs quickly or flexibly enough for him to continue his degree uninterrupted \textit{(service, program and institutional conversion factor)}. At a systemic and institutional level, although there were processes in place for appeal \textit{(institutional conversion factor)}, the context of Tom’s particular complaint and need were outside the predetermined structure of issues with which the Disability Ombudsman could deal. Tom had no access to other more flexible and responsive avenues for appeal and redress so that he could participate more actively in decisions being made about his funding \textit{(institutional conversion factor)}.

Tom’s geographic location also limited his opportunity to continue studying due to lack of nearby universities with his preferred program \textit{(environmental conversion factor)}.

At a personal and socio-cultural level, stronger stocks of social capital, in the form of more friends and community networks \textit{(personal and socio-cultural conversion factors)}, may have combined to address his access problems in the short term or offer alternative opportunities while he waited for new funding to materialise. His mother and service provider were strong supports, working actively for Tom in their advocacy, support, and co-ordination activities \textit{(conversion)} in an effort to keep him connected and participating in ways which held meaning for him \textit{(functionings)}. However, the increased pressure on his mother came at an emotional and economic cost to her as she worried about his funding and had to reduce her hours of work to support him at home.
Her health condition was also further impacted by Tom's circumstances. Tom's agency manager also absorbed costs by advocating for him in her own unpaid time.

In the changed circumstances Tom's level of personal care needs do not change but the purpose and potential of his support funding has been redirected from supporting him at university toward his goals to supporting him at home where he is bored and non-productive. This situation exemplifies what was argued in Table 5.1. Here the commitment of the same resource (support for personal care) produces different outcomes due to the latent potential of the resource remaining untapped. In university the resource has a multiplying effect as its use is directly aligned with Tom's goals and interests. The conversion and multiplying effect is also due to leveraging off existing social and practical networks of potential and actualised support within the university. In contrast, committed in the isolation of the home, the funding simply contributes to maintaining his situation, does not improve it, and there is no multiplying effect.

This vignette also demonstrates how formal and informal resources interact and adapt to changed circumstances. Now that the multiplying effects of his university opportunity have been stalled and given that his ISP has always offered very limited funding for community access hours, Tom’s mother has converted a key resource (her time) to support one aspect of Tom’s well-being (his connection and social networks) whilst reducing another key resource (income). Notably, as the income to family reduces this too has a fundamental impact on family resources and their capacity to flourish. This vignette demonstrates that the 'unit of operation' here is the family and that this unit typically absorbs costs of systemic limitations. Small changes to an individual’s circumstances can have potentially significant 'knock-on' effects socially and economically for the individual and their supporters. Tom’s situation demonstrates how making funding decisions on purely individualistic terms fails to acknowledge that the ‘operational unit’ for decision-making and active conversion is often a system of interdependent resources within a family or other network of relations.

There are implications here for assessment and planning when the original conditions upon which decisions were made change. When conditions shift, the complexity of resource systems and networks also need to transform and adapt so that they remain capable of supporting the person’s choices without simultaneously undermining those of their family and network.
The findings and the vignette demonstrate the interdependence of the person’s system of personal and formal resources and how deficits or strengths in one area, as well as changes, can fundamentally impact the person’s capacity to access the potential of these resources and the opportunities they can create.

The following section presents in more detail the supplementary analysis of conversion and non-conversion factors or constraining mechanisms as identified in the data.

7.3 A systematic analysis of conversion and non-conversion factors

Examination of the data presented in Chapters Five and Six identifies a range of positive and negative conversion factors influencing conditions and opportunities for participants to take up increased choice and self-determination in the ISP framework. It can be seen that resources and the processes and mechanisms through which they are provided can enable or constrain self-determination, depending on the conditions in which they operate and, often, the willingness and capacity of those involved. The table below shows this range and Sections 7.3.1 to 7.3.3 further explore the tabulated data. In these sections, the data which led to table 7.1 is noted.
<table>
<thead>
<tr>
<th>Resources – Formal and informal</th>
<th>Conversion Mechanisms and Characteristics</th>
<th>Non –conversion or constraining mechanisms and characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Individualised Support Packages</strong></td>
<td><strong>Adequacy</strong> in relation to goals and needs</td>
<td><strong>Inadequacy:</strong> deficit based funding for personal and critical care needs which does not support capabilities and opportunities required for longer term social and economic goals and well being</td>
</tr>
<tr>
<td></td>
<td>• Assessment and funding builds on strengths, capabilities, and potentials rather than deficits.</td>
<td>Informed by:</td>
</tr>
<tr>
<td></td>
<td>• Goals and capabilities based, with needs supported as part of the pathway toward social, cultural and economic goals</td>
<td>• Deficit based assessment, funding and planning</td>
</tr>
<tr>
<td></td>
<td>• Assessment, planning and funding acknowledges, supports, protects and develops social capital i.e. family carers, social, and community networks</td>
<td>• Ignores and does not build on potential and strengths</td>
</tr>
<tr>
<td></td>
<td>• Supports flourishing, well beyond ‘bare minimum’ basic survival needs</td>
<td>Results in:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Minimal impact on person’s capacity to address barriers to social and economic participation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Maintaining not flourishing e.g. ‘holding pattern’, taking ‘one day at a time’, maintenance</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Over reliance on personal and social resources, depleting stocks of social capital and limiting capacity for more innovative use of funding, advocacy, service co-ordination</td>
</tr>
<tr>
<td></td>
<td><strong>Consistency, transparency, equity</strong></td>
<td><strong>Inconsistent and non-transparent</strong> decision making in approval and allocation phases</td>
</tr>
<tr>
<td></td>
<td>• Applies to all phases of the ISP funding pathway, from early stages of gathering information about eligibility, through assessment, planning, funding approval processes and reviews.</td>
<td>Informed by:</td>
</tr>
<tr>
<td></td>
<td>• Reduced complexity and increased clarity of information about rights, entitlements, and processes</td>
<td>• Different ideologies within and across DHS regions regarding social participation and how to fund these goals</td>
</tr>
<tr>
<td></td>
<td>• Greater accountability for DHS decision makers at</td>
<td>• Funding limits placing pressure on DHS regional staff who make decisions on plan approvals, based on diverse understandings of barriers to participation</td>
</tr>
</tbody>
</table>
the regional level
• Access to independent advocacy and information
• Face to face contact with helpful and informed staff, both DHS and service

Results in:
• Inconsistent funding outcomes across and within DHS regions for people in similar circumstances
• Perceptions of people using ISPs and services of lack of transparency and lack of equity

Timeliness and responsiveness of funding decisions and provision offering greater and earlier certainty regarding funding available and how it can be used. Also applies to requests for modifications to existing package.

Delays and waiting periods of more than one year led to uncertainty and exacerbation of social, economic, and health conditions

Complexity in funding and service frameworks acts as a barrier to access and understanding

Flexibility and portability
Shifts control to the funds and service user; allows funding use to reflect the rhythms of everyday life and allows for greater spontaneity and choice

• Capability and opportunity development
• Service commitment to service user choice and autonomy with capabilities and rights based culture and practices aligned to this commitment
• Person centred and rights based culture, values, and practices
• Capability development building on strengths and potentials
• Relationships based in trust and mutual regard
• Based in dialogue capable of managing competing tensions
• Flexibly prioritises service user choice and autonomy to the limits of the individual and organisational boundaries i.e. beyond minimum expectations
• Can ensure continuity of service if this is service user choice

• Inflexible service boundaries and roles which limited and define service user’s freedoms and opportunities
• Working to minimum standards regarding service user choice and autonomy rather than to their limits
• Concerns over maintaining service user base, ‘client capture’, prioritised over service user rights and freedoms regarding choice and autonomy
• Risk averse culture which maintains rather than challenges the status quo e.g. not explaining potential of individualised package, not exploring more creative inclusive pathways toward the person’s goals

Disability specific Services and the market
(Processes and activities are characteristics of services)
- Community development focus, collaboration, and partnership
- Can do the thinking, linking and bridging work required to build community based pathways and opportunities
- Personalised choice making support in the context of relationship and knowledge of the person

- A developed market with enough diversity such that authentic choice can be exercised, regardless of geographic location.
- Robust safeguarding, complaints, and regulatory systems to support and manage the consumer and market relationship

**Planning: Personalised, strengths and capabilities based, emergent**

- Educatve and participatory
- Strengths based and informed by an understanding of the person's social context, resources, preferences, and aspirations
- Specific enough to be funded and broad enough to allow the person flexibility over time in line with changing needs and preferences
- Tailored to the person's needs in terms of time and

- Lack of market diversity and service options, such as in regional centres, reduces choice and ability to use portability feature of funding i.e. to move from one provider to another

- Standardised allocation of planning time regardless of diverse needs, capabilities, and contexts
- Hurried and superficial planning processes which do not coach or educate regarding new skills and knowledge required in the context of individualised funding and services.
- Conflict of interest for planners when managing DHS and organisational demands against those of service users
### Personal and Social Resources/ Capital

**Personal: skills, history, attributes, capabilities/ potential**

**Social: the capital residing in intimate relationships and social networks**

<table>
<thead>
<tr>
<th>Process e.g. different people require different levels of support to gather information and plan for supports they will require</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Planning process supported by people free from conflict of interest</td>
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</table>

#### Skills, attributes, experience and confidence to manage and navigate the demands of individualised funding and services e.g. information gathering, developing local knowledge, relationship management, funds management, choice making

- Material resources to supplement formal funding to ensure desired level of independence
- Social resources to supplement and convert formal funding in line with goals, i.e. to:
  - Provide information, emotional, social and practical supports
  - Support everyday choice making
  - Fill support gaps created by funding inadequacy
  - Link and bridge to community based pathways and opportunities
  - Advocate for improved conditions and resources.

**Independent advocacy, brokerage and advisory supports to build individual and family based capabilities.**

<table>
<thead>
<tr>
<th>Lack of personal capacity, information, and confidence to formulate and pursue choices and pathways and the actions required for this.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of social supports is a significant barrier to operationalising potential of individualised funding i.e. to fill funding gaps, to help create bridging and linking opportunities into the community.</td>
</tr>
<tr>
<td>Exhausting social supports risks potential and capacity to access and convert resources into opportunities</td>
</tr>
</tbody>
</table>
Table 7.1 categorises the conversion factors into three main sub-categories of resources to which they primarily relate: those relating specifically to the individualised support package framework; those relating to disability support services, the community, and broader environment; and, those relating to personal and social resources. The following sections explain these key categories as well as sub categories highlighting those factors which had the capacity to address constraints and enable the conversion of resources into choice actions and outcomes. The factors constraining and enabling conversion are in bold font and off-set to the right hand side of the page at strategic points for emphasis.

7.3.1 The ISP package and process

The scope and adequacy of the ISP package, the timeliness of its provision, and issues related to transparency and equity were highlighted throughout the data as impacting choice and as highly variable. Deficit (rather than strengths) based and narrowly defined support funding limited to mainly critical practical and personal care needs failed to address many barriers to broader social participation. Such funding threatened the dignity of choice and also forced sometimes unreasonable rationing decisions down onto the individual and family unit. More than half of the participants experienced their package as either significantly inadequate or as just offering enough funding to support basic needs. The result as presented in Figure 5.1 is that when only critical impairment related aspects of support and care are funded, it was difficult for participants and their supporters to expand their opportunities for social participation. For example, Therese had only eight hours for paid support each week and most of was needed for her personal care, leaving very little for flexible community access. Other aspects of the funding process were also found to be important, as are detailed below.

Transparency, certainty and timeliness

Transparency, greater certainty and timeliness were also important in promoting the capacity to plan and take control. Gaps of more than one year between applying for support funding and receiving it maintained or increased individual and carer vulnerability. In addition, the inconsistency of assessment and funding decisions for people in similar circumstances was concerning and unsettling for both ISP recipients and providers.
Analysis of the exemplars in the study, such as the stories of Shane, Simon, and Jade, discussed in Chapter Five, Section 5.1.1, demonstrate the above points and the power of strengths rather than deficits based assessment and funding. Taking Simon's example, his package was transformative because it did not only attend to his basic impairment related personal care needs but more importantly gave him scope to pursue the activities, relationships and goals which gave his life meaning and purpose, such as study, writing his memoir, lots of socialising, and weekend camping trips. The amount and flexibility of his package and the fact that he could engage so actively in life beyond the home also offered his mother, a key resource in his life, some respite so that she could return to her interests and other relationships and consider increasing her work hours. This in turn enriched her life emotionally and economically with flow on benefits not just for Simon but for the rest of the family and other people in her life.

Adequacy
The data shows how the adequacy and flexibility of the ISP and its alignment with what adds meaning to a person’s life are central to optimising its impact and effectiveness, as demonstrated in Simon’s example. The analysis underlines how if the intent of the ISP is to be realised there must be a move beyond the medicalised assessment of need to a more holistic and comprehensive assessment of the resources required for people to flourish. For Simon, it was about being able to engage in the mainstream and away from disability specific services to pursue educational and social goals. For Jade, this was about living independently, and for Jess, this was also about living independently in her own home, adapting it and getting the paid supports she need to ensure she could remain there as her physical condition changed and support needs increased. Adequate and flexible funding gave her important control over the timing, content, and quality of her services.

Adequacy therefore is necessary but not sufficient on its own, particularly if funding guidelines restrict more autonomous and flexible use. It was also important that the structure of the ISP and associated planning recognised, leveraged and supported other available resources and opportunities in the person’s life. It was the difference between, for example, slotting someone’s needs and goals into a predetermined package allocation and instead tailoring a package of supports around a person’s life, context, and meaningful goals. Bess and Simon’s experiences and the importance of their family
and social supports highlights the critical importance of incorporating family carer and whole of family's needs during the assessment and planning stage.

Adequacy of funding, transparency, timing and certainty are key factors supporting conversion as are a strengths-based non deficit approaches to assessment and planning.

It was also clear that funding and planning often failed to account for the secondary or articulation processes associated with enabling and operationalising choice and opportunity. As has been repeatedly shown, there was generally little funding for the time and energy required to think, plan, source and co-ordinate community based pathways. Instead, this work was typically taken up, unfunded, by the ‘operational unit’ i.e. the individual, family, and services or, for those without such supports, did not take place.

Support funding and planning must recognise the secondary (‘articulation’) work processes required to enable self-determination and expand opportunities for more typical and inclusive pathways. This work involves time, energy and capability which are key to converting resources into meaningful outcomes.

Planning and review
The analysis highlighted the importance of the planning process in managing the balance between optimising and supporting natural resources in participants’ lives, such as their personal attributes, the time, energy and commitment of family and friends, and opportunities in the broader community. Problems existed when planning was undertaken by professionals with only a superficial understanding of the person, their goals, and their broader social context. Time limits for planning, imposed within the ISP framework, further impacted the quality of the planning process and the capacity of the planner to develop a relationship with the person over a longer period. This was particularly problematic for those with more complex needs and circumstances. Some participants were also troubled by planners who did not
understand their histories and the challenges of developing realistic choices and goals. There were also experiences of planners who appeared more focused on compliance and regulation and on what people should not do with their funding rather than testing the boundaries of what they could.

For example, Nancy, who was unfamiliar with the disability and funding sector, described her planning as transactional and highly unsatisfactory at a time, soon after her brother’s illness, she needed support and information over time about the potential rather than limits of her brother’s package. The following quote demonstrates this concern:

*It’s just so hard to predict and because they made it sound like it wasn’t really able to be changed. They made it sound like this is it and that’s that. And in a year we will reassess but that year never came. No one ever came back.*

In contrast, other participants highlighted the benefits of planning which offered a supportive, coaching, and educational role. For example, Mandy, support worker to Bess, commented on how useful and informative the ISP planner had been in easing Bess’ father’s anxiety regarding the transition to new ISP funding.

*We needed more strategy on what to do because it is a lot [his daughter’s package]. … And it works well now. Planner X……I remember thinking wow that is fantastic. And they really came in and helped work out the extra times, the extra hours for Andrew too……….. And by having XX come to the forefront it’s been wonderful. It’s been great. Otherwise we wouldn’t have been able to do it.*  Mandy, Support worker

Similarly, Val praised her planner’s skill and foresight in mapping out a ‘global’ and far reaching plan, specific enough to be approved, but flexible enough to allow her to decide where her ‘priorities’ lay.

The review process, designed to occur every three years or at the person’s request, was also described as inconsistent and limited in its quality and usefulness. While for some it served as a useful tool in ensuring plans and funding reflected real life needs, for others reviews felt simply procedural. Candice did not know she could request a review within the three year time frame. A consequence of this was that, for some, their plans
did not adequately reflect changing circumstances and needs. It has been shown that changes in life circumstances will have major ramifications and ‘knock-on’ effects. Without adaptability in the system and more flexible ways of meeting changing needs, there is the risk that as circumstances change, the potential in resources may be untapped or conversely overly stressed.

The above findings highlight the importance of the planner and the planning process understanding and being attuned to the diverse and individual needs, goals, and circumstances of the person. Knowing the person, their priorities, histories and hopes was a central but sometimes unacknowledged aspect of planner competence and the planning process.

Related to this was the importance of flexibility and innovation, particularly when planning pathways beyond traditional disability services. Innovative thinking about funding use was shown to mobilise the potential of the funding package and other resources, as in Simon’s conversion of his disability camp funding into personalised weekends away. This was also critical in the context of limited resources, both formal and natural. Flexibility and innovation are thus a key and vital theme in the data and applies well beyond ‘individualised’ planning:

Conversion is facilitated by a person centred and flexible planning process where the person, their priorities, strengths, histories and goals are known and central and where the system is adaptable to change and the repercussions of change on the conversion of resources.

The data showed that in some cases, rigidity in how ISP funding could be used, or lack of clarity regarding spending rules, was a constraint on participants’ choices and self-determination on a day to day basis. For example, both Nancy and Val used their own money for various disability related supports because of either delays in approval from DHS or being unsure about whether ISP funding would cover certain items. Greater flexibility in funding guidelines and transferring more control to the ISP holder would go some way to addressing these frustrations.
The analysis has also consistently highlighted the many benefits to participants of increased flexibility in the timing and nature of services. This allowed for greater spontaneity in everyday life and choice in who provided services and how. Examples include: being able to roster for unpredictable lives and fluctuating symptoms (especially last minute roster changes); negotiating preferred workers; accessing support in the evenings and weekends; having more spontaneity and independence of movement and travel; and, banking, saving and converting hours to accommodate changing needs and circumstances.

The portability feature in the ISP was central to increased levels of choice and control in services, giving participants the option of leaving services and moving to those better able to meet their needs, including non-disability options in the community. For example, Dolores, Nancy and Jess described the autonomy of being free to actively manage and move between services in order to find the best fit for their needs and circumstances. Dolores and Simon also gave numerous examples of innovative conversion of his package funds including converting his disability group camp funding to personalised weekends away with a friend. Kate and Bess were able to reduce their day program days for home and community based time, Jade was freed to use her funding for very flexible supports in her new accommodation, and Nancy and Shane used their funding to keep life as ‘normal as possible’ by supporting Shane at home and using funding to maintain many of his previous interests such as going to the football and seeing friends. Such flexibility and portability shifted power and control toward the funds user, and potentially changed the nature of service and service user relationships.

Some participants, such as Nancy and Val, found ways of increasing their control in services, circumventing the limitations of the system to further optimise this benefit. For example, Nancy sometimes paid her ‘good’ support workers for hours not worked as a way of informally increasing their wages and building loyalty with those she wanted to retain. Whilst this was not legal it was a functional way for her to ensure she and her brother kept a team of preferred staff. Some participants also spoke of organising rosters directly with workers, circumventing agency procedures, whilst others chose to reward preferred support workers by choosing them for concerts and events:
I know the carers love coming out with me on community access and that is why I try to get the carers who have been very loyal to me I like to take them out and give them a change and give them free movies or pay to go to lunch.
Val, ISP holder

But not all participants were able to optimise the potential of funding portability. Some participants were not in a position to think through and negotiate such changes; moving services was more difficult for those with complex support needs especially where there was a long history with that provider; and one participant had not understood he could change providers for some time after receiving his ISP. For others the level of resources meant there was little scope for flexibility beyond critical care needs. Some also had limited information about other services and were restricted in their capacity to make an informed choice.

Conversion took place where there was flexibility and innovation built into the system of support. On many occasions people built in their own flexible arrangements to overcome service-related barriers. However funding level, capacity to take control of decisions, lack of information about options, and complexity of support needs often acted as barriers to innovation.

Information and communication
As indicated above, accessible, timely and personalised information was shown to be critical to informed choice and the capacity to optimise the potential of available resources. Lack of information and understanding of the disability service and funding system as well as mainstream community options was a key barrier to acting with greater agency. This was particularly so in the early stages of planning. For example, Candice described the difficulties of operating with only bits of information, the accuracy of which was sometimes questionable. She described a previous provider who ‘didn’t tell me anything. I wasn’t even aware of the amount in my package’. Several participants also found the ISP funding guidelines as ‘quite vague’ and not specific enough yet at the same time ‘overwhelming’ and ‘too much to be useful’. This then impacted choice making. It was difficult to gather information when new to a system
and unsure about the questions to ask, as demonstrated by Candice’s circular conversation with a service, reported on in Chapter Five and demonstrated in the quote below:

One time I rang them [a support service] because I didn’t know what I needed but knew I needed some help. They said well what do you need? I said well I need to know what is available to know what I need. Candice, ISP holder.

Similarly, Nancy also needed personal advice and information in the early days of receiving her brother’s package however struggled to find this from her planner or her services, as the following quote exemplifies:

It’s so hard because I had just got Stu home in the October and she was there in March and at this stage you really don’t know what you are doing. So you really need to have someone who is driving it.

It was also evident that much useful information appeared to be through informal sources and by chance. For example, Dolores only discovered that TAFE offered free support worker assistance when someone ‘happened to mention it’. This was critical information for this family as it made TAFE study a realistic option for Simon and freed up part of his package for other community based participation.

Conversion can only take place where the person is able to use information and where the information is timely and reflects their needs and interests at that moment. Too much information, not explaining and personalising the relevance of information to needs and circumstances and being vague all acted as barriers to accessing resources capable of converting to their chosen outcomes.

Section 7.3.2 below takes up a more systematic examination of conversion features related to personal and social resources identified in the data.
7.3.2 Personal and social resources and capital
The new self-directed framework placed new demands on individuals and families related to conceptualising, planning and co-ordinating supports and services using both disability and mainstream community based options. This work required new skills and knowledge, time and energy, the capacity and confidence to take up new responsibilities, and the related capacity to negotiate and advocate. As the data shows, not all participants were equally skilled or confident to do this and the funding and service system did not consistently recognise or ameliorate the inequity created by such diversity. These conditions left some participants at a disadvantage regarding how best to convert funding to outcomes. Conversely, those with experience and skills were better equipped to modify and manipulate the system.

Advantage was also created for those with disposable material assets over and above ISP funding. Personal material assets leveraged the support package and operated in many ways as a buffer against inadequate and delayed funding. For example, because Jess owned her own home she could modify her flat to her liking and dictate the terms of her accommodation, staying close to family, friends and community. As her condition deteriorated, she was confident she would be able to maintain her independence because her personal funds could buy in the additional supports and modifications she would require. Similarly, Dolores did not have to work full time and could support Simon at home, thus freeing up more of his funded support hours for other purposes. Conversely, those without access to these personal assets were more vulnerable to and dependent on formal funding and services.

Succeeding in the self-directed system called upon skills, knowledge, and capabilities related to informed choice and operationalising goals. But not all participants had access to these skills and attributes and formal systems to assuage this disadvantage were patchy. Lack of these prerequisites acted as a barrier to conversion. Personal material assets provided more opportunities to convert additional resources into valued outcomes.
Social capital, manifest in the value of relationships and networks, was also identified as a key resource, enabler and outcome within the ISP system and beyond in everyday lives. Valued relationships with family, friends and networks in the community enabled and supported use of other resources, improved advocacy and negotiation with services, and connected participants with further networks and opportunities in the broader community through recreation, work or study. There were examples of some service relationships operating as a form of social capital in people's lives, operating as quasi friends and ‘family’ when natural networks were limited. Jan, for example, said that:

*And we (she and her workers) have such a good relationship. They’re like family. And they said can we help you in any other way.*

Building social capital is key policy intent of the ISP program and a goal for most people. Those with strong family supports and friendship networks were clearly emotionally, financially, and practically advantaged within this framework whilst those without were more vulnerable to the vagaries and inconsistencies of the system. Although service co-ordination was a funded option, only two participants paid for this service due to the cost and also lack of clarity regarding its benefit.

*Social capital is a resource in itself as well as a key conversion factor and desired outcome of a successful support funding framework. But where lack of funding stresses these resources, their potential is constrained if not threatened and limited to maintaining existing conditions rather than supporting growth.*

As identified above, family carer advocacy was particularly critical as funding arrangements transferred to ISPs and in the context of a transitioning service sector, uncertainty, and uneven service approaches. Family carers Shirley, Nancy, Dolores, Sally, and Andrew each emphasised the importance of being there for their family members, advocating and negotiating for conditions and resources with DHS and services. For example, Nancy observed that she would ‘hate to think’ what might have happened to her brother if she had not been there to monitor staff quality and service delivery as well as make service changes on his behalf. Similarly, Dolores spoke with
some exhaustion of her three efforts to secure an adequate ISP for Simon, and Sandra
described her ongoing efforts in trying to find affordable community based options for
her daughter Kate as well as her role in advocating for Kate's rights at her CRU.

These conditions correspondingly highlight the disadvantage for those with few or very
weak social supports and who were limited in their own capacity to operate within the
ISP framework.

Support networks of family, friends and others have an
important role to play in advocacy, negotiation and
innovating alongside the person and are particularly
critical for those who cannot do this for themselves.
These roles convert and multiply potential outcomes,
and their absence for those who are isolated or unable
to advocate constrains choice and self-determination.

7.3.3 Services, the community, and the broader context
Disability service providers and generic community services were key resources in
participants' lives with the power to significantly shape and influence their experience
of choice and self-direction. However the analysis in Chapter Six showed significant
diversity in approaches to 'individualised' services. Importantly, differences in
approaches and the consequences these might have on choice and opportunity were
often not explicitly revealed to service users. It was not apparent to some participants
that other services may have been a better fit for them and it is clear from the analysis
that more nuanced information about service ideologies was not well or easily
communicated within the current system. Although funding portability gave
participants the option of moving between services, this was for some notional rather
than real given lack of information about how services actually worked or real options
to move to another service. Indeed the grounds for decision making were often based
on considerations other than quality such as proximity, convenience, concerns
regarding the upheaval of moving, and comfort with existing relationships.

Informed choice and the capacity to convert resources
relies on service users having accessible information
about service approaches and assumptions but such information is currently often not visible or easily known. Choice also relied on the availability of suitable options and capacity and support to make changes. Not having such information, support or options challenges notions of the rational consumerism in this funding and service context.

Relational approaches
Trust and continuity of support relationships were shown to be key enablers in the everyday processes of choice and self-direction. Continuity of support was highly valued because it grounded service in the context of relationship and did not silo needs. Continuing service relationships operated on a more holistic understanding of the person’s practical, social and emotional context and preferences. All participants bar one spoke of valuing continuity of care and choice of worker, including the right to choose different workers for different activities.

Related to continuity was trust. The many accounts outlined in Chapter Five demonstrate participants’ desire for multifaceted care and support located in the context of a trusted and continuous relationship. Trust laid the basis for the ongoing dialogue and negotiation both parties needed for planning and the new thinking which individualised arrangements and community based pathways required. Norms of trust were developed over time and built up social capital which further contributed to participants’ sense of well-being. For example, Nancy commented on the friendships she built with support workers whom she ‘welcomed’ into her home ‘every day’.

Relational rather than transactional service approaches offered personalised and proactive services rather than approaches which just ‘filled shifts’ or in other words commodified people’s support and care needs. For example, Jess left one service because of their continued failure to appreciate her need to have rosters sent in advance as well as warnings of staff changes. She selected a new service based on her belief they understood and acknowledged her needs in a way her previous provider could not.
Respect and dignity in service interactions was in itself a valued outcome for many participants, demonstrated by services and individual staff caring enough to go ‘above and beyond’ their official role boundaries. For example, Therese commented several times on how much one of her providers seemed to care about her, as demonstrated in the extra advocacy work this agency took up on her behalf beyond what they were being funded to do.

\[
\text{[Name of service provider] go outside the job description and help with all this other stuff, they make an effort, they care about the clients.} \quad \text{Therese}
\]

This was in contrast to another provider which she felt didn’t care, ‘couldn’t be bothered’, and which failed to understand her as a whole person.

Reciprocity in these relationships also held benefits for providers. As outlined earlier, several participants described their pleasure in rewarding and treating individual workers, describing them as friends.

However, competitive conditions created by lack of staff further compromised participants’ choices regarding worker selection and continuity. Contract staff called in to fill staffing gaps were experienced by some participants as providing a poorer quality of care, devoid of the benefits of relationship developed over time.

For example, Bill was frequently sent contract staff by his provider and although he complained about neglect and poor service quality he was told by his provider to ‘just try harder’. He was told that staff shortages meant there were no other options. His long term support worker, Carol, confirmed the problem and noted that the agency was ‘having issues trying to fill the shifts with decent people’. Bill could not cancel these shifts as had no other supports to call on.

In terms of shifting relationships, there seemed to be a general acceptance by both providers and service users of the emergent and sometimes ambiguous nature of the relationships as formal service boundaries and roles blurred. Whilst benefits existed, when participants and support workers engaged with each other in more complex and personal ways, relationships and expectations challenged traditional notions and power relations of the provider user relationship. The findings showed that not all services
were comfortable with this transition, with some preferring instead to maintain
traditional service boundaries and demarcation lines between service and service user.

Further, although working ‘outside the job description’ was appreciated by service
users and perceived as a sign of caring, there are potential risks to both parties in the
context of such boundary blurring and sense of emotional obligation. Just as family
carers absorbed many transaction costs in this system so too did services and
individual support staff. The potential risks and costs to paid staff in feeling obligated to
fill undocumented gaps in a service user’s funded supports reflects concerns in the
literature regarding risks to workforce in the context of individualised funding and
service approaches. These risks are associated with overwork, underfunding, and
emotional over involvement and feelings of obligation and responsibility for the person
(Rubery & Urwin, 2011; Laragy et al, 2013). The implications of these risks for
workforce policy reform and practice is an area requiring further focus through
empirically based research as the field evolves and role boundaries continue to morph.
These implications will be discussed in more detail in Chapter Eight.

Whilst the potential for these risks must be acknowledged, this research also revealed
the benefits associated with service willingness and capacity to manage shifting role
boundaries in efforts to support changing service structures and to explore innovations.
Services’ capacity to engage in new forms of relationships with service users, to work
holistically, and to manage transitional ambiguities were shown as important workforce
capabilities in the context of personalisation.

Collaborative approaches in which there was ongoing dialogue were also important in
managing potentially competing interests such as, for example, tensions between
service user need for flexibility and the organisation’s need for systems and routine. For
example, both Jill and Jess appreciated that they she could cancel a shift at late notice
because of changing personal plans. Jess gave the following example:

_I just rang yesterday and said I really need to go shopping till 12.30 and they_
_[provider] rang me back and said so and so could do it but could you just go till 12.
_I said, yep, OK. Jess, ISP holder_
Dolores also described the importance of dialogue and collaboration with service providers in her efforts to produce and manage more flexible supports, in line with Simon’s changing needs:

I’m e-mailing, talking to someone, meeting with other people regularly. I’m always in talking to the [Provider Name] to the girl who runs his package every second day. Dolores, family carer.

The findings highlight the importance of collaborative approaches, showing that participants’ confidence and empowerment to take up the opportunities of individualised support resourcing was clearly shaped by the parallel capacity and willingness of services to enter into participatory working relationships. Participants who felt enabled by their service described a sense of shared responsibility and power in how services were negotiated and provided. Collaboration was characterised by a working together rather than a working for approach. It involved working at the boundaries between support and friendship, challenging older models of ‘traditional professional care’.

7.4 The resources and capitals cycle.

The findings in this chapter have highlighted the interdependent nature of participants’ combined formal and natural resources within the ISP framework and how deficits or assets in one area can deplete or sustain resources in another. This has flow on and often unintended consequences for choice and self-determination. This analysis highlights the ISP package as simply one resource within this complex pool. The findings have also demonstrated that activating the potential of each form of resource relied on the characteristics of the resource, the mechanisms through which that resource was delivered, and the conditions in which it was accessed. Further, because of diverse personal and social contexts, participants were differently able to access and
optimise their resources. And yet formal systems did not consistently recognise or deal with such diversity.

The analysis has demonstrated how when certain enabling characteristics, processes and conditions were in place, formal and informal resources could animate each other to produce outcomes greater than their individual constituent parts. When this occurred, as for Simon, Jade, or intermittently for other participants, a positive and sustaining capitals or resource cycle was induced with multiplying effects. It was clear that strength in participants’ personal and social resources enabled them to more effectively access, operationalise and optimise their formal resources. In a similar way, holistic, adequate, and goals based funding worked to nurture and develop social capital in participants’ lives.

However, when stocks of personal and social resources were excessively fatigued through over reliance and lack of formal resources, extra pressure was placed on other supports in their lives, such as services. A negative resources cycle developed here where it was difficult to access new opportunities or progress goals beyond day to day living, so contributing to the holding pattern phenomenon several participants described. Thus, the findings showed how a positive capitals cycle could be either disrupted or facilitated by key factors within the context of individualised funding and services. When deficits in one or more of these resource areas placed stress on the other resources, the analysis shows a series of transaction costs were absorbed by individuals, families and/or services.

Compensatory practices developed to account for the pressure being placed on families, inadequate funding, or lack of viable service options. These adaptive practices then reduced the potential of each resource to enable conditions for the person’s greater choice and self-direction. Examples of adaptive compensatory practices included swapping community access hours for personal care and reducing expectations to fit with limited opportunities. At the service level, there was evidence of support staff working unpaid hours and providing supports they were not funded to do such as case management and advocacy.

These findings demonstrate the central role of formal funding and service approaches in protecting and building upon personal and social resources and capabilities. They
consistently demonstrated that positive experiences and outcomes were accomplished when participants’ personal and social strengths and resources were recognised and supported as a key resource and enabler as well as a desired outcome.

7.5 Summary of key findings

The following summarises key findings from this chapter’s analysis.

- Assessment, funding, and planning need to recognise and resource the work and processes required to operationalize choice, self-determination, and participation in everyday lives. This core work has been described as the thinking, linking, and bridging activities and processes which effectively convert or translate formal and informal resources into the meaningful opportunities participants valued. This work has been typically underfunded and absorbed by families and services. This has paradoxically stressed and sometimes threatened the key resources in people’s lives.

- A deficit based assessment model which focuses primarily on critical care needs and what participants could not do rather than on overarching social and economic goals limits people’s capabilities and opportunities to break out of their holding pattern and participate on their terms.

- Self-directed planning is only effective when collaborative and strengths based, when the person is well known in terms of their priorities, social context, history and goals, and where the system is adaptable to demands and changes.

- Lives are complex and even small changes in the resources for conversion or the roles in that conversion magnify the effect on all others.

- Information about services may not adequately explain or communicate information about the processes and detailed delivery nor the unspoken organisational arrangements upon which such services are built. Once engaged with an agency, it can be difficult for some to explore other perhaps more suitable service options, particularly when needs are complex and information is incomplete or difficult to gather and understand.
• Provision of services through relationships of trust and respect where critical. Most participants valued continuity of support relationships for the practical, emotional, and social benefits these produced.

• Social capital, in the form of intimate relationships and broader networks of support is a key resource, conversion factor, and desired outcome. These supports advocate and negotiate for those who cannot do so themselves and also enriched quality of life and opportunities. But not all participants have access to these supports, despite their importance in the self-directed framework. Lack of voice is significant for those who are most disadvantaged or who cannot independently optimise the system to their advantage. The lack of support from community based advocacy as well as independent advisory services was notable and points to the need for improved investment in these resources.

• New forms of relationship between service providers and service users are testing traditional boundaries and notions of professionalism. Through the blurring of these boundaries producing greater opportunity for new thinking and innovation.

• The funding and service system tended to lag behind participants’ desire for more innovative use of funding in line with the goal of more typical mainstream pathways. Organisations which were willing and able to adapt and respond to the changing individual and community expectations enabled new opportunities for service users.

• Social networks produce additional gains as the resources held in those networks get converted into relationships that matter to the person. They are often organic and emergent and exist independently though linked to services and funding. These networks are nourished or threatened by the degree to which they are recognised and resourced in ISP funding and planning.

These findings are taken into the discussion chapter to follow. This chapter will summarise how the findings of this study informs the literature, policy and practice as well as its more immediate relevance to the implementation of the National Disability Insurance scheme in Australia.
Chapter Eight

Embedding conversion for choice and self-determination: A discussion of the study’s findings

8.1 Introduction

Whilst the findings from Chapters Five and Six confirm previous research by identifying dichotomised experiences under individualised funding arrangements, Chapter Seven has clearly shown how such diverse outcomes are produced in the system. This chapter seeks to further explore the nuances of these conversion factors, the capability-based term adopted by this study, and discusses the policy and practice implications of these findings.

This chapter will first reprise the debates from Chapters One and Two. Understanding the implications of the study findings for these debates is critical in the Australian context as the government, market and community prepare for the national roll out of the NDIS from 2016 onwards. The introduction of the NDIS represents the community and government’s faith in market mechanisms and individualised approaches and offers, potentially, one of the most significant opportunities to reform the lives of people with disability (Goggin & Wadiwel, 2014). The study findings are therefore timely and current despite the data being collected prior to NDIS adoption and implementation.

The chapter will go on to discuss the key findings in relation to the tensions and debates outlined in the introductory chapters in an effort to offer new insights regarding the conditions in which the potential of individualised funding and services may be optimised by people with diverse capabilities in diverse contexts. It is argued that the findings go some way to explaining the mixed experience of advantage and inequity from different stakeholders’ perspectives and in doing so help explain why some
benefited in this system and why others did not. The chapter will also discuss how risk as well as benefit has been individualised within this funding framework.

The dynamic of conversion is presented as a fresh way of understanding the mechanisms and forces, across personal, social, programmatic and contextual levels which constrain or enable choice and self-determination. In line with others (Clarke, 2005; Terzi, 2005) I argue that a central measure of a policy framework’s social justice impact is a focus on conversion and commitment to the structural and institutional reforms necessary to create conditions in which people have the ‘real freedoms’ to achieve better lives. The capabilities approach therefore addresses the study aims and interests in applied human rights and, in particular, choice and self-determination.

Importantly, it will be argued in this chapter that a capabilities based analysis exposes the flaws in a policy and program logic which assumes a direct causal relationship between individualised resources and choice in services and an expanded social citizenship. The findings consistently highlighted how increased choice and control in everyday service decisions, whilst valued, can continue to co-exist with ongoing marginalisation and exclusion from valued social and economic opportunities. We have seen how a transactional form of individualism within social support and care can reduce opportunities for collective voice and representation and potentially cut across the relational building blocks of interdependence, trust and partnership necessary for social connection. This study therefore strongly reflects the cautioning literature in demonstrating that the significant potential of individualised funding reform may remain limited to individual benefit if not also embedded in the fabric of social relations and the structural and social arrangements which shape these. The analysis also highlighted the interdependence between needs, goals, and rights and the need for this interdependence to be reflected in assessment, planning and resourcing processes. Choice as an organising principle was thus shown as potentially limited in addressing barriers to citizenship in the absence of correlate social, economic, and structural innovation.

Finally, this chapter concludes by showing how a capabilities based analysis, in following Sen (2012) and framing core capabilities as human rights, helps clarify the role and obligations of the state and other duty holders in this funding and service
framework. These duties include ensuring access to the foundational capabilities and opportunities people require for good lives, particularly regarding social, cultural and economic freedoms. I argue that the responsibility for meeting the diverse needs of diverse communities, and ensuring consistent and equitable access to critical capabilities and opportunities cannot be left to market forces alone. I argue based on the analysis, that the state and the market, as duty bearers and stakeholders, must work together to ensure the structures, processes, and conditions people with disabilities require to convert the potential of their combined resources into lives they choose and value. Central to this argument is to understand choice, self-determination, and participation as ongoing processes and means toward meaningful lives and not as fixed end points (Dean, 2013). Systems and resources must therefore be directed toward supporting informed and active participation in these processes at all points in the funding and service pathway.

8.2 A Reprise of the Literature

Chapter Two canvassed the significant empirical support for individualised funding approaches. It reviewed the international and local research showing positive personal and social outcomes for individuals and families produced through more choice, autonomy, flexibility, service quality and control over supports and activities (Fisher et al., 2010; Laragy, 2010; Ottman et al, 2009; Carr & Robbins, 2009; Chenoweth & Clements, 2009; Arkesey & Kemp, 2008; Williams, 2007; Stainton & Boyce, 2004; Glendinning et al, 2000). It has been argued that individualised funding programs shift the levers of control toward people with disabilities and their families and reduce the influence and interference of professional and bureaucratic decision-makers (Dozar et al.2012), positioning people with disabilities as architects of their own lives (Rabiee & Glendinning, 2010; Lord & Hutchinson, 2003). In line with these arguments, individualised funding as a mechanism for promoting choice and self-determination has been vigorously supported in Australia and internationally by systemic advocacy and user-led organisations as a significant advance on the inadequate funding and service systems of the past (Rioux et al,2011; Barnes, 2007).
Others have argued that personalisation and individualised funding leads to economic efficiencies for public authorities (Stainton 2009, 2006). Factors contributing to this include reduction in bureaucracy derived from outsourcing the costs of care organisation and in some countries savings made when people employ relatives as care assistants on lower wages than would be paid to professional agency staff (Arksey & Kemp, 2008). Choice has been promoted as a central device for managing inequity and addressing inconsistent service system standards (Clarke et al, 2007; Arksey & Glendinning, 2007), a means of producing more flexible supports (Yeandle & Ungerson, 2007) and a way of maximising the market’s redistributive capacity (Greve, 2010).

This research has empirically confirmed the potential and many of the benefits of individualised arrangements as outlined by proponents and the empirical literature. These have related largely to increased choice and flexibility in day to day services and, for some, increased opportunities to pursue significant social and economic goals associated with independent living, study and different forms of social participation. The analysis also highlighted the significant practical, social, and relational benefits associated with having greater influence in choice of services and the individual workers so intimately involved with everyday support and well-being. These benefits included participating and collaborating in service decisions and the value participants placed on responsive services offered in the context of familiar and trusted relationships built over time. Trust, a sense of partnership with services and individual workers, and continuity of relationship were shown to be important in creating the conditions in which participants could explore more personalised, ‘typical’, and community based pathways in line with their goals and aspirations.

Portability of funding was shown to be an important ISP feature and critical for some participants in their efforts to optimise their independence. However the benefits of the portability feature relied very much on the person’s actual capacity to execute a service change given variables such as knowledge of their right to ‘exit’, informed understanding of other services options and how these might differ, and the actual availability of other affordable and accessible alternatives. Having the confidence to change services was also a factor, particularly when there was a long association, complex support arrangements, and concerns regarding the administrative and emotional challenges of transfer.
Ultimately, the findings confirmed that participants and their family carers valued any increase, no matter how incremental, in their level of individual choice and control over services and, flowing from this, greater spontaneity and control in everyday life decisions. Unsurprisingly, these findings reflect the broader literature driving the individualisation of support funding which unambiguously supports the notion of services shaping more closely around individual needs and preferences and giving people and their supporters more choice and control in their lives (Duffy, 2011; Leadbetter et al, 2008). The findings show that there were many winners in respect to the above matching at least some of the key aspirations of ISP policy.

However, the literature also outlines significant tensions and constraints to choice and self-determination within individualised funding arrangements which persist despite being identified and discussed (van Toorn & Soldatic, 2015). Many of these were reflected in the mixed findings from this study and continue to point to the gap between policy intent and the everyday experience of people with disabilities using support funding and services. These concerns are outlined below in conjunction with key findings from this study.

The tension between the personalisation rhetoric and the reality of inadequate funding levels (Henwood & Hudson, 2008; Spall et al, 2005) was evident in the findings where, funding shortfall, inequity, and inconsistency, provided some participants with only enough support to meet basic impairment related personal care needs. Figure 5.1 showed how such limited support funding failed to support higher order aspirations associated with inclusion, participation, self-determination, and active citizenship. For some in this study, despite benefits of flexibility and choice in day to day services, there remained an overarching theme of living on the margins of everyday community and the ‘life chances’ (Barnes, 2007) people without disability regularly take for granted. Titchkosky (2012) describes this marginalisation as living at the ‘end of all that counts to be human’ including opportunities for work, leisure, love and home. This finding reflects ongoing concerns in the literature regarding the persistent ‘lack of opportunities for meaningful choice, participation, and autonomy’ despite legal reforms and market mechanisms designed to produce these opportunities and outcomes (van Toorn & Soldatic, 2015, p.110). The analysis showing these shortfalls points to a form of human rights ‘ritualism’ (Charlesworth, 2012) whereby aspirations upon which policies and
programs are marketed are in many ways lost in the translation to implementation and practice.

For example, inconsistent administrative decisions across DHS regions which seemed at times disconnected from the reality of people’s everyday needs became the ‘public policies’ participants experienced, reflecting Lipsky’s commentary on street level bureaucracy (1980). This contributed to the ‘operational gap,’ warned of in the literature, between espoused disability policy, everyday practice and participants’ lived experience (Kendrick, 2009). There was a lack of responsiveness and agility in the ISP system evidenced, for example, by the long and uncertain waits on the Disability Services Register and the time taken to respond to new and changing funding needs. During this period participants were ‘on hold’, limited in their capacity and agency to plan, caught in a welfarist rather than an entitlement culture (Foster et al., 2012). Lengthy and uncertain waiting periods also risked already precarious health and social wellbeing and cut across the principle of early intervention despite this being a key goal of individualised funding approaches (Lymbery, 2014). The extent to which the NDIS and its Local Area Co-ordinator system will address this lack of responsiveness is yet to be explored. This study reflects the literature in identifying systemic agility as a key condition for empowering self-determination and shifting control towards individuals, their families, and the community (Duffy & Williams, 2012).

As the findings clearly demonstrated, in the absence of a robust advocacy network and opportunities for a collective voice, individualism and competition for scarce resources can emerge. Funding shortfalls and a deficit based approach to resourcing produced adaptive behaviours such as, for example, participants describing the need to accentuate their deficits (tick the worst boxes) in order to optimise their funding chances and thus reproducing the deficit based model.

Disadvantage was further reinforced and evidenced in other ways. The study consistently highlighted both the advantage and disadvantage created by the information, knowledge, and resource demands of the ISP and service framework. These conditions and the demands of the system consistently privileged those most able and best resourced to compete in this environment and risked perpetuating
disadvantage for those least able to engage with self-directed models, particularly in the absence of adequate independent advocacy supports.

These findings thus reflect the tensions described in Chapter Two regarding the risks of implementing individualised funding reform without also reforming the administration and systems through which it is delivered and investing in the broader community based services and social infrastructure required to support sustained change and choice (Ferguson, 2014). The findings reflect the unresolved nexus between competing neoliberal drivers and disability rights politics and principles, and an uncritical acceptance of a form of personalisation overly dependent on individualism and market based solutions (van Toorn & Soldatic, 2015; Dodd, 2012; Stevens et al, 2011; Ferguson, 2007). The analysis showing the individualisation of disadvantage as well as benefit aligns with the literature suggesting that true reform and citizenship for people with disabilities must also include greater opportunity for the cohesive and ‘collective organisation’ of those using and those providing services (Ferguson, 2006, p.401). Whereas neoliberalism privileges individual choice, responsibility, and market forces, disability rights have historically been based in collective action, representation and pressure for structural reform (Dodd, 2012; Stevens et al, 2011). Dodd (2012) references Oliver (1990) and Priestley (1999) in arguing that disability politics extends well beyond the meeting of individual need and that confining reforms to individualistic measures will consistently fail to address the broader disabling barriers of oppression and discrimination. Similarly, Bigby (2014), Lymbery (2013) and Ferguson (2012) among many others (see Chapter Two) have warned that individual budgets alone cannot achieve social inclusion if not implemented in tandem with innovation and investment in the collective, community and structural transformations required to address discriminatory barriers to inclusive communities. Yoshida, Willi, Parker, and Locker (2004) also found that individualised arrangements are most effective when ‘embedded’ in the community and resourced beyond the provision of individualised payments (cited in Arksey & Kemp, 2008, p.13).

Dodd (2012) summarises his argument as follows:

To be clear, by concentrating solely on personalising services to individual needs, personalisation holds the danger of taking the focus away from disabling
barriers that affect all disabled people and obscuring possible alternative agendas. (p.263)

Despite progressive services working at the edges, the providers interviewed described the slow pace of reform in the disability sector and how traditional, centre and group based service structures continued to be offered and used despite the move to individualised packages. There were concerns that some services, by limiting opportunities and choices for their services users, also slowed the overall sector transition toward more individualised, inclusive, and community based approaches. Resistance to change was explained as in part due to concerns for financial viability given the real cost of quality individualised services as well as the challenge change posed to established power relations, epitomised by the phrases ‘client capture’ and ‘building of empire’.

These perspectives and explanations comment on the policy practice paradox in which ‘traditional’ group based service approaches have continued to ‘thrive and be funded’ (Kendrick, 2009) despite policy reforms toward personalisation in the community context. Providers’ experiences and concerns also mirror Carr’s contention that resistance to service and sector reform can be explained by the ‘unsettling effect’ this has on traditional systems of power and control and concerns regarding ‘performance and financial viability’ (2007).

Traditional lines of power and control were not the only challenges to the ideal of choice as a device for market transformation. Choice and exit as mechanisms for voice and change in services (Hirschman, 1970) were also shown to be complicated by personal, practical, and contextual circumstances related to geographic location and access to and knowledge of options. The findings also showed that whilst the right to exit was important, participants often did not have a preferred alternative to move to, particularly those in the regional centre. There was also for some a lack of opportunity, support and resourcing to create new options despite the desire to do so. For example, the lack of opportunity to create new housing arrangements meant that pre-existing group housing was the only option for participants in this study. The practical and emotional upheaval of developing new relationships and service arrangements, particularly for those with complex support needs, also mediated the potential of choice.
and exit. Trust, as a critical factor in service interactions, took time to establish and even though there might have been dissatisfaction with one aspect of service, other aspects were sometimes deemed as ‘good enough’.

These findings challenge assumptions regarding the sophisticated and self-directed consumer market relationship which is arguably assumed in the personalisation and choice rhetoric (Greve, 2010; Mol, 2008). The everyday reality of most participants in this study bore little resemblance to the ‘ideal like environment’ assumed by free market proponents (Greve, 2010). Choice was often not based on informed analysis of options and a diverse market but instead in the context of: limited knowledge and information; anxiety about change; lack of preferred and accessible service and community options; limited choice making support; limited resources; and, mediated by the needs and preferences of family carers. The findings revealed a complex and contingent relationship between individual choice and market mechanisms in the context of Victoria’s ISP framework.

The findings also reflect previous research in highlighting conflicts of interest experienced by service providers and planners as they struggled to manage competing obligations to the funder, the service in which they were placed, and the service user. For the ISP planners, standardised time allocations for planning plus workflow pressures compromised person centred planning and decision making. Planners were also conflicted by the deficit based nature of the planning process and related expectations of DHS administrators in some regions.

This analysis reinforces the recommendations in the literature to separate funding and planning functions to avoid such conflict of interest and to promote the independence of the person (Lord & Hutchinson, 2003). Contemporary advice underlines not only the necessary separation of key roles, such as funder and planner, but also the provision of independent advice, information and support through peer support and community networks (Duffy, 2011; Baxter et al. 2008; Lord and Hutchinson, 2003). In addition to information, these services can also provide practical support for the administrative and organisational demands of self-directed approaches, including brokerage with services and assistance in managing staff. In the absence of these independent supports, as the findings have shown, people using funding can remain vulnerable within the planning process. And yet the two functions were tied in the Victorian
framework and this is also the case in the new NDIS model although some trial sites are experimenting with outsourcing pre-planning supports with the aim of more adequately preparing the NDIS participant for the planning meeting with the NDIA planner (NDIS, 2015).

Finally, and importantly, the findings have highlighted how cost and risk as well as benefit were individualised within the ISP framework. There were many examples of individuals and families bearing the costs and consequences of economic efficiencies and decisions made at the government level. Cost shifting was a recurrent theme, reflecting previous research (Ryan, 2010). Hard rationing decisions were regularly pushed down onto individuals and families such as, for example, sacrificing limited community access hours for essential personal care. Such trade-offs highlighted the benefits of flexible funding but also the personal and social impact of an under resourced program. A related risk for research and evaluation, described by Ferguson (2007), is that the private nature of this cost shifting phenomenon makes it difficult to measure the consequences of inadequate funding.

In addition, as noted above, much of the new and critical planning, co-ordinating, linking and bridging work of self-direction (i.e. the conversion work) was generally not well enough acknowledged, planned for, or resourced, in terms of individual funds as well as investment in the independent community services and infrastructure required to support these activities. Instead, much of the cost and effort of this work was absorbed into the existing load of families, services, and individual workers with very little additional recognition or support. These extra responsibilities further stressed already burdened support networks which should have instead been strengthened to continue not only their existing support role but also the new work involved in promoting increased independence and community participation. This study found limited evidence of ISPs formally resourcing the needs of family carers and taking into account how the additional needs and challenges of self-direction could be more creatively and holistically supported.

Related to the above, the findings also showed how some services and support staff worked in the liminal spaces between the legislated and the unlegislated, ‘above and beyond’ their role description and formal accountabilities. These findings reflect the argument that ambiguity and fluidity in roles may be seen as a necessary part of the
transition from ‘service led to person led’ services (Osgood, 2005, p.55) and important to managing the changing nature of power relations in the shift toward individualised approaches. These findings point to the ongoing tensions between sector and workforce sustainability and the evolving and expanding demands of people using services for greater choice, flexibility and skill diversity among workers.

Relational approaches, characterised by trust and reciprocity, are important in managing such ambiguity and have been shown as critical to empowering people to take up choice and control in new and innovative ways. Relational approaches necessarily involve an interdependence and reciprocity at odds with a separation of interests and represent the ‘muddled give and take of everyday caring life’ (Herring, 2013, p. 35). At the same time, however, there are implications in these findings regarding the need to manage risks to services and workers more carefully and strategically, particularly during times of transition when service vulnerability and uncertainty is at its peak. These findings reflect cautions outlined in Chapter Two regarding the risks to both parties of blurred boundaries, over work, emotional over involvement, and feeling obligated to compensate for funding gaps in the absence of other options (Rubery & Urwin, 2011). This study’s findings showed a high level of care and a sense of responsibility to people using services which, in a context of adequate resourcing for these activities could be a key relational resource. However, as several providers noted, providing unpaid work is not a sustainable long term business practice and has implications not only for service viability but also for the well-being of paid staff. Implications for managing these risks as service models transform through industrial reform and workforce strategy will be explored in more detail in Section 8.3.2.

These examples of cost transfer and the programmatic and contextual constraints to choice lead to some key arguments for employing conversion and capability as central concepts in policy and practice if the pluralistic needs of people with disabilities are to be better met. Given the above, the findings also suggest that future reforms must include greater recognition and resourcing of the everyday role of families and services in supporting conversion of resources into meaningful and chosen outcomes.

Although this study was undertaken in just one jurisdiction, the findings mirror the arguments and debates set out in Chapters One and Two from local and international experience of the benefits and risks of individualised funding and self-directed reform.
The study has reflected a local context but one which will soon be translated into a new national initiative under the NDIS as it is rolled out across Australia beyond the trial sites from 2016.

8.3 Applying study findings

Sen’s principle of conversion has been employed in this study as a significant analytic mechanism for understanding the diverse and mixed findings and explaining the relationship between latent resources and actualised opportunities and freedoms. By focusing on the funding and service processes, as well as the structures beyond, which expand rather than constrain meaningful opportunity and choice in everyday lives, we move beyond the dichotomies in the literature as summarised above. By focusing on the positive conversion factors, we are able to establish a more nuanced understanding of how to optimise the potential of self-directed funding and services in diverse contexts. Further, I suggest that by introducing a capabilities perspective we address the limits of a more utilitarian lens in understanding complex social policy, its implementation, and how people diversely engage and benefit within it (Duffy, 2012b).

In the capabilities framework, conversion of resources is understood to be produced in the interactions between personal, social, institutional, and environmental factors and mechanisms which enable or constrain development of and access to meaningful capabilities or opportunities (Goerne, 2010). It is this dynamic which mobilises the otherwise latent potential of resources, and the formal rights promised within them, to meet and promote diverse individual needs and aspirations in manifest and meaningful ways (Sen, 2005). The key findings reflect this, showing the relational nature of choice and self-determination and how these are produced in the relationship between the person and the socio-cultural, institutional and environmental factors which enable or constrain the conversion of resources into chosen and valued outcomes. The conversion factors and processes at these interfaces are discussed further below in Section 8.3.1 through a vignette developed from the data. Implications for policy and practice will be elaborated in this section.
As the findings have demonstrated, without due attention to these conversion mechanisms, the potential of the individualised funding framework and associated arrangements may remain unrealised, or as the findings have shown, may be consistently realised for only a few. These conditions fail to fulfil state and policy obligations and promises to all.

Berthet et al (2009) further explain the role of conversion factors as follows:

In the absence of adequate conversion factors, resources could remain purely formal rights and perpetuate inequalities. Public action must intervene in these different scenarios and propose resources to individuals by simultaneously ensuring individual, social and environmental conversion factors. Without adequate factors of these kinds, public policies risk two pitfalls: offering freedom that is only formal; and requiring “compliant” behaviour without an equitable distribution of the ability to comply. Public action in this case is characterised by a form of paradoxical injunction encouraging individual responsibility in the framework of behaviour that conforms to social and legal norms, but leaving aside the question of the actual capability of individuals to comply. (p.5)

Berthet et al’s (2009) work helps to explain the mixed findings in this study as well the risks posed by the ISP framework in requiring certain forms of compliance and engagement (as summarised above) in order to succeed, yet failing to provide equitable access or supports for diverse capacities to do so such as systemic advocacy and independent advisory and resource services.

Despite the unresolved tensions within individualised funding reform generally, and the Victorian ISP program specifically, the positive findings suggest that conversion of resources does occur and that understanding the factors enabling this is key to mobilising the potential of this framework for all rather than just for some. Drawing from Ferguson (2012), these findings encourage us to reject the binary arguments within the literature as outlined earlier and to instead to embrace a more nuanced and complex understanding of how people interact with policy and program systems in their efforts to build better lives.
8.3.1 The need to recognise and fund the dynamics of conversion

The key findings relating to conversion have been presented at the end of Chapter Seven. An important finding was that the core activities, processes, and mechanisms critical to conversion of resources into chosen and valued opportunities lay in the enabling systems, relationships, and processes through which resources and supports were provided, and in the thinking, linking and bridging activities undertaken by individuals, their families, and services. These mechanisms highlighted the relational and socially produced nature of choice and autonomy and therefore what should be a key focus of the funding and service framework. And yet, these central dynamics for conversion were generally not well acknowledged in assessment and planning processes, well-resourced or systemically supported within the formal ISP framework. On the contrary, the findings revealed insufficient support for family carers, inadequate funding for case management services, minimal use of independent advocacy organisations, and a systemic over reliance on the energy and resources of family carers, service providers and individual workers. Despite its function as a critical form of social capital, family resources were frequently stressed and weakened beyond what might be regarded as reasonable community norms. These deficits and pressures further stressed rather than nourished participants’ informal and formal supports and resources, resulting in the pervasive cost and risk shifting effect discussed earlier and weakened potential for conversion of resources into meaningful outcomes.

Importantly, the analysis extends upon traditional understandings of social capital as a resource upon which people draw to meet their economic or human capital interests in mutually beneficial ways (Coleman, 1988; Bourdieu, 1986). In highlighting the central and multifaceted role of social capital, the analysis shows different forms function not only as a key resource but also as a core social and cultural conversion factor and a desired outcome in and of itself, reflecting a capabilities perspective (Migheli, 2011). The power and potential residing in the social connections and bonds in participants’ lives stimulated other resources, increased access to diverse opportunities, developed desired capabilities, and produced wide ranging benefits not just for the person but for their family as well as the community networks in which they were engaging. This was particularly highlighted for those with fragile social networks and for whom social participation and inclusion were long standing challenges.
These findings reinforce arguments in both the social capital and capabilities literature that a key task of government, its social policy, and the community sector should be the protection as well as generation of social capital in more collective efforts toward social inclusion (Migheli, 2011; Winter, 2000a). This is particularly critical in a policy and practice framework aiming to expand social citizenship for people with disabilities, such as the individualised funding framework.

There are various definitions of social capital depending on philosophical emphasis (Winter, 2000b) however the following captures the conversion role of social capital and related meanings identified in this analysis:

The resources people develop and draw on to increase their confidence and self-esteem, their sense of connectedness and belonging, and ability to bring about change in their lives and communities. (Edinburgh Health Inequities Standing Group, 2010).

Winter (2000b) has described the bonding, bridging and linking activities required to generate these different layers of relationship and stocks of social capital. These range from strengthening intimate relationships between family and friends, connecting across groups and communities, and linking across hierarchies to influence and participate in decision making.

The analysis however revealed the paradox, many times over, of the risks to social capital in Victoria’s individualised funding program. Inadequate resourcing, inflexible and unresponsive service systems, and lack of accessible mainstream opportunities for participation continued to constrain, for some, the linking, bridging, and bonding activities required to develop and sustain social capital.

There are strong implications here for the community development work which was highlighted as a priority by both providers and participants. Services emphasised their role in building social capital as demonstrated in efforts to build bridges into the community through active relationships and arrangements with external partners, both disability and mainstream and commercial and community based. This work was intended to support new pathways and opportunities for people with disabilities beyond those relating to family and close friends. The ISP package was conceptualised as just one tool in this process with this view exemplified by one manager’s observation.
that ‘money can’t buy relationships’. Instead, it was the conversion role services, individuals and families played in doing the ‘thinking and linking work’ that ultimately would shift community attitudes and connect people to more ‘typical’ pathways and relationships. In other words, it was this that converted notional opportunities into real experiences (Migheli, 2013).

These findings directly reflect arguments outlined earlier in Section 5.4 which describe individualised funding as a latent commodity brought to life only by the personal and social capital available to people (Duffy & Murray, 2013; Williams, 2013). Duffy and Murray (2013) assert that a ‘good’ life is not created by a budget but that the budget enables ‘our real wealth to come into use’ (p.311). In line with this, Duffy and Murray argue that the focus of funding, professionals, and resources must be in people’s lives and relationships, and in the development of their resources and capabilities rather than on bureaucratic systems and processes.

In line with the above, the particular role of support workers as social capital builders was also repeatedly highlighted. In transcending the traditional limits of support and care, the support worker role emerged as both a multi-dimensional resource and conversion factor, developing new forms of social capital through relationships of trust and mutual regard and creating the conditions for participants to generate new networks within the community. Again, this analysis builds upon similar descriptions of the evolving support worker role in individualised arrangements as more than just a ‘pair of hands’ but rather as a multifaceted resource (Vernon & Qureshi, 2000). The findings also highlighted the further dimension of advocacy, with support workers filling a well-documented void in this regard. Examples included in funding, legal, financial, and medical matters.

These findings again have strong implications for workforce reform and capability development. In particular, there is a need for greater recognition of the value residing in and offered through the relational nature of paid supports in the context of individualised services. These challenges of recognition reflect those within informal carer relationships as documented by Henderson and Forbat (2002) who have argued that the critical but ‘invisible’ relational value within informal support roles is not adequately reflected in policy and government strategy relating to carers. This study suggests these arguments apply equally to paid support roles where the intangible
emotional and social content of the interaction is not well enough acknowledged or reflected in workforce policy, funding, and development frameworks or in industrial relations (SPRC, 2013).

This analysis underlines the potential for disadvantage within the individualised funding framework for those with low stocks of social capital, such as the isolated and marginalised. The data suggests presupposing an uncomplicated correlation between individualised funding and choice, the data suggests that this assumption further disadvantages those who do not have the personal and social resources to support conversion of funding into meaningful outcomes. These people are of course further disadvantaged if their funding only covers basic needs and does not extend to opportunities which would encourage the creation of new networks and relationships.

The lack of focus in assessment, planning, and funding on the dynamics of conversion must be acknowledged and addressed. The findings of this study consistently highlighted the lack of formal attention to the interplay between factors across levels, and the thinking, linking and bridging work required to operationalise self-determination in everyday lives. The following section now seeks to demonstrate these key points, showing how and where conversion of resources can be disrupted. A composite scenario drawn from examples in the data is followed by a discussion of the implications for policy and practice. This scenario represents negative extremes, as they occurred across cases in the data, and the convergence of these is unlikely to occur in one example. However this vignette is used as a device to demonstrate the range of disruptions and barriers to conversion which can occur in the complex interplay between resources and desire outcomes, when assessment and planning is not located in an understanding of the complexity of a person’s context and the dynamics of changing needs and preferences.

Sam, 25, has a mild cognitive and significant physical impairments. He lives in a community residential unit but does not get on with the other residents. His family lives a 45 minute car ride away on the other side of the city. He has little contact with his community and feels isolated however most of his funds have gone to paying the CRU fees, with only a little left for community access. He attends day program but does not see these people outside the group. He has been allocated an ISP and is developing his funding proposal with an ISP planner he has not met
before. As one of the strategies, his planner suggests he attend a leisure centre one evening a week.

Sam takes up his planner’s suggestion and decides he will go to the pool one night a week. But the nearest pool with an accessible entry is 30 minutes away and it is not on an accessible public transport route. His family cannot assist. He will need to pay a support worker to drive him the one hour round trip and time spent waiting whilst he swims. But he is unsure if he will like it or whether it will be an environment in which he will feel comfortable. He would ideally like to try a few other different activities before settling on one. But he is anxious about trying new things and will need additional support and encouragement to engage with new activities and people.

The findings showed that for participants in this study planning experiences were highly variable, with some planners failing, or unable due to time and workload constraints, to take the time to understand the broader context of the person’s life, history, and resources, and what was required to effectively transform these resources into meaningful opportunities. In Sam’s case, his planner did not adequately address the extra supports Sam, compared to someone else, would need to achieve similar outcomes given his social isolation combined with physical access issues, limited funding, low confidence, and fears and anxiety about trying new things. His conditions meant that he needed more resources and support to accomplish his goals than someone with strong social networks, access to a ‘free’ driver in the form of a friend or family carer, the confidence to try new things with little emotional support, and someone with accessible options closer by.

For Sam, the planner’s failure to understand and resource what was required to positively convert his combined resources and strengths into more meaningful and self-directed pathways and outcomes limited the value and potential of these resources and the institutional supports available to him in the form of planning and services. This vignette shows how such shortfalls limit the individual’s capacity for self-determination but also the capacity of ISP policy intentions to play out in real terms in everyday lives.
8.3.2 Implications for policy and practice
The following section expands upon implications of this study’s key findings for policy and practice. These implications reflect the study findings regarding the interdependence between the interests and needs of the different stakeholder groups in this study as opposed to positioning them as separate entities. When assessment, funding and planning processes understood the nature of this interdependence and attended to the principle of conversion, meaningful outcomes were more likely. However, as the findings have detailed, this often did not occur, with adverse impacts on choice and self-determination. The following draws from the data to show the negative impact of failing to attend to the principle of conversion at key phases in the ISP pathway and in key resource relationships and activities. The first set focuses on conversion factors in the relationship between personal/social and service, program and institutional conversion factors, described here as Conversion Interface A.

Conversion Interface A – relationship between personal/social and service/program/institutional factors

- Consequence 1: WHEN THERE ARE INADEQUATE RESOURCES AVAILABLE TO BE CONVERTED INTO MEANINGFUL CHOICES

Formal ISP resources, following assessment, combined with the person’s informal resources in the form of family supports, social networks, and material assets may only cover critical disability related personal care needs. There is insufficient consideration, support and resourcing to allow for conversion and choice beyond basic support and care, resulting in maintenance of the status quo.

Policy and practice implication 1- Policy and practice need to ensure that the assessment and planning process for all funds users differentiates between assessment of critical disability related support needs on the one hand, and the person’s socio-cultural and economic goals on the other hand. Additional and different planning, resources, supports, and processes will be required to convert combined resources into meaningful outcomes related to these goals.
Consequence 2: WHEN THE POTENTIAL IN LATENT RESOURCES (formal and informal) ARE NOT CONVERTED

Individuals and their family supporters are not always clear about choices and pathways, may not have the information needed to make decisions or the decision-making capacity or supports required, may not know the questions to ask or how to do the research, and may not have access to the sort of opportunities they want. There may also be no supported decision-making, brokerage and/or independent advocacy available or if so, the person is not aware of it. In these circumstances, uninformed choices can be made in a vacuum within a delimited range of options.

Policy and practice implication 2 – There is a major need for greater resourcing and development of supported decision-making, community brokerage and advocacy as a conversion factor and dynamic for valued lives. These services have operated effectively in other jurisdictions as an adjunct to self-directed frameworks. Examples include the Centres of Independent Living in the UK (Barnes, 2007) and the brokerage organisations in Canada (Power et al, 2013), many of which are user led. This independent sector is part of a ‘quasi-service’ sector which has a critical role not just in relation to supporting the individual but also more broadly in stimulating innovative, more ‘typical’ and inclusive options in the community (Dowson & Greig, 2009). Whilst shown internationally to be central to conversion, these resources do not appear as priorities in the Australian context. But this study supports the argument that collective strategies, advocacy, and user led innovation are vital in activating conversion at the individual and community levels.

Related to this is the need for improved systems of information provision and communication so that decision making can be more informed. Different mechanisms for information and communication need to be tested such that potential users can be more informed when making decisions about services. Key principles of accessibility, relevance, timeliness, and consistency need to be incorporated into communication strategies at the service, community, and government levels (Laragy et al, 2015).
• Consequence 3: WHEN EXCESSIVE DEMANDS ARE MADE ON INFORMAL RESOURCES

Assessment and planning assumes but does not consistently or always adequately acknowledge or support the work required of family, friends and services in operationalising self-determination and enabling new more typical pathways. Costs are effectively shifted to individuals and families, placing them under stress particularly given existing roles and responsibilities. Other functions and relationships may suffer as a result. This can then weaken the family unit and reduce the collective resources available for conversion.

Policy and practice implication 3 – Assessment and planning needs to acknowledge and document the natural resources in a person’s life, the roles they currently play and how they can be further supported in these roles. There needs to be attention to maintaining a reasonable balance between natural and formal supports and avoidance of the systematic over reliance shown in the data. It is important that social capital is protected and the integrity of the person’s net resources from the family and broader networks are not threatened. This may involve undertaking joint or separate assessments of carer needs, depending upon the context and relationships therein. Australia and the UK have both instituted legislation for carers. In Australia it is the Carer Recognition Act 2010, and in the UK the 2004 Carers Equal Opportunities Act.

Consequence 4: WHEN CHANGE AND NEW OPPORTUNITIES ARE NOT ENCOURAGED AND USED TO PROMOTE CONVERSION

People using funding and services can be influenced to maintain existing services and options in the absence of ideas and discussion about alternatives. Without exposure to different pathways toward goals, people can settle or be ‘satisfied’ with the old and familiar rather than risking change, i.e. they show an ‘adaptive preference formation’ (Elster, 1983). Concerns regarding moving away from traditional disability options toward mainstream pathways may influence people’s assessment of the risks involved if they are not supported and encouraged to think beyond what they have always known.
Provider concerns regarding financial viability as well as traditional power relations may impact efforts to fully inform service users of the potential and portability of their individualised resource.

Policy and practice implication 4 – Policy and practice should reflect social inclusion policy aspirations by driving innovation, showing leadership and sharing exemplars of new, more typical and inclusive community oriented opportunities for people seeking choice and change. Policy and practice should also be responsive to changing individual and community needs and expectations. Responsiveness takes place in situations where the person and their network have more control over their resources and can be more agile in responding to changing needs and new opportunities. This requires less complex, more streamlined, and timelier systems of approval and administration such that the levers of control are more firmly in the hands of the funds holder. Without these systems conversion is interrupted, spontaneity is difficult, and choices continue to be unreasonably constrained.

Consequence 5: WHEN INADEQUATE AND NON PERSON-CENTRED ASSESSMENT AND PLANNING FAIL TO CONVERT

Assessment and planning interactions in the absence of sufficient knowledge of the person’s history, preferences, strengths, and social context are unlikely to direct resources and supports in ways which will leverage on the person’s potentials and aspirations, producing limited outcomes for the person.

Policy and practice implication 5 - Assessment which deals with critical support care needs alone becomes welfarist and deficit based in its orientation. Instead, assessment and planning needs to be holistic and ‘strengths and potentials based’. Finding the conversion factors and sources for valued lives represents a new way of exploring strengths and assets. These rest in the range of personal, socio-cultural, and environmental resources that can be accessed and activated and as such should feature as the primary tool in assessment and planning processes (see also Duffy & Williams,
It is critical to know the person’s history in order to understand their lives as an historical development towards the fulfilment of their capabilities.

- Consequence 6: WHEN SLOW AND INFLEXIBLE BUREAUCRACY IMPEDES INNOVATION AND CONVERSION

When funding bureaucracies and processes are not agile or ‘light’ enough (Duffy, 2013, p. 7), they impede rather than enable innovation at the individual and collective levels. Risk aversion in the bureaucracy and services can limit capacity to optimise the potential of new opportunities, circumstances, and contexts. As a consequence lives are put on hold as people await administrative approvals and decisions about how funding can be used or outcomes of protracted complaints procedures. Managerial models impose limits on planners and practitioners, leading to conflicts of interest and encouraging transactional rather than relational approaches. In doing so, these processes risk not optimising the person’s expertise regarding what is best for them in terms of funding and service use.

Policy and practice implication 6 – The findings show the need for more responsive, agile, and person centred systems and approaches in order to reflect the natural rhythms of people’s and support people with disabilities to explore innovative ways of meeting their needs. This requires more flexible and robust systems for complaint and safeguarding which ‘run interference’ such that people with disabilities are freed to enjoy the dignity of risk in new and uncertain funding arrangements. These systems needs to extend to apply not just to the individual with a disability but also to disabling institutions which have the potential to further disadvantage vulnerable people. These considerations for ‘positive interference’ would afford fund holders greater discretion and should be a major part of any quality framework for individualised funding and service models.
Consequence 7: WHEN INADEQUATE FUNDING RESULTS IN WORKING OUTSIDE FORMAL ROLES AND RESPONSIBILITIES TO FACILITATE CONVERSION

When planning and funding does not take into account the full range of activities and work required to progress a person’s goals as well as their basic care needs, services and individual workers sometimes feel obligated to work outside their paid responsibilities to promote service users’ self-determination and quality of life. Alternatively, workers are paid for hours not worked as recognition of poor wages and attempts to build loyalty. These different ways of meeting needs are functional in the short term however hold potential risks for both service providers and users. These include risks to individual worker well-being as well as risks to the sustainability of working conditions and practices. Improper use of funding, such as paying for work not done, also introduces an unfair element of competition which disadvantages those with neither the funding nor opportunity to use similar strategies.

Policy and practice implication 7 – Communities of service providers and users are developing new economies of care and support at the boundaries of traditional systems and service relationships. These are functional in terms of optimising and converting available resources into meaningful and personalised outcomes but also hold risks for both parties. Services absorb costs and individual workers can feel obligated to fill unfunded care gaps as boundaries blur and lines of accountability become more ambiguous. Whilst this ambiguity can have benefits, it also carries risks associated with over work and over obligation. These risks can be avoided if pay awards, working conditions and regulatory frameworks are reformed to reflect the expanding and evolving demands of people with disabilities and their family carers in the context of home and community based support so that the need to work outside formal and protected work conditions is reduced. Parallel to this is the need for funding to cover the full and real cost of personalised support and particularly the unseen co-ordination, linking and bridging activities so necessary to build social capital and support inclusion. Funding and planning which can ensure more holistic approaches to meeting goals as well as practical care needs should reduce pressure on services and workers to absorb the real costs of social participation and inclusion. It is also recommended that people
with disability are given more choice and control regarding who they employ together with the supports and resources they require to take up these choices and responsibilities. These recommendations have strong implications for broader workforce reform and strategy including investment in new capabilities, culture, conditions, and supports if the well-being and professional pathways of workers in this new environment are to be nurtured and the needs of services users well met.

- Consequence 8: WHEN CONVERSION IS RESTRICTED BY LACK OF TRUST AND RELATIONSHIP

Lack of continuity and trust in service and support relationships can impede realisation of the person’s goals and disrupt active conversion of resources and assets into meaningful choices. Many service and support relationships are built over time and lead to the development of trust and collaboration with long term practical, emotional, and social benefits. The quality of the support relationship is, for most, a critical resource.

Policy and practice implication 8 – Recognition of the importance of relational approaches as well as service continuity and the trust developed in these relationships is critical. Trust is an essential element in ongoing dialogue and communication, in moving lives forward, and in making changes, particularly in periods of transition and uncertainty. This needs to be supported by ensuring people using services continue have voice and choice within services, as well as the right to exit to other services. In making decisions about the risks and benefits of change some may factor in the relationships they may lose in the transition to another service. Slow introductions across to new services and more streamlined financial arrangements would aid smoother transitions to new service relationships.
Conversion Interface B and C – the relationship between personal and family and socio-cultural, community and environmental factors

This interface relates to the conversion occurring in the relationships between individuals and their supporters and the socio-cultural, community, and environmental resources to which they do or do not have access.

- Consequence 9: WHEN LACK OF OPPORTUNITY LIMITS CONVERSION

For some people choice in services and community resources is not available or accessible due to location, cost, lack of information or understanding, and/or waiting lists. Those living in rural or remote environments can have fewer options than those in urban environments. Services must consider financial viability and few may choose to locate in rural or remote areas where business may not be viable. This has implications for all but especially for people with complex and specialised impairment related needs.

Policy and practice implication 9 – More innovative thinking regarding service distribution and community development is required. There is a need for policy and leadership in circumstances where the profit motive and market forces fail to ensure service choice for all people with disabilities, including those in rural and remote areas. It is important for services to adopt a strong external and community development focus working in partnership with mainstream businesses and community organisations to increase physical and social access for people with disability. It is necessary for services to work at the collective and community as well as individual levels with commensurate implications for workforce and organisational capabilities.

- Consequence 10: NON-CONVERSION OF COMMUNITY RESOURCES BECAUSE OF LACK OF LINKING, BRIDGING AND BONDING

Wider community networks and the social capital these produce are critical and multiplying resources but people need bridges to these networks. This takes time,
energy, creativity, and collaboration. For most, the linking and bridging work required to connect with the wider community and to create new opportunities cannot take place without trusting relationships, innovation, informed decision making, community based advocacy, brokerage and personalised community development planning.

Policy and practice implication 10 – Much of the thinking, linking, and bridging work of self-determination and participation in the everyday implementation of the ISP framework has been transferred to disability services. This has the potential danger of simply repeating the silos of segregated services that have existed previously. An important and vital part of any mixed economy of care lies in accessing and converting the capacity and potential of the wider community. Given the demographics for care indicate higher care costs for the formal sector in years to come and a reducing informal care sector (Productivity Commission, 2011), the importance of the community as a largely untapped source of care, support, and inclusion, needs to be recognised. It is a major area for development in the future. As reported by Lord and Hutchinson (2003), this study found that these networks should be recognised and supported as a central building block of ISP funding and planning.

- Consequence 11: NO CONVERSION DUE TO ENTRENCHED COST SHIFTING
This relates to the above two points and the risks of cost shifting to the family and other supporter network so that the balance between making the most of natural resources and stressing them is tipped. Often the secondary or articulation processes for choice and participation, such as service co-ordination, physical and emotional care and support, dialogue and planning, and practical supports such as transport, are assumed to exist within the family. Whilst families generally take on responsibility for such tasks, the balance is often tipped beyond what they can sustain. Often too little emphasis, energy, or resources are given to exploring how generic community resources can be used in more innovative ways to build opportunities for independence from family into a person’s daily life.
Policy and practice implication 11 – The implications of the above have been touched upon previously in this section. Over reliance on family carers at the expense of the individual and the family unit has reverberating costs and potentially weakens the conversion process. Assessment, planning and service approaches need to mobilise the community and its latent potential and create conditions in which the individual and their social supports are nourished.

The above discussion represents a starting point however more work is needed to fully explore the concept of conversion and the relationship it describes between resources and outcomes. More work is needed to understand application of this concept to the individualised funding context, how conversion occurs across personal, socio-cultural, and institutional levels, and its relevance to policy, practice, and future research. I have aimed to demonstrate the merit of understanding this conceptual framework as a major theme for both the ISP model and for the NDIS in its national roll out this year. I present summary points about conversion in the next section.

8.4 A Paradigm shift

These understandings of conversion have much to offer the analysis and subsequent progress of personalisation policies in terms of their impact on individual freedoms (Goerne, 2010). A rights and capabilities perspective aligns closely with the broader narrative of capability building, diversity, and voice and participation already promulgated by advocates and commentators as central to the success of individualised approaches (van Toorn & Soldatic, 2015; Duffy, 2012; Duffy & Wiliams, 2012; Kendrick, 2009; Bigby & Fyffe, 2008).

These approaches share a focus on empowerment and enablement and the freedoms and capabilities required for this. This represents a central analytic shift from the standardisation of inputs and processes or normative outcomes as measures of success to instead the mediating forces through which resources can be accessed by diversely resourced and abled people. This paradigmatic shift should inform a more dynamic and
rights based interpretation of self-directed models and their design and evaluation in the future. This is a key strength of the capabilities approach and why it is proposed as a useful alternative lens for understanding the findings and as a vehicle for change into the future.

Therefore, questions regarding the conditions for real choice and freedom turn on an understanding of individualised funding as both a resource and a tool, the potential of which ultimately rests in the network of relationships, systems, practices and processes through which it is carried. The study therefore contributes to and hopefully extends existing and similar arguments but offers an alternative lens through which to understand the dilemmas and opportunities within individualised models of funding and support.

The positive findings suggest that despite the unresolved tensions within personalisation and individualised funding reform generally, and the Victorian ISP program specifically, that potential for choice and control exists, given enabling personal, social, institutional and environmental conditions. It is argued based on the analysis that these conditions will enable experiences and outcomes more closely aligned to the rights based intent of the ISP framework and help reduce the gap between policy promise and lived experience. These findings encourage us to embrace a more complex understanding of the relationships between resources, systems, and structures, and the people engaged with them.

In highlighting the socially constructed nature of rights and freedoms, the findings underline the potential as well as the limits and risks of individualised support funding models. The findings showed that improvements to everyday choice and control were highly valued but, in the absence of broader structural and social change and opportunity, many participants in this study remained on the outskirts of community and society. A key finding has been that the full potential of personalisation mechanisms, such as individualised funding, will remain limited if people with disabilities are not afforded choice and freedoms beyond everyday service choices. Enabling people to pursue choice and self-determination in all life domains requires social, institutional and structural reforms well beyond individual choice in funding and service arrangements.
The conversion factors identified in this study were shown to create or restrict access to the real opportunities and capabilities participants required for higher order self-determination. Understanding the interplay between the person, their social world, institutions and the broader environment is critical to understanding how the person can be better supported to convert the potential of their resources into the better lives they seek. The implications of this understanding for policy, funding, and service approaches are significant and build upon related perspectives and arguments already made regarding the relationship between individualised funding models and active citizenship (van Toorn & Soldatic, 2015; Duffy, 2013; Duffy & Williams, 2013).

8.5 New insights based on a capabilities based analysis of the findings

The diverse and mixed experience of the individualised funding approach, as outlined in the above section from the perspectives of both users and providers, reveals the tensions and challenges of evaluating such programs on the basis of outcomes and utility alone. The original analysis confirmed what we know about the benefits and limitations of individualised funding and service approaches and also offered fresh insights particular to the Victorian context. However, as already explained, further analysis was required in order to deepen understanding of the findings and offer an alternative frame for thinking about practical implications for policy and practice. As explained in Chapter Two, I argue that the tensions and contradictions exposed in the findings may be at least partially resolved both practically and theoretically by exploring the mixed findings from a capabilities based understanding of human rights.

Reinforcing the capabilities argument, we can see from the analysis that the promotion of rights cannot be judged only on what a person ultimately chooses, given the limited selection of opportunities from which people must often select, but more crucially on the freedoms and opportunities which were effectively available to that person and from which they could choose (Welch Saleeby, 2007). This principle is central to understanding the mixed findings in this study and for understanding the significant differences in benefit and advantage. It describes the gap as well as the relationship between potential and reality, between the promise of rights and their realisation. A capabilities perspective therefore challenges policy and rhetorical implications of a
direct causal relationship between individualised resources and self-determination by underlining the complex and non-linear relationship between resources, agency, and outcomes.

I have introduced a capabilities perspective in a second tier of analysis as part of a more comprehensive and holistic disability rights approach to explaining the data (Stein & Stein, 2007). The capabilities literature has argued that a focus on capability and opportunity development, as opposed to equality of input or outcome is of particular importance for the disadvantaged, marginalised and under-resourced, and in potentially inequitable systems (Nambiar, 2013; Goerne, 2010). It is argued that the ISP program and the community of people with disabilities fit these criteria. A capabilities perspective acknowledges diverse starting points and aspirations, privileges policy means over ends, is synergistic with both human rights principles and the social model of disability, and is grounded in social justice principles of equity and dignity (Klein, 2015; Vizard, Fukuda-Parr & Elson, 2012). Sen describes capabilities as ‘notions of freedom, in the positive sense: what real opportunities you have regarding the life you may lead’ (1987, p.36). It is thus a valuable extension to the original human rights analytic framework of this study and offers an alternative lens through which to evaluate disability policy and practice.

A capabilities perspective also assists by conceptualising capabilities as a form of rights (Sen, 2012) and thus helps clarify, in real rather than abstract terms, the state’s and other duty holders’ positive obligations in actively promoting these rights, and provides a practical framework for doing so (Nussbaum, 2012).

Understanding key responsibilities and duties within the ISP framework is important in reshaping provision of current resources and also, critically, in identifying the nature and scope of what is not being provided and the impact of these deficits on real choice. George (2015) argues that well-being involves ‘genuine choice’, described as the ‘absence of coercion, both stark and subtle and not one in which a person is forced in a particular life, however good it might be otherwise’ (p.34). He points out that constraint can often be subtle and intangible rather than expressed through explicit obstructions. For example, in this study the lack of adequate funding, advocacy supports, choice making resources, consistent and accurate information, and diverse market options, were deficits which subtly or in some cases not so subtly constrained and restricted
agency and choice. Without access to such freedoms, what participants did and became was often not a reflection of their agency and potential. For many participants, this sense of limitation, of not being in control of their lives and choices as they would like, was a defining feature.

Trade-offs and compromised ‘choices’ where consequences of these constraints and limits. Individuals and their family carers were routinely compelled to make hard choices about very limited resources, choices it may be argued which were often well beyond general community expectations. As well as making these hard choices, service users as well as some providers absorbed many of the real costs of empowering and enabling self-determination. The work of converting resources into meaningful choices and outcomes was shown to be critical and yet this work was often not formally acknowledged or resourced, increasing pressure on the central capitals in people’s lives.

Related to the above, evidence of adaptive preference formation explained how significantly compromised choices were produced. This is explained in the literature as the adaption of choices based on previous deprivations, negative experiences and the lack of realistic and relevant opportunities (Teschl & Commim, 2005). These adaptations are particularly applicable to oppressed groups with histories of social and structural constraints on their freedoms, such as people with disabilities (Nussbaum, 2006). As has been suggested in this study, the possibility of autonomy and authentic self-determination is seriously challenged for groups whose hopes continue to be limited by ‘oppressive’ histories and ongoing contextual constraints (Veltman & Piper, 2014).

The capabilities lens has extended and populated the original rights based analysis by unpacking in practical detail the mechanisms which shaped the experience and processes of choice and self-determination. In doing so, the analysis was able to partially explain factors contributing to the gap between the ISP policy promise of citizenship and rights and the diverse realities of participants’ lived experience. This extended framework seeks to answer the emerging questions raised in this study as well as the second and third research questions regarding the processes, relationships and opportunities required for real choice and capability development. Importantly, the capabilities approach also offers the concept of conversion to help explain the
relationship between different resources and between resources and outcomes. A capabilities perspective of human rights has therefore focused the analysis on the dynamics and conditions required for people with disabilities and their families to structure self-determining lives, based in real choice and core freedoms. This analysis has helped explain why some were able to fully optimise the potential of their resources and others were not.

In challenging the policy rhetoric implying a simple relationship between individualised resources and choice, the analysis highlights complex and dynamic interplays of opportunity and constraint. Diverse starting points, fluctuating stocks of personal, social, and material capital, and diverse histories, attributes and skills produced highly divergent pathways and capacities to navigate, negotiate, and extract benefit within this system.

Importantly, a capabilities perspective highlights the importance of process and the means of freedom and capability development as more important than the ends in terms of evaluating social justice and the success of social programs (Klein, 2015). Such framing conceptualises the freedom to choose, to be self-determining, and to participate in decisions affecting one’s life as important capabilities and as the ultimate point of the social exercise. Expanding these capabilities is a dynamic process rather than one aimed at producing fixed and static outcomes. The analysis supports this interpretation and in turn reflects key commentators in calling for increased and embedded flexibility within individualised funding and self-directed service frameworks if they are to deliver on their promise of enabling and expanding both individual and community capabilities (Duffy & Williams, 2012; Duffy 2014). This argument also reflects Dean’s (2013) conceptualisation of social citizenship as an evolving and dynamic process rather than a fixed or normative state, with subsequent implications for policy, institutions, and programs. It is important therefore, to think of individualised funding and service approaches as emergent and dynamic rather than ‘fixed’ tools in the progressive development of citizenship rights for people with disabilities (Duffy, 2012, p.17, 2014). To do so such models must be able to adapt to and shape around diverse contexts and potentials, with the flexibility and nuance to be driven by each individual’s needs and goals within a broader agenda of social and structural reform.
In line with this logic, I have argued, based on the findings, that the notion of conversion, of understanding the complex and contingent relationship between resources available to a person and their capacity to mobilise them into chosen and valued opportunities is key to this work. This concept is central to understanding the key findings in this study and has implications for policy and practice, as outlined above in Section 8.3.1.

To summarise, in answering the main research question, there was limited evidence in the data suggesting that the Victorian ISP model was able to consistently and equitably promote the level of flourishing and social inclusion its policy rhetoric promises, given its resourcing, administration, and broader contextual constraints. There were particular failings regarding planning, support, and resourcing for social and economic inclusion, complicated by the emergent and slow nature of service sector transition and barriers to accessing community based opportunities. There were several exemplars and a theme of increased choice and flexibility however there remained a penetrating theme in many participants’ narratives of constraint and unfulfilled potential. Important questions for this and similar systems then turn on a more sophisticated understanding, based on the exemplars, of how the self-directed framework can embed mechanisms which will more flexibly and equitably recognise and respond to diverse capacities for engagement and conversion.

In short, whilst previous studies have identified the winners and losers they have had limited success in identifying what it is that produces these divergent experiences and outcomes. Capabilities as a conceptual framework and the ‘conversion’ of resources, as a key device within it are the central defining features that distinguish this thesis and analysis from others in the field.

In the next and final chapter, I conclude by discussing implications for future research.
Chapter Nine

Conclusion

9.1 Study Summary Statement

This study has examined, from a capabilities and rights based lens, if, to what extent, how, and for whom the Victorian individualised funding framework delivers on its human rights promise of choice, self-determination and inclusion. The study provides empirical evidence from the Australian and Victorian context, located in the lived experience of a small group of people with disabilities, family carers, planners and service providers. The research has revealed the contingent, dynamic, and highly diverse experience of choice and self-determination as well as the socially produced nature of these rights. In doing so, the findings resonate with the concerns and aspirations reflected in the local and international experience outlined in Chapter Two.

The complex relationship between individualised resources and self-determination challenges the more linear assumptions suggested in the ISP and other individualised funding policy rhetoric. This study emphasises the need to understand more deeply the processes, relationships and conditions which contribute to the better lives that people with disabilities using individualised funding seek.

I argue that a capabilities lens offers a fresh, more nuanced and useful way of understanding the dichotomous experiences and outcomes and the contingent and fragile nature of choice and self-determination within this funding and service model. Applying the core concept of conversion has been helpful in understanding why some benefitted and others did not and in deconstructing experience to identify contributing factors. Simply linking individualised resources to a person does not in and of itself produce choice and self-determination. Critically, the study has shown that it is not just adequate funding, based on strengths and potentials, which is important to more self-determining lives, but also the systems, processes, and relationships through which funding and other resources, including information and advocacy, are provided. The
values and assumptions underpinning these structures must be examined if the
dilemmas and issues associated with individualisation of funding and care are to be resolved.

What makes a difference is how assessment, planning, support funding and services
effectively target those mechanisms which convert the latent potential of combined resources into chosen and valued lives. Therefore, the factors and mechanisms responsible for conversion must be understood and this has implications for the goals and processes of policy development, for practice in both disability and mainstream services and organisations, and for future research. This study has demonstrated that regardless of the context, the need to focus on conversion, to understand, plan for and support it in ways that are meaningful to the person, is a universal policy and practice implication.

For this study's participants, key conversion factors related to: personal and social capital and the networks of support available to the person; services and support staff characterised by empowering, relational, person directed, and innovative approaches; simplification of the bureaucracy and lines of control to facilitate access to and control over funding and support; strengths and capabilities based assessment and planning; adequacy, equity and flexibility of funding and related processes; improved access to information about rights and opportunities; and, accessible, tailored, and diverse community opportunities for social and economic participation.

There are implications for the structures and policies required to support these conversion factors such as a workforce strategy which can respond to the changing demands and expectations of people with disabilities whilst also ensuring good working conditions for an adequately skilled, diverse, and flexible workforce. Early experience from the NDIS trial sites show a dynamic and ‘rapidly evolving’ sector in which providers are being challenged to review and adapt practices and culture in line with NDIS participant choices (NDIS, 2014). Workforce priorities arising from the trial sites relate to investing in and building workforce capability and flexibility, improving efficiencies, and developing the workforce in rural and remote areas (NDS, 2014).

Using a capabilities framework builds on recent applications in social policy and practice research (see Elson et al, 2012) however this study is the first application in the
area of individualised funding. By re-examining the Victorian model from this perspective, the study findings reflect and develop existing arguments about the relationship between personalisation reform and citizenship. Specifically, the findings demonstrate the need to continually review the degree to which the freedoms and self-determination of people with disability remain central to policy and practice innovation (Duffy, 2011). A capabilities lens provides a way of deepening this examination by distinguishing between the outcomes people achieved, and what people had the real freedom to accomplish, given the capabilities and opportunities from which they could choose (Nambiar, 2013; Sen, 1992). In analysing the impact of individualised funding in everyday lives, this distinction helps us understand the gaps as well as the barriers and enablers, in the form of conversion factors, to more authentic and sustained forms of self-determination.

The previous chapter has outlined implications of this study for policy and practice and built on key critiques and conceptual frameworks as outlined in Chapter Two. I have drawn from the study findings to detail implications for policy and resourcing, assessment and planning, service approaches and priorities, community engagement and capability development across each of these domains. This conclusion will now briefly focus on the implications of this study for the NDIS and for future research, based on its limitations and the key study findings.

9.2 Implications for the NDIS

The NDIS has been designed to address key problems in Australia’s disability support and service system as identified in the Productivity Commission’s 2011 report. It promises a rights based approach to meeting the needs and hopes of people with disability. However there remain concerns regarding its basic architecture and lack of agility and capacity to shift real choice and control toward people with disabilities and their families (Duffy, 2013). There are also early concerns regarding funding cuts to advocacy groups and the impact this will have on representation and access to funding and services for certain groups, particularly the most disadvantaged (van Toorn & Soldatic, 2015, citing Macey, 2015; Williams, 2015). By examining the exemplars in this
study and potential of the ISP model from a capabilities lens, this work aims to contribute to knowledge regarding how the NDIS may avoid replication of previous design and implementation flaws as it rolls out across states this year.

The capabilities approach is not a theoretical framework but rather a way of thinking about justice and freedom (Terzi, 2005), identifying the wellbeing, opportunities, and freedoms of people as a central goal of good social policy and practice. A capabilities lens complements and extends a human rights approach, offering potentially a more applied framework for examining how rights are realised in the intersection between funding, services and community (Vizard et al, 2012; Burchardt & Vizard, 2012).

In highlighting the dynamic of conversion as a central argument, this study challenges policy makers, services, and practitioners to understand, in the reality of everyday lives how, in what conditions and through what mechanisms resources are transformed and converted into chosen and meaningful lives. An important response to these challenges lies in improving the way policy and practice can bend to diverse needs and contexts in more responsive and flexible ways. The previous chapter has argued that personalisation cannot expand self-determination or citizenship, as models propose, if these approaches are not located within the context of difference and a more sophisticated understanding of the social and relational nature of choice (Ramcharan, Leighton, Moors, Laragy, Despott & Guven, 2013; Duffy, 2011, 2014; Terzi, 2005). This equity argument distinguishes itself from a policy preoccupation with standardised approaches which ultimately fail to adequately account for difference (Welch Saleeby, 2007). Instead, this study has significant implications for key phases and processes within the funding and service pathway, particularly assessment and planning, and the need to ground these processes in a more nuanced understanding of how the interplay between the personal, social, and contextual factors shape individual capabilities and opportunities.

The analysis raises questions about how well current individualised funding and service models respond to diversity and also implies the need for closer examination of the responsibilities and obligations of those who bear duty to people with disabilities, such as the state and the service sector, in ensuring resources, processes and conditions for justice and equity (Nussbaum, 2012; Sen, 2012). Central to these questions is the need for closer examination of the relationships between duty bearers, such as between the
state and services, and the level and type of regulation and safeguards required to promote more equitable and fair conditions for people with disabilities. Not only do duty bearers have a positive obligation to provide for critical capabilities as important freedoms, such as social and economic participation, but also and importantly to proactively reduce barriers to their promotion and realisation. This understanding calls for greater critical reflection by government and services regarding the degree to which their processes and approaches are based on principles of citizenship and inclusion as opposed to control and economic efficiencies. There are implications for the NDIS here, in terms of giving more practical substance to the idea of rights and positive obligations in the context of individualised funding and service models. Policy and practice implications for individuals, family carers, support staff, services, and the broader community have been discussed in detail in the preceding discussion chapter.

9.3 Implications for future research

The study raises questions about the relationship between resources and outcomes and what is required to convert the latent potential of often scarce resources into meaningful and chosen lives. The study has shown that key conversion mechanisms were typically unrecognised by the formal funding process and under resourced, resulting in systematic cost shifting to individuals, families, and services. These key findings have implications for future research and evaluation in the area of individualised funding and self-directed approaches. The findings have implications for what is valued and therefore measured, how such measurement occurs, and by whom. Important questions for future research and evaluation relate to what constrains and what enables conversion of resources and what should be the roles of policy, services, the community and market in actively removing constraints and embedding enabling and empowering processes and relationships. How can these conversion activities be more fully recognised and funded under the NDIS?

A capabilities lens and cognisance of conversion encourages research and evaluation beyond administrative and normative measures of input and output. It suggests a
greater analytic focus on those processes, relationships and structures which, in real terms, activate resources and operationalise choice and self-determination. If criteria for impact of individualised funding policy and practice hinges on the extent to which they expand freedom and opportunity, in line with what people value, new questions and research priorities need to emerge.

Such research would capture not only the choices people using funding and services make but more importantly, the choices they were able to make given the nature of the resources and opportunities available to them (George, 2015). Research of this nature would examine institutional and service capacity to empower and convert with implications for assessment, planning, and funding processes. For example, were relevant and meaningful opportunities available, was the person supported through accessible information and appropriate resources and advocacy to make informed choices, and did the person have access to the resources, relationships and opportunities required to operationalise their choices in the community? These research foci have implications for the purpose, scope, and focus of the policy framework in building individual, family and community capability.

Future research could test the conversion mechanisms identified in this study but importantly should also look for other factors relevant for different groups and environments. Expanding on this small study by examining conversion in larger more diverse samples and across jurisdictions would offer valuable comparative analyses and inform future innovations in this area.

Further, while this study has focused predominantly on the principle of conversion, there is much to achieve in pursuing other concepts offered in the capabilities framework. These include developing capabilities sets for different groups of people with disabilities using individualised funding and services through participatory and ground-up approaches (see Burchardt, 2008, and Burchardt & Vizard, 2011).

Working more closely with groups to identify what they value as central and important in their lives, in the form of capabilities and opportunities, would directly inform individualised funding policy and practice. It would also have implications in relation to priority areas for resourcing, processes, and systems. Missing in this research, and yet vital in any further study, are the ways in which collective interests impact on such
processes and systems and the role of self and systemic advocacy in this. It is critical that the collective voices of people with disabilities should feature in any future work.

Ideas presented in this research have the potential to directly inform the development and objectives of social support and care policy beyond individualised funding reform. Such research would follow and build upon existing projects and studies which similarly used the synergies between human rights and the capabilities approach to examine policy and practice from a grounded social justice perspective (see Kimberley et al, 2012; Burchardt & Vizard, 2011; Gorecki & Kelly, 2011; Burchardt & Vizard, 2011).

Finally, this study, whilst small and limited to the Victorian model, has important implications for policy and practice and future research priorities in the field of individualised and self-directed funding reform. With the development of self-directed approaches beyond disability to aged care and in the context of increased pressure on limited social support budgets, there is a need for fresh and more nuanced approaches to managing the balance between the right to a good life and limited public resources.

I suggest that a capabilities based lens, as tested in this research, offers one new way of thinking and practising if the potential of the NDIS, one of Australia’s most significant social policy reforms to date, is to be converted to support diverse and complex circumstances and life choices and deliver on its promise of a better life for people with disabilities.

In order to meet the needs and aspirations of people with disabilities whilst also attending to complex economic and political imperatives, administrative changes to how funding is provided must be accompanied by investment in community infrastructure and resources, workplace capability and development, sustainable market diversity, and critically, culture change in services and the values, principles and assumptions underpinning current practice.
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UK 2004 Carers (Equal Opportunities) Act


Appendices

1. Appendix A: Information sheet and invitation to participate – ISP holder group
2. Appendix B: Easy language information sheet and invitation to participate – ISP holder group
3. Appendix C: Consent Form for Persons participating in Research Projects involving interviews, questionnaires or disclosure of personal information
4. Appendix D: Information sheet and invitation to participate – family carers
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Appendix A: Information sheet and invitation to participate - ISP group

Invitation to Participate in a Research Study

Participant information

Delivering on its promise? Exploring individualised funding for people with disabilities from a human rights based approach

Project title:

(A project committed to plain language to enable maximum inclusion)

Investigator:

- Christina David, PhD candidate, RMIT University, Bachelor of Education, Bachelor of Social Work, Graduate Diploma Business (Organisational Change and Development)
- Supervisors: Associate Professor Paul Ramcharan and Dr Carmel Laragy
- Email address: Christina.david@rmit.edu.au
- Phone: 99253199

Dear .............,

You are invited to participate in a research project about the relationship between individualised funding and important human rights such as dignity, autonomy, choice and independence. The research is being conducted by Christina David, a PhD candidate at RMIT University. The research is seeking to understand how individualised funding, such as the Individual Support Packages (ISP) allocated by DHS, impact upon the human rights of people with a disability. You are being invited to participate in this study as you have recently been allocated an ISP and may be interested in sharing your experiences, goals and hopes with the researcher.
Please read this sheet carefully and be confident that you understand its contents before deciding whether to participate. If you have any questions about the project, please contact the researcher, Christina David, for more details on 9925 53199 or email her on Christina.david@rmit.edu.au.

Who is involved in this research project? Why is it being conducted?

- Christina David is conducting this project as part of her work toward a PhD award. She is being supervised by Associate Professor Paul Ramcharan and Dr Carmel Laragy, both from RMIT University, Melbourne.
- The project has been approved by the RMIT Human Research Ethics Committee.
- (Insert name of agency) is helping Christina find people with a disability who have been recently allocated an Individual Support Package (ISP) and who might be interested in talking to her about their experiences.

Why have you been approached?

You have been invited to participate as you have been allocated an Individual Support Package by the Department of Human Services. Participation in this research is totally voluntary. Please note that because annecto is sending you this invitation, your private details have remained confidential and have not been released to Christina, the researcher.

What is the project about? What are the questions being addressed?

The aim of this study is to better understand how individualised funding, such as the Individual Support Package you have chosen, impacts upon important human rights such as dignity, autonomy, choice, independence, non-discrimination, inclusion, respect for difference, equal opportunity and accessibility. These rights are outlined in the Convention of the Rights of Persons with Disabilities which Australia ratified in 2008. This convention represents significant progress in the area of human rights for people with disabilities and provides a new framework for expectations and opportunities.

The researcher will interview 12 people with disabilities receiving an ISP and some of their family members twice over a period of nine months. Other people such as support workers, representatives from advocacy groups and staff from disability service providers will also be interviewed to get their perspectives on how individualised funding impacts on people's rights.

The primary research questions are:

- To what extent and in what ways do individualised funding models promote, protect and ensure the human rights of people with disabilities choosing this approach?

- What are the key factors enabling and limiting the promotion, protection and progressive realisation of individual and collective rights across multiple systems levels and what are the tensions, risks and opportunities from a human rights based perspective?

If I agree to participate, what will I be required to do?
If you agree to participate in this study you will be asked to participate in two interviews with Christina David. The interviews will be held about seven months apart. They will be between 60 and 90 minutes and will be held at a place convenient to you. There will also be several telephone conversations between the interviews just to see how things are going and to discuss any changes to your circumstances which may have occurred. If you agree, the interview will be recorded.

The type of questions Christina will ask you in the first interview will relate to the following areas:

- Reasons why you chose a self-directed approach in relation to your disability funding
- What is important to you in your life and your goals and hopes for the future
- In what ways you think your ISP may help you move closer to your goals, especially in relation to having greater choice, autonomy and independence.

The second interview, about seven months after the first will discuss how you have experienced having an Individual Support Package and how it has changed anything in your life. This interview will also explore what types of opportunities and resources have helped you move toward your goals as well as what barriers have prevented you from achieving your goals.

What are the possible risks or disadvantages?

We don’t think there are any significant risks in participating in this research however we will be asking you to discuss personal issues such as your expectations, hopes and dreams and sometimes this can bring up emotions such as sadness or anger. If at any time during the interviews you wish to have a break or stop the interview completely, that will be absolutely fine and there will be no negative consequences for you. Your participation in this research is at all times voluntary.

If at any time during the study period you wish to discuss your participation with the researcher please contact Christina on 9925 3199 or email on Christina.david@rmit.edu.au. Christina will discuss your concerns in confidence and suggest appropriate follow up if necessary.

We are also asking for your time and understand that you will have to make arrangements to get to the venue for the interviews. In order to reduce inconvenience to you, the researcher will travel to wherever is convenient and safe for you when organising the interviews. It will also be possible to do telephone interviews if this is more convenient for you.

In relation to protecting your identity, all your personal details such as your name and where you live will be taken out of the final report and my thesis. In this way, you will not be able to be identified in the final reports and your privacy will be maintained.

What are the benefits?

Your participation in this project will provide valuable information about the everyday experiences of people with disabilities choosing individualised funding. Understanding how individualised funding impacts on people's human rights will give greater meaning and substance to human rights ideas and legislation such as the Convention on the Rights of Persons with Disabilities and, in Victoria, the Charter of Rights and Responsibilities. Understanding the ways in which individualised funding impacts on your
ability to achieve your goals and, as part of that process, your human rights, will be valuable information for all sorts of people and organisations include government, disability service providers and advocacy groups.

What will happen to the information I provide?

The interviews will be recorded with your permission and then transcribed using voice recognition technology. Your name and other identifying personal details will be removed from the transcripts. The information you provide will be seen by the researcher, Christina David, and her supervisors, Assoc. Prof. Paul Ramcharan and Dr Carmel Laragy. Documents containing information you have provided will be stored on a password protected computer at RMIT University and hard copies of documents such as this consent form or notes from the interviews will be stored in a locked filing cabinet at RMIT. All records will be shredded five years after publication of the final report and the researcher’s thesis.

The information you provide will combine with information from other participants and be analysed to identify key issues for people with disabilities using individualised funding, from a human rights based perspective. The researcher will do this by reading, many times, the transcripts of your interviews and also be speaking with family members and staff from disability service providers. The researcher will also speak with representatives from advocacy groups, government and other community organisations to try to get as many perspectives as possible in relation to the research questions listed above.

Ultimately, all this information and analysis will be written into a final report which will be publicly available. You will be sent a copy of this report. The information will also be part of the researcher’s PhD thesis, to be submitted to the RMIT by the end of 2014. The information may also be included in presentations at conferences and journal articles.

Information that you provide can only be disclosed to people other than the researcher and her supervisors if (1) it is to protect you or others from harm (2) a court order is produced, or (3) you provide the researcher with written permission.

What are my rights as a participant?

- The right to withdraw from participation at any time.
- The right to have any unprocessed data withdrawn and destroyed, provided it can be reliably identified, and provided that so doing does not increase the risk for the participant.
- The right to have any questions answered at any time.

Whom should I contract if I have any questions?

Please contact the researcher, Christina David, on 9925 3199 or email Christina.david@rmit.edu.au if you have any queries about the project and/or your involvement in it.

What other issues should I be aware of before deciding whether to participate?
You should consider whether you are happy to commit to two interviews and several telephone conversations over a period of up to nine months. Consider whether you will be able to participate fully in the interviews either independently or with your normal support strategies and whether you want to give information about your life experiences and future goals.

What do I do now?

If you would like to participate, please send back the expression of interest form attached to this letter in the envelope provided. Christina will then get in touch with you soon.

Yours sincerely

Christina David, Principal Researcher
PhD student, BEd, BSW, Grad Dip Bus.
RMIT University
9925 3199
Christina.david@rmit.edu.au
Appendix B: Easy language information sheet and invitation to participate to ISP holder group.

Invitation to participate in a research project

(A project committed to plain language to enable maximum inclusion)

Project title:

**Delivering on its promise? Exploring individualised funding for people with disabilities from a human rights based approach**

Dear

You are invited to participate in a research project about people with disabilities who have an Individual Support Package (ISP). The research is looking at how having individualised funding might change things about people’s lives, their hopes and their ability to enjoy their human rights.

The research is being done by Christina David, a student at RMIT University. She has approval from RMIT to do this research. (Insert name of disability agency...... ......) is helping her find people who might be interested in speaking with her about their experiences. She is being supervised by Associate Professor Paul Ramcharan and Dr Carmel Laragy from RMIT University.
By human rights, we mean people's rights to have control over their lives, to have dignity, to make choices, to be independent and to be included in community life if they choose to.

Christina is planning to speak with 12 people who have ISPs.

Insert name of provider …….. is sending this letter to you so that your details can remain private unless you decide you would like to speak with Christina about joining the study.

What would you have to do?

If you want to be involved, Christina will contact you to organise a time and place to meet. The place would be convenient and safe for you. If you normally have someone to support you, that person would need to be with you so that Christina can be sure she understands what you are saying.

Christina will ask questions like these:

- Why did you choose to have an ISP?
- What do you think it might change?
- What was your experience of your disability services when you didn’t have an ISP?
- How do you think it will help you get what you want out of life?
Christina would like to interview you twice over seven months and also speak with you by telephone several times if this suits you. With your permission, the interviews will be audio recorded.

The interviews will each take about one to one and a half hours each and if you normally have someone to assist you with your communication or other needs, that person should be with you.

**What will happen to your information?**

The things you tell Christina will join with all the information she is collecting from other people. Your name and personal information will be taken out so that no one will know what you tell her.

The information will help Christina understand how individualised funding might change people’s chance to enjoy important rights.
Christina will write a final report and you will get a copy. She will also write a thesis which is a document she needs to write to get her PhD. The information may also be published in papers for conferences and in academic journals.

**Are there any risks or disadvantages?**

You will be asked about things that are important and personal to you. Sometimes this might make you feel sad or angry. If this happens and you want to stop the interview, you just need to tell me or your support person and I will stop the interview. If you want to leave the study at any time, you are free to do so.

**What are the benefits?**

By joining this study, you will be sharing your story and helping other people understand what needs to be done to make sure people with disabilities can have the human rights they deserve. You will also be helping government and community organisations understand more about how having more control over disability funding affects people's lives.

**What do I do now?**
If you have any questions, please call Christina on 03 9925 3199. If you want to be involved, please email or phone Christina, see details below.

Yours sincerely

Christina David,
PhD Student, BSW, BEd, Grad. Dip. Bus.
Centre for Applied Social Research
RMIT University

PH: 9935 3199: email Christina.david@rmit.edu.au
PARTICIPANT’S CONSENT

1. I have had the project explained to me, and I have read the information sheet.

2. I agree to participate in the research project as described. I agree to be interviewed and to have the interview audio recorded.

(a) I understand that my participation is voluntary and that I am free to withdraw from the project at any time and to withdraw any unprocessed data previously supplied (unless follow-up is needed for safety).

(b) The project is for the purpose of research. It may not be of direct benefit to me.

(c) The privacy of the personal information I provide will be safeguarded and only disclosed where I have consented to the disclosure or as required by law.

(d) The security of the research data will be protected during and after completion of the study. The data collected during the study may be published, and a report of the project outcomes will be provided to you in late 2013. Any information which will identify me will not be used.

Participant’s Consent

Participant: ___________________________ Date: ___________________________

(Signature) ___________________________ ___________________________

Witness:

Witness: ___________________________ Date: ___________________________

(Signature) ___________________________ ___________________________

Where participant is under 18 years of age: delete if not required

I consent to the participation of ___________________________ in the above project.

Signature: (1) ___________________________ (2) ___________________________ Date: ___________________________

(Signatures of parents or guardians) ___________________________ ___________________________
Witness: ____________________________ Date: ____________________________

(Witness to signature)

[only required if research is assessed as more than low risk; otherwise please delete]

Any complaints about your participation in this project may be directed to the Ethics Officer, RMIT Human Research Ethics Committee, Research & Innovation, RMIT, GPO Box 2476V, Melbourne, 3001. The telephone number is (03) 9925 2251. Details of the complaints procedure are available on the Complaints with respect to participation in research at RMIT page.

Participants should be given a photocopy of this PICF after it has been signed.
Appendix C : Consent Form for Persons participating in Research Projects involving interviews, questionnaires or disclosure of personal information

Centre for Applied Social Research
RMIT University
GPO Box 2476
Melbourne VIC 3001

Project Title:

**Delivering on its promise? Exploring individualised funding from a human rights based perspective**

Investigator and supervisor details:

Christina David, PhD candidate, RMIT University. Bachelor of Education, Bachelor of Social Work, Graduate Diploma Business (Organisational Change and Development).

Supervisors: Associate Professor Paul Ramcharan and Dr Carmel Laragy, both of RMIT University.

Email address: Christina.david@rmit.edu.au

Phone: 99253199

PARTICIPANT’S CONSENT

I have had the project explained to me, and I have read the information sheet
I agree to participate in the research project as described. I agree to be interviewed and to have the interview audio recorded.

I acknowledge that:

(a) I have read the Plain Language Statement and agree to the aims, methods and requirements of the study.

(b) I understand that my participation is voluntary and that I am free to withdraw from the project at any time and to withdraw any unprocessed data previously supplied (unless follow-up is needed for safety).

(c) The project is for the purpose of research. It may not be of direct benefit to me.

(d) The privacy of the personal information I provide will be safeguarded and only disclosed where I have consented to the disclosure or as required by law.

(e) The security of the research data will be protected during and after completion of the study. The data collected during the study may be published, and a report of the project outcomes will be provided to you in late 2013. Any information which will identify me will not be used.

Participant’s Consent

Participant: ___________________________ Date: ___________________________

(Signature) ___________________________

Witness:

Witness: ___________________________ Date: ___________________________

(Signature) ___________________________

Parent or guardian’s consent if required.

I consent to the participation of ___________________________ in the above project.

Signature: (1) ___________________________ (2) ___________________________ Date: ___________________________

(Signatures of parents or guardians) ___________________________
Witness: __________________________________________  Date: _______________________________

(Witness to signature)

[only required if research is assessed as more than low risk; otherwise please delete]

Any complaints about your participation in this project may be directed to the Ethics Officer, RMIT Human Research Ethics Committee, Research & Innovation, RMIT, GPO Box 2476V, Melbourne, 3001. The telephone number is (03) 9925 2251.
Details of the complaints procedure are available on the Complaints with respect to participation in research at RMIT page.

Participants should be given a photocopy of this PICF after it has been signed.
Appendix D: Invitation and information for family member interview

Centre for Applied Social Research
RMIT University
GPO Box 2476
Melbourne VIC 3001

Invitation to participate in a research project

(A project committed to plain language to enable maximum inclusion)

Project Title: Delivering on its promise? Exploring individualised funding for people with disabilities from a human rights based approach.

Investigator:

- Christina David, PhD candidate, RMIT University, Bachelor of Education, Bachelor of Social Work, Graduate Diploma Business (Organisational Change and Development)
- Supervisors: Associate Professor Paul Ramcharan and Dr Carmel Laragy
- Email address: Christina.david@rmit.edu.au : Phone: 99253199

Dear ..............,

You are invited to participate in a research project about the relationship between individualised funding and important human rights such as dignity, autonomy, choice and independence. The research is being conducted by Christina David, a PhD candidate at RMIT University. The research is seeking to understand how individualised funding, such as the Individual Support Packages (ISP) allocated by DHS, impact upon the human rights of people with a disability. You are being invited to participate in this study as you are the family member of a person receiving disability support funding and because you are closely involved
with the day to day care and support of your family member. As such, your thoughts and experiences are important to this research.

Please read this sheet carefully and if you have any questions about the project, please contact the researcher, Christina David, for more details on 9925 53199 or email her on Christina.david@rmit.edu.au.

Who is involved in this research project? Why is it being conducted?

- Christina David is conducting this project as part of her work toward a PhD award. She is being supervised by Associate Professor Paul Ramcharan and Dr Carmel Laragy, both from RMIT University, Melbourne.
- The project has been approved by the RMIT Human Research Ethics Committee.

Why have you been approached?

Family members often play a significant role in the life choices of a person with a disability and are also in many cases responsible for the administration and organisation of support funding. Thus families can have significant vested interest in making these arrangements work. Part of this research is to explore how families work to forge connections and networks within the community to increase social participation and access. You are being invited to participate in two interviews with Christina as your views and experiences are important to this research. Participation is voluntary and if you choose not to participate in this study there will be no repercussions or consequences for you or your family member.

What is the project about? What are the questions being addressed?

The aim of this study is to better understand how individualised disability support funding impacts upon people’s choices and important human rights such as dignity, autonomy, independence, non-discrimination, inclusion, respect for difference, equal opportunity and accessibility. These rights are outlined in the Convention of the Rights of Persons with Disabilities which Australia ratified in 2008. This Convention, together with Victoria’s Charter of Rights and Responsibilities, represents significant progress in the area of human rights for people with disabilities and provides a new framework for expectations and opportunities.

The researcher will interview people with disabilities receiving disability support funding and, where relevant and appropriate, their family members. Other people such as staff from disability service providers and representatives from advocacy groups will also be interviewed.

The primary research questions are:

- To what extent and in what ways do individualised funding models promote, protect and ensure the human rights of people with disabilities?
- What are the key factors enabling and limiting the promotion, protection and progressive realisation of individual and collective rights across multiple systems levels and what are the tensions, risks and opportunities from a human rights based perspective?

If I agree to participate, what will I be required to do?

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If you agree to participate in this study, Christina will organise an interview with you in the next month or so and, if relevant, another interview in six months time. The interviews will be held at a place and time convenient to you. If you agree, the interviews will be recorded.

The interviews will explore your experiences with disability services and the ways in which the services and supports you receive enable your family member to develop and work toward their goals as valued members of their community. The questions will explore your ideas about what sorts of resources, people and opportunities help you and your family member realise important human rights such as choice, independence, autonomy and respect on a daily basis. You will also be asked about the barriers and obstacles which prevent you and your family member from developing the sort of life you want.

**What are the possible risks or disadvantages?**

There are no significant risks in participating in this research however I will be asking you to discuss personal issues such as your expectations, hopes and dreams and sometimes this can bring up emotions such as sadness or anger. If at any time during the interviews you wish to have a break or stop the interview completely, that will be absolutely fine and there will be no negative consequences for you. Your participation in this research is at all times voluntary.

If at any time during the study period you wish to discuss your participation with me please contact Christina on 99253199 or email Christina.david@rmit.edu.au.

In order to reduce inconvenience to you, Christina will travel to wherever is convenient for you when organising the interviews. It will also be possible to do telephone interviews if this is more convenient for you.

In relation to protecting your identity, all your personal details such as your name, where you live and other identifying features will be removed from the final report and my thesis. In this way, you will not be able to be identified in the final reports and your privacy will be maintained.

**What are the benefits?**

Your participation in this project will provide valuable information about the everyday experiences of people with disabilities choosing individualised funding. Understanding how individualised funding impacts on people's human rights will give greater meaning and substance to human rights ideas and legislation such as the Convention on the Rights of Persons with Disabilities and, in Victoria, the Charter of Rights and Responsibilities. Understanding the ways in which individualised funding impacts on your ability to achieve your goals and, as part of that process, your human rights, will be valuable information for all sorts of people and organisations.

**What will happen to the information I provide?**

The interviews will be recorded with your permission and then transcribed using voice recognition technology. Your name and other identifying personal details will be removed from the transcripts. The information you provide will be seen by the researcher, Christina David, and her supervisors, Assoc. Prof. Paul Ramcharan and Dr Carmel Laragy. Documents containing information you have provided will be
stored on a password protected computer at RMIT University and hard copies of documents such as this
cconsent form or notes from the interviews will be stored in a locked filing cabinet at RMIT. All records
will be shredded five years after publication of the final report and the researcher's thesis.

The information you provide will combine with information from other participants and be analysed to
identify key issues for people with disabilities using individualised funding, from a human rights based
perspective.

Ultimately, a final report will be written and this will be publicly available. You will be sent a draft copy of
this report to ensure you are happy with the anonymity provided. The final report will be published in
late 2014. The information will also be part of the researcher’s PhD thesis, to be submitted to the RMIT by
the end of 2014. The information may also be included in presentations at conferences and journal
articles.

Information that you provide can only be disclosed to people other than the researcher and her
supervisors if (1) it is to protect you or others from harm (2) a court order is produced, or (3) you
provide the researcher with written permission.

**What are my rights as a participant?**

- The right to withdraw from participation at any time.
- The right to have any unprocessed data withdrawn and destroyed, provided it can be reliably
  identified, and provided that so doing does not increase the risk for the participant.
- The right to have any questions answered at any time.

**Whom should I contact if I have any questions?**

Please contact the researcher, Christina David, on 9925 3199 or email Christina.david@rmit.edu.au if you
have any queries about the project and/ or your involvement in it.

**What other issues should I be aware of before deciding whether to participate?**

You should consider whether you are happy to commit to two interviews and several telephone
conversations over a period of up to nine months and also whether you are comfortable about discussing
the issues outlined above.

**What do I do now?**

If you would like to participate, please contact Christina on 9925 3199 or email her advising of your
interest at Christina.david@rmit.edu.au. Christina will then get in touch with you to arrange times.

Yours sincerely

Christina David, Principal Researcher

PhD student, BEd, BSW, Grad Dip Bus.

RMIT University

9925 3199
PARTICIPANT’S CONSENT

3. I have had the project explained to me, and I have read the information sheet

4. I agree to participate in the research project as described. I agree to be interviewed and to have the interview audio recorded.

   (f) I understand that my participation is voluntary and that I am free to withdraw from the project at any time and to withdraw any unprocessed data previously supplied (unless follow-up is needed for safety).

   (g) The project is for the purpose of research. It may not be of direct benefit to me.

   (c) The privacy of the personal information I provide will be safeguarded and only disclosed where I have consented to the disclosure or as required by law.

   (d) The security of the research data will be protected during and after completion of the study. The data collected during the study may be published, and a report of the project outcomes will be provided to you in late 2013. Any information which will identify me will not be used.

Participant’s Consent

Date:

Participant:

______________________________
(Signature)

Witness:

Witness:

______________________________
(Signature)
Appendix E: Information to Disability Service Provider

Centre for Applied Social Research
RMIT University
GPO Box 2476
Melbourne VIC 3001

Delivering on its promise? Exploring individualised funding for people with disabilities from a human rights based approach – a research project

(A research project committed to plain language to enable maximum inclusion)

Investigator and supervisor details:

Christina David, PhD candidate, RMIT University. Bachelor of Education, Bachelor of Social Work, Graduate Diploma Business (Organisational Change and Development).

Supervisors: Associate Professor Paul Ramcharan and Dr Carmel Laragy, both of RMIT University.

Email address: Christina.david@rmit.edu.au / Phone: 99253199

Dear (insert name of manager)
Thank you for agreeing to support this project by sending out prepared information packages inviting people registered with your agency who have been recently allocated an Individual Support Package (ISP) to participate in the research.

**Recruiting participants**

As we have discussed, you have kindly agreed to send invitations to people registered with your agency who have been recently allocated an ISP, as per the recruiting strategy outlined below. We have discussed this process verbally but please feel free to call me at any time to discuss any questions you may have.

You will be one of three service providers in three regions involved in this project. The sample frame in relation to people using an Individual Support Package is outlined in Table 1 below. Each provider is asked to recruit a sample of four people recently allocated an ISP as detailed in Table 1.

You will be asked to send a prepared information sheet and invitation to people registered with your agency as they are allocated an ISP and until their category i.e. male, female, disability type and funding arrangement is filled for your region. Support groups for people with Direct Payments will be approached for assistance in identifying the next person allocated an ISP after a specified date.

**Table 1. Sample frame for ISP holders**

<table>
<thead>
<tr>
<th>Category</th>
<th>Metro region</th>
<th>Rural region</th>
<th>Remote region</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>disability service provider</td>
<td>disability service provider</td>
<td>disability service provider</td>
</tr>
<tr>
<td></td>
<td>holding funds (1)</td>
<td>holding funds (1)</td>
<td>holding funds (1)</td>
</tr>
<tr>
<td>2</td>
<td>financial intermediary holding</td>
<td>financial intermediary holding</td>
<td>financial intermediary holding</td>
</tr>
<tr>
<td></td>
<td>funds (1)</td>
<td>funds (1)</td>
<td>funds (1)</td>
</tr>
<tr>
<td>3</td>
<td>person holding funds – Direct</td>
<td>person holding funds – Direct</td>
<td>person holding funds – Direct</td>
</tr>
<tr>
<td></td>
<td>Payments (1)</td>
<td>Payments (1)</td>
<td>Payments (1)</td>
</tr>
<tr>
<td>4</td>
<td>To be determined balancing</td>
<td>To be determined balancing</td>
<td>To be determined balancing</td>
</tr>
<tr>
<td></td>
<td>male/female &amp; primary disability (1)</td>
<td>male/female &amp; primary disability (1)</td>
<td>male/female &amp; primary disability (1)</td>
</tr>
</tbody>
</table>

| Total 4  | Total 4                         | Total 4                         |

This project and all information you are sending has been approved by the RMIT Human Research Ethics Committee in accordance with their guidelines and in accordance with the National Statement on Ethical Conduct in Human Research, 2007.
A confidential interview

We have also discussed my request to interview you in your role as the manager of your agency. During this interview I will ask you about your ideas regarding individualised funding in relation to the following key areas:

- organisational processes and broader systemic issues supporting or obstructing successful implementation of the ISP initiative e.g. recruitment, staff availability, conditions
- impact of individual funding on the rights of people with disabilities, their families and the community
- hopes and reservations in relation to changing agency roles and shifting boundaries
- local innovations aiming to progress the rights of people with disabilities i.e. social inclusion and participation, independence, self-determination, choice
- understanding of implementing a human rights based approach

Please find attached a consent form regarding that interview and please call or email me if you have any queries.

What are the questions being addressed by this research?

The aim of this study is to better understand the ways in which individualised funding, such as the Individual Support Packages available in Victoria, impacts upon the human rights of people with disabilities. The Convention of the Rights of Persons with Disabilities (CRPD), which Australia ratified in 2008, offers an unprecedented opportunity to appraise individualised approaches from within a human rights based framework. The CRPD, together with the Victorian Charter of Rights and Responsibilities, represents significant progress in the area of human rights for people with disabilities and provides a new framework for expectations and opportunities.

The research will take place during 2012 and will involve interviewing 12 people with disabilities receiving an ISP and some of their family members twice over a period of nine months. Other people such as support workers and representatives from disability advocacy groups will also be interviewed to get their perspectives on how individualised funding impacts on people’s rights.

The primary research questions are:

- To what extent and in what ways do individualised funding models promote, protect and ensure the human rights of people with disabilities choosing this approach?

- What are the key factors enabling and limiting the promotion, protection and progressive realisation of individual and collective rights across multiple systems levels (i.e. micro, meso, exo and macro) and what are the tensions, risks and opportunities from a human rights based perspective?

Who is involved in this research project? Why is it being conducted?

I am conducting this project as part of my work toward a PhD award. I am supervised by Associate Professor Paul Ramcharan and Dr Carmel Laragy, both from RMIT University. I have also been working
with Paul Ramcharan on a component of the Australian Research Council (ARC) funded project, Auditing the Victorian Charter. I have been working with Assoc. Prof. Ramcharan in developing a human rights audit tool to be used with people with disabilities. It is anticipated that my work on the audit tool and my PhD research project will complement and support each other in contributing to the body of applied knowledge available in Australia regarding the human rights of people with disabilities.

What are the benefits?

It is hoped this project will provide valuable information about the everyday experiences of people with disabilities choosing individualised funding. Understanding how individualised funding impacts on people’s human rights will give greater meaning and substance to human rights ideas and legislation such as the Convention on the Rights of Persons with Disabilities and, in Victoria, the Charter of Rights and Responsibilities. Understanding the ways in which individualised funding impacts on people’s ability to achieve their hopes and goals and, as part of that process, their human rights, will be valuable information for all sorts of people and organisations include government, disability service providers and advocacy groups.

Confidentiality and anonymity provisions

All interviews and the focus group will be recorded with participants’ permission and then transcribed using voice recognition technology. All identifying personal details will be removed from the transcripts. Apart from myself, the information collected will only be seen by my supervisors, Assoc. Prof. Paul Ramcharan and Dr Carmel Laragy. Documents will be stored on a password protected computer at RMIT University and hard copies of documents such as consent forms or notes from the interviews will be stored in a locked filing cabinet at RMIT. All records will be shredded five years after publication of the final report and the researcher’s thesis.

The data will inform my PhD thesis, to be submitted to RMIT by the end of 2014. You will be sent a draft copy of an executive summary prior to publishing and will be offered the opportunity to check that all identifying information has been removed. It is also hoped that the data will be used in academic papers and conference presentations. The data will inform my PhD thesis, to be submitted to RMIT by the end of 2014. It is also hoped that the data will be used in academic papers and conference presentations.

Whom should I contact if I have any questions?

Please contact me on 9925 3199 or email Christina.david@rmit.edu.au if you have any queries about the project and/ or your involvement in it. I look forward to working with you over the coming months.

Yours sincerely

Christina David, Principal Researcher
PhD student, BEd, BSW, Grad Dip Bus.
Centre for Applied Social Research
RMIT University
Appendix F: Interview Schedule – ISP holder and family carer

Created: May 26 2012 by Christina David

(As noted in Chapter 5, this schedule was used as a base set of questions and questions which I adapted and modified depending on the context, the participant’s capacity to respond, their particular interests, and the flow of the conversation. )

A: Personal details

Name:
Address:
Referred by/from:
DHS Region:
Date of interview:
Age:
First language/language spoken at home:
People present at the interview and roles:

B: Living situation i.e where, with whom, choices?

How satisfactory is this is for you?
Is this what you want? If not, what would you prefer?
Positives and negatives of your living arrangement

Daily activities - social, work, recreation, sport, family

What do you do during your days? What sort of routine do you have?
What do you enjoy about your days and what don’t you enjoy?
Who do you see and do things with?
What other things would you really like to be doing?

C: Decision to have an ISP and service history

How long have you had your ISP?
What disability services and supports did you have before your ISP - what services, where, when, how long
Where these services what you wanted? If not, what did you want?
How did you come to have an ISP? (a, b, c? see prompt questions below)
a) Got rolled over from other funding?
   - Discuss details: What sort of conversations did people have with you about this? (who, what, when)
   - Was it explained to you what an ISP was?
   - Were you involved in the development of an ISP plan and how did this happen? (explore participation, choice)
   - What was on your ISP plan?
   - Have you been receiving any different services or doing anything else different since you have been on an ISP? (discuss changes and if no changes, discuss what hasn’t changed)
   - Do you feel you have more choice about the services you receive now you have an ISP?

b) Already had funding and applied to change to an ISP

c) Didn’t have any disability services funding and applied for an ISP
   - *Why did you apply for an ISP? (explore issues re choice, flexibility, inclusion, autonomy)
   - Discuss reasons including role of family and supporters in decision making.
   - What happened, what was the process to apply? (discuss how long it took, who was involved, feelings about this)

D. The application and planning process
   - Who and what helped you with the application and ISP plan? (discuss roles of DHS, agency staff, planners, family, carers)
   - Was it a positive or negative experience? Why?
   - Did your plan reflect what you wanted to achieve (goals) and how? Discuss (explore choice, knowledge of options)
   - Did you feel involved in the development of your plan? (explore participation, respect for choices, needs and decisions)
   - Did you feel your needs were taken into account? Discuss, examples
   - What and who was difficult during this process? What were the barriers?

E. Timeframes
   - How long did it take from applying for the ISP i.e. application, time on the DSR, allocation and actually using the funding
   - In relation to how long it all took, how did you feel during that period and did any new needs come up?

F. Goals and Funding
   - Did you receive the funding you requested?
   - Discuss the original proposal, goals and strategies/ funding request and what was actually funded
• If not fully funded, what was funded, what wasn’t? How has this impacted on your daily life and choices? Did you have to make compromises, give things up? Impact on your family?

• If fully funded, what services are you receiving now? Discuss details, clarifying what is different to before. Are there services you want but aren’t receiving? Why?

G. ISP administration (Direct payments, financial intermediary, held by agency)

• If someone is assisting you, who is it?
• Why did you choose this option?

Prompts: Comments regarding this funding arrangement? How could it work better for you and your family, supporters? Examples of positive and negative experiences.

H. Impact of ISP

• Has having individualised funding changed the way you live and how you feel?
  o Discuss and elaborate
• Discuss if and how having an ISP has impacted on each of the following. Examples? (Try to capture key changes, if any)
  • Choice
  • Control
  • Autonomy
  • Self-determination
  • Dignity
  • Flexibility
  • Independence

• If not already discussed, how has IF impacted on family and friends?
• Enablers, barriers - If not already captured, ask for examples of how the ISP system could be improved for individuals and families.
• Do you feel your funding will cope with your changing and future needs?

I. Additional comments you would like to make?

• July 2012 Note: Question C regarding why people chose to have an ISP is not relevant for many people, more relevant is the question of how they choose to administer it i.e. direct payments or other. Also, as I progress with the interviews, the above questions are increasingly only prompts as the conversation takes its own turn. However, I do not complete the interview without the key areas of life, hope, rights and opportunities as outlined above discussed.
Appendix G: Service providers and ISP Planner Interview Schedule

Created: October 2012 by Christina David
Note that questions and prompts in this schedule were modified depending on the role of the person i.e. manager, program co-ordinator, or planner

Name:
Position:
Agency:
Date of interview:
How long in this role?
How long working in the disability sector?

Role description (specific question for ISP planner)
1. ISP planners are in a unique position working on the boundary between DHS, client, services and community. Describe the role of the ISP planner/facilitator including its challenges?

2. Do you see any conflicts of interest in your role and work, as part of a large disability service provider of services? How do you manage these?

Organisational Structure
1. General questions regarding how agency operates, key services and overall objectives and principles

Human rights outcomes and approaches
1. Do you think individualised funding has increased people’s key human rights such as independence, autonomy, choice, dignity and inclusion and, if so, how?

2. Examples where this has occurred?

3. Examples where it makes no or little difference? Why is this? What are the barriers?

4. Do you think individualised funding is meeting its policy goals?

5. In your experience, what factors (social, family, financial, emotional, history) promote the ability of people to maximise opportunities offered by individualised funding? Examples?

6. What factors restrict people’s ability to do this? Examples?

7. How do you work with people using your service? If you are developing a plan, what sorts of questions do you ask? Would you say you take a rights based approach?
8. Different funding administration arrangements – what differences do you see in outcomes for people who use direct payments? Is it much different for them? (some say this is the group which gets maximum benefit regarding independence and choice)

9. What are your thoughts regarding services and groups designed especially for people with disabilities e.g. CRUs, day program, work training for PWD?

10. There are agencies which have transformed into service free agencies and who prioritise the use of mainstream services, avoiding disability specific group programs. What is your opinion of this approach?

**Funding availability, adequacy and certainty**

1. In relation to the people you are seeing, what would be the balance between new ISP packages and reviews?

2. Discuss the scope of the ISP package and the plans you develop or are involved with?

3. Inconsistency – have you experienced inconsistency in how funding is allocated and what is allowed on plans? Examples?

**Knowledge, the consumer/ customer and the future**

1. Knowledge, information and the consumer – do you think people have appropriate information and do they understand that information enough to make informed decisions, as a consumer of services?

2. What is your opinion about the impact of greater choice in how funding is used? Will they really be a consumer in the ordinary sense of the word? What are the barriers to operating as a real consumer?

3. What do you think is the future for disability service providers like yours in the NDIS?

4. Hopes and concerns for the NDIS?
Appendix H: Table of Master Themes

The following table shows the master themes developed from emergent themes in the interview transcripts with ISP holders, their family carers and support workers. The themes developed from interviews with service providers have been incorporated into this table.

<table>
<thead>
<tr>
<th>Master themes</th>
<th>Emergent themes identified in the transcripts</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Outcomes</strong></td>
<td>Flexibility in services: times and tasks; swapping and saving hours; greater spontaneity; choice of worker and service</td>
</tr>
<tr>
<td>1.1 Positive impacts, outcomes, benefits of individualised funding</td>
<td>Choice and control: worker, tasks, and services; timing of activities; dignity in choice; portability feature increases choice; direct payments increase personal control, reduce ‘interference’ from others, allow things to be more ‘ordinary’</td>
</tr>
<tr>
<td></td>
<td>Increased opportunities for chosen types of social participation in community: tailored to needs, interests and goals; can leave disability day program; scope for more innovative solutions</td>
</tr>
<tr>
<td></td>
<td>Independent living and autonomy: to stay home, leave home, move back home; independent movement, more spontaneity in day to day activities</td>
</tr>
<tr>
<td></td>
<td>Family carer benefits: closer controls on staff and services; portability – can change services if not happy; sharing care with trusted support staff; more flexible respite with more opportunities to pursue own interests and relationships</td>
</tr>
</tbody>
</table>
### 1.2 Adverse impacts, outcomes and risks

| Lack of opportunity: for fundamental change in how funding is used; to explore more community based options; still in a 'holding pattern' approach to life; lack of resources for life goals beyond basic care and support needs. |
| Dealing with the funding system: a complex bureaucracy; lack of transparency; difficult and time consuming to access funding; inconsistent experience in applying for funding, planning, and funding approvals. |
| Inadequate funding: to support choice in social participation beyond personal care and support; not targeting the thinking, linking, bridging work for self-determination; cost shifting to individuals, families and services; stressing and depleting personal and social resources a risk to choice; transaction costs involved in engaging with the demands of the self-directed framework. |
| Lack of choice in how funds are used due to: lack of service options in some locations; lack of knowledge about options and how to use funding; lack of knowledge about potential of ISP; risk averse services; withholding information about right to choose; restrictions on ISP spending not consistent with what person needs and chooses. |
| Direct payments: not enough support to manage this option, not enough benefit given time and energy required. |
| Information about ISP funding guidelines and resources: confusing, overwhelming, vague, inconsistent. Lack of information led to uncertainty and restricted autonomy in spending. Some services withhold information. |

### 2. Conversion Factors - Relationships, processes and resources

| Positive conversion factors and mechanisms |
| Relationships with workers and continuity in service relationships builds trust; trust facilitates change and new ideas, trust is a resource in and of itself; service relationships a social and emotional resource as well as practical; family carer benefits in developing supporting relationships with staff; relationships convert resources into choice. |
| Formal resources – ISP funding which is based on strengths and goals, building on personal and social resources in positive ways: creates opportunities beyond personal supports; can support the planning, linking, bridging work required to benefit from individualised resources. |
| Service resources: relational; helpful, willing to go extra mile; innovation and encouraging in thinking about community based options; do the thinking, linking, bridging work; community development focus; opportunities to develop service continuous relationships; role in conversion of resources into choice. |
| Informal/ natural personal and social resources: personal attributes, assets, and history, family, friends, and social networks interact to enable greater choice and self-determination; social supports compensate for funding and resource gaps by providing practical support, advocacy, planning, co-ordination, knowledge. There is a multiplying effect of social capital in transforming resources into choice if protected and supported; social capital is a resource and an outcome. |
| Planning: global, flexible, informed, enough time, with a planner who understands personal and social context, strengths and goals |
### Negative conversion factors and mechanisms

- **Service sector**: there can be inconsistent approaches with some still operating along tradition service user relationships where maintaining power and control is important; some maintain the boundary between person and community, are risk averse, do not support change, and engage in ‘client capture’, ‘empire building’, welfarist and paternalistic service approaches.

- **ISP funding**: accessing funding can be difficult, complex, adversarial; inadequate for goals; deficit based and non-person centred; slow to respond to unmet needs.

- **Planning**: can be uninformed; not located in understanding of personal and social context; not flexible or far reaching; not linked to social and economic goals; not accounting for existing resources and new ones required; over reliant on existing family carer support.

- **Independent advocacy, support and information**: limited evidence re access to independent advocacy to support planning and co-ordination; conflicts of interest for ISP planners in meeting DHS and managerial demands as well as goals and needs of the person; risks for those with weakest personal and social supports in managing the system in independent community based supports not available; costs transferred to those services who offer this work unpaid on top of DHS hourly rates.

### 3. Context

#### Positive and negative conversion factors

**Funding, program and policy**

- Community options accessible/ not accessible
- Services having a community development role with workers as linkers and enablers
- Social capital as a facilitator of opportunities
- Individualised funding as tool supported by services to convert resources into opportunities.
- Leadership and exemplars of self-directed practice in the sector
- Culture change in the service sector and the community
- Funding for the work associated with choice and self-determination, not just practical supports
- Services on a continuum of ideological differences with some supporting choice and self-determination
- Different ideologies regarding disability specific services e.g. day program, accommodation options