

A Longer Journey: An Exploration of Individuals' with Disabilities
Experiences of Employment Programs
in Vernon, B.C.

by

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Abstract

Researching disability and employment is a daunting task due to the need to explore many societal systems and the historical evolution of policy. This thesis used qualitative description to document the experiences of 12 people with a variety of disabilities with results-based employment programs in Vernon, B.C. To provide a context within which to situate this research, a discussion of the evolution of Canadian Disability Social Policy from the federal to provincial level is provided. This is followed by an overview of disability and identity and the common discourses encountered by people with disabilities on their employment journey. A thematic analysis was used to identify two themes: connection and control. These themes are discussed in relation to their role in defining inclusion. The experiences detailed in this study illustrate the broad impact of results-based employment programs within the diverse contexts of the participants' lives, offering insights into the challenges these individuals face. The relevance of such insights should not be underestimated as they not only contribute to our understanding of an individual's experiences but suggest ways in which employment initiatives for people with disabilities might be improved.

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Dedication

This research is dedicated to everyone at ILV that kept me going. To Bill, the 'poster child of neo-liberalism' for the constant challenge and to my family and friends for helping me to keep my sense of humour.

CHAPTER I Introduction

Employment is a major part of most people's lives. This is where people spend the majority of their time, meet most of their friends, and dedicate their energy for advancement and financial security. By the year 2020, Canada may have a shortage of nearly one million workers and many employers are already reporting difficulty recruiting and retaining skilled workers (Health Canada, n.d.). As part of a strategy to respond to this demand, there has been a shift in government policies at both federal and provincial levels affecting the funding and delivery of employment services. This is one factor contributing to the lowest unemployment rates Canada had posted in decades prior to the recent global recession. Despite this milestone, people with disabilities are still only half as likely to be employed as those without disabilities even though Canadian adults with disabilities are about two thirds as likely to have post secondary education as adults without disabilities (Statistics Canada, 2001). The concentration of people with disabilities in low-status employment or in economic inactivity is concerning given the profusion of evidence from Canada and other countries (e.g., Evans, Barer, & Marmor, 1994; Raphael, 2004) “supporting the notion that the socioeconomic circumstances of individuals and groups are equally or more important to health status than medical care and personal health behaviours” (Health Canada, n.d.). Thus, social determinants of health such as income inequality, social inclusion and exclusions, and employment and job security become particularly relevant when considering the health and wellness of individuals with disabilities in Canada.

People with a variety of disabilities are only half as likely to be employed compared to those without disabilities (Government of Canada, 2000). When reviewing the literature on disability and employment, two main areas were identified. The first area was articles documenting research conducted in a medical setting about chronic health problems or psychiatric disabilities and implications on employment (e.g. Crosse, 2003; Drew, Drebing, Ormer, Losardo, Krebs, Penk, & Rosenheck, 2001; Johnson & Favreault, 2001; Kreider &

Pepper, 2002). The second area identified included research reports evaluating effectiveness of programs and the labour market conditions limiting people with disabilities to gain employment (e.g. Adams & Tait 2004a & 2004b; Butterwick & White, 2006 ; Strunin & Boden 2000). There was no research found which documented employment supports provided by employment services that are results-based. This is particularly relevant given that the federal, provincial and territorial governments of Canada have moved to an emphasis on funding results-based employment programs for all clients receiving income assistance or employment insurance, including services directed to people with a variety of disabilities. By results-based employment services I am referring to the funding partnerships government enters into with organizations that are contracted to provide employment services to clients of government programs. These services are also referred to as performance based services. Essentially these services link payments with the achievement of completion of a predetermined deliverable (Province of British Columbia, 2004, p. 38). Given these trends, it is important that researchers examine the efficacy of results-based employment programs particularly their ability to support individuals with disabilities.

There is a high degree of similarity in the services offered to people with and without disabilities. In this thesis, however, the host of barriers that people with a variety of disabilities encounter when attempting to access these results-based services are explored: for example, limited information provided about assistive technology for job accommodations or difficulties dealing with an income assistance model of Disability Benefit Program are discussed.

Given the fact that Canadians with disabilities continue to experience exclusion when it comes to employment and meaningful labour participation (Statistics Canada, 2001), it becomes paramount to investigate how government policies either create opportunities for meaningful labour participation or create barriers to employment. This is particularly important in light of the 1996 announcement of the Prime Minister and the provincial and territorial

premiers that disability issues are to be priorities for social policy renewal with a goal of full inclusion for individuals with disabilities in Canada (Government of Canada, 2002b). In fact, the Government of Canada recognizes the importance of gaining knowledge of people with disabilities' current situations, the issues they face, and the successes and limitations of existing policy for future policy directions (Government of Canada, 2002b). Unfortunately, much of the policy research concerned with employment has been conducted analyzing the impact of the Americans with Disabilities Act on employment experiences of individuals with disabilities in the United States (e.g., Burkhauser & Stapleton, 2004; Wehman, Revell, & Brooke, 2003). Thus, this proposed research will provide important contributions concerning the impact of government employment policy on the experiences of individuals with disabilities in a Canadian context.

Currently, statistics are commonly used as evidence about the needs of people with a variety of disabilities. The Participation and Activity Limitation Survey (2006) found that the disability rate for the Canadian population increased from 12.4% (2001) to 14.3%. In B.C., the survey found 355,430 people with disabilities between 15 and 64 years of age in B.C., of which 136,720 were not in the labour force and 18,060 were unemployed. People with disabilities were significantly more often not in the labour force compared to those without disabilities (38.5% vs. 21.5%, respectively). The lack of labour force participation and over-representation in low-paying jobs is further reflected in the annual income of persons with disabilities as compared to their non-disabled counterparts: in 2001, the total average income of people with disabilities ages 15 and greater was \$22,228 and the median income was \$15,921 compared to the average income of persons without disabilities ages 15 and greater at \$30,814 and a median income of \$24,000 (Statistics Canada, 2001). Clearly, the experiences of individuals with disability and their employment experiences is a critical area for further and ongoing research. But the statistics do not provide all the answers about how to increase the number of people with disabilities who gain and maintain meaningful

employment. Statistics do not provide the answers as to how to address the issue of meaningful employment for people with disabilities.

Despite the efforts to evaluate the effectiveness of government funded programs, people with a variety of disabilities continue to face significant barriers to achieving and maintaining meaningful employment at both a policy and program level (e.g., Cohen, Goldberg, Istvanffy, Stainton, Wasik, & Woods, 2008; L'Institute Roeher Institute, 2004). Given this, the focus of this thesis will shift the gaze from effectiveness to experience. *A Longer Journey: An Exploration of Individuals' with Disabilities Experiences of Employment Programs in Vernon, B.C.* is an exploratory study of 12 participants' experiences of accessing results-based employment programs in Vernon, B.C. Hereinafter, this research will be referred to as *A Longer Journey*.

A Longer Journey was guided by the research question: How do people with disabilities experience their employment journey in the current political context that emphasizes results-based employment programs? This question centres the experiences of participants, time (e.g., length of time it takes to be employed), and the current political context of government policy and trends. While the focus on the experiences of people with disabilities in results-based employment may draw criticism for appearing to attack the current system, this research is meant to provide a different perspective to employment and possibly open a new path to the kind of independence that government wants and people with disabilities strive for.

To examine the research question, a fundamental qualitative description was used as described by Sandelowski (2000). The goal of this qualitative approach is to describe an event or experience to enhance understanding. Researchers using fundamental qualitative description focus on preserving the voices of the participants by presenting their experiences in their own words to the greatest extent possible, with minimal inferences by the investigator (Williams & Brackley, 2009, p. 215). The description in qualitative descriptive studies offers a

comprehensive summary of an event in the everyday terms of those events; language is a vehicle of communication, not itself an interpretive structure that must be read (Sandelowski, 2000, p. 336). A descriptive exploratory design was chosen for this study in order to provide a fuller understanding of the experiences of people with disabilities accessing results-based employment programs. Gaining insight into the perspective of individuals' with disabilities experiences with results-based employment services will highlight what is important to each individual and what motivates each person to comply with the requirements of the service. This insight will also enhance service delivery and guidance by employment service providers (Bogan, Powell, & Dudgeon, 2007, p. 215).

A fundamental qualitative description was chosen as the methodology due to qualitative descriptive studies being less interpretive, "in that they do not require researchers to move as far from or into their data". Although no description is free of interpretation, fundamental qualitative description entails a kind of interpretation that is low-inference, or likely to result in easier consensus among researchers (Sandelowski, 2000, p. 335).

The research question was first identified through my own experience as a Career Development Facilitator when I was first employed at Independent Living Vernon (formerly called Vernon Disability Resource Centre). Consumers on provincial disability benefits expressed considerable frustration and fear when the provincial government required them to complete an employment plan, which included attending provincially funded results-based employment programs. Consumers described receiving basic labour market and job search skills information, but no support around important employment issues such as connecting to employers, disclosing their disability or job accommodation, required assistive devices. Although most consumers became motivated and re-energized to look for work, the overwhelming barriers they discovered, made them feel more discouraged than before. Consumers shared feeling concerned about the loss of their disability benefits and medical coverage. During this time, government research reports and press releases reported about

the success of these programs in getting people off income assistance and back to work (Wallace, Klein, & Reitsma-Street, 2006). The reality described by consumers did not fit the media coverage. In order to provide options for consumers, I needed to find out the why there was such a significant disparity between the government programs and people with disabilities.

My employment has provided me with an intimate understanding of the Independent Living Philosophy and enlightened me to an established paradigm that was congruent with my personal views about people with disabilities. While I am familiar with subtle and explicit forms of discrimination and oppression being a native person growing up off reserve in an urban setting, it was not until college when I realized the discrimination and oppression experienced by people with disabilities and women. Being from a matriarchal clan system, I always felt very empowered as a native woman. In my immediate and extended family, there were always many people with various disabilities of all ages. These family members had various roles or duties to perform in our community, and many times it was my job to assist them with personal care in order for them to complete their duties. They were not isolated or left without a purpose. Once in college, I was shocked to learn how many people with disabilities were treated and that their contributions were not valued.

I chose carefully the glimpse about my upbringing in order to provide the layout of the foundation on which I position myself as a social worker and a researcher. My upbringing dovetails easily with the Independent Living Philosophy due to its emphasis of consumer control and choice, and the dignity of risk for people with disabilities. Oppression and discrimination experienced as a native person pushes my desire to confront social oppression which fits tightly with the emancipatory paradigm. Finally, the pragmatist paradigm appeals to my role in my family as a worker and caregiver. Each of these research paradigms will be outlined further in chapter three on methods.

It was intimidating to learn the many challenges I would face when researching

employment and disability. The report *Improving the Odds: Employment, Disability, and Public Programs in Canada* (L'Institute Roeher Institute, 2004) outlines the difficulties when undertaking research on employment and disability, and how “daunting” a task it can be. First, the variety of stakeholders, publicly regulated employers, different levels of government, educators and community agencies each have different levels of accountability and mandates with regard to the employment of persons with disabilities (L'Institute Roeher Institute, 2004). For example, the majority of front line services offered to people with disabilities are funded by provincial government departments; however, the federal government provides funding for wage subsidies and funding for disability supports through the Opportunities Fund, administered through Human Resources Development Canada.

Second, research on employment and disability amounts to research into many societal systems which directly impact the lives of people with disabilities and can contribute to their economic disadvantage or advancement. Issues of gender, age, sexuality, cause of disability, nature and severity of disability, visible minority status, and geographic location all impact employment. Disability is not relegated to one silo of service but crosses the service silos of health, education, social services, politics, etc.

Lastly, finding reliable information on issues of disability and employment was difficult. When conducting a review of the academic literature for this research, this issue was prevalent. Information describing employment and disability came in the form of government policy, annual reports and strategic planning documents, marketing materials published in media outlets, literature reviews, information directed to employers about hiring people with disabilities, and research reports outlining the effectiveness of government employment initiatives. This information was produced by a variety of stakeholders, from different levels of government, community groups, results-based employment agencies, disability and charitable organizations with a mandate to promote and fund employment programs, and/or interested media outlets where some sources support and others oppose the employment

initiatives being undertaken to increase employment for people with disabilities.

The interdisciplinary nature of research, disability, and employment necessitates the outlining of terminology that will be used throughout this thesis. Three common terms which will be used in this current research are disability, consumer, and results-based employment programs. While it is beyond the scope of this thesis to provide an exhaustive definition of the terms, the definitions provided are meant to highlight the meanings or aspects of the terms that are relevant to this thesis.

Terminology

Disability

A review of the literature revealed an overwhelming preoccupation to define the parameters of disability; for example, the Office for Disability Issues created an 86 page document titled *Defining Disability: A Complex Issue* (Government of Canada, 2003). The document provides a review of, and framework for understanding, disability definitions in key Government of Canada initiatives. The report aims to illustrate and clarify the complex and multi-dimensional nature and concept of disabilities found in policy, programs and benefits. It highlights the fact that confusion exists between definitions, eligibility criteria, and program objectives. For the purposes of this research, participants were required to self identify as people with disabilities. This is in line with the Independent Living Paradigm and the social model of disability. This approach is in contrast to most approaches which attempt to define disability and impose external criteria to a definition of disability.

Consumer

Consumer is a term used in the Independent Living (IL) Paradigm which refers to people with disabilities who access Independent Living Resource Centres (ILRCs). IL emphasizes control and choice which illustrates why in the Independent Living movement the term consumer is used versus terms such as client or patient. Consumer implies the power to decide what services to access and under what circumstances (CAILCa, n.d; Yoshida, Willi,

Parker & Locker, 2006).

Results-based employment programs

While scanning websites, readers will come across the term results-based in any or all federal and provincial government departments. Forestry, Health, and Indian and Northern Affairs all use the term in reports, service plans, and policy documents to refer to a management style that is held as the benchmark to promote accountability of government services.

With regard to employment and people with disabilities, results-based refers to the funding partnerships government enters into with organizations that are contracted to provide employment services to clients of government programs. These services are also referred to as performance-based services. Essentially these services link payments with the achievement of completion of a predetermined deliverable. Deliverables are usually divided into two categories outputs and outcomes. For example, outputs can include: software packages and other employment equipment purchased for clients, job descriptions created for clients, or number of clients placed in jobs. Outcomes typically include clients who are independent of government financial assistance for a certain length of time (Province of British Columbia, 2004, p. 38).

Thesis Structure

The second chapter will focus on the political context in Canada. While not the main focus of this thesis, I provide an introductory discussion of neo-liberal ideology and its link to the evolution disability social policy that is responsible for the creation of employment programs and services directed to people with disabilities. While it might be argued that the description of disability policy documents from the early 1980s to the present can be tedious, it provides a historical context for the discussion of disability and employment. In a review of the literature, not one document was found that provided a comprehensive overview of all government disability policy documents. Thus, this overview is critical for two reasons. First,

this overview illuminates the shrinking disability agenda of the federal government from *the Obstacles Report* (Government of Canada, 1981) which identified 130 recommendations in 20 different areas to the *In Unison* (Government of Canada, 1998) report that involved three levels of government with a focus on three areas: disability supports, employment, and income. Second, the overview demonstrates how the shrinking of the federal agenda shifted increasing responsibility to provincial government departments, which are designed to deliver income assistance programs not broad based initiatives designed to promote inclusion and improved quality of life.

Chapter three explores disability and identity. This explores an understanding disability as multiple and shifting subject positions versus a single category of identity. The various subject positions of disability are informed by, but are not limited to, demographics, identity politics, citizenship, the medical model, and the social model. A discussion of the possibilities of adopting a position beyond the medical and social model of disability concludes chapter three.

Chapter four will outline the methodology used in *A Longer Journey*. The three research paradigms that guided and informed decisions throughout the research process are presented; and, the methods used to conduct the research are described. The chapter concludes with a discussion of issues of validity and the strategies employed to attend to validity.

Chapter five will focus on the findings of *A Longer Journey*. First, a detailed description of the identified topics from the transcripts are presented which is central to the iterative process needed in a thematic analysis (Braun & Clarke, 2006). It is not enough to just identify themes, but they must be checked against each topic to increase the validity of the identification of the thematic findings. Second, this discussion is followed by a description of the two prominent themes – connection and control. Lastly, chapter five concludes with a discussion about the complex interconnectivity of the two themes.

Chapter six will provide a discussion of topics relevant to practice and policy in terms of research, social work, and employment service providers. Topics of this chapter include inclusion, directions for new programs and further research, the limitations of this research, knowledge translation activities that will be undertaken, and knowledge sharing in accessible formats.

Chapter II Canadian Political Context

Income support programs are a reality for many people with disabilities due to a variety of barriers that interfere with their ability to maintain meaningful employment (Driedger & Owen, 2008). Barriers include, but are not limited to, disincentives to employment from income and disability support programs, lack of accessible transportation, low education levels, limited ability to change jobs due to limited training, limited willingness of employers to provide accommodation, and discrimination by employers and coworkers (Andersson & Mattisson, 2001; Bystritsky, Saxena, Maidment, Vapnik, Tarlow, & Rosen, 1999; Crawford & Martin, 2000; Moss, Ullman, Starrett, Burris, Johnsen, 1999 ; Satariano, DeLorenz, 1996; Short, Vasey, & Tunceli, 2005; Yelin, Trupin, & Sebesta, 1999). Other barriers to employment for people with disabilities documented in the literature included limited support with substance abuse issues, lack of community resources to assist with integration, difficulty disclosing a disability, and pressures on personal relationships and finances (Crosse, 2003, Drew, Drebing, Ormer, Losardo, Krebs, Penk, & Rosenheck, 2001; Kreider & Pepper, 2002; Johnson & Favreault, 2001; Piggott, Sapey, & Wilenius, 2005). Further, the need for people with disabilities to receive time-unlimited and intensive support from an agency is an essential ingredient in finding and maintaining meaningful employment (Waghorn, Chant, White, & Whiteford, 2004). Time limits on support with employment are essential due to the dynamic nature of both a person's disability and the changing work environment (Barrett, Scott, Wiles, & Symmons, 2000; Blanc, Cisternas, Smith, & Yelin, 1996; Kaye, 2003).

In fact, Wilton and Shuer (2005) contend that people with disabilities are being squeezed between “a hostile welfare state and a labour market in which the 'able-body/mind' remains a largely unquestioned norm” (p.186). At the provincial and federal level, recipients of income support are mandated to enter into an employment plan, which can include the

participation in employment services in order to re-enter the workforce and, thus, to reduce their dependency on financial assistance. These employment services are provided by non-profit and for-profit agencies and are referred to as results-based or performance-based programs. The sole focus of these services is to get recipients employed and off income support programs.

The limited focus of these results-based services on the employment needs of the person creates frustration for the person with a disability. Much of this frustration stems from the fact that many barriers fall outside the mandate of these employment services (Cohen et al., 2008; Barrett, Scott, Wiles, & Symmons, 2000; Blanc, Cisternas, Smith, & Yelin, 1996; Kaye, 2003). Issues that fall outside the parameters of these services but directly impact the persons employment situation include, but are not limited to, lack of affordable housing, one-on-one advocacy services, accessible transportation, difficulties accessing income assistance and related benefits, medical coverage, and home support services (Cohen et al., 2007). These issues directly limit the person's ability to gain and maintain meaningful employment. Generally, workers of results-based services make referrals to other community organizations that specialize in information on disability supports, government services, and one-on-one advocacy to navigate the jungle of disability services (Cohen et al., 2007; Timmons, 2006).

While a focus on employment is not inherently a bad thing. Employment programs for people with a variety of disabilities have primarily focused on the individual with a disability and what he/she needs to do to improve/rehabilitate him/herself to gain employment versus initiatives to improve accessibility and accommodation. These results-based services employ experts and specialists to improve the person with a disability to “human capital and employability” (Wilton & Shuer, 2006, p. 187).

This chapter will focus on the evolution Canadian policy relevant in order to provide a

context within which to situate this research: the political context that people with disabilities must navigate on their employment journey. In this chapter, I will begin by focusing on the influence of neo-liberal ideologies that are arguably responsible for the creation of results-based employment programs and services directed to people with disabilities. Second, I provide a sketch of the evolution of disability social policy in Canada with a focus on British Columbia and Federal trends. While it might be argued that the description of disability policy documents from the early 1980s to the present can be tedious, nowhere in a review of the literature was a comprehensive overview of all government disability policy documents found.

Neo-liberalism

The “squeeze” referred to in the opening paragraph of this chapter (Wilton & Schuer, 2005, p. 186) results from the reforms made by both the federal and provincial governments to the welfare state that are informed by principles of neo-liberalism. “Most broadly, neo-liberalism argues that private market mechanisms, even when imperfect, perform better than state planning” (Mitchell & Simmons, 1994, p. 523). Further, it is argued that “state programs, especially those designed to promote equality, stifle competition and innovation from business and the voluntary sector, thereby dampening economic efficiency and growth” (Lobao & Hooks, 2003). Thus, based on these principles, economic policy in the post 1979 period moved decisively toward a laissez faire, deregulated approach. Industries like transportation and communications have been largely deregulated (Basu, 2004 ; Russell, 2002); and, the emphasis of the 'market discipline' and the emergence of competition for contracts has appeared in many areas of social life (Wilton & Schuer, 2005). Neo-liberal ideologies and practices position paid work as the primary way of ensuring social inclusion for people with disabilities (Wilton & Schuer, 2005). One consequence has been the emergence of results-based employment programs.

The governmental shift to results-based programs has increased pressure on community agencies and resulted in the commodification of disability. Commodification of disability occurs when monetary value is placed on meeting needs that arise from a disability and then services for individuals with a disability are directed toward realizing that monetary value (Albrecht & Bury, 2001; Pedlar & Hutchinson, 2000; Stainton, Hole, Charles, Yodanis, Powell, & Crawford, 2006). This commodification of disability is a direct result of the emergence of the laissez faire policies and has occurred in a number of areas such as housing, health care, home care, education, and employment services (Pedlar & Hutchinson, 2000).

The influence of neo-liberalism on social policy in Canada is dramatic in the area of employment and disability. Individuals are constructed as human capital; and, as such, neo-liberal policies and practices privilege paid work as the primary way of ensuring social inclusion for people with disabilities (Wilton & Shuer, 2005). Neo-liberal policies were not adopted and implemented overnight by governments; in most cases it took decades to lay the groundwork before sweeping changes were made.

There is a range of academics from a variety of disciplines that have tried to pin down a concise description of neo-liberalism which has resulted in a “myriad of ways that neo-liberalism has been used in scholarship across the social sciences” (Ward & England, 2007, p. 11). Ward and England provide a useful description of four ways neo-liberalism has been used. First, they describe neo-liberalism as an ideological hegemonic project.

Political dominance is exercised through the formation of class based alliances at a variety of spatial scales, actors and institutions who produce and circulate a coherent program of ideas and images about the world, and its problems, and how these are best solved (p. 11).

Secondly, they explain neo-liberalism as a policy and program, which refers to the transfer of ownership from the public to the private sector. The logic underpinning this transfer is that ownership by the market creates a more efficient system (p. 12). Thirdly, neo-liberalism is a state form, which refers to the restructuring of nation-states and includes the redrawing the boundaries between civil society, market, and state (p. 12).

The final way neo-liberalism is used, as described by Ward and England (2007), is neo-liberalism as governmentality, which refers to the ways which the relations among and between peoples and things might be imagined, assembled, and translated (p. 13). Governmentality “aims at transforming recipients of welfare and social insurance into entrepreneurial subjects, which may be motivated to become responsible for themselves” (p. 13). This understanding of neo-liberalism as a process, versus a set of principles etc., acknowledges the intended and unintended successes and failures of policies and programs (p. 13). Governmentality as a practice of neo-liberalism has direct implications for the current research which centres the experiences of individuals with disabilities; in particular, governmentality shapes the priorities and practices of employment services affecting the ways these programs are offered and designed for people with disabilities including the relations between workers and consumers.

Parton (1996) discussed the influence of neo-liberalism on social work practice. Specifically, highlighted is the “antagonism towards public expenditure on state welfare, an increasing emphasis on self help and family support, the centrality of individual responsibility, choice, and freedom, and an extension of the commodification of social relations” (p. 10). As a social worker in the area of people with disabilities, I have seen the impact of these themes and witnessed the dramatic change in the services delivered to marginalized groups of people. But, in recent years, the diversity of the changes and the speed at which they were

made seemed to be very different than past government changes I had witnessed. This prompted me to explore neo-liberalism further.

While it is not possible to fully explore the parameters of neo-liberalism for the purposes of this thesis, a description that expands on the sketch provided by Parton (1996) is needed. Basu (2004) provides a historical overview of Canada after World War II and how the Great Depression of the 1930s provided the “the intellectual-political context for the Keynesian breakthrough” (p. 622). This time is noted for the activist government, expansion of public services and the welfare state, and substantial constraints on corporate power. However, as the conditions changed in the 1970s with the increase of globalization, there was a “crisis of the Keynesian state” which provided fuel for the principles of neo-liberalism to grow: individualism, privatization, and decentralization (p. 622).

Neo-liberalism is not only an end state. Neo-liberalism is also a process “consisting of a multiplicity of openings and closings” (Ward & England, 2007, p. 3) that lead to transformations. One of the unique techniques to change is “the stealth approach” (Basu, 2004, p. 629). The main goals of this approach are eliminating deficits and reducing debt, and the changes needed to make this happen are usually expressed in “arcane and technical language involving changes to obscure legislation and are carried out with considerable speed” (p. 629). Ward and England (2007) explain that key to neo-liberal transformations are the expansion in the time and space of the market – e.g., the expansion of trading hours, the creation of a new transaction-intensive market and development of artificial transactions, and transaction costs - and a shift from an emphasis on property to the valuing of contracts. The growth of the financial services market is related to these neo-liberal features. The entire sector is itself a transaction cost. “The expansion of the sector and its office employment are in direct contradiction of propaganda about 'more efficiency and less bureaucracy' in the free

market” (p. 5).

With the emphasis on contracts versus property, the privatization and splitting of services is common. The period of these contracts is reduced, therefore, increasing the frequency of contract change (p. 4). As contracts change, assessments and audits are intensified. Another result of the emphasis on contracts is supplier maximalization, which includes a range of enterprises that compete for each contract:

The ideal would be that every enterprise competes for every contract offered, maximizing competition and market forces. In the case of the labour market, the neo-liberal ideal is the absolutely flexible and employable employee, who can (and does) apply for every vacancy. In reality, an individual cannot perform every kind of work – but there is a real development toward non-specialized enterprises, especially in the producer service sector. In neo-liberalism, instead of the traditional 'steel tycoon' or 'newspaper baron' there are enterprises which 'globally link people and knowledge and cultures' or 'advise and implement solutions to management issues' (Ward & England, 2007, p. 6)

This quote is particularly relevant to the situation people with disabilities find themselves in when accessing support with employment programs. If the neo-liberal ideal is the “absolutely flexible and employable employee, who can (and does) apply for every vacancy”, then many people with disabilities are excluded even before they access these services. Neo-liberalism is influencing the development of policy which oversees the structure of results-based employment services, resulting in services created that operate from a premise that does not fit the needs of the people it is meant to serve.

The above highlights of neo-liberalism help to illustrate the development of results-

based employment programs. While results-based programs have had both positive and negative influences on employment for people with disabilities, there is a gap that needs to be addressed. When results-based services have not been effective, what is available in order for people with disabilities to access the support they need to gain meaningful employment?

Evolution of Policy

An overview of the federal and provincial disability social policy documents reveal several important findings. First, neo-liberal ideologies have played a prominent role in the recent developments and trends in social policies influencing the employment experiences of people with disabilities (Parton, 1996; Wilton & Shuer, 2005). Second, people with disabilities face significant barriers to achieving and maintaining meaningful employment (Cohen et al., 2008; EEO Trust, 2005; Province of British Columbia, 2003). Third, although disability and employment are discussed in policy and government reports, there is a clear need for better coordination of policies, programs, and services among governmental departments, business sectors, educational institutions, and community groups (Barnes & Mercer, 2001; Litvik & Enders, 2001; Stainton et al., 2006). Fourth, it is important for policy makers, service providers, and support workers to examine and to understand the particular ways in which individuals with disabilities experiences are shaped by social policies (Jongbloed, 1998, 2003, 2006; Swanson, 2004). In fact, Jongbloed (1998) urges that it is paramount to understand the ways social policy shapes people with disabilities lives in order to assist clients “to engage in occupations which are important to them and which are physically and financially feasible” (p. 200). And, finally, although complex and requiring a breadth of knowledge, research focused on disability and employment is urgently needed. These findings support the importance of my current research - *A Longer Journey*. The current research emphasizes the experiences of people with disabilities in order to design better employment programs tailored

to their needs. Thus, a fundamental premise of this research is that if the employment of people with disabilities is to be improved, then the experiences of people with disabilities must be emphasized (Strunin & Boden, 2000).

Government policy documents are crucial in the area of disability and employment. Policy documents reflect popular perceptions of disability and prescribe how disability should be responded to (Titchkosky, 2006). Titchkosky (2006) writes, “treating policy text as a social action means resisting the idea that policy is merely a basis, or plan, or preparatory sketch for future activities” (p. 56). Policy interprets what disability is, and is not, for readers. The consequences of this definitional process are important to consider because these conceptions are connected to future policy development and implementation that directly impact the daily lives of people with disabilities (p. 57). For example, in her examination of the Government of Canada's *In Unison* reports (1998; 2000), Titchkosky (2003) reveals that the Canadian governments' discourse on disability and inclusion “is a technology by which individuals and populations are constituted as a problem, and is the mechanism through which collective relation this 'problem of disability' are governed” (p. 517). Thus, in order to address how governments constitute disability as a problem, the underlying social attitudes need to be exposed.

Government policy documents reinforce that employment for people with disabilities is the primary concern for all levels of government in order to reduce dependence on income support programs (Prince, 2008). The number and scope of policies that have been introduced and developed can be construed positively because from the government's point of view, people with disabilities are an important source of potential labour (Grover & Piggot, 2005). Either way, the purpose of government programs is to move people into employment as soon as possible; this has an immense and immediate impact on the experiences people

with disabilities have with these programs and services.

Federal Policy Trends

An overview of disability social policy documents developed by both the federal and provincial levels highlights an evolution of policy priorities aimed at getting people with disabilities employed. These documents provide a foundation for the development of employment programming accessed by people with a variety of disabilities.

At the federal level, the first major disability policy document was *the Obstacles Report* (Government of Canada, 1981). As the name suggests, *the Obstacles Report* identified key barriers faced by people with a variety of disabilities and outlined practical actions. Of the government reports reviewed for this research, *the Obstacles Report* was the only report to highlight the experiences of 12 Canadians with disabilities, including pictures in the report. When introducing the profiles, the authors state “[t]he Members of the Special Committee feel that these twelve profiles need no commentary” (p. 8). Throughout the document were quotes from people with disabilities, reinforcing the participation of people with a variety of disabilities in the development of the report. The 130 recommendations made in the report are divided into 20 topics which included employment, health care, income, human rights, education, attitudes, international perspectives, and prevention.

The recommendations of *the Obstacles Report* led to various standing committee reports of federal government departments, most of which received little attention from disability groups until *Equal Citizenship for Canadians with Disabilities: The Will to Act* (1996) was released. The intention of this report was to answer one question: “What is the federal role in the area of disability?” (Government of Canada, 1996). This report was one of the first to emphasize the concept of full citizenship for people with disabilities.

In Unison: A Canadian Approach to Disability Issues (Government of Canada, 1998)

outlined federal objectives and policy directions for disability supports, employment, and income representing the first time federal, provincial, and territorial governments have agreed on a common vision and policy direction in the area of disability. It is astounding that in the years between the Obstacles report and the first *In Unison* report, disability issues and federal responsibility were condensed into three areas: disability supports, employment and income. Prince (2004) argues when disability policy-making is reviewed, a 'deja vu discourse' is evident.

Advancing the Inclusion of Persons with Disabilities (2002) introduced an “accountability framework”, which provided a framework that would allow Canadians to assess the following questions: What does inclusion mean, and what are its key elements? How close is Canada to fully including persons with disabilities in society? How can progress toward inclusion be measured? How does the Government of Canada help advance inclusion? (Government of Canada, 2002b). The report provides an overview of key the initiatives that federal departments and agencies have implemented. *Advancing the Inclusion of Persons with Disabilities* (Government of Canada, 2004, 2005, 2006) does not set key policy decisions; rather, they reflect what has happened in a variety of federal government departments.

One of the only sources offering direction for a federal government vision on disability issues is the *Office for Disability Issues (ODI) Strategic Plan 2002-2007*. This plan was developed to “serve as a guide to working with partners' to promote full participation of Canadians with disabilities in learning, work, and community life” (Government of Canada, 2002a, p. 4). While the strategic plan does not identify any specific goals or directions of the department, it does outline how the department will use a horizontal management style to “work across organizational boundaries in a coordinated and collaborative manner in order to

achieve mutually agreed-upon objectives” (Government of Canada, 2002a, p. 21). One consequence of the trend to the narrowing of the federal disability agenda has been the offloading of responsibility onto provincial governments. Policies related to income and employment are individualistic in nature because change in these areas would require fundamental changes to how government approaches unemployment and significant reform to the income assistance system (Jongbloed & Crichton, 1990).

Disability Benefits in British Columbia

In British Columbia, Service Plans and Annual Service Plan Reports are the equivalent to federal policy documents. Provincial departmental service plans provide information about priorities and a basic recipe as to how the government will conduct its business. The Ministry of Human Resources (now called Ministry of Housing and Social Development - MHSD) Service Plan 2002/2003-2004/2005 states that these reports “will become the key tool by which government will manage public resources to ensure government programs are contributing in a measurable way, to key government priorities in an efficient and effective manner” (Province of British Columbia, 2002a, p. III).

In April 2002, the *Employment Strategy for Persons with Disabilities* provided a framework for the development of the Minister's Council on Employment for Persons with Disabilities. The principle goal of the Minister's Council was to advise the government regarding solutions and strategies for increasing the employment and independence of persons with disabilities, particularly through partnerships with business and industry in British Columbia (Province of British Columbia, 2002b).

The MHSD mandate includes the provision of income assistance, disability benefits, and emergency services in BC. *Ministry of Housing and Social Development 2006/07-2008/09 Service Plan* notes that the proportion and number of clients with employment

obligations declined significantly since June 2001 due to strong economic growth, improved employment opportunities, and an increase in the number of people designated as Persons with Disabilities (Province of British Columbia, 2006). However, Adams & Tait (2004a) suggested that the effectiveness of provincially funded employment programs as evidenced by the decline in numbers in the caseloads of provincially funded employment programs between 2002 and 2004 relates to changes in government policies with respect to eligibility and benefits, versus the interventions provided by results-based services (p. 4).

This finding was also supported by the report *Denied Assistance: Closing the Front Door on Welfare in BC* (Wallace, Klein, & Reitsma-Street, 2006). This report examined the changes to the eligibility for income assistance and demonstrated through studying Freedom of Information requests that the decrease in caseload is not from more people leaving or exiting welfare, rather there are less people entering the system and accessing assistance (Wallace, Klein, & Reitsma-Street, 2006). This was part of the neo-liberalization of the income assistance system in BC.

In B.C., disability benefits are tied to the same system which regulates income assistance. There have been significant changes to Income Assistance, first in 1996, the B.C. government brought in the new Disability Benefit program, Level I and Level II. Then in 2002, the government introduced sweeping changes to the eligibility requirements for income assistance and Disability Benefits. With the new B.C. Employment and Assistance Act, income assistance levels decreased, restrictions on eligibility increased, verification activities increased, and the use of for profit companies delivering employment programs increased (Boyce, Boyce, & Krogh, 2006; Swanson, 2004; Tang & Peters, 2006).

Schafer & Clemens (2002) graded the reforms made in B.C. and gave the B.C. government high marks. For example the report articulates,

The commitment by the B.C. government to focus on back-to-work programs on employment as demonstrated by the strong emphasis on employment...while making limited training and education available...is positive. Moreover, the inclusion of performance-based payment systems ...is a step in the right direction. For this, the B.C. government earns a B+ (Schafer & Clemens, 2002, p. 21).

However, the B.C. Government was chastised for actions pertaining to canceling the earnings exemptions:

Although the increase in the earnings exemptions for disabled welfare recipients is commendable. The dismantling of the earnings exemptions for all almost all welfare recipients in the province is an unfortunate development in B.C. and as result, is worthy of an F (Schafer & Clemens, 2002, p. 22)

The most drastic changes in 2002 was the introduction of the required two year independence test, a three week waiting period, and only able to receive income assistance for two out of every five years. These changes were so drastic they received international attention from the UN Convention on the Elimination of all forms of Discrimination against Women (Tang & Peters, 2006, p. 577).

At the time of this research (2008), to apply for disability benefits in the province of B.C. applicants must first qualify for income assistance, which requires applicants to have no financial resources available to them: a person who could not work and was accessing Sickness benefits thirteen weeks through Employment Insurance, would not be eligible for income assistance until those benefits were exhausted and they “must divest themselves of most of their assets” (Prince, 2008, p. 28). This system of last resort creates enormous uncertainty and stress for applicants. Once eligible for Income Assistance with a standard rate of \$610 per month (as of April 2007), then individuals are eligible to apply for either

Persons with Persistent Multiple barriers (PPMB) or Disability Benefits, which can take anywhere from four to fourteen weeks to qualify; and, a high percentage of applications are turned down requiring applicants to navigate a tedious appeal process. Finally, once a person qualifies and is designated as a Person with Disabilities (PWD), they are made to apply for Canada Pension Plan Disability, in case they are eligible for financial support through the federal program.

Eligibility for disability benefits through the provincial government can be significant for people with disabilities who rely on the standard rate for financial support of \$906.00 and medical coverage. All recipients of Income Assistance (IA), People with Persistent Multiple Barriers (PPMB) and People designated as persons with disabilities (PWD) are required to have an employment plan in place. For many people with disabilities their employment plan includes accessing results-based employment programs to maintain eligibility. One of the incentives to encourage recipients designated as people with disabilities to access support with employment is an earnings exemption of \$500.00 per month. In 2004, the evaluation of the provincially funded employment programs revealed that a number of people who access the program do not benefit; more than 40% of people accepted into these programs do not achieve independence within the program time-lines (Adams & Tait, 2004b, p. 4). People who were considered more employable and did not need extra support or additional job related expenses and accommodations are placed first. This leaves clients who are not as job ready on the caseload of results-based contractors. During my employment as a Career Development Facilitator, I referred to this as 'creaming' or as one federal department manager described it to me as 'cherry-picking'. The limited supports from these results-based services, combined with the restructuring of caseworkers in government departments (e.g. MHSD, Community Living British Columbia, and Service Canada), has changed the role of the

helping relationships (Parton, 1996, p. 11). Now the focus is to assess need and risk and centralizing the need for monitoring and review are central (Parton, 1996, p. 12). Casework provided a distinctive contribution in its claim to be concerned with the whole person: “it provided a method for assessment and intervention and thereby appeared to legitimate social work and to overcome its essential ambiguities” (p. 9). The lack of casework and available workers are especially evident in the services provided by results-based employment programs. Services are directed with one goal in mind: securing employment for clients. Clients are referred out to other agencies for any issues that fall outside of that realm. This restricted mandate matches the evolution of policy by the federal and provincial governments to a narrow area of responsibility with regards to people with disabilities.

Request for Proposal Process

The difference in delivery and program policy between provincial and federal approaches are significant and have a direct impact on the delivery of service. The provincial government uses a lengthy Request for Proposal (RFP) process in order to reduce the number of contracts in the programs and the province. This process favours large organizations with the financial and human resources necessary to successfully compete for contracts and to compete for large regions of the province (Johnson, 2006). Large non-profit and for-profit organizations have the capacity and the resources to put together complex proposals and the resources to deliver on all aspects of the contract, including significant administrative responsibilities. As well, these organizations have the resources to be able to work under a results-based contract where payment is delivered only after certain incentives are met. Most small non-profits exist from month to month and, therefore, cannot compete effectively in this environment (Johnston, 2006, p. 11). As a result a large number of contracts are being awarded to large organizations that are frequently not from the

community being served. Thus, this approach does not allow for the building of relationships with either the client or the local community; the focus is solely on the employment opportunities at the expense of providing individual solutions (Johnson, 2006). Further, services being delivered from outside the community do not provide long term support and are not able to quickly and adequately address setbacks that can occur when entering the labour market (Johnston, 2006, p. 9). Participants of *A Longer Journey* commented on how if they needed information or support with accessing services from government departments or health services, the results-based employment service referred them to a local disability organization. Further, in Vernon, results-based services do not appear to have any strong community partnerships with other employment or disability organizations. Two participants of this research questioned what partnerships these results-based services have with disability organizations.

In contrast, the federal model of delivery is more concerned with local realities and more responsive to community concerns. This model emphasizes more flexibility and more mutual problem solving to find something that works for the government priorities and the needs of the client group (Johnston, 2006, p. 14). Currently, much of the federal funding and results-based employment contracts are in the process of being transferred to the provinces. In B.C., it is expected that by 2010 many of the federally funded contracts will be transferred over to the Ministry of Housing and Social Development, and in order to renew the contracts, organizations will have to go through the current RFP process. With no indication by government to change the current structure, there is not much hope that services will improve (Johnson, 2006).

In conclusion, the narrowing of the policy by governments at the provincial, territorial, and federal levels has led to the limited spectrum of services offered matches the limited

spectrum of services offered by results-based employment services. As the executive director for a disability organization, I witnessed the frustration of people with disabilities, many of whom stated, “I do contribute to my community in many ways, not just through employment”. People with disabilities became further frustrated when they had to navigate so many community resources in order to meet their diverse needs. The overarching discourses of these government policies and practices will be expanded on in the next chapter.

Chapter III Disability and Identity

The preceding chapter “demonstrate[s] the messiness of and the contradictions within” (England, Eakin, Gastaldo and McKeever, 2007, p. 170) neo-liberalism and how it impacts the lives of people with disabilities to secure employment through results-based employment programs. This “messiness” can be attributed to the overarching discourses that permeate government policy and practices. Titchkosky (2003) highlights that the discourse of government on disability and inclusion “is a technology by which individuals and populations are constituted as a problem” (p. 517). The depth and breadth of this “technology” is deeply embedded in policies and practices, which in turn has had enormous implications for disability and identity. Freund (2001) highlights that being labeled as a person with disability has socio-political consequences ranging from exclusion (e.g. job discrimination) to the ability to claim special accommodation (e.g. parking spaces for people with disabilities). Freund (2001) underscores that definitions of disability change overtime, along with rules for applying those definitions.

To tackle disability and identity, I will first highlight the perpetual evolution of the macro contexts which significantly impact the identity of people with disabilities. Next, I will illustrate common discourses encountered during an employment journey and the implications on disability and identity. Discourses to be explored will include demographics, citizenship, identity politics, and the medical and social models of disability. These discourses were chosen due to their prevalence in the contexts in which people with disabilities navigate their employment journey. Lastly, a new way of viewing disability that is informed by post-modernism, called dis-modernism (Davis, 2002), will be introduced to address the instability of concepts of disability and identity.

Macro Context, Disability, and Identity

People with disabilities have been isolated, incarcerated, observed, written about, operated on, instructed, implanted, regulated, treated, institutionalized, and controlled to a degree probably unequaled to that experienced by any other minority group (Barnes & Mercer, 2003, p. 41). The oppression of women and black people was first justified by perceived biological deficiencies; however, as new knowledge and conceptualizations have emerged, these perceptions lessened. With regard to disability, there continues to be an emphasis on the deficiencies of the mind and body of people with disabilities in both policy and public attitudes (Barnes & Mercer 2003).

Shakespeare (1996) emphasized that disability identity is important because it is through identity that an understanding of the complex relationship between individuals, societies, and biology can be explored. Outside of the disability studies literature, most of the writings about disability and identity have presented identity as something fixed or stable, and unproblematic for a person with a disability. The role of the body in identity formation and the social ascription of role and its political implications have tended to be ignored (Watson, 2002). This current research focuses its attention to underscoring the diversity of disability and identity

During a recent branding process for the national disability organization I work for, it became obvious early on that it would be years before all 28 centres would adopt the new branding. But above all, one aspect that everyone agreed on was the need for the inclusion of the word disability in the slogan and the emphasis of independent living in the logo. As one national board member described, “[d]isability is our business and Independent Living is how we conduct our business”. This emphasis of disability in the identity of the organization was

meant to emphasize the diversity of people with disabilities. What became clear was that with such diversity, one theory of disability and identity is insufficient and current models are too restrictive and run the risk of essentializing disability.

Corker (1999) cautions that a social theory that does not take into account the changing relations of macro and micro contexts will diminish the relevance of that theory to the experience of people with disabilities (p. 631). In this current research, I seek to underscore the relevance of this point by highlighting the impact of neo-liberalism and government policy on the experiences of people with disabilities and results-based employment programs, while recognizing that neo-liberalism and social policy only partially influence the complex experiences of people with disabilities have during their employment journeys. Two examples from Taylor (1998) are outlined to link the previous discussion of neo-liberalism and social policy to disability and identity.

Within macro contexts such as the welfare state, specific groups need to highlight their differences and focus on what is particular about their social identity. At the same time, groups need to deny their specificity by appealing to a wider criterion (Taylor, 1998, p. 332). For example, when disability organizations call on governments for action on disability issues, governments emphasize the need for disability organizations to present a unified position about priorities for action that represents all disability groups (Barnes & Mercer, 2001; Boyce, Krogh, & Boyce, 2006; Prince, 2006; Stienstra & D'Aubin, 2006). For many disability groups this is difficult to achieve due to the diversity within groups and organizational structures. Thus, macro processes and practices actively constitute the identities of people with disabilities.

Further, Taylor (1998) differentiates between categorical and ontological identity. Identity as sameness, categorical identity, results from the recognition and classification of

others as the same. Identity as uniqueness, ontological identity, results from the recognition of individual selves as different from other selves (p. 345). Using the categories Taylor describes adds a different perspective of analysis when applied to people with disabilities accessing employment services and income support programs at the same time. In order for people with disabilities to qualify for income assistance and/or provincial disability benefits under the current structure, they must emphasize their identity as a person with a disability. In doing so, the provincial ministry totalizes (or essentializes) their identity as being a “person with disabilities”. Paradoxically, government language and policies surrounding the continuation of eligibility for disability benefits centre around discourses of “gaining independence”, “being a worker”, and “contributing to society” (Swanson, 2004). This tension furthers reinforces the squeeze people with disabilities experience between the welfare state and labour market as described by Wilton and Schuer (2005).

Demographics

Demographics is another discourse that has implications for disability and identity. Statistical information can be a useful tool to illustrate how many people will be negatively impacted or will benefit from changes to social policy. Most of the current statistical information about people with disabilities is provided by the *Participation and Activity Limitation Survey* (PALS 2001; 2006). PALS is a national survey designed to collect information on adults and children who have a disability, that is, whose everyday activities are limited because of a condition or health problem (Statistics Canada, 2006). According to the 2001 PALS, 3.6 million Canadians or 12.4% of the population were people with disabilities and were residing in 10 provinces (excluding residents of First Nations communities). PALS 2001 did not collect data in the three Territories or in institutions, meaning there is an undercount of seniors with disabilities in 2001 (Furrie, 2006, p. 22). However, in the 2006

PALS, the totals do include the Yukon, Northwest territories, and Nunavut, which would account for the increase of people with disabilities to 4.4 million Canadians or 14.3% of the population are people with disabilities. The percentage in British Columbia of people with disabilities is 638,640 or 16% in 2006 (Statistics Canada, 2006).

In the 2001 survey, limitation in activity as a result of pain was an addition to the screening questions, and it resulted in the addition of 148,755 individuals who reported a limitation in activity due to pain (Furrie, 2006, p. 28). In 2001, mobility was the type of disability most often reported by Canadians aged 15 and older; in 2006, pain was the type of disability most often reported (Statistics Canada, 2006). Other statistics related to employment and disabilities reported by PALS includes the finding that the cost of post secondary education has been steadily increasing in the past decade (Furrie, 2006, p. 28).

Before PALS 2001, statistical information was provided by the *Health and Activity Limitation Survey* (HALS 1986;1991). This ten-year gap between the HALS and the PALS offered an opportunity to review the approach and develop a new survey strategy (Statistics Canada, 2001). Accordingly, to better identify the PALS target population, major changes were made to the structure of the sample and the filter questions identifying persons with disabilities. As a result, comparisons cannot be made between the HALS surveys (1986; 1991) and the PALS (2001; 2006). Statistics Canada (2001) outlined these filter questions would serve as the standard for identifying persons with disabilities in other Statistics Canada surveys, and it will be possible to compare information from one survey to another (Statistics Canada, 2001). With the inclusion of the territories in the 2006 PALS, the structure of the sample is again changed, reducing the comparisons that can be made between PALS 2001 and 2006.

This fluctuation between HALS 1986, PALS 2001 and 2006 in the number of people

with disabilities due to change in the sample has a significant implication for people with disabilities. Linton (1998) highlighted that when people's identity and access to resources is based on how the government defines their existence, a change to the methodology of the survey that proves their existence has serious implications for resource allocation to the group. Further, the fluctuation in the numbers of people with disabilities impacts the political pressure they can exercise to influence policy change (Linton, 1998).

Citizenship

A third concept interacting with notions of identity and disability is citizenship. Torjman (2001) explained people with disabilities have been pushing the agenda of citizenship because they believe that citizenship represents the key to opening the doors to employment, disability-related supports and services, and access to transportation and communications (p. 161). Further, the Charter of Rights and Freedoms makes specific reference in Section 15 to disability. The Charter overrides all other statutes therefore requiring all jurisdictions to confer similar rights consistently across the country. This would provide more consistency in the availability and delivery of supports and services for people with disabilities (p. 162).

Despite the inclusion of disability in statutes to recognize their status as equals, has not resulted in actual equality for people with disabilities. "To be a citizen is to be able to participate in key functions such as work, leisure, political debate, travel, and religious observance. The opposite of citizenship is social exclusion" (Drake, 1999, p. 41). Disability organizations taking up the discourse have not had the breakthrough needed for true equality to be achieved.

The original intent of using the concept of citizenship in relation to disability was to emphasize the responsibility of government to develop and implement inclusive policies. Drake (1999) emphasized that however a group of people choose to identify themselves, it is

the responsibility of government to ensure they are included due to their inherent human rights. Further, equating citizens with consumers, their exercise of power is limited to a particular set of predefined choices or merely to the expression of a preference.

Consumerism has little to do with taking control (Drake, 1999, p. 43). Where citizenship is used to mean 'choice', it may offer people with disabilities no more than a different sort of shackles (Drake, 1999, p. 44).

Finally, the notion of contestation in relation to citizenship has been well documented (Drake, 2001; Prince, 2007; Shakespeare & Watson, 2001). For people with disabilities, claiming income security benefits can be understood as an experience of contested illness and contested citizenship (Prince, 2007). Reports by governments, disability organizations, and disability policy advocates are filled with discourses of citizenship, participation, and inclusion. However, this is problematic due to the contested nature of citizenship (Prince, 2007, p. 54).

Identity Politics

Identity politics is based on the particular life experiences of people who seek to be in control of their own identities and who claim that socially dominant groups have denied them this opportunity (Sampson, 1993). Consumer driven organizations are an example of identity politics in action and have emerged in response to deteriorating social conditions from the political and economic climate created by laissez faire governmental policies. Consumer organizations within disability communities fundamentally exist because they understand that people with disabilities need a strong voice in the disability movement (Hutchinson, Arai, Pedlar, & Lord, 2004); and, these organizations have played a significant role in the protection and advancement of rights for people with a variety of disabilities.

With the dominance of the “neo-liberal doctrine of 'one size fits all” (Basu, 2004, p. 623), it is critical that disability is not viewed using only one lens. For example, the social model of disability focuses on the barriers in society which prevent people with disabilities participating fully. This focus on the social construction of disability and related barriers, emphasizes only one aspect of a person's experience, a person's disability. Identity as a person with a disability may not always be the key defining characteristic of the person, the way they define themselves depend on place, time and context (Bransfield, 1999, p. 401). This emphasis on one aspect of a person's identity is not unique to the disability movement. The fundamental problem is that each oppressed group focuses on a single system of oppression, believing it to be the primary cause discrimination (Vernon, 1998). It is not possible to “simply prioritize one aspect of our oppression to the exclusion of others” (Begum, 1994, p. 61).

The concept of multiple oppression has been used to illustrate the complexity of issues surrounding people with disabilities (Vernon, 1998). However, it can be misleading because it implies that aspects of identity and different dimensions of inequality can be separated “as if they can be compartmentalized in everyday experience and then added together in an overall balance sheet” (Barnes & Mercer, 2003, p. 61). The idea of multiple oppression has been referred to as interlocking equalities (Dish, 2003), interlocking oppressions (Razack, 1998) and overlapping oppressions (Wendell, 1996). Vernon (1998) stated the issue of multiple oppression is treated as though it is an issue which concerns only a minority of people with disabilities. The majority of people with disabilities consists of cultural groups (black, aboriginal etc.), women, LGBTI, older people, those from the working class, all of whom experience the negative effects of being rendered a multiple “other” in consequence of deviating from an established norm in several ways (Vernon, 1998). Davis (2001)

underscored “the solution to the problem of identity is not the inclusion of disability to the roster of favoured identities” because the list of identities will only grow larger (p. 537).

Medical Model

The focus of the medical model of disability is on the biological aspects of disability, the physical or mental impairment; thus, the goal centres on fixing or curing the person from this biological deficiency/problem (Rioux & Samson, 2006; Williams, 2001). With such a limited focus there are direct implications for identity possibilities. Defining a person solely on the basis of a physical, mental or emotional condition does not provide a rich and full illustration of the experience of people with disabilities. Medical issues for a person with a disability may be a small aspect of her/his whole life, but medical professionals have considerable power to control other aspects of the person's life (Bricher, 2000; Humphrey, 2000). For example, to access disability tax credits and government income support programs at both the federal and provincial levels, a medical report is needed from a doctor. In essence, when it comes to the disability sectors, doctors are the gate keepers for society's social safety net.

The medicalization of disability frames variation of people as a deviance from the norm, as a deficit, and a personal tragedy for the individual and society (Linton, 1998; Oliver, 1986). This perceived deviance emphasizes the difference of people with disabilities, and has in turn been used to conceptualize the disability rights movement in the US and Canada as a minority group, who are disadvantaged and denied full citizenship (Russell, 2002). This conceptualization has significant implications for people with disabilities wanting to articulate an identity that is in direct opposition to the medical model of disability.

Both Shakespeare (1996) and Linton (1998) make the point that the dominance of the medical model definition of disability separates people with disabilities into diagnostic categories, and this definition assumes a certain standard from which people with disabilities

do not meet. This definition focuses on particular groups of people with impairments and ultimately denies disability as common social experience which unites people with disabilities (Shakespeare, 1996). This idea of a common social experience of people with disabilities provided the foundation for formation of the social model of disability.

Social Model

There has been a significant change in the analytical frameworks that have been applied to disability theory in the last century. In 1996, Mike Oliver described these changes in the literature as evidence of a major transformation in disability theory from strictly a medical definition of disability to a host of new paradigms (Donoghue, 2003). In order for these new paradigms to be articulated and moved forward through research, disability issues and ultimately the identity of people with disabilities have to be articulated differently.

With such depth and complexity surrounding the oppression experienced by people with disabilities, it is easy to understand how the social model of disability has become one of the most popular disability models. It is used by people with disabilities to convince government decision makers to increase physical accessibility and promote inclusion and full citizenship. Shifting the focus from the limitations of people with disabilities and turning attention to the physical structures in society has been pivotal for the advancement of disability rights. Using a social model approach, the focus is put on issues such as affordable housing, health, welfare, education, employment, or immigration (Humphrey, 1999).

Oliver (1990) originally conceptualized the Social Model for his students to make sense of the complexities related to disability. The development and articulation of the social model of disability by people with disabilities embodies a rejection of the individual model of disability (Oliver, 1990). The social model of disability does not deny the problem of disability but locates it within society and its failure to provide appropriate services which adequately

ensure the needs of people with disabilities are being addressed (Oliver, 1990). In the broadest sense, the social model is a dramatic concerted shift away from an emphasis on individual impairment as the cause of disability (Barnes, 2001).

The social model of disability was pivotal in providing an alternative in how to conceptualize disability that was in direct contrast to the medical model. Tregaskis (2002) highlighted that various competing positions have been elaborated on from the original starting point of the social model. In the early development of the social model, it was criticized for adopting values of a capitalist society by emphasizing work and independence and ignoring the differences that various disabled people experience as a consequence of gender, sexuality, race, culture or other distinctions (Marks, 1999). Further, the social model requires people to identify as a person with a disability. In an attempt to avoid medical criteria associated with the nature of impairment, the social model emphasizes a person must have a primary identity as a person with a disability. This requirement, therefore, may exclude many people with medical conditions that may be considered a disability. For example, many people with chronic illnesses and seniors would not necessarily identify themselves as having a disability (Marks, 1999).

As these criticisms emerged in the mid to late 1990s, the social model evolved and a new focus was placed on the experience of the people with disabilities and their bodies. Early in the articulation of the social model, the social model asserted that the body and the impairments have nothing to do with disability (Freund, 2001). Yet, many people find it is the experience of their bodies and not only physical and attitudinal barriers such as inaccessible public transportation which make full integration difficult (Crow, 1996). Crow (1996) emphasized that it is vital not to assume people who experience pain and illness are

experiencing a kind of 'false consciousness'- that if all the external disabling barriers were removed they would no longer feel like this.

Pinder (1995) underscored the social model has glossed over the impact of illness episodes and the silence of pain. In doing so, it may paradoxically have added to, rather than alleviated the difficulties people with disabilities experience when accessing the labour market (p. 623). Pinder articulated that attempts to sanitize disability and present it as something mechanical and distinct from cultural beliefs is detrimental to the overall understanding of the experience of disability (p. 624).

Demographics, citizenship, identity politics, the medical model, and the social model of disability have all been used to describe the experience and understand the identity of people with disabilities. When these discourses are encountered, on their own or in combination during an employment journey, they dictate what aspect of the person's identity will be emphasized in a particular setting. Fragmentation of identity causes significant frustration for many people with disabilities. The coexistence of old and new discourses limits identity possibilities. However, it is possible to introduce new ways of understanding the experience and identity of people with disabilities. These new directions for disability and identity guide my research.

New Directions for Disability and Identity

Academics in the field of disability studies aim to develop a social theory of disability, which comes as close to explaining the 'reality' of people with disabilities (Corker, 1999). Crow (1996) proposed a new model that would operate on two levels: a more complete understanding of disability and impairment as social concepts, and a recognition of an individual's experience of her body over time and in variable circumstances. Crow (1996) argued disability and impairment interact. Impairment must be present in the first instance for

disability to be triggered: disability is the form of discrimination that acts specifically against people with impairments. This does not mean impairments cause disability, but rather that it is a necessary condition for that particular oppression to exist (Crow, 1996).

Susan Wendell (1997) pushes for a social and political theory of disability that is feminist because disability is largely socially constructed and more than half the people with disabilities are women and approximately sixteen percent of all women have disabilities. Further, I would assert that theory development should also reflect the experience of cultural groups. In a Canadian context, it would be imperative to include the perspective of Aboriginal people with disabilities due to the disproportionate number of Aboriginal people who have disabilities; rates of disability among aboriginal people in most reports are twice the rates of non-aboriginal people (Government of Canada, 2004).

Post-modernism offers numerous perspectives to assist in reducing the risk of essentializing people with disabilities. Williams (1996) explores developments in feminist post-modern theorizing in relation to other social theory and hopes to “elaborate on some conceptual background to inform anti-oppressive practices in social work” (p. 61). Williams' (1996) description of postmodern thinking dovetails with aspects of the current research.

According to Williams (1996), post-modernism provided a major challenge to universalism of social and political theories by pointing out that there a “myriad of different subjectivities and different realities” (p. 63), and emphasizing both the relativity and the constructedness of knowledge or so-called 'truth' (p. 63). This challenge to universalism is key in introducing the diversity of people with disabilities. Post-modernism also represents a “shift away from finding a cause for social phenomena, a shift away from fundamentalist or essentialist thinking towards exploration of the meanings of social phenomena and how they constitute themselves through those meanings” (p. 64). Therefore, the focus is not on the

cause of social problems, but on how social problems come to be defined and constructed: how meanings are articulated through discursive practices (p. 64). The common discourses encountered by people with disabilities on their employment journey previously explored emphasized the impact on disability and identity, therefore, shifting the focus away from defining disability. Finally, post-modernism stresses “the specifics of time and space, the contingencies and constellations of specific moments” (Williams, 1996, p. 64). Power (2004) stated from “a postmodern epistemological perspective, the pursuit of 'the truth' has been replaced by the search to understand multiple, localized, contextual truths” (p. 859).

An example of the search to understand multiple, localized, contextual truths is explored in Leonard Davis' book *Bending over Backwards: Disability, Dismodernism, & Other Difficult Positions* (2002). The title immediately provides a visual of the instability of disability and identity. Davis argued that disability can be seen as a postmodern subject position, referring to the locations people occupy in relation to different and opposing ideologies (p. 14). Davis emphasized that other discourses of race, gender, and sexuality began in the mid-nineteenth century because this is when the scientific study of humans began informed by the scientific ideology of eugenics. Eugenics original purpose was to improve the human race by ridding it of problematic people and their problematic behaviours. “Women, people of colour, homosexuals, the working classes and so on, were all considered to be categories of disability, although we do not think of them as connected in this way today” (p. 16). Understanding disability as a subject position versus an essentialized category of identity, challenges us to expand the notion that identity is socially constructed. This significantly differs from how disability has traditionally been understood, defined and promoted by governments and people with disabilities themselves.

Davis (2002) proposed a new way of thinking called dis-modernism, which rests on the

analysis that post-modernism is still based on a humanistic model. Politics have all been directed toward making all identities equal under a model of the rights of the dominant, often a white male 'normal' subject. A dis-modernist model aims to create a new category based on the partial, incomplete subject whose realization is not autonomy and independence but dependency and interdependence (p. 30).

The dis-modernist subject is in fact disabled and only completed by technology and by interventions. Rather than the idea of the complete independent subject, endowed with rights (which are in actuality conferred by privilege). It acknowledges the social and technological to arrive at functionality (Davis, 2002, p. 30).

This dis-modernist vision performs two critical functions. First it acknowledges the instability of disability identity and allows for a clear notion of expanding privilege to the entire population and making a commitment to physical and attitudinal accessibility for all. More importantly, dis-modernism:

attempts to remove “the veil of ideology from the concept of the normal, and denying the locality of identity. Dis-modernism argues for a commonality of bodies within the notion of difference. It is too easy to say “we're all disabled”. But it is possible to say we are all disabled by injustice and oppression of various kinds (p. 31).

Discussion of the dis-modern vision was meant to present a new perspective on disability and identity. The discourses that were discussed earlier in the chapter are prevalent on the employment journey for people with disabilities. However, new perspectives must be presented in order to look at issues through a different lens. Viewing disability as a post modern subject position addresses the instability of identity and aligns with my commitment to

the Independent Living Paradigm which informs my research. Independent Living does not mean people with disabilities must live alone, but rather it emphasizes consumer control and choice and dignity to assume risks. Therefore, Independent Living acknowledges the consumers' expertise on their own disability and needs to be able to control the supports they require to pursue their goals etc. In essence, I propose Independent Living Paradigm and Dis-modernism as two compatible means to provide a framework to view and understand disability in various contexts, personal or political.

The purpose of the discussion of the macro context of disability and identity, demographics, identity politics, citizenship, medical and social models of disability, and dis-modernism was three-fold. First, it provided a fundamental portrait of the contextual ingredients which make up the current views of disability that people with disabilities still face. Second, it demonstrated the messiness of disability; there is no single solution or position on disability and identity. Finally, the overview will help to further contextualize the narratives shared by participants in this research, all of whom were recipients of provincial and federal income support programs and, therefore, mandated to access support from results-based employment programs.

Chapter IV Methods

There is limited research in the area of employment and disability which centres on the experience of people with a variety of disabilities accessing government funded employment programs and services. *A Longer Journey* was inspired throughout by Mike Oliver's call for research to be useful to disability communities and “faithfully capture the experience” of people with disabilities (Oliver, 1998, p. 4). Limited attention is given to the voice of people with disabilities and their opinions about the priority and significance of employment barriers. It is this point where *A Longer Journey* aims to highlight and centre the experience of people with disabilities. Thus, the central question guiding this research is: “How do people with disabilities experience their employment journey in the current political context of results-based employment programs?” In this chapter, I outline the methodology guiding my inquiry. The epistemological stance informing the methodology was informed by three paradigms: the Independent living paradigm, a pragmatist paradigm, and an emancipatory paradigm. Methods refers to a specific technique used to gather data (Bryman, 1984; Mercer, 2002).

Methodology

To examine the research question, a fundamental qualitative description was used as described by Sandelowski (2000). Reference to this method as fundamental or basic is meant to differentiate it from other kinds of qualitative description. Sandelowski (2000) addresses how “the words basic, fundamental, and surface connote something elementary, superficial, simple, or merely preliminary; with regard to methods, no method is absolutely weak nor strong, but rather more or less useful or appropriate in relation to certain purposes” (p. 335). Any comparisons Sandelowski makes to other methods are for the purposes of illumination, not ranking or denigration (2000, p. 335).

The goal of this qualitative approach is to describe an event or experience to enhance

understanding . In contrast to research designs that present findings in abstract terms, fundamental qualitative description is distinguished by being low inference and presenting findings in everyday language (Sandelowski, 2000). Researchers using fundamental qualitative description focus on preserving the voices of the participants by presenting their experiences in their own words to the greatest extent possible, with minimal inferences by the investigator (Williams & Brackley, 2009, p. 215). The description in qualitative descriptive studies offer a comprehensive summary of an event in the everyday terms of those events; language is a vehicle of communication, not itself an interpretive structure that must be read (Sandelowski, 2000, p. 336). Sandelowski (2000) elaborates:

Yet such surface readings should not be considered superficial, or trivial and worthless. I intend the word surface here to convey the depth of penetration into, or the degree of interpretive activity around, reported or observed events. There is nothing trivial or easy about getting the facts, and the meanings participants give to those facts, right and then conveying them in a coherent and useful manner (p. 336)

A descriptive exploratory design was chosen for this study in order to provide a fuller understanding of the experience of people with disabilities accessing results-based employment programs. Gaining insight into the perspective of individuals with disabilities experiences' with results-based employment services will highlight what is important to each individual and what motivates each person to comply with the requirements of the service. This insight will also enhance service delivery and guidance by employment service providers (Bogan, Powell, & Dudgeon, 2007, p. 215).

As the graduate researcher, I was the primary researcher involved in the research design, recruitment, data collection, and data analysis. However, critical insights and questions from the principal investigator and supervisory committee provided guidance during

the entire research process.

The deciding factor to use a fundamental qualitative description as the methodology was due to qualitative descriptive studies being less interpretive, “in that they do not require researchers to move as far from or into their data”. Although no description is free of interpretation, fundamental qualitative description entails a kind of interpretation that is low-inference, or likely to result in easier consensus among researchers (Sandelowski, 2000, p. 335). This feature of qualitative description was consistent with the consumer-control aspect of the Independent Living Paradigm, which informed many of the decisions throughout the research design.

Research Paradigm

The epistemological stance of this research is informed by three paradigms: Independent Living, pragmatism, and an emancipatory paradigm. The Independent Living paradigm emerged out of the Independent Living Movement of people with disabilities which is founded on the right of people with disabilities to live with dignity, to participate in all aspects of their life, and to control and make decisions about their own life (Shannon, 2007). As the Executive Director of Independent Living Vernon, which adheres to and promotes the Independent Living Philosophy (IL), IL is the primary paradigm which guides *A Longer Journey* research.

The IL paradigm differs significantly from its rehabilitation counterpart in defining outcomes. While self care, mobility and employment are stressed in the rehabilitation model, Independent Living stresses a much larger constellation of outcomes, including the importance of living arrangements, intimate relationships, consumer knowledge and assertiveness, and outdoor and out of home activities (Gadacz, 1994). The IL paradigm represents the emergence of a new value system and an entirely new lifestyle for people with

a variety of disabilities. Consideration of environmental barriers and constraints is key to understanding the thrust and impact of the Independent Living paradigm in the context of the disabled consumer movement (Gadacz, 1994).

Complementing the IL paradigm, a pragmatist paradigm also informs my methodology (Rocco, Bliss, Gallegher, & Perez-Prado, 2003). Pragmatism fits with an IL approach for two reasons. Firstly, pragmatic principles emphasize using whatever paradigm or methodological approach that works for the particular research question under study (Rocco, Bliss, Gallegher, & Perez-Prado, 2003). This concept of using “whatever works” addresses one main concern of researchers conducting disability research - the issue of full participation and accessibility (e.g. option to conduct interviews in a setting of the participants choice). In any research project which involves people with disabilities, ensuring full participation is crucial. This includes addressing needs such as plain language, physical access for people who use wheelchairs or other mobility devices, and assistive technology needs. Secondly, the pragmatist paradigm emphasizes consideration of the practical consequences of ideas (Johnson & Onwuegbuzie, 2004). Emphasizing the practical consequences of research attracts me to this paradigm for the possibilities it can offer to advancing the rights of people with disabilities and their inclusion in society.

Mike Oliver (1992), in his article *Changing the Social Relations of Research Production?*, called for the development of a new research paradigm: the emancipatory paradigm. This paradigm is also congruent with the IL and pragmatist paradigms. As the name suggests, it “is about the facilitating of a politics of the possible by confronting social oppression at whatever level it occurs” (p. 110). Emancipatory research requires the transformation of the material and social relations of research production: meaning people with disabilities should have control of the research process, including the funding and the

research agenda (Barnes, 2001). This emphasis on control is in alignment with the IL paradigm and its emphasis on consumer control. For research to be truly emancipatory, the entire research process must be accessible to people with disabilities, and there must be a workable “dialogue” established between the research community and people with disabilities to facilitate the empowerment of people with disabilities (Barnes, 1992). Once a dialogue is established and working relationships built, in addition to producing new knowledge, research can “actively seek change rather than hoping that the right people read the work and act upon it” (Kitchin, 2000, p. 44).

While the entire process of this research is not truly emancipatory as outlined by Mike Oliver (1992), the research question under investigation was initiated as a result of the questions and frustrations people with a variety of disabilities were expressing when mandated to access results-based employment programs. Further, this current research centred the experience of people with a variety of disabilities in the research question and through the research design (e.g., designing an individual interview guide that would centre participants' voices and experiences). Lastly, as a researcher who identifies as a person with a disability, I bring an intimate knowledge of disability, the need for accommodation and disability supports, and the considerations to ensure accessibility. Oliver & Barnes (1997) expressed that there is a need for more researchers with disabilities in disability research and in research in general; but, limited accessibility and resources continues to have serious implications for successfully accommodating researchers with disabilities (p. 812).

Research Method

Sampling and Recruitment

In order to centre the experience of people with disabilities and their employment journey in a research project, people with a variety of disabilities were asked to participate in

individual semi-structured interviews. Recruitment information (see appendix A) was distributed to employment service providers in Vernon, B.C. and posted in the monthly newsletter and the office of Independent Living Vernon (ILV) . Two presentations about the research project were made to the consumers of the ILV EmployAbility 12 week employment program. Seven consumers accessing support with employment through ILV agreed to participate. A volunteer of ILV circulated recruitment information to the Peer Support program, three consumers from this group agreed to participate in an interview. Two participants heard about the research through word of mouth and contacted the graduate researcher to participate.

Participants were selected based on the following inclusion criteria: a person with a self identified disability, a person who accessed support with employment issues from a results-based employment program in B.C. currently residing in Vernon, B.C., and a person over the age of nineteen years old. In order to adhere to the principles of the Independent Living paradigm, participants only needed to self identify as having a disability. The participants had a variety of multiple and significant disabilities, mobility, sensory, psychiatric, developmental, fibromyalgia, chronic pain, auto immune, and depression. In addition to cross disability issues, participants also represented other aspects of diversity. There were four male and eight female participants. Two of the female participants identified as being Aboriginal. All participants were accessing provincial income assistance or federal or provincial disability benefits.

Purposive and snowball sampling were used. “As in any qualitative study, the ultimate goal of purposeful sampling is to obtain cases deemed information-rich for the purposes of the study” (Sandelowski, 2000, p. 338). These sampling techniques are in line with a qualitative description methodology, due to the need for individuals who have the appropriate

characteristics for the research for a pragmatic solution when time and financial resources are limited (Higginbottom, 2004, p. 11). In *A Longer Journey* the appropriate characteristics would be people with a variety of disabilities which match the inclusion criteria outlined above. Each participant was given a copy of the recruitment information and asked to circulate the information to anyone they thought might be interested in participating in an interview (Miles & Huberman, 1994).

In the original research proposal, eight to ten interviews were suggested as the number of interviews to be conducted. After completing the first seven interviews and reviewing the total interview minutes and amount (and quality) of data, it was decided to recruit more participants. The average length of the first seven interviews was 45 minutes. After assessing the twelve interviews, it was determined that the data collected was substantial enough to answer the research question guiding this exploratory study. Further, conducting twelve interviews provided a total of 9 hours of interview time and 334 pages of transcripts; thus, for reasons of feasibility no more interviews were conducted.

Data Collection

Data collection in qualitative descriptive studies is typically directed toward discovering the who, what, and where of events or experiences, or their basic nature and shape (Sandelowski, 2000, p. 338). Interviews are a useful qualitative method for getting people to talk about their personal feelings, opinions, and experiences (Mack, Woodsong, MacQueen, Guest, & Namey, 2005). Thus, semi-structured interviews were developed to elicit participants' experiences of their employment journey (See appendix C). Semi-structured interviews provide a guiding framework and questions but also allow the interviewer flexibility to seek in-depth information and clarification of answers given, and to explore unanticipated questions which may emerge in the interview (Warren, 2002).

This study used the interviews as the primary source of data. Interviews were scheduled to last between 1-1.5 hours. In reality, the interviews lasted on average forty eight minutes, with the longest interview lasting one hour and thirteen minutes and the shortest lasting twenty six minutes. All twelve interviews were conducted in the meeting rooms at the People Place building in Vernon, B.C. People with disabilities frequently visit the People Place for a number of community services, particularly the Independent Living Vernon, Family Resource Centre for the North Okanagan, and the Multiple Sclerosis Society of B.C.

Interviews were conducted between November 2007 and February 2008. Winter weather and the Christmas season delayed the data gathering phase; one interview was rescheduled three times to accommodate weather and impacts of disability. When scheduling the interview time and location, participants were asked about any required disability supports to maximize their full participation: e.g., participants were informed about length of the interview, potential childcare concerns explored and addressed, and accessible transportation to the interview location was ensured (Khanlou & Peter, 2005). Participants were informed that the interview would be recorded and asked about possible concerns that they may have about the research project. None of the participants asked questions or expressed concerns about the interview. Only one participant specifically requested a disability support, a comfortable ergonomic chair for chronic pain of the neck and back, which was provided to the participant's satisfaction.

To start the interview, the researcher ensured the participant had a comfortable place to be seated and the room temperature was comfortable. Recording of the interview began following a detailed review of the information letter (see appendix B) and consent form (see appendix D), and following the signing of the consent form, the participant was given a copy of the documents for his/her records. In an effort to ensure that the participants understood

the research process, the role of the graduate researcher was clarified, a discussion of future uses of the findings were reviewed, and information regarding the participants' potential ongoing relationships with Independent Living Vernon was discussed – individuals were assured that any future contacts with Independent Living Vernon would not be affected by their decision to participate. Finally, the interview process was discussed including reviewing the possible length of the interview, ensuring that the participants knew how to navigate the building to access washrooms, and assuring the participants that flexibility was possible. In addition, the researcher was conscientious to be mindful of participant fatigue; both in order to ensure that no harm was done and to maintain the quality of data from the interviews.

Information included on the informed consent form included (see appendix D): background on the project, the purpose of the research, how findings will be distributed, the measures that will be taken to ensure participants' confidentiality and anonymity, role clarification of the graduate researcher in this project, the participants' right to ask questions of the researchers, the right to refuse to answer any questions, and the right to withdraw at any time during the interview (Morse & Richards, 2002; Swain, Heyman, & Gillman, 1998). The consent form was written in plain language to ensure accessibility for participants with a variety of disabilities. It is interesting to note that the Research Ethics Board made a comment on the use of plain language in the consent form stating that the language may be construed as demeaning by participants. Krogh and Lindsay (1999) highlighted that “few studies have emphasized, explored, and documented the process of establishing a research relationship with augmentative and alternative communication users and representatives from disabilities organizations” (p. 223).

On the consent form, participants were asked if they would be open to the researcher contacting them in the future if verification was needed to clarify information. Member-

checking would provide an opportunity to ensure appropriate representation of their experiences with employment programs. Disability research using an emancipatory paradigm has concentrated on participant validation; that is the involvement of people with disabilities in identifying research questions, collecting data, and disseminating findings. The notion of taking field work back to respondents for verification is widely regarded as a key marker of emancipatory research (Mercer, 2002) and adheres to the principle of consumer control in the IL paradigm. Respondent validation is an important strategy used to establish trustworthiness as it gives authority to the participants' perspectives, therefore, managing the threat of bias (Mercer, 2002). Having flexibility to clarify information during the interviews, prolonged engagement with many participants, and being the one to conduct and verify the transcripts, allowed me to decipher the parts of the interview that the researcher assistant was not able to transcribe. These strategies, along with issues of feasibility, informed the decision to not engage in intensive participant validation. Instead eight participants contacted me by phone and in person after the interview to ask questions about the progress of the research process and what themes were being identified from their interview. This provided the opportunity to have a dialogue with participants, where they would add more information they thought of afterwards. I described preliminary themes which were identified and the status of research process. This use of participant validation was more physically accessible for participants and the flexibility met their individual needs, which in turn lessened their anxiety that they were required to provide more information.

Once consent was obtained, the researcher began the interview. The interview was digitally recorded and later transcribed verbatim by a university research assistant. The interview guide (see appendix C) consisted of three main questions. The opening question was “Can you tell me about your employment journey over the last three years?” This

question helped to focus the time frame and the topic of the information shared by each participant. Accompanying probes were designed to elicit narratives about the participant's experience of results-based employment programs (Bogan, Powell, & Dudgeon, 2007, p. 216). Probing questions were used as necessary to clarify, inviting participants to elaborate on their experiences; for example, the researcher probed about how many employment programs were accessed, expectations of these services, and interactions with staff at these services. The second question focused on the meaning of work for each of the participants. Some probes included asking what their idea of a perfect job was, what were the most important activities in their day, and would they see themselves differently if they were able to have their perfect job? The third main question asked participants to describe what the term future means to them and how has it influenced how they live their lives. To bring closure to the interview, participants were asked if there was anything that they would like to add, and, finally where did they see their employment journey going after the interview?

The structure and order of the questions helped the participants to organize their experience into past, present, and future. The interviews flowed easily, many times the researcher would say to the participants, "That leads right into the next question," or "You answered some of this question already".

Throughout the data preparation and analysis process, two main sources informed the data analysis: Sandelowski (1995) and Braun and Clarke (2006). This step kept the researcher grounded in the process of preparing the data and alert to the cautions outlined by Braun and Clarke (2006); for example, they advise that the data collection questions (interview guide) facilitate the identification of "themes". A *Longer Journey* interview guide was organized around three main areas: the past, present, and future employment journey of participants. While this was helpful for participants to organize their thoughts during the

interview and share their experiences, participants focused on the results of their experience with results-based employment services and what their future direction will be. All participants were provided with an advance copy of the interview guide in the information package, along with the recruitment poster, information letter, and consent form. Four of the participants came to the interview prepared with pages of notes answering each of the questions. Participants expressed this helped to “keep them on track” and “jog their memory”.

Data collection techniques may also include observations of targeted events and the examination of documents and artifacts (Sandelowski, 2000, p. 338). Field notes made by researcher during and after the interviews included observations about participant fatigue and impact on concentration and emotion and questions and concerns raised by participants. This information was useful in subsequent interviews for the purposes of this research, and also contributed to data analysis and as a resource of possible issues for future researchers to be aware of when conducting research with people with a variety of disabilities.

Another source of data was a journal kept by the graduate researcher. The purpose of this journal was to ensure reflexivity during the research process. Reflexivity is defined by Horsburgh (2003) as the acknowledgment by the researcher that his/her own action and decisions will inevitably impact upon the meaning and the context of the experience under investigation. Reflexivity is not a point in time event, reflexivity is a process that occurs throughout the research (Horsburgh, 2003). The journal was a place to express issues as they arose during the research process. Issues included ethical considerations, difficulties and delays with data collection, and initial impressions of topics covered in the interviews and how they linked to the review of academic and government literature. The research journal was also the place to track any decisions made about the research as they happened and the

justification for making such decisions. This journal formed part of the research audit trail (Leitz, Langer, and Furman, 2006).

The researcher's supervisor was available to debrief after and between interviews in person and through email correspondence. This debriefing provided immense support to the researcher, while being able to maintain confidentiality and remain sensitive to the participants' experiences (Warr, 2004). It was anticipated that participants would share difficult experiences related to their employment journey. Such experiences included incidents related to discrimination, abuse, poverty, and the impact of disability on the participants' physical ability, emotional well being, and mental health.

Data Analysis

I conducted all twelve interviews and they were transcribed verbatim by a research assistant. I reviewed all the transcripts for accuracy and made any corrections (Lapadat & Lindsay, 1999). After verification of each interview was complete, transcripts were formatted with line numbers, page numbers and a footer.

The data from the interviews was analyzed using thematic analysis (Braun & Clarke, 2006). Thematic analysis does not require a detailed theoretical and technological knowledge of the approach, making it an “accessible form of analysis particularly for those early in a qualitative research career” (Braun & Clarke, 2006, p. 81).

Once the transcripts were verified, I read through the transcript and made notes in the margins about initial thoughts from the interview. An abstract was prepared for each interview, which included key story-lines, demographic information, and theoretical frameworks (Sandelowski, 1995). The abstracts were circulated to the members of the supervisory committee. Once the abstract was prepared, transcripts were read through for general topics. “Categories were generated from the data to emphasize the experience of

participants as represented in the interviews rather than a predetermined code set developed by the researchers” (Bogan, Powell, & Dudgeon, 2007, p. 216). For each topic, I made notes about what participants included as examples under each topic. As topics were identified, they were colour coded. Topics used the same colour coding for each interview and the 'colour key' of topics was attached to each transcript. This allowed me to see at a glance what topics were present in each interview and illustrated the prevalence of some topics as compared to others. Notes describing how each topic linked to the research question, and/or other identified topics, were kept. Parameters of each topic were outlined and steps taken to prepare and identify each topic were documented providing an audit trail of the analytic process.

The topics identified in the analysis included: positive support, negative support, mistrust, relationships with service providers, personal attitude and values, volunteering, disclosure, self-care and disability accommodation, negative impact of disability and positive reference to pre-disability employment experiences, financial pressures, transportation, family/relationship difficulties, present uncertainty, and societal attitudes.

To ensure the thematic analysis remained on track, the research question was visible in the work space and consistently referred to during analysis. This step of the process kept the analysis grounded in the experience of the participants versus focusing on how the effectiveness of results-based employment services could be improved. Early in the course work, the graduate researcher expressed this research will emphasize the experience of participants, not evaluate the effectiveness of employment services. As government funded agencies, results-based employment services are required to evaluate their services and seek feedback from clients; however, I explicitly wanted to emphasize participants' experiences, not evaluate the effectiveness of employment services. Thus, this research

answers the research question: “How do people with disabilities experience their employment journey in the current political context of results-based employment programs?” The emphasis in the question on “how” differentiates between the ways participants interact with services and their experience of that interaction. For example, the analytic question “What are the elements of the experience?”, further focused the inquiry onto participants' experiences. The elements highlighted by participants for this research included interaction with staff in federal and provincial government departments, visiting different community agencies, filling out a number of forms to be eligible or appealing denials for services and programs, completing a job search, preparing and distributing resumes and cover letters, accessing community agencies for advocacy. These interactions took place through the phone, Internet, in person, by mail and fax. While these elements impacted the experience of participants, they are not the experience itself.

Validity

Validity is the conditions of the legitimation of knowledge in contemporary post positivism (Lather, 1993). For this research, to address rigour and validity, the work of Lincoln and Guba (1985) which describe the concept of trustworthiness, will be used.

Trustworthiness is established when findings as closely as possible reflect the meaning described by the participants (Lincoln & Guba, 1985, p. 444). Leitz, Langer, and Furman (2006) also use this concept of trustworthiness and outline seven strategies to authentically represent the meanings as described by the participants (p.444): prolonged engagement, triangulation, peer debriefing, member checking, negative case analysis, audit trail, and reflexivity. *A Longer Journey* utilized five of the seven strategies outlined by Leitz, Langer and Furman (2006) in the research process: the use of reflexivity, peer debriefing, an audit trail, participant validation, and prolonged engagement. Reflexivity was used through journal

writing and during peer debriefing. Peer debriefing in person and through electronic communication with the principal researcher was valuable for myself to deal with the emotional impact, while maintaining confidentiality of the participants. The journal formed the audit trail, which provided a place to describe reflexivity within each step, to track justifications for decisions made during research procedures, and document issues with ethical considerations, initial impressions of topics in interviews, and any data collection difficulties (Bogan, Powell, & Dudgeon, 2007, p. 217). Participant validation took place two ways. First, during the interview, the semi-structured interview allowed me the flexibility to clarify information with participants in the moment to ensure I was understanding what they were describing, and participants would contact me after the interview and ask questions about the progress of the data analysis. During these conversations with participants, I would describe the initial themes that were identified, which participants eagerly agreed with. Second, at the time of the research, I was the executive director of the disability resource centre, therefore, I had prolonged engagement with many of the participants before and after the interview. Prolonged engagement with participants helps to build trust and provides an opportunity to check for misinformation that stems from distortions introduced by the researcher or informants (Creswell, 1998).

Prolonged engagement with participants through presentations to the peer support groups, the EmployAbility employment group, and being available in the centre provided the opportunity for participants to initially inquire about the research project. This prolonged engagement increased participants level of comfort at the time of the interview, thereby increasing their willingness to share their experience. Mercer (2002) states a bench mark of validity in emancipatory research is reflected in the quality of the relationship with participants. Friendliness, openness, and general close rapport with participants have

acquired a confirmatory status. Researchers using an emancipatory paradigm have documented how participants expressed their appreciation that their views were taken seriously and they were encouraged to express their real feelings (Mercer, 2002). Specifically, these experiences provided a strong foundation for carrying out research and facilitated access to the field and recruitment of participants.

This idea resonates with Donna Haraway's (1998) concept of situated knowledges, where she argues for epistemologies of location, positioning, and situating, where partiality is needed to make rational knowledge claims. Situated knowledges fits with the epistemological stance of this current research.

Ethical Considerations

This background knowledge could be construed as a way of pressuring participants to share private thoughts. Mercer (2002) underscores that there are ethical issues relating to exploiting an individual's willingness to reveal private thoughts and to using one's relationship in order to enhance the quality of the research data. Consideration of this issue was paramount in the development of this research; particularly in how the research relationship would impact my professional relationship with participants during and after the research. To address this issue, role clarification was critical during the recruitment and informed consent process.

Ensuring that confidentiality was maintained in a relatively small community was a continuous battle (Swain, Heyman, & Gillman, 1998). Consumers' questions and concerns about confidentiality were addressed in a thorough manner; answering questions about how the data will be safeguarded, then reporting back and checking in with consumers about any further questions. In addition, when participants inquired about the progress of the research report, every effort was made to not identify them as having participated in the research.

From the beginning, the importance of keeping the identity of participants confidential was explained to the staff at Independent Living Vernon, which is where the majority of the recruitment occurred.

Another important ethical issue related to issues of accessibility. Decisions regarding accessibility and full participation of people with a variety of disabilities were ensured in the design of the research. This commitment to accessibility is in line with the pragmatist, emancipatory and Independent Living Paradigms informing this research. For example, the location of the interviews in the meeting rooms at the People Place was chosen for the high level of accessibility it offered: an elevator, availability to assistive technology or other disability supports, accessible washrooms on all floors, and six designated parking spaces. These practices focusing on ethical considerations have implications for future researchers engaging in disability related research highlighting the importance of reflective ethical research practice.

Despite prolonged engagement with the majority of the participants, the stories and experiences created an emotional and mental roller-coaster for myself. During the analysis process, I was reminded of a comment made by a health researcher during a informal presentation about Grounded Theory. She said "emerge" is a common term in Grounded theory analysis, but themes and theories do not emerge, they are 'dragged kicking and screaming by researchers out of the data'. This comment resonated with me during data analysis. My intimate knowledge and prolonged engagement with the majority of the participants made analysis intellectually and emotionally difficult.

I was surprised as a new researcher, how relevant my expertise, paradigms, and my attitude that emphasizes hospitality were in the research process. The methodology and methods were a good fit for both the participants and myself. The methodology and methods

in this research provided participants an opportunity to describe how they experienced their employment journey. While the discussion and description of the methods gives the impression of a linear process, in reality the process can be best described as unpredictably messy. This is also the case with the discussion of the findings. In the next chapter, the two identified themes of connection and control are illustrated and their interaction is described; that is, how they existed separately and how they intertwined.

Chapter V Findings

A Longer Journey centres the experience of participants with disabilities. In this chapter, I present the findings arising from the research. The use of verbatim quotes will underscore the voice of these participants, provide examples of the findings of this research, and further support and enhance the validity of the interpretations included (Smith, 1996). Fundamental qualitative description leads the researcher to concentrate on the preserving the voices of the participants by presenting their experiences in their own words to the greatest extent possible, with minimal inferences by the investigator. (Bogan, Powell, & Dudgeon, 2007, p. 215). From the analysis, two prominent themes came to the forefront: Control and Connection. Themes were conceptualized by myself as representative of participant's collective experiences and labeled using participant's words or meanings (Bogan, Powell, & Dudgeon, 2007, p. 216). To demonstrate how these themes were pulled from the data, each preliminary topic will be described in detail. The detailed description of the identified topics is critical to ensuring the iterative process needed in a thematic analysis (Braun & Clark, 2006). It is not enough to just identify themes, but they must be checked against each topic to increase the validity of the findings (Braun & Clarke, 2006). This discussion will be followed by an overview of the thematic findings. This chapter will close with an illustration of the interconnectedness of the two themes, connection and control.

Identified Topics

The following topics concerning the participants' experiences of employment and disability were identified: positive support, negative support, mistrust, relationships with service providers, personal attitude and values, volunteering, disclosure, self-care and disability accommodation, negative impact of disability and positive reference to pre-disability employment experiences, financial pressures, transportation, family/relationship difficulties,

present uncertainty, and societal attitudes. The subsequent section provides a description of these topics as they relate to this study.

Positive Support

Participants in this research highlighted the importance of positive support in their employment journey. Participants talked about programs they enjoyed, and interestingly, none of the programs that participants liked were results-based. To understand this topic of positive support, my analysis was informed by the question, “What does positive support look like?”. On a page in the notebook, I listed what participants noted, such as the importance of being provided with lots of information about a variety of community resources, not just employment services. Participants discussed that positive support entailed being able to access a spectrum of services from one agency. Participants appreciated being given specific information about what to expect from other services, physical directions to get there, and encouragement to come back for more information as needed. More critically, participants appreciated a welcoming atmosphere and the opportunity to build relationships with other people with disabilities. To describe agencies where participants felt positively supported, they would use words like “felt welcomed with opened arms”, “home away from home”, “relaxed”, and “fun”.

For example, one participant described his experience in an employment program that was very positive because of the various options provided:

We all sat down and voted on which ones we’d like to do. What’s important to us as a group. So I thought – I thought that was a really interesting spin on how to do that and a wide variety of accessible options. It’s just incredible, the arm supports, foot rests, the special screens and keyboards and mice. I think it’s very good, the partnership with ACE and I can see it’s progressing as far as the amount of stuff

that's available and the support that's available from them too. (30078, Lines 467-476).

Negative Support

The topic of negative support had several dimensions. First, participants discussed how they were given no information about other resources to meet their diverse needs, other than support with employment. For example, one participant described: "because it's only employment related. Anything for my personal life I will have to access through my family doctor or through Agency V" (30083, Lines 585-587). Such experiences left participants feeling frustrated. If participants needed information about advocacy, government benefit programs and services, they had to access a variety of community services and disability organizations.

A further dimension of negative support related to the frustration and confusion expressed by participants when they talked about not being eligible for some programs and services, or being given misinformation about services. Participants used words like "they booted me here", "assembly line", "production line", "put in a corner and forgot about....like you are all used up", and "I felt like I was bothering them".

Negative support was also described by participants as a frustration about not being given enough time in appointments to express their needs and ask questions about services in the community. One participant was very clear about this:

They're so regimented in what they do. It was really hard to to peg them down and say, "Hey, I wanna discuss how this is gonna work". We can make an appointment such and such a day. And I says "Well book 3/4s of an hour. You know, if it's not 3/4s of an hour, it's not long enough for us to discuss it. [laughing]" You know, so I had to be quite...forceful. You're not just putting me on the production line, which is how their service works. They're just after that funding and how their model works I think to be

effective there's gotta be a better model (30078, Lines 328-343).

The majority of participants wondered if the results-based services were really for people with a variety of disabilities. First and foremost, participants highlighted the limited physical accessibility of the employment services for people with disabilities in the community. "Location, Location, Location" was emphasized. One employment service rents from another disability organization, but there is no dedicated signage or clear reception area to make finding the service easy to access. The other employment service is located in a building on the second floor without an elevator. In addition, there is no bus stop close to the building, making the use of local transit difficult for participants with physical disabilities.

A final dimension of "negative support" related to participants' experiences of being misunderstood. Participants shared specific examples of being set up in a job that they were neither able to do because of their disability nor were they interested in. For example, one participant shared:

I just came in one day and the lady that was doing the workshops, I was the only one there at that time and she said "Well, so and so that runs this program has a job for you" but she told me it was in retail. And I said, but I put down in writing and I said in person, you know, orally many times that I did not want to go back into retail. I was trying to get a different kind of job placement. Then when I said, "But I can't stand or run around for 4 hours or 6 hours like I used to when I worked in retail for 12 years a long time ago, before I was disabled". I have physical problems and I have mental problems. She didn't seem to make any suggestions about what I would do, like standing on my feet for 4 hours or because I have mental problems, if I had a problem with a customer. (30073, Lines 172-190)

Mistrust

Mistrust was another topic that emerged in the analysis that directly related to experiences of negative supports. There was a significant level of mistrust of results-based employment services that made participants sign a consent form giving the staff permission to share information from the participant with the Ministry of Housing and Social Development (MHSD). Participants articulated feeling the need to censor the information they shared with the results-based service for fear their eligibility for income assistance or disability benefits would be impacted. One participant described her extreme reaction to any contact from MHSD however, it is not uncommon for many consumers to report experiencing significant anxiety and fear when they receive a phone call or letter from MHSD.

If I got a letter in the mail from welfare and they say that I have to contact them about an issue. I would just go in panic mode and I'd stress right out for days. You know?

Break into a sweat if I have to pick up the phone, and trying to get the courage just to phone other people [laughing] (30081, Lines 535-540).

It is not surprising that participants expressed significant concern over employment service providers sharing information with MHSD. There were numerous examples from participants about this fear.

You have to withhold a lot of information from them. You can't tell them the true feelings because they can, and legally you sign a document saying they will report you to social services if you're earning extra money, or got Christmas money (30083, Lines 612-616).

This participant continued on to emphasize that income assistance has "permission to basically rat on you" (30083, Line 651). This reality creates significant frustration and mistrust because of the constant "fear of the audit and the fear of losing their income" (30083, Lines

818-819).

Participants had no control about the information the staff included in their file and potentially reported to MHSD. During the intake interview at a results-based service, one participant asked the staff person why they needed certain information about her and her personal life. The staff person responded to her by saying that if she did not provide the information her file would be closed. This participant expressed how this response made her feel “not wanted”.

Another participant made an appointment with a results-based employment service and asked specific questions about the information that would be required to provide and how the information would be shared with MHSD. This participant expressed to the staff that he would not sign the consent form giving them permission to share his information with MHSD, therefore, making him ineligible for that service.

The Ministry required that I meet with them. I thought that was unfair too, they say I have to meet with them. I can't remember – I don't think I was on disability yet, but they knew I had an injury. In the questioning I drilled her as far as how the information they're getting from me is going to be used, and I told her that that was very important to me. And she says, “Well I could look at what they submitted after they submitted it.” You know, and I says, “So I have no opinion in what is submitted?” You know so as it's submitted, if I said, “I don't agree with this paragraph and I put a note on that,” you know, I don't think this is true? She says, “No.” I said, “Okay fine, interview's over” (30078, Lines 193-209).

Another participant had a cash job and was fired because of her disability. Because she was not reporting the minimal income she was receiving to MHSD, she was not able to share with the employment service provider about the work experience she gained. A further implication

was that she could not pursue a human rights case for discrimination against the employer, to preserve her eligibility of her provincial disability benefits.

Relationships with Service Providers

Relationships with service providers was another topic discussed by participants. In particular, participants highlighted the critical role the quality of the relationship between the service provider and the participant plays in the perception of participants about whether the experience is positive or negative. The first participant provided a key example of the difference and distinction between positive support and negative support. The participant shared how when she accessed a results-based service, she was not given enough time to meet with a staff person one-on-one and she was “made to do it herself”. They “booted” her to a disability organization that she described as providing positive support where she “felt welcomed with open arms”. The disability organization gave her the same information as the results-based employment service did, but her description of this disability organization was positive and she expressed pride about what she accomplished on her own.

Personal Attitude and Values

A fifth topic throughout the interviews centred on the concepts of personal attitude and values. Under the topic of personal attitudes/values, participants included the importance of maintaining their integrity; fulfilling their responsibility to themselves, their family/friends, and their community; feeling respected and showing respect; communication with other people with disabilities; being happy' and maintaining a positive attitude about employment and their disability. Having a purpose in life and keeping their life on track was emphasized by all participants. It was interesting to note that participants seemed careful not to be perceived as modest, overly proud or seeking positive feedback and recognition of their skills. Instead they were more likely to minimize their skills or describe their skills more as qualities of their

personality. But all participants expressed a desire to feel needed and valued as an employee.

One participant talked about accessing the results-based employment service and being motivated to fulfill the requirements because the staff at the service said that if he does, he will gain the skills needed to become a “valuable employee”. “It allowed me to learn skills I was told would help me to get a job and fit in as a valued employee” (30076, Lines 176-178). The participant elaborated on the dramatic revelation of being a valuable employee and why it is so critical to his employment:

It means being able to get a feeling that I’m a valued employee, employable person, that I’m needed by some business. It helps me to deal with depression that haunts my mind and lowers my self-esteem, to further lower my self-worth. Sometimes it works on the psychological part of your brain where you’re in an apartment by yourself and don’t have the money for gas, you don’t have the money to go anywhere, you have a hip injury that gives you a lot of pain when you walk too far in the cold. You get home and and you sit down. You’re okay for a while and then you get up and go to walk somewhere and you have to limp, sometimes use a cane around the house, to get around ‘cause it hurts some more and then ‘cause you walk too much when you’re outside and then you look at yourself and wonder what you’re really doing here in life, but you can’t quit because that would be the, the wrong thing to do, and you’re never gonna change your future if you give up so then you carry on. But then get up each day and wonder, “Well, what can I do next to try to improve my life, ‘cause if I just sit here and watch TV I’m not really going anywhere, not really doing anything. I’m just, just wasting my life watching TV.” So you have to try to be innovative and change things in your life. It can get depressing” (30076, Lines 326-350).

The participant articulated the significant struggle many people with disabilities experience with chronic pain and fatigue, and how it impacts thoughts and emotions dramatically. Later in the interview, this participant explained being a valuable employee also means that he would be able to meet other people and not have to talk to himself when he was alone. Further, if he had employment, he hoped he could make enough money to have a social life and increase his network of people. His goal for an expanded social network will give him hope of being able to meet someone he could have a relationship with and start a family. The idea of being a “valuable employee” was present in the majority of the interviews.

Volunteering

Volunteering was another evident topic throughout the interviews. Since many participants were unable to gain and or maintain paid employment, participants volunteered at either a disability organization or a seniors organization. In their roles as volunteers, they were helpers in the classroom of an employment program, sat as a Board member, organized a peer support group for people with a variety of disabilities, were involved in volunteer housekeeping, and volunteered to mail out monthly newsletters. “I’m treating my volunteer journey as my employment journey” (30078, Lines 1649-1650).

This participant further emphasized:

I can [volunteer] on my own terms. I don’t have anybody to answer to, as far as how I’m doing it, when I do it. Now I get a, I get a sense of pride out of it. So in one area I’m losing some pride. Here, I’m gaining that pride, it’s internal, nobody has to see it. But it, it’s what keeps me going (30078, Lines 1665-1681).

Overall participants viewed volunteering as a positive aspect of their employment journey, due to the social aspect and chance to improve and learn new skills.

Disclosure

Disclosure was another topic present in the interviews. Originally, it was thought that disclosure would be a prominent topic given the focus of the study, however, this was not an explicitly visible finding in the interviews. Eleven of the twelve participants had invisible disabilities, therefore leaving the decision to initially disclose their disability to an employer up to the participant. However, the topic of disclosure lurked in the background as the decision as to whether to disclose a disability weighed heavily on participants: they did not want to “try and fool anyone,” but they also had to consider their own self care, in case their job required them to do something that would exacerbate their disability. For all the participants who discussed the decision to disclose their disability, the pivotal aspect for them to disclose or not was relational. As one participant worded it:

Myself...depends on who you're gonna work for. If I feel that the employer, if I feel that he or she is understanding, and I can feel the vibe from who I'm having an interview with, and then I will let them know that I have a disability. And if I see that [they're] not very good, then I won't, I won't disclose it (30073, Lines 301-307).

In order for participants to disclose their disability, they needed to feel like the employer would be willing to accommodate their disability, whether through purchasing needed equipment and disability supports or by providing flexibility with job duties and scheduling. This reinforces the emphasis that participants placed on the need for a supportive relationship and positive attitude from employers.

Self-care and Disability Accommodation

Linked with disclosure of a disability were the topics of self care and disability accommodation. When participants' discussed self care for themselves, they emphasized the need not to exacerbate their disability and balance their desire to move forward in their

employment journey. Participants described self care as “not doing too much” or “hopefully I will find a job that is good for me because of my disabilities” (30073, Lines 94-95). Although expected to be a key topic in the interviews, there was limited discussion of self-care and disability accommodation, most likely due to the employment situation of the participants. None of the participants shared having a positive employment experience since acquiring their disability. Therefore, while self care and disability accommodation would be a consideration in planning for employment, it would not be a prominent topic for participants if they have not had the experience negotiating accommodation to ensure self care.

Negative Impact of Disability and Positive Reference to Pre-disability

Employment Experiences

The identified topics of negative impact of disability and positive reference to employment before disability were throughout the interviews. It was interesting that all participants who acquired their disabilities later in life reflected about their employment before their disability as positive, while describing their employment journey since their disability as negative. One participant stated, “It could be a combination of both, or it could be related to my disability. All I know is that, years ago before I was disabled, I didn’t have a problem obtaining a paid job, or keeping it. So, obviously now there is difficulties” (30077, Lines 496-499).

For the two participants born with a disability, there was still a negative view of disability. One of the participants' described:

I don’t want to be labeled as mentally handicapped. I don’t want to be in a special program. I want to be like everybody else. I want to go to work and feel proud of what I do and know that I can do it and strive to better myself and to overcome my disability (30083, Lines 1132-1136).

The participant born with a developmental disability wished there was more recognition for the diversity of disability with regards to government programs. “I find that these type of programs they should have broken off in different classes. Because right now everybody is put in the same pot” (30084, Lines 243-250).

It was interesting to note how all participants referred to their disability as part of themselves. This view of disability is in contrast to the significant emphasis by government departments to define disability and its impact on daily living activities, in order to determine eligibility for programs and services.

Financial Pressures

Financial pressures of participants were expressed in all the interviews. All the participants at the time of the interview were accessing either a federal or provincial government income support program. The majority of the participants were accessing the provincial disability benefits program, which at the time of the interviews provided eligible people with disabilities \$906.00 per month for support and shelter costs. Two participants at the time of the interview were receiving regular provincial income assistance, which provided people with \$610.00 per month for shelter and support costs. Two participants were receiving Canada Pension Plan Disability Benefits, which provided people with a maximum of \$1,077.00 for support and shelter costs. One participant articulated how difficult it is to secure basic needs while being expected to look for employment:

Here you get on with the Ministry and you're making \$610 a month, you know, how are you ever supposed to get back on your feet and get going again in life when you're just digging you a bigger hole? Here you're getting that so you gotta scrounge around town and say, well what am I gonna do about food? Okay I can't afford to buy the food because my housing is costing me more. What's more important? Well I need a roof

over my head, otherwise I'm gonna be out in the street and then where am I? (30078, Lines 293-302)

Another participant related the difference prior to her disability to the current financial difficulty she has on provincial disability benefits

Before I got hurt I had very good jobs which the money was very very good for me.

And now that I'm disabled, it's only \$879 a month I live on, which is not very much compared to what I was making before was always \$2000 every two weeks, so that's a big downfall on employment (30073, Lines 60-65).

Complicating the financial pressures was the frustration that some participants experience if they were not eligible for discounts or government benefits. For example, one participant expressed the disparity in cost for a bus pass: 'whereas if I had that provincial designation, it would cost \$45 a year. Not 600. That's a huge disparity' (30075, Lines 474-475).

Transportation

The topic of transportation issues was only minimally discussed throughout the interviews, but this was an important topic for participants who did not have a car of their own and/or had limited mobility. For these participants they had to rely on the local transit system, which has limited hours of operation and routes. Participants who highlighted the topic of transportation linked its significance to accessing health care services versus accessing employment.

Family/Relationship Difficulties

This topic was present across all the interviews but was discussed minimally by participants. The topic surfaced when participants described recurring barriers that interfered with the progress they made on their employment journey. That is, difficulties with relationships were expressed as a constant consideration as they navigated their

employment journey. Some participants described that they had to choose between employment or addressing family/relationship difficulties, and the latter took precedence for these participants.

Present Uncertainty

One significant and prominent topic throughout the interviews was the issue of present uncertainty. This topic was continuously linked to when participants discussed what is occurring with the requirements of the results-based services.

I felt uncomfortable there in ways. I felt that it wasn't for disabled people, even though they say that it is. And I talked to some other people that had gone through the workshops too and they seemed to reflect my view; so I'm not sure if I've finished with them yet because of the counsellor came back from holidays and I believe I was supposed to get in touch with her, but I haven't yet because I'm confused about the whole program (30077, Lines 122-129).

Another participant echoed the topic of uncertainty:

And then they say, "Well, we've talked to this employer, here you go, and work for this guy" and I said, "Yeah but I can't do this and I can't do this" "Oh I forgot about that. I forgot about that. I forgot about that" and all these different things they forgot about. "You can start on Monday" and I says, "I'm not gonna do that job, 'cause I can't do these things. Do they have these kind of things that can help me out?" "Well I'm not sure, I didn't check that out. Because of our policy, you – we can't really support you on that" and I said, "Well...then this is no good. I have to go somewhere else" (30076, Lines 143-153)

A third participant clearly stated, "Can't really plan anything. All I know is I got a Plan A and a Plan B. Plan A is hopefully [Agency B] is successful in getting me back to [Business A] and

Plan B is maybe packing up, moving to the Kootenay's" (30083, Lines 1469-1472).

Most of the uncertainty expressed by participants originated from being unsure of what were the next steps with the results-based services. Consistently throughout the interviews, participants expressed they were waiting for a call from the results-based service providers. While participants waited for the call, they would continue to look for work. One participant got a seasonal job while waiting for a call from the results based service. Later, when he met with the result-based service provider, he was shocked when they disapproved of the job he had secured for himself:

They didn't really think that was the right thing I should be doing and now they're trying to help me get some other job. She said, "Well that wasn't really a good thing, you shouldn't been doing that." And I said, "Well you guys weren't really helping me." She said , "Well, you know, at the time, that was our scope was to just find you a job, but what we should have been really trying to find you a permanent part-time job and that's what we're gonna try to do in the future." But they haven't called yet and they said "We'll call you in a couple of, in the next week or something, start working on it" (30076, Lines 297-308).

This participant was confused why the worker would try now to get him a job. He was under the impression that was what they were suppose to be doing when he signed up with them months previous.

Societal Attitudes

Finally, although not always explicitly named, the topic of societal attitudes was present in all interviews. The topic of societal attitudes was alluded to in relation to decisions participants made about their employment journey and seemed to have significant influence on decisions participants made and the barriers they experienced on their employment

journey. Participants did not clearly identify the source of the societal attitude or if the influence was positive or negative. Once the two main themes were identified during the analysis phase, the need to explore the impact of the societal attitudes became evident and will be elaborated on in the discussion chapter.

Themes: Connection and Control

From the topics identified in the transcripts, two themes were found. These themes were the importance of “control” and “connection” as participants navigated their employment journey. Because I was the one who conducted all the interviews and completed the data analysis, themes were uncovered quickly due to the familiarity I had with the data and the prolonged engagement with participants.

Connection

The theme of connection was identified first, after the repeated emphasis by participants on being able to communicate with others and to be heard by service providers, family, friends, and government departments. The word “connection” was used by participants to describe what they wanted from service providers and employers. Qualities associated by participants with connection were trust, active listening, empathy and compassion. For participants these qualities were critical to establish a foundation for any kind of working relationship with service providers. It is important to acknowledge the conditions under which the staff of these results-based employment services work, including large caseloads and regular monitoring and restructuring.

In order to ensure the theme of connection was firmly grounded in the data, I used an iterative process to check the themes against all the identified topics. The theme of connection was linked by participants to many of the topics previously identified and described. As with the description of the topics, where possible direct quotes from the

interviews will be used to provide clear examples and promote the voice of participants with disabilities. While some of the quotes included might be considered longer than necessary, the quotes were chosen for the ability of participants to link the complex interaction between their disability, emotional functioning and choices. It is this complexity which needs to be understood in order to increase opportunities for connection.

Participants primarily viewed being employed as means of making a connection with other people, versus making a contribution to society or for financial gain. The previous example described under the topic of Attitude/Personal values about the participant striving to be a 'valuable employee' is a prime example of the theme of connection. When participants discussed being a valuable employee, they were not referring to how much they were paid, but the degree to which they felt connected to the employer and co-workers. For example, one participant shared,

I would have more confidence in myself because I found that when I was working that I was around different people and I felt good about myself. Sure I had leg pain but I got to talk to different people and people talked differently to me. I wasn't by myself so I was not having to talk to myself anymore and it raised my self-esteem a lot. So I was feeling more like being there on time and being there to help if you needed help. I made some pretty good money and I got to buy a vehicle. Helped to fix up a few things at home and buy some new clothes and even got to go out to dinner with some people a few times because I had extra money. I was feeling good about myself and then even helped buy some clothes for some other people because I had some extra money (30076, Lines 521-535).

Repeatedly, participants linked the theme of connection to how much they would work for employers. For example, participants would talk about working for two dollars an hour if they

liked an employer. “I’ll work for you for...\$2 an hour. Swear it. I would work for you for \$2 an hour. Because I like you. But I won’t work for you \$50 an hour if I don’t like you” (30082, Lines 448-451). It is connection that motivated many of the participants to struggle through complications with their disability such as chronic pain and fatigue, in order to continue to work for an employer they felt valued by. For example, one participant stated:

Now some mornings it was painful but you still crawl out of bed because you’re working for a good person. But...when you have to put your hands on your head and go, “Why am I doing this?” Just to put butter on my bread, a roof over my head because you don’t like working for the person, you move on (30082, Lines 868-873).

The issue of disclosure of a disability to employers as described by participants was related heavily to connection. If participants did not feel the “vibe” off the employer and had an invisible disability, the participant was less likely to choose to disclose his/her disability. Thus, disclosure was heavily contingent on the theme of connection.

Participants viewed organizations that offered a wide spectrum of services directed to people with disabilities as providing positive support because participants felt like their needs and the barriers they faced were understood. In addition, participants enjoyed the convenience offered by disability organizations that offer employment programs and information and referral services under the same roof. This model of one stop shopping for services reduced the time and effort required by participants to connect with various organizations to secure the supports they need to meet basic needs.

Connection through peer support was highly valued by participants. Any organization which was familiar with and encouraged peer support among people with disabilities was viewed as providing positive support. Participants valued this type of interaction not only for the feeling of empathy received from other people with a variety of disabilities, but also for the

perceived expertise it indicated of the organization. Some of the participants shared experiences of providing peer support themselves. For these participants, peer support allowed them the opportunity to support and to treat people in the manner they wished to be treated by others. Peer support provided the opportunity to connect with other people with disabilities on a level not understood by service providers without disabilities. As one participant described, “until they actually live with the disease themselves they’re just going by the book and the knowledge that they have in front of them and they’re not stepping out of the box” (30080, Lines 872-875).

The intense reaction of participants to negative support provided by results-based services further reinforced the significance participants placed on the theme of connection. Participants were unforgiving when describing examples of negative support from results-based employment services.

The most poignant example of the theme of connection was provided by a female participant whose fear of people severely limited her ability to find or gain employment. At the time of the interview, her goal was to find a job that would allow her to work at home in order to have the flexibility she needs to take care of herself and keep her stress level low:

If I was in a room of people, that I have a place. Cause it’s kinda hard sitting with people, “Oh, what do you do?” Everybody’s got their answer and then it comes to me, it’s like “Aah, nothing.” Yeah, well what’s wrong with you? Look it, I’m 46 – what’s wrong with you?” But it would really, really help my self-esteem (30081, Lines 585-599).

For this participant being able to have an answer for the question, “What do you do?”, in a social setting would make her feel like she has a place not only in that social setting, but also in society. The question “What do you do?” implies that working, or what the government

considers contributing is important. The societal attitudes which associate disability with being unable to work, or incapable of making a meaningful contribution exacerbated the desire for participants to feel connected. In this research, participants did not explicitly articulate the societal attitudes that interfered with feeling connected to community organizations, but they knew they were present. The examples of societal attitudes covered a variety of topics. One participant described how one of the main barriers to her getting her dream job as a front desk clerk at a hotel was her teeth. “One thing that’s held me back is my teeth. My denture work. It doesn’t matter what you look like on the road traffic controlling, but when you get older your looks are fading. You don’t wanna smile with 3 teeth hanging out. And that’s what’s held me back a lot” (30088, Lines 463-473). This participants' other concern was how society viewed her daughter and her being on income assistance. “I want her to know there’s a work ethic out there. She was wanting to work when she was 11. So I want her to know that. Because I find that I didn’t realize that with welfare families, it goes from generation to generation. And I don’t want that to happen” (30088, Lines 557-561).

Two participants discussed the embarrassment from not being employed and friends or family asking “What are they doing?”. One participant describes the anxiety when she is “sitting with people, “Oh, what do you do?” And everybody’s got their answer and then it comes to me, it’s like “Aah, nothing. Yeah, well what’s wrong with you? It would really, really help my self esteem” (30081, Lines 589-599). Another participant links societal attitudes and his pride.

Its very hard on the pride from my standpoint. I see people that are in the industry I was in and they say 'What are you doing now?' and I say 'Ahh not much' I say 'Ah I’m involved in Agency V'. I’m starting to take a different spin on that and say “I’m involved with Agency V and take that a notch farther and tell them what we are doing” (30078,

1484-1488).

Societal attitudes surrounding ideal qualities in a worker was discussed by one participant.

[Employers] are looking for speed. I have a problem getting around and maybe if you trip and fall and you'll have trouble walking again and they want guys who can just get up and go. So it puts road blocks up and then you start to demean yourself and belittle yourself and then you feel bad about yourself. So then you have to pick yourself up and say 'Well I'm a strong guy', I just have to find something else. This isn't gonna work (30076, Lines 681-688).

Participants highlighted how having invisible disabilities sparks questions from people about not looking 'disabled'. The first participant was surprised by people's reactions:

I've actually had negative comments said to me. I've noticed it more since I've been disabled that 'You don't look like you're disabled, or why don't you have a paid job or what's wrong with you?' It makes me feel uncomfortable. I'm not blaming anybody, maybe I don't understand where they're coming from and they don't understand where I'm coming from. I've felt negatively but not about me or about disabled people, they're about myself being disabled (30077, Lines 375-383).

The other participant stated "People would look at me and say 'What's wrong with you? You look healthy enough.' But they really don't know what I go through, day and night with my arms. It's hard. It's hard to live in a society that is so judgmental" (30073, Lines 338-341). A third participant stated "peoples' outlook on people who are homeless are kinda like the people that are having the bad outlook about people with disabilities. You never know how they got there, what their story is. We all have a story. (30080, Lines 1306-1310).

Control

The second theme identified from the interviews was the concept of control. I was in

disbelief at first when the theme of control was identified due to my long relationship with the Independent Living paradigm which emphasizes choice, control, and encourages people with a variety of disabilities to assume responsibility and take risks. But it was this familiarity with the Independent Living paradigm that assisted me to explore the parameters of the theme.

Initially, I named the theme choice and control. However, after analyzing the idea of control, I realized that choice is a necessary condition of control. In other words, it is not enough for participants to have the illusion of choices. For example, participants having the choice between sharing information with a results-based service or being cut off income assistance was not a choice at all, and certainly not control. Having control over the choices which are available to them is the essence of control.

One participant highlighted the importance of choice and partnerships between agencies and how it influences the control that is available to clients of results-based service:

We all sat down and voted on which ones we'd like to do. What's important to us as a group. So, I thought that was a really interesting spin on how to do that and a wide variety of accessible options. It's just incredible, the arm supports, foot rests, the special screens and keyboards and mice. I think it's very good, the partnership with ACE and I can see it's progressing as far as the amount of stuff that's available and the support that's available from them too (30078, Lines 467-476).

For this participant, choice was a way of providing hope that having control would help to move him forward in his goals. This participant indicated that when people have no choice or control in their lives then this is when they it may lead to people being homeless or struggling with substance abuse issues. He described:

I think it's had an enormous cost to our society, where we're dumping people on the street and then what do they do? They have no hope for the future. They get into

drugs and alcohol and crime and who knows, but I don't think they were predestined to go there. I think it's how they're being kicked around is actually steering them in that direction. So, it's sad for me to see but for me to get more involved than I already am, it takes a toll out of me. That is a hard point where I find myself? That, to go through the doors of the [agency C] affects me more than it affects everybody else (30078, Lines 1034-1047).

Participants expressed that they felt like they were not being heard by staff of results-based employment programs and not being given enough information about programs and services to meet their diverse needs in the areas of mental and physical health, recreation, income assistance, government programs and benefits. Further, many participants described being discouraged by results-based employment service providers to look for employment that was already available, versus employment that required additional training. For example, one participant was told by a results-based employment program that she may not be able to find paid employment and may have to be satisfied with volunteering.

I hope my employment journey will give me access to a paid part-time job. One of the workers in the employment program that I was taking said I may not be able to access a paid job, and may have to be satisfied with volunteer jobs. That was disappointing to me, as I love volunteering but I need extra income for my day to day living expenses, etcetera. That kind of stunned me in a way. But the employment counsellor didn't seem to be able to go into any further discussion. So, maybe I didn't clarify enough, although I put it down on paper, and I said orally many times that I am here to obtain a paid part-time job. I felt really low and I felt like maybe they didn't take the time to read their reports or to listen to me when I spoke? (30077, Lines 679-723).

Similarly, in some cases participants were told to find lower skilled jobs, versus being able to

access funding to upgrade skills. One participant who had very specific skills and training found it humiliating that a results-based service provider “[suggested that] maybe I go work, you know, at a lower level job with no skills” (30083, 256-257). She elaborated that “there’s a strong sense that you should apply for a job that’s already out there. Even though it may not be a fit for you” (30083, Lines 927-929). For this participant, and others like her, there are limited options when accessing support with employment. Other results-based employment services are directed to people without disabilities; therefore would generally have fewer options for many people with disabilities due to physical and attitudinal barriers.

For other participants who had limited skills and education and acquired a disability, available positions were not a feasible choice in most cases. For example, one participant who mainly worked as a bartender, waitress, and in customer service, developed a fear of people and public places after an assault. This participant needed to find employment that would give her the flexibility to work at home where she feels safe and could manage her stress effectively. Many of the jobs that are readily available that do not require training and higher education are in the service industry. Therefore, this participant had to upgrade her skills in order to get a job would accommodate her disability and the self-care she needs to be successful in employment. Without financial support from the results-based employment services, this participant had to cover the costs of upgrading her skills and education. Other participants described similar experiences of balancing the financial pressures of upgrading education and skills without economic support and on a limited income. Covering educational costs can be a gamble for participants, due to the cyclical nature of many of disabilities. The majority of participants who committed to the cost of educational/training costs ended up not being able to complete the course due to complications with their disability.

One participant was considering for tuition for an online diploma course:

I thought maybe I should go and spend the \$12000 and do it. Go and get a payroll diploma. Um...payroll supervisor diploma. I never went and got it through Academy of Learning but it was uh \$11999 and it would take a year to do (30076, Lines 618-623)

Considering such a risk to investing a significant amount of money for tuition for a course that is not likely to be recognized as a reputable credential, demonstrates the urgency participants felt in order to create choices they needed to have control in their life. It also reinforced the topic of the uncertainty that participants highlighted throughout the interviews in relation to results-based employment services.

The physical and attitudinal barriers and lack of positive support from results-based employment services, made participants wonder if these services were really for people with disabilities and impacted their sense of control in their employment journey. For example, one participant wondered:

It didn't seem like they were able to find me a job, that they were just looking for jobs that able-bodied people could do? They weren't looking at what something that a person with a disability could do and so it didn't seem like they found me anything (30076, Lines 256-261)

Another participant described,

I don't know what she put down, because she didn't show me but then the lady that was doing the workshop said some comments to me and I said, "But I didn't say that to her" and she says, "Well, it says that right here" and I said, "Well...I didn't say that to her." So, that was confusing to me too. The job counsellor was away so I couldn't interact with her, about why she put this in her report, but didn't tell me. Maybe because of my disabilities, maybe I don't understand certain things or maybe I have communication problems; so maybe that's another reason why I'm saying "Is it for

disabled people?”. To me, it didn’t seem like it was. You walk out of there thinking, “well, I’m a disabled person. They know that. I don’t seem to be getting anywhere here” (30077, Lines 210-249).

The strong sense by participants that results-based services were not designed for people with disabilities was closely linked to the resistance of these services to take into account the expertise of the participants and, thus, empowering participants' sense of control. Participants have significant experience managing and accommodating the nuances of their disability on a daily basis. The services accessed by the participants in this study did not use the expertise participants have on their own disability, highlighting the emphasis on a medical model of disability in these services where complexity surrounding a person's disability was overlooked.

Blurring of the Themes

Some examples of the themes of connection and control give the illusion that these themes run parallel to each other. However, this was not the case. Participants' narratives demonstrated how having meaningful choices and, ultimately, having a sense of control in their lives increases one's sense of pride and self-esteem. Increased pride and self-esteem are critical to a positive attitude, level of motivation, and fulfilling an overarching personal sense of responsibility and contributing to their community. One participant stated, “I know I can, I can function again. I know I have to” (30081, Lines 1020-1021). Further, participants expressed having a positive or negative attitude is related to how much connection and control they would feel. Participants emphasized using self help books and free counselling resources to help keep a positive attitude and gain support. One participant described the relationship between having control and how this impacted her outlook on life:

I wanna be able to make enough money that I won’t be getting a disability cheque

anymore. 'Cause right now I'm allowed 500 dollars a month. But like, why would I want to just only live on that? If I could do...more? I'd rather make maybe two or three thousand dollars a month. Then I'd be able to pay for my own prescriptions. It'd be like, pfft. 'Cause first they'll take away the money, but I'll still be on the dental and everything. But it would be really nice to be able to walk in like, with my eye glasses getting...here's room with people and I'm going, 'Well, could you show me the frames that are covered by welfare' You know? And then everybody knows. It would be nice to be able to walk in there to the dentist or the eye doctor and go, "Here's a cheque." Like for a filling or a cap instead of a tooth extraction, you know? That'd feel really, really good (30081, Lines 971-1000).

I questioned why there was such an emphasis on choice and control. Many participants discussed the need for structure in their routine being critical to manage and accommodate their disability. Structure was indicative of control over choices. The need for structure and control over a routine that allowed the participant to ensure self care was related to employment options. One option epitomizing the relationship between connection, control, choice, and self-care for participants was self-employment. Eleven out of twelve participants discussed self-employment as an option they would like to have available to them in order to have control over a routine that would not exacerbate their disability. Further, self-employment was viewed by participants' as the best way to have control, choice, self care and connection.

Another example of the ways the themes connection and control intersected was demonstrated in participants' discussion of peer support. Peer support provided the opportunity and experience to connect to others who share a similar experience of disability while at the same time provided a context and opportunity to control the information they

provide to others' about their lives. Some participants' also expressed their desire to control and influence how people with disabilities are conceived.

A final example from one participant further highlighted the relationship between the two themes. This participant described in detail how she was given information at a results-based employment service and made to feel she had do it on her own. Then as she described it, “they’re the ones that booted me” (30073, Line 114) to a disability organization. She was surprised how welcome and at ease she felt at the disability organization. The disability organization provided her with the same information as she was previously given, however, she positively described the disability organization as providing positive support and feeling pride about having the choice to get the information she needed on her own. This example underscored the degree to which participants sense of connection was a key to their experiences of control and choice in their employment journey.

In conclusion, Cook & Burke (2002) emphasize that disability and employment is a complex phenomenon that encompasses more than the individual's level of impairment and functional limitations. Other factors include employer attitudes, labour market conditions, availability of workplace accommodations, and prior employment are all part of the environmental context that is critical to understanding (p. 544). The identified topics and themes in this research demonstrate the complex environment influencing the experiences of people with disabilities with results-based employment services.

Chapter VI Discussion

It was not until undertaking this research that I truly experienced and understood how my varied professional and personal roles as the Executive Director of Independent Living Vernon, a graduate researcher, a native woman with disabilities, and a Registered Social Worker overlap and merge. It is the merging of these roles that account for the paradigmatic position informing my research and the emphasis on the Independent Living Paradigm, pragmatist paradigm, and the emancipatory paradigm. The influence of these paradigms guides the discussion of the research. This chapter will include a discussion of the following topics in relation to the present research: inclusion, directions for new programs and further research, the limitations of this research, knowledge translation activities that will be undertaken, and knowledge sharing in accessible formats.

Inclusion

The prominence of the themes connection and control was unexpected. As a social worker, I am involved on the front lines with consumers and asked to participate in community initiatives set up to address the lack of physical and attitudinal accessibility, limited accessible transportation, lack of affordable housing, homelessness, and the increase of drug trafficking and sex trade workers in the area surrounding IL Vernon. These initiatives are a reflection of the priorities of local residents, consumers, and in some cases the community as a whole. Various levels of government validate the concerns of citizens by giving these issues attention in various ways, such as including identified concerns as part of strategic plans, community plans, or election platforms. However, in this research the topics of disclosure, access, and transportation were not very prominent in the findings. This disconnect between the prominence of the issues in government priorities and what the participants of this research emphasized forced me to ask “Why connection and control? What is the relationship

between the two themes and experiences of inclusion?” Further analysis of the participants' narratives revealed that the level of connection and control people with disabilities feel directly impacts how they view and respond with motivation to results-based employment services.

The concept of control in this research is critically different from the concept of control the government uses in marketing strategies. For example, a press release by the Ministry of Human Resources (now called Ministry of Housing and Social Development) dated February 26, 2003 states that it is “precisely the goal of BC Employment and Assistance: to assist people to move away from dependence and take control of their lives”. This message of control and independence is a relatively new one in the long history of people with disabilities and the welfare system. In fact, these discourses did not emerge until the mid-1990s when a major revision of the Disability Benefits programs was undertaken. *A Longer Journey* participant described how she was told in the early 1990s by an income assistance worker “well with your past and background and your health issues, there is no point in you even bothering to try to find a job. Or get a job”. (30086, Lines 30-32). However, by mid 2004, the message from income assistance to this participant had changed:

I was told by social services, I was under multiple barriers at that point in time.

To me it's confusing. I mean I don't understand their reasoning or why they do what they do. I was sent a letter and I was told I had to take this course at [agency]. No if's, and's, or but's. I had to get my rear end over there and I was to do it. Well, I tell you I was extremely resentful about being forced to go to a course. If they would of told me about the course, and asked me if I would of wanted to go, I probably would have went with no problem, but it was like my...um, survival basically hinged on that 3 month period (30086, Lines 107-121).

The use of the concept of control in the provincial ministry's press release conjures an image of the perfect neo-liberal subject: a person that is independent and does not require financial assistance from the government will be an accepted member of society. In a *Longer Journey* research control meant connection with others, which leads to a feeling of belonging and inclusion. Thus, in order to truly connect with others, control must be present and will result in inclusion. This finding has important implications for promoting the goal of inclusion.

Bringing about belonging and inclusion was one of the main goals of the social model of disability, by removing the physical and social barriers in society that interfere with people with disabilities having access to basic services and privileges (Oliver, 1990). In response there has been an extraordinary amount of financial resources and effort by disability organizations, various levels of government, and other community stakeholders dedicated to projects focusing on physical accessibility and to projects promoting the importance and practice of politically correct language to refer to people with disabilities. While the significance of such projects cannot be underestimated, people with disabilities experience more than just physical barriers. Many times it is the attitudinal barriers from societal attitudes that interfere with control, connection and, ultimately, inclusion of people of with disabilities. As one participant stated, "I don't want to be labeled as mentally handicapped. I don't want to be in a special program. I want to be like everybody else. I want to go to work and feel proud of what I do and know that I can do it and strive to better myself and to overcome my disability" (30083, Lines 1132-1136). The themes of connection and control have the potential to inform practices of inclusion.

Crawford (2003) outlines two key elements of inclusion. First, people with disabilities want to participate as valued, appreciated equals in the social, economic, political, and cultural areas of community life. Second, like others, people with disabilities want to be

involved in trusting appreciative and respectful interpersonal relationships with family, peers and the community as a whole (p. 5). Inclusion was the main focus of the *Advancing the Inclusion of Persons with Disabilities* (Government of Canada, 2002). The report introduced an “accountability framework”. This was the first attempt at a framework that would allow Canadians to assess the following questions: What does inclusion mean, and what are its key elements? How close is Canada to fully including persons with disabilities in society? How can progress toward inclusion be measured? How does the Government of Canada help advance inclusion? (Government of Canada, 2004). In order to gain insight on these questions, the findings of this present study suggest that the focus on disability has to be shifted away from societal issues, where more attention is given to the price tag than the benefits to the whole community. And I assert that in order to accomplish this, people with disabilities have to be actively involved and control the agenda on the discussion and description of inclusion, which is in line with the Affirmation model of disability introduced by Swain & French (2000). This model is a non-tragic view of disability and impairment which includes positive social identities, at both the individual and collective levels, for people with disabilities grounded in the benefits of lifestyle and life experience of having a disability and impairments (Swain & French, 2000, p. 569). The authors assert that this model is central to the concept of inclusion. Policies and practice can only be inclusive through full recognition of the complexity of disability and the affirmative model generated by the experiences of people with disabilities (p. 580); thus, supporting the emphasis by this current research to focus on the experiences of people with disabilities.

The aspects of success identified in Cohen, Goldberg, Istvanffy, Priest, Stainton, Wasik, and Woods (2007) were also expressed by *A Longer Journey* participants. The identified aspects of success included support that is ongoing without time limits; unrelenting

focus on participants preferences, skills, and employment goals; strong working relationships between agencies, employment staff and program participants; welcoming working environments with strong natural supports; effective coordination between employers and employment staff; funding structures that provide flexibility to meet individual needs; and, a connection to a disability specific agency that provides long term non employment, person-centered social supports (p. 6) . It is important to note the participants of Cohen et al (2007) were primarily people with developmental and psychiatric disabilities, while participants of this research identified as having a variety of disabilities, including developmental and psychiatric, but mostly physical disabilities. With the emphasis on the same aspects of success by participants of both studies, the overlap could point to systemic barriers that interfere with the full inclusion of people with a variety of disabilities.

The report by Cohen et al. (2007) highlights that people with developmental and psychiatric disabilities often work part time or episodically, making it necessary for them to be dependent on both employment and income assistance (p. 2). This was also the case for many of the *A Longer Journey* participants. This should be used as a starting point by the Ministry of Housing and Social Development to reform disability benefits legislation, the current request for proposal process, and recognize the critical aspects needed in a employment program for people with disabilities.

Directions for New Programs and Further Research

All the participants of this research accessed provincially funded results-based services and were uncertain about what the next steps would be because they were waiting for the results-based service to call them with a job placement. They were given no direction about what to do while they wait for their potential job. Some of the participants had been waiting for three months. This continuous journey of uncertainty resulted in some participants

being left vulnerable to financial, physical and emotional abuse. In one instance, while a participant waited to hear from the results-based service, he found a seasonal job from May to September. When he informed the results-based service, he was told that he should be looking for a permanent part time position. This example highlights ways that the practices of results-based employment services contribute to feelings of discouragement which may lead individuals to consider less legitimate options for training and employment in order to assuage the service provider. This participant was contemplating enrolling in an online training course that will cost thousands of dollars from an unknown institute. Other participants considered re-taking an employment program they have already completed. Many participants contemplated moving to a new community, which would require them to set up a new social network for support and navigate a new community and jungle of resources. One participant shared that she moves about every four years; the longest she has stayed in one community was seven years. Another participant ended with asking “What are my options after Agency B?”. This vicious cycle of uncertainty occurred more often in regard to provincially funded versus federally funded results-based employment services.

As discussed in chapter two, the RFP structure dictates the limited spectrum of services offered to clients of results-based services, which causes significant frustration for clients accessing these services as is evidenced by the participants in this study. The focus on employment to the exclusion of other needs for people with disabilities reduces the effectiveness of the results-based services. If results-based services do not recognize how severe other barriers and issues impact people with disabilities, how can they make effective and appropriate referrals and assessments to increase a person's employability?

There is limited recognition of the complexity of disability. For example, the majority of participants in this research and many consumers supported through employment programs

at Agency V expressed self employment as their employment goal. This option would allow people with disabilities to ensure job accommodation and flexibility for their disability. One participant wished to “have an entrepreneurialship going. I could make time for myself without the too demanding physical anymore” (30082, Lines 1244-1246). As a career development facilitator from 1999 to 2002, I witnessed the development of many different programs directed to offering self employment support to people with disabilities. Many people with disabilities were hopeful these programs would offer them the skills and knowledge to be able to start their own successful business (Hughes, 1999). After attempting to access these programs, consumers reported the program was not able to accommodate their disability adequately for them to complete the program. Further, the curriculum of the program did not include information about how to start a business with a disability: for example, important issues for how to include expenses for disability supports in the business plan or the cost to renovate premises to be accessible for the business owner who uses a wheelchair were not covered. Many of these programs do not exist anymore and only one organization in Vernon offers support for people with disabilities seeking self employment.

This background knowledge was useful during data analysis. When participants were expressing self employment as a goal, I realized they were striving for the benefits of self employment, such as flexibility, control over work environment, and the opportunity for connection and control. With this in mind, an ideal employment program to be developed and delivered by a disability organization would be “Be Your Own Boss..... while you work for someone else”. A program like this could emphasize to participants how to take control of aspects of self care, disclosure of a disability, required disability supports, and developing an accommodation plan. If results-based services structured their services to be more in tune with the needs people with disabilities, they would be better able to develop responsive and

effective programs for people with a variety of disabilities.

All the participants of *A Longer Journey* emphasized connection and control as being necessary conditions for inclusion. One model most often stressed as being inclusive and trusted by people with disabilities is peer support. Peer support contributes to feeling supported and understood, and this support often facilitates the finding of needed community resources. Currently, peer support is not widely understood or accepted by government as a useful model of service delivery. Exploration of people with disabilities and their experience of peer support would provide insight on two aspects: first, to give credibility to using peer support as a legitimate service delivery model; and, secondly and more importantly to highlight how peer support is useful due to the absence of societal attitudes. In this present study, peer support provided an opportunity for participants to connect with other people with disabilities and control the degree of that connection. Thus, the apparent absence of negative societal attitudes within peer support may provide the space to explore the impact of societal attitudes that block inclusion of people with disabilities within communities.

The dismissive description of societal attitudes by participants suggests that there is a need for more research into the process of developing and maintaining societal attitudes that promote inclusion, and the coexistence of old and new attitudes. In Erica Pinsky's book, *Road to Respect, Path to Profit* (2009), she highlights how society "tends to categorize us from the moment we are born and how our life is affected by this categorization" (p. 137). These external categories that are imposed by society affect people no matter where they work. There is always pressure to fit in, which was a common message heard from participants' of *A Longer Journey*. When the dominant culture appears to reject people, sentiments again shared by participants' of *A Longer Journey*, people don't try to be included in the workplace. Instead they join one of the many subcultures organized on the basis of

difference (Pinsky, 2009, p. 138). The author continues to describe:

These are by definition problematic for employers interested in a profitable and productive workplace; they go against fostering a sense of connection between employee and the work team, employee and supervisor, employee and the organization as a whole. It dampens the sense of connection between employee and organization's purpose, product, and goals. Failure to appreciate how allowing subcultures to form affects relationship and connection can be a costly failure to employers in today's multicultural and diverse marketplace (Pinsky, 2009, p.138)

While the above quote resonates with neo-liberalism, it describes the reality of many current workplaces. Therefore, to address the issues of poverty and discrimination experienced by many people with disabilities, employers and employment service providers must be cognizant of the impact of societal attitudes in the workplace and need to focus on a common message of respect.

Gill (2001) highlights how disability prejudice is subtle in its expression compared to the often overt demonstration of racial bigotry or anti-gay views. Further, racial/ethnic minority groups share their marginalized status and experience with relatives, while many people with disabilities feel isolated within their own families and community as a whole (Gill, 2001). The subtlety of the prejudice and isolation experienced by many people with a variety of disabilities are key issues that need to be explored in order to underscore the experiences of people with disabilities.

In this present research, societal attitudes and the attitudes of support workers were a factor in the participants' employment experiences in this present study. Results-based employment programs can be seen as a microcosm of how disability is viewed and responded to by society. The complexities surrounding employment and people with

disabilities need to be reflected in the approach used by results-based service providers. Results-based employment services require clients to have a medical report confirming their disability which prevents them from being employed; in essence, these services heavily rely on the medical model approach to disability. Using a program service delivery model that is inspired by the medical model has not been successful in addressing the barriers people with disabilities experience in relation to employment. Governments at all levels make significant investments in employment services for people disabilities, but this investment has not significantly increased the participation levels of people with disabilities in the labour market or reduced the barriers that people with a variety of disabilities experience. People with disabilities and their organizations have been calling for a holistic approach to employment issues which acknowledges the diversity and centers the experience of people with disabilities as important (Litvik & Enders, 2001). People with disabilities pointed out that a consumer-driven approach to training and vocational rehabilitation initiatives permits the fine-tuning that is needed to proceed at their own rate and with the full range of interventions they require (Government of Canada, 2000). Research which focused on experiences of people with disabilities that accessed employment services that used a consumer-driven model would provide insight into new approaches to employment for people with disabilities. Further, additional attention is required to provide community and employment supports to veterans returning to their communities (O'Day & Berkowitz, 2001). Most outreach services to veterans are through local veteran clubs (e.g. Legions and Army and Navy Clubs).

While qualitative descriptive studies are different from phenomenologic, grounded theory, ethnographic, and narrative studies, there may be 'hues, tones and textures' from these approaches. "Some qualitative descriptive studies have narrative or phenomenological hues as researchers might seriously attend to certain words or phrases, or moments of

experience, but not produce narrative or phenomenological renderings of the target phenomenon” (Sandelowski, 2000, p. 337). This current research suggested directions for possible narrative studies. For example, during participant interviews two terms were used 'valuable' and 'valued'. *A Longer Journey* focused on the term 'valuable' as it related to participant's experience with results-based employment programs. While it appears the difference is subtle between these two terms, the difference is critical in how the terms are used by people with disabilities, results-based services, and employers. Further examination of these terms in relation to neo-liberalism would increase our understanding of discourses used in the context of provincial policy.

While a postmodern discourse analysis is beyond the scope of this research, this research heightens the importance of examining the discourses used by governments in policy and has the promise of furthering our understandings of the experience of people with disabilities. Specifically, the discourses used by the provincial government need to be examined. Titchkosky (2003, 2006) and Prince (2004, 2006, 2007, 2008) both focus their research and discussion on federal disability social policy, leaving no apparent analysis of provincial discourses. I would assert a discourse analysis at the provincial disability policy level would reveal a, intimate discourse of disability, poverty, and exclusion. This would be in line with Corker (1999) when she proposes a “paradigm of communication” to open up political discourse to issues of language and difference and their relationship to the unequal distribution of knowledge, and the often sticky issue of discriminatory language (p. 640). I would also add the preoccupation with politically correct language. While I believe in addressing people in a respectful manner, focusing on what to call groups of people diverts attention away from issues that significantly impact people with disabilities, such as poverty, violence, abuse and neglect, and the lack of physical and attitudinal accessibility.

One of the goals of this research was to ensure it is relevant to social work practice, including research in the area of disability. Parton (1996) highlights that social work is heavily influenced by the more established discourses of law, medical, psychiatry and education; therefore, defining the nature, boundaries, and settings of social work difficult. Essentially social work operates between civil society, with its allegiances to individuals and families, and the state and its statutory responsibilities. “Social work fulfills an essentially mediating role between those who are actually or potentially excluded and the mainstream of society” (Parton, 1996, p. 6). With the rise of neo-liberalism and its impact on federal and provincial disability policies, social work has had to adapt to many changes. For example, Meekosha & Dowse (2007) describe the “mutual obligation strategy” that has emerged through welfare reforms, where 'rights' are dependent on carrying out 'responsibilities' and the market is the most appropriate environment to fulfill basic needs (p. 170). This strategy has resulted in reducing entitlements and forced a significant number of people with disabilities into mandatory employment programs. This creates professional challenges for social workers, as disability becomes more contested and “paradoxically, a more valuable category of entitlement” (Meekosha & Dowse, 2007, p. 170).

An example of disability becoming a more valuable category of entitlement is in regard to the changes made to the provincial disability benefits application. During this research, six participants had recently completed or were in the process of appealing their denied application for Persons with Disabilities Designation. Their applications were filled out by medical professionals who were not familiar with the new application and its emphasis on daily living activities. There are three sections to the application. Registered social workers are one of the prescribed professionals that are qualified to fill out the assessor portion of the application. Assessors are paid a \$75.00 dollar fee for completion of this section from the

Ministry of Housing and Social Development. When the fee structure was introduced, local physiotherapists and psychologists began advertising in the newspaper that they could fill out these applications. When consumers accessed advocacy support to appeal their denied application, social workers at Independent Living Vernon realized these professionals were not filling out the applications completely or correctly. No matter the quality of the report assessors were still paid the fee. This issue was of significant concern because in order for applicants to access additional benefits related to medical, transportation, and employment supports, they must first be designated as a Persons with Disabilities (PWD) by the Ministry of Housing and Social Development. As social workers, the first priority was to advocate for the person to appeal the denial, versus focusing their efforts on providing employment support to people with disabilities. Given the importance of PWD designation for persons with disabilities, this research illuminated valuable implications for social work practice in this area. Sharing this research with local social work programs will demonstrate to students the complexity of disability.

Limitations of the Research

Mercer (2002) states some disability theorists argue against an obsession with experience because of its overlap with impairment and individualistic concerns. Subjective experience is not necessarily the same as critical awareness and experiential studies often ignore power relations and wider contextual factors (Mercer, 2002). To balance the focus on experience of this research, discussion of the macro context and its direct influence on disability and identity provided a context to ground the experiences that participants of this research described. To understand disability as an experience, as a lived thing, more than the medical 'facts' are necessary (Brisenden, 1986). Gill (2001) emphasizes that investigation at the individual and interpersonal level of experience “yields crucial information

about social forces and cultural values affecting the group” (p. 352). Moreover, an exploration of experience differs from the traditional emphasis of evaluation and auditing in relation to results-based employment programs.

This research contributes to the ongoing examination of the medical model and its influence in the lives of people with disabilities. In the 1950s, the medical profession seemed above criticism. This has been succeeded by a policy change in western societies towards de-medicalization. As a result, orthodox medicine is less able to regulate as societies move toward community care and de-institutionalization (Marks, 1999). Marks (1999) highlights a belief held by some that the continuing critique of the medical model is out of date. However, the impact and influence of the medical model is still very strong and can be felt by people with disabilities in their everyday life. In most cases, people with disabilities rely on doctors for the most basic needs: for example, when a doctor is required to confirm the existence and severity of their disability to qualify for financial support and medical treatments. As discussed previously, physicians are required to complete significant sections in the federal and provincial disability benefit applications, the federal disability tax credit, or the application for a designated parking permit. This continued influence of the medical model necessitates continued opposition by people with disabilities. The Independent Living Paradigm is an alternative to the medical and rehabilitative discourses and has the potential to promote choice, dignity and control in the lives of people with disabilities. The Independent Living paradigm by no means circumscribes the disability movement as a whole, but is a practical political strategy and a strong underlying ideology (Oliver, 1990).

Accountability to the disability community is a key component of the emancipatory research model (Moore, Beazley, & Maelzer, 1998). This poses particular problems for researchers working within a market led environment where continued employment and future

career prospects are all too often determined by an ability to secure lucrative and long term research contracts (Barnes, 2001). The commercialization of research has meant that competition for research contracts has intensified considerably (Lidz & Ricci, 1990).

Rioux (1997) highlights “pressure for this type of objectivity and scientific positivism creates incentives for researchers to present their research designs and methodologies in ways that mask the complexity of the experience and causalities of disability” (p. 109). The methodological prejudice in favor of quantitative methods often makes it difficult for researchers wishing to use qualitative or PAR methods to gain access to such funds (Lidz & Ricci, 1990). This methodological prejudice also works to privilege certain accounts of experience that fit with the preferred methodology, which is troubling for people with disabilities working to promote a new perspective on disability.

The idea for this research was suggested by myself after six years of witnessing results based employment programs being funded, while receiving an average of four referrals a week from these services of consumers they were unable to support. Having the research topic come from the disability community aligns with the emancipatory paradigm. However, due to time constraints and budget, all aspects of the research design did not follow an emancipatory research process, but where possible participants were given the opportunity for significant and meaningful participation.

Knowledge Translation

According to CIHR's Knowledge Translation Strategy 2004-2009, knowledge translation (KT) “is the exchange, synthesis and ethically-sound application of knowledge, within a complex system of interactions among researchers and users, to accelerate the capture of benefits of research” (CIHR, 2004). This definition emphasizes that KT involves an active exchange of information between researchers and the users of the research and the

strategies and activities depend on the type of research and the intended user audience (CIHR, 2004).

For this research, physical accessibility is the first consideration in knowledge translation for people with a variety of disabilities. Independent Living Vernon has access to a variety of assistive technology, such as a pointing and input devices, software for people who are blind and/or have limited mobility, adjustable desks and ergonomic chairs. These accommodations will be available for use when the final written analysis of the findings and process is complete. The use of plain language when writing the findings is a second consideration; there is no assistive technology that can compensate for inaccessible vocabulary and terminology. To address this, an executive summary written in plain language will be made available upon request when the findings are released through public presentations.

Knowledge Sharing

The findings from this research will be made available to government departments, consumer disability groups, both local and national, employment service providers and researchers interested in disability research. Findings will be presented to the general community and in particular to the participants of the research and those excluded due to the selection criteria in a public presentation. This presentation will promote dialogue between the researchers and the users of the research and provide an opportunity for consumers to express their views and enter into discussions about the findings (Minkler, Fadem, Perry, Blum, Moore, & Rogers, 2002).

The findings will be summarized in an abstract to be submitted as a conference paper and submitted to a peer reviewed journal for further dissemination to researchers and

research funding bodies. The findings will be released through Independent Living Vernon's (ILV) website and newsletter. Copies of the findings will be circulated to the research participants, all Independent Living Resource Centres across Canada, Independent Living Canada, local Service Canada and Ministry of Housing and Social Development offices, local employment service providers, Vancouver Foundation, Neil Squire Society, BC Coalition of People with Disabilities, and the Disabilities Health Research Network (DHRN). Independent Living Canada has expressed interest in having these research findings presented at their national annual general meeting in the fall of 2009.

In closing, this research has highlighted the significance of connection and control for people with a variety of disabilities in all areas of their lives. And like people without disabilities, there is a desire for this connection and control in all aspects of their lives, not just employment. All people make contributions to their community in a variety of ways, not only through employment and being the good neo-liberal subject. Creativity and flexibility are needed with regard to employment for people with a variety of disabilities. Currently, the structure of funding results-based employment services further reinforces the dominance of the medical model and adds to the exclusion of people with disabilities. This is in stark contrast to the emphasis connection and control and its role in peer support and inclusion, by the participants of this research. By directing funding with the sole goal of securing employment to the exclusion of all other issues in people with disabilities lives, recreates the exclusion through negative societal attitudes that limits employment opportunities in the first place.

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Appendices



Appendix A- Recruitment Flyer

"A Longer Journey" An Exploration of Individuals' with Disabilities Experiences of Employment Programs in Vernon, BC

Laura Hockman, from the Vernon Disability Resource Centre, and Rachelle Hole, from the University of British Columbia, are doing research on employment services for persons with disabilities. We are interested in your experiences of receiving services when looking for work.

We are looking for interested people who:

-Self identify as a person living with a disability

-Are at least 19 years old

-Have had experiences accessing employment services in British Columbia

We will be holding interviews to invite people to tell us about their experiences with employment services. Interviews will take about 1.5 hours.

Snacks and refreshments will be offered

If you would like to participate or would like more information, please contact:

Laura Hockman at 545-9292 (Telephone), 542-2193 (TTY), or laura@vdrc.ca

OR

Rachelle Hole at (250)807-8741 or rachelle.hole@ubc.ca

This research is supported by the Disabilities Health Research Network
Research Team: *Rachelle Hole (Principal Investigator) – University of British Columbia;*
Laura Hockman (Co-investigator/Graduate Student)

APPENDIX B - INFORMATION LETTER

"A Longer Journey" An Exploration of Individuals' with Disabilities Experiences of Employment Programs in Vernon, BC

Invitation to Take Part

This research project is a shared project with the University of British Columbia and the Vernon Disability Resource Centre, and funded by the Disabilities Health Research Network. Our goal is to learn about the experiences of people with disabilities when they access employment services in British Columbia. We hope that this information will be used to improve the lives of people with a variety of disabilities. We also want to get new ideas from people about what they would like to see in the future. Our hope is that this information will contribute to ensuring a good life for people with disabilities. You are being invited because you are currently accessing, or in the past have accessed, employment services in British Columbia. We think your experiences are important to know. Taking part is voluntary, and you can leave the project at any time.

How will the project work?

We will be holding interviews to ask people about their experiences with employment services in British Columbia. The interviews will be audio-recorded. They will take about 1 to 1.5 hours.

What if there are some things you want to say but want them to be private?

We will make sure that only people on the interview team will be able to tell what you said. No one will be allowed to use your name when repeating what you said. Your name will not be on any tapes or reports. Your name will only be on your consent form.

All of the information collected at the interviews will be kept in a locked office and locked filing cabinet at UBC.

What if you don't want to participate; or if you start and then decided you don't want to continue?

That is okay. If you change your mind, that's okay. We don't want anyone to do anything that they aren't happy to do. We want this project done in a good way from start to finish; so, if you decide halfway through to stop, that's OK – no one will get into any trouble. If you decide to stop, and you want us to, we will give you back or destroy any of the earlier interview materials you gave us and be happy with that.

Sometimes when people start talking about things that have happened it can be hard. We hope this won't happen, but if it does, you can choose to not answer a question, we will find someone (like a counselor or a support person) for you to talk to privately if you want.

What happens to the material after?

Answers to the interview questions will be audio-recorded. Then we will write a report. The report will be shared. We also might write an article to go into a journal or magazine; or present the information at a conference. Your name will NOT be included in any reports or presentations.

Do you have any questions?

If you have any questions or concerns about anything to do with the project you can ask or talk to Rachelle Hole (250)807-8741 or Laura Hockman (250)545-9292.

What's next?

This sheet is meant to tell you basic information about the project.

After you've had a chance to think about it, and ask any questions you want, you can let us know if you want to participate.

If you want to take part we need you to go over the **consent form**. This tells us that you understand the project and want to take part.

Right now we want you to think things over, and we will contact you in about week's time to see if you want to say **Yes or No**. If you say yes, you will need to sign the consent form and give it to a member of the research team.

You can ask a trusted person (for example a family member or friend) to help you with the consent form. A member of the research team will also go over the consent form with you to help you understand and answer any questions you have.

We want to thank you in advance for any consideration you give to participating in this research project.

Thank you,

Rachelle Hole and Laura Hockman

Appendix C

“A Longer Journey” An Exploration of Individuals' with Disabilities Experiences of Employment Programs in Vernon, BC

Interview Guide

Can you tell me about your employment journey over the past three years?

P- How many employment programs have you accessed?

P- What has been your experience with results based employment programs?

P- What expectations did you have of this employment service to help you accomplish?

P- How did you experience your interactions with the staff in these employment services? Can you provide me with some examples?

P- Were there programs available through this employment service that you could not access?

P- Had you talked to other people with disabilities about their experience with this service? What did they say? Was it similar to your experience?

What is your meaning of work? (Probe: what does “work” mean to you?)

P- What is your idea of the perfect job?

P- What are the most important activities to you in your day? (For example, going to work, reading, hanging out with my

friends.)

P- If you could work as much as you wanted, what would that look like for you?

P- How would you see yourself differently if you were able to have your perfect job?

What does the term 'future' mean to you right now? How has this influenced how you live your life?

Is there anything else that I have failed to ask you in this interview which is important for me to know?

Where do you see your employment journey going after today?

Thank you for your willingness to participate.

APPENDIX D- Informed Consent Form

"A Longer Journey" An Exploration of Individuals' with Disabilities Experiences of Employment Programs in Vernon, BC

Principal Investigator: Rachelle Hole, PhD
Assistant Professor
University of British Columbia Okanagan
School of Social Work
Phone: (250) 807-8741

Student Investigator: Laura Hockman, Master's student
Interdisciplinary Graduate Studies
University of British Columbia Okanagan
Phone: (250) 545-9292

This research project is a shared project with the University of British Columbia(UBC) and the Vernon Disability Resource Centre (VDRC). The Disabilities Health Research Network contributed funding to support this research project.

Our goal is to learn about the experiences of people with disabilities when they access employment services in British Columbia. We also want to get new ideas from people. We hope that this information will be used to improve the lives of people with a variety of disabilities.

You are being invited because you are currently accessing, or in the past have accessed, employment services in British Columbia. We think your experiences are important to know. Taking part is voluntary, and you can leave the project at any time without any consequence to yourself.

We will be asking people about their experiences with employment services in British Columbia. The interviews will be tape-recorded. They will take about 1.5 hours.

Upon request, disability supports and alternative formats required for

your full participation will be made available. To offset the costs of transportation and to thank you for your time, you will be given a \$25.00 honorarium.

Sometimes when people start talking about things that have happened, it can be hard. We hope this won't happen, but if it does, you can choose to not answer a question and we will find someone (like a **counselor** or a support person) for you to talk to privately if you want.

Privacy is important. Your name will not be on any tapes or reports. All of the information from the interview will be kept in a locked filing cabinet in a locked office. The only people who will have access to this material are Laura Hockman or Laura's thesis advisor, Dr. Rachelle Hole.

Once we have gone through all the material we will be writing a report. The report will be shared with VDRC and UBC, however, the names of people who took part will NOT be shared. We will also write an article to go into a journal and/or magazine, and do a presentation at a conference or meeting.

This research is part of Laura Hockman's Interdisciplinary Studies Master's degree. The information will be used as part of her thesis document. But the names of people who took part will NOT be shared in the thesis. Theses at the University of British Columbia become public property of the university and are kept **in the library**.

If you have any concerns about your treatment or rights as a research participant, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598 or if long distance e-mail to RSIL@ors.ubc.ca.

If you have any questions or concerns about anything to do with the project you can ask Laura Hockman (250)545-9292 or Rachelle Hole

(250)807-8741.

Your signature indicates that you are saying Yes to taking part in this study. Your signature also indicates that you have received a copy of this consent form for your records.

Name of Person

Signature

Date

We might have a question about what you said in the interview once the interview is over. If we have any questions, we would like to call you to make sure that we properly understand what you said. If you say "Yes" we can contact you once the interview is over, please sign below. It is okay to say No.

Name of Person

Signature

Date

Counselling Resources in Vernon
Appendix E

Family Resource Centre, Vernon
201, 3402 - 27th Avenue
Vernon, BC V1T 1S1
Phone: (250) 545-3390
Fax: (250) 549-1548
E-mail: frcadmin@shawcable.com
Hours: Monday to Friday Office: 9:00-4:30 (some evenings)

First Nations Friendship Centre
2902 - 29th Avenue
Vernon, BC, V1T 1Y7
Phone: (250) 542-1247
Fax: (250) 542-3707
E-mail: fnfc@junction.net

Whitevalley Community Resource Centre
2114 Shuswap Avenue
Box 661
Vernon, BC
Phone: (250) 547-8866
Fax: (250) 547-6285
E-mail: wcrc@cablelan.net
Hours: Monday-Friday 9:00am-4:00pm

Vernon Disability Resource Centre
107, 3402 - 27th Avenue
Vernon, BC, V1T 1S1
Phone: (250) 545-9292
Fax: (250) 545-9226
Toll Free: 1-877-288-1088
TTY: (250) 542-2193
E-mail: info@vdrc.ca
Hours: Monday-Friday 8:30am-4:00pm, closed 12-12:30pm for lunch

Crisis Line
Vernon, BC
Phone: (250) 545-2339
Hours: 7 days per week 24 hours/day

Appendix F – B.R.E.B. - Certificate of Approval



The University of British Columbia
Office of Research Services
Behavioural Research Ethics Board
Suite 102, 6190 Agronomy Road, Vancouver, B.C. V6T 1Z3

CERTIFICATE OF APPROVAL - FULL BOARD

PRINCIPAL INVESTIGATOR: Rachelle D. Hole	INSTITUTION / DEPARTMENT: UBC/UBCO Health & Social Development/UBCO Social Work	UBC BREB NUMBER: H07-01276
INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:		
Institution	Site	
N/A Other locations where the research will be conducted: Participant choice, accessibility, privacy, and comfort will be guiding principles for deciding on the locations of the interviews. Interviews will take place in Vernon BC and possible options will be the People Place meeting rooms, interview space at Okanagan College in Vernon, or the participant's home.		
CO-INVESTIGATOR(S): Laura Hockman		
SPONSORING AGENCIES: Michael Smith Foundation for Health Research		
PROJECT TITLE: "A Longer Journey": An Exploration of Individuals' with Disabilities Experiences of Employment Programs		
REB MEETING DATE: August 9, 2007	CERTIFICATE EXPIRY DATE: August 9, 2008	
DOCUMENTS INCLUDED IN THIS APPROVAL:		DATE APPROVED: September 26, 2007
Document Name	Version	Date
Protocol:		
Community Research Exchange Proposal	N/A	February 28, 2006
Longer Journey Research Proposal	Version 2	July 15, 2007
Consent Forms:		
Appendix D - Consent Form	Version 2	September 18, 2007
Appendix D - Consent Form	Version 1	July 15, 2007
Advertisements:		
Appendix A - Recruitment Flyer	Version 1	July 15, 2007
Questionnaire, Questionnaire Cover Letter, Tests:		
Appendix C - Interview Guide	Version 1	July 15, 2007
Letter of Initial Contact:		
Appendix B - Information Letter	Version 2	September 15, 2007
Other Documents:		
Appendix E - Counselling Resources in Vernon	Version 1	July 15, 2007
The application for ethical review and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.		

Approval is issued on behalf of the Behavioural Research Ethics Board
and signed electronically by one of the following:

Dr. M. Judith Lynam, Chair
Dr. Jim Rupert, Associate Chair
Dr. Laurie Ford, Associate Chair