

**Self-directed Disability Support at the Local Level –  
Whose Power, Whose Control? Exploring Models for  
Municipal Service Provision**

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## ABSTRACT

Australia is undertaking a major, six-year reform of the nation-wide system of support and care services for people with disabilities. This research explores the implications of systemic changes at a microsystemic level – the provision of in-home disability support services by a Victorian municipality through the Home and Community Care program.

As the reform involves a change from the current organisational-controlled arrangements to a Self-directed Care model, this practice-based research focusses on investigating how the new approach may enhance the empowerment of the service recipients in this municipal setting. The study explores the perceptions of service users and service providers of aspects of power and control important to them. It aimed to generate findings from these insights that the council can apply to its service planning.

The study uses a participatory action methodology, extended by the principles of the Critical Disability Studies approach, to carry out collaborative research with three community groups representing cultural diversity in the municipality. Data from twenty semi-structured interviews and three focus groups were analysed initially by clustering responses for the two participant groups (service users and service providers) separately into a number of experiential ‘realms’. The second stage of analysis applied an abductive reasoning process to the data as a whole, resulting in the synthesis of the realms into six ‘themes’ representing the participants’ insights into the key factors that needed to be considered in designing empowering services. The six themes were: the personal in everyday life; environmental barriers: negotiating the external world; the relational sphere; institutional barriers to empowering services; the realm of cultural difference; and, the macrosystemic sphere: personal, relational and institutional interfaces.

The findings contribute to Critical Social Work research and practice in the field of disability services through the identification of the action strategies of a comprehensive planning framework. These include: maximising service user ‘agency’, resisting neo-liberal control; pursuing cultural competence; promoting human rights practice, and enabling interdependent relationships. Together the strategies provide insights into how a range of theoretical perspectives of disability empowerment intersect with the application of a Self-directed Care model. In generating a holistic and integrated framework the study’s findings have relevance both as a potential model for service user empowerment at the local level and beyond, and as a guide for life planning for people with disabilities in the new Australian disability support and care system.

## STUDENT DECLARATION

'I, Rosalyn Mary Roberts, declare that the DSW thesis entitled:

Self-directed Disability Support at the Local Level – Whose Power,  
Whose Control? Exploring Models for Municipal Service Provision

is no more than 60,000 words in length including quotes and exclusive of tables, figures, appendices, bibliography, references and footnotes. This thesis contains no material that has been submitted previously, in whole or in part, for the award of any other academic degree or diploma. Except where otherwise indicated, this thesis is my own work.'

Signature:

A black rectangular box redacting the student's signature.

Date: 14/04/2016

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## ABBREVIATIONS AND ACRONYMS

<b>ATSI</b>	Aboriginal and Torres Strait Islander
<b>CALD</b>	Culturally and Linguistically Diverse
<b>CDS</b>	Critical Disability Studies
<b>CRPD</b>	Convention on the Rights of Persons with Disabilities (United Nations)
<b>DAC</b>	Disability Advisory Committee
<b>DSW</b>	Doctorate of Social Work
<b>FPAR</b>	Feminist Participatory Action Research
<b>HACC</b>	Home and Community Care Services
<b>ISP</b>	Individual Support Package
<b>ILM</b>	Independent Living Movement
<b>NDA</b>	National Disability Agreement
<b>NDIS</b>	National Disability Insurance Scheme
<b>NDIA</b>	National Disability Insurance Agency
<b>PAR</b>	Participatory Action Research
<b>SDC</b>	Self-directed Care

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## INTRODUCTION

### COME INTO MY WORLD

Getting up in the morning, getting washed, dressed, fed and prepared for the day's activities is usually a matter of habit, routine and willpower. This is not the case for at least 3% of the Australian population.<sup>1</sup> For many people with disabilities the start of the day, and indeed all waking hours, entail a carefully orchestrated arrangement of personal assistance from paid and unpaid carers arriving at their homes, entering their personal space, carrying out pre-determined caring tasks, and departing – at least until the next day.

Behind these simple caring tasks lies the machinery and labour of agencies, paid workers, service policies, frameworks and practices that make up the 'world' of disability support and care services in Australia. Together, these components constitute the web of institutional and systemic structures and relations that encompass the daily experiences of those who depend on these critical services to survive, and to lead as fulfilled a life as their respective conditions allow.

Within this system are many provider agencies: large and small, government and non-government, for profit and not for profit, specialist and generalist. Some are controlled by people with disabilities; more commonly, they are controlled and managed by people who do not have a disability. Each Australian state has its own distinct array of policies, providers, systems and outcomes. In Victoria local government is a provider of in-home support and care services for people with disabilities through the Home and Community Care (HACC)<sup>2</sup> program. This role of local government is unique in Australia. In no other state is local government the major provider and funder of these services within this program.

Framed by the highly complex nature of the service system, the daily experiences of people with disabilities<sup>3</sup> using these services vary enormously. The services may

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<sup>1</sup> An estimated 300,000 Australians who: 'have significantly reduced functioning in self-care, communication, mobility or self-management and require significant ongoing support' (Productivity Commission 2011, p. 14). This figure is indicative and likely to be an underestimation.

<sup>2</sup> See page v. for a list of abbreviations and acronyms used in this thesis.

<sup>3</sup> Note on terms used in this study: the term 'people with disabilities' is used here as it was chosen by people with disabilities as research participants in this study. At the time of the study's commencement it was also the term preferred by the Victorian State Government Department. During the course of the study, the preferred term of the Commonwealth and State Governments has changed to 'people with disability' and 'people with a disability' respectively. While recognising that these terms are now in common use (in the second decade of the twenty-first century), the original term has been retained in this study for clarity.

operate to support their individuality and life goals, they may provide them with comfort, reliability and security, and they may enable them to exercise control over decision making within the demands of each person's unique impairments and aspirations. As the following chapter sets out, much evidence suggests that, in many cases, they do not. By the first decade of the twenty-first century, the system of in-home support services for people with disabilities in Australia was described in two government reports as being in a parlous state – creating more of a barrier than an enabler to participation. Chapter One discusses in detail the findings of these of government reports.

Defining 'disability' is complex; there is no single definition (Productivity Commission 2011). At one level it means the opposite of 'ability' and implies a condition of incapacity and negativity (Goggin & Newell 2006). Definitions of disability have been made for specific purposes, most notably for denoting a legal status or for inclusion in government policy. In the case of the definition contained in the Convention on the Rights of Persons with Disabilities, derived after extensive collaboration with people with disabilities, 'disability' is seen as an interaction between bodily impairments (physical, mental, intellectual and sensory) and barriers that prevent people from participating equally in society.<sup>4</sup> 'Disability' is conceptualised as interplay between individual characteristics and societal relations, and a denial of equality – a connection between the individual and societal structures.

The second example of defining disability focusses on the impact of 'impairments' on activities of daily living.<sup>5</sup> As the purpose of the definition is, at least in part, to distinguish people with disabilities from others in respect to their eligibility to access government resources, it contains a detailed specification of the types of disability (functioning of the mind, senses, anatomy or physiology), types of limitation or restriction (communication, mobility self-care, schooling and employment), and severity of limitation (mild, moderate, severe or profound).

This thesis does not attempt to develop an operational definition of disability; however, Chapter One discusses further the Australian Bureau of Statistics definition as it relates to the eligibility criteria for disability support services – the focus of this study.

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<sup>4</sup> Convention on the Rights of Persons with Disabilities 2006, Article 1 'Persons with disabilities include those who have long-term physical mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.'

<sup>5</sup> In the context of health experience, the International Classification of Functioning, Disability and Health (ICFDH) defines disability as an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environment and personal factors) (Australian Bureau of Statistics 2013).

This is my world. As a social work-trained middle manager in a small Melbourne inner-city municipality<sup>6</sup>, I coordinate the operations of a number of front-line staff in the Council's HACC services as well as carrying out aged and disability services planning and policy development. A second part to my role, separate but complementary to direct in-home service delivery, is the responsibility for overseeing the promotion of disability access and inclusion measures in the community, both through community development and through the coordination of the Council's disability action planning. In contrast to the activities of services planning and provision, the latter role is more strategic as it covers actions across all of the Council's activity areas and functions. It also covers responsibility for coordinating the resourcing of the Council's Disability Advisory Committee – a task that has much significance for this study, as later chapters reveal. Both parts of my role constitute the framework for the 'world' of professional social work practice – the focus of this research.

'Whose Power, Whose Control?' is a study that directs its attention to a small part of the Australian system of disability services in order to explore in depth how these aspects of my role operate in a specific context. The importance of this inquiry lies in a number of reasons, the first being that the national field of disability services is in a state of flux, and has been since the commencement of the reforms in 2013. A fundamental change in the philosophy of 'care' and 'control', major new policy developments, a radically different service model, and a refiguring of government roles and resourcing – all of these changes that were merely hovering on the horizon at the initial stages of the study – have gathered speed over its life and reinforced the need to investigate their meaning and impact as they unfold. A change process of this magnitude brings with it uncertainties about how stakeholder power and influence will operate in the new system. Reliable and well-grounded knowledge is needed to inform the impending transformation of the Council's support and care for people with disabilities.

The second reason for the study's importance is the urgency for people with disabilities to have maximum opportunity to exert their influence regarding reform outcomes as the principal stakeholders. The structures of local government that enable and encourage people to participate in collective action provide a potential pathway for citizen advocacy in intergovernmental communication. The nature of local government, as a

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<sup>6</sup> 'The Council' refers to the municipality that is the setting for this study. For ease of reading it is called the Council in this thesis. To observe confidentiality it is not named as the organisation was not requested to give its permission to be identified in the thesis.

disability service provider organisation and (simultaneously) an institution that has a role to further democratic participation, is a key feature of the microsystem that is put under the searchlight in this study.

A third reason is there is very little Australian literature pertaining to local government service provision in the disability field. This study adds to this field by documenting one example at a critical point in time. As a place-based study, it offers insights into aspects of geographically defined communities, such as cultural difference and relational qualities over time. As revealed in the following chapters, 'the local', as a site of services organisation and context of daily living and working, is a recurring theme in this study.

The final reason stems from the nature of this research as a Doctorate of Social Work (DSW). A DSW, as framed by Victoria University, my university of choice to undertake this program, has the requirement of being an inquiry into the professional practice of the researcher's workplace with the purpose of benefiting its recipients, and thus contributing to the social work knowledge base. In the chapters in this thesis, the story unfolds of how this requirement guided the study's design and implementation in order to achieve these criteria. It gives an account of the process adopted to achieve the objective of learning more about how people with disabilities can have greater influence in the microsystem and beyond, and how the Council can use this knowledge to plan with them for better outcomes.

In respect to the criterion of contributing to professional knowledge, it is relevant to briefly consider my motivation for carrying out a DSW. This stemmed primarily from deep-seated questions about the direction of human services policy and practice over the past thirty years in my work in local government. As a very experienced practitioner, my 'long view' of the evolution of organisation-based social work towards greater bureaucratic control has raised many concerns. At the forefront were critical issues of how the relationships of the users of social work services and professional practitioners were being re-shaped. A concomitant of the 'culture of change' adopted by organisations such as local government, has meant that the pace of work has increased, leaving less and less time for critical reflection on these issues. Undertaking a DSW has offered me the opportunity for satisfying a strong intellectual curiosity about the changing discourses and underlying empirical influences operating in my workplace. What the DSW promised was space, time and legitimacy for this endeavour. In this sense, my motivation to undertake a work-based doctorate related

more to intrinsic sources of personal fulfilment through professional development, rather than so-called extrinsic sources of career enhancement or career promotion (Wellington & Sikes 2006).

Although my local government employer was supportive of my undertaking the DSW, it was not the initiator of the research, or in partnership with the university to define the learning objectives. While this aspect of the study as a 'first generation' professional doctorate (Maxwell 2003) was beneficial to me in the resulting autonomy I had in shaping the research purpose and design, it also resulted in a degree of conflict between full-time workplace duties and research demands: a factor exacerbated by the extended time span of the research. As the following chapters set out, the practice environment of escalating change became a factor of significance in and of itself over time.

The thesis is structured as follows: Chapter One scopes the practice field by describing the characteristics of the Australian disability services system at its many government levels with an emphasis on Victorian local government role, and identifies some of the factors associated with its operational inadequacy in meeting disability support needs.

The emerging themes identified in Chapter One are further interrogated and developed in Chapter Two through a consideration of theoretical debates in the literature relating to perspectives on disability empowerment and on human services provision.

Chapter Three commences with a re-statement of the factors leading to the research question, followed by a statement of the purpose and aims of the inquiry as an exploratory study. It then sets out the epistemological journey that has guided the choice of methodology for transformative and social justice research outcomes. It details the choice and application of the methods selected and concludes with an explication of the process by which the findings were analysed.

In Chapter Four the voices of study participants on aspects of power and control in their lives and services are presented in their words. It gives an account of the analysis of their perceptions and opinions leading to the identification of six analytical themes that have potential to catalyse change in the Council's services planning.

Chapter Five concludes the thesis by discussing how the research has achieved its purpose of exploring perceptions of power and control in the local context, and how the six themes have been further interpreted and synthesised into a set of key elements

that will inform the Council's future services framework. Finally, this chapter offers a reflection on the insights of 'empowerment', as a conceptual plank of Critical Social Work, for people with disabilities who use support services in their local community.

## CHAPTER ONE

### DISABILITY SUPPORT AND CARE – THE CASE FOR CHANGE

#### Introduction

This chapter sets the scene for this study of ‘Whose Power, Whose Control?’ within the disability services program of a Victorian municipal council. Disability services are provided to municipal residents who experience a level of disability that prevents them from carrying out their personal activities of daily life without assistance from paid carers. They are provided primarily in their homes. ‘Whose Power, Whose Control?’ refers to the participants in this program: those who use the services and those who plan and deliver them.

Chapter One introduces the topic of the need for service system change. It does this by giving an account of the history of disability support and care in Australia through early forms of ‘state’ care, and the development of government policy at the national, state and local government level. I argue that attempts to establish clarity in intergovernmental roles resulted in a lack of equity of service provision across Australia. This led to a high degree of systemic complexity that seriously disadvantaged people with disabilities. The section concludes with a damning indictment of the dysfunctionality of the disability services system given by personal accounts of recipients.

The second section of this chapter describes the day-to-day operations of the Council’s disability services. It examines how aspects of reduced ‘power and control’ appear to be manifested for service users and service providers through the far-reaching impact of ‘contractualisation’ of Victorian local government services, resulting in control and regulation of the day-to-day management. Empowering and disempowering elements are then contrasted with aspects of ‘power and control’ in a radically new service design that replaces ‘organisation-controlled’ models with a ‘user-controlled’ service design. This section focuses on aspects of the Council’s disability services that shape the dimensions of the impending change at the local level, and are pertinent to the service planning process the Council must undertake to respond to them.

In order to identify the origins of the study’s concern with power and control Chapter One commences with an overview of Critical Social Work, the social work theoretical approach adopted in this research. In locating the study within the critical paradigm, the

principles of this approach have been applied to the historical and current description and analysis of the service system in this chapter, with the result that the analysis has focussed primarily on the systemic impacts sustained by people with disabilities and their contribution to unequal power relations.

Finally, the chapter concludes with a summary of the factors that have contributed to the definition of the research problem.

In this study the term 'macrosystem' is used to define the disability support and care services sector at the national government level in partnership with the Victorian State Government as joint funders of the HACC program. The Council's HACC services provided to people with disabilities in its local municipality is referred to as the 'microsystem'.

### **Critical Social Work**

Critical Social Work is a theoretical approach to social work practice based on the aim of addressing discrimination and oppression experienced by many, if not most, of the people receiving social work services. Its objective is to transform socio-political relations that institutionalise unequal power relations in order to further social justice (Briskman, Pease & Allan 2009; Gray & Webb 2013a; Morely, Macfarlane & Ablett 2014; Pease 2013). In their definition, Gray and Webb emphasise the place of critical theory in the promotion of social justice, while expanding the reach of the Critical Social Work approach beyond practice to wage labour and the promotion of economic justice (Gray & Webb 2013b).

Critical Social Work provides a framework and tools for understanding how power operates at all levels within social work relationships (Allan, Briskman & Pease 2009). It emphasises critique of socio-political structures and relations through discourse analysis and critical reflexivity, with the purpose of challenging inequality and oppression. Despite variations in the way Critical Social Work is practised, Allan has identified a number of 'core principles'. These include: a commitment to greater social justice and equality and to working alongside marginalised and oppressed communities; an analysis of power relations in order to challenge hegemonic assumptions and beliefs; and a commitment to further emancipatory personal and social change (Allan 2009b).

Critical Social Work has been adopted as the underpinning frame for this study of planning support and care services for people with disabilities. Johnson (2009) has argued that the application of Critical Social Work to the field of disability is very important due to the marginalisation and discrimination this particular population experiences. Critical Social Work authors have argued that social work practices, including practice research, must seek to avoid perpetuating oppressive practices (Allan, Briskman & Pease 2009). This chapter therefore considers in some detail the 'world of disability services' from the point of view of people with disabilities in regard to their experiences of discrimination and marginalisation.

Two essential elements of Critical Social Work – critical reflexivity and critical analysis – have informed all processes of this research. The process of 'critical reflection', a cornerstone of Critical Social Work practice (McDonald 2009; Taylor 2013), requires the Critical Social Worker (in this case the researcher), to interrogate their own position in dominant and minority groupings, and consider how this affects their beliefs and actions relevant to hegemonic world views. As McDonald has written, critical reflection: 'makes me attend to my personal mix of economic, cultural and social capital in terms of what my embodied self "says" to others' (McDonald 2009, p. 254). It is relevant to acknowledge here that I do not have a disability, nor do I have lived experience of disability, a characteristic that is likely to affect my world view of 'disability', as it has been formed in the hegemonic dominant frame.<sup>7</sup>

The process of critical analysis is discussed in more detail in the next chapter in light of theoretical conceptualisations of 'empowerment', both as a strategy or goal of Critical Social Work and in its applications in the disability field in general.

The next section traces historical eras and trends in support and care for people with disabilities to the present day.

### **History of disability support and care services in Australia**

Over more than two centuries of European invasion of Australia there have been two prominent strands in the story of providing personal assistance to people with disabilities: caring carried out in the family sphere by parents, relatives and friends,

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<sup>7</sup> My starting point as an experienced social worker is to acknowledge my position within the seven critical moments of gender, race, class, age, 'able-bodiesm', sexual preference and indigeneity. I am a 67-year-old heterosexual woman of Anglo-Celtic origin, living an affluent life of a middle-class home owner, city-based professional, and who does not (at this moment) have a disability, nor lived experience of disability, and is atheistic in belief.

and caring provided by 'the state'. Family members have met these needs over lifetimes and centuries within caring family bonds. As children with disabilities grow into adults, many have continued to receive extensive support from within their family to meet their personal needs. However the last fifty years of social policy change towards fostering 'independent living' for people with disabilities and the changes in families, including women's greater participation in the paid work force (Hancock & Moore 1999), have meant that in-home services have progressively been seen as a responsibility of the state. It is the latter focus on 'the state', as a site of caring services that is addressed in this study.<sup>8</sup>

### Institutionalisation

Disenfranchisement, isolation, abuse, oppression, segregation, and discrimination: these are the themes threaded through the history of charitable and state care for people with disabilities. Institutionalisation of people with disabilities occurred from the earliest days of English settlement. Many people whose impairments prevented them from living unassisted and who lacked family care were locked away in institutions: some purpose built, some penal. The early incarceration of 'lunatics' and the 'feeble-minded' in prisons and other institutions was compatible with the convict origins of Australia (Goggin & Newell 2005). As these authors assert, this had the effect of associating perceptions of people with disabilities with the need for segregation, control, even punishment. Institutionalisation assigned people with disabilities, often as children, to hazardous lives of dependence, isolation from family and community life and relationships, poverty, and at times physical, emotional and sexual abuse (Bigby & Fyffe 2006). It did this by depriving people of citizenship rights through disenfranchisement, isolating people from their families, depriving people of choice and individuality, and failing to protect them from abuse (Young et al. 1998).

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<sup>8</sup> It is acknowledged here that there is an extensive literature on 'caring', covering many perspectives that are not directly addressed in this study. While there is insufficient space in this thesis to address this literature in detail, it is relevant to note that debates have continued about the discourse of 'caring' (see Shakespeare (2006) for a critique of 'traditional' care and its problems, the limitations of the independent living discourse and the early feminist ethic of care). One theoretical conceptualisation has been to link the purpose and outcome of 'caring' with sustainability – economic, environmental and societal. For example, Tyson and co-authors proposed moving notions of 'caring' beyond welfare and into the arena of its significance as a form of social capital, a critical resource in the process of 'co-production' (an approach to thinking about how society and community can work together for mutual support) (Tyson et al. 2010). The labour of 'caring' as an economic resource has also been reflected in the concept of 'provisioning', that is the work, primarily carried out by women, that funds the necessities and conveniences of life (Neysmith & Reitsma-Street 2005; Neysmith et al. 2012).

Recognising this heritage of the damaging effects of institutionalisation is important as it resulted not only in the individual pain of profound disempowerment and deprivation, but a lasting collective memory within the disability sector today. As Goggin and Newell note: 'institutionalisation is not as remote as it seems' (2005, p.127). These authors document how, in the present day, many people with disabilities are left with a fear of professionals or carers making decisions on their behalf in every area of their lives. In their view, the era represented the process of 'othering': systematic exclusion of people with disabilities so entrenched that it has been described as a process of societal 'apartheid' in Australia (Goggin & Newell 2005).

### A time of change

From the 1970s the role of the state in disability care changed markedly. During this period when many social movements addressing major areas of discrimination flourished, 'the state' was receptive to change. Like many other Western governments in countries such as the UK and USA (Young et al. 1998), Australian national and state governments responded to the growing demand for alternatives to segregation and isolation of people with disabilities. They implemented a radical policy change described by one author as a composite process of 'de-institutionalisation, integration and mainstreaming' (Reidy 2011, p. 6). De-institutionalisation in Australia was achieved through programs that relocated people with disabilities, including those with intellectual disabilities, from congregate living into community settings (Bigby & Fyffe 2006). Despite its socially progressive intentions, this policy has been subject to the criticism that it failed to anticipate resource needs, and replaced discrimination in an institutional setting with discrimination in the community setting (Young et al. 1998). In fact, the aim to replace previous ideologies of charity, 'sub-normality' and segregation with those of social inclusion, 'normalisation' and 'social role valorisation' (Wolfensberger & Thomas 1994) was not achieved as effectively as intended. Provision of income support and community housing alone did not address social barriers to community participation, nor guarantee the necessary resources to address long-term goals of 'individuals becoming participants in their own households and members of their local communities' (Bigby & Fyffe 2006, p. 579).

One of the effects of de-institutionalisation was to put pressure on local resources to care for people with disabilities as they moved into housing in the community – some

into small scale group housing, others into public housing (Goggin & Newell 2005). At this time, many Victorian councils, like many other community-based organisations, had already been providing in-home care and support services for residents with disabilities for many years (Wills et al. 1985). However, as these authors explain, they were not resourced sufficiently to meet deep-seated needs of people who had experienced a lifetime of institutional care.

Concurrently with the move to the closure of large institutions, the social movements of the 1970s exerted pressure on the national government to take broader responsibility for people with disabilities. The 1980s witnessed a range of major government reviews of its policies, catalysed by the International Year of Disability in 1983. One of the most significant of these was the Handicapped Programs Review (1985) which 'offered a comprehensive set of proposals for improvement of disability services by all three levels of government' (Goggin & Newell 2005, p. 65). Also in that year, the Home and Community Care (HACC) program was legislated as a jointly funded Commonwealth and state government responsibility with the objective of providing 'basic' support to people at a 'low level' of need to enable them to continue living at home and thus avoid admission to residential care (Healy 1990).

Another step forward was the definition of roles and responsibilities of the Commonwealth and state governments through legislated agreement. Between 1991 and 1993, all governments had signed the first Commonwealth, States and Territories Disability Agreement, better known as the National Disability Agreement (NDA). Annual agreements defined state government responsibility as policy makers and providers of a range of disability supports such as accommodation, respite care, community support, day activities, aids and equipment, and community access (Commonwealth Government 2010).

There appears to be little evidence that the establishment of intergovernmental agreements resulted in a sustained, nationally led momentum for comprehensive progress at the time (Goggin & Newell 2005). To the contrary, the definition of roles left the state governments with primary responsibility, but with limited, uncertain and inadequate funding from the Commonwealth.<sup>9</sup> This was a virtual guarantee of the development of an inequitable system, as it was matched by a lack of national standards and national program policy frameworks. For most state governments, the combination of the legacy of de-institutionalisation and the fiscal demands of

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<sup>9</sup> Both the NDA and HACC services have been described as 'severely rationed' (Productivity Commission 2011, p. 120).

redressing centuries of neglect of disability needs meant they were obliged to prioritise the most urgent needs. Consequently their services, known as specialist NDA services, have tended to focus on those people with the highest levels of disability and the greatest needs, for example, people living with high levels of intellectual disability.

#### Interface between Victorian state government disability services and local government HACC services

Specialist disability services and mainstream HACC have existed as parallel programs over the past 30 years, adding to the complexity of the disability services system in several ways. In Victoria, for example, where, under Commonwealth/State agreements, the state government has much broader responsibilities for younger people with disabilities<sup>10</sup> than local government; they both fund and provide home-based services under different programs, with different aims and different eligibility criteria (Victorian Government Department of Health 2013). This has resulted in a degree of service overlap.<sup>11</sup>

Within HACC services the needs of older people and people with disabilities are combined within the one program, revealing an assumption of similar or compatible needs. Early government reports show that the national HACC program was always intended to include younger (under 65 years' old) people with disabilities as a target group. The first three-year national review referred to the justification for this inclusion on the grounds that it was consistent with the (then) philosophies of 'mainstreaming' services (i.e. making them commonly available by non-specialist providers such as local government) and therefore contributing to 'the objectives of normalisation' (Commonwealth Department of Housing and Aged Care 1989, p. 20).

Despite this commitment to non-aged people with disabilities, the HACC program, through its almost thirty-year existence, has been seen primarily as an aged care, rather than disability care program (Hancock & Moore 1999). In 2006 almost two thirds (64%) of the HACC service users in Victoria were aged 70 years and over and 22%

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<sup>10</sup> Under the age of sixty-five years.

<sup>11</sup> There are also a number of separately funded and administered state government programs that cover disability care services, such as that run by the Transport Accident Commission, that covers people who have sustained injuries leading to permanent disabilities. The Productivity Commission Report (2011) points out that these accident schemes are able to provide a greater level of support than the State/National Disability Agreement and HACC programs, partly because they have a smaller target group and a stable and predictable funding base from insurance income. They are not covered in this study.

were aged between 50 and 69 years (Victorian Government Department of Health 2010). It is significant that, at the state level, the HACC program has been managed since 2009, by the state government department responsible for aged care (i.e. the Department of Health) while specialist disability services have been managed by the Department of Human Services Division responsible for disability. At the time of research, there was little communication and coordination between these departments: a factor that added to the systemic complexity experienced in the local HACC service system.<sup>12</sup>

### History of HACC services in Victorian local authorities

In contrast to the 'top-down' policy changes discussed above, localised HACC services in Victoria can be traced back to 'bottom-up' initiatives of neighbourhood assistance to those who needed it, supported by municipal governments. Early examples originated in the Second World War when some pioneering councils instigated small scale, local domiciliary programs to assist young mothers, older people and people with disabilities who needed practical help at home (Wills et al. 1985). These included 'Meals on Wheels' and 'Home Help' (home cleaning, personal care and respite care), which gradually became incorporated into the Commonwealth/State HACC program. By the time the HACC program was legislated as a Commonwealth/State agreement (1985); most Victorian local governments had well established domiciliary services for older people and those with disabilities that were resourced by local rate revenue as well as Commonwealth/State grants (Healy 1990).

It is relevant to note that, for some Victorian inner-city councils, the expansion of HACC services in the decades of the 1970s and 80s (along with a wide range of other human services) was part of the development of a municipal social planning role. Wills and co-authors documented the development of a radical model of social planning called the 'social developmental model' practised in a small Melbourne inner-city council at this time (Wills et al. 1985). This model is interesting for several reasons: it rejected the 'welfare model' of social work practice and replaced it with an explicitly structural model of planning for social change. 'Social developmental' practice, as defined by these authors, was based on a Marxist/Feminist ideology of municipal services as politicised services, whose purpose was to oppose dominant beliefs that perpetuated inequality,

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<sup>12</sup> It is important to note that the Victorian Government has been implementing a model of user-controlled disability services called Individual Support Packages since 2008; however, there has been little interface between these and local government HACC services, adding to system complexity, boundary confusion and services gaps (Victorian Government Department of Human Services 2009, 2014).

particularly in regard to social class and gender. The function of social planning was to engage residents in determining their own needs and to collaborate with council workers on planning that was built on a mutual understanding (critique) of the hegemonic socio-political system. In this sense, this model was a precursor of Critical Social Work practice (Mendes 2009).<sup>13</sup>

Following the era of social planning, Victorian local governments were subject to a more comprehensive change that was to have profound effects in re-shaping municipal human services. Local planning, with its emphasis on participatory processes, was forced to give way to a new policy called Compulsory Competitive Tendering and to an era of compliance with contract law.

From the early 1980s Victorian local government was subject to major changes in structure, ideology and practice imposed by the (then) neo-conservative Liberal State Government (Mowbray 2000). Initial changes, such as corporatisation and encouragement of voluntary amalgamations, were ushered in by the Labor State Government during the late 1980s. These were followed in the early 1990s by the actions of the Liberal State Government to radically reduce the number of Victorian local authorities through forced amalgamations and the replacement of all elected councillors by state government-appointed commissioners. The introduction of the paradigm of economic rationalism had far-reaching effects in all council activities, particularly in their human services roles. As contemporary accounts argue, the pathway to 'the contract state' was achieved through the processes of enforced 'contractualism', restructuring and centralised executive decision making (Alford & O'Neill 1994; Connoley 2007). In their view, the discourse of business and the private sector replaced the discourse of citizen decision making, local activism and local area planning.

By the mid-1990s, 'the contract state' was fully implemented in Victoria (Alford & O'Neill 1994). This involved: the reduction in the size of the public sector and public service; the definition of core and non-core functions; and the use of market mechanisms to contract out non-core functions via the competitive processes of tendering (Connoley 2007). All Victorian local government services, including human services such as aged and disability services, were partially privatised through

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<sup>13</sup> As a social work staff member for eight years at the inner-city council at the time of the formulation and implementation of the social developmental model, this experience was influential in the adoption of the Critical Social Work approach in my practice.

Compulsory Competitive Tendering legislation.<sup>14</sup> Influenced by the ideas on the preferred role of government to 'steer' (lead, fund, and govern), rather than to 'row' (deliver services), competitive tendering policy was intended to achieve efficiencies and cost savings by disengaging the purchaser role from the private provider role (Osborne & Gaebler 1993). In order to meet contract law compliance, the tendering process required detailed service specification containing quantifiable outcome measures (Hancock & Moore 1999). As noted by these authors, this factor had the effect of reducing the autonomy of contracted human services agencies to be innovative, as well as imposing a hierarchical relationship between the purchasing agency and the provider (contracted) agency.

Together, the policy of Compulsory Competitive Tendering and the influence of economic rationalism in human services policy at all government levels have had lasting effects on the HACC services in Victorian local government. Mandated introduction of the discourse of business consolidated the pre-eminence of the language and practices of efficiency, fiscal accountability and distrust of non-quantifiable activities such as the application of professional judgement and relationship-based practice. It paved the way for the acceptance of 'managerialism' at all levels of government – a factor discussed in more detail in the next chapter.

Changing government policy at all three levels of Australian government, 'bottom up' and 'top down' program development and a poorly integrated system meant that very little of this reform appears to have involved people with disabilities directly, as collaborators in planning or participants in decision making. How did they fare as intended beneficiaries? The next section presents a picture of a very flawed national system and its significant detrimental effects for people with disabilities.

### **'Broken and broke'? Disability support and care services as a macrosystem**

In 2008, the first Australia-wide consultation was carried out with people with disabilities and their carers on behalf of the Commonwealth (Deane 2009). Over 750 submissions were made during the consultation, documenting examples of extensive discrimination in all areas of life. More than 50% of these submissions recorded significant concerns with lack of services and support for people with disabilities. The report, aptly named 'Shut Out', revealed just how deeply flawed the disability support

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<sup>14</sup> Local Government (Compulsory Competitive Tendering) Act 1994.

and care system was, as experienced by the people for whom it was designed (Deane 2009). While there were significant differences between the resource levels, coverage and equity of service access between states and between rural and city areas, the overall inadequacy of the service system was a major finding.<sup>15</sup> Survey respondents experienced their services as crisis driven, hard to navigate, of poor quality, frequently unavailable and giving little choice. They were seen as unable to respond to individual needs and operating under inflexible categories of need. They were described as operating to meet organisational needs rather than the needs of service users. In the words of the author of *Shut Out*, the system was clearly: 'broken and broke' (Deane 2009, p. 18).

For people with disabilities, the likelihood that their support and care services were unable to meet their needs was extremely significant when it is acknowledged that they are among the most disadvantaged and oppressed groups in Australian society (Productivity Commission 2011). Together the Productivity Commission report and the *Shut Out* report, have documented in detail both the areas of disadvantage and their direct, personal effects on people with disabilities. In its analysis of census data, the Productivity Commission gave comparative figures for people with disabilities that demonstrated they experienced severe levels of social isolation, significantly lower levels of education, employment and income, and limited accommodation options, in contrast to the Australian population as a whole (Productivity Commission 2011). As this report documents, only two thirds of people with disabilities over the age of twenty-five years progressed their education beyond Year ten, compared to around 80% of the general population.<sup>16</sup> Differential rates of participation in the labour force reveal a similar disparity between the general population and those with disabilities – here the rates were 83% and 54% respectively. The report also noted that people with disabilities are amongst the most disadvantaged groups financially and are more likely to live in public housing than those without disability. It is important to note the interrelated nature of this disadvantage – limited education reduces employment options – thus lack of access to paid employment severely limits income. Over time these factors are likely to multiply and accumulate, resulting in entrenched poverty and restricted relationships – a point also addressed in the comprehensive national report (Productivity Commission 2011).

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<sup>15</sup> Granted that a submission-based inquiry cannot claim to be representative, the consistency and volume of the responses indicate extensive agreement amongst the respondents.

<sup>16</sup> The Productivity Commission Report (2011) uses census figures published in 2009 and 2010 in this analysis.

‘Shut Out’ gave poignant, first-hand accounts of the effects of this significant disadvantage on individuals and families (Deane 2009). It touched every area of their lives from unmet service needs to the shared frustrations of the inaccessible built environment, the experiences of impaired health and wellbeing, and impacts on family relationships and social networks. The experiences of social exclusion and discrimination were identified as barriers to full participation in social and economic life, and of equal concern to that of the harmful experiences arising from the inadequate service system. Discrimination was seen as ‘both systemic and systematic, entrenched in the everyday practices of government, businesses, community groups and individuals’ (Deane 2009, p. 4).

Having now considered aspects of empowerment at the macrosystemic level, this chapter moves to the microsystemic level by taking a closer look at the Council HACC services, as they operated at the commencement of the study. Within the description of the day-to-day processes is an initial analysis of some aspects of service structure and implementation that, it is argued, potentially impose limitations on empowerment of service users and service providers.

### **A ‘traditional model’ – the Council’s HACC services as a microsystem**

The Council provides HACC services to residents who are frail older people and residents of any age who have a level of disability that restricts them from carrying out necessary activities of daily living without assistance, and their carers. Activities of daily living include, but are not limited to, personal care tasks, house cleaning and maintenance and using public transport. HACC eligibility criteria are stated in the Victorian HACC Manual as: ‘frail older people with moderate severe or profound disabilities, or younger people with ‘moderate, severe or profound disabilities and their carers’ (Victorian Government Department of Health 2013, p. 65). The terms ‘moderate, severe, and profound’ are not defined in the HACC Manual. Although a definition of these terms has been used in surveys carried out by the Australian Bureau of Statistics<sup>17</sup> this has not been strictly incorporated into the Victorian practice of HACC eligibility determination. In this state the process of assessing HACC eligibility takes into account the level of functional restriction for every person in their *particular* home,

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<sup>17</sup> In the Australian Bureau of Statistics definition the levels of limitation caused by chronic impairments are: ‘profound’: the person is unable to do, or always needs help with a core activity task; ‘severe’: the person sometimes needs help or has difficulty understanding or can communicate more easily in sign language or other non-spoken communication mode; ‘moderate’: the person needs no help but has difficulty with core activity tasks. Core activities are defined as communication, mobility and self-care (Australian Bureau of Statistics 2013).

family and community context, as well as the level and nature of the disability. It is carried out by dedicated assessment officers during a compulsory home visit.

The Council provides services to people of any age<sup>18</sup> with any type of disability, including chronic mental illness and other forms of chronic illness, on the basis that it has caused permanent or long-lasting functional impairment. Exceptions include people whose personal care needs require invasive medical procedures, and/or are of a level of severity that requires highly specialised care, or entails risks that are out of the scope of the 'basic' services of HACC. The implication of this point for this study is that the focus of the research involves service users with all types of disabilities (physical, mental, intellectual, or sensory), at a level of severity sufficient to prevent them from carrying out their activities of daily living unassisted, but not at the level where their needs require specialised resources such as twenty-four-hour care, beyond the scope of HACC.

Specific HACC funded activities (services) provided by the Council are: Assessment and Care Planning – the gateway into the services to determine eligibility and develop a care plan; Home Care – the tasks that paid care workers do to maintain a person's home environment (cleaning, unescorted shopping, food preparation); Personal Care – the tasks relevant to activities of self-care ('rise and retire' activities, bathing, eating, toileting, dressing and escorted shopping); Respite Care – the provision of a respite care worker who relieves the 'informal' carer (family, friend or neighbour) of their caring duties by occupying the person while the carer can do other things; Long-term Case Management for twenty-five people through the Linkages program; Delivered Meals – commonly called Meals on Wheels; Home Maintenance – minor repairs to the home and the installation of aids such as ramps and rails; and, Planned Activity Groups – Day Centre care for older residents, and group programs run from the municipality's neighbourhood houses.

HACC services are defined by the state government as 'eligibility', but not 'entitlement' services (Victorian Government Department of Health 2013). In effect, this means that potential recipients can be deemed eligible for these services, but are not entitled to receive them automatically. A range of factors may prevent service delivery such as the person's needs may be 'too high', the service task may require specialised training beyond the resources of the HACC agency, or may not be available at a particular

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<sup>18</sup> Children with disabilities are eligible to receive respite care services to provide their parents or carers with a break.

time. the Council holds the power to determine eligibility and decisions regarding entitlement.

Gaining acceptance into the HACC program and commencing services follows several consecutive stages. After primary eligibility has been established, potential service users must accept an obligatory home-based assessment leading to the development of a care plan. Service users must provide evidence of the level and nature of their disabilities and the impact on their daily lives. Receipt of a Disability Support Pension is accepted by the Council assessment officers as an initial qualifying status.

As part of the assessment phase, assessment officers discuss the applicant's service needs during a home visit. On the same occasion, they carry out an occupational health and safety check of the home environment to uncover risks associated with the home as a workplace for paid care workers. Discussion of fees is another obligatory component of the process. The required outcome of the assessment phase is an agreed and documented 'Care Plan' containing the applicant's goals, service plan and specified tasks.

Service users have some negotiating power within the assessment phase to advocate for the amount, type and nature of the services they need (Victorian Government Department of Health 2013). In the Council HACC services, however, this advocacy is limited to the pre-set scope of defined HACC service activities (personal care, home care, etc.) and their availability. In line with the Victorian Government HACC program guidelines (Victorian Government Department of Health 2013), the Council assessment officers consult with service users on their individual needs and service preferences such as type and frequency of service, gender and language of worker and specific tasks carried out, but there is no guarantee that specific needs and preferences can be met. Care plans are agreed on a 'proviso' that services will be supplied 'if resources permit'; for example, personal care to assist a service user to go to bed may be provided at the hours this service can be arranged, as determined by the Council rather than by the service user.

Potential limitations on service flexibility arise from the tight rostering of each paid care worker's time. In order to meet the needs of the maximum number of service users efficiently, paid care workers' hours are rostered on a half-hourly basis, with allocated travel time to enable workers to get from job to job. Punctuality is taken seriously and each paid care worker's performance is closely monitored. This system reduces the capacity of the Council HACC program to meet ad hoc requests for individual changes

due to other commitments and emergency requests for extra hours of care. While many service users depend on reliable and predictable service delivery, other service users can be frustrated by the inability of the Council to meet unforeseen circumstances.

the Council HACC services include a long-term case manager. As there are limited places on this program, residents with disabilities (eighteen years and over) must meet stringent qualifying criteria to be offered a place, and there can be an extended waiting time of several years. Qualifying criteria are that the applicant has both 'high and complex needs', and requires the services of a case manager for coordinating their services from the Council and other providers. HACC funding grants are provided to the Council on the basis of an annual, flat-rate 'package of funds' for each Linkages service user. Once in the program, service users do not have control over their individual 'package' of funds. The Council pools the funds into one annual program budget, enabling the case manager and coordinator to make decisions on budget expenditure on the basis of comparative service user need, rather than limiting expenditure on predetermined individual package funds. This facilitates flexibility to vary service levels so that service users with higher needs can receive more intensive services (perhaps on a temporary basis) than those whose needs are lower and less urgent. However, control over individual service levels still lies with the Council.

This description of the operation of the Council disability services has highlighted its features as a 'traditional' model of disability care services, defined by its nature as an organisational rather than service user controlled system (Shakespeare 2006). There are other aspects of services that reinforce organisational control through external demands. Like all Victorian local governments, the Council HACC services operate under multiple accountabilities as they are jointly funded, planned and audited not only by the Commonwealth and Victorian State Government, but also by municipal policy and political imperatives. As a result, they are subject to an array of control mechanisms of internal and external reporting.

Under annual funding agreements between the Victorian Government Department of Health and the Council, services are codified, categorised, 'unitised', and monitored. Each HACC 'activity' is defined as a unit of service delivery, most commonly an hour of care, or a number of completed tasks. Unit outputs (actual service delivery hours) are measured against specified targets, generating data that are interpreted as over- or under-service performance. Cumulative service outputs are contained in a national

electronic database that allows reporting against individual service users, service provider organisations and any combination of data sets over time.<sup>19</sup>

A further contributing factor to these regulatory processes and their accompanying reporting mechanisms is that of contract law. A significant portion of the Council's HACC services are provided by external contractors under service contracts. This entails the operation of a range of accountability processes, such as contract performance monitoring, that are internally and externally scrutinised.

In this way, all of the Council's HACC service 'outputs' are regulated through a number of monitoring systems including periodic standards auditing, key performance indicator reporting, budget reporting, continuous improvement action outputs and contractual performance reporting.

In summary, it can be seen that there are potential constraints on the power and control of local service users within the traditional model. In its service structure, the Council does not include practices or policies to empower individual service users to have significant control over their services such as control over their individual budgets, or over what and how many services they can receive. Whilst the organisation retains power over these decisions, it is subject to external controls that constrain its autonomy. Although service users have access to more flexible, individually tailored and intensive services in the Linkages case management program than in other HACC services, they do not control their own services funds. There are therefore, significant aspects of local disability services that are potentially disempowering for service users.

Despite this conclusion, there are other aspects of the structure and function of the Council as a government organisation aimed at empowering residents with disabilities. Some of these features arise from the legislated roles and functions of all Victorian local governments and some stem from the policies and practices of the Council. They are unique to local government as a service provider agency and therefore not shared with other disability care agencies.

First, residents of the municipality with disabilities share citizenship rights with other residents to participate in the Council's governance and decision making through becoming an elected councillor. Apart from standing as an elected candidate, residents can participate in decision making through the Council's endorsed Advisory Committee

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<sup>19</sup> This is called the Minimum Data Set established initially in 2004 by the Commonwealth Government to gather individualised data showing a service user's HACC usage for each quarter. Regular updates of the database have enabled it to increase its functionality to monitor organisational output as well as individual service usage.

structure, of which the Disability Advisory Committee (DAC) is a part. Although empowerment for people with disabilities on the DAC is limited to a formal advisory role; there is evidence in the broad range and scope of policy issues consulted on that advice given is taken seriously. A further aspect of empowerment lies in the exposure it gives to members to build ongoing relationships with councillors who regularly attend monthly committee meetings, and to enhance their skills of self-advocacy through making direct representations to meetings. Considerable support, such as training, transport and attendant care, is given to members to become familiar with these procedures and to participate in the committee.

Second, the DAC advises the Council on policy frameworks for its four-year Disability Action Plans, and steers the definition of action priorities across all functions for each plan. As a result of the DAC advice, the social model of disability has been adopted to guide the Council's planning focus on the need for structural change, for example, in built environment planning, and in eliminating discrimination. Human Rights policies and practices have been progressively strengthened following DAC advocacy on its importance in the local setting as an empowering paradigm. The theoretical implications of both of these are discussed in detail in the next chapter.

In this detailed scoping of the disability services microsystem it has been argued that empowerment of service users can be considered as multidimensional in the local setting. There are sources of disempowerment in the 'traditional' model as practiced by the Council. The impact of these, the extent to which they may be offset by citizenship rights and the consequent multi-functional relationship the Council has with its residents, are questions explored in this study.

### **The challenge of a new approach: organisation vs user controlled services**

At the commencement of this research, a new model of disability support and care – Self-directed Care – was gaining attention in Australia as research studies of its effects in other countries were becoming more available. At the time, the Council was gradually being introduced to this research and was beginning to explore its potential. 'Self-directed Care' (SDC),<sup>20</sup> was seen as a (potentially) transformative approach in its

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<sup>20</sup> Several different terms have been used to refer to user-controlled models: in the UK: 'Individual Budgets' (Duffy 2005; Social Care Institute for Excellence 2007, 2009) and 'Direct Payments' (Spandler 2004; Stainton & Boyce 2004); in the USA: 'Cash and Counselling' (Carlson et al. 2007), and 'Consumer-directed Programs' (Tilly & Wiener 2001); in Norway: 'Cash for Care' (Christensen 2010); and in Australia: 'Consumer-Directed Care' (Ottmann, Laragy & Haddon 2009).

emphasis on redefining power relationships between service users and service providers. The promise of empowerment for people with disabilities through SDC has acted as a driver for the direction of this study.

The roots of SDC have been dated as far back as the 1970s Independent Living Movement (ILM) prominent in the UK, Europe, USA and Canada (Gibson et al. 2009). As a movement that advocated for people's greater autonomy and control over their life decisions, the ILM has been seen as an antecedent to SDC in its emphasis on the search for a means for people to receive daily assistance that supported their independence rather than treating them as charity recipients. One of the central tenets of the ILM was that 'the assistance should be identified and controlled by disabled individuals themselves' (Gibson et al. 2009, p. 318). Tilley and Wiener (2001) have identified early versions of this approach in the USA from the late 1970s. In the UK, there were early models of individualised funding in the form of direct payments for younger people associated with Independent Living grants in the 1970s and '80s, but the accepted date for broader implementation by local authorities was 1997 (Stainton & Boyce 2004). By the early 2000s, implementation of various forms of SDC, backed up by policy and legislation, had been underway for some time in many other countries (Aged & Community Services Australia 2008). However, as Fisher and co-authors have pointed out, apart from pilot programs in Western Australia and Victoria, Australia lagged far behind (Fisher et al. 2010).

As a direct challenge to traditional models of care, the SDC approach represents a paradigm shift in the sense that it is both a major philosophical change and a practical, applied model for replacing the organisation-driven model of disability care with that of a service-user-driven model. It represents an ideology and detailed service design. At the heart of the model, its basic concepts, while complex in relation to systemic implications, are simple to grasp (Duffy 2005; Fernandez et al. 2007). They consist of a belief of empowerment through transfer of control over services from providers to the recipients through the re-allocation of funds from the former to the latter (Ottmann, Laragy & Haddon 2009; Social Care Institute for Excellence 2007, 2009; Spandler 2004; Tilly & Wiener 2001). Empowerment is linked to values of recipient self-determination through the means of having 'Choice and Control' over key areas of their services (Laragy 2002).

Recognising the antecedents of SDC in the work of the ILM is important as it highlights that the origin of user-controlled services lay in the disability movement itself. Members of the ILM were the people who experienced firsthand the effects of the charity/welfare model of service provision. In their campaigns, the movement challenged ideas of people with disabilities as passive welfare recipients (Shakespeare 2006). SDC constituted a means to define the position of people with disabilities as 'agents' in control by means of giving them information, building knowledge and providing material resources to enable them to have a role in determining the shape of their own services (Tyson et al. 2010). Thus SDC challenged the ideology behind the discretionary nature of agency-controlled service models such as the Council's HACC services that appear to be based on assumptions that people with disabilities are entitled to services only through professional intervention, and are, at times, ineligible and undeserving of them as well (Goggin & Newell 2005).

SDC operating principles relate to: transparency of information; participation in planning; and administrative control of budget expenditure. Service users are given access to upfront information about their individual services budget, input into planning the scope and content of their services, and operational management of their service delivery including budget expenditure control (Hatton et al. 2008; London Borough of Richmond upon Thames 2010). Service user 'control' is translated into control over budgets, and 'choice' is represented by choice over service providers. Self-determination through self-management implies the exercise of administrative responsibilities. People participating in SDC can manage their own services, employ their own carers, set their conditions, pay them and direct them. While the emphasis in the approach was on the means for people with disabilities to gain control through service purchase and management, it also gave them a degree of control over the relationships they had with service provider organisations (Gibson et al. 2009).

Control over one's own care plan was also seen as enabling service users to be innovative in planning resources to meet their needs without the restrictions of service providers dictating the types and volume of services they could access. Expenditure could be much more flexible and cover a broader range of social and personal needs such as activities that facilitated access to education and employment (Hatton & Waters 2011; Hatton et al. 2008). This feature has been linked with the notion of

'personalisation' of support services (Cree 2013; Tyson et al. 2010) and the practice of 'person-centred care' (Productivity Commission 2011).<sup>21</sup>

It is important to note that SDC has largely been introduced in the UK, USA and other countries as an 'opt-in' model. People with disabilities have been free to choose whether they take up this model or stay with the traditional agency-driven model. The fact of having this choice was seen in itself as a benefit to service users (Davey et al. 2007). A further incentive for participation is that the funds attached to a service user are portable.

In practice, there were differences in the specific design of each SDC program. The major difference was the degree to which service users had control over budget expenditure and management of the employment of their workers. These varied from country to country (Fisher et al. 2010) and within countries (Tilly & Wiener 2001). It is common for options for different levels of control to be offered so that service users can choose between full control (i.e. direct payments or cashed out benefits), semi-control through contracting an agency to manage funds (i.e. financial intermediary), or notional control by requesting (and paying) for a disability service provider to manage funds and service delivery arrangements on their behalf (Victorian Government Department of Human Services 2009).

There is extensive evidence to indicate that SDC has been well-received by people with disabilities and improved their lives in many areas (Glendinning et al. 2008; Kemper 2007; Tyson et al. 2010). In a comprehensive literature search on the impact of user-controlled services (Productivity Commission 2011), the authors concluded that benefits have been reported by service users in areas such as general health and wellbeing, better planning, increased feelings of control in their lives and greater satisfaction with the services provided both in the UK (Glendinning et al. 2008; Tyson et al. 2010) and in the USA (Kemper 2007). Due to the more recent adoption of a number of SDC programs, there are fewer Australian studies that focus on outcomes. Fisher et al's (2010) paper on the effectiveness of individual funding approaches in all states of Australia found that most people said they were happy or very happy that SDC provides choice about service providers (92%) and were satisfied with the help in

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<sup>21</sup> 'Person-centred approaches' or 'person-centred care' are very common terms in the disability and aged care literature. Definitions tend to be imprecise and consist of statements of intention rather than clarification of characteristics that would distinguish this from other approaches. For example: 'the intention of person-centred approaches is to maximise, as much as possible, the capacity for people with disabilities to take control of their lives' (Productivity Commission 2011, p. 345); or person-centred care is: 'focussed on clients/user; promotes independence and autonomy rather than control; involves services that are reliable and flexible and chosen by users; and tends to be offered by those working in a collaborative/team philosophy' (Innes & Macpherson 2006, p. ix).

choosing their support (81%). Nearly three quarters (71%) reported that the support was better, or much better than before. Better outcomes were also reported in this study in community participation, social relationships and access to support services. While concurring on the positive benefits of SDC, a longitudinal study of Australian families caring for children with disabilities found that family carers experienced a feeling of being isolated and lacked support over time.

Other outcome studies have addressed impacts on other stakeholders in SDC. While there is insufficient space to consider these here, some studies have looked, for example, at impacts on paid carers (Christensen 2010; Gibson et al. 2009; Social Care Institute for Excellence 2009). These authors have highlighted the need for broader interpretation of outcomes in the context of interpersonal aspects of the 'caring' dynamic, and pointed to possible conflicting impacts for paid carers such as poorer pay and conditions, but greater job satisfaction.

### **Summary of key issues**

This chapter has introduced four key factors that determined the need for this practice-based study and contributed to the definition of the research problem. The first key factor is the application of Critical Social Work as a theoretical paradigm that establishes the purpose of social work, including social work research, as the implementation of anti-oppressive practices to confront social inequalities and seek transformative social change. As a consequence, aspects of power and empowerment in the social relations of the Council's services have come to the fore as critical elements to be considered in this inquiry.

The second key factor is a critical appreciation of sources of oppression in historical forms of disability support and care services by the state, extended by the evidence presented above of the continuation of discrimination and marginalisation in the evolution of a dysfunctional macrosystem that has failed markedly to meet the needs of its users, and has thus failed to empower them.

Third, the description of the operation of the Council's HACC services, the researcher's workplace and the setting for the study, has revealed many aspects of the limitation on the power and control of its service users and service providers represented by its structure as a traditional model of service design. Other factors however, in the Council's structure as a level of government, may provide opportunities for and sources of empowerment. Together, these first three key factors make the case for the need for

microsystemic change – a change the Council faces with the requirement to plan for its future services model.

The fourth factor arises from the potential of a ground-breaking alternative model of disability services design – the Self-directed Care model. As a user-controlled model, SDC has been described in this chapter as one that explicitly seeks to empower people with disabilities by increasing their choice and control over their services in a number of ways.

These four factors have established that the Council's services planning task must address questions of how to increase power and control for people with disabilities as service users. Given this need, the study is designed to investigate how this process can be informed by data on the operation of power and control in the dynamics of the local government setting, within the framework of a critical approach.

The next chapter develops this journey concerning power and control further by considering theoretical conceptualisations of disability empowerment in the literature, through the lens of Critical Social Work principles and practice.

## CHAPTER TWO

### DISABILITY STRUCTURES, RIGHTS AND REGULATION, CHOICE AND CONTROL: THEORETICAL INSIGHTS

#### Introduction

In Chapter One the origins of key elements of ‘power and control’ for service users of the Council’s disability services have been located in the effects of: the history of oppressive state care; the impact of the era of de-institutionalisation and the disability rights movement; early forms of local community care; and the reframing of Victorian local government human services through the principles of business regulation and ‘contractualisation’. The previous chapter argued that the inter-relationships of national, state and local government policy resulted in a severely inadequate macrosystem that impacted on local services provision, and created the imperative for the Council to plan for change in its microsystem structure.

In establishing the research within the Critical Social Work frame, Chapter One introduced the need for a critical understanding of the nature of empowerment. It has therefore set the scene for this study’s broad purpose: to explore aspects of empowerment for people with disabilities relevant to the municipal practice setting, in order to inform the Council’s services planning process. Chapter Three will set out the research purpose and aims in more detail.

Chapter Two has a broad scope. First, it considers how empowerment has been conceptualised in the Critical Social Work literature. Second, it examines theoretical and discursive perspectives on empowerment which give insights into how the disability community and scholarship has conceptualised sources of power and control. Third, it critically analyses how the Australian human services industry has been seen in the literature as shaped by discourses on the role of government. This chapter’s focus is, therefore, both on service provision and service users in the context of the microsystem environment, and the broader theoretical frames relating to people with disabilities.

The literature consideration is guided by the recognition that the municipal services planning process involves two primary stakeholder groups – service users and service providers. As they have different roles in this process, it cannot be assumed that their interests coincide. Reflecting this consideration, the chosen theoretical/discursive

frames discussed below (the Medical/Professional Discourse, the Social Model of Disability, the Human Rights Approach, and neo-liberalism), address empowerment issues as they impact differently on both groups. The chapter argues that these are valid frames for examining the conceptual approaches relevant to designing empowering disability services in a specific local government context.

At the conclusion of this chapter it will be seen that the literature offers a number of alternative conceptualisations of how people with disabilities view pathways to increased power, and how the empowerment promised by the Self-directed Care model may be further investigated in the local services context.

### **Empowerment and Critical Social Work**

‘Empowerment’ is difficult to define as it is both a process and a goal (Cree 2013; Mullaly 2007). It is, moreover, highly context-dependent in its meaning and its application (Allan 2009a). According to this author, it consists of three primary dimensions: the personal; the relational or social; and the structural/political (Allan 2009b). At each of these levels, enhanced power and control for those who experience oppression and discrimination can be promoted or enacted through individual agency and self-confidence, the reduction of discriminatory societal attitudes and practices, and strategies to challenge political and institutional power that perpetuates inequality (Allan 2009b; Cree 2013; Mullaly 2007, 2010). Some authors have noted that due to the difficulties in defining ‘empowerment’ as a practice and/or outcome, it has become devalued. Thus Critical Social Work practitioners prefer to use the term ‘anti-oppressive’ social work (Morely, Macfarlane & Ablett 2014). Cree has argued, however, that empowerment remains a valuable concept for current social work, when it is understood ‘as part of a radical response to the problems faced by individuals, groups and communities’ (Cree 2013, p. 145). ‘Empowerment’ is the term used in this study for its usefulness in identifying one way that ‘power and control’ can be ‘deconstructed’ in its operation in the Council’s service planning, particularly from the standpoint of the people who receive services.

Empowerment can be conceptualised from the point of view of perceptions of marginalised people (groups and individuals) on what they have experienced as a change in their lives, and/or a process that Critical Social Work practitioners engage in to effect change in the lives of others. Although these two aspects may coalesce, this cannot be assumed. Mullaly’s definition of empowerment: ‘a process through which members of subordinate groups reduce their alienation and sense of powerlessness

and gain greater control over all aspects of their lives and their social environments' (Mullaly 2007, pp. 298-9) is considered useful for the purposes of this study because it emphasises the change process from the point of view of disempowered people themselves. In this writing, Mullaly conceptualises this change as a transition (for them) from a state of passivity to one of action towards taking control. Given that people with disabilities have been subject to entrenched lack of power and exclusion from decision-making (see Chapter One), an important axiom for this study is the need for people with disabilities to speak for themselves in how they can achieve greater control.

Referring to the process of Critical Social Work, Allan (2009a) has identified the need for practitioners to address inequalities in their relationships with service users by seeking to equalise power imbalances. The connection of empowerment with the creation of equal relationships, or more accurately, seeking to minimise power inequalities, has methodological implications for the study. This will be further elaborated in the next chapter.

The term 'empowerment' in this study, therefore, refers both to outcomes as perceived by service users and to the practice of Critical Social Work in local microsystem services planning. It links with the frames of structural change as a strategy of empowerment as represented in the Social Model of Disability and the Human Rights Approach frames discussed below.

### **Empowering theories and discourses from the disability field**

#### Medical/Professional Discourse of disability

Before considering the empowering elements of the Social Model of Disability and the Human Rights Approach, it is necessary to address the literature on the Medical/Professional Discourse as a competing and dominant frame that has been influential in defining 'disability' in a way that the disability sector has experienced as disempowering (Thomas 2007).

The Medical/Professional Discourse of 'disability' has been identified by several authors as originating in attempts to 'cure' or ameliorate certain forms of impairment by medical intervention (Johnson 2009; Thomas 2007). The underlying assumptions of the discourse are that 'disability' is caused by impairments. And because of their permanent effects in reducing 'normal' functioning, represent a condition of individual 'abnormality', 'deficiency', or 'pathology' (Kayess & French 2008; Thomas 2007).

Although many people with disabilities experience chronic pain, chronic illness, or permanent physical and mental conditions that necessitate constant medical treatment (Goggin & Newell 2005), it is the negative terms in this discourse that place people with disabilities 'outside of the boundaries of the 'normal'. These terms also imply they will stay there, because the condition of being 'disabled' – framed as an incurable one— cannot be changed (Johnson 2009, p. 191). In Johnson's view and of others, this is the profoundly disempowering effect of the Medical/Professional Discourse (Johnson 2009; Oliver 2004; Thomas 2007).

Several authors have argued that the underlying discourse of 'disability' as 'deviance' has persisted to the present day in the medical/health sector, despite well-accepted paradigm shifts represented by the theories discussed below (Thomas 2007). Kayess and French (2008) have identified the persisting influence of the discourse in its reach beyond the medical profession into other areas such as services, accommodation and employment. Examples of how this medical/professional power has been encoded into the everyday life of people with disabilities include the roles of doctors or other health professionals: to determine eligibility for income (e.g. the disability pension) and access to aids and equipment or permits (e.g. disability parking permits); to act as gatekeepers to essential programs (e.g. 'special education'); and finally, even to attempt to predict and define a person's right to live based on the estimated severity of certain health conditions (Goggin & Newell 2005).

Within the perspective of the Medical/Professional frame as a hegemonic discourse in the field of disability practice and service, the role of other professionals such as social workers and allied health workers, is limited to caring, supporting and mitigating the effects of impairments within the permanent state of 'disability' (Johnson 2009). This point reveals a further disempowering implication of the Medical/Professional Discourse that attaches 'disability' to a personal 'affliction', that is, that people so 'afflicted' are assumed to be dependent on others for care and support, or at least suffering reduced capacity in some way (Thomas 2007). Thomas's critique refers to the impact of this discourse as an underlying set of ideas that leads to generalising and stereotyping attitudes (e.g. those detailed by Goggin and Newell (2005).

Acknowledging the literature on the enduring nature of the Medical/Professional Discourse is important to this study in regard to its assumptions of people with disabilities' dependency on others and their incapacity to make decisions rather than emphasising agency.

Other critiques of the impact of the Medical/Professional Discourse have come from multiple sources and perspectives, for example, Critical Social Work (Johnson 2009), Feminism (Corker 1999), Critical Disability Studies (Meekosha & Shuttleworth 2009; Mertens, Sullivan & Stace 2011), Human Rights (Kayess & French 2008; Rioux 2002) and Indigeneity (Griffis 2011). They share the argument that the individual pathology discourse 'marginalizes people with disabilities and forces them to conform to social contexts that do not account for their needs' (Rioux & Carbert 2003, p. 11). And they argue that a structural analysis is important for understanding disability in terms of power and control, not only in service provision, but in its social construction (vis-a-vis what is normal). As will be discussed further in this chapter, they propose different perspectives on the nature of structural inequalities that must be removed to increase power and control for service users.

### Social Model of Disability

As a structural paradigm, the Social Model of Disability has been seen as constituting a profound paradigm shift, from disability as 'the medical, individual or tragedy discourse' to one of disability as a concomitant of disabling social arrangements (Johnson 2009, p. 191). Rather than locating disability in personal characteristics, the social model has reframed disability as a consequence of the way society is organised that favours the capacities of the majority – the non-disabled (Thomas 2002). Societal structures embedded in social institutions and social relations, could and should be changed to accommodate the range of human abilities, and remove the barriers that discriminate and oppress the category of people deemed 'disabled' (Peters et al. 2009). According to one well-known UK author, the model conceptualises barriers as not just physical, but social, economic, cultural and attitudinal (Oliver 2004). In Oliver's view, the focus on social change gave the hope of political power to people with disabilities.

The term 'societal structures' has been defined here as 'enduring social patterns, power divisions, institutions and inequalities' encompassing dimensions such as political, historic, economic and gendered relations, that 'exist independently of the action of any one individual' (Morely, Macfarlane & Ablett 2014, p. 4). 'Structural inequalities' is taken to mean the operation of societal structures in relation to a person's class, gender, ability, cultural background, indigeneity, sexuality and age, that result in reduced power and resources. The first chapter gave evidence of broad ranging structural inequalities experienced by people with disabilities covering employment, income, housing, and so on.

Historical accounts of the beginnings of the Social Model of Disability describe how it grew out of the dissatisfaction and frustration of the disability community with ongoing dependency and lack of agency of its members (Shakespeare 2006; Thomas 2007). This model gained increasing influence from the 1970s concurrently with the Disability Rights Movement in the UK and USA and in other Western countries (Mertens, Sullivan & Stace 2011). Its genesis has been located in the UK with the formation of the Union of the Physically Impaired Against Segregation (UPIAS), an organisation that advocated for the replacement of segregated living with opportunities for independent living (Barnes & Mercer 1997). In his detailed account of the model's history, Shakespeare (2006) sets out how the statement of the Union's 'Fundamental Principles' of 1976 identified disability as a situation caused by social conditions that unnecessarily isolated and excluded people from full participation in social activities. In the USA the emergence of the social model was also associated with the Independent Living Movement<sup>22</sup> where it became aligned with civil rights. Worldwide it was part of the groundswell of related anti-oppression movements of the late 1960s and 1970s such as the Women's movement, Disability Rights movement, the peace movement, and gay movements (Mertens, Sullivan & Stace 2011).

The model was a 'breakthrough' for people with disabilities in two equally important ways. First, it proposed a new way of defining disability that had profound implications in creating a new self-perception that released those with disabilities from personal responsibility for their disability status – a status that was (potentially) negative and disempowering (see Chapter One). Second, the model proposed a concrete way forward to remove structural inequalities: a way that depended on and reinforced the agency of people with disabilities to change societal structures. These ideas, revolutionary for their time, were the crux of the Social Model of Disability and were present from the beginning, as expressed in the four axioms of the UPIS statement: disability is caused by the way society treats people with impairments, not by themselves; social change on all fronts is required; 'disabled people' must win control over their own lives; and the control that health and care professionals have over the lives of 'disabled people' must end (Thomas 2007, p. 104).

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<sup>22</sup> As a long-lasting and influential movement the Independent Living Movement was a contributor to the development of Self-directed Care through establishment of the disability-controlled UK organisation called In Control (Duffy 2005).

In regard to the first aspect of the 'breakthrough', early explications of the Social Model of Disability made an important distinction between 'impairments' and 'disability' for the purposes of distinguishing between features of bodily function or inherent characteristics ('impairments') of individuals, and the consequences of societal structures that 'caused' restrictions ('disability'). This distinction was to become a source of critique, especially from feminist and post structural writers, on the grounds that it created a false dichotomy that did not reflect the lived experience of people with disabilities. This is discussed in more detail below.

Referring to the second 'breakthrough' aspect – that of removing structural inequalities – the Social Model argued for comprehensive social change to counter the effects of prejudicial attitudes and behaviour, institutional discrimination, inaccessible built environments, inaccessible transport, and inaccessible information and communication, excluding work arrangements and segregated education (Oliver 2004). The concrete nature of the model was reflected in the call to remove the barriers (specific and definable) that restricted people's activity and participation. The targets of action included the processes of policy development, of enactment and policing of laws and regulation, of practice guidelines, all forms of planning, and others. In the Council's local context, structural change could involve reversing building regulations that did not mandate the construction of: accessible buildings; influencing accessible public transport planning; demanding the use of accessible modes of communication and information provision; and advocating for employment practices and accessible services.

The Social Model was and still is an influential paradigm, responsible for examples of government policy and planning reforms at all levels including legal reform and inclusive practice. Although Johnson (2009) has maintained that it has had a greater influence on government policy in the UK than in Australia, it has been prominent in Victorian State Government legislation, such as the Disability Act 2006, and in the Victorian State Government Disability Action Plan (Victorian Government Department of Human Services 2012). Internationally, the Social Model has been incorporated into the Convention on the Rights of Persons with Disability, the significance of which is discussed in more detail in the next section.

As the Social Model has been a part of the disability scene for over thirty years, it is not surprising that it has been extended by critiques arising from the development of critical

theories related to feminism, critical race theory, postcolonial theory and others (Mertens, Sullivan & Stace 2011).<sup>23</sup> The most relevant of these for this study are the writings of authors proposing the adoption of the Critical Disability Studies approach (Meekosha & Shuttleworth 2009; Mertens, Sullivan & Stace 2011). These authors argue that the Social Model has promoted a narrow view of disability as social oppression, where change in political, social and economic structures is presumed to be sufficient to eliminate the negative effects of disability. They state that in its operation the Social Model has not adapted to, nor incorporated the range of critical theories, such as those mentioned above, and therefore neglected the 'psychological, cultural, discursive and carnal' aspects of life (Meekosha & Shuttleworth 2009, p. 50). In this way the Social Model has been seen to focus too narrowly on the material aspects of structural inequality (i.e. the political economy of disability), and failed to consider the subjective and experiential perspectives of embodied disability (Corker 1999; Crow 1996).

Mertens et al. (2011) argue that disability must be conceptualised and studied from the more complex perspective of how different critical frames intersect. This would lead to a more nuanced understanding of disability as 'embodied, gendered, raced, classed and sexed' (Mertens, Sullivan & Stace 2011, p. 230). The concept of 'intersectionality' has methodological implications for this research to be discussed in the next chapter. Further, the Critical Disability Studies approach's emphasis on the importance of disability research being culturally informed has mandated the need for disability researchers to develop 'cultural competence' – a concept that has also been adopted for its methodological 'fit' with this study.

It is clear, therefore that the emphasis on structural change actions in the Social Model of Disability has application to the local services setting in reframing disability as an issue of societal inequality and its potential for disability agency. However, critiques from Critical Disability Studies need to be taken into account. The model provides useful insights for this study on the connection of disability empowerment with collective action to remove structural barriers existing in a person's daily life, and impacting on their interactions with their environment and in their social relations. The critique of the Social Model of Disability's perceived tendency to stereotype disability,

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<sup>23</sup> Critical Disability Studies, like Critical Social Work, requires an understanding and application of critical theory, defined here as: a means to conceptualising the relationship of oppressive social relationships to social characteristics; exposing the source of social inequalities; imagining a future where they have been eliminated; and committing to transformative action to achieve this (Briskman, Pease & Allan 2009; Garrett 2013; Morely, Macfarlane & Ablett 2014).

and ignore the differential and bodily impacts of impairments provides insight into the need for a more nuanced approach to disability research.

### Human Rights approach

The Human Rights paradigm and the Social Model of Disability share a common assumption: the way society is structured prevents people with impairments from equal participation, rather than inherent bodily characteristics that 'cause' disability. In contrast to the Social Model of Disability, which locates social change in actions to change all discriminatory structures of society (see the discussion above), the Human Rights approach places emphasis specifically on changing the structures of law and international covenants. The literature on the Human Rights approach, considered in the following paragraphs, reveals theoretical underpinnings that can further inform this study on aspects of disability power and control at the local level.

Many writers in the disability field have advocated for increased adoption of a human rights discourse as an effective means of empowering people with disabilities through their citizenship status (Johnson 2009; Kim 2010; Muir & Goldblatt 2011). With Australia's signature to the United Nations Convention on the Rights of Persons with Disabilities (CRPD) on 30 March 2007, followed by its ratification in 2008, human rights for people with disabilities in Australia were put firmly on the national and global stage (Kayess & French 2008), as well as the local.<sup>24</sup> Its adoption was described by these authors as a 'great landmark in the struggle to reframe the needs and concerns of persons with disability....' (Kayess & French 2008, p. 2).

Human rights are commonly seen as universal, inalienable, indivisible and in-abrogable entitlements inherent in shared humanity (Nipperess & Briskman 2009). The preamble to the CRPD states that it reaffirms the 'universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms and the need for persons with disabilities to be guaranteed their full enjoyment without discrimination' (Convention on the Rights of Persons with Disabilities, 2006, p.1). This statement reflects the conceptualisation of rights as a fixed set of mutually dependent claims possessed by every individual, applying to everyone in the same way, which cannot be

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<sup>24</sup> the Council was one of the first in Australia to sign on to the Convention in 2007 on the advice of the Disability Advisory Committee. It also advocated for the Commonwealth Government to sign and ratify the convention. Two members of the Committee had attended United Nations Committee meetings in the USA as Australian representatives, and took part in the development of the articles of the Convention. In 2008 Australia endorsed the CRPD.

taken away, or voluntarily given up. Aspects of 'universalism' as applied to disability rights have been subject to a number of critiques discussed below.

The comprehensive coverage of the fifty articles of the CRPD<sup>25</sup> spells out the rights to equal recognition, access and freedom from abuse and respect. It covers rights to education, health, habilitation and rehabilitation, work and employment, and adequate standards of living and social protection. It addresses the right to participation in cultural, political and public life. Article 19 is particularly relevant here, as it documents the right of all persons with disabilities to live independently and be included in the community. While the growth in human rights legislation and practice has been seen as an empowering frame for people with disabilities, it has also been seen as an important mode of practice for Critical Social Workers (Hugman 2013; Ife 2008, 2010; Nipperess & Briskman 2009).

In its coverage of a wide range of rights, the CRPD also reflects these as individual, collective and communal matters, described by Ife (2008, 2010) as three generations of rights. These encapsulate different types of rights which are briefly summarised here, because many of the potential applications of rights literature critiques relate to different generations.<sup>26</sup> According to Ife's view, first generation rights refer to civic and political rights such as the right to vote, to be afforded citizenship status, and to enjoy full participation in social and civic life. They have been identified as 'negative rights' in the sense that their recognition restores individuals to full humanity, denied to them by rights violations. (Ife 2008). (Articles 10-23 and 29 of the CRPD are based on civil and political rights.)

In contrast, second generation rights refers to economic, social and cultural rights that must be pursued through positive measures by government to ensure that people can obtain the means to be educated, earn a living, access housing, and receive health

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<sup>25</sup> The CRPD (and its optional protocol) was adopted on 13 December 2006. It entered into force on 3 May, 2008. Article 3 sets out 8 principles:

- a. Respect for inherent dignity, individual autonomy including the freedom to make one's choices, and independence of persons;
- b. Non-discrimination;
- c. Full and effective participation and inclusion in society;
- d. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- e. Equality of opportunity;
- f. Accessibility;
- g. Equality between men and women; and
- h. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

<sup>26</sup> They are called 'generations of rights' in Ife's 2008 publication because they reflect the historical unfolding of rights through the centuries and build successively on earlier rights.

care as well as other necessities to realise their potential (see Articles 24-28 and 30 of the CRPD). Explication of these rights is more complex, as it involves cultural values and expectations about matters such as 'adequate' standards of living. Moreover, because these rights are realised primarily through government policy; they are more context-specific than first generation rights and challenge ideas of immutability and universality (Ife 2008).

Developed more recently, third generation rights relate to collective or 'relational' rights of groups, communities and societies, to entitlements to economic and environmental benefits and community cohesion and harmony (Ife 2008, 2010). Examples of these less easily defined rights can be found in Articles 28 and 32 of the CRPD, which refer to the right to an adequate standard of living, to social protection programs and poverty reduction programs.

Three aspects of human rights application to the field of disability are considered here in their relevance to the local setting. They relate to contested concepts of equality and universality. First, in discussing the aims of the CRPD to achieve equal treatment and equal participation of people with disabilities, Kayess and French (2008) have suggested it is important to distinguish between the notion of 'formal equality', where people are treated the same, and 'substantive equality', which recognises and attempts to remedy historical inequality (Kayess & French 2008, p. 8). They have emphasised that the notion of historical inequality is important for people with disabilities, given the degree of past denial of human rights. Policies such as positive discrimination to assist people with disabilities to access paid employment, for example, address substantive equality. To achieve formal equality, a range of strategies based on redressing historical barriers, such as the barrier to paid employment, would have to be developed parallel to application of formal rights such as those in the CPRD. In the local services microsystem this would require attention to equality in its historic as well as contemporary context.

A second aspect stems from the concern with human rights as universal and therefore assumed to apply to all cultures in the same way. As Nipperess and Briskman (2009) have pointed out, the Human Rights Approach could be seen as 'culturally imperialist', that is, imposing Western cultural values, such as liberal individualism, on other cultures (Nipperess & Briskman 2009, p. 63). In their view, however, universalism and cultural relativism should not be considered as necessarily opposing or mutually

exclusive stances in practice. Cultures are fluid and change over time; moreover there is a strong history of human rights ideas in other cultures. Nevertheless, as they argue, cultural difference is an important frame in human rights practice. And Critical Social Work practitioners must recognise where cultural traditions may conflict with discourses of 'common humanity' that underpin a universalist Human Rights Approach. Similarly, Hugman (2013), also writing within the Critical Social Work frame, has offered the view that the universal view of rights can be based on collective agreement on what it is to be human, while recognising that values can vary, be they the subject of debate, and be interpreted differently in different contexts.

Finally, several authors have drawn attention to the impact of different types of impairments that place people at greater risk of denial of human rights. People with intellectual disabilities, in particular, were subject to incarceration, not just in institutions for the 'disabled', but also in prisons (Stevenson 2010): 'In the history of Human Rights violations, there are few social groups who have endured the discrimination and abuse as have people with an intellectual disability' (Stevenson 2010, p. 37). According to some authors, routine breaches of human rights have continued across every aspect of the lives of people with learning disabilities (Fyson & Kitson 2010). This point relates more to limitations in the application of human rights than their intent. In the local context it is important to acknowledge that a human rights approach must recognise difference in the types of impairments experienced and their effects on exposure to the risk of rights abuse. Strategies for human rights practice (i.e. promoting understanding, recognition and compliance with human rights laws), in the local government context, must take into account the impact of the level and nature of disabilities.

In summary, this section has discussed the contribution of theoretical insights of the Social Model of Disability and the Human Rights Approach as two empowering paradigms, and contrasted these with the Medical/Professional Discourse. The discussion has shown that the structural change strategy of the Social Model of Disability, extended by the Critical Disability Studies approach, takes the concept of disability beyond the impairment/disability divide to one of disability as embodied, and intersecting with other social divisions of gender, class, culture/ethnicity, sexuality and age. Within this model increased power and control for people with disabilities are seen to be afforded by collective action for structural change, addressing a broad range of structural inequalities informed by critical theory. In the local setting this has two implications. First, that potential empowerment through the application of the Social

Model of Disability must include the participation of people representing different social characteristics, and second, that the exploration of power and control must address disability as embodied and subjective.

In concert with the Social Model of Disability, the Human Rights approach also has much to offer as a structural change model. In the first place, human rights, codified into covenants, laws and charters, provide the disability sector not only with protections and aspirations, but with a competing discourse to other frames such as the Medical/Professional Discourse.<sup>27</sup> Victorian local governments are obligated to comply with human rights laws and people with disabilities can prosecute councils as public authorities for failure to do so. As Rioux and Carbert have stated: 'Human rights are an international issue, practiced at the local level' (Rioux & Carbert 2003). The Council, as the local service provider, is part of an organisation that can create a space for discussion and dialogue on contested aspects of human rights such as cultural differences and equality and universalism.

### Neo-liberalism in the Council services

The following section shifts the focus from discourses of power and control relating to structural change and rights to theoretical insights into the organisation as an institution including its practices, policies and systems. Evidence is provided in the literature discussion below that the current<sup>28</sup> organisational practice of the Council is situated in the context of a powerful frame, neo-liberalism, that has been viewed as hostile to social work practice, seeking to increase power and control for service users.

Within the Critical Social Work literature, many authors have identified neo-liberalism as the key discourse influencing the operations of Australian human services organisations<sup>29</sup> at the start of this century (Halfpenny 2009; Lawler 2013; McDonald 2006, 2009; Morely, Macfarlane & Ablett 2014; Pease 2009). In their view, neo-liberalism, along with the related ideology of economic rationalism, has transplanted the value systems, beliefs, discourse and techniques of the private business world to the public world of government funded and sponsored human services provision, with

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<sup>27</sup> Refer to Article 12:2: All States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with other in all aspects of life. The article sets the right to be deemed competent or capable as a prior condition, challenging the Medical/Professional Discourse revealed in HACC guidelines that assume people have high and complex care needs that prevent them from giving directions on their care.

<sup>28</sup> At the time the study was conducted (2009–2014).

<sup>29</sup> And in the UK social work services (see Lawler, 2013).

the result that the relationships between service users and 'the state' has been profoundly altered, as discussed in more detail below.

The ideology of Individualism that underpins the rise of the individual as the primary organising principle of capitalist economies is a foundational idea of neo-liberalism (Briskman, Pease & Allan 2009). 'Liberalism' refers to the espoused valuing of freedom for individuals to advance their own interests with the least amount of government interference. The hegemony of economic rationalism framed this 'freedom' as an economic aspiration, thereby limiting human motivation to financial self-interest and ignoring social, relational and collective interests. In the neo-liberal state, 'all aspects of social behaviour are reconfigured along economic lines' (McDonald 2006, p. 63).

Neo-liberalism has been defined as a policy framework that replaces the traditional welfare state with one that aims to further international competitiveness (Lawler 2013; McDonald 2006). As McDonald (2006) has argued, the neo-liberal discourse espouses significant advantages for all through the process of maximising individual choice and control afforded by access to more competitive and 'free' markets. In her view, however, the concomitant of the (supposed) benefits for recipients of welfare in exerting increased choice and control, is that they will be deemed more responsible for their own wellbeing, whether the 'market' operates efficiently or not.

The reach of neo-liberalism has been influential in redefining the role of government on all social policy issues, and therefore on the roles of services planning and provision (McDonald 2009). Social work as a 'bureau-profession' is closely bound to government policy and ideology, as it cannot exercise the same autonomy and discretion as other semi-privatised professions such as doctors, psychologists and lawyers (McDonald 2006, p. 70). It is, therefore, inevitably reflective of, and virtually forced to, implement the prevailing politics, policies and discourses of the machinery of government. Australian government at all three tiers (national, state and local) funds welfare practice both in the public and semi-public spheres; it sets the agenda for programmatic responses and, according to writers such as Halfpenny (2009), increasingly seeks to regulate and control. (The effect of the large degree of government control and regulation in the Council's HACC services has been described in the previous chapter.)

In the human services arena, neo-liberalism is evidenced by two main discourses: that of management, indicated by terms such as 'managerialism', 'risk culture' and

‘marketisation’, and that of business, in terms such as efficiency, effectiveness, best value, profit and business planning (Halfpenny 2009; Lawler 2013; McDonald 2006; Rogowski 2011).

Why was this movement so successful that by the early 1990s it had become the new orthodoxy and continued to influence the field for the next two decades? Muetzelfeldt (1992) has linked the growing hegemony of economic rationalism to its attraction as a ‘coherent body of thought’ about the power of the market to generate benefits to all and replace the need for welfare state obligations (Muetzelfeldt 1992). Economic rationalism is certainly consistent with the increasing consumerism of capitalist societies, particularly one with high per capita income such as Australia. Halfpenny has also commented on the power of these ideas as mutually reinforcing in his reference to ‘the unifying discourse of managerialism’ (Halfpenny 2009, p. 259).

‘Managerialism’ has been defined as ‘an array of reforms and restructuring techniques with the general aim of aligning practices more closely with market, and market-like modes of organisation’ (Halfpenny 2009, p. 257). According to this author and others, such as Harlow (2003), there are many techniques to achieve this including: ‘contractualisation’; increased control by managers through specification of objectives, hierarchical line management and technical control; compartmentalisation of practice modes; and the introduction of a regime of audit and accounting procedures.

‘Compartmentalisation’ of tasks and ‘unitisation’ of activities are two strategies of managerial control that have been seen to disrupt and distort social work practice (Rogowski 2011). Critical Social Work principles foster holistic approaches and the establishment of reciprocal relationships between service users and service providers (Allan 2009a). The managerial tool of dis-aggregating tasks and funding them on the basis of units interferes with the social worker using her/his judgement to adapt responses to specific situations. This occupies the social worker’s time in meeting the obligations of unit output accounting. Power has described this process as ‘the shallow rituals of verification at the expense of other forms of organizational intelligence’ (quoted in Halfpenny 2009, p. 264). Another possible effect on social work practice is that of factoring out discretionary or extraneous worker’s effort. This has potential implications for service users, such as those with disabilities, whose particular needs and situations require responsive services, which can be met only through the innovation and flexibility of discretionary effort (Harlow 2003).

Risk management is another key technology of managerialism that has implications for this study (Green 2007). Assessing and minimising risk in human services has been seen as an unavoidable and common-sense imperative, as people are in contact with human services workers primarily because of experiences of vulnerability and need that expose them to heightened risks (Culpitt 1999; Gray & Webb 2013a; Lawler 2013). While there is insufficient space to detail here the literature on the impact of 'risk culture'; it is helpful to refer to a thorough exposition of the rise of the 'rhetoric of risk' in the social work field made by Green (2007), as this connects with issues of potential disempowerment for people with disabilities in 'managerialist' services. This author has identified four significant effects: a shift in focus from service users' interests in the present to their (supposed) interests in the future; a changed role for social workers from supporting and empowering to public accountability for risk control; a relocation of responsibility to individuals in the general community with penalties for inability to discharge this responsibility; and enforced organisational processes of 'risk identification' and 'harm minimisation' that take on a quasi-reality in dealing with threats such as litigation (Green 2007).

People with disabilities, whose common experience has been of externally imposed constraints on the freedom to make decisions, have been severely restricted in their freedom to take risks (Goggin & Newell 2005). As discussed above, the human rights discourse frames individual decision making (including decisions on risk-taking) as a right to be protected by laws and conventions. This is expressed in the articles of the CRPD as the right to be deemed competent.<sup>30</sup> Managerialist strategies for risk management could be seen as limiting the control that service users have to exercise decision making over their personal risk at any point in time, as the 'conversation' about risk-taking has been shifted to one controlled by service providers.

### Neo-liberalism and Self-directed Care

From this general account of neo-liberalism in human services practice, attention is now focussed on its theoretical and discursive connections with Self-directed Care. In the fundamental ideas and discourses of neo-liberalism, several key concepts can provide potential analytical scaffolding for investigating power and control in the Self-directed Care model. These are the key concepts of 'individualism', 'consumerism',

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<sup>30</sup> Article 12: Equal recognition before the law: "persons with disabilities shall enjoy legal capacity on an equal basis with others in all aspects of life".

‘marketisation’ and ‘culture of risk’. Discussion of these concepts in the literature highlights areas of potential divergence of interests of service users with service providers, especially service managers operating under ‘managerialist’ imperatives.

It has already been noted that individualism features at the core of Self-directed Care philosophy in respect to giving individuals more power and control over their services in order to promote their self-determination. It is important to be reminded that this feature has been of crucial significance to people with disabilities and given them hope of better services and a better life (see discussion in Chapter One). It has been the cause of high levels of user satisfaction reflected in the research literature documented in the previous chapter. The intent of the model is to transfer power from the organisation to the service user. Power in this respect refers to control over many areas of service decision making, and is closely related to choice in the services plan, choice of the service provider agency or agencies, and choice exercised through direct or indirect purchasing.<sup>31</sup> Individualism is related to the Self-directed Care principle of ‘personalisation’ that underpins goals of tailoring services to meet individual needs. Cree has critiqued ‘personalisation’ as an empowerment strategy from the perspective of neo-liberalism (Cree 2013). As she states, UK government policy, which has overseen many years of implementation of the SDC model, has translated the discourse of empowerment into the neo-liberal ideology of individualisation as self-help. Allied with government welfare cutbacks, the self-help discourse has been used in the UK to promote the idea that people are responsible for themselves (i.e. through the expectation of their active role in managing the personalisation of their services), and if they are unable to do so, are deemed ‘unworthy’ of government support. This point raises the potential for ‘personalisation’ to reactivate the charity discourse of disability, referred to earlier in Chapter One. It resonates with the proposition made by McDonald (2006) above that greater choice and control in a competitive services market may result in unachievable expectations for discharge of personal responsibility for one’s well-being.

‘Consumerism’ and ‘marketisation’ as fundamental discourses of SDC have an obvious resonance with neo-liberalism. In SDC, choice and control is brought about by purchasing services from a market of service providers, that is, service users become consumers. Several authors have commented on the effects of the change in role from

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<sup>31</sup> In most SDC models, service users can choose to directly employ their paid workers and manage their service budget, or contract another agency to do this on their behalf.

service user to consumer or customer, in regard to its possible reconfiguring of their relationship with the state, and with service providers (Cree 2013; Lawler 2013; McDonald 2006). Marketisation rests on the assumption that the market is 'the most appropriate mechanism to allocate resources in meeting the needs of citizens in the public as well as the commercial arena' (Lawler 2013, p. 100). As McDonald has pointed out, in order for the market to operate successfully in a competitive environment, people must be persuaded that 'choice' is inherently good and that exerting choice (to purchase services), is in their interests (McDonald 2006). Further, she has argued, because services are translated into commodities in the marketplace, service consumers' relationships with provider organisations become largely those of financial transaction. This point has many implications for potential longer term operation of power and control for service users in the SDC model.

McDonald has broadly argued that the ascribed status of service users as customers is of most concern to social work practitioners because it redefines citizenship as a matter of consumption (McDonald 2006). In her view, neo-liberalism conflates the status of customer or consumer into that of 'good citizen' – an active and responsible person (as an *individual*) who consumes, engages in self-surveillance (as a *self-regulator*), is disciplined (as a *self-manager*) and therefore morally good. In this view, people who cannot or do not consume and self-regulate are denied the status of moral acceptability. Although this is a broad assumption, it raises possibilities of potential limitations in empowerment of the SDC model, relating to inability of people with disabilities to carry out the consumer role in the Australian capitalist system, because of lack of purchasing power, for example, and therefore unable to be deemed a 'good citizen'.

Finally, other authors have focussed more on the effects of neo-liberal ideology in SDC from the perspective of service providers. Lawler (2013), for example, has highlighted the effects on provider organisations (in the UK) of developing and prioritising the role of managers as technical and generic positions rather than professional social work roles. This has come about by the demands on provider organisations to position themselves in a competitive market and to favour the abovementioned managerialist strategies to achieve this. Lawler is of the view that this has had many negative effects: transferring accountability of front-line workers from service users to managers; reducing access to professional supervision and professional autonomy; and preventing them from practising in an integrated, 'holistic' manner. One of the most

concerning effects, noted by two UK authors, has been the devaluing of the relationship-centred aspect of social work practice (Cree 2013; Lawler 2013).

These are complex arguments. As the literature has established, analysis of the efficacy of empowerment for people with disabilities through SDC presents very different views, depending on whether the perspective is on the agency of either service users or service providers. In this study, this literature has reinforced the need to include both these interests, at least at the outset, as different groups. It has underlined the point made earlier that the interests of both stakeholder groups must not be assumed to be the same.

## **Conclusion**

In the last section we have seen that ‘choice and control’, as central elements in Self-directed Care, are promised as empowering outcomes for people with disabilities. Increased ‘control’ is related in the SDC service design to increased opportunity for decision making over one’s own services. Control is operationalised through choice of the provider and type of services along with financial management of one’s budget. ‘Control’ in this model is related to individual decision making. It depends on purchasing power within the marketised system.

This chapter has argued there are other empowering frames important to the disability community that are relevant to the local setting and operations of the Council as a service provider organisation. Both the Social Model of Disability and the Human Rights Approach identify sources of power and control for people with disabilities that connect with the multi-layered relationship the Council has with service users in their status as citizen residents. The Social Model of Disability locates empowerment in strategies for structural change aimed at affording more control through the removal of barriers for full participation of people in *all* aspects of life, not just in their service usage. However, the implications that arise from the criticism of the model’s perceived failure to incorporate aspects of multiple difference plus its inbuilt dichotomy of impairments and ‘disability’ must also be recognised.

The Human Rights approach has also been embraced by the disability community as a mechanism for empowerment through the definition, statement and legal machinery for enacting human rights. As this chapter has shown, the UN Convention on the Human Rights of Persons with Disabilities reveals the breadth of human rights violations

experienced by people with disabilities. It is closely allied with the Social Model of Disability in recognising societal barriers to participation. This relates to the local services microsystem, as there is Human Rights legislation that applies to the local government as a public authority. In addition, the local setting can provide a space for discussion and contest on applied human rights practice.

Finally, this chapter considered the literature on neo-liberalism for the insights into how managerialist dominated services, such as the Council's services (identified in Chapter One as a 'traditional model of disability services'), can inhibit Critical Social Work practices directed toward outcomes of empowerment and social justice. The analysis also relates critiques of Western liberal values underpinning neo-liberal-influenced human services of pre-eminence of the individual with underlying values of the Self-directed Care model. In particular, it draws attention to different perspectives on the potential for power and control to be attached to purchasing power and the role of service users as consumers in a marketised model.

In conclusion, this literature review has argued the case that researching the question of how to design empowering services for people with disabilities must explore what power and control mean to service users and service providers in a broad sense, rather than being limited to dynamics of the services' experience and design. In the municipal setting, empowerment, as increased control, must take into account other potential sources that connect control with agency for structural change and for prosecution of human rights. It must also take into account critiques of the constraining effects of neo-liberalism as a source of externally and internally imposed control of organisational practice that limits Critical Social Work professional outcomes in bureaucracies such as local governments.

Chapter Three sets out how these theoretical and discursive insights have informed the epistemology and methodology of the study of 'Whose Power, Whose Control?'

## **CHAPTER THREE**

### **THE PATHWAY TO METHODS FOR ANTI-OPPRESSIVE DISABILITY RESEARCH**

#### **Introduction**

This chapter covers four areas. First, it summarises the journey to this point, to remind the reader of the factors that have initiated and shaped this practice study and led to the definition of the practice research question, purpose and aims. Second, it considers the methodological questions relating to the aim of carrying out anti-oppressive research with people with disabilities as service users, and with service providers in a particular local government services setting – the researcher’s workplace. This section gives an account of why participatory action research methodology, extended by the insights of the Critical Disability Studies Transformative approach, has been selected for the inquiry. Third, it sets out the methods chosen to carry out the study based on the parameters of participatory and transformative methodology. A range of measures that have been taken to ensure ethical conduct, covering both general protection such as anonymity of participants and the right to withdraw, as well as protection relating to potential conflict between my role as researcher and service manager, are described in detail. Finally, Chapter Three explains how the data has been analysed.

#### **Building the research question, purpose and aims**

Earlier chapters have established that the Council, at the commencement of the research, was facing a process of change, some of which was externally driven by national macrosystemic reform, and some of which was more internally driven by the perceived limitations of its existing traditional service structure plus the challenges of Self-directed Care as a future, potentially empowering model. These factors were the instigation for the Council to undertake a process of services planning. In the context of the Council’s obligation to improve the overall quality of life of people in the municipal community, and its commitment to plan services that reduced discrimination and marginalisation for resident citizens with disabilities, it was faced with the question of how to design future HACC services that were empowering for them. The imperative for this practice-based research was therefore the need to generate data that could inform the Council’s collaborative disability services planning process at a time of major systemic change.

The adoption of Critical Social Work as the theoretical framework for the research has mandated the use of an anti-oppressive research design. Anti-oppressive research postulates two major principles: the involvement of participants (who experience discrimination and marginalisation) in ways that minimise inequalities of power within the research relationships; and a research result that furthers social justice. This chapter describes how these have been addressed in the research design, applied here to the field of disability research.

Chapter One has established sources of social inequality for users of disability support services in systemic complexity and inadequacies at the macro- and microsystem level. It has been argued that at the commencement of the practice research; systemic inadequacies have severely curtailed the power and control that service users can exert over services decision making at policy and operational levels. Chapter Two has examined theoretical approaches to concepts of disability empowerment and identified perspectives on power and control relevant to this study. Insights from both chapters emphasise the importance of enabling people with disabilities to define what power and control mean for them, both in their services and in their lives, and the critical nature of maintaining a nuanced concept of 'disability' that includes interaction with other forms of diversity.

Taking into account the systemic and theoretical factors in Chapters One and Two that have clarified the focus of the inquiry as 'power and control' in a local government micro-service system, the research question and definition is:

*What information does the Council need to plan for a more empowering model of local service provision for residents with disabilities? A 'more empowering model' is defined as one that reduces discrimination and oppression, and affords increased power and control in decision making by service users.*

The purpose of the research is stated as:

*To explore, in a process of collaborative inquiry, the perceptions of service users and service providers of the aspects of local services that they consider to be empowering. From this knowledge, the significant change elements will be determined in order to develop a framework for future Council services.*

In order to carry out the purpose, three research aims have been identified:

1. *Using the Self-directed Care approach as a template, to explore key aspects that must be addressed in designing and implementing an improved service model at a local government level for in-home services for people living with disabilities.*
2. *To generate a positive outcome for service users and service providers.*
3. *To strengthen the researcher's professional practice and contribute to Critical Social Work theory and practice.*

### **Epistemological underpinnings of anti-oppressive research**

From the research question, purpose and aims a number of key methodological imperatives follow. The research is required to be collaborative, to deal with sensitive issues of perception, to have an action outcome; and to be transformative in achieving a social justice outcome by reducing inequalities for and *with* an oppressed group.

Four epistemological assumptions have underpinned the choice of Critical Participatory Action Research as the 'best fit' for the study's purpose and aims. The first is that of knowledge building as a *social construction*. As this study was to be carried out within, and through the social relationships of the municipal services setting, insights and shared meaning would necessarily be created through social interaction, and take form 'in the eyes of the knowers' (Lincoln, Lynham & Guba 2011), that is, those with lived experience of disability and local service providers.

Second, the imperative for the research to be anti-oppressive is related to the epistemology of knowledge building as *relational power* (Denzin, N & Lincoln 2011; Lincoln, Lynham & Guba 2011). In the field of disability, as earlier chapters have discussed, the use of subjectivity was seen as an important means of challenging alienating social relationships and understanding the nature of disability as a lived experience. Anti-oppressive research methodology is built on a critical appreciation of the nature of past and present oppressive practices and social relations in regard to people with disabilities, the standpoint of the researcher and the means of research production (Stone & Priestley 1996). In these authors' seminal article on the role of non-disabled researchers, they state that anti-oppressive, or 'emancipatory' research must reject or minimise distancing of the researcher from the 'researched' that can occur with design that sets up the researcher as the objective expert. This necessitates

a rejection of positivist approaches that label and marginalise 'disabled people' as 'objects' of study, and thus regard knowledge as objective 'facts' to be uncovered.

Third, the research aim of generating a beneficial outcome is connected to the epistemology of knowledge through *action* (Brydon-Miller et al. 2011; Lincoln, Lynham & Guba 2011). As these authors assert, transformative or emancipatory research is social change oriented. Outcomes must be evaluated by people with disabilities in terms of its benefits to them. In order for this to be achieved, ongoing and meaningful participation is necessary so they can understand the research aims and processes.

Together, these three epistemological imperatives place the research within the qualitative, participatory/action methodological paradigm. The fourth epistemological imperative of knowledge building of '*disability*' as *embodied, experiential and intersecting*, is located in the Critical Disability Studies (CDS) paradigm. The next section considers, in more detail, the origins and implications of participatory/action and critical/transformative approaches, and explains how they have been combined in this study as 'Critical/Transformative PAR' methodology.

### **Participatory Action Research as emancipatory**

Participatory Action Research (PAR) and other forms of action research, have a long tradition in the family of qualitative methodologies (Denzin, N. & Lincoln 2005).<sup>32</sup> Many writers agree on four key characteristics: it is action based; participatory; builds practical knowledge; and aims to be transformative (Brydon-Miller et al. 2011; Gaventa & Cornwall 2008; Reason & Bradbury 2001, 2006). Brydon-Miller et al. argued that while PAR is part of the broader family of qualitative action research approaches, it can be distinguished by its focus on collaboration, political engagement and commitment to social justice.

Each of the four characteristics resonate with the methodological imperatives of this inquiry: addressing the '*action*' of exploring the change process; the *participation* implied by collaborative investigation; *building the knowledge* needed for a better service model; and the *transformative effect* of enhancing the control service users have over their services. Park's definition connects PAR with this study: 'Participatory Research is action-oriented research activity in which ordinary people address

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<sup>32</sup> PAR's origins have been variously located in the post WW2 work of social psychologists Kurt Lewin and John Collier (Reason & Bradbury 2006), the social movements of the 1970s (Brydon-Miller et al. 2011), liberation theology (Kemmis & McTaggart 2003) and in the growth of community development practices and theory (Kemmis & McTaggart 2005). PAR has been applied across many fields such as health, education, community work, organisational practice, psychology and others.

common needs arising in their daily lives and, in the process, generate knowledge' (Park 2001, p. 81).

PAR is values-based research. Values of equality and human rights underpin the belief that people have the right to have a say in the decisions that affect them *and* which claim to build knowledge about them (Reason & Bradbury 2001). As these authors assert, this guides the assumption that the research participants, as the holders of situational and experiential knowledge, should be placed at the heart of involvement of the research as co-researchers, and that PAR must aim for authenticity in participation through the democratisation of all stages of the research process. It has also been seen as explicitly politicised methodology in the sense that all research is political in either reproducing dominant power relationships in the research dynamic, or finding ways to challenge and change them (Gaventa & Cornwall 2008; Kemmis & McTaggart 2005).

Choosing PAR methodology for this study, therefore, raises the need to select methods that gain 'authentic' participation of service users and service providers, as well as addressing the power and privilege of the researcher in her dual status as researcher and middle manager in the Council microsystem. At this point, it is worth noting that PAR principles of 'democratising the research relationships and production', gaining 'authentic participation' and 'promoting participant ownership' of the outcomes cannot be regarded as absolute or formulaic applications. The operation of PAR is highly contextualised, with the result that it is difficult to generate operational definitions of these principles in action. Some authors have noted that PAR projects involving professional practice are susceptible to particular challenges as there are likely to be multiple accountabilities in the workplace (Wadsworth 2006; Waterson 2000).

### **Contribution of the CDS Transformative Paradigm**

Earlier in Chapter Two, the central ideas of Critical Disability Studies (CDS) were introduced as they emerged in theoretical critiques of the Social Model of Disability. In essence, CDS authors, such as Meekosha and Shuttleworth (2009), argued that the Social Model of Disability in its emphasis on structural change, has failed to represent a nuanced view of disability. These critiques have been highly influential in the development of the 'Transformative Paradigm in Disability Research' proposed by Mertens et al. (2011, p. 230). The central ideas of this paradigm have informed this study, as they provide practical guidance to strategies that can be incorporated into the

PAR methodology, to ensure that the research is 'more attuned to handling diversity in communities, aims to build on strengths within communities, develops solidarity with other groups that are marginalized, and changes identity politics to a socio-cultural perspective' (Ibid. p230). Such strategies are compatible with the aims of anti-oppressive research in the disability field.

Specifically, the Transformative Paradigm has shaped the PAR design here in three ways. First, it shares with Critical Social Work a commitment to the application of critical analytical skills to the consideration of critical social theory, covering many forms of human diversity. From this point, it follows that the PAR aims of participation and collaboration should not be based on assumptions that the interests of people with disabilities are necessarily shared, or compatible. Opportunities for different voices (and thus different points of view) to be heard must be incorporated into the methods of disability research. In this way, the Transformative Paradigm highlights the potential limitations for disability research of seeking consensus among participants (through PAR processes of collective decision making), based solely on their disability status.

Second, the CDS conceptualisation of disability as embodied, experiential and subjective has a methodological implication that research must not 'silence' these aspects and is obligated to use methods that enable their expression. Referring to the discussion of CDS in Chapter Two, this conceptualisation implies that research in the field of disability must seek to uncover a range of aspects of humanity such as psychological, cultural and carnal expressions.

Further, the notion of intersectionality, as the intertwining and interaction of various forms of diversity, is a cornerstone of CDS and an important epistemological perspective for this study. In the view of Mertens and co-authors, its practitioners must 'deploy critical theory in a more nuanced and complex exploration of disability in terms of...the intersection of disability with the social divisions of gender, race, class, and sexuality' (Mertens, Sullivan & Stace 2011, p. 230). In particular, transformative research must express cultural respect, an axiom that necessitates the development of 'cultural competency' in the research dynamic. These authors define 'cultural competency', a central concept in CDS, as a process of researchers building rapport across various groups while respecting difference, gaining trust and critically reflecting on their own biases. This involves efforts to address emerging theoretical frames such as those of indigenous and postcolonial theories.

Critical/Transformative PAR, as it has been operationalised in this inquiry, can therefore, be summarised as: first, participatory and collaborative; second, giving voice to different groups in the community and seeking to develop ‘cultural competence’; third, maintaining a nuanced and embodied view of disability; and fourth, aiming for transformative action outcomes that benefit people with disability. In each of these areas the politics of Critical PAR demand that the research relationships – between the researcher and participants and between the participants themselves – are designed to minimise power imbalances as much as possible. The paragraphs below give a broad outline of how these methodological imperatives were put into practice in the study. More detail about methods is presented later in this chapter.

### **Putting Critical/Transformative PAR into practice**

Maximising a participatory and collaborative approach was achieved by several processes. First, as researcher, I consulted with and sought the advice of people with disabilities through the Disability Advisory Committee (DAC). This was described in Chapter One as a setting where their interests were represented collectively through their role as citizen advocates and disability experts. Two presentations were made to the DAC during different phases of the research. Developing a collaborative approach to the research was therefore enhanced by seeking input from DAC members in an interactive context, where power relationships between community members vis-a-vis staff members and councillors were a constant source of discussion in relation to the Council decision making.

Second, the establishment of a Steering Group consisting of people with disabilities was designed to provide more in-depth advice on research design and conduct in order to maximise informed participation of service users. As a person without lived experience of disability, I was in the minority in this group, a factor that reduced power imbalances.

Third, gaining informed participation entailed the provision of information on the Self-directed Care model using strategies designed for different audiences and for different modes of ‘accessible’ communication.<sup>33</sup> Information was presented both in individual and group settings. More details of the range of communication formats are given later

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<sup>33</sup> ‘Accessible’ in this context means designed to meet the communication needs of people with different types of impairment, for example, people who are Blind or have vision impairment, people who are Deaf or have hearing impairment and people with intellectual disability or learning disabilities. The terms ‘Blind’ and ‘Deaf’ (with capital letters) indicate people who have no sight or no hearing to distinguish them from people who have a degree of sight or hearing. The latter are referred to as having a ‘vision impairment’ or ‘hearing impairment’ (no capitals).

in this chapter. The provision of accessible information on aspects of power and control, as conceptualised in this (generally unfamiliar) model, was important to raise awareness of how power and control could operate in current and future disability supports. It was also designed to clarify why the research was important as a means to inform the Council on how it could improve its service model. In this way power differentials between service users and service providers were directly addressed for both groups as the focus of the research.

Intersectionality was incorporated into the study design by inviting participation of service users and service providers from three cultural backgrounds: Anglo, Vietnamese and Aboriginal backgrounds. Vietnamese residents with disabilities and service providers of a local Vietnamese support agency were selected on the grounds that this was a major population group in the municipality that spoke a language other than English. As this group was not represented through membership on the DAC, the voices of Vietnamese people with disabilities had not been heard in this advocacy setting.

Similarly, Aboriginal residents with disabilities were not represented on the DAC at the commencement of the research. Members of this community group were invited to participate on the grounds that the incidence of disability was significantly higher in Aboriginal communities than in Anglo communities.<sup>34</sup> At the time the Council did not have well established relationships with Aboriginal service providers and therefore these residents' voices were in effect 'silenced'.<sup>35</sup> Inclusion of this community group as participants in the research was an expression of the Critical/Transformative PAR methodological imperative to seek out 'hidden voices'.

The processes of developing 'cultural competence' (defined earlier in this chapter as actions employed in disability research to build rapport and trust while respecting cultural difference and engaging in critical reflection), were therefore different for both the Vietnamese and the Aboriginal participants. For the former group, my existing relationships, built up over many years with local Vietnamese provider agencies, facilitated recruitment and participation and the furthering of ongoing partnerships with this community. For Aboriginal residents and Aboriginal community managed agencies, my relationship with them started with my researcher role, and required strategies to

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<sup>34</sup> It has been estimated that the rate is 2.2 times higher (after standardising for age distributions) for Indigenous Australians compared to non-Indigenous Australians (Productivity Commission 2011, p. 533).

<sup>35</sup> Approximately 300 Aboriginal people live in the municipality, and ten Aboriginal-controlled organisations are located there.

build rapport and gain trust from the beginning, rather than building on established partnerships.

Incorporating the Critical/Transformative PAR principle of seeking an embodied and nuanced disability identity was addressed by adopting methods that enabled the exploration of subjective meanings of 'power and control', both in face-to-face settings and in group settings. Discussions at the Steering Committee meetings assisted in the application of critical reflexivity in considering how my status as 'outsider' researcher would be likely to reduce my ability to 'hear' and understand nuances in power and control. Advice from the Steering Committee was also sought on the use of methods to minimise power differentials in the research dynamics. More detail on this advice is given below in the chapter section on Methods.

While there was no 'single action' intervention that participants were involved in designing, evaluating and redesigning, the methodology met the criteria of participatory action research for the following reasons. First, the participants were involved in a process of collaborative planning albeit at different levels ranging from providing their views on service dimensions to participation as ongoing co-planners. Second, some participants were fully involved from the beginning in the action research 'cyclical feedback' loop set out later in this chapter in the section PAR research phases. Other participants were able to define and take part in an action outcome in a later phase, as a result of their participation in the Vietnamese focus group.

Strategies to meet the methodological aims of achieving action outcomes were built into the study in several ways. Collaboration with both participant groups (service users and providers) was carried out in order to clarify with them the purpose of the research as an action inquiry. A 'feedback loop' was established to report back on findings to these groups at different phases of the research. Further, other action outcomes were discussed at feedback points and also in focus groups where some action outcomes were initiated and discussed by participants. Critical/Transformative PAR principles of recognising different voices, and avoiding the assumption of shared points of view based on disability status, were addressed by building in processes to discuss action outcomes with groups from different cultural backgrounds separately.

## Methods

### Selection of participants

Participants in the study from the two groups consisted of 11 service users and 12 service providers. The service user group consisted of 6 females (Felicity, Hayley, Kie, Kylie, Ruth and Susan) and 5 males (Binh, Dennis, Kurt, Phil, and Vien), ranging in age from 37 years to 60 years of age. Their backgrounds were Anglo-Australian, Vietnamese and Aboriginal. A range of disabilities were represented in the group, with physical disabilities predominating. Intellectual impairments and chronic mental illness were also represented. All of the service users required disability support services, some receiving these from the Council and others from other agencies, or relying on friends. No-one in this group was in paid employment at the time of participation, although most had been in the paid employment workforce at some stage in their lives.

Appendix A provides short vignettes of each participant to bring them to life as individuals. It also provides details of the focus group participants and Steering Group members.

Individual vignettes of the participants in the service provider group are provided in Appendix B. This group comprised 10 females (Beryl, Carol, Han, Josie, Julie, Nancy, Nina, Pauline, Tinh and Truc) and 2 males (Andrew and Charles), most of whom were in their 40s or 50s and had considerable experience as human services workers with people with disabilities. Four service providers worked in Aboriginal-managed agencies, 3 worked in ethno-specific or multi-ethnic agencies, 1 worked for a disability advocacy agency and 4 worked for the Council.

Purposive sampling, an example of non-probability sampling (Alston & Bowles 2012), was used for selection of all participants for individual interviews and focus groups. Service users were selected on the basis of characteristics relating to residency, level and type of disability, age, service eligibility, ability to communicate verbally, and cultural background. Adult residents (people who lived in the municipality)<sup>36</sup> who were below the age of 65 years were invited to participate. Selecting 'younger aged' residents<sup>37</sup> increased the likelihood that participants' lived experience of disability would be of longer duration, and not be the result of age-related illnesses or conditions. Participants who lived with a level of chronic and severe disability that necessitated

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<sup>36</sup> Excluding those who lived in residential care, as they were ineligible for HACC services.

<sup>37</sup> As discussed in Chapter One, HACC services are provided to people of all ages, but are primarily used by older people over the age of sixty-five years.

assistance in the home with their activities of daily living were invited. They were also selected on the basis that they either received services from the Council, or were eligible to do so. This did not preclude the inclusion of people who received services from another agency, or did not receive any services (although eligible).<sup>38</sup> The necessity to invite participation of non-Council service users resulted from the methodological decision to include cultural diversity from groups that were under-represented in the Council user population, and were therefore, as mentioned before, 'hidden voices' at the time of the research.

Further service user characteristics purposively selected for were the ability to communicate verbally<sup>39</sup> and interest in discussing issues of power and control in their services and lives. In addition, the overall service user sample was selected to include a range of physical, cognitive and intellectual impairments, and those residents from Vietnamese and Aboriginal community backgrounds.

Purposive sampling for service provider interviews and focus group was made on the basis of generating a sample that included service providers from the Council services representing various authority levels in the organisational hierarchy, and service providers from other agencies who provided disability support services to residents of the municipality with disabilities. The overall service provider sample was designed to include those from Vietnamese and Aboriginal community/managed agencies.

### Recruitment

Several strategies were used to recruit service users: invitation to all DAC members; use of contacts through local HACC organisational networks and my work relationships with local agencies; invitation to the Council's HACC service users including the Linkages Case Management program participants; and invitation to Vietnamese participants through their contact with a local Vietnamese agency. Invitations were made in various forms including letter, email and verbal communication.

The importance of communicating with Vietnamese participants in their spoken language in all phases of the research necessitated the translation of all written

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<sup>38</sup> People with disabilities may be eligible for service provided by multiple agencies.

<sup>39</sup> One exception was made: the mother (and carer) of one young Vietnamese adult with intellectual disabilities was interviewed with her daughter and other family members. The daughter's impairment prevented her from communicating verbally. She communicated her consent to take part through non-verbal means by smiling and nodding.

materials,<sup>40</sup> and the use of an interpreter in the interviews and the Vietnamese focus group. A Vietnamese community worker assisted me at all stages of recruitment including facilitating and interpreting interviews and the focus group.

Recruiting Aboriginal community residents and service providers had limited success due to the lack of established relationships. One Aboriginal community member with disabilities, who although not a resident, was a regular visitor to the municipality and had strong links to the municipality in his capacity as volunteer with a local Aboriginal Disability Sports organisation, agreed to participate in an interview as a service user. Contacts were made through him with Aboriginal controlled health and service organisations in the municipality, resulting in a group interview with three case managers (service providers) at one agency. Contacts with the agencies did not result in further recruitment of Aboriginal service users on the grounds that case managers considered their Aboriginal service users were not familiar with the term 'disability', or with disability issues, and that participation would be likely to be confusing or unhelpful to them.

The twelve service providers were recruited for individual interviews from several sources: the Council's Aged and Disability Services Branch; a local disability advocacy agency; a local Vietnamese agency; an Aboriginal agency; and a multi-ethnic agency.<sup>41</sup> Two Council service providers interviewed also attended the service provider focus group. The inclusion of the service provider from the disability advocacy agency was made on the basis of her extensive experience of Victorian council HACC services.

Due to my difficulty in recruiting local Aboriginal service users and service providers, I consulted with Aboriginal disability advocates concerned with state and national networking. This resulted in the inclusion of a Victorian Aboriginal service provider involved in setting up an Aboriginal Disability Network in Victoria in the interview sample, on the basis of her consent to discuss her experience (as provider) of the Self-directed Care model, and issues of power and control in its application to Aboriginal community members.

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<sup>40</sup> Materials translated by accredited translation services were vetted by the Vietnamese community worker who was familiar with the study. He checked the translations for accuracy and altered words or phrases to better reflect the meaning of the terms in the context of the research topic and aims.

<sup>41</sup> Both of these latter agencies were regional and therefore not located in the local area, but provided disability services to the municipality's residents.

## Data gathering

Individual interviews and focus groups were chosen as the methods to gather data on verbally expressed perceptions of power and control in the two participant groups. For service users, they were chosen to elicit qualitative data on their subjective views and experiences of power and control, both in the receipt of their services and in their everyday lives, and how power and control might operate in a future model of Self-directed Care. For service providers, they were chosen to elicit qualitative data on the perceptions of providers on how power and control operated for the service users they worked with and for themselves in the current services, as well as in a SDC model. Focus groups were chosen to enable small group discussion for two reasons: to deepen the exploration of topics raised in the interviews; and to further the definition of possible action outcomes that would benefit participants.

Interviews were semi-structured and conducted in a conversational format, rather than in a more structured, question-and-answer mode in order to facilitate 'voice', by enabling the interviewee to have some control within this setting, and to stimulate exchange of information (Alston & Bowles 2012). The conversational format freed me as researcher to follow leads given by each participant in discussing what was important to them. It was also chosen to enable me to develop a degree of reciprocity in the researcher/participant relationships by engaging in two-way interchange on the interview topics, and to be able to answer questions as well as ask them. As Alston and Bowles (2012) have pointed out, the use of the social work skill of empathy was important in the service user interviews especially where participants were expressing uncomfortable and painful aspects of their lives.

Each conversational interview for service users focussed on their perceptions about: current service use; ideas about 'power and control' in current service use and in other areas of the participant's life; the Self-directed Care model as an alternative service model that promotes choice and control;<sup>42</sup> views on being part of the local community; views on the Council as service provider (where applicable) or on other provider agencies; and any other aspects of lived experience of disability relating to power and control that were important to the participants. Interview topics for service providers covered aspects of power and control in current service systems, aspects of Self-directed Care, and perspectives on cultural fit.

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<sup>42</sup> At the time the interviews the majority of service users (eight) did not have prior knowledge of Self-directed Care.

Interview topics in the form of open-ended questions were mailed or emailed to each participant prior to interview with an explanation that the questions were sent as 'conversation starters'. Each set of questions was adapted according to the stage of the research and the existing relationship (if any) I had with the participant. (See Appendix C for examples of interview questions for service users.) Given a choice of venue, all service user participants, except one, chose to be interviewed in their homes.<sup>43</sup> Service providers were interviewed in a range of venues of their choice such as their agency workplace (Andrew, Josie and Tinh, Truc and Han, Pauline, Beryl and Nancy), their home (Nina) and a café (Charles).

Communication prior to interviews included information on Self-directed Care as well as information on the research aims and objectives. Service user participants were notified prior to the conversational interview that the contribution of their time would be acknowledged by an honorarium (a \$25 Coles Myer voucher).

Consent to record interviews electronically was given by all except two of the service user interviewees (Felicity and Kurt). One of these interviews was held by request in a café; the other, with the Aboriginal participant and his wife, was held in their home. These participants consented to notes being taken of the interview. Interviews varied in length from one to two hours. Post each interview, typed transcripts (some translated) were emailed or mailed with a request for any comments or alterations to be made. Two interviewees responded by email with amendments, clarifications, or commentary on points they had made in the interviews.

Individual interviews with service providers were also conducted in a conversation format. Questions presented as 'conversation starters' were emailed to them before the interview. Each set of questions was designed to cover the same areas as the service user interviews from a provider point of view, and tailored to each agency's specific role and function. (See Appendix C for examples of service provider interview questions.)

Focus groups were included in the methods design to follow the individual interviews in order to enable a setting where group discussion could explore further the themes of power and control (Alston & Bowles 2012). Three focus groups were held: one with English-speaking service users (Dennis, Renee and James), one with Vietnamese-speaking services users (Kie and her daughter Thien, Kylie, Vien and Binh and other attendees listed below), and one with the Council service providers (Josie and Tinh).

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<sup>43</sup> One participant chose to be interviewed in a café.

Questions for each focus group were circulated to participants before the meeting. All were recorded; however, this was not successful for the English-speaking service user focus group due to an equipment malfunction. Successful recordings were transcribed.

All service user interview participants were invited to either the English speaking focus group or the Vietnamese speaking focus group. There was a very low take-up for the former group, as only one participant in the individual interviews attended. The other English speaking focus group participants were DAC members who had not participated in interviews, giving a total of three service users and the researcher.

In contrast, all Vietnamese-speaking interview participants accepted the invitation to attend the Vietnamese focus group. Two of these participants brought along other people (a family member and family aid worker) resulting in a total of nine attending including the interpreter and researcher.

Service user focus group participants were given an honorarium of \$40 in recognition of their time. Focus groups varied in length from one and a quarter to two hours. Service providers did not receive an honorarium as interviews and the focus group were carried out in their paid work time.

It is important to point out here that although two of the focus groups were very small, all groups were clearly structured as focus groups and not as small group interviews. This was done in the following ways: participants were invited to take part as focus group members; a list of pre-set discussion points was provided to each participant prior to the focus group meeting; and the responses for two of the groups were able to be treated as one unit, although it was made clear that to all focus group participants that consensus of views was not a necessary outcome. Further details are given in Chapter Four of the responses of the English-speaking focus group, where the varying views meant that the data could not be analysed as one unit.

### Steering Group

As mentioned above, a Steering Group of service users was established to stimulate 'insider' comment and advice on the research purpose and aims, methodology and methods, particularly from the perspective of how to minimise any discriminatory practices that might arise from my status as a non-disabled researcher. All DAC members were invited to participate. Of the three acceptances, Phil (also an interview participant) and DAC member Beverley attended the two Steering Group meetings,

while one DAC member withdrew due to illness. Both meetings were held in one member's home. The first Steering Group meeting focussed on a discussion of the inquiry's purpose, value, aspects of concepts of power and control, and specifics of communication means. Steering Group members agreed with the proposed purpose of the research and the choice of Critical/Transformative PAR methodology. The second meeting discussed the design of focus groups, aspects of power and control in Self-directed Care, and perspectives of human rights in relation to disability research. Specific advice was also given by Steering Group members in a number of areas, particularly relating to the need for critical reflection of my position as a 'non-disabled' researcher such as: the potentially discriminatory and distancing use of 'People with Disabilities' as a label in communication with people I did not know;<sup>44</sup> awareness of the different perspectives of people with disabilities from that of their carers; ways of deconstructing my worker views on the concept of services and the operation of trust and care; and the need to adopt a contextualised view of disability as related to Western colonisation and global human rights. In regard to advice on methods to minimise power imbalances, Steering Group members recommended some changes to proposed methods that were adopted into the study design. These included: recommending against the use of a PAR co-researcher group (with a mix of service users from different cultural backgrounds) as they believed this would be likely to obscure or silence different voices; recommending against the use of a focus group combining service users and service providers on the grounds of uneven power differentials between providers and users; and recruitment of people with lived experience of disability rather than their family or friendship carers.

### PAR research phases

The progress of the research process consisted of a series of phases incorporating the PAR requirements of collaboration, maximising participation in all processes and facilitation of action outcomes. It was designed to enable feedback to participant groups at various intervals as well as implementation of the data gathering methods. Phase One, the pre-data collection phase, was aimed at preliminary consultation with service providers and service users on knowledge of Self-directed Care and the proposed research topic, relationship-building, and recruitment to the Steering Group. Phase Two, the first data gathering and data feedback phase, consisted of three steps: conducting interviews, convening the second Steering Group meeting, and the second

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<sup>44</sup> As a result Consent forms and the Plain English form were edited to remove disability as a label, and re-titled as 'Consent form and Plain English form for Participants in the Research.'

consultation with DAC members. Phase Three, the second phase of data gathering and data feedback, informed by the collaboration and consultation of Phase Two, consisted of convening the three focus groups, reporting to the municipal councillors and staff, and to other service providers. Phase Four (non-data gathering) resulted from the participation of Vietnamese service users in Phases Two and Three, and represents one action outcome that was generated before the research was concluded. Table 3.1 summarises these four 'linear' phases, and illustrates how the participation of the service users and service providers was extended beyond that of interview and focus groups attendees, and, therefore, how the design included steps to democratise the research process.

**TABLE 3.1: METHODS AND PHASES OF THE STUDY**

PHASE	METHODS
Phase 1 <b>Collaboration and engagement</b> Consultation with key stakeholders, seek advice on research aims and methods, build relationships, start conversations on SDC, and recruit participants.	Individual and group conversations with local service providers of Aboriginal, Vietnamese and mainstream agencies for preliminary exploration of research themes such as knowledge of SDC, different cultural frames of disability, and aspects of power and control.  Presentation to the Disability Advisory Committee (DAC) to seek members' advice on research aims, ethics and methodology.  Set up Steering Group of service users and convene first meeting to collaborate on methodology and methods.  Presentation to the Council staff group on the Self-directed Care model and research aims.
Phase 2 <b>Data gathering</b> Individual interviews for service users and service providers.  <b>Data feedback</b> To service users.	Semi-structured, conversational interviews with 11 people with disabilities and 12 service providers.  Second Steering Group meeting.  Second presentation to DAC meeting to share preliminary interview findings, seek advice on focus group questions, and invite participation in service user focus groups.
Phase 3 <b>Data gathering</b> Focus groups.  <b>Data feedback</b> To service providers.	Three focus groups held: one for service providers and two for service users.  Report made to a councillors' briefing session <sup>45</sup> on research findings and implications for Commonwealth Aged Care and Disability Care Reforms.  Presentation of the research findings to service providers from a range of agencies in the municipality, and discussion of the development of an inter-agency local planning framework.
Phase 4 <b>Follow-through</b> on PAR action outcomes  <b>Data feedback</b> To service users	Establishment and resourcing of the Vietnamese Disability Action Group.  Feedback and discussion of research findings in the context of preparing DAC advice to the Council as part of its response to National Disability Insurance Scheme (NDIS) consultation papers.

<sup>45</sup> This is a formal meeting of all councillors of the Council for the purposes of providing a briefing on current issues through an officer's written report and verbal presentation. It is held *in camera*, allowing councillors to freely discuss and debate issues that are in development and not at a decision-making point.

## Procedures to address ethical issues

### Protecting service users

In this practice-based study the research process was carried out simultaneously with my work duties. Ethical issues were anticipated in regard to the possible perceived (or actual) 'contamination' of my role as student researcher, by my substantive role as services middle manager. At the outset, it is relevant to re-state that the research was embedded in a setting (the council) where every service user was viewed as more than a 'client' and actually, or potentially involved in multi-level roles and relationships with the organisation. Therefore the change in role from 'client' to research participant was supported by the values attached the varying citizenship rights and roles of residents referred to in Chapter One.

Many measures were built into the study to ameliorate any social desirability bias, and minimise the possibility of any resulting harm to service users and service providers. These measures related to the procedures for gaining consent, maintaining privacy and minimising conflict of interest. The strategies listed below were implemented to engage participants as equals and co-creators in the investigation of factors involved in future services planning. Three main strategies to achieve this covered: the use of empowering communication; clarification of the purpose of the study; and the use of safeguards and assurances.

First: throughout the research process steps were taken to ensure that accessible and non-discriminatory communication was used to maximise the capacity for participants to have adequate and easily understood information targeted to their specific communication needs. This was designed to enable them to exercise an informed decision to freely give or withhold their consent to participate.

Communication that relied on sight was sent in electronic text and/or related verbally. A Blind<sup>46</sup> participant received electronic communication in 'plain text' (.txt). A Deaf<sup>47</sup> participant was interviewed with an Auslan (Australian sign language) interpreter. Easy English format (an established language that includes signs, symbols and pictures), was used for people with intellectual disability and was also found useful by Vietnamese participants, as well as translated and interpreted

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<sup>46</sup> Refer to footnote 33.

<sup>47</sup> As above.

communication. All written information was provided in translated format to Vietnamese participants in interviews and in focus groups.

Following advice from the Steering Group, the language used in the Consent form and the Plain English information sheet was amended to ensure that non-discriminatory and 'de-jargonised' terms were used, and that they were addressed to the different service user groups (according to whether they were current Council service users or not). All adapted forms were submitted to the Ethics Committee and accepted on 31 March 2011. Appendix D includes the Participation Information sheet and the Consent form.

Second: service users were invited to take part in a research study about future policy input as a citizen of the municipality. The Plain English information sheet and consent forms stated the purpose of the research was to improve services for people with disabilities and to inform the Council's future service planning. Potential participants were given a formal assurance by the Council's Manager of Aged and Disability Services in a covering letter that their decision to accept or decline the invitation to participate would not affect their ongoing service delivery in any way. This was designed to reduce the perception of adverse consequences for current service users, and for potential future users. The letter included the manager's full contact details should invitees have any enquiries. It also stated that the Council supported the research project so future services could be better informed, and based on well-researched information on how they could assist local residents to fully enjoy their rights to participate in the community.

Verbal clarification was also given as part of the consent process that the research was not designed as a service evaluation study. Although service user participants would be asked to talk about their perceptions of aspects of their present and future services, it was explained to them that this was for the purpose of understanding their views on power and control, and enhancing their role in collaborative planning. Where possible, as researcher, I had telephone, face-to face or email communication with interviewees prior to interviews in order to explain research objectives, methodology and participants' roles.

For those participants not currently using the Council services, there was less likelihood they would be apprehensive that their services could be reduced or altered, as a result of their decision to participate or not. There were potential

benefits in access to more information about disability services that were spelt out in the consent form and addressed verbally.

Third: other security safeguards, such as the right to withdraw at any time and the guarantee of confidentiality and non-identifiability, were also affirmed in writing. Potential participants were verbally assured that privacy would be observed and that all research documents and reports would use non-identifying pseudonyms.

A further protection made available to service users and service providers was the option of choosing an alternative, independent interviewer who would not be associated with the Council services in any way. This option was presented in written and verbal formats. No participant chose to be interviewed by an independent interviewer, indicating that they did not require this distance from face-to-face engagement with the researcher.

#### Protecting service providers

For service providers with whom I had a pre-existing working relationship, the perception of undue pressure to participate and/or fear of adverse consequences would be most expected for those who reported to me as their line manager. In order to minimise undue influence, the purpose of the research was explained at an initial staff meeting (Phase 1 of the study), where information was given about the Self-directed Care model. At this meeting an assurance was given that participation was entirely voluntary, and that a decision by staff members to give or withhold consent would have no adverse consequences for their employment or work relationships with me. In this group setting, staff members were invited to approach me individually, if they were interested in being involved in the research.

Following clarification that the research did not involve any indirect or direct aspects of their work performance review; staff members were invited to discuss any concerns they had with me in confidence prior to giving consent. One staff member whom I supervised requested further clarification. Following discussion about the purpose of the research and the further assurance that participation was voluntary and could be ceased at any time, this staff member accepted the invitation and decided to give consent.

CALD and Aboriginal service providers were offered an opportunity to participate after an initial conversation was held on the nature and purpose of the research.

Because I did not have a prior relationship involving any organisational authority with these providers, it was less likely that undue influence would operate in their decision to give consent to participate, or that social desirability bias would be operating in their responses.

With these measures, the scene was set to involve both groups of participants (as equally as possible) as collaborative planners. Tensions in power relationships were anticipated and addressed where possible. There were many indications that potential harm was reduced by the above strategies. Several people approached me and declined to participate for various reasons, indicating they felt comfortable to exercise the power of saying 'yes' or 'no'. No participant requested an independent interviewer be used. The 'rich' conversations that resulted suggest that the assurance of no adverse outcomes was effective.

Ethics approval was given by the Victoria University Faculty of Arts, Education and Human Development Human Research Ethics Subcommittee on 22/04/2009, valid until 30/03/2011, and subsequently on 31/03/2011, valid until 30/03/2012 (refer HRETH09/23, MEMO\_APPROVAL HRETH\_22 April\_2009\_FA[1] ).

### **Reliability and validity**

In considering the question of validity and reliability, it must be noted that the research was not intended to be replicable, or to generate data that was representative of disability services provision in general or Victorian local government disability services systems in particular. It constituted a snapshot of the perceptions of key stakeholders of an inner-city services microsystem at a critical point in time. In doing this, it has modelled a version of disability services that investigated and critiqued local provision by 'the state' (at the third tier of government), that would potentially be useful in other local settings. As professional, practice-based research, the primary aim was to generate applied knowledge for this setting at a higher level of rigour.

Positivist research design has long associated standards of reliability with replicability, and standards of validity with assurance that the results accurately reflect the operationally defined phenomenon identified. In contrast, the qualitative paradigm has established legitimacy through more nuanced means (Lincoln, Lynham & Guba 2011). This is necessitated by the fact that in the social research field it is accepted that people construct meaning through relational interaction, and

therefore research validity reflects this principle. The words of two authors resonate with this point: 'Any method that obliterates the essential role of emergence, negotiation and tacit knowledge, will not be valid' (Altheide & Johnson 2011, p. 593). In their view, 'quality' criteria for participatory methodology have been forged through aspects of trustworthiness, authenticity and credibility. Lincoln and Guba (2011) regard the central question of validity in participatory and critical paradigms as follows:

How do we know when we have specific social inquiries that are faithful enough to some human construction that we may feel safe in acting on them, or more important, that members of the community in which the research is conducted may act on them? (Lincoln, Lynham & Guba 2011, p. 121)

These authors identify five sources of 'validity as authenticity', all of which can be recognised in this study. They cover authenticity arising from 'fairness' (attempting to avoid marginalisation), from awareness-raising and sharing knowledge, and from catalytic and tactical research outcomes. The rigour lies in transparency about how these aspects of authenticity have been incorporated into the design, and analysis of how well they have been realised. 'Catalytic and tactical authenticity' (i.e. efficacy of the research in stimulating action on behalf of the participants, and informing them of social action strategies), apply in this study as the above discussion of action outcomes has demonstrated. A further point regarding validity is that the research findings remain in the interactional dynamics of the Council organisational setting and are subject to continuing examination and debate over time. The application of the five key elements of change will support the agency of participants to engage in accepting, rejecting and reformulating the findings. In other words, research validity, trustworthiness and ethical practice will continue to be tested into the future.

## **Data processing and data reduction**

### Stages of Data Analysis

Data processing occurred in two stages, both applying a form of *abductive* reasoning, to move from 'first order constructs' (i.e. people's perceptions and explanations) to 'second order constructs' (i.e. the researcher's interpretations) (Blaikie 2007). Induction and abduction are forms of non-deductive reasoning, as they represent learning by examples or instances. In contrast to deductive reasoning where the theoretical premises, if correct, aim to connect with the empirical data so as to support the earlier hypothesised conclusion; the premises

(or examples/instances) of inductive and abductive reasoning assist in building a case, leading to or offering qualified and partial support to the conclusion: the latter growing out of initially 'bracketed' assumptions (which may be 'theoretical' or more 'organically' generated). Abductive reasoning takes the examples/instances further, especially if they are unexpected, by trying to find explanations for and deeper meanings of the observed phenomena (Teddlie & Tashakkori 2011). In qualitative methodology, Grounded Theory constitutes one example of abductive processes (Charmaz 2011). Whilst the methodology adopted in this study is not Grounded Theory, the data analysis process includes elements of abduction as the key points of the theoretical critiques (discussed in earlier chapters), have been referenced in the data reduction process, especially in stage two.

Stage one consisted of initial data reduction by scrutinising interview and focus group transcripts and clustering or 'bracketing' items from participants' responses into categories that 'condensed' into inductively generated *shared meaning*. I applied this first order analysis of the transcripts of my interviews and the focus group notes for each participant group *separately*. I wanted to optimise the uncovering of 'voice' from the different points of view of service users and service providers, bringing the former to the front. I was thus able to identify a number of '*experiential realms*' (my term): five for service users and four realms for service providers.

The experiential realms for service users were:

1. Experiences of living with disability.
2. Experiences of disability services in the local context.
3. Relationships with family and friends.
4. Aspects of choice and control in every-day life.
5. Attitudes to Self-directed Care.

For service providers the experiential realms were:

1. How service providers work within the 'system'.

2. Empowerment and disempowerment in the Council disability services.
3. Choice and control for service users.
4. Organisational threats of Self-directed Care.

These experiential realms were derived partly based on the degree to which they were common concerns for all or most respondents (in each group), or on the basis of the importance of each to respondents who expressed them, even if they were not shared by all. Appendices E and F set out how all the response clusters were bracketed into the nine experiential realms.

At this level of initial coding (data reduction) the experiential realms were largely descriptive. For example, the first service user experiential realm was derived from the negative and positive emotional, cognitive and bodily impacts of enduring impairments, such as pain and frustration, and the positive mental attitudes adopted to deal with negative impacts. It is significant in that the responses were spontaneously expressed by all service users, rather than being directly linked to specific interview questions. The other four realms related more directly to the planned and conversationally introduced research themes.

For service providers, the first experiential realm represented their spontaneous perceptions and observations about how their work is influenced by the current 'systemic' context. Unlike the other three realms, realm 1 identified critical aspects of importance to respondents that were not addressed directly in the interview questions. It comprised four clusters: the role of mediating between the service system and service users, working within a highly regulated system, building long-term relationships, and practising culturally embedded services.

Stage two applied a further analytic process to the materials (largely descriptive) gathered and condensed within experiential realms. In doing this, I combined the data from both groups for analysis. From the process of interweaving analysis and synthesis, six catalytic themes emerged that had discursive potential to inform and stimulate the services planning process, acting as 'transmission belts' between

emerging theoretical/conceptual understanding and practical relevance and application.<sup>48</sup>

The process I used to derive the themes was to compare and contrast the experiential realms for the two groups – seeking common themes, but finding that some experiential realms were particular to service users and not evidenced in the service providers' responses. Given that the participatory/critical methodology focussed the study on 'giving voice' to service users, as a group that were likely to have less power in the services user/provider dynamic, I was not operating under assumptions that their perceptions of power and control relevant in their lives, were necessarily shared by service providers. A further factor pertinent to the analysis was that service users were expressing perceptions relating to personal and sometimes intimate aspects of their lives, in contrast to service providers who were not. The epistemological underpinnings directed attention to the significance of this factor in the analysis.

In summary, my analysis, guided by the participatory methodology, influenced the interpretation to 'discover' themes that were based on evidence of shared insights that could be used to inform a service planning framework. Similarly, my analysis, guided by Critical Disability Studies methodology, led to the interpretation of themes that had 'catalysing' power for service planning in generating greater understanding of the standpoint of the service users.

The catalytic themes were:

1. The personal in everyday life: disability as embodied.
2. Environmental barriers: negotiating the external world.
3. The relational sphere.
4. Institutional barriers to empowering services.
5. The realm of cultural differences.
6. The macrosystemic sphere: personal, relational and institutional interfaces.

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<sup>48</sup> Although primarily a term from chemistry for a substance that accelerates the rate of a reaction, a catalyst also refers to an agent that precipitates change (Allen 1990).

As mentioned before, deriving these themes was influenced by the theoretical frames discussed in Chapter One. The first theme of: The personal in everyday life: disability as embodied (derived primarily from the experiential realm of: experiences of living with disability), resonated with the theoretical critiques of disability paradigms that failed to incorporate the individual impact of impairments that limited personal power and control. Similarly the second catalytic theme: Environmental barriers: negotiating the external world, reflected theoretical perspectives on power and control attained through structural change to external barriers. Catalytic themes four and six connected experiential insights of service users and providers with the barriers to power and control emanating from highly regulated and controlled services, considered in Chapter One as those typical of neo-liberal influenced human services. Catalytic themes three and five were integrative themes that conceptualised relational and cultural aspects of power and control that extended and illuminated the critiques of the Critical Disability Studies paradigm that connected disability to aspects of cultural diversity and interdependency. These theoretical connections and insights are discussed in greater depth in Chapter Five.

I named the themes 'catalytic' rather than 'analytic' as they operate between the realms of theory and experiential reality, addressing the aim of the study (and the aim of the Professional Doctorate): to further practice outcomes, and thus represent 'analysis with a transformative purpose'. In Chapter Four the six catalytic themes are presented and discussed as the findings of the study.

### Reflection on Research Rigour

Research rigour was maintained in the data analysis through applying 'critical distance' and recognising the use of inter-subjectivity in the data reduction. I define 'critical distance' as the capacity of the researcher to stand back from the empirical/experiential data, maintain a critical stance vis-a-vis theoretical influences, and remain open to the emergence of unfamiliar, even uncomfortable or surprising meanings. Maintaining a mode of authentic inquiry requires researchers to expect to be surprised.

Three steps were used to seek maximum critical distance. First, critical reflection about the practice site (the Council) and the critique of the literature as contained in Chapters One and Two enabled a level of understanding (as an 'outsider'), of the

nature of the oppression experienced by people with disabilities in the local setting. Second, my intellectual grasp of this critique was matched by the emotional learning resulting from critically reflecting on my role as a member of the non-disabled majority in this study, especially through discussions in the Steering Group. Third, the quality of empathy was critical towards participants feeling valued in expressing their points of view on personal and, at times, painful matters. As a researcher, my task in enabling the expression of multiple dimensions of disability required the same critical distance during the data gathering and data processing.

Earlier in this chapter I discussed the place of subjectivity in research based on the epistemology of knowledge as a social construct. The use of objectivity, particularly as it applies to disability research, can exacerbate the 'othering' of people with impairments. When establishing reciprocal relationships, inter-subjectivity is to be embraced as a means of exploring difference and shared meaning. Inter-subjectivity creates the dialogical space in which trust can develop in the production processes of the research. In this context, it does not signify over-identification, or the merging of the researcher's interests with those of participants, aiming for the pretence of full understanding and agreement between research partners. Rather it describes a process of recognising the uniqueness of each participant without suspending 'critical distance'.

## **Conclusion**

In this chapter, the epistemological pathway to participatory and critical methodology has unfolded. I have shown how the principles and practices of PAR and Critical/Transformative methodological paradigms have been operationalised in the choice of methods for this study. They have been designed to create space for 'disability' to be explored and understood from many perspectives, particularly from diverse cultural perspectives, in order to avoid assumptions of single identity, and to seek and hear multiple voices. The next chapter brings us into the world of the participants themselves through their own words.

## **CHAPTER FOUR**

### **WHAT WAS SAID AND WHAT WAS HEARD**

#### **Introduction**

In the previous chapter the purpose of the research was defined as generation of data with value in informing the framework for the Council's disability service planning. It set out how the research was designed as a collaborative exploration of perceptions of power and control by service users and service providers. The chosen methodology of Critical/Transformative PAR was selected to enable the inquiry to give people with disabilities 'voice' in their expression of aspects of power and control that had meaning in their lives. The aim of the research was to be able to apply the data from the participants' expressed views to achieving the goal of services that empowered recipients.

Initially the interview and focus group data were analysed and coded separately for both groups into descriptive categories called 'experiential realms'. This was done to reflect the individual perceptions of aspects of participants' lives in the local government setting. Following this preliminary coding the second stage of data analysis was designed to further the interpretation by analysing the combined data, looking for connections between responses across the 'experiential realms' and applying a process of synthesis towards the derivation of deeper meaning. The result of this second stage of data analysis was the generation of six themes that had catalysing (or change-precipitating) value to provide a well-informed base for the Council's transformative service planning aims.

In this chapter the voices of participants are presented as the findings of the study. The chapter commences with an overview of the catalytic themes and clarifies how they relate to the interpretation of power and control. It then presents each theme with illustrative verbatim quotes from interviews and focus groups. The chapter concludes with a summary of the participants' views on power and control through interpretive analysis contained in the catalytic themes.

## Constructing meaning

To recap, the six catalytic themes were named as:

1. The personal in everyday life: disability as embodied.
2. Environmental barriers: negotiating the external world.
3. The relational sphere.
4. Institutional barriers to empowering services.
5. The realm of cultural differences.
6. The macrosystemic sphere: personal, relational and institutional interfaces.

Together they span personal, relational, institutional, cultural and systemic aspects of power and control. Although these themes resulted from the analysis of experiential realms as a whole, not all of them contain responses from both participant groups. The first three themes emerged from responses made by service users only, indicating the importance to them of bodily aspects of disability, barriers in the physical environment and the nature of relationships in furthering or impeding their sense of power and control. The perceptions in these three themes relate to subjective lived experience of disability and therefore they are not shared by service providers. These perceptions consist of views spontaneously offered by service users in response to open-ended questions about power and control in their lives.

The remaining themes were integrative as they include perspectives from both service users and service providers. The responses were more directly concerned with current service experiences and views on the potential future service model of Self-directed Care. Participants in both groups expressed views that were analysed and synthesised into Theme 4: institutional barriers to empowering services and Theme 5: the realm of cultural differences. Theme 6: the macrosystemic sphere, integrated not only the responses from both groups, but also linked the first three

themes as interface issues with the macrosystem. (This system was undergoing changes in national disability reforms during the course of the research.)

The analysis of responses to the catalytic themes takes into consideration theoretical insights discussed in Chapter Two. Both empowering paradigms of the Social Model of Disability and the Human Rights approach, contrasted with disempowering aspects of the Medical/Professional Discourse, were theoretically influential in the interpretation of service user responses contained in Themes 1, 2 and 3. The neoliberal frame, as applied to managerialist human service practice and to the Self-directed Care model, underpinned the derivation of Themes 4 and 6, which combine service providers' and service users' responses. Theme 5 relates to the Critical Disabilities Studies theoretical conceptualisation of disability as a multiple and intersecting identity.

It must be noted that catalytic themes are not discrete or mutually exclusive categories, but are interconnected, overlapping and intersecting. Cultural perspectives, for example, were interwoven into all of them. Although they have been discussed previously from the point of view of 'difference' in determining how non-majority cultural beliefs differ on specific issues, cultural perspectives should also be viewed ontologically, leading to a 'world view' on 'everything'. They have, therefore, been identified as a catalytic theme in their own right (Theme 4) so as to fore-ground certain significant, indeed 'catalytic' differences in practice. Addressing and highlighting cultural insights in this manner was considered to be more helpful than discussing them only in the context of comparisons with the Council mainstream services and practices, part of the majority, hegemonic discourse. The aim of developing a higher level of 'cultural competency' – a key aspect of Critical/Transformative PAR methodology – was better served by bringing forward minority views rather than treating them only as comparative considerations.

### **Theme 1 – The Personal in Everyday Life: Disability as Embodied**

All service users responded to the interviews and focus groups with frank comments on the 'dark' and 'testing' side of impairments and disability. Theme 1, which contains responses only from service users, showed how their bodies and minds were affected by stress from many sources on a daily basis. For some people, however, surviving chronic pain and frustration was assisted by the cultivation of a positive view of their lives in a broader context of the 'disability services' system, nourished by the experience of long-term paid employment, and

expanded life choices that this enabled. Some service users were familiar with exerting choice and control in their current lives; others felt they suffered lives of highly restricted choice and opportunities, especially where lack of familiarity with the Australian culture and language limited their access to information and resources.

### *Pain and stress*

A powerful aspect of living with disabilities was indicated by the fact that all service users commented on the negative emotional impact of living with chronic pain, daily frustration and stress. Dennis, who suffered from fibromyalgia syndrome, articulated his experience of constant pain as:

*'The best way to explain it is your pain levels are high on a daily basis and it's like a car alarm that's stuck, blaring away and you can't turn it off. Physical things, sweeping, or typing or playing piano, or anything repetitive – vacuuming kills me. I just can't do it. I have to go to bed after that....So it has a big impact on my life, but I remind myself every so often – because I need to, particularly when it's hard work and you're really grumpy. I am managing this very well and give myself a big tick because you have to do that, because you can get some depression coming in because of the things you are doing, which is just part of life really.'*

Five participants spoke about feelings of anger and fear; others described the impact of loneliness and poverty. Some spoke of the frustration of encountering barriers to full enjoyment of life by being unable to shop alone, to take holidays and go on spontaneous outings. For example, Susan said:

*'My best mate Dave, who has a mental illness and is jobless, still manages to go out and to parties and go to gigs. ...I've not done anything like that for maybe ten years. ...It just terrifies me....There's a chapter in a book, Day of the Triffids called "world narrowing" and that pretty well sums up my life – you know?... I get more scared of people as I get older'.<sup>49</sup>*

Social isolation was a source of painful feelings for some. Vien,<sup>\*50</sup> who used a wheel- chair, stated that he was on his own and did not join any groups. In answering the researcher's question about what he did for pleasure, he replied:

*'Only when it a sunny day I just go out and just wheel around and then come back home on my own.... It's like, because it's my situation, it's lonely...but what can I do? With everything I do, it seems like I can't have money so I just give up'.*

<sup>49</sup> All italicised narratives in this chapter are taken verbatim from the transcripts. Non-italicised insertions in square brackets are made to clarify content of a quote.

<sup>50</sup> The asterisk is used to refer to an interpreted interview. As all quotes are verbatim, interpreted responses may include incorrect grammatical expression.

Binh described experiences of loneliness, insomnia and memory loss following the effects of a stroke he suffered ten years ago:\*

*'So sometimes I get the pain on my hand and frequently forget things like go out and forgot to lock the door... My wife and my children, they left me here and then they go away. So it be very lonely...so sometimes I get a sore head, so really hard to sleep, ...and I feel that a lot of things in my life are hard...'*

A source of anger and frustration for one participant was the effect of increased impairment on her sex life. She demonstrated through actions her loss of hip rotation, and commented on her weight gain and decreasing mobility. Commenting on a series of hip operations that had not worked, Susan shared a joke: *'That's a nice pair of legs! When are they opening?'* She then described her own situation: *'I can't get my legs apart now. I don't think I will ever be able to get a "shag" now'*. Perhaps the most extreme negative emotion was that expressed by Kylie, whose disability related to chronic mental illness. In regard to the periodic attacks of schizophrenia and depression, Kylie said:\*

*'Every time I get sick I get a shock on my nerves. So every time this happens I wouldn't go, do anything. I wouldn't go anywhere, just stay at home on my own and...hmm...the world to me is quite painful. I want to give up my life as well'*.

#### *Adopting a positive attitude*

Five service users expressed attitudes and behaviours that revealed their resilience in dealing with negative impacts of their impairments. For Ruth, who has quadriplegia from a progressive muscle wasting disease, this was indicated by her positive attitude: *'Well I think I'm just, I've just been lucky. Cos I'm sure other people aren't as lucky in different councils and different arrangements'*. For Felicity, her participation in high level paid employment for many years led to a sense of achievement. In the context of describing how she chose to actively avoid stress and pain where possible, she said: *'I have a life to lead and work to do. I have a fulfilled life. I don't want more bureaucracy, I have friends'*. Others described the sense of personal satisfaction they achieved in getting a desired outcome. In this sense, it was not just optimistic attitudes that were demonstrated, but problem solving capacity, strategic thinking, negotiating and influencing skills. For example, in relation to how she deals with the Council in finding a worker to match her needs, Hayley commented:

*'I am stubborn. I have to be. It's like if you can't do the big things, it's like you have to appreciate that you can do the little things, and if the little things are getting through a day of lots of appointments and being organised and following up on things, then that's what you get self-appreciation for. It definitely kind of narrows down my...it limits me a bit with who I can get, when I can get them, and to an extent that.... I think I have the capacity, I guess to negotiate and work those things out, and I have the flexibility that if I can't get the person I want for food prep when I want them, I might get someone else that I am happy to have.'*

These comments indicated strengths through cognitive and relational means that were mentioned by six service users. Overall, in Theme 1 the service user's comments revealed embodied aspects of impairment that ranged across emotional, cognitive, sexual, social and material impacts. For some, the negative effects mentioned by all were mediated by the adoption of a positive orientation and the exercise of personal influence.

## **Theme 2 – Environmental Barriers: Negotiating the External World**

Physical barriers, including inaccessible features of the built form and of transport modes, were mentioned as sources of restriction for two service users. They were, however, significant factors in their sense of lack of control over the environment. The effects of these barriers defined here intersected with negative emotions highlighted in Theme 1, as they constituted an ongoing source of stress.

Dealing with the physical barriers to moving around freely was experienced as lack of control over many areas of daily living. Service users remarked on limitations on choice of housing, inaccessible buildings, dangerous public transport, poor taxi service, and inaccessible community facilities. For one service user, inaccessible public transport and unsafe taxis were the source of feelings of impotence, because it led to constant restrictions on travelling to places and events. Susan said:

*'Well this place here – it's really hard to direct a taxi to. I really dislike the whole disabled taxi thing, being strapped into a cab just scares the B'Jesus out of me. I can't direct people. I don't have a sense of direction'.*

She also commented on the difficulties of using public transport:

*'What would give me more control over my life is a transport system that was actually...with stations that were actually staffed, and trams that were actually staffed. That's what would give me more control.... Disabled loos, they're locked, they're always locked except at Flinders Street. They're locked in the underground because they're afraid of junkies. I can get the key, but guess what? Hey, I can't unlock the door!'*

Binh also commented on lack of control over taxi transport. Taxi drivers refused to drive him the short distance of approximately one kilometre to the local recreation centre. Binh remarked:\*

*'I go to (the Council) Recreation Centre, but the taxi wouldn't drive me over there. Very short distance. I have to walk over there; it takes me about forty minutes to go over there.... The driver is not very good, you know. They just want to take customer for long distance like to Footscray or Sunshine.'*

The fact that these comments were volunteered by service users in the context of interview questions about how they experienced power and control in their lives indicates that physical barriers were an important, limiting aspect to them in reducing their sense of control. They experienced the effects of structural barriers arising from inadequate planning, design and operation of the built form they felt they had no influence to redress. The environmental barriers reduced their ability to lead independent lives and make choices about where they lived and how they carried out social and recreational activities. The implications for disability support services are that ignoring this source of limitation on independence could reinforce assumptions of dependence by service users.

### **Theme 3 – The Relational Sphere**

Similar to Themes 1 and 2, Theme 3 contains responses initiated by service users themselves rather than being directly addressed in interview questions. This theme shows that the qualities of relationships varied within the group of services users. Some spoke of enduring and supportive familial, friendship and community bonds; others expressed the loneliness of losing family members, and their ambivalence in relying on friends for day care support. Relationships with local paid carers were also valued highly by some users as they were seen as multidimensional, containing both nurturing and practical qualities. As well as these aspects, four service users identified a sense of strength and capacity through the skills they exerted within their relationships with paid carers, to influence their behaviour in ways that resulted in a better outcome for their care. The availability of reliable and trustworthy relationships, both unpaid and paid, was shown in service user responses to be important in adding to their sense of control. Where these were missing, responses indicated a sense of need and vulnerability.

#### *Family bonds*

Six out of eleven service users spoke about their close and supportive family relationships. Four service users did not have close family ties, and one had a very ambivalent relationship with her parents.

Five service users referred to their experience of lack of family support including: family relationships experienced as ambivalent – swinging between destructive and protective over a lifetime of disability; dislocation of families in the refugee process, resulting in having no family members in Australia; separation following experience of family violence in the context of chronic mental illness; and family separation as a result of onset of impairment. Three out of four Vietnamese participants, all of whom lived in high rise public housing, expressed the impact of disability as restricting social and family life. They spoke poignantly of the effects of the double disadvantage of social isolation and language barriers, both compounded by the effects of poverty.

Family relationships were fraught for one interviewee of non-CALD, non-Aboriginal background. Throughout her interview, Susan described passionately, using expletives and strong gestures, her feelings about her conflicted relationship with her father. She saw this as stemming from her congenital disability.

*'I don't know. I've always felt lesser. My folks have always treasured me, but they've always made it abundantly clear that I'm the disabled child, you know. If I wasn't the disabled child I would have fucked off to the UK long ago. And because my folks played such flagrant favourites with their children, it stuffed up my brother's life a bit.....But if he [Susan's father] stops and he's hassled by someone collecting for the Spastic Society, he'll say: "I've got a disabled child" and there's me in the front seat and I'm forty-three or whatever, or if someone's nicked the disabled spot at the car park there at Nunawading Station, he'll immediately write to the Council and say look at my poor disabled daughter, and it's like I'm not a fucking adult. Ooooooh, he loves me, Ro, he does, and I love him. That's the real cunt about it all.'*

In contrast to this account of fraught family ties, Kurt described the strong Aboriginal community bonds of acceptance that embedded his family in a dense network of relationships.<sup>51</sup> He spoke about the care and support he receives from the community in regard to his own disability, and the daily support he and his wife provide to their adult child, who has an intellectual disability, and her family. Kurt and his wife described how they assisted her as often as needed (sometimes daily) with financial and other advice, and helped to avert crises.

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<sup>51</sup> Note: this interview was not transcribed resulting in lack of direct quotes.

Responses from Vietnamese participants were mixed. One interviewee, who is the carer of her daughter, described her own close family ties and friendships within the neighbourhood Vietnamese community. Close family relationships were not available, however, for three out of four Vietnamese participants. Kylie, Vien and Binh remarked on their lack of family support due to the impacts of migration and disability. Kylie spoke about the effects of leaving behind her family and experiencing violence from her husband after settling in Australia. In her words:\*

*'All my family's in Vietnam...and when I came to Australia I got a divorce...because of his behaviour from me, like the violence on me, and all kinds of things...did not care for me...and other things. So when I get the mental illness my husband likes to still do more violence on me and does the bad thing to me.'*

#### *Friendship bonds*

Close friendships were mentioned by six participants. Five either did not mention friends, or spoke of the difficulties of maintaining friendships because of the impact of living with disabilities, or feeling lonely and isolated.

Friendship relationships were significant for Vietnamese participants who did not have family members to help them. Vien, who does not receive personal care services, spoke about his very close friends, who came nearly every day to help look after him. They had his door key and could also come any time he had an emergency or was unwell. Vien said: \* *'They come and help me cook. ...Anything I need, my friends will help. I can still do some cooking, and sometimes, between five and six they will come.'* In contrast, Binh mentioned that his friends occasionally helped him clean his flat when he asked them to; however he commented: *'Before when I was healthy I had a lot of friends to come over here, but after the accident my friends are leaving me'*.

#### *Relationships with paid carers*

In contrast to the sometimes fraught nature of family and friendship bonds, service users' relationships with their paid care workers were generally spoken of positively. Four out of five service users of the Council services identified these relationships both as a source of comfort and care, and as an opportunity to exert influence to achieve a particular outcome – a source of personal agency. Service users spoke of the benefits of continuity and reliability of their paid workers over

time. Paid workers were described by one service user as 'sort of friends' who were able to meet her emotional, social and physical needs. Ruth explained:

*'They don't patronise me, and they come valiantly and help me every week, and they're always there. So they're doing two things. They're keeping my spirits up, they're keeping me feel connected, and they're keeping me clean and checking my underpants and other things like that. They underpin everything I do, as a safety net, an enveloping kind of support.'*

Hayley spoke about a range of qualities that she valued in her team of paid carers and that indicated a source of reciprocity:

*'Yeah their personality, their friendliness and then, you know, some younger people are really fresh and interesting, and because I'm young, I can fit in with the younger people. And then some older people – I had a nice Greek lady here today who I pick up a lot of her Greek, kind of characteristics with her speech patterns, and I end up speaking what I consider Greek for the rest of the day!'*

Two service users spoke of occasions when they actively took responsibility to change the relationships in some way over time, or to influence an outcome.

Hayley described how she intervened when one paid carer ate food that was not paid for while shopping with her in a supermarket. Hayley said:

*'I had one naughty little carer who is now on my "never ever" list because she used to eat her way around a supermarket and, when we get to the register she just neglected to pay for things. And I talked to her first and tried to problem solve things, kind of "in-house" as I like to consider, and I tried to point out that that was not very appropriate and, whether it was how she chose to do things or not, it wasn't something that she should be doing in the work environment. And my conversation with her, which I thought was quite friendly and well-intentioned it got me nowhere, and so the next step was I talked to the normal person I would talk to in the office and they said they would talk to her. And it didn't come back to me through the carer, but the behaviour didn't change. ...In the end I asked for the manager at the supermarket and actually asked for her to say a little thing I had scripted, which was to give her a little bit of an adrenalin rush, a little bit of a shock: "Don't do this, I don't do that I don't want anybody associated with me doing that when they're out with me". And then she decided to take a piece of me as we were going around a supermarket shopping and I don't get her anymore. And it's like I didn't want her to lose her job, I just wanted her to know that her behaviour was not appropriate and to not do it.'*

Like Hayley, Dennis felt empowered to intervene directly within his relationship with his paid carer. He explained how he remonstrated with a distracted worker who was not paying attention while providing personal care in driving him to the shops.

*'I'm dealing with pain on a daily basis; I get very tired and cranky and I have to manage that. I would never be rude to a worker intentionally. The only person I spoke to one day said: "Look, please concentrate on what you are doing!" and*

*there was another young guy who – and I obviously will not mention names – but in the conversation he seemed to have been dealing with depression that was one of his things...and I realised there was stuff going on and he was driving me to go shopping, right? So I was in the car with him. And you'd say "Oh turn left at the next one" because we had to go past the library on the way, and he would turn right so he wasn't with what he was doing. ...I didn't yell at him but it was probably a little sharp. ...and suddenly he snapped out of it and really started to focus on what he was doing. ...I thought, okay I'll work with him and see where we are. And he's very obliging um, and I thought okay, it's coming back on me now to manage this thing, and to just ask him will you dust this, will you do this, and be a bit more managerial.'*

Another service user spoke about using his personal qualities to mould his relationships with paid carers. Phil reflected:

*'Yeah, and that I think it gets back to personalities. So if I was a mean bastard it would be much more difficult for people to want to come and be happy when they're helping me. And I know many people who are, you know, quite abrupt in the things that they ask people to do. I try not to be that myself. Yeah, and I don't know that compliant is the right word, but certainly I'm happy unless I'm specifically not happy for some reason, and that's very rare. So mostly, you know, anybody comes along I'm quite happy to see new people, as long as I know they can do the things I might need done. ...Well, yes, and that works both ways I suppose, where if I yelled at people, you know, when something happened or whatever, I rarely do that. I mean, sometimes I do get insistent about asking for something to be done, and yeah, I'm mindful, but I don't want to put people in any occupational health and safety problems.... There's sometimes a conflict that comes in of people with the medical model or the welfare model where "I'm only going to do certain things", and on the other side of that my needs for something different at that particular time, that's what I need'.*

Catalytic aspects are therefore contained in the recognition of the value of nurturing relationships (where these were available) to people with disabilities in this study; in those relationships that enable the expression of reciprocity over time, and that include opportunities for service users to exercise influence and change behaviour in their interaction with paid carers. Service users were dependent on family, friends and paid carers in ways they were well aware of. They expressed their views about what would help or hinder these relationships. And they expressed a sense of independence and took conscious control in many ways by steering their relationships with paid carers in a certain direction. The majority of the Council service users expressed a sense of empowerment in their relationships with their paid carers.

Relationships with paid carers were carried out in the interface between service users and the institution. The next theme deals with powerful aspects of institutional

policy and practice that have determined many of the qualities of relationships between service users and service providers.

#### **Theme 4 – Institutional Barriers to Empowering Services**

The extent and nature of institutional barriers to local services were a major concern to service users and service providers. 'Institutional barriers' here refers to the operations of organisational policies, procedures, and practice and covers primarily the Council as a provider organisation. Although there were factors in the current services mentioned by both groups that mediated the barriers to some extent, it was clear that impediments to the provision and receipt of empowering services arose from many sources. Service users identified problems with the inflexibility of the rostered services model and lack of acknowledgement or understanding of the nature of dependence within the lives of people with disabilities. Cultural aspects compounded these barriers. Service providers identified similar barriers from their perspectives. Responses from the Council providers indicated they were troubled by service procedures that controlled entry, operated within an 'over-reliance' on Occupational Health and Safety measures, and limited access by users to information about services.

##### *Service barriers from service users' point of view*

Of the six service user participants who described aspects of their experiences of the Council's service provision, the majority (four) were positive about what they saw as the benefits of local services; one found them wanting, and one spoke of positive and negative aspects. They expressed views about valued aspects of the Council services that covered perceptions of greater efficiency, continuity, professionalism, proximity and accountability. From their perspectives, the provision of local services removed barriers by making them accessible and answerable.

Ruth, for example, commented on their efficiency. In describing how the paid workers work together, she said:

*'They do get together and discuss different cases. They time themselves between people. They do have experience about what's available locally and they provide a service that's probably unique and once it's gone, you can't put that back. ...it's just because of having this unique configuration of having your local care workers who do have 15 minutes of travel time between each person...and they provide you with the local flavour as well. ...cos a lot of their work is getting from a to b as well. And getting there on time and having a clear head and remembering what they are supposed to do'.*

Hayley commented: *'Yeah...your carers – they've got the commitment and they get the regular work and they know they will be well looked after.'*

The benefits of proximity and accessibility of the Council paid carers, other staff members and councillors, were mentioned by Ruth. She described how reassured she was that her paid workers were part of her local scene:

*'I've been talking about the workers themselves being local...they're just there, and, most of the issues I face are to do with where I live. Most disabled people – you don't roam far from home...that's why it's really nice to have that accountability. It might be a bit of a nightmare for local council, but it still is really nice to have that much smaller emphasis.... I think the accessibility of councillors here is very good.'*

Dennis's comments on how much he valued his ability to directly approach the Council to sort out difficulties also showed how much local accountability mattered to him. He said:

*'There is a system that's working at the moment. Hmm, you do know that you can ring up the service provider, and you do know, as I did eventually having dealt with it for quite a while, that I could then go to the Council and say: "These are the problems – who do I speak to?" And then you have another process in there, and it is answerable'.*

Two service users, both of Vietnamese background, did not agree. They spoke in their interview about their unsatisfactory experiences of local services. They described the services as lacking in flexibility, both in the limited type of support and care tasks that were permitted, and in the lack of capacity of the Council services to respond to fluctuations in their need. This factor constituted a barrier to them in obtaining in-home support. Vien spoke of the inadequacy of the Council services he had tried unsuccessfully:\*

*'I know about these services, but the time they come it's just one hour or two for a week. And they cannot do very much home care, cooking or shopping. It's not enough for me. So it's just better for me to ask my friends to help.'*

In discussing her frustration that the Council services were not available to her on an irregular basis when she became acutely ill, Kylie said:\*

*'I have no-one to support me here, so sometime I need some help.... Every time my mental illness happens, I would like to go out to buy some food, but I can't do it. So it means I have to, yeah, get the noodle packet.'*

Both service user focus groups gave more in-depth information about service barriers. Members of the Vietnamese focus group shared their deep concerns about their lack of information about disability services in general, and their perceptions of the gap between what they needed and what was available. There was general agreement within the group that they did not know if they could access the types of services that met the scope of their particular needs. These included assisting them to handle official documents in English, providing emotional support as well as physical care, and operating in a way that was sensitive to their slow pace. Vien stated:\*

*‘So talking about, for example, the time effectiveness that compare between the normal persons and the disabled persons when we’re doing some tasks, this requires more time for the disabled person to be able to complete that task. .... So like, for example, when we receive someone come and provide the support, we might need a lot more time’.*

Participants in the Vietnamese Focus Group wanted disability services from different providers to be more integrated and synchronised with each other. Kie said:\*

*‘And secondly when we’re talking about the day care centre or the other outings services, it requires the connection, you know, like all the agencies need to work together when they provide the support for the person.’*

Binh noted the potential detrimental emotional impact on people with disabilities when services were not available:\*

*‘...at the time they might find it’s really hard to deal with the problem and they don’t have any support person to help them, they might give up and they just let go. And they might lose confidence or cannot help themselves, that’s the problem.’*

Vietnamese focus group members were critical of the view that people with disabilities should be independent and look after themselves. While noting that it was good that some people were able to be independent, Kie pointed out that this did not apply to all:\*

*‘But on the other hand for my point of view, I see that about 80% of disabled people who are really frail or very disabled, who cannot help themselves, or they require a lot of support, and the carers who have to be very patient, or have to understand the person so that they can help or provide directions on their daily needs. And alongside, they need to work with the care manager, the case manager, to be able to better support the person’.*

Other focus group members agreed that an emphasis on independence could create a barrier to services.

In discussing their shared concern about lack of access to information, Vietnamese focus group participants agreed they did not know where to go for specific assistance to install aids such as hand rails and other home adaptations. This systemic issue was complex for most participants because they lived in public housing. As tenants, changes such as installation of home modifications necessitated their communication with several government levels and departments. Communication was further complicated by language differences, as well as the lack of clear and translated policy on public tenants' rights and entitlements. Kie made the point that lack of knowledge impeded service access and the realisation of rights. She said:\*

*'When we talk about our right to receive the services, you know at the moment few people know really well about the system, and that they can access into both the state government and the federal government services and support, whereas many people, they are not aware of the services and they can't receive it.'*

In their discussion of the Council as service provider, members of the English-speaking focus group<sup>52</sup> expressed varied and contrasting views. Renee believed there was trust in local government to '*do the right thing*' and to employ high quality workers. She stated her view that local government demonstrated a responsibility for the whole community, and on this basis it should continue to provide services in the future. Focus group member Malcolm disagreed: he said he did not like the Council services because he found them too inflexible, as he could not commit to being at home at a certain time to fit in with rostered services. He went on to say that he had a positive experience of a non-'Council' centralised disability service that supplied aids and equipment around the state. He was delighted with the efficient and effective service given in replacing his scooter. On this basis he believed that centralised services, such as the NDIS, would work better than localised services (i.e. council services). Malcolm questioned the role of local government and said that it did not keep its promises. He believed that its commitment to people with disabilities was in doubt as the Council did not reveal how many people with disabilities it employed. Other focus group members Rebecca and Dennis did not agree with this point of view.

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<sup>52</sup> Few direct quotes are given for this focus group as it was not recorded successfully due to equipment malfunction.

### *Service barriers from service providers' point of view*

Responses from the Council service providers indicated their concern that institutional barriers or impediments disempowered them from meeting the needs of residents with disabilities. Andrew described Council HACC services as having:

*'a relatively rigid scope of services or tasks, so at the moment we're in control of those aspects, and do that in the context of the whole service.... At the moment we have responsibility and the client becomes...while they're important to the service, they need to fit in with the overall parameters of rostering etc., and how many showers can you do at eight o'clock in the morning or whatever.... So, yeah, at the moment we retain that power about saying what we can do and can't do and I assume that over time clients and residents get accustomed to that, and therefore we may get less requests than actually is out there...because we condition people to what's possible. And then there's an acceptance perhaps of: "I won't even try that. I know from experience that they can't do it within 24 hours etc., so the negative impact is that they have the care perhaps when they're not really wanting the care, so that's not right care at right time, really"'*

Tinh agreed about the tightly specified dimensions of the tasks: *'so, for example, we'll take personal care and we'll have a list of personal tasks that can be done under personal care; we can do this but we can't do that....'* Josie commented that, as case manager, she was frustrated she could not currently get Council HACC workers to provide the needed services after hours.

Andrew pointed out that the Council service providers retained control over access to information about the extensive rules and regulations of its HACC services. He reflected:

*'Now, I think a lot of the rules that we work to at the moment we hold on to, and how many of those we have out there, documented well and truly for the consumer to pick and choose from? Again they could be looking at something to know what Council can or can't do quite clearly. We probably, at the moment, retain a level of that knowledge ourselves, and it's only on request that people learn what right they have to change them.'*

In the Service Provider focus group, the primary topic the Council service providers wanted to discuss was their shared experience of the effects of working in, as they perceived it, an inflexible service system constrained by resource limitations. The participants gave many examples of situations where this factor affected service users negatively. These covered: the service's inability to provide specific language speaking care workers; its rigidity in being unable to vary the tasks within the care plan to suit different needs on different days; and its failure to meet service user

preferences for service delivery at certain times. In discussing how she attempted to accommodate these preferences, Tinh said:

*'Whenever a client asks for a specific language speaking care support worker I tell them "We can only guarantee you a service, we cannot guarantee your worker".... So we actually make the client suit our needs instead of we suit the client's needs.'*

Josie observed there was a tendency for the Council's services to seek to exert maximum control over paid carers. She said:

*'Yeah, I think it's about wanting to be perfect and having total control over what's happening with the workers because of fear of whatever's happened in the past, I don't know. ....it's a fear that, when you're managing that group of people, you try to pull in and have all these restrictions that they must do this, they must do that, they can't do this, they can't do that – protecting not only the workers but also wanting to have control of them.'*

In her interview, Carol, a service provider of a statewide, non-Council disability advocacy organisation located in the municipality, gave a strong critique of her perception of the disempowering practices of HACC services provided by Victorian local authorities. While these criticisms were not specifically of the Council, they resonated with the critical comments of service providers discussed above. Carol's advocacy experiences led her to say that councils in general: demonstrated insufficient knowledge of the effects of different types of impairment; made it difficult for people with disabilities to access services they were entitled to; were too bureaucratic and not person-centred; and worse, they were both discriminatory and operated within a welfare/charitable ideology.

*'Local government is the worst as a bureaucracy – you have to prove your needs. You need to open the door, not just put hoops in place. Local government needs to stop making people beg or make them feel guilty for asking. People are sick of having to prove they have a disability. This breaches HACC standards of treating people with dignity and respect. ....Always in service providers' and governments' minds is [the fact] that people will abuse the system.'*

In contrast to this negative view, the Council service provider Andrew reflected on some aspects of the HACC services he believed were empowering for service users:

*'HACC services enable people to remain at home. That's an advantage for them. I'm also thinking that obviously service provision and independent carers enable some distance from family and friends doing particular activities or tasks*

*for individuals...without having all of their immediate family and or friends knowing everything of their business, so it gives them another level.'*

Second, Andrew commented on his view of the empowering aspects for service users related to the political nature of Council as a service provider. He believed that they could expect that it would be accountable as a level of government to resolve problems. Service users were empowered, in his view, through the potential of elected representatives to represent their interests and advocate on their behalf.

*'I had a situation just the other day where a resident who indicated significant arthritis and back pain etc. was having difficulty accessing the local community health centre GP, and was having to travel because they have a wait[ing] list or couldn't provide the GP services. And she wasn't happy with that arrangement, and the travel was in fact causing her great difficulty because of the back pain etc., yet the health centre was just around the corner. So she came through her local councillor to complain about that situation, who referred her to me, and then I worked with the health centre in seeing what the issue was with access, to be clear on that now. We just had a good outcome yesterday on that, because they've been able to make the service accessible for her, and so she has utilised her local government contacts etc. to achieve a good health outcome.'*

Theme 4 has therefore demonstrated that institutional barriers to services were mitigated to some extent in the Council services through their perceived qualities raised by service users, of high quality, efficiency and reliability, as well as accountability. Most service users found local services empowering. This point of view was not shared by Vietnamese service users, two of whom had found the Council services too limited for their needs. All of the Vietnamese service users experienced further institutional barriers with the general lack of accessible (translated) information on disability resources.

While the Council service providers shared the view of service users that strategies for local accountability provided some power and control in resolving problems with services, they also felt disempowered through their experiences of the HACC services. They linked this to features of service rigidity and tight control. In their eyes, these aspects were disempowering for service users as well. This view was reinforced by the responses of a service provider of a local advocacy agency in her perceptions of local government HACC as too bureaucratised.

The institutional barriers identified in this theme have catalytic promise, drawing attention to what aspects can be maintained to further empowerment and what must be addressed to minimise them.

## Theme 5 – The Realm of Cultural Differences

As already discussed in earlier catalytic themes, Aboriginal and Vietnamese service users identified cultural aspects in their particular experiences of service barriers, in their relationships with family, friends and paid carers, and in their focus on their personal realm. For the Aboriginal service user there was a sense of security in being embedded in an inclusive community that did not distinguish people on the basis of being categorised as 'disabled'. For all but one of the Vietnamese service users, their responses suggested a sense of alienation and isolation. Families were absent, negotiating the boundaries and expectations of friendships was difficult, and to compound this, information was not accessible.

CALD and Aboriginal agency service providers confirmed these responses. Both sets of providers recognised the profound differences between the beliefs and experiences of Aboriginal and Vietnamese service users and those of mainstream Anglo-Australian background. In their view they underpinned every aspect of their reaction and that of their service recipients' interaction with the broader disability services system. As revealed in the responses below, service providers further expanded on how attitudes to the concept of 'disability' were culturally defined. In the case of Aboriginal people, the term was seen as an individual identifier that conflicted with collective community membership. Likewise, for Vietnamese people, the socio-political beliefs and experiences of their country of origin conflicted with those of their adopted country, and resulted in the disability services system being virtually incomprehensible to them.

All CALD and Aboriginal service providers identified a number of characteristics of their service users that interacted with features of the service system and exacerbated the effects of other barriers to services. They said it was common that the people they worked with had little or no background knowledge about how the system worked, and had great difficulties in grasping its dimensions when explained to them. In the case of Vietnamese-speaking people, not being fluent in English compounded the incomprehensibility of systemic features. Vietnamese service providers Truc and Han talked about the difference in the educational background of people born in Vietnam to those educated in Australia and the consequent barriers to understanding arising from illiteracy. The gap in experience was huge as it covered not just educational differences, but lack of familiarity with the Australian welfare and political systems. As Truc explained:\*

*'....we have got a totally different system over there, everyone fend for themselves, and we have no welfare system; everyone when they get sick they go to hospital...and they don't have the social safety net like we have here, so people really don't understand their rights, they don't understand the system and they don't know the language'.*

Speaking in the context of working with different language speaking groups Nina commented: *'I think that the critical thing is...for many people, the service system is just so bamboozling...so that for a lot of our families just even finding a way in is so complex'.*

Case managers of Aboriginal services<sup>53</sup> spoke also of the barriers of lack of understanding of the complex service system. They explained that the chronic and severe poor health of most of their service users, caused by conditions such as Acquired Brain Injury, mental illness and dementia, impaired their (service users') cognitive capacity to learn and understand unfamiliar concepts as well as their physical wellbeing.

Reflecting on the impact of different understandings of 'rights' in the Vietnamese culture, Truc spoke of the effects of growing up under the Confucius doctrine, where the authoritarian regime underpinned private and public life. She believed that this cultural belief that conformed to authority was internalised.

*'And culturally they live in that regime; they live in the authoritarian system, Confucius system or doctrine – the order, the community order, the order in the family, the order in the society. So they always have to be obedient to the authority. So the way they are brought up and the cultural belief that way, that's internal, not rational.'*

Han expressed her view that people were disadvantaged in Australia because of this experience, and because they were unaccustomed to having human rights in Vietnam, and were therefore unlikely to be able to assert their rights in Australia.\*

*'so they come here and they don't know their rights that they have in Vietnam, and now they are going to stand up with the way they've already been brought up to be obedient. So if you asked them to stand up to advocate or speak up, I think that is very hard to find'.*

Both Aboriginal and Vietnamese service providers commented on the rejection of the term 'disability' in their communities. Aboriginal case manager Pauline stated

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<sup>53</sup> The group interview with three case managers of an Aboriginal agency was not recorded. Notes were taken (by consent) during the interview.

that in the Aboriginal community: *'disability is nothing.'* Another Aboriginal service provider Julie reflected on one source of community discomfort with acknowledging disability. She stated there was still a stigma attached to the term 'disability' in the Aboriginal community because of the fear that many Aboriginal families had, that their child with disabilities might be removed from them if they sought out or received services.

Vietnamese service provider Han spoke of the reluctance of community members to discuss issues of disability. She said: *'Yeah, even the family, they don't want to talk about that with others so the issue of connecting with other services is even more difficult.'*

### *Culturally embedded services*

CALD and Aboriginal service providers described how these factors were taken into account in their culturally embedded services. These were characterised by two main elements: creating an enabling interface between service users and the system, and creating flexible programs that were holistic in nature. In regard to the first characteristic, CALD and Aboriginal service providers were clear about how they mitigated the effects of service barriers by adopting a mediating role between their service users and 'the system'. In order to do this they had, at times, to act as buffers, and carry out a 'protective' role to screen people and make decisions on their behalf.

First, service providers spoke at length about the importance of their 'bridging' role to mediate between, interpret, facilitate and cushion the operations of macrosystems in a culturally relevant way. In respect to working with Vietnamese service users, Truc said: *'I think in order to help them you have to go to the middleman always: the middleman who knows the rights and who cares.'* The difficulties of the system seemed to be taken for granted as service providers did not mention their role in regard to changing it. Rather, the emphasis was placed on the intention to build a close and enabling relationship between service users and service providers. As Nina commented in regard to how she and her colleagues worked in her organisation: *'This is very much about developing a sense of trust and rapport with the families, and I guess being a bridge to the service system and how the service system works.'*

Advocacy was also seen by these service providers as individual case advocacy, rather than systemic advocacy. Aboriginal service providers Pauline, Beryl and Nancy expressed a sense of responsibility for protection of service users, particularly in regard to money management and possible financial exploitation. The forced separation from family ties and support that many service users had experienced as members of the Stolen Generation meant that providers felt a strong responsibility to build this support through their services. The poverty and lack of resources experienced by their service users shaped the protective nature of their relationships. Pauline pointed out that the case managers needed to be the conduit for information as many people could not read. In commenting on the gulf between Aboriginal-controlled services and mainstream services Pauline described the latter as *'white-fella way'* and *'gubba shit'*.

Both Vietnamese and Aboriginal service providers described the imperative in their practice of aiming at countering the compartmentalisation of service activities by integrating programs at the institutional level. Their responses indicated that their idea of 'holistic' needs included addressing the range of physical, social, emotional, cultural and spiritual needs of individuals. It also covered the idea of people not as disconnected individuals, but as social beings inextricably linked to their family and community life. As Nina stated:

*'What's going on with the person, with the disability, what's going on with the primary care, what's going on with the extended family; we make sure that all are part of the planning and review process, and where there are conflicting needs that we've identified, then we have a conversation about those...'*

As a case manager in a Vietnamese agency, Truc said: *'so we not only provide the care, the practical care, but we pay a lot of attention to the emotional and social'*. In this way the culturally embedded agencies deliberately broke down boundaries between the institutional realm and the personal realm, by broadening the sphere of attention from the disconnected individual to the relationships (both family and professional) of the social sphere.

Power and control in Theme 5 have been illuminated from the perspective of cultural difference, as perceived by Aboriginal and Vietnamese service providers. This theme has catalytic promise through the alternative modes of culturally embedded practice described in their words above. Based on their knowledge of the significant cultural differences between their community member service users and Anglo service users, these service users have developed roles in their service

to act as buffers, protectors, and advocates to enable the complex services system to be navigated. They have described ways they avoided 'compartmentalisation' by ensuring their service meets needs holistically, and works with service users as family and community members, rather than as disconnected individuals.

## **Theme 6 – The Macrosystemic Sphere: Personal, Relational and Institutional Interfaces.**

Theme 6 includes responses from all participants covering perceptions relating to macrosystemic change, based on their views of the (hypothetical) implementation of the Self-directed Care model. It builds on the earlier catalytic themes and reflects interconnections between them.

Analysis of the responses reflects how service users and service providers have engaged with the macrosystem through three levels or 'interface'. The first interface (between the personal and the macrosystem) contains service user perceptions of how they would personally be affected, ranging from possible detrimental effects of exacerbation of stress, to potential positive effects of having greater choice and control. The second interface (between the relational realm and the macrosystem) also covered service users' perceptions of likely impact on their current and future relationships. The third interface (representing the institutional or organisational impacts of macrosystemic change) covered service user views on the connection of human rights to organisational change, as well as service provider views on the broad ranging impacts of organisational change towards Self-directed Care.

### *Interface between the personal and the macrosystem*

While service users spoke both about their anxiety that SDC could cause detrimental personal effects, such as increased stress without the guarantee of in-built, practical backup; some were also excited by their hope that it could enable the employment of friends and neighbours as known and trusted paid carers. Other service users were concerned that SDC might detract from a broader view of individual life planning, if it were seen as an 'end' rather than a 'means'. SDC was therefore seen as potentially diminishing individual power and control if it was imposed, and did not ensure that ongoing support was available on demand. It could also increase individual power and control, if it increased real choice of carers and part of life planning that addressed structural barriers. Service provider comments also concurred with views of potential benefits to service users, by

increasing their (service users') power to have more individually tailored, holistic and integrated plans.

Expanding on the components of the first catalytic theme (the Personal Realm of Everyday Life), responses from five service users noted potentially problematic implications of the SDC model. Three commented on the likely detrimental effects on them of the added administrative load. They asked how the government would require accountability for services expenditure and what level of documentation was required; and, how people would be able to develop the skills needed to employ their own workers. Felicity, who described her earlier experience with individualised funding models, commented that she would not choose SDC for herself, because it would add more stress to her life. She wanted to be able to make a choice in favour of leading a fulfilled life, which included time for paid work and spending time with friends. She did not want to deal with the responsibility for managing, and being accountable for her paid workers. She saw this as potentially harmful in her self-management of the debilitating effects of her paraplegia. Felicity stated: *'I want to keep confrontation out of my home and keep stress low key.'*

Phil addressed the likely difficulties in managing one's services:

*'I mean their choice obviously might be then to go out and hire their own people, but that's a lot harder...it sounds very easy to do, but that's very hard to do, particularly because you've got to have a few skills in being able to find people, organise people....'*

Dennis added:

*'And you may well have people who are dealing with pain on a daily basis – I mean, this is not a considered opinion, but a thought, you might say "Well I don't really need to be doing all that as well, because the current thing is simpler".'*

Two service users questioned whether resources would be readily available for backup in the event of problems in SDC self-management. Dennis reflected on his current relationship with Council where he had made input in the past into policy and practice regarding his services. He valued the opportunity to influence 'the system' by giving feedback. Over time, this had clarified his understanding of how the Council services worked, and given him confidence in being able to contact Council when he needed help. He asked: if he were to choose self-management of his services, how would he deal with problems?

*'Supposing I was using that model, and I was finding someone to do the cleaning and take me shopping and stuff. Now if it happened to – I'm not thinking of a specific incidence – go off the rails, who do I talk to to help get it back into a workable system? ... I know I'm going to need someone at some point to talk about it with.... just to bounce off, even if I don't necessarily get them to do anything, it's just sort of advice and a person to mull it over with.'*

Members of the English-speaking focus group also touched on these points about the interface between their personal situations and the macrosystem. They all shared a concern of how they would be individually supported under SDC in regard to ongoing backup such as accessing locally employed case managers. Dennis questioned who would be there to help if the scheme fell over. Malcolm wanted to know how people would be able to complain, if the new system did not work, and what rights they would have to be heard. Rachel had a positive suggestion for the role of what she called '*an inter-communicator*' to translate and interpret the new model.

Vietnamese service users however expressed positive views of the personal impact of Self-directed Care. Vien and Binh, for example, welcomed the idea of having more say over what they could spend their personal budget on. They said they would prefer to be able to choose to purchase items such as entertainment, alternative medicines (e.g. acupuncture) and taxi travel, rather than personal and home care. Vien: '*I think it's a very good idea that we can have more money to support our situation and we can manage it for ourselves*'.

Kie expressed the benefits of being in control of prioritising her daughter's needs. She noted that the model would be potentially very efficient for her. She said:\*

*'One more thing, sometimes people, they know a lot of different services so they might not use the new model. But for myself, my situation, I know my daughter very clearly and I know her needs very clearly, so I can use the money to provide, to get the services for my daughter very quickly and straightforward. So I know which one is the first priority and which one is last. Which one is most important.'*

One service user Ruth, a trained economist, discussed in detail her views on choice and control in the 'market' of disability service providers. She gave an example of choosing her own aids and equipment within the existing system where she was allocated a fixed budget. Although she was well able to consider options and make an informed choice, she described the complexity of this process, when this choice was intended to last for her lifetime, yet many of the critical factors involved in the choice were unknown to her. She did not know how quickly her

needs would increase, or what new products would be developed. Ruth acknowledged that although it seemed to be a simple process: *'to me it's one of the most difficult decisions...'* She related this experience to the issue of increased choice by service users, to supply and demand in the market of services. It was clear to her that choice was restricted if there were too few providers. She said: *'if there's nothing to choose from then there's no, there's no upside for the disabled person.'* She pointed out that in a situation where supply was low, prices could rise. This also would reduce choice for service users. Ruth believed that changes in the providers' market, resulting from the employment of family and friends as paid carers, could have a detrimental effect on local services.

*'If I was a carer at (the Council) and you gave everyone, all the clients there, a budget and some of them said "Oh," as I'm sure they may, "I'll get my mother-in-law to do the cleaning"....or whatever, and they would reduce demand for [the Council] and [the Council] would say: "Oh good, we don't have to have these people on our books", then they'd drift off to other areas and there wouldn't be the kind of local supply of carers available locally to drive around and do [service] a number of local people. Maybe they'd come back if the demand was big enough, but it would probably end up going to agencies and that service would disappear because there wouldn't be the critical mass of people, and once that service wasn't on offer, then people wouldn't know that that's what existed.'*

Further elements of the SDC approach, as a market-based model, were raised in the English-speaking focus group. Both Malcolm and Dennis commented on the disadvantages (as they saw them) of increased employment of low paid workers with CALD backgrounds. They agreed that they had found paid carers with different language backgrounds hard to understand, not able to speak English, and were apt to 'cut corners'. They feared that CALD workers would come in to take the jobs of local workers. Malcolm related this to the operation of a 'global slave trade'. At this point, Rachel presented her opposing view that CALD workers had a lot to contribute to disability care.

Four service users spoke of their grasp of disability services within a broader policy context. All four had worked for many years in government departments. Their life experience and extensive knowledge of the disability service system, as a whole, gave them an ability to conceptualise aspects of 'disability' from a variety of systemic perspectives. Felicity was aware that not all shared this quality: *'A lot of people living with disability don't see the big picture. They can be isolated and dysfunctional, and move serially from one provider to another'*.

Felicity's 'bigger picture' perspective led her to conclude that disability service providers, in non-government organisations, in particular, were prone to focus too much on service delivery models, to the exclusion of addressing structural barriers to participation. In her opinion, the consequence of this narrow view was that service providers failed to address all the life barriers in planning for service users. Felicity commented:

*'Services planning is not around Self-directed Care. It is how we develop aggregated plans for a meaningful and enjoyable life. Individual plans should be about this and used as a vehicle so that systemic issues can be addressed and the repeated masking avoided.... The plans should be based on a dream – "I will live independently" – in this sense attendant care is the beginning and not the end.'*

#### *Interface between the relational and the macrosystem*

A range of nuanced views were put by service users in regard to the interface between relationships and macrosystemic change. Some saw positive outcomes from SDC that could strengthen existing relationships, while others would not chose to involve family and friends as paid carers. How relationships with existing paid carers could be affected was raised by service users. Again, responses were nuanced – varying from potentially empowering effects to potentially negative ones.

Service user responses illustrated each person's consideration of the possible impact on their existing relationships, and their wish to preserve the qualities of these relationships. Among the four interviewees who expressed their perceptions of how SDC would be likely to impact on their families and friends as potential paid carers, both positive and negative impacts were raised. One service user already relied on friends to provide unpaid daily support and care as his HACC services were not sufficient. For him, there would be great advantages in being able to pay his friends for their care. Another interviewee, who also had friends who volunteered their help occasionally, did not wish to risk exploiting this friendship. As Binh said:\* *'Because my friends just came here to visit me, so I just ask them for help a little bit, but I don't want to ask them too much. So I don't want to take advantage on them.'* In contrast, Ruth had close family bonds with her husband and grown-up son, but did not see it as beneficial to employ them as carers, as she thought it would add to existing stress in the family:

*'I would be very loath to involve my relatives in that kind of arrangement. It just adds to the pressure cooker. Maybe different families – families are different. And the carer allowance works I think, because it goes straight to the carer and*

*so it softens the situation. But I don't know whether it increases the tension in a family, to give the power to the person whose disabled, you know what I mean? You know I like the idea of giving people who are disabled the control over the funds, but in the situation where they can sack someone, but they can't get anyone else anyway, well they can't sack them cause they pay their uncle or their aunty, well the tension's even....it would compound their lives, lives that are already complicated.'*

Kie saw great benefits in being able to choose to employ trusted friends to provide services to her daughter who has an intellectual disability. She said:\* *'... once I keep the control of the money, I can pay for who I really know ... so that person very clearly would not do anything that harm to my daughter.'*

Comments from four interviewees on the likely impact of the SDC model on paid carers, demonstrated their concern for *their* interests in systemic change. These responses indicated awareness of reciprocity in their institutional, interpersonal relationships. One service user Dennis, who said he was aware of the risks of worker injury from manual handling<sup>54</sup>, asked who would be looking after the workers to help them avoid occupational health and safety risks. Another interviewee Phil saw potentially positive outcomes. He contrasted the restrictive conditions for paid workers in the current, traditional system with potentially more empowering relationships with service users in the SDC model. In commenting on his relationships with his paid carers, Phil said:

*'You know, where there's an organisation between you and the person, the allegiance [of the paid carers] is to the organisation, and for them to do anything outside the box they need to be directed by the organisation to do that. Well, it is because then you've [the organisation] got to get too prescriptive about what and how to do things.'*

In his view, SDC would counteract this, because service users would direct them to prioritise their needs. He believed that service users would also be empowered, as well as paid workers in the SDC model, as they would manage their own workers by clearly defining the parameters of their tasks. He continued:

*'And what you need is people to,... we need certain boundaries to be as flexible, and thinking about that,... what you want from them is that if they're asked to do something that's unsafe, they certainly say "No, look I can't do that, that's not safe" or "Well, I can't do that because I don't have the time to do that".'*

*Interface between institutional realm and macrosystem*

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<sup>54</sup> 'Manual handling' in this context means moving a person into different positions with or without mechanical aids, when they are not able to move themselves. It requires the application of physical strength and can lead to injury.

Service providers engaged with issues concerning macrosystemic change. Many responses were lengthy, reflective and nuanced. Most service providers demonstrated their primary focus on institutional impacts, but also spoke of impacts on service users. In regard to the potential 'fit' of the model to Aboriginal and Vietnamese service users, CALD service providers' comments indicated significant cultural differences between these groups and non-CALD service providers. Two service users gave responses that connected empowerment in macrosystemic change with the potential of human rights practice to influence organisational change.

Considering the service users' responses, one service user Ruth referred to SDC as a 'necessity' and a 'right' for people with disability to have self-determination. However, in her view, this right was not sufficient in and of itself to empower people with disabilities, because of the reliance of the model on the structures and operations of the services market. In contrast, service user Phil connected the issue of increased power and control over decision making for people with disabilities with the necessity for organisational change (at the macrosystemic level), to implement human rights in everyday services practice.

*'And, as I said, although many organisations ....have taken on a very philosophical "Yes, residents' rights come first, we believe in the Human Rights model", when it actually comes to the implementation of that, then organisational needs and then staff routines and staff whims, I suppose, can impact on that. So it's not something yet you can say....it's good to have this philosophy and that filters down, but it's something you need to be constantly on guard to make sure that you're fulfilling it. You know, it's not just a matter of saying "Oh yes, we have this in place therefore this is what we do".'*

In answering the researcher's question as to whether this situation would be different under the SDC model, he said:

*'Well, it won't be different. The only thing that's going to make it different is that there's a gradual shift in thinking and commitment, otherwise it won't be different... If there's not a shift in the commitment of organisations to actually respond to the human rights model then it's just doubling up of funding of the same old problems that we've had before.'*

In order to illustrate his argument, Phil discussed the issue of the right to be deemed competent to make decisions in one's interests. He described how the

rights of people with disabilities under the CRPD<sup>55</sup> were curtailed by the actions of professionals exercising ‘Duty of Care’.<sup>56</sup> In his view, professionals say:

*“Well, we need to decide for you what is going to harm you”. When things are decided for you in your best interest, the right is taken away from you to decide for yourself.’*

When asked if case management could work within a human rights perspective, he replied:

*‘Where case managers are overly worried about subjecting people to risk and protecting their own back...then I think that’s where it comes into conflict. And that’s probably what the old system was about, because case managers are not only protecting their own, making sure they don’t make risky decisions, but they’re doing it on behalf of the organisation as well.’*

Service providers were concerned with different issues in the interface between macrosystemic change and institutional impacts. Their responses indicated they questioned the survival of their organisation if SDC were to be implemented. They talked about service changes that would erode their resource base, responsibilities and legitimacy. These included: the effects of possibly working in a mixed model (part organisational-controlled and part service user-controlled); losing control over their block funded service budget; losing management responsibility to address service quality and protect workers; and the impact of losing their organisational ‘discretionary effort’.

In service providers’ responses ‘discretionary effort’ referred to the ability of organisations (under the traditional model) to carry out activities that were not directly funded, and were outside of unit output control and therefore unregulated. They were seen as necessary to engage with people needing the services in order to remove barriers and smooth the pathway into services. As described by providers in both Council and ethno-specific and multi-ethnic agencies, they were ‘discretionary’ in the sense that they required the exercise of professional judgement and planning, and in some cases, putting in place programs to diversify

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<sup>55</sup> CRPD Article 12: Equal recognition before the law: 2. States parties shall recognise that people with disabilities enjoy legal capacity on an equal basis with others in all respects of life.

<sup>56</sup> Duty of Care is a term within the human services field to describe legal and professional responsibility for the wellbeing and safety of the ‘client’. Duty of Care can lead to the professional taking protective action on behalf of the person, with or without their consent.

relationship-building between workers and service users, and between service users. External service funding guidelines did not recognise or fund these activities although they required organisational budget expenditure and staff time. Service provider Charles spoke about the hidden nature of this non-funded aspect of services. He said:

*'It's the discretionary effort of organisations, it's the, you know, effort of people around...the individual...that would be lost... You know the service system, if you look at the funded service system, it's that big, if you look at the real service system it's, it's that big! And it's all that other stuff in the grey area that's not able to be costed, not able to be recognised in that sort of conventional model.'*

Nina gave an example of the discretionary effort of her multi-ethnic organisation designed to foster a sense of group belonging. The program she described was also a good example of holistic planning, mentioned above.

*'And the thing is that when services are provided it's more than just, there's more than just that service transaction...it's also something about having a sense of belonging to something as well, ...One of the things that we chose to do with our program was to...set up some of what we called "cluster groups" or "activity groups" which brought together some of our people with disabilities around shared interests and activities, some on a regular basis, weekly, others more on an occasional basis. .... We were trying (to)..... build on that extended family model where people have come from an acknowledgement that people with disabilities are so isolated, and carers of people with disabilities are equally isolated.'*

Service providers, like service users, were concerned with the increased 'marketisation' of disability service provider agencies that a SDC model would rely on to expand purchasing choice. Service provider Charles reflected on the possible detrimental effects of the application of a competition-based market system on small scale disability service providers such as the Council. He referred to the 'frailty' of this system that would be threatened by the transaction-based model of Self-directed care, which he described as:

*'...chunks of cash shifting around...threatening the viability of organisations. And you know maybe organisations' viability should be threatened if they're not delivering services, but is the market the right mechanism to do that?'*

In his view, the existing service provider system would be vulnerable to annihilation in a market-driven environment because of the small size and smaller resource base of many agencies, the entrenched way of operating, and their consequent marginal status. He also commented on the indirect effects on provider agencies of what he called: *'the unconscious nature of the market'*.

He said:

*'I can't see how it would work except for making the sector more anxious and...and, yeah, less motivated and...if there's no certainty,....the programs are not making huge profits, and you know there's no motivation, so....if it becomes more marginal, or if it's reducing or whatever then, yeah, you can see how, how the bottom will fall away.'*

At the same time as raising organisational threats of SDC, other service providers also acknowledged some potential benefits of the model for service users. They considered the aspects of service user choice and empowerment from the perspective of how institutional change could remove barriers to choice and control. They considered that user-control would lead to more flexible and individually tailored services. Service users could integrate their own services better than the Council could, because it (the latter), practised within an organisation-centric perspective. As Andrew expressed it:

*'At the moment we probably see ourselves as the service for the individual but, in fact, they're getting many other services or many other aspects to their support. And perhaps we see ourselves as being too central to that whole process; but in reality there's a whole other range of other players in their lives and (that) just turns that over.'*

Here he referred to the benefit for service users in the Council providers seeing themselves as: *'just one part of their choices about a whole life....'*, and also in being able to make choices about whether they invested in their physical care, social care, or learning. Andrew commented that the Council might be taking that choice away from people by determining their service priorities for them.

Another Council provider discussed potentially better avenues for people with disabilities of gaining influence over decision making, such as through Council advisory structures, or through direct political activity as an elected representative. Charles raised the comparative advantages and disadvantages of these as models of empowerment. Despite his concerns that service user advisory committees at a local government level, were generally not well resourced, he concluded:

*'So I think that if you work from an empowerment model, which, you know allows the services to be as effective and efficient, and respond to policy and deliver quality services, but have a range of audit functions coming from above, but also audit functions coming from below.....that's, I think that's where it would be, it would be more effective, you know, you'd have strong advocates from people with disabilities, or their carers or whatever, having a real voice in... in how the organisation's operated.... without threatening their viability. And, obviously,*

*there needs to be... and I think it's a bit like the governance stuff, you know, or the citizenship stuff. That if we were really serious about it, you wouldn't be doing it through a transactional model at a service level, you'd be doing it at a governance level.'*

He goes on to say that the way the political system operates has significant barriers to empowerment:

*'Yeah, at a policy level, at a governance level and what have you....but, in fact, that's where you start meddling with real power, so in many ways I think that ....the thing about the political process, ...it's quite excluding. You know, ...it is gerrymandered towards political parties so... And political parties themselves are quite...you know, prejudicial and they favour a particular style and type of person. ...and to be elected at any level in, in Australia... it's a party driven system, and the parties themselves are totally unrepresentative. They're not, you know, particularly democratic. They would say that they're democratic, but they're not democratic... There are a very small number of members choosing who is going to be...you know, the party candidate, and what have you and it's...yeah...and you think about the real power in state or federal government. It rests with a very, very small number of people, you know the majority of people are back benchers, silent, get no say whatsoever apart from on a committee from time to time, and maybe a trip in spring time if you're lucky. So, you know, from...yeah, so, from a political process, and local government's just the same, you know, that,.... it's very rare, like we have a very active disability advisory committee, and they are influential, but influential to a point.'*

In regard to the interface between macrosystemic change and their institution, service providers from Aboriginal and CALD agencies commented primarily on whether the model would be compatible with cultural values. Vietnamese service providers Truc and Han commented that the SDC model would perhaps suit Vietnamese people who were middle class, educated and knew their rights; however, it would not suit their service users who did not understand the service system as it was now. Truc said:

*'But people who have no understanding, no language I think it just doesn't work. ....with certain clients we can imagine that they would be: "What's going on? What am I going to do now"?''*

Han agreed: *'Yes, that is the worry, they may use the money they have for the other purposes....'* Both service providers were concerned with the negative institutional impacts on their work as case managers. They believed that the SDC model would in fact involve them in more work as 'middlemen' than the current system. This would possibly lead to more inefficiency and greater costs in service delivery for their service users. Truc said:\*

*'I think it may end up costing more that way, because, if like, take a very simple example, if we're a case manager we arrange services directly to that person, and then we do all sorts of things, you know, payment, everything, within ourselves. In the future we will help that person to buy services from other organisations or something. So we arrange for this person to buy, and we will take more time to do it, that way that we have to accrue the information here and there and, rather than within ourselves we do the whole thing very quickly, now we have to go this way, that way. It's really complicated and [takes] a lot of time and energy'.*

Other CALD service providers had a less negative point of view, perhaps related to the fact that they had had experience with user-controlled services in the past. Nina described a situation where she had worked as a case manager with a service user (M)<sup>57</sup> on an ISP<sup>58</sup> who, along with his family, was empowered to ask questions of another agency's use of his ISP funding. Nina said:

*'And in the end they, you know, got a very good outcome in terms of more resources coming to M, they made clear informed choices about how they were going to handle the money and they actually nominated the facilitating organisation to handle the money.'*

The Council service provider Tinh (of Chinese/Vietnamese background), presented an alternative view that SDC was in fact compatible with Vietnamese cultural values of favouring negotiation between neighbours and friends. She said:

*'And back home [in Vietnam] we didn't have service providers, we didn't have manufacturing. It's all very informal, you organised with your neighbour, never an issue. So it's similar – informal and a system already set up. So they use the social network.'*

The three Aboriginal case manager service providers saw great difficulties in applying the model to the Aboriginal community. In their experience, their service users needed intensive contact from case managers, and would be unable to self-manage their services. They were seen as potentially vulnerable to financial exploitation by community members who expected that those who had financial resources would share it with those who did not.

Julie, an Aboriginal service provider who worked as an advocate for Aboriginal people with disabilities across the state, spoke of her experience of the application of the ISP model to Aboriginal service users in a regional town. In discussing this version of SDC, Julie raised many concerns. She stated: *'A lot of the community*

<sup>57</sup> Initials given in this quote rather than the full name of the service user as recorded.

<sup>58</sup> ISP (Individual Support Package): a form of SDC provided as a part of the Victorian State Government specialist disability services (see Chapter One).

*does not have any idea about advocacy and therefore they don't quite see the idea of self-determination.*' From her work with a regional Aboriginal Services Cooperative, she had found that Aboriginal people had little comprehension of the system. However, they did need to have choices about services. Some people did not want to use the services of the cooperative, but relied on it for information about how the services work.

She believed that there was a lack of consideration by mainstream Victorian State Government providers of Aboriginal cultural practices in their current application of SDC through ISPs. Julie said there were very few Aboriginal people on ISPs. For one recipient of an ISP she had spoken to, the knowledge about the program was imparted to him by his Department of Human Services contact person, who did not, in her experience, have relevant cultural knowledge about who was the service user's culturally accepted spokesperson. Julie gave some detail of how the self-management aspect was perceived by community members:

*'Aboriginal people on ISPs want to know why they don't get the full amount of money in their hands. They do not understand what the money is to be used for, what is the scope of things the money can be spent on, what services cost, and do not understand that an administration cost (\$3,000) will be taken out of the ISP allocation total e.g. \$15,000. The DHS Disability officer just told the ISP recipient that it was for accommodation and help with fishing. The DHS Disability officer did not have sufficient cultural knowledge to help the Aboriginal person plan for what they needed; for example, what cultural activities it could or should pay for. For example, it could pay for activities on the weekend, but services are not open on weekends to provide the support needed. Also there was an expectation that friends and family will "take you there" and help out with transportation etc.'*

She said that ISPs could work if people had information about the value of the money and what it does not pay for.

Julie noted another feature of cultural incompatibility – the use of paid carers from particular cultural backgrounds. In her view:

*'most personal care assistants are migrants. This is not appropriate for Aboriginal people. There can be a bad match. New Zealand carers should not be put with Aboriginal clients as the cultures are not compatible. NZ and Pacific Island First Nation cultures are more oppressive, and can be more dominant than Aboriginal cultures. Also Arabic workers are not a good fit as the cultures are not complementary.'*

Theme 6 presents complex and nuanced views of power and control. Both service users' and service providers' responses showed that they appreciated that

potentially empowering aspects of Self-directed Care coexisted with likely negative effects (i.e. threats to the viability and autonomy of provider organisations such as the Council). Both groups commented on empowering or disempowering outcomes for themselves and on others such as the paid carers in the microsystem.

Increased power for Vietnamese service users was linked to the possibility of increased control over budget expenditure and determination of one's individual service priorities, and over increased choice of employment of trusted carers. For non-CALD service users, however, power and control could be reduced rather than enhanced, if Self-directed Care added an unwelcome load to their lives, or failed to have adequate backup support built-in to the services model. Service providers also commented on potential benefits for service users of SDC affording them more decision-making power over their individual services plans, and by reducing the level of organisational control such as that referred to in Theme 4.

## **Summary**

In this chapter, service users and service providers have spoken candidly and passionately about aspects of their lives and their work that matter deeply to them. Their views are varied and heartfelt. In most cases they demonstrate their ability to think of the needs and interests of others in the dynamics of the services microsystem, while reflecting on their own, intensely personal experiences and views of how they wield power and control, and what, for many, repeatedly stops them from doing so.

Individual voices have resonated with the theoretical and discursive aspects of disability addressed in Chapters One and Two. In this chapter, we have heard Ruth's words speaking of the local: 'Most disabled people – you don't roam far from home'. Phil's words have revealed relational insights: 'If I was a mean bastard it would be much more difficult for people to want to come and be happy when they're helping me'. Felicity has expressed a powerful view rejecting Self-directed Care: 'I have a fulfilled life. I don't want more bureaucracy'. Service providers were equally articulate, revealing a grasp of the complexities of Self-directed Care as a new model likely to have potential benefits for service users, but, in reducing organisational power, may have negative consequences as well.

While this chapter has presented the findings as individual voices, it has also presented shared views where these have been supported by the analysis.

Through the analytical data processing, six catalytic themes have emerged, organising the data into interpretive conceptual categories ranging from the embodied aspects of impairment as they have interacted for the participants with experiential aspects of power and control, to the level of macrosystem change perceived as interfaces between the individual, their relationships, provider organisations and the macrosystem.

The findings have revealed a deeper understanding of how disability power and control resides in embodied realities of life, how it affects the availability and quality of the relationships vital to aspects of caring, and how structural barriers limit freedom and autonomy in the pursuit of daily activities. They have illuminated how aspects of local services can both increase a sense of agency and power through accountability and continuity and, at the same time, restrict service user and service provider power through managerial regulation and organisational control. The promise of increased power and control through the transfer of purchasing power from organisations to service users was responded to by nuanced views, indicating that research participants had a wide-ranging grasp of potential benefits and potential disadvantages of a SDC model.

Through all of the responses, strong aspects of cultural difference were evidenced, emphasising the importance of cultural understanding and appreciation of culturally responsive practice.

The next chapter applies each of the catalytic themes to a further process of synthesis in order to determine their application to the framework for future services planning.

## CHAPTER FIVE

### SELF-DIRECTED CARE AT THE LOCAL LEVEL: WHOSE POWER, WHOSE CONTROL?

#### Introduction

The aim of this final chapter is to further interpret the meaning of the rich and varied voices captured in the previous chapter, as findings that can be applied to the professional workplace of the Council services microsystem. This chapter does two main things: it sets out how these findings, interpreted into the six catalytic themes, were synthesised into key elements to inform future services planning; and it provides a reflection on how the research has contributed to my professional practice, and to Critical Social Work theory and practice knowledge. It concludes with a consideration of the question posed in the study's title: whose power and control will be enhanced through the impending era of Self-directed Care systemic reform?

To re-state the purpose and aims of the research: this inquiry has focussed on the question of how the Council can be informed by research-based knowledge on the operation of power and control in the lives of residents with disabilities, and in the practices of the service providers who work with them. As described in Chapter One, the proposed, massive change at the macrosystem (national) level was a driver for the Council to investigate the local impact of the Australia-wide introduction of a Self-directed Care model of service provision. The challenge facing the Council at the end of the first decade of the twenty-first century, was to develop a deeper understanding of disability empowerment in order to plan for its future service model. The purpose of the research was to carry out a process of collaborative inquiry to explore the perceptions of service users and service providers about aspects of local services they considered empowering. This was undertaken in order to generate findings that could be applied as significant change elements for the Council's services planning in response to the likely implementation of Self-directed Care.

Earlier chapters have set out why the study did not adopt a narrow focus on the dynamics of the disability services microsystem only, but enabled exploration of power and control in everyday life in a broader sense, guided by what the

participants identified as meaningful to them. In order to investigate power and control in the field of disability, the inquiry has addressed generic theoretical perspectives on empowering and disempowering frames and discourses that apply to the local government setting. The Social Model of Disability and the Human Rights approach have provided important theoretical underpinnings as they relate disability empowerment to structural change to remove barriers to participation and observance of human rights. These frames connect with the Council's multiple roles beyond those of service provision. The discourse of neo-liberalism has provided powerful conceptual insights into the Council as a human services bureaucracy as it relates both to potentially disempowering aspects of managerialist services operation, and to potentially empowering aspects of individual service user choice and control in self-management.

#### Anti-oppressive research as collaborative inquiry

Based on the adoption of the principles of Critical Social Work as the practice-based theoretical approach for the study, the inquiry implemented strategies to achieve an anti-oppressive research design to enable people with disabilities to speak for themselves. In order to identify and minimise power inequalities in the research dynamics, qualitative methodologies from the participatory action research (PAR) (Brydon-Miller et al. 2011) and Critical Disability Studies paradigms (Mertens, Sullivan & Stace 2011) were applied. These were used to address expected sources of power imbalances by guiding the choice of methods that encouraged reciprocal research relationships, collaborative processes and researcher accountability to the participants. Power differentials were located in my roles as a researcher and, concurrently, a middle manager, and my status as 'outsider' vis-a-vis participants living with disabilities. Critical/transformational methods were employed to ensure that lived experience of disability, extended by the intersection of cultural difference, was recognised in the methods employed. By these means, 'hidden voices' were sought and included (Meekosha & Shuttleworth 2009; Mertens, Sullivan & Stace 2011).

Eleven residents with disabilities who used the Council services (or were eligible to do so) participated in semi-structured conversational interviews on their perceptions of power and control in their day-to-day lives, which included, but were not limited to their experiences of support services. Three cultural backgrounds were represented in this participant group: Anglo-Australian, Vietnamese and Aboriginal.

Seven service users participated in two focus groups: four in the Vietnamese group and three in the Anglo-Australian group.

Twelve service providers participated in semi-structured interviews and two in a focus group. The study included four service providers from the Council, representing roles of assessment, case management, and senior management. Eight other local providers of disability support services represented a Vietnamese agency, an Aboriginal-managed agency, a multi-ethnic agency and a disability advocacy agency. An Aboriginal disability advocate was also included.

As well as gathering of the data from individuals and focus groups, the study built into the design a process to maximise participation and accountability by reporting back at key points on its progress, and seeking advice from residents with disabilities. This was carried out in the group format of the Disability Advisory Committee. In this setting committee members were empowered as citizen advocates in the Council's decision making. Chapter Three sets out in Table 3.1 how the four phases of the study combined a 'loop' of data gathering and data feedback. Phase 4 includes an action outcome of the study, the establishment of the Vietnamese Disability Action Group that arose from the Vietnamese focus group. It reflects a further aspect of anti-oppressive research, the aim of achieving a beneficial outcome for people with disabilities – an imperative of the Critical Transformative/PAR methodology.

In addition, the role of the small Steering Group of service users formed part of the collaborative research design. Members of the Steering Group acted as advisors on the study's usefulness, purpose and design. They made recommendations on avoiding methods that would be likely to exacerbate power inequalities between service users and service providers. Their involvement was a critical factor in providing a setting where my role as 'outsider' researcher could be examined and critically reflected on.

In order to retain clarity of voices, interview and focus group transcripts were first analysed separately, for service users and service providers, into a number of 'experiential realms'. The second stage of data reduction comprised a further analysis of the data as a whole, resulting in the derivation of six 'catalytic themes' set out in the previous chapter. These were: Theme 1 – The Personal in Everyday Life: Disability as Embodied; Theme 2 – Environmental Barriers: Negotiating the External World; Theme 3 – The Relational Sphere; Theme 4 – Institutional Barriers

to Empowering Services; Theme 5 – The Realm of Cultural Differences; and Theme 6 – The Macrosystemic Sphere: Personal, Relational and Institutional Interfaces.

## **Insights to action**

A further stage of analysis of the findings was needed to achieve the task of synthesising catalytic themes into key change elements for the Council's planning framework. The next section discusses insights afforded by these themes on empowerment reflected in current experiences and into the future. The discussion links the insights from the findings to theoretical considerations in Chapter Two. These include the critique of the Medical/Professional Discourse of disability (Thomas 2007), empowering aspects for people with disabilities of the Social Model of Disability (Johnson 2009; Oliver 2004; Peters, Gabel & Symeonidou 2009; Shakespeare 2006) and of the Human Rights approach (Ife 2008, 2010; Kayess & French 2008; Kim 2010; Muir & Goldblatt 2011; Rioux & Carbert 2003), and finally, the critiques of neo-liberalism as a potentially disempowering discourse within the Australian human services field in general, as applied to the model of Self-directed Care in particular (Cree 2013; Gray & Webb 2013a; Halfpenny 2009; Lawler 2013; McDonald 2006, 2009).

### Empowerment and Self-directed Care

Self-directed Care promises greater empowerment for people with disabilities through self-determination and services control than in 'traditional' models of services (Fisher et al. 2010; Glendinning et al. 2008; Hatton & Waters 2011; Hatton et al. 2008; Kemper 2007; Productivity Commission 2011; Tyson et al. 2010). Rejecting notions of disability care based on Medical/Professional Discourses and welfare/charitable philosophy, SDC philosophy locates disability empowerment in 'personalisation' and 'fiscalisation' of the services system. It requires a transfer of power from provider organisations to individuals through budget reallocation (Ottmann, Laragy & Haddon 2009). However, as earlier chapters have discussed, the macrosystemic change enacting SDC in Australia<sup>59</sup> involves a transfer of power from provider organisations to the Commonwealth Government to administer and govern the scheme. In Victoria this centralisation of power to the national

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<sup>59</sup> Through the implementation of National Disability Reforms in the second decade of the twenty-first century via the 'roll-out' of the NDIS across Australia, which commenced in 2013.

government will result in a reduction in power of two levels of government – state and local governments.

Centralisation of power to the national level will be considerable as it involves overall policy determination and national budget control. For individuals, this will determine their eligibility for entry into the NDIS and the funds available to them to purchase services. While macrosystemic change is likely to benefit people with disability who live in states poorly serviced by disability providers; in Victoria, with its mixed economy of provider agencies, the national model may result in fewer checks and balances and, in the case of local government, access to advocacy via locally elected representatives.

The findings of this study reinforce the contradictory, fraught and competing nature of the elements of SDC model as an empowering model. As Chapters One and Two have discussed, while positive aspects of SDC, (in meeting a broader range of needs and affording greater power and control over life decisions) have been identified (Fisher et al. 2010; Ottmann, Laragy & Haddon 2009; Productivity Commission 2011), potentially disempowering aspects of SDC embedded in neo-liberalist-driven government policy, such as an over-emphasis on individualism, consumerism and marketisation, have also been put forward in the literature (Briskman, Pease & Allan 2009; Cree 2013; Lawler 2013; McDonald 2006).

All participants raised a broad range of issues likely to affect them. Across the different participant groups there was no consensus of views, or even a majority view on whether SDC would result in a net benefit of increased empowerment. Some service users saw clear potential in being able to plan and purchase their services, and employ their chosen paid carers, or at least to have a say in this. These were primarily the Vietnamese service users who were not currently receiving any, or a satisfactory level of services. They had in fact very little power and control in the services system. Anglo-Australian service users were less enthusiastic. Their responses varied from outright rejection to questioning and weighing up of benefits and disadvantages for themselves and for important others – their family, friends and paid carers.

Potential disadvantages covered personal impacts of SDC such as harmful psychological repercussions of increased stress that could exacerbate the levels of pain contained in the poignant words of Theme 1 (The personal in everyday life:

disability as embodied). This response underlay a concern that a SDC model would not necessarily guarantee that backup support would be available for service users at times that their physical and emotional resources were depleted, or their services failed in some way. In these responses, an underlying fear is revealed that people would be left to self-manage and bear responsibility for themselves without assistance to do so.

These findings resonate with the critiques of the ideology of 'individualism' played out as increased personal responsibility, and connected to the notion of the 'good citizen' outlined in Chapter Two (McDonald 2006). Participants in this study were acutely aware that embodied impairments meant their needs for support and care could vary substantially, leaving them at times with less strength and emotional resources to self-manage. If supports were not available to 'step in' when needed, this would represent an 'uncaring' system – one that failed to anticipate periods of increased need, be they short or long term. It would represent a less caring system than the existing local microsystem, as described by (most of) the Council service users.

Service user views on the potential effects of services marketisation included a concern that it could result in a loss of the current pool of local workers available from the Council, and the ensuing loss of: local travel time efficiency; local information dissemination; and sharing a sense of local neighbourhood knowledge with carers. They were also concerned about the potential for fewer protections for paid carers associated with the likelihood of less investment in quality measures of training and risk management, an anticipated result of provider agencies needing to increase their competitiveness. While this view might be seen to represent a degree of service user self-interest in ensuring they continued to receive the high quality of services they were familiar with, it was expressed in the context of the aspects they valued highly in their relationships with their paid carers, indicating their capacity to be concerned for their (the paid carers') wellbeing as well as their own.

One service user Phil, however, presented an alternative view of how SDC could empower paid carers as well as service users. In transferring their accountability from their provider organisations to their service users; paid carers would be enabled to engage in a more direct and reciprocal negotiation with them on what they could and should do to meet their needs. In his view, relationships between

paid carers and service users would potentially be more equal and empowering for both of them. In Theme 3 (The relational sphere), Phil's words identified his consciously cultivated skills in being pleasant and assertive in his relationships with his paid carers. The likelihood of mutual empowerment of service users and paid carers, through potentially more direct relationships in a SDC model, would be a topic for future research into the relational aspects of power and control.

Service users as a group, therefore, demonstrated a comprehensive grasp of the nuances of power and control within SDC. Most, especially those with many years' experience with Council services, appreciated that the scope of impending change would be likely to affect all the players in their service dynamics. Self-directed Care did not guarantee a beneficial outcome unless the new model preserved the aspects of support and caring they valued in their local services. For them 'individualism' and 'consumerism' did not lead to a simple equation for empowerment.

From their 'birds-eye' perspective across the service system as a whole, service provider responses indicated even more serious reservations of contested aspects of power and control within SDC. While they were able to recognise potential benefits for service users to access more flexible, individually tailored services, Council providers were fearful of the very survival, in the long term, of locally provided and managed services. From their standpoint, the future marketisation of disability care agencies and the 'fiscalisation' of the macrosystem – both features of the neo-liberal-influenced human services described in Chapter Two – would expose the Council microsystem to even greater threats of loss of organisational autonomy to respond to local needs than currently experienced in the 'traditional' model of disability services provision as described in Theme 4 (Institutional barriers to empowering services).

If the Council did not survive as a market competitor, this would have potential implications for loss of service user agency in several ways. In the findings of Theme 6 (The macrosystemic sphere: personal, relational and institutional interfaces), service provider views reveal the complexity of empowerment considered in a broader light than service choice and control. On the one hand, the Council service providers acknowledged the clear benefits to their service users in the Council giving up its status of organisational power to make decisions affecting their lives. However, the service provision function of the Council was already

connected to avenues for residents with disabilities to exert influence in service governance and political decision making. Service provider Charles expressed his view of an empowerment model that was built on these two mutually reinforcing sources of agency. First, people with disabilities could promote their interests collectively in services governance and operational decision making. Second, they could be empowered in political decision making, either as elected members or through their elected representatives. Given that local government provides these potential avenues of empowerment, its demise as a provider agency would be likely to diminish one or both sources of agency.

Even if the organisation did survive, the findings indicated there were other likely effects of the transition to a SDC model that could negatively affect the Council and other local providers' capacity to act in the interests of service users. The concept of 'discretionary care', the capacity of block-funded organisations to redistribute funds to programs that sat alongside direct service delivery, and functioned to enhance service access, was raised in Theme 6. These were the sort of programs that Nina described as operating in her multi-ethnic agency. In a SDC model, block funding would be minimal or non-existent. Discretionary care capacity in the current traditional services model was referred to by one service provider as the real service system.

Discretionary care requires agency flexibility, energy and effort (Harlow 2003). A more subtle impact of SDC and service marketisation identified by service providers was that of a psychological effect of uncertainty in the services sector. Loss of motivation would potentially weaken energy and effort over time, especially for smaller agencies such as the Council and local ethno-specific agencies.

#### Empowerment and cross-cultural perspectives

Cultural perspectives on SDC were linked by Vietnamese and Aboriginal service providers to its lack of 'fit' with their current mode of supporting their service users. In describing their current service delivery (as reflected in Theme 5), a clear picture emerged of a model that was shaped to maintain cultural values of collectivism, community identity and protection of those in need, in the face of macrosystemic complexity and its dominant Western value base. The more 'holistic' approach of the Vietnamese, multi-ethnic and Aboriginal-managed service agencies could be interpreted as a form of resistance to neo-liberalism, in the sense that these

providers have minimised features of managerialism such as compartmentalisation and rigidity (Green 2007; Halfpenny 2009; Lawler 2013; Rogowski 2011). Self-reliance, independence and self-responsibility are not the primary expectation, as service providers accepted the role of 'buffers' between the impenetrable system and service users. As Truc and Nina expressed, they were acting as a 'middleman' or a 'bridge'. In the greater emphasis of Vietnamese and Aboriginal agencies on notions of community as a source of resources and relationships, the primacy of 'individualism' is replaced by that of 'communitarianism' and mutual support. In a municipality of cultural diversity, the need for ongoing provision of ethno-specific services that successfully challenge the restrictive nature of neo-liberalism is an important finding of this study.

Like Vietnamese providers, Aboriginal service providers were very specific in distinguishing between the values of their service delivery and that of mainstream Anglo disability support services. For them, the extreme disadvantage that Aboriginal community members experienced in all areas of their lives (physical, emotional, material and relational) placed great demands on the providers to prevent further harm. Aboriginal service provision was, as they explained, of necessity protective of their interests, thereby assuming a level of responsibility to prevent macrosystemic features from alienating Aboriginal people from services and from the support of the community.

Self-directed Care therefore was seen by Aboriginal and Vietnamese providers as problematic for their communities because of significant areas of poor cultural 'fit'. The operation of SDC would be likely to make their work more complex and result in greater difficulty, both in maintaining holistic and integrated practice, and in countering the effects of bureaucratic control. Overall, empowerment was not seen as the likely result of services self-management. Service providers did not discuss aspects of empowerment, but were more concerned with their role in mediating the discriminatory effects of the barriers existing for people who were unfamiliar with the services system at many levels.

Interestingly, this point of view was not shared by the Vietnamese service users interviewed. Kie, Kylie, Vien and Binh saw benefits for them personally in having greater choice and control by being able to purchase the services they wanted, when they wanted them, and who they wanted to employ as their paid carers. Greater choice for them would be empowering in enabling them to choose only

known and trusted carers, to diversify their funded activities, and purchase alternative treatments.

As the only Aboriginal service provider who had experience of a form of SDC, Julie's comments gave greater depth to knowledge of lack of cultural fit. These consisted of ignorance of mainstream non-Aboriginal government officials of how communication and responsibility operated in Aboriginal communities, and how information could be provided in a culturally meaningful way. This point was shared with Vietnamese providers and service users. The findings illustrated that it was not just translated information that was needed, but information that incorporated understanding of where the recipient was coming from, that is, knowledge of their standpoint. The findings emphasised that the voices of service providers and service users need to be heard in order to inculcate non-hegemonic cultural standpoints in disability services planning.

To summarise, increased power and control is not a straightforward outcome of SDC, as viewed by the participants of this study. Despite the strong concerns of the Council providers of the limiting and disempowering effects of working in the existing highly regulated HACC services (as reflected in Theme 4), service users expressed equally strong views about what they valued in their HACC services and what they did not want to lose in any new SDC model. Some of these factors (i.e. accountability to service users, backup, information sharing and continuity in relationships with paid carers) related to the local nature of the Council services. The competitive nature of a marketised SDC service sector would be unlikely to have inbuilt requirements for quality standards encompassing these factors. In a system highly sensitive to price, the structures needed to implement meaningful organisational accountability to service users and ensure their input into governance decision making, such as those described in this study, would be likely to wither away. In fact, this disempowering effect (of the implementation of SDC in the longer term) was exactly what Cree (2013) and Lawler (2013) (discussed in Chapter Two) identified in the 'top-down' regulated and controlled UK model. They wrote that neo-liberal 'managerialism' in this system, in place for over ten years, had resulted in the redirection of staff accountability from service users to managers, thereby reducing professional accountability of social workers and weakening relationship-centred practice.

The conclusions drawn above indicate that this study has contributed new knowledge to theoretical debates about the empowering value of SDC. Through the investigation of power and control in a particular services microsystem, a number of factors have been identified as critical to any consideration of increasing empowerment in the defined locality of the service recipients' homes. Two major factors are the impact of cultural diversity intersecting with impairments and the status of people with disabilities as citizen residents. This point is expanded further below.

### Empowerment and structural change

Self-directed Care is not revealed in these findings as a smooth pathway to empowerment for the participants in this study. There are, however, other sources of power and control identified in structural change connected to people's everyday lives. The two frames (i.e. the Social Model of Disability and the Human Rights approach) were raised as potential sources of agency. In the first case the experience of environmental barriers of inaccessible buildings and transport significantly reduced a sense of power and control for Binh and Susan (as reflected in Theme 2). Their comments located the structural barriers in a particular time and place. They thus 'concretised' the inaccessible environmental features to be addressed, potentially enabling the citizenship advocacy of people with disabilities to influence the Council's decisions in land-use planning and regulation of the built environment. In the local setting, residents with disabilities contribute through the Disability Advisory Committee to the process of breaking down structural barriers to identifiable targets, and work with the Council to remove them. Their personal experiences are linked to collective agency. The application of the Social Model of Disability in the Council's decision making legitimises this agency.

While this study is not focussed on investigating the effectiveness of citizen advocacy, its findings reinforce the connection of personal disempowerment, as a sense of lack of control over access to the physical world, to the need for action on removing environmental barriers. As presented in Chapter One, the Council provides a model for the incorporation of the personal reality of disempowerment into the public sphere, for the purpose of supporting action to reduce discrimination. Theme 1 contains findings that indicate the high emotional and physical cost of stress and frustration arising from structural barriers (for some service users) in their interaction with the pain of chronic impairments. These findings support the critical importance for people with disabilities to have access to agency to change

their world (Goggin & Newell 2005). They reinforce the theoretical frameworks of the Social Model of Disability discussed earlier, that emphasise the place of collective action for structural change both to remove barriers, and also to assert the agency of people with disability by countering the marginalising and excluding effects of the Medical/Professional Discourse of 'disability' as individual pathology and dysfunction (Johnson 2009; Peters, Gabel & Symeonidou 2009; Thomas 2007).

Another source of agency through structural change was raised by a few powerful voices. In regard to the second empowering frame of Human Rights, the findings supported the point of view in the literature that this approach is a significant source of empowerment for people with disabilities (Kayess & French 2008; Muir & Goldblatt 2011; Rioux & Carbert 2003). Several participants pointed out that SDC would be ineffectual as an empowering model, if it were not underpinned by a commitment to human rights organisational practice. It is important to note that cultural differences in knowledge of human rights, in the Australian context, were revealed in the findings to be an important consideration to be taken into account in the application of rights practice at the local level.

What was interesting in the responses of Theme 6 was the insight that the pursuit of human rights for people with disabilities should be enacted through a gradual process of organisational change. Moreover, organisational change was seen not solely as the result of policy development, but also to be enacted in everyday operational decision making. As a human rights expert, Phil's detailed response on how human rights should be practised 'on the ground' in provider agencies was significant. He believed the Human Rights approach gave a key alternative to the welfare/medical discourse to people with disabilities, enabling them, individually and collectively, to challenge decisions made by service providers (ostensibly) on their behalf. In this way, the codification of individual and group rights in legislation and covenants, such as the Victorian Charter of Human Rights and the CRPD, provided service users with a legally-backed line of argument to hold service providers to account to explain how any decision made was not discriminatory. In the findings, organisational change towards better human rights practice was envisaged as a process of dialogue carried out within more equal relationships between service users and service providers.

In applying human rights practice in the local setting, cultural values and beliefs would need to be sought and addressed. As Vietnamese service providers and users pointed out, there was a lack of familiarity with Western democratic human rights law and practice by Vietnamese community members. Organisational change to implement human rights would, therefore, need to engage in raising awareness and information strategies for people with disabilities, of varying cultural backgrounds and with varying impairments. Given the importance of recognising the historical denial of rights for people with disabilities (the recognition of 'substantive' inequality) (Kayess & French 2008), and the complexity of the development of different kinds of rights (individual, collective and communal), organisational change must include continuing education for service providers on human rights codification and practice.

### Empowerment through relationships

In the literature discussion in Chapter Two, the connection of relationships in the services to empowerment were touched on in reference to the impact of neo-liberalism on professional relationships, and the impact of SDC choice and control on relationships with family and with paid carers. However, in the analysis of the findings, the relational sphere has emerged as a theme in its own right, because of its catalytic power to deepen understanding of what aspects of their relationships service users (and providers) saw as important to maintain or establish, to enhance power and control. Theme 3 and part of Theme 6 have provided valuable insights for practice of perspectives on independence and interdependence, mutuality, reciprocity and caring. Relationships were very much in the foreground of participants' responses.

Disability services are carried out by means of human interaction of relationships. Public and private, enabling or controlling, distant or close, enduring or episodic: these relationships enact the complexities of 'caring' every day and every hour in the lives of people with disabilities. In this study, the relationships between service users and paid carers were viewed through the eyes of the former. They spoke of how they valued them. Even where they were unsatisfactory in some way, some service users were able to use their relationship skills to guide or elicit the actions of their paid carers that increased the efficacy of their caring. Acknowledging here that this was a one-sided view of the relationship,<sup>60</sup> it was, nevertheless, an

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<sup>60</sup> Paid carers were not included as study participants.

important one. It established aspects of agency for service users in their knowledge, built up over time, of managing the dynamics of relationships in the Council traditional service model.

Service users demonstrated they were able to 'step into the shoes' of paid carers. Evidence of mutuality and reciprocity were contained in their comments, not just in the concerns about how the wellbeing of paid carers would be protected in a SDC model, but also recognising that effective services depended on their carers' empowerment as well. Paid carers could potentially be disadvantaged in a SDC services system through a loss of operational supports, reduced industrial conditions and lower wages. However, as one service user commented, paid carers could also be advantaged through the more direct relationships with service users of SDC, by clearer communication, less confusion and conflict arising from mixed accountability to the employing organisation and the users, and the opportunity to be more assertive in the caring dynamic. This indicated a sophisticated appreciation of the way mutual relational empowerment could work.

Amongst the group of service users, views were divided about their interest in employing family members or friends as paid carers. Relational aspects of sustaining existing levels of trust and fear of exploitation were revealed as factors that service users would consider in choosing whether to employ the people they were closely bonded with. Service users clearly depended on these relationships for crucial support, and did not wish to take action that threatened them. As responses in Theme 3 indicated, family and friendship relationships were complex. For some, aspects of their impairments had shaped these relationships in negative ways. Disability, intersecting with the effects of migration, resulted for some in the loss of contact with family members. It is relevant here to note that seven out of the eleven service users lived alone. This factor of physical separation from sources of relational support was not explored further in this study, but it suggests a degree of separation from caring relationships.

The theoretical and practice connection of interdependency to caring relationships is a fruitful and important topic in its own right for further research. As mentioned in Chapter One, there is insufficient space here to discuss the findings of relational power and control of this study in the context of models of disability services and the discourse of caring. For the purposes of this practice research, the catalytic power of Theme 3 lies in the insights into sources of complexity in relationships

available to participants in the local microsystem, and the criticality of maintaining these as enduring bonds that can be both supportive and a source of agency. Service users depended on relationships that were experienced by them as caring, and ones in which they were able to exert influence over desired outcomes. The descriptions of the relationships here, indicated they were valued because they achieved meaningful engagement, characterised by one service user as emotional and physical support and reliable companionship.

### **Planning for future services**

Following the explication in the previous section of the theoretical connections of the interpretive framework (consisting of the six catalytic themes), this section further synthesises the framework into a set of key change elements that ‘the council’ must address in its future planning. They are expressed below as actions that can further the achievement of the theoretical and applied aspects of empowerment contained in each of the themes. The paragraphs below set out how each of the five change elements has been synthesised from the themes. Together, the interpretive framework and the key change elements constitute the major findings of the study. They represent a significant outcome in establishing the necessary conditions for increasing service user power and control in decision making in service development.

The first key change element is: **Maximising Service User Agency**. ‘Agency’ (i.e. the ability to act and influence outcomes in one’s own interests) has been located in many sources in the responses. Themes 1 and 3 contain insights into the effects for service users of maintaining a positive attitude, of adopting cognitive orientation into the disability services system as a whole, and of exercising relationship skills with paid carers. Theme 6 includes sources of potential agency in exerting an informed choice in macrosystemic change, and in personal and organisational strategies to increase observance of human rights. These aspects of ‘agency’ uncover perspectives on ‘empowerment’ in the local setting as multifaceted, situational and contestable.

The second key change element is: **Resisting and Critiquing Neo-liberal Control**. ‘Choice and control’ in SDC, as a source of agency, was shown in this study to be complicated by ‘fiscalisation’ of the proposed program model with its emphasis on individual power through purchasing. The many negative effects of neo-liberal discourse, and its *modus operandi* of marketisation and managerial

control, were very evident in the perceptions of service users and service providers in regard to identified institutional barriers of the existing traditional service model, and a future SDC model. These effects would be likely to impede, if not prevent, enhanced service user agency that was promised through self-determination and self-management. Benefits for service users from SDC could be eroded over time for several reasons: if purchasing power became diminished; if people were left to self-manage alone; and/or if they were obliged to purchase their services in a system that was not culturally compatible.

Critiquing and resisting neo-liberal control in disability services necessitates conditions for enabling discussion that creates opportunities for action and agency. The local setting provides a space and place for this to occur.

Connected to the change element of resisting neo-liberal control is the third key change element: **Pursuing Cultural Competence**. In the face of the disempowering effects of macrosystem complexity and significant barriers to accessing mainstream services; Vietnamese and Aboriginal service providers designed culturally embedded services that countered neo-liberal control by practising in a holistic, non-compartmentalised model. In its mainstream services, the Council's role was to ensure that culturally diverse voices were heard, and that alternative service models were supported in the municipality, either by the incorporation of this into its own service model, or by advocating for their survival in a future competitive services market.

Maintaining informal and formal relationships was certainly at the centre of ethno-specific and Aboriginal services. For service providers in Vietnamese and Aboriginal agencies, their relationships were loaded with a complexity of roles and responsibilities over and above those of the Council service providers.

For mainstream services such as the Council, it is critical to develop a deeper understanding of the many differences connected to specific cultural beliefs and values, not just to ensure that the intersection of disability with cultural background does not multiply the effects of marginalisation and discrimination, but also to share practices such as holistic program planning, that can offer ways to counteract neo-liberalism. Local government can provide a leadership role in agency sharing and networking in the local space.

The fourth key element is: **Promoting Human Rights Practice**. This element expands insights into service user agency through structural change. Human Rights practice was seen as a source of individual and collective agency in the study findings. It was in the application of a Human Rights organisational policy through discussion, debate and exchange of service relationships that Human Rights could be observed and promoted. Pursuing Human Rights in disability care services was seen as a source of personal and community agency in its capacity to provide a legitimate, legally enforceable base for negotiation or dispute resolution between service users and service providers. This constituted a powerful challenge to the medical/professional model, of which the basis of legitimacy is contained in the (generally) inaccessible and protected codes of professional practice.

The final key change element is: **Enabling Interdependent Relationships**. This element is built on the insights of findings into aspects of caring. This fifth element of the planning framework is that of establishing and maintaining relationships in caring services that enhance social engagement and nurture interdependency. Dimensions of time and continuity, space and face-to-face contact, mutuality and shared concern; these demonstrated the qualities of dependence and interdependence that were spoken of positively by service users and service providers. For some, the connection of paid carers to the local geographical community accentuated the social connection to the neighbourhood – a critical factor for people living alone.

Finally, in concluding, this section has demonstrated how the interpretive framework of the six themes, along with the derivation of the five key action strategies, has achieved the purpose of the investigation: to determine the significant change elements for future Council services. The processes of analysis and synthesis have generated a comprehensive and holistic approach that 'adds value' to the benefits of local service models such as 'the council's' that emphasise local accessibility, community identity and belonging. In this regard, the findings have potential application as an assessment tool for individual plans in the new national Self-directed Care system.

The study's findings are significant also in adding new knowledge to theoretical perspectives by suggesting how the structural change aims of the Social Model of Disability and the Human Rights approach can act together in a local service microsystem. In this setting the ability of people with disabilities to influence

decision making in their interests can be enhanced by the collaborative relationships with local government service providers. Their reach can be expanded by insights from critical perspectives such as that of Critical Disability Studies and Critical Social Work, both of which illuminate how and why cultural and other forms of difference must be incorporated in a nuanced view of disability empowerment. In addition, these critical paradigms give emphasis to the need for ongoing critique of hegemonic discourses such as neo-liberalism. Ferguson's writing on strategies that Critical Social Work practitioners must employ to be 'agents of change'; strategies of challenging managerialism, engaging in collective activity and political campaigning, as well as working alongside service users and carers resonates with the framework for empowerment set out above (Ferguson 2013).

### **Research weaknesses and strengths**

Two limitations in the Critical/Transformative PAR research design must be noted. Given that the purposive sampling method was not intended to generate findings that could be extrapolated to other settings, the sample of participants could possibly have been strengthened by the inclusion of paid carers. Services users raised many aspects of power and control in the relationships with their paid carers. This study contained a one-way view of how these relationships worked.

A further relative weakness of the study was the conduct of focus groups. Two of the three groups were very small (two and three members) resulting in limitations in the spread of views and the interplay of individual and group perceptions. In one group (unexpected) conflictual dynamics between the three members interfered with the creation of the positive experience. This limitation in conducting focus groups with people with disabilities could possibly have been averted with better planning and careful preparation, a point made by Kroll et al. (Kroll, Barbour & Harris 2007).

Contrary to the argument postulated by Mertens et al. (2011) that PAR, as emancipatory research, was in some way incompatible with CDS as transformative research; this study found that the approaches were complementary. While the nature of the participation of interview groups was culturally different, the dynamics did not appear to set up an 'us and them' division, or assume that participants were 'ready to take leadership' (Mertens, Sullivan & Stace 2011, p. 231). A strength of this study, therefore, is that it offers an example of participatory action research in

the disability field that includes cultural diversity, and connects disability to other marginalised groups in a geographical community.

### **Critical Social Work as research and practice**

The final aim of this research for the Doctorate of Social Work was to strengthen my professional practice and to contribute to Critical Social Work theory and practice. This section of the thesis contains my reflection on the impact of the inquiry on my praxis as Critical Social Worker.

My role in the Council as middle manager has given me great scope to interact with residents with disabilities in a variety of ways, each reflecting different dimensions of power. Operational management of case managers and HACC assessment officers entails responsibility for overseeing day-to-day decisions on all service dimensions (i.e. determination of eligibility, nature, volume and continuity of services) and all decisions that affect access for individuals needing the Council's support services. The second part of my professional role, (i.e. the coordination of the Council's disability access and inclusion planning across all functions of the organisation and all community sectors), is focussed not on individual needs and agency, but on collective agency through collaborative planning and citizen advocacy. The role is essentially to provide resources to residents to enable them to influence the Council's decision making to remove discrimination in all areas of their lives.

For me, the value of this practice research has been to legitimate a more in-depth exploration with residents and colleagues about the factors that can enhance this mutual search for empowerment. While my unique role, practised in a particular setting of time and place, has limited application as a subject of a replicable inquiry, it has relevance as an example of empowerment of people with disabilities within a level of 'the state' in Australia, with the defined set of structures of local government. For social work practice it provides a model of the connection of the individual (i.e. embodied disability as it is played out in the operations of individual services planning and provision) to the collective, in a setting where these two aspects can be synchronised and mutually reinforcing. This point is evidenced by the participation of (some) service users in the study, simultaneously as recipients<sup>61</sup> of the Council's services and as members of the Disability Advisory Committee. In

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<sup>61</sup> Or eligible to be recipients.

this way, empowerment for them has proved to be less about moving from a 'passive' state to an 'active' state, as Mullaly has asserted (Mullaly 2007) and discussed in Chapter Two, than about the *removal of barriers* to their action, and hence their control over their lives. In other words, access to power and control has not appeared in this study to be a matter of initial passivity, but the experience of conditions that enable agency to flourish.

Unfortunately, the necessary brevity of this thesis prevents a more considered critical reflection here on the politics of disability, the discourses of caring and limitations of the Council as a generalist rather than specialist organisation. However, the application of critical theory has expanded my professional knowledge about multiple aspects of human difference in interaction with disability, and the embodied, subjective nature of chronic impairment. These are the insights afforded particularly by the critiques from Critical Disability Studies writers, such as Mertens et al. (2011) and Meekosha and Shuttleworth (2009), of the limitations of mainstream structural change frameworks such as the Social Model of Disability. There are many ways that these insights can be applied in the microsystem setting.

First, the call to recognise my cultural bias, and counter this by seeking and hearing 'hidden voices' has resulted in a deeper awareness of the intersecting barriers experienced by Aboriginal and Vietnamese people with disabilities. This knowledge can be, and has already been, applied as a motivating factor for me, as a practitioner, to continue to analyse the disparities of resources that flow to these groups from the Council and all systemic levels. I am now better informed for my ongoing work to support their self-advocacy. I have found this to be a transformative outcome for me, both professionally and personally. The research has enabled a stronger base for consolidating the relationships needed to challenge the power of mainstream structures including that of local government. For Vietnamese residents, their continued attendance at the Vietnamese Disability Action Group indicates that this opportunity for collective activity has been, or has the potential to be, transformative for them.

In regard to work with Aboriginal community members, the task for me and for the Council is more complex. Although the barriers to obtaining the level of resources enjoyed by other sectors of the community are substantial, Aboriginal self-management of human services is well established and strong in the municipality. Knowledge and power of the disability 'industry', contained in non-Aboriginal

mainstream organisations, can be a threat as well as a potential pathway to resources for Aboriginal communities. In my role as a member of the Aboriginal regional disability network, I have an opportunity to learn (as a minority member) how I can be more a source of the latter (a conduit to resources) than the former. This entails carving out a new role in the network as learner and facilitator under guidance by Aboriginal community members. The status of learner also contributes to ongoing critique of neo-liberalism, as culturally embedded practice constitutes a working alternative to managerialist control as demonstrated in this study.

A second practice outcome has been that of building my confidence in the use of multiple levels of knowledge in the organisation. Research findings can be used to challenge hegemonic and deeply-embedded professional values and paradigms such as that of Duty of Care and Occupational Health and Safety Risk Management. Practice wisdom is likely to build over time into a fixed set of beliefs. As I have experienced, practice research is a key tool of the Critical Social Worker to introduce rigour into the interrogation of one's beliefs, and therefore assists the process of critical reflexivity.

Finally, the research can contribute to Critical Social Work practice on the promotion of human rights in the workplace of the local setting. Some writers in the social work field have noted that social work education has been slow to respond to addressing Human Rights as an empowering approach in general, and to Human Rights applications in the field of disability in particular (Kim 2010; Stainton, Chenoweth & Bigby 2010). This study contributes to an understanding of Human Rights and citizenship by challenging the view that people with disabilities do not, or have not been able to, participate in political decision making (Goggin & Newell 2005). From the point of view of this study's findings, the conditions for participation were contained in the integration of, first, the opportunities for resident citizens for self-advocacy *and* systemic advocacy in publicly accountable structures of participatory democracy, and, second, the commitment to Human Rights awareness and practice.

An important learning of this study is that a disempowering discourse, such as the Medical/Professional Discourse, can be challenged through an alternative discourse when it (the latter) has formal authority. Human Rights laws and conventions provided such authority in the local setting, enabling people with disabilities to directly confront disabling outcomes of the Medical/Professional

Discourse. This study has generated findings that illustrate how this 'agency' can be exerted in a setting where people are encouraged not only to develop policy advocacy skills, but have opportunities to experience their efficacy over time. That the findings have potential application to the furtherance of human rights for people with disabilities in other settings is another example of the heuristic value of this research.

Clearly the practice of Critical Social Work is not a matter of social workers merely aligning with Human Rights practice and advocating on behalf of others, but contributing to the 'agency' of people with disabilities and of other marginalised groups to self-advocate. In my role as a middle manager, furthering 'agency' is connected to my accountability for my decisions, in private and public spheres, and to the demonstration of due process for their observance of the law.

This is not to assert that all people with disabilities have these opportunities for 'agency', or that all people have the same knowledge of their human rights. As this study has demonstrated, people with different cultural backgrounds have very different experiences of human rights. This factor necessitates the use of critical reflexivity in constant examination of assumptions about rights, including the Western liberal view of rights as being primarily individual rights. As (Calma & Priday 2011) have pointed out, it is crucial when working with Aboriginal communities that social workers have a thorough knowledge of the United Nations Declaration on the Rights of Indigenous Peoples, as well as the CRPD and other Human Rights conventions and laws.

In summary, the research has afforded me a rich and valued opportunity to carry out a Critical Social Work project, to be able to introduce rigour into an inquiry, to build on the reciprocity and mutuality of my relationships with the people I work with, and to create a learning space that could challenge my biases more effectively in my everyday work role.

Practice-based research is professionally stimulating because relationships with residents and colleagues continue after the research is concluded. In this way the learning and applied nature of the research findings continue to inform the mutual search for meaning. The doctorate has fulfilled my intrinsically motivated goal to satisfy both my intellectual interest in theory, and to have a better knowledge of contextualised power relationships so that my future social work practice can contribute to a more just nation.

## Whose power, whose control – to a better future

This study has demonstrated how people with disabilities, and those who care for them or offer their services, can exercise more control and agency in structural change, in challenging organisational power, in cultural confirmation, and in gaining recognition of their individual and collective rights. In the defined locality of the Council, they can be supported by enduring relationships based on shared knowledge and shared aspirations. As shown in this case, 'localism' can foster the conditions for the forging of 'just' relationships through face-to-face interactions. In the local service dynamics, the relationships between service users and service providers can benefit from a deeper understanding of 'the personal' and its connections to the critical and embodied perspectives of disability, as well as a more critical appreciation of the meaning of interdependency. Moreover, these relationships will continue to develop in the time and place of the municipality on issues much broader than service use.

There are high stakes for Australians with disabilities in systemic change. The role of 'the state' in redistributing financial and other resources through the NDIS to people sorely in need of them has much promise. However, this reform is occurring at a time when the conservative forces of neo-liberal-created fear of economic collapse through such redistribution are very powerful.<sup>62</sup> Self-management of one's services through Self-directed Care is not a guarantee of increased power and control. Empowerment through major systemic reform depends on many factors, not the least of which is the degree to which the new arrangements reproduce alienating aspects of neo-liberalism at the expense of conditions for caring and culturally responsive relationships.

Local governments can be significant allies in the struggle to improve the life chances of their residents with disabilities. The framework for change developed in this study leads to the conclusion that, within the commitment to the agency of people with disabilities, it is *shared* power and *shared* control that can lead to more equitable and just arrangements for full participation in community and civic life.

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<sup>62</sup> 2015 – completion of this thesis.

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## APPENDICES

### APPENDIX A

#### **Vignettes of SERVICE USERS INTERVIEWED as they were at the time of interviews.**

**Note:** Pseudonyms are used. All names of service users identified with an asterisk had a previous relationship with the researcher in her capacity as Council middle manager, before the commencement of the study.

Service users participating in focus groups are also listed in this attachment.

#### **CURRENT USERS OF THE COUNCIL'S SERVICES**

**DENNIS\*** has lived alone for twenty years in a small public housing unit set in a pleasant garden courtyard. He is fifty-five years old and has an Anglo-Australian background. Before becoming seriously ill 25 years ago with fibromyalgia syndrome, he was a concert pianist. As a consequence of this chronic illness he was forced to stop playing. Currently he volunteers for a community-run radio station. Maintaining his garden and his activities in the music world are extremely important to him.

Dennis has received in-home services from the Council for more than a decade. He describes the strategies he has developed over time to 'manage' these services so that he can continue to gain support he needs and deal with the negative effects of variations and lack of consistency from time to time. Some years ago, he provided advice to the Council on his services as part of consultation with services users during the service tendering phase. Now, he is acutely aware of the need to reduce his stress as this exacerbates the effects of his illness such as bouts of debilitating pain. He was very interested to hear the, for him, new idea of Self-directed Care. He welcomed the opportunity to explore its possible effects, both positive and negative.

Dennis also consented to participate in the Anglo-Australian service user focus group.

**HAYLEY\***, of Anglo-Australian background, is thirty-seven years' old and lives with a boarder in a private rented house in the municipality. Prior to developing chronic ill health she worked for a state government department and also for a Union where she developed strong administrative and advocacy skills. With the onset of a brain tumour in her twenties, she has experienced increasingly impaired mobility and loss of eyesight and balance. Despite the struggle to live on a Disability Support Pension, maintaining her independence by living in private housing rather than public housing is very important to her. She values her sense of being part of the local neighbourhood.

Hayley receives in-home services from the Council and from other agencies. Her needs for support and care services are increasing and she is frustrated that her current services are inadequate in scope and coverage. She is very interested in the potential of Self-directed Care to give her greater flexibility through affording her the financial means to purchase what is of most priority to her at any one time, rather than relying on rostered services that are hard to change.

Hayley has close contact with her immediate family, who live in the country, however she finds these relationships strained now that she has a greater need for their emotional and physical support than (she feels) they are able to provide.

**PHIL\*** lives with his cat in a privately rented flat in the municipality. For much of his adult life he has worked part-time for in the public service as a disability access advisor. Now fifty-eight years' old, he retired several years ago. Apart from the recognition he has received in the disability field from his paid work, Phil has built up an impressive reputation as a national and international human rights campaigner for which he has received several Australian honours. He has an Anglo-Australian background.

Phil has lived with a chronic illness for most of his life and because of the resulting quadriplegia he uses a wheelchair for mobility. The debilitating effects of the illness are increasing, necessitating the use of an intensive level of Council services several times a day, and including case management. Additional services are funded by an Individual Support Package.

Phil has close family ties and a wide circle of friends and colleagues. He has been a long-term and much respected member of the Council's Disability Advisory Committee, volunteering his time to local issues. He was familiar with the concepts of Self-directed Care prior to the interview. Phil also volunteered to be a member of the Steering Group.

**RUTH**, forty-five years' old, and of Anglo-Australian background, has lived with her husband and son for many years in the municipality. She is a university graduate and was in full-time employment in private and public organisations until ten or so years ago when the impact of a serious progressive disease affected her general functioning, substantially reducing her mobility, and forcing her to retire. She identifies strongly with the neighbourhood and feels supported by the long-term relationships she has formed.

Ruth was familiar with the principles of Self-directed Care prior to the interview, particularly as these connected with concepts such as 'marketisation' that resonated with her professional knowledge and past employment. At the time of the interview Ruth received a high level of Council services consisting of several hours of in-home personal care daily and intensive contact from Council's Case Manager. As her disease has progressed she has difficulty in accessing the level of services required to keep her at home. Ruth was keen to give her views of how Self-directed Care related to her own situation and to wider issues of employment and services design.

**SUSAN** lives alone in a small, single story public housing unit in the municipality. She is of Anglo-Australian background. Now forty-three years of age she has experienced a lifetime of severe impairment from a congenital condition. Highly intelligent and articulate, she feels keenly the disabling effects of this impairment in all areas of her life. She views her education in a school for children with disabilities as a painful and segregating experience. She is angry that she has never been able to enter the paid workforce. Although close to her family she has experienced her family relationships as being negatively affected by her impairments.

Susan receives daily intensive in-home services from the Council as part of the Case Management program. Susan had not heard of the Self-directed Care model prior to being involved as a participant. This was not an idea that was appealing to her. For her, the major impediments to enjoyment of life were less about how her services were provided and more about the frustration of the ever-present barriers in the environment and restrictions on her personal, family and social activities. Susan had not chosen to live in the municipality when she was allocated her public housing accommodation, and does not feel a part of the largely elderly neighbourhood community she lives in.

## **DO NOT USE THE COUNCIL SERVICES**

**BINH** is a forty-seven-year-old man of Vietnamese background. He lives alone in a high-rise public housing flat in the municipality. Binh had a stroke when he was thirty-seven years' old, and he feels very lonely as his wife and his children left him some years ago. He does not have other relatives in Australia. The stroke has caused him great difficulty in walking and resulted in weakness on one side of his body. He is reliant on taxis for transportation.

Binh finds his life very difficult particularly with the restrictions on pursuing social contacts and getting about the community to go shopping and enjoy recreational pursuits.

Binh does not use the Council services. He received some in-home services in the past from another agency, but was not sure what it was called. He has some friends who help him at home from time to time, but not on a regular basis. He was very interested to hear about Self-directed Care and found the central ideas easy to understand.

**FELICITY\*** is a fifty-one-year-old resident of the municipality of Anglo-Australian background who lives with her partner and owns her home. She is well known for her work in the public service, predominantly in the equal opportunity field. She has lived all her adult life with a progressive disease resulting in quadriplegia necessitating the use of a wheelchair. Felicity uses a range of in-home disability care services provided by another agency that she helped to establish several decades ago. In the past few years she has taken part as a user of the Council

facilities such as leisure centres, to advocate for better disability access in the built environment and in the Council's general services.

At the time of the interview she was familiar with the Self-directed Care approach as well as knowledgeable about disability issues from a broad perspective. She has a strong social support network involving close family and friendship bonds.

**KIE** is the forty-two-year-old mother and carer of her twenty-four-year-old daughter Thien. Kie, of Vietnamese background, was the only carer interviewed. Although Thien was present at the interview, she was not able to communicate verbally on this occasion. However she indicated her willingness to be present by smiles. Kie explained that Thien was born in Australia and has had a severe intellectual disability from birth. Kie and her husband came to Australia as refugee 'boat people' in the 1980s. Thien's family have lived in the municipality for all her life, and have strong local relationships with the municipality's Vietnamese community and with friends in their neighbourhood. Thien went to a 'special school' (for children with severe impairments) until Kie withdrew her at age fifteen because she was dissatisfied with the poor care and lack of stimulation provided. Thien does not use Council in-home services, but participates in various respite programs run by other local agencies.

Ideas of Self-directed Care were new to Kie when they were provided to her in translated format before the interview. She embraced the principles with enthusiasm, keen to discuss how it would work and what its benefits could be. She demonstrates a quick grasp of its basic principles. Intelligent, energetic and warm, Kie has qualities that make her a potential leader in the local Vietnamese community.

**KURT** is a sixty-year-old Aboriginal man who lives in outer metropolitan Melbourne. His links to the municipality relate to his work over many years for a well-known, locally-based, disability sports organisation. He has received national and state awards for his work in the Aboriginal recreation and leisure field. Prior to this he worked for the Government in a leadership role in promoting Aboriginal programs.

He is part of a strong Aboriginal community with close, extended family connections. As a result of an accident in his teenage years he was seriously injured resulting in paraplegia. His family provides most of his care at home and he receives minimal in-home services. He described the high regard he has for Aboriginal-managed health services, which he said 'saved his life' on several occasions. Prior to the interview Kurt had not heard of Self-directed Care.

**KYLIE**, aged thirty-eight years' old, is a single mother of two boys who lives in 'walk-up' public housing in the municipality. She is friendly and cooperative, expressing her gratitude for the opportunity of participation in the study. Of Vietnamese background, she spoke during the interview of the effects of living with a violent husband (from whom she separated several years ago), of loss of her family contacts through migration, and of suffering from chronic mental illness. This

illness restricts her life in many ways causing her extreme hardship and need for constant support.

Prior to the interview, Kylie had had part-time paid employment in a Australian Disability Enterprise Organisation that provides work for people with disability. She criticised this organisation explaining that it did not support her when she experienced a repetitive strain injury, and paid her very little based on the assessment that she was at a low level of productivity. She was frustrated in her attempts to improve her income by higher paid work. Kylie, who does not have a high level of English proficiency, is well connected to the local Vietnamese community. She receives counselling and other services from the Vietnamese organisation, but does not feel that these are sufficient, particularly when she is experiencing an episode of acute illness. She received the Council services in the past but did not find them adequate.

**VIEN** is forty-five years' old and lives on his own in a high rise public housing flat in the municipality. In the early 1980s he was injured on a boat while travelling to Australia from Vietnam as a refugee. He continued to work in the technology industry until seven years ago when his condition deteriorated and he became paralysed in both legs. Since that time he has been unable to continue in paid work. Vien uses a wheelchair for mobility. He tries to maintain a positive outlook despite feeling lonely at times, and describes himself as having a strong will.

Vien used Council in-home services briefly several years ago, but found that they were not adequate to meet his needs. Now he relies on his very good friends to assist him on a daily basis with his self-care and home care.

Vien did not know of Self-directed Care before the interview, but grasped the fundamentals quickly and was very interested in exploring what it could mean for him.

## **SERVICE USER FOCUS GROUPS**

Interviewees **KIE** and her daughter **THIEN**, **KYLIE**, **VIEN** and **BINH** all participated in the Vietnamese focus group.

Interviewee **DENNIS** participated in the Anglo-Australian focus group with two other service users listed below.

**JAMES** uses a wheelchair to travel in the municipality and volunteers his time to advocate for better disability access in the built environment. In his early forties, he lives in public housing in the municipality. James has been a member of the DAC for six years. He uses disability support services provided by another agency.

**RENEE** is in her late fifties and lives alone in a small cottage in the municipality. She is a great contributor to the literary world and a long term member of the DAC, representing the interests and rights of Blind residents in a predominantly sighted

world. She lost her sight in early childhood and attended a special school for Blind children where she was very happy.

### **SERVICE USER STEERING GROUP**

Interviewee **PHIL** participated in the Steering Group with Beverly.

**BEVERLY** has been caring for her two adult children since they both developed a debilitating and incurable disease in their late primary school years. Both now require twenty-four-hour care leaving her little time for herself and her interests in creative arts. Despite the increasing caring demands she has been a long term member of the DAC where she advocates for the interests the rights of carers and young adults with disability. In her fifties she has lived with her family in a public housing house in the municipality for many years.

## APPENDIX B

### Vignettes of SERVICE PROVIDERS INTERVIEWED as they were at the time of interviews

**Note:** Pseudonyms are used. All names of service providers identified with an asterisk had a previous relationship with the researcher in her capacity as Council middle manager, before commencement of the study.

#### THE COUNCIL SERVICE PROVIDERS

**ANDREW\*** is in his fifties, of Anglo-Australian background, and has been managing the Council Aged and disability services for thirteen years. His role covers the senior management of the the Council services for residents with disabilities (as well as older-aged residents), and he also attends the monthly meetings of the Disability Advisory Committee in his role of providing senior management support for its operations. He does not have a disability. Andrew does not have professional qualifications in health or social work, however he has had more than thirty years of experience in local government, twenty years of which were in human services.

**CHARLES\*** is the Director of the Council Division that includes the Aged and Disability Services Branch. In his late forties he has been in this role for ten years. He has an Anglo-Australian background and a social work degree among other professional qualifications. His professional life has been carried out in Victorian local governments. He does not have a disability.

**JOSIE\*** has been a Case Manager for the Council for six years and is in her forties. She has worked in case management and other roles with people with disabilities in other agencies for fifteen years. She is also of Anglo-Australian background and has nursing qualifications. She does not have a disability.

**TINH\*** works as an assessment officer for the Council where she has been in this role for six years. She is in her fifties. Of Chinese/Vietnamese background, she speaks Vietnamese, Cantonese and English fluently. Her professional background is Occupational Therapy. Trained as a Doctor in Vietnam, she travelled to Australia as a refugee, finding it very difficult to retrain and obtain work as a health services professional. She does not have a disability.

#### SERVICE PROVIDERS FROM NON-COUNCIL AGENCIES

**BERYL AND NANCY** both work as case managers at the same Aboriginal-managed agency as Pauline. They both have an Aboriginal background.

**CAROL** works in an Advocacy agency for people with intellectual disabilities located in the municipality. Of Anglo-Australian background she has worked in the disability field for several decades primarily on advocacy roles. Although her

agency is state-wide she has a working knowledge of the municipality and the Council HACC service provision through her advocacy work.

**HAN** is a case manager at the same agency as TRUC and is supervised by her. She has been in this role for five years and speaks Vietnamese and English. Although the case management program works primarily with Vietnamese-speaking residents of older age, it also includes some younger age people with disabilities.

**PAULINE** is the Coordinator of the Case Management program for an Aboriginal-controlled organisation covering the residents of the Council municipality. She provides case management to Aboriginal adults with disabilities and supervises two other case managers. She is part of the Aboriginal community and has local ties through her and her husband's work, and family.

**JULIE**, in her forties and of Aboriginal background, works as a regional Aboriginal disability advocate. She has ties to the local area through state-wide disability networking initiatives. She is Deaf and uses an Auslan signer for communication. Julie has been at the forefront of opening a dialogue on disability within Aboriginal communities in Victoria.

**NINA\*** works at a multi-ethnic organisation that provides a range of services to residents of the municipality with CALD backgrounds, as well as residents of other municipalities. She has an Anglo-Australian background and has worked with people with disabilities in this agency for ten years in a range of roles including case management. She has a community development background and has had long ties with the municipality through many joint projects focussing on cross-cultural practice. Much of her practice has been involved in projects with people of different cultural backgrounds.

**TRUC\*** is a manager at a local ethno-specific agency that provides many services for Vietnamese people of all ages. In her fifties, she has been in this role for eight years and speaks Vietnamese and English fluently. She has a social work and law background. Truc has taken part in many local partnership initiatives promoting the interests of Vietnamese residents. She has worked on partnership projects with the Council in the Aged and Disability field.

## **SERVICE PROVIDER FOCUS GROUP**

**JOSIE** and **TINH** participated in the Service Provider Focus Group. A third service provider from the Council consented to attend the focus group, however was prevented from doing so due to a work emergency.

## APPENDIX C

### EXAMPLES OF INTERVIEW QUESTIONS

#### SERVICE USERS

Email  
2 April 2011

Dear [Service User of Council Services]

Thanks for agreeing to consider being interviewed for my Victoria University Studies. The studies are part of a Doctorate of Social work and they are based in my work place [City of xx, Aged and Disability Services]. They are intended to improve our services to residents with disabilities.

I am interested to find out if a new model of service delivery called Self-directed Care could improve our local government services by giving people who use them, more power and control. I am also interested in what power and control mean in general to people with disabilities, and whether receiving local services assists (or not) their involvement with their local community. Big questions!

I am interviewing people to find out:

*Do you know about the Self-directed Service model? If not I will explain about this.*

*What do you think about the services you are getting now?*

*Would you like to have more choice and control in your services?*

*What would give you more power and control in your life in general?*

*Do you feel part of your local community?*

*What benefits or disadvantages are there for you to get your services from your local government?*

The interview will take the form of a conversation as I am interested in your point of view and your opinions. It will take about an hour. I have a Coles Myer voucher for \$25 for all the people I interview in recognition of the donation of their time.

I will call you mid next week to find a time to suit you. I will be asking if you are okay with me using a tape recorder to record our conversation. As the enclosed consent form says, my study will not reveal any personal information at all.

I really appreciate your assistance.

Best wishes, Ro Roberts  
Doctor of Social Work student, Victoria University  
M: xxxxxxxxxxx or email: xxxxxx

Translated letter]  
9 April 2011

Dear [non-Council service user]

Thank you for agreeing to be interviewed for my Victoria University Studies. The studies are part of a Doctorate of Social work and they are based in my work place [City of xx, Aged and Disability Services]. They are intended to improve our services to residents with disabilities.

I am interested to find out if you receive any support services at home and what you think of them. There is a new model of service delivery called Self-directed Care. Do you know about this? I will explain to you what this means and how it might affect your services.

I want to ask you about what power and control you have in your life now and how you might like to change things.

I am interviewing people to find out:

*What would make a difference to give you more power control over your life?*

*What do you think about the services you are getting now?*

*Do you know about the Self-directed Service model?*

*Would you like to have more choice and control in your services?*

*How can we help to make the Government understand better the support needs of people with disabilities?*

*If you receive services from Council what benefits or disadvantages are there for you to get your services from your local government?*

The interview will be like a conversation between us. I am interested in your point of view and your opinions. It will take about an hour. I have a Coles Myer voucher for \$25 for all the people I interview in recognition of the donation of their time. When I come, I will ask you if you are okay with me using a tape recorder to record our conversation. As the enclosed consent form says, my study will not reveal any personal information at all.

Thank you again for agreeing to talk with me. [Vietnamese Interpreter] will come to the interview to interpret for us.

Best wishes, Ro Roberts  
Doctor of Social Work student, Victoria University  
M: xxxxxxxxxx or email: xxxxxx

## **SERVICE PROVIDERS**

### **Council Service Providers**

Email  
8 June 2011

Dear [Council Service Provider]

Thanks for agreeing to be part of the research interviews. Following our conversation, here are the questions (conversation starters):

*Do our current HACC services enhance power and control for service users with disabilities? How?*

*What are some of the constraints for us as service providers in meeting the needs of these residents?*

*What does the Self-directed Care model have to offer people with disabilities?*

*How does it increase choice and control over their services? As a transactional model?*

*If self-directed care was to become the preferred model for funding, what implications would this have? From an organisational perspective? From a service system perspective?*

*What are the issues of cultural fit or cultural lack of fit for this model?*

*Could we/should we change our services to move towards self-directed care?*

*What would be the outcome for residents with disabilities if local government was not a provider of their in-home services? Does local government have something to offer that other providers do not?*

### **Vietnamese service providers**

Email  
1 June 2011

Hi (service providers Truc and Han)

Thank you for agreeing to be interviewed. As we spoke earlier, here are the interview questions (or conversation starters).

*What has been your experience of in-home services to people with disabilities?*

*Have you any experience of Vietnamese community members who have an Individual support Package from DHS Disability? Or CACPS Self- directed Care package?*

*What does the Self-directed Care model have to offer people with disabilities?*

*How does it increase choice and control over their services? As transactional model?*

*What are the issues of cultural fit or cultural lack of fit?*

*What are the issues from an organisational point of view? What about un-costed discretionary effort of organisations?*

*What is the role of case managers – in non SDC and in Self-directed Care issues?*

*What role does local government service provision have for Vietnamese community members with disabilities?*

*Do you think the way services are organised and provided can help or hinder service users to get involved in community events or affairs?*

*Do you think the way services are organised and provided can help or hinder service users to get involved in civic affairs such as activities of local council, advocacy/self help/peak body groups, political activities?*

*Describe what services should be like if they were “rights based”?*

## APPENDIX D

### PARTICIPANT INFORMATION SHEET

#### **INFORMATION FOR PEOPLE WHO WANT TO TAKE PART IN THE PROJECT**

The research project is called: **Self-directed services at the local level – whose power, whose control? Exploring models for local service provision.**

##### **What is the research about?**

This research project will ask people with disabilities their opinions on the personal care services that they get at home. There is a new way of providing services that will give people with disabilities more say in what services they get and who they would like to be their paid carers. This new model is now being used for people with disabilities who get funding from DHS Disability. Ro Roberts is carrying out the research to find out if this new model (called Self-Directed Services) could help Yarra City Council to improve its services for people at home. The Council provides Home and Community Care services to people of all ages who live in Yarra and have disabilities or who are older and frail. The aim of the research project is to find good information about the best way to improve these services for residents.

##### **What will you be asked to do?**

Ro will ask you if you agree to take part in an individual interview with her about your services. She will tell you about the new model (Self-Directed Services) and talk with you about what you think about this and how it might affect you. Ro will record the interview, but will not use your name in any reports that she writes.

Following this, Ro may ask you if you agree to take part in a focus group to share ideas and experiences about how you would like to see your service improved with other people who live in Yarra and who use personal care services.

##### **What will you gain from participating?**

You will learn more about how the Government funds and provides services to meet your needs at home. You will have more knowledge and understanding about your rights and how you can have more control over the services you receive. You will understand more about your local Council and how you can become more involved if you want to. You will have the opportunity to share your ideas with other people and hear what they think. You will help Council to understand more about what people of Vietnamese background think about what is good, and what is not so good about in their services.

##### **How will the information you give be used?**

The information that you give in the interviews and focus groups will be recorded on a tape recorder (if you agree). The record of your interview will be sent to you to read and comment on. The research report that Ro will write from all the interviews will not include any names of people who are interviewed.

When it is written, Ro will send the report to you. She will explain to you how the report is going to be used to improve the services.

##### **How will your rights be protected if you agree to take part?**

You can be sure that:

- You have the right to agree or to say no to take part in the interviews.
- The services that you use now will not be affected in any way if you agree to take part, or if you say no.
- You may withdraw at any time from the study.

- Any information you give will be kept confidential

**Who is carrying out the study?**

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Ro Roberts, Coordinator, Services and Planning, Yarra City Council, and part-time doctoral student will be doing the research: Tel: (03) 94817515, email: [rosalyn.roberts@live.vu.edu.au](mailto:rosalyn.roberts@live.vu.edu.au)

Any queries about your participation in this project may be directed to Ro Roberts, or to the Principal Investigator: Professor Carolyn Noble, 99192917 or [Carolyn.Noble@vu.edu.au](mailto:Carolyn.Noble@vu.edu.au). If you have any queries or complaints about the way you have been treated, you may contact the Secretary, Victoria University Human Research Ethics Committee, Victoria University, PO Box 14428, Melbourne, VIC, 8001 phone (03) 9919 4781.

# **CONSENT FORM FOR** **PARTICIPANTS IN THE RESEARCH**

## **INFORMATION**

This form asks if you agree to take part in a research project. The project is about the Self-directed Services model for people with disabilities who live in Yarra.

First, please read the form called: **INFORMATION FOR PEOPLE WHO WANT TO TAKE PART IN THE PROJECT.** This gives you more information that you need to know about the project.

It explains:

- what the research is about and how it will be done,
- what you will be asked to do if you participate,
- how your information will be used,
- how you may benefit if you participate,
- how your rights will be safeguarded if you participate.

## **CERTIFICATION BY PARTICIPANT (your written agreement)**

I, \_\_\_\_\_ (your name)

of \_\_\_\_\_ (the suburb you live in)

certify that I am at least 18 years old and that I am voluntarily giving my consent to participate in the study:

SELF-DIRECTED SERVICES AT THE LOCAL LEVEL – WHOSE POWER, WHOSE CONTROL?  
EXPLORING MODELS FOR LOCAL SERVICE PROVISION, being conducted at Victoria University by Ro Roberts.

I certify that the aims of the study, together with any risks and safeguards associated with the interviews and focus groups to be carried out in the research, have been fully explained to me by Ro Roberts.

and that I freely consent to participate:

- individual interviews
- focus groups.

I certify that I have had the opportunity to have any questions answered and that I understand that I can withdraw from this study at any time and that this withdrawal will not jeopardise me in any way.

I have been informed that the information I provide will be kept confidential.

Signed:

Date:

Any queries about your participation in this project may be directed to the researcher: **Professor Carolyn Noble 0422196461**

If you have any queries or complaints about the way you have been treated, you may contact the Secretary, Victoria University Human Research Ethics Committee, Victoria University, PO Box 14428, Melbourne, VIC, 8001 phone (03) 9919 4781

## APPENDIX E

### STAGE ONE DATA REDUCTION: DERIVING THE EXPERIENTIAL REALMS FOR SERVICE USERS

Service user responses from interviews and focus groups were analysed and grouped into five experiential/conceptual realms: Experiences of living with disabilities; Experiences of disability services in the local context; Relationships with family and friends; Aspects of choice and control, and Attitudes to Self-directed Care.

Reading the table below (from left to right) reveals the process in Stage one of bracketing responses from transcripts into initial clusters and realms.

Note: responses in column one are not an exhaustive list, but a representative sample of the transcript responses that comprised each cluster.

**TABLE D.1 DETAILS OF RESPONSES BRACKETED AND CLUSTERED INTO EXPERIENTIAL REALMS**

Components (transcript responses) that made up the clusters	Clusters of responses	Experiential realm
<ul style="list-style-type: none"> <li>experiences of pain, stress and frustration</li> <li>feeling alone, isolated, restricted</li> <li>feelings of anger and fear</li> <li>sexual frustration</li> <li>feeling infantilised, being labelled</li> <li>experiences of discrimination and racism,</li> <li>feeling helpless in the face of external (environmental) barriers</li> <li>negative impacts of chronic poverty - feeling like giving up</li> <li>living a full and fulfilled life</li> </ul>	<ul style="list-style-type: none"> <li>Harmful, negative emotional impacts of impairment</li> <li>Adoption of a positive attitude to life</li> </ul>	<p>1. Experiences of living with disabilities</p>

<ul style="list-style-type: none"> <li>• seeing the 'big picture'</li> <li>• feeling lucky</li> <li>• being flexible</li> <li>• strength in being a good self-advocate</li> <li>• adopting an analytical approach</li> </ul>	<p>as a source of personal strength and control.</p>	
<ul style="list-style-type: none"> <li>• Not using Council services because not sure how to</li> <li>• the Council services too limited and inflexible</li> <li>• "the Council" services are efficient, don't patronise, highly trained, reliable, have local knowledge</li> <li>• the Council services have good work ethic and commitment</li> <li>• the Council staff have greater professionalisation</li> <li>• the Council needs to stay in service provision</li> <li>• the Council holds meetings to sort out problems in services</li> <li>• the Council is an answerable body</li> <li>• councillors can sort out local issues</li> <li>• local council's planning role is important</li> <li>• relationships develop over time</li> <li>• relationships need to be reciprocal and develop trust</li> <li>• paid workers need empathy, need to keep connected</li> <li>• relationships with paid carers have continuity,</li> </ul>	<ul style="list-style-type: none"> <li>• Positive and negative aspects of the Council local service provision</li> <li>• the Council's planning and citizen advocacy role</li> <li>• Nature of ongoing relationships with paid carers</li> </ul>	<p>2. Experiences of disability services in the local context</p>

<p>complexity, emotional support, control and influence</p> <ul style="list-style-type: none"> <li>• personal compatibility and 'fit' are important</li> <li>• services as 'rights-based'</li> <li>• occupational health and safety as reducing users' rights</li> <li>• contrast of welfare model and right-based model</li> <li>• local services and 'markets'</li> <li>• aspects of organisational change</li> </ul>	<ul style="list-style-type: none"> <li>• 'Big picture' view of local services</li> </ul>	
<ul style="list-style-type: none"> <li>• close intergenerational relationships of caring in Aboriginal family</li> <li>• connection of family and friendship relationships as part of the community of belonging for Aboriginal people</li> <li>• mother 'rescues' daughter from bad special school experience</li> <li>• close friends come every-day to help</li> <li>• neighbourhood relationships provide support and help</li> <li>• parents have played 'favourites'</li> <li>• as disabled daughter feeling 'used' by parents</li> <li>• has no family in Australia</li> <li>• experienced domestic violence from husband</li> <li>• wife and children have gone</li> <li>• has no family or relatives here (in Australia)</li> </ul>	<ul style="list-style-type: none"> <li>• Family and friend relationships as positive and supportive</li> <li>• Family relationships as conflictual, unsupportive or absent</li> </ul>	<p>3. Relationships with family and friends</p>

<ul style="list-style-type: none"> <li>family must not be further stressed (by SDC)</li> <li>do not want to ask friends to do more</li> </ul>	<ul style="list-style-type: none"> <li>Family and friends as actual or potential daily personal carers.</li> </ul>	
<ul style="list-style-type: none"> <li>can't access disability accessible tourist facilities</li> <li>can't get to local recreation centre</li> <li>local leisure centre is not fully accessible transport and train stations are inaccessible and dangerous with locked toilets</li> <li>no choice with housing</li> <li>can't move around freely to go to social events such as music gigs</li> <li>barriers to control over the accepted level of personal risk, over assumption of competence to make one's own decisions, and over access to human right-based services</li> <li>taking local action over speed humps</li> <li>taking local action over neighbourhood changes</li> <li>learning to have more control over how paid carers by 'managing' their work</li> <li>can confront a worker and set limits to attempt to change paid worker's behaviour</li> </ul>	<ul style="list-style-type: none"> <li>Barriers to exerting personal choice and control in the built environment</li> <li>Barriers to personal control from 'deemed incompetence'</li> <li>Exerting control through local action</li> <li>Exerting personal control through relationships with paid carers</li> </ul>	4. Aspects of choice and control in everyday life.
<ul style="list-style-type: none"> <li>SDC means I could employ carers I trusted</li> <li>SDC offers me the chance use my budget for</li> </ul>	<ul style="list-style-type: none"> <li>Positive attitudes to SDC</li> </ul>	5. Attitudes to Self-directed Care

<p>alternative medications and treatments</p> <ul style="list-style-type: none"> <li>• SDC could give me more money for everyday things</li> <li>• I could use my budget for someone to drive me to gardens and walk around</li> <li>• Can SDC be used to enhance employment?</li> </ul> <ul style="list-style-type: none"> <li>• SDC would be hard for people with disabilities as they need constant assistance</li> <li>• Don't want to have responsibility for hiring and firing</li> <li>• I might need backup if something goes wrong</li> </ul> <ul style="list-style-type: none"> <li>• Who looks after the paid carers?</li> <li>• Who pays attention to occupational health and safety risks such as manual handling issues for paid carers?</li> <li>• Under SDC paid workers are accountable to people with disabilities</li> <li>• Under SDC paid workers can be empowered in their relationships with service users</li> </ul> <ul style="list-style-type: none"> <li>• Concerns that SDC is 'money-saving' exercise, or may divert attention from the need for structural change</li> <li>• SDC will not change 'same old problems' in services unless accompanied by an organisational commitment to human rights model</li> </ul>	<ul style="list-style-type: none"> <li>• Stressful impact on vulnerable people</li> </ul> <ul style="list-style-type: none"> <li>• Issues for paid carers – rights, protections and benefits</li> </ul> <ul style="list-style-type: none"> <li>• SDC as systemic change</li> </ul>	
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## APPENDIX F

### STAGE ONE DATA REDUCTION: DERIVING THE EXPERIENTIAL REALMS FOR SERVICE PROVIDERS

Service provider responses from interviews and focus groups were analysed and grouped into four experiential realms: How service providers work within the 'system'; Empowerment and disempowerment in the Council disability services; Choice and control for service users; and, Organisational threats and benefits of Self-directed Care.

Reading the table below (from left to right) reveals the process in Stage one of bracketing responses from transcripts into initial clusters and realms

**TABLE E.1 DETAILS OF RESPONSES BRACKETED AND CLUSTERED INTO EXPERIENTIAL REALMS**

Components (transcript responses) that made up the clusters	Clusters of responses	Experiential Realm
<ul style="list-style-type: none"> <li>• As case managers we act as a 'bridge' (Vietnamese agency)</li> <li>• As case managers we explain and interpret (multi-ethnic agency)</li> <li>• Service providers act as 'middleman' and advocates for service users who do not understand the system</li> <li>• Case managers cushion and protect service users from the system in Aboriginal agency: we provide a buffer between people with disabilities and their family and friends in financial matters</li> <li>• the Council services carry out segmented,</li> </ul>	<ul style="list-style-type: none"> <li>• Critical roles of mediating between the service system and service users</li> <li>• Working within a highly regulated</li> </ul>	<p>1. How service providers work within the 'system'</p>

<p>inflexible and highly specified tasks</p> <ul style="list-style-type: none"> <li>• CALD and Aboriginal service providers simplify procedures, refuse to compartmentalise: we don't want to compartmentalise (multi-ethnic agency)</li> <li>• we get to know people through a variety of strategies (multi-ethnic agency)</li> <li>• We want to build an ongoing relationship to provide continuity and a continuum of care over time (the 'Council')</li> <li>• We want to develop a sense of trust and rapport (CALD agency)</li> <li>• We provide emotional support (Aboriginal agency)</li> <li>• We provide and arrange for all service needs (Aboriginal agency)</li> <li>• We provide counselling, emotional and cultural and social support, not just practical support (Vietnamese agency)</li> <li>• We see people as part of a whole family, not just as individuals (multi-ethnic agency)</li> </ul>	<p>system</p> <ul style="list-style-type: none"> <li>• Building long term relationships between service providers and users</li> <li>• What culturally embedded services do</li> </ul>	
<ul style="list-style-type: none"> <li>• Local government HACC services make people 'prove' they have a disability (disability advocacy service provider)</li> <li>• Local government services are not 'user friendly' and believe people with disabilities 'rip off' the system (disability advocacy service provider)</li> <li>• the Council service providers: services have a rigid scope, lack of flexibility and inadequate levels; the</li> </ul>	<ul style="list-style-type: none"> <li>• the Council services as disempowering</li> </ul>	<p>2. Empowerment and dis-empowerment in the Council disability services</p>

<p>organisation controls the budget and service information; service users are made to fit the pre-determined services</p> <ul style="list-style-type: none"> <li>• the Council service providers: practising locally means you get to know in-depth how services function; local services enable autonomy and independence; they give information about what is happening;</li> <li>• the Council service providers: people can go to local government to address things</li> <li>• the Council manages resources and distributes them across the whole municipality according to need</li> <li>• the Council is publicly accountable for its service provision</li> <li>• the Council can act as political advocate for service users</li> </ul>	<ul style="list-style-type: none"> <li>• the Council services as empowering</li> </ul>	
<ul style="list-style-type: none"> <li>• Past experience of SDC has given me an example of how service users can have more say</li> <li>• SDC would give more choice and control by focussing on service users' goals - not service providers'</li> <li>• SDC would use language of service users not bureaucracy</li> <li>• SDC would be more energising for users</li> <li>• Service users could knit all their services together, prioritise their needs and make choices with SDC</li> <li>• SDC is driven from the human rights perspective</li> </ul>	<ul style="list-style-type: none"> <li>• Potential for enhanced choice and control in SDC</li> </ul>	<p>3. Choice and control for service users</p>

<ul style="list-style-type: none"> <li>• If there are insufficient providers, enhanced choice and control will not work</li> <li>• SDC may introduce an administrative burden on service users</li> <li>• Choice and control will be influenced by costs</li> <li>• Service users already get maximum choice and control in non-SDC services (Vietnamese service provider)</li> <li>• CALD service users of SDC may lose the protection of case managers for system navigation, language support and leveraging information (multi-ethnic agency)</li> <li>• SDC is not compatible with Aboriginal needs</li> <li>• SDC is not compatible with older, illiterate Vietnamese people</li> <li>• Under SDC who will manage payment of workers for Aboriginal service users – it will fall back on case managers</li> <li>• Other means of citizen empowerment may be more effective than transaction model</li> </ul>	<ul style="list-style-type: none"> <li>• Potential limitations on choice and control in SDC</li> </ul>	
<ul style="list-style-type: none"> <li>• The current system is not competitive-market based</li> <li>• Chunks of cash flying around can threaten the viability of an organisation</li> <li>• How would we deal with a mixed model of people on SDC and others not?</li> <li>• Distinction between funded service system and 'real' service system - change from block funding can limit discretionary effort</li> </ul>	<ul style="list-style-type: none"> <li>• Threats to organisational survival</li> <li>• Threats to organisational discretionary effort</li> </ul>	<p>4. Organisational threats of Self-directed Care</p>

<ul style="list-style-type: none"><li>• There is more than just the service transaction – there is group work and other activities to create a sense of belonging</li><li>• Who will support the paid workers under SDC?</li><li>• Currently workers are trained to Cert level - how can we retain a skilled workforce?</li></ul>	<ul style="list-style-type: none"><li>• Threats to support for paid workers</li></ul>	
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