

“I see big gaps”: The Community Volunteer Supplement and Disability Income Policy in British  
Columbia

By

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Bachelor of Social Work, University of Victoria, 2010

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in Studies in Policy and Practice

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## ABSTRACT

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This research explores a disability community's success in drawing public attention to an unlawful development of policy, that community's efforts in resistance, and the experiences of those individuals in relation to subsequent neoliberal silencing. Specifically, this study examines the experiences of people on disability assistance in British Columbia who successfully appealed the Ministry's unjust denial of the Community Volunteer Supplement (CVS) and documents participants' reactions to the government's later repeal of the CVS program. Five individuals were interviewed about their experiences in resisting the Ministry of Social Development and Social Innovation's practice to wait list CVS applicants, a benefit they were legislatively entitled to receive. Of the participants interviewed, three identified as women and two identified as men. Utilizing a post-structural feminist theory, influenced by critical disability theory and Foucault, a key finding of this research is that participants' experiences with the CVS is connected to their experiences of poverty, resistance, and community.

Keywords: disability policy, Community Volunteer Supplement (CVS), appeals, British Columbia, resistance

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Finally, I would like to acknowledge the love, fire, and patience of my daughters, Harmony and Sage. Without you, all of this would be for nothing.

## **DEDICATION**

I dedicate this research to the participants whose wisdom built this thesis. You each demonstrated vulnerability, power, and a raw strength that I was lucky to bear witness to. Thank you for trusting me with your stories, for sharing your thoughts and kind words, and for demonstrating the power of experiential knowledge.

## ABBREVIATIONS

*Table 1: Abbreviations*

BCCPWD	British Columbia Coalition of People with Disabilities
BCPIAC	British Columbia Public Interest Advocacy Centre
CAP	Canada Assistance Plan
CMHA	Canadian Mental Health Association
CVS	Community Volunteer Supplement (formerly known as the CVP)
CVP	Community Volunteer Program
DBPA	<i>Disability Benefits Program Act</i>
DBI	Disability I
DBII	Disability II
DWPN	Disability Without Poverty Network
EAAT	Employment and Assistance Appeals Tribunal
EAW	Employment and Assistance Worker
EAPWD	<i>Employment and Assistance for Persons with Disability</i>
LICO	Low Income Cut Off
MBM	Market Basket Measure
MHR	Ministry of Human Resources
MEIA	Ministry of Employment and Income Assistance
MSD	Ministry of Social Development
MSDSI	Ministry of Social Development and Social Innovation
NDP	New Democratic Party
PPMB	Person with Persistent Multiple Barriers
PWD	Person with Disability
TAPS	Together Against Poverty Society

## CHAPTER ONE

### Neoliberal Realities: Biomedical Policies and the “Never-Deserving” Poor

#### *Introduction*

The fact that services for people with ... disabilities perceive citizenship in ambiguous, partial and fragmented ways is not surprising, especially if we take into account the perceptions of this group in policy over the last century, i.e. defective, subnormal, disabled and finally citizens. (Gilbert, 2005, p. 293)

Where disablement and poverty intersect is a difficult place for individuals and families to be, particularly in relation to disability income policy in Canada. The way society portrays both people with disabilities and poverty has changed somewhat over time, yet ableism and classism still permeate within Canadian society. A scan through the media or literature demonstrates that public discourse still echoes much of the Elizabethan constructions of disability (Jolly, 2003, p. 515; Prince, 2009). Of the many consequences of ableist ideologies dominating disability policy in Canada, one is that the development of policies occurs hierarchically; policies are created *for* not *with* people with disabilities (Jongbloed, 2003, p. 204; Stienstra, 2012, p. 103). A biomedical perspective of disabilities has ascendancy over disability policies in Canada; people with disabilities are reflected in policy as inferior, abnormal, and as overall social deficits requiring rehabilitation (Pothier & Devlin, 2006, p. 203). Raphael (2007) explains the poor-bashing experienced by people with disabilities living in low income, in relation to “many prejudices against the poor ... [and the] stereotypical thinking, labeling of people” (p. 162). Many scholars blame dominant neoliberal ideologies for shaping the public perception of individuals on low income and with disabilities as “being overly dependent on welfare, and lacking motivation to participate fully in the labour market” (Graham et al., 2009, p. 14). When examined critically, disability and social assistance policies are unfortunately reflective of this way of thinking (Raphael, 2007; Swanson, 2001).

Persons with Disability (PWD) assistance provided under the Ministry of Social Development and Social Innovation (MSDSI) embodies neoliberal ideologies all too well. Advocates observe that people on PWD assistance “find themselves dealing with a benefits system that, from its legislation to the interpretation and execution of policy, is informed by a focus on gatekeeping and cost-cutting” (BC Coalition of People with Disabilities, 2007, p. 3).

Benefits and supplements intended to offset different barriers experienced by people on disability assistance such as significant nutritional needs or mobility aids, provided for individuals who have PWD designation are subject to equal scrutiny.

The intent of this thesis is to explore the often unjust gatekeeping experienced by individuals seeking a benefit available under provincial disability legislation related to supporting the civic participation of people with disabilities. The Community Volunteer Supplement (herein referred to as the CVS) is a benefit intended to provide PWD recipients with an additional \$100 per month to offset costs associated with volunteering (Ministry of Social Development and Social Innovation, 2013d). The CVS made a significant difference for people with disabilities wanting to engage in their community through volunteerism (Clarke, 2011, July 07). Costs resulting from health issues (such as incontinence pads or pain medications), transportation, meals, appropriate clothing, and other expenses associated with community engagement, were intended to be offset by the CVS program.

My interest in this research comes from having first-hand knowledge as a woman living in poverty with invisible disabilities in British Columbia and from working as a Legal Advocate at the Together Against Poverty Society (TAPS) for several years. During my time at TAPS, I came across individuals being denied the CVS, despite being eligible according to the legislative criteria established under Section 47 of the *Employment and Assistance for Persons with Disabilities (EAPWD) Regulations* (Ministry of Social Development and Social Innovation, 2013d). Unfortunately, in a classic cost-saving effort, Ministry personnel implemented a policy of wait listing eligible CVS applicants, resulting in a *de facto* denial of benefits (Columbia Human Rights Law Review, 2011, p. 1076).

Such cost-saving efforts are all too reflective of neoliberal ideologies which “emphasize individualized independence from the state, individual responsibility for success or failure in the job market” (Chouinard, 2010, p. 149). Neoliberal ideology is centered within capitalism and perceives the economy as a means to resolve all social, political, and financial problems (Harvey, 2005). In this way, neoliberalism serves to reduce human beings to their function within the economic market, prioritizing privileged, able-bodied individuals. This neoliberal perspective, which dominates much of Canadian disability policy, fails to recognize the firsthand experiences of people with disabilities in navigating systemic social issues and intersectionality. In relation to disability policies the “rise of neo-liberal ideas has led to an increase in policies and programs

that view disablement as primarily an individual pathology” (Rioux & Valentine, 2006, p. 51). When each individual is valued purely for their ability to contribute to the economy, then individuals with disabilities are reduced in social priority and perceived only as deficits. It is this problematic pairing of economic functionality, embodied by neoliberal ideologies, and a deficit perspective of disability that permeates provincial disability assistance in British Columbia that is of relevance to this research (Townson, 2000; Chouinard & Crooks, 2008; Chouinard, 2010).

Given that public policy constitutes an administering organization’s interpretation of relating laws or legislation, policies cannot be created which supersede or contradict the relevant governing legislation (Birkland, 2014). Despite the existence of such basic legal foundations for interpretation, the MSDSI created a policy to waitlist individuals for the CVS. In doing so, the Ministry effectively introduced a practice that superseded and directly contradicted provincial eligibility criteria legislated within the Acts and Regulations pertaining to the CVS. I advocated in support of many individuals to successfully appeal the Ministry’s practice of wait-listing individuals, forcing the Ministry to remove people from the waitlist and provide them with the \$100 per month supplement. Furthermore, many individuals were being denied back pay for benefits they had been unjustly denied. Following a successful appeal, we sought the accumulated CVS benefits the individuals were entitled to during the time they continued to volunteer while on the wait list without receiving the CVS benefit. For many, these withheld funds amounted to a substantial sum when compared to their meagre monthly PWD benefits. After dozens of repeated CVS appeals, we at TAPS solicited the support of advocacy agencies around the province to publicly demand the province to provide the \$840,000 per year necessary to fully fund the CVS program (Clarke, 2011, July 05). The Ministry responded by announcing that they would fund the CVS program with \$5 million in funding that year, and \$10 million in funding thereafter to “clear a backlog of almost 8,000 applicants from the waitlist of its popular Community Volunteer Supplement program” (Clarke, 2011, August 10). Community advocates were overjoyed. Previously struggling to find a topic for my Master’s thesis, I immediately decided to use my graduate work to document how people with disabilities living in poverty made such a historic, systemic change.

Unfortunately, in a blatant silencing of people with disabilities through neoliberal governance, Section 47 of the EAPWD Regulation was repealed only months after the provincial government’s promise to fully fund the CVS program. New applicants could no longer apply for

the CVS. Existing CVS recipients were denied their right to appeal, as the appeals process only pertains to legislated benefits (Legal Aid, 2011). As a result, this research now explores the disability community's success in drawing attention to an unlawful development of policy, that community's efforts in resistance, and the experiences of those individuals who bared witness to subsequent neoliberal silencing. This research will examine the experiences of people on disability assistance in British Columbia who successfully appealed the Ministry's unjust denial of the CVS and also document these participants' reactions to the government's later repeal of the CVS program.

### *About the Researcher*

I would like to acknowledge that I am a visitor on Coast Salish territory as well as on the Tsuu T'ina nation. I am a Caucasian Queer female-bodied single mother of European descent. I have come to my thesis topic through my personal experiences as a woman living in poverty in British Columbia and later as an advocate for people with disabilities living on provincial disability assistance. I was homeless for a significant amount of my youth, with undiagnosed mental health issues, and came to understand firsthand the challenge of seeking assistance in Victoria, BC. Unfortunately, the dominant discourse still echoes that it was only by 'pulling myself up by my bootstraps' that I have gotten through my history, when in fact I know it is a complex interaction of resiliency, supports, access, and timing.

There is no 'protestant work ethic' moral of the story that can be taken from my experiences. Really, it is all too classic. A young girl, growing up around poverty, addiction, and abuse quickly seeks refuge on the streets with her own pattern of addiction to self-medicate, and a sharp edge for survival. It was only when I witnessed a friend's overdose that I was shocked into wanting to cease my medicating habits. Shortly after my attempts at 'being healthy,' I found myself pregnant at sixteen years old. Supports like a women's shelter for victims of domestic violence, low-income housing, social assistance, young parent supports, alternative education, and counseling services contributed to my success story.

I had arduously come to a place where I was ready to accept help, but it truly was only the timing that I, unlike many others, had been lucky enough to apply for low-income housing while I was staying in the women's shelter. I was unaware that such a loophole was rare, and had I waited a few weeks until after I left the transition house, I would have been on a two-three year

wait-list for low income housing. Because I applied for low income housing *while in the transition house*, I was placed at the top of the waiting list. I was then informed of an alternative school for parenting teens called the Girls Alternative Program, which would help change my life dramatically. I entered the program only two years prior to severe cutbacks that would have reduced the number of seats available. If I had tried to apply to be a student in the Girls Alternative Program a few years later, it is unlikely I would have been able to attend. Had it not been for the countless (unpaid) overtime hours the staff contributed to help piece together the city's most broken young girls, I certainly would have never been permitted to keep custody of my child. A seventeen-year-old ex-addict, with less than a year off the streets, isn't child welfare's favourite candidate for parent of the year. Luckily, when you have a well-known program backing you, you can sometimes get off the hook.

Being able to go to school because my child was under three years old and receive provincial Income Assistance provided me with only enough to pay for my low-income housing (had it been market rent, I would have starved even more than I did). I had just enough to feed my baby every day (I ate every second day, or as far as I could stretch myself on coffee and food bank rice so my baby could have her food groups the little chart from Vancouver Island Health Authority said she needed). Sometimes, I even got a Starbucks Frappuccino on "welly day" (aka welfare day) as a treat for myself.

Unfortunately, the welfare system did not support single mothers attempting to become high school graduates, so my application for a transportation subsidy to get to school was denied. Although I was found ineligible for a bus pass at my Tribunal Panel hearing, one panel member offered to pay for my bus pass, every month, until I got to university. I was fortunate enough to receive free counseling services from the Single Parent Resource Centre to begin working on my healing and to build my parenting skills; by 2004 these services would experience drastic cuts. After attending the Girls Alternative Program, I enrolled at SJ Willis, an alternative education program for adults. I finished the one final course required for a high school graduation, as a result of an empathetic English teacher who worked to build the confidence of an ex-street kid single mother enough so she might try for a post-secondary education. It was the college and university professors who let a young mother bring her newborn to class. It was the student loans, scholarships, and bursaries that ensured my (now two) young children could manage to eat every day (quite a nice change in comparison to the sparse meals experienced on Income

Assistance). It was the Legal Aid system (prior to recent cuts) that defended me through separation as an eighteen year-old, single mother. While I was doing my undergraduate degree, it was a well-known tenancy advocate who gave me a reference so I could apply for a job as a Legal Advocate at TAPS, an agency of which I had previously been a client. This reference enabled me to obtain the job that three other candidates, law degrees in tow, had applied for. It was an agency taking a chance on hiring me, a young, tattooed twenty-two year-old (who often had to work random hours due to single parenthood), that sparked my passion for poverty and disability advocacy.

I mention these details to give credit to the countless systems and supports that helped me go from living on the streets, selling homemade jewelry and using drugs, to writing my thesis for my Master's degree. I do not discredit my own strength, however by no means is this story of me 'finding my inner strength to *overcome* my struggles.' I will never be a movie of the week, because the focus would have to be on the services that helped me and the number of people denied the same opportunity due to the long and steady string of cuts thanks to neoliberalism.

### ***The Context and Purpose of this Research***

In Canada, people with disabilities have been subject to the eugenics movement and sterilization, institutionalization, widespread exclusion, deep poverty, and more in the name of (neo)liberal, paternalistic, and ableist ideologies. Historically, people with disabilities have been denied citizenship in the very decision-making processes and resulting policies that directly impact and substantially define their lives. The systems that govern the lives of people with disabilities have consistently denied and sought to erase the experiences of people with disabilities both throughout and from history.

There is a "pressing need" to explore the experiences of people with disabilities in receiving provincial disability assistance (Chouinard, 2009, p. 155). It is important to note that experiences of disablement are not absent from other intersections of marginalization. This research speaks to the resistance of people with disabilities, and experiences of power and processes of 'othering' by the government. However, this research is only one facet of the multitude of intersections of oppression within the context of biopolitics. Within the systemic issues in disability policies, women, people of colour, and Aboriginal peoples, as often is the case, are more adversely impacted by barriers to access, discrimination, and other aspects of

stigmatization (Graham et al., 2009; Jongbloed, 2003; Minister of Public Works and Government Services Canada, 2007; Raphael, 2007; Tang & Peters, 2006). As Townson (2000) notes, the “feminization of poverty is a concept that has been around for a long time ... [since] poor people are disproportionately female” (p. 1). Women also make more than 50% of the population of people with disabilities in Canada, making women more adversely impacted by neoliberal policies within social welfare systems (Minister of Public Works and Government Services Canada, 2007, p. 3; Stienstra, 2012, p. 54; Teghtsoonian, 2003). Poverty for people with disabilities is even more prevalent for Aboriginal peoples, people of colour, and newcomers to Canada (Raphael, 2007; Stienstra, 2012). People of colour are disproportionately represented among statistics of people living in poverty, as they are more than twice as likely to experience poverty than people of European descent (Raphael, 2007). Neoliberal perspectives within Canadian public policy often seek to blame individuals for their experiences of marginalization, however post structural and other critical perspectives attest that,

those with less education, women, people with disabilities, people of colour, or immigrants become more likely to be included in those living in poverty ... Changes in Canadian public policy have resulted in worsening housing situations, reductions in social assistance benefits in many provinces, and increasing food insecurity in many cities. All of these developments make the situation of people living in poverty even more precarious than it is already. (Raphael, 2007, p. 78)

The experience of being a marginalized person, with a disability, *and* living in poverty is further complicated by oppressive ideologies over the body, ideologies that dictate much of public policy (Knoll, 2009; Foucault, 1994; Jolly, 2003).

Many services for people with disabilities continue to embody the oppressive dominant discourse that fails to acknowledge disability as a social construct (BC Coalition of People with Disabilities, 2007; Wendell, 1989; 2013). Disability, when interpreted as a social construct, “is posited as a situational or conditional experience that can be modified or eliminated” (Putnam, 2005, p. 191). In this way, viewing disability as a social construct places the onus for change on society as a whole, rather than on the individual. However, current disability policies are rampant with the construction of ‘othering’ through public services, ensuring that recipients of such services must accept the labels regarding their bodies and health that are assigned to them in order to receive supports (Shriner, 2000). The act of ‘othering’ or invalidating people with disabilities is argued by some theorists to result from the fear and discomfort of dominant, able-

bodied individuals seeking to illustrate how people with disabilities are somehow different from themselves (Hughes, 2009; Wendell, 1989). Feminist and critical disability theorists' experiences of the politics cultivated within and onto their constructed bodies similarly echoes much of the externally constructed concepts of disablement,

We need a feminist theory of disability, both because ... women are disabled, and because the oppression of disabled people is closely linked to the cultural oppression of the body. Disability is not a biological given; like gender, it is socially constructed from biological reality. Our culture idealizes the body and demands that we control it. Thus, although most people will be disabled at some time in their lives, the disabled are made 'the other,' who symbolize failure of control and the threat of pain, limitation, dependency, and death. If disabled people and their knowledge were fully integrated into society, everyone's relation to her/his real body would be liberated. (Wendell, 1989, p. 104)

The impact of social othering has broad and harmful effects; people with disabilities are excluded from forms of civic participation and contributing to the development of the very policies that often govern their lives. The resistance exercised by people with disabilities is discounted as a means of 'othering.' The ways in which feminism has sought to problematize external constructions of the body intersect with much of disability theory. The experiences of being placed on the margins as a result of one's body is intertwined with the feminist experiences of body politics, and in this way, disability politics are intertwined with feminist thought (Foucault, 1990a; Roeher, 2005).

Before social services for people with disabilities in British Columbia can be understood, the dominant neoliberal ideologies and firsthand experiences relating to such power must be explored (McBride & McNutt, 2007). The construction of histories through systems of power adversely result in manipulated narratives, or subjugated knowledges, that led to the denial of some histories amongst the margins (Foucault, 1980). Documenting the perspectives of people who exercised resistance within the PWD system highlights people's experiences of one of many unjust provincial policies that severely impacts the lives of people with disabilities. Moreover, such research also speaks to the complex appeals process endured by people with disabilities, and provides an explicit example of the harms of neoliberal policy.

I sought to delve into the concepts of disability politics as experienced through the denial of the Community Volunteer Supplement amongst people on disability assistance in British Columbia who first resisted a policy that, on the outset, was presented as unchangeable. From a

policy perspective, I was interested in hearing about how the MSDSI's policy to wait list CVS applicants was encountered by people on disability assistance. This research explores the experiences of people who were wait listed for the CVS and successfully appealed. In addition, I wanted to document these individuals' reactions to later hearing that the MSDSI removed PWD recipients' opportunity to appeal denied CVS cases or to apply for the CVS as a new client. The experiences of resistance coupled with the first-hand observations of PWD policy changes contributes to the significance of this study. Through examining their experiences in resisting the system that seeks to define and control their identification as a person with disabilities, I want to give voice to the reality that the system that claims to provide assistance is in fact an agent of oppression. I analyze participant testimonies by drawing on Foucault's concepts of biopolitics and power, relevant post structural feminist literature, and disability studies theory.

### *Significance of this Study*

The aim of this study is to examine the experiences of people with disabilities who challenged systemic issues through the appeals process and explore how disability assistance policy served to further stigmatize and 'other' people with disabilities living on PWD assistance. Exploring the ways in which people experience provincial disability policies in British Columbia is integral to understanding the oppressive nature of the social services system in this province. The dominant discourse demonstrates an Elizabethan construction of the deserving and the undeserving poor, 'heroic' and 'unheroic' disabilities, and an assumption of a just and righteous provision of services. In much of the Western world, the onset of neoliberalism sought to redefine the concept of 'deserving' people in need:

The policy ... clearly depicted the disabled welfare subject as historically shirking their civic responsibilities, thus requiring extensive surveillance and monitoring to ensure that they were no longer able to defraud the system. Disgust had finally stuck, and the normative realm of deservingness had been categorically reclassified and reconstituted to depict a new class of disabled citizens as inherently undeserving of state welfare. The morally deficient and deviant disabled welfare subject now had a range of responsibilities, including civic obligations, in addition to undertaking individual behavioural modification through specifically targeted interventions. Workability was no longer singular, but was coupled with moral normative assumptions of respectability, which required the disabled welfare subject to earn the right to deserve state welfare incrementally. (Soldatic & Pini, 2009, p. 88)

Public structuring of peoples' experiences of disability and accessing disability services are largely influenced by neoliberalism (Chouinard, 2010; Townson, 2000; Tang & Peters, 2006). There is a common lack of respect and blatant disregard for a recipient's right to object to the services they receive given that many would argue that "welfare bureaucracies are intentionally designed to deter and deflect complaints" (Lens, 2007, p. 402). People with disabilities on PWD assistance in this province are considered shameful if they object and exercise resistance, and are often subject to poor-bashing (Graham et al., 2009; Swanson, 2001). In this way, the dominant ideology often restricts opportunities for people to be empowered and autonomous as service consumers, particularly in relation to experiences of the body (Klein & Pulkingham, 2008; Prince, 2009). Until such constructions are changed, people living on disability assistance in this province will continue to face policies and practices that embody this ideology.

### *The Research Questions*

This thesis addresses two main questions. First, "For people on disability assistance in BC, what are their experiences in resisting the Ministry's practice to wait list Community Volunteer Supplement (CVS) applicants?" Secondly, "How do these experiences connect to relations of power and processes of 'othering' by government?" These questions relate to exploring ways in which dominant oppressive ideologies become embedded within policy and legislation, and give people with disabilities who personally experienced these issues the opportunity to define the resulting impacts. In asking a question of experience in relation to examining the dominant ideology, this research question makes explicit the ways in which governmental systems are disconnected from the voices of those who experience the issues firsthand. Through acknowledging this disconnect, this research aims to demonstrate the need to construct policy that is informed by the people who are directly impacted by such policies. To construct policy without direction from people with disabilities is a means of systematic 'othering' and an exertion of power and control, rather than support.

In Chapter Two, I discuss the relevant literature relating to people with disabilities' experiences of legislation and relating concepts. I explore how the body has been situated as a site of oppression through biopolitical power relations. I provide an overview of historical disability policy to provide a contextual understanding of the ways in which disablement has been both constructed and erased through past public policy. Following this, I review current

disability policy in British Columbia to present the existing context within which participants' lived experiences are situated. Navigating the appeals processes available within current PWD policy is discussed to understand the limited avenues for formalized resistance, and to also provide a summary of the various processes endured by participants within this research. Concepts of resistance are briefly discussed in relation to overarching theories utilized within this research. Chapter Three presents how I have approached the data and relevant considerations, including ethical protocols. I draw on feminist post structuralist research influences and critical disability theory, referencing Foucault, to formulate my approach to the research process. In Chapter Four, I present a themed analysis of the data to illustrate how participants exercised resistance in navigating the Community Volunteer Supplement and other experiences of resistance accessing provincial benefits. Chapter Five explores the means by which the participants' experiences of resistance are reflective of power and processes of othering by the government. The thematic organization of these findings groups participants' experiences as they relate to power and processes of othering by the government. These findings were divided up by surfacing the ways in which the participants were subjected to inequitable power relations. Chapter Six highlights and themes participants' experiential recommendations and provides points of consideration for future disability policy development. Chapter Seven provides a concluding summary of this thesis and its findings.

## CHAPTER TWO

### **The Literature: Policies and Histories Impacting People with Disabilities**

The real political task in a society such as ours is to criticize the workings of institutions, which appear to be both neutral and independent; to criticize and attack them in such a manner that the political violence that has always exercised itself obscurely through them will be unmasked, so that one can fight against them. (Chomsky & Foucault, 2006, p. 171)

This chapter examines ways in which social policies regulate the lives of people with disabilities. It begins by introducing literature pertinent to the concept of biopolitical ‘othering’ to illustrate the ways in which post structural feminist theory and disability theory will be drawn upon later to analyze participants’ experiences in chapters four and five. The cumulative impact of historical disability policy in Canada will then be explored to establish the foundation on which present day PWD legislation operates and to illustrate the collective injustices experienced by people with disabilities in Canada. The ways in which historical policy sought to privilege bodies that are useful for capitalistic production will be surfaced to exemplify the compounded reality for people with disabilities. In doing so, the varying ways in which disabled bodies have been treated as deserving or undeserving will be surfaced within the provision of past social policies. Historical resistance amongst the disability community will be highlighted by identifying instances where collective resistance or ideological shifts influenced changes in public disability policy. This chapter also provides a brief synopsis of the current PWD benefits under the *Employment and Assistance for Persons with Disabilities* legislation and relating eligibility requirements in an effort to illustrate present-day disability policy. Individuals wanting to apply for the Community Volunteer Supplement had to have received PWD designation, so it is important to understand these policies and processes. Furthermore, limited information is available within the literature regarding the CVS. The final section of this chapter explores the PWD appeals processes to provide an understanding of the administrative avenues for resistance the participants in this research endured.

#### ***Oppression of the Body***

The concept of the constructed body has been taken up by critical disability theorists and feminists alike. Within this research, I will explore the ways in which the constructed body, and resulting dichotomies such as illness/wellness relates to PWD policy. Michel Foucault viewed disability, and other kinds of social marginalization, as constructs created and, at the same time, regulated by systems in power (Foucault, 1994; Jolly, 2003; Sawicki, 1991). Foucault brought light to the ways in which government, institutions, and systems designed to respond to social, economic, and political issues are also constructs of power whose function is to *govern* the margins to ensure order and social control (Foucault, 1994). Furthermore, disability movements have “[d]rawn attention to the ways in which dominant ableist norms and practices work, on the one hand to exclude people with impairments from the mainstream of contemporary society while, on the other, confine them to ‘special’ areas and venues” (Paterson & Hughes, 1999, p. 587-598). The existence of oppressive policies, and the subsequent resistance amongst the disability community, offers a foundation to this research in that it is within the friction of being defined, restricted, resisting, and surviving that the cumulative reality of disablement must be understood.

To understand the location of people with disabilities within the systems that govern their lives, one must understand the government of disability, or broadly, the government of the body. The government of disability, in the way that Foucault uses the term, specifically means the *governing of* or the *governance over*, referring “to the processes through which disabled peoples’ lived experience is influenced by economics and power in welfare and in work” (Jolly, 2003, p. 510). The Foucauldian understanding of the ‘politics of the body’ or ‘biopolitics’ can be understood as the systems and policies created to govern, regulate, and manage, “the social to accord with the tasks and exigencies faced by the state. It is Foucault’s contention that the body, individual and collective, becomes the raw material for this undertaking” (Hewitt, 1983, p. 67). Thus, the construct of disability can be understood as politics exerted *onto* or *over* the body, rather than as a *product* of the body.

Feminist post structuralists have taken up Foucault’s ideas on the constructed body as the practices which serve to construct and govern societal ‘deficits’ significantly mirror the experiences of women within society (Price & Shildrick, 1999, p. 434). Historically, the feminine body has been classified by the state, overlapping with the ways in which disability is

externally constructed. In this way, utilizing layered perspectives to analyze the constructed body serves to surface, and create tension amongst, the regulatory systems over the body:

Foucault wrote about the sexualization of women's bodies and of concepts of pathology related to it such as hysteria, neurasthenia, and frigidity. Foucault intended to locate the process through which women's bodies were controlled through a set of discourses and practices governing both the individual's body and the health, education and welfare of the population, namely, the discourses and practices of 'biopower.' (Sawicki, 1991, p. 67)

The systemic disciplinary practices that then serve to regulate and restrict the biopolitically constructed 'other' are intertwined with systems of care, creating a challenging coupling of concepts of care and control. Systems of power over disability sought to define what is *abnormal*, outlining the margins for anyone who does not fit into what is considered 'normal.' The construction of deficits was birthed; medicalized, theologized, and epistemologized until one could not escape from the margins as every system became reflective of what it is to be normal and what it is to be deficit. Consequently, "normalization becomes one of the great instruments of power" (Hewitt, 1983, p. 69). Current public policies are highly reflective of ableist ideologies, whether policy administrators would like to admit this or not, and serve to provide "a foundation for keeping people with disabilities in the status of second-class citizens both within nation states and as world citizens" (Rioux, 2003, p. 288). The body of a person with a disability then is a location of political and ideological hegemony.

Disability policy in Canada has served to define and control constructions of the disabled body, and therefore, has significantly affected the ways in which people with disabilities are represented in social policy. To access benefits, people with disabilities must adhere to externally constructed definitions of what it means to be disabled. People on PWD assistance are subject to constant scrutiny under provincial disability policy as to whether they are 'disabled enough' to receive assistance. In this way, people with disabilities on PWD assistance are subject to privileges or consequences, as a result of how their body is defined or understood within provincial disability legislation:

Biopower emerges as an apparently benevolent, but peculiarly invasive and effective form of social control. One of these, disciplinary power, is a knowledge of and power over the individual body – its capacities, gestures, movements, location, and behaviours. Disciplinary practices represent the body

as a machine. They aim to render the individual both more powerful, productive, useful *and* docile. (Sawicki, 1991, p. 67)

This concept, as it is utilized within this research, is largely influenced by Foucault's analysis of freedom and power in that both are largely constructed and maintained through dominant discourse (1980; 1990; 1994). Historical policies are extremely reflective of how representations of people with disabilities facilitate a politicized control over the bodies and lives of people with disabilities. The intersection of poverty and disability stigma is even more complicated by other intersections of marginalization, such as racism or sexism.

Little & Marks (2006) compare how the political climate of British Columbia enacts a neoliberal take on poverty, with the dominant discourse arguing that many individuals on social assistance could be permanently employed if they so chose. Welfare policies in BC are meant to give the illusion that recipients on assistance are graduating towards independence, however many individuals leaving PWD assistance do so as a result of systemic gatekeeping (Little & Marks, 2006, p. 18). Foucault (1994) argues that because the upper classes hold power over those in poverty, the lower classes are subject to the loss of power and control:

We may say that, from that moment, this moral control was exerted by the upper classes, the holders of power, over the lower, poorer strata ... It thus became an instrument of power for the wealthy over the poor, for the exploiting over the exploited, which conferred a new political and social polarity on these agencies of social control. (p. 63)

An individual's freedom is reflective of the current socio-political context in combination with historical considerations, so the level to which PWD assistance recipients perceive and enact freedom is relational to the stigma that has been forced upon them via disability policies.

### ***Historical Policies Impacting People with Disabilities***

Understanding ways in which the human body has been politicized throughout historical policies, we can begin to appreciate present day disability policies. The thread of resistance to less generous policies becomes visible within different eras by understanding the contextual reality of being a person with a disability within the Canadian systems. Legislation affecting people with disabilities has transformed significantly since the *British North America Act* of 1867 (Rice & Prince, 2000, p. 34). The beginnings of a welfare state in Canada can "be traced to the first thirty years or so after Confederation, from 1867 to 1900" (Rice & Prince, 2000, p. 36).

The economic conditions of Canadians were changing markedly and the increase in populations, urbanization, and social problems resulted in a growing need for social welfare considerations in public policy. The medicalization of social issues has had a longstanding partnership with colonization in the British monarch system, so when the newly colonized nation of Canada developed, so did the development of asylums and eugenics. Prior to 1872, “the prison was the only place in which people with mental illnesses were confined” (Roman et al., 2009, p. 25). Many individuals who were dubbed mentally ill or a genetic risk to society who would have previously been incarcerated were now institutionalized. Institutionalization was seen as such a promising practice to address social issues of deficit that, “in order to determine who was a potential candidate for sterilization or institutionalization, intelligence tests were being administered in schools, hospitals, and boys and girls schools” (van Heeswijk, 1994, p. 33). The *British Columbia Lunacy Jurisdiction Act* of 1872 was intended to enforce the rights of government, professionals, and legal guardians to institutionalize “natural born fools, lunatics, and persons deprived of understanding and reason by the act of God” (Roman et al., 2009, p. 27). To be a person with a disability during this era was to be subject to biologically-assigned criminality. To be a person with a disability during this era was to be subject to institutionalization or criminalization based on the status of one’s body. For many, being Indigenous, low income, a person of colour, an unwed woman, or a newcomer meant an additional justification for legalized oppressive measures (Boyer, 2006; Hansen & King, 2013; Jhappan, 2002; Stote, 2015).

In the earlier part of the last century, legislation and policy impacting people with disabilities was intended to diminish the existence of the disabled body as “disability was seen as a personal tragedy” (Jongbloed & Crichton, 1990, p. 26). In 1930, the Eugenics Society of Canada was founded in Toronto, Ontario with the mandate to “further a national policy of race betterment by developing legislation to safeguard racial progress” (Revie, 2006, p. 125). The Eugenics Society of Canada was largely influenced by the principles of early eugenicists. Francis Galton first coined the term “eugenics” in 1883, which was essentially the “science of improving stock” (Pearson, 1930, p. 221). The *Sexual Sterilization Act of BC*, previously called *An Act Respecting Sexual Sterilization* (1933), justified sterilizing individuals as follows:

If upon such examination of the inmate the Board of Eugenics is unanimously of the opinion that the procreation by the inmate would be likely to produce

children who by reason of inheritance would have a tendency to serious mental disease or deficiency, the Board may by an order in writing signed by its members direct such surgical operation for sexual sterilization of the inmate as is set out in the order, and may appoint some legally qualified medical practitioner to perform the operation. (van Heeswijk, 1994, p. 95)

The surgical sterilization of “‘mental defectives’ during this period served an ambitious political agenda, one that promoted a healthy citizenry while minimizing state expenditures” (Wilson et al., 2010, p. 3). Indigenous peoples, particularly women, were largely subjected to the genocidal aims of the Canadian eugenics efforts (Boyer, 2006). Thousands of Aboriginal women were said to have been sterilized without their consent, though most expect these estimates to greatly exceed those on record (Boyer, 2006; Stote, 2015). People of colour, newcomers, and Indigenous peoples were subject to sterilization, medical testing, and other unethical biopolitical controls (Hansen & King, 2013; Jhappan, 2002). Public health research at the time utilized the claimed motivation of care, enforced by public policy, to criminalize people of colour by testing large populations of Black communities for the “crime gene” (Jhappan, 2002, p. 97). Foucault would argue that during some significant periods throughout history, medicine was about maintaining “control of the health and the bodies of the needy classes,” asserting an “obligatory medicalization of their bodies” (1994, p. 155).

In the early 1900s, industrialization and urbanization brought an onset of new risks for Canadians: “There was increased risk of industrial accidents, sickness from living in an urban setting, and unemployment from volatile changes in the economy; increased likelihood of mental illness due to social stress; and then rising threats to the family from crime” (Rice & Prince, 2000, p. 40). Industrialization brought about a greater chance for poverty, isolation, and other social issues that had traditionally been a personal, rather than social, concern. During this time, sociologists found that “the biomedical system of care emerged as a direct response to the needs of developing capitalism” (Jongbloed & Crichton, 1990, p. 26). As a result, social issues could no longer be personalized solely onto the individual and demanded a public response.

Following the Great Depression during the 1930’s social issues such as poverty and homelessness started to impact the perceived ‘deserving’ ranks; no longer was poverty an issue isolated to the ‘feeble-minded’ or ‘immoral classes.’ With a number of war veterans returning from World War I with combat-acquired injuries, disability was not limited to particular classes (Jongbloed & Crichton, 1990, p. 26). Although war brought about the construction of heroic and

unheroic disabilities, meaning limitations acquired through publicly acceptable forms (defending one's country) vs. socially condemned forms (abject poverty), disability was suddenly a topic of discussion outside of impoverished classes. As a result, the public demanded some type of support for the industrial classes who were suddenly experiencing disabilities and extreme poverty. In an early example of resistance, a section of the disability community pushed back against the externally enforced personalization of disability. The constructions of disability during this era were challenged to include a broader understanding of the right to need public assistance based on disability.

Social policy started a slight shift towards recognizing the need for some kind of social safety net as "citizens encouraged the provinces to take major responsibility" (Rice & Prince, 2000, p. 39). Of course, such shifts were reflective of Canada's vertical mosaic in that most people of colour, newcomers, and Indigenous peoples were not considered eligible for such benefits until many decades later (Boyle, 2006; Hansen & King, 2013; Jhappan, 2002). Following these early shifts in social policy, "it was not until the early twentieth century, when Workmen's Compensation Boards were established, that a worker with disabilities received income support" (Jongbloed & Crichton, 1990, p. 26). Reflective of the longstanding perception of the body as a means for capitalistic production, early versions of disability policy were inherently tied to one's contribution to, and retraction from, the workforce. The *Pension Act* of 1919 was the first "universal income benefit in Canadian social policy" intended to respond to the needs of war veterans (Rice & Prince, 2000, p. 44). The *Pension Act* was amended several times, with the *Old Age Pensions Act* of 1927 later becoming the *Old Age Security Act* in 1952 (June Dewetering Economics Division, 1990). In 1940, the *Unemployment Insurance Act* was created, followed by the *Hospital Insurance and Diagnostic Services Act* in 1957 and the *Medical Care Act* of 1967 (Jongbloed, 2003, p. 204). Although generally intended to benefit able-bodied, employable individuals, many would argue this era marked a shift in the ideology around public policy relating to early concepts of disability assistance policy.

The 1950s to 1960s are considered by many to be a historical time for the development of policies that were intentionally designed to benefit people with disabilities living in low income. Collaborative federalism, essentially having the provincial and federal governments work collaboratively towards the same effort, is generally accepted to have been birthed somewhere between the Great Depression and the post-World War II era (Cameron & Simeon, 2002, p. 49;

Prince, 2001, p. 794). Collaborative federalism has greatly influenced the development of disability-centered public policy and resulted in greater democratic engagement (Prince, 2001, p. 794).

Between 1950 and 1970, “it began to be acknowledged that economic hardship and personal crises could defeat people” (Jongbloed, 2003, p. 203). Although still embodying a paternalistic ideology, policies began to shift (Vanhala, 2009, p. 987). Social movements during this time had an influence on the development of public policy for people with disabilities. In 1958, the Canadian Association for Community Living was founded in the wake of the deinstitutionalization movement (Canadian Association for Community Living, 2014). A few years later, in 1961, the *Vocational Rehabilitation of Disabled Persons Act* was passed which offered “agreement to the provinces and territories for federal sharing of 50 per cent of the costs for a range of services designed to help people with physical or mental disabilities become capable of pursuing a gainful occupation” (Prince, 2001, p. 796). Again, the prioritization of people with disabilities in relation to their desire to contribute to the capitalist system sought to define who was deemed ‘deserving’ within this era. In 1966, the Canada Assistance Plan “consolidated a number of welfare programmes, including the cost-shared programs under the *Old Age Assistance Act* of 1951, the *Blind Persons Act* of 1951, the *Disabled Persons Act* of 1954 and the *Unemployment Assistance Act* of 1956” (Prince, 2001, p. 797). The Canadian Assistance Plan (CAP) of 1966 was intended to improve federal-provincial relations, increase public spending, and consolidate a number of different income assistance programs:

The Canada Assistance Plan...was developed over a three-year period beginning in 1963 and was designed to consolidate, extend and replace the Unemployment Assistance Act, and the three existing ‘categorical’ programs - the Old Age Assistance, Blind and Disabled Persons Allowances Acts. It provided for federal contributions for the first time to provincial mothers’ allowance schemes, to provincial costs in providing health services to public assistance recipients, to rehabilitative and preventive welfare services, and to the administrative costs of such programs. (Dyck, 1976, p. 588)

The CAP was considered revolutionary in terms of Canadian public policy in the sense that it was the first program to not only encourage provincial spending, by matching provincial spending on social programs at a rate of fifty percent, it also emphasized that no individual would be denied assistance if they demonstrated they were in need (Michael & Reitsma-Street, 2002).

People of colour, newcomers, and Indigenous peoples were not excluded from CAP, but were prevented from accessing or receiving many other social benefits (Galabuzi, 2006; Stote, 2015; Walker, 2008). Whether covertly denied access to social benefits, or directly excluded within legislation, many people found that the intersection of their race and disability provided grounds for systemic exclusion. For many, the *Immigration Act* of 1976-77 was considered one of the many ways in which the brief universality of the welfare system that followed the Great Depression came to an end (Hanes, 2013; Thobani, 2007). Steeped in colonial, capitalistic ideologies, the history of immigration policy in Canada has served to prioritize white, able bodied males above all else. The 1976-77 Act prioritized the economic capability of potential newcomers, leaving people with disabilities and women particularly undervalued (Hanes, 2013). The neoliberal *modus operandi* of policies impacting people with disabilities have typically placed a deficit value on the bodies of people with disabilities. In this way, the powers of the medical system in defining issues of access and citizenship were furthered within Canadian policy:

The assumption that people with disabilities are ill or weak simultaneously dismisses their potential contributions to Canada's economy or social systems or workforce while emphasizing the cost they will pose to these systems. In the cost-benefit analysis of immigration applications, immigrants with disabilities are disadvantaged by ableist assumptions of both their cost and value. (Penner, 2012, p. 9)

Immigration policies in Canada have always enforced various versions of biopolitical controls in the name of economic interests, however current policies still echo the ableist rhetoric of previous legislation. Immigrants can still be deemed inadmissible to Canada if they are assessed on health grounds to be an “excessive demand on health or social services” (*Immigration and Refugee Protection Act*, S.C. 2001, c. 27, section 38 c).

From 1972-75, the New Democratic Party (NDP) formed the government in British Columbia and sought to address social inequalities through strategic legislation. Like many periods of social advancement in British Columbia, the successes were short lived (Strega et al., 2002, p. 182). In 1975, Bill Bennett was elected as Premier and prioritized drastic cost-saving efforts on social programs (Graham et al., 2009). In 1983, Bennet’s Social Credit government slashed millions of dollars from social programs, education, and human rights budgets and on August 10, 1983 “40,000 people stood in solidarity at Empire Stadium in Vancouver against

Bennett's reforms" (Graham et al., 2009, p. 13). Such a significant act of resistance demonstrates a longstanding history of a push-and-pull relationship within public policy and the people such policies impact. However, such efforts were of little effect; social program benefits and eligibility requirements waived for the remainder of the 1980s. Up until the early 1980s, "an attitude of paternalism dominated disability issues ... on a policy level, this meant that disability was perceived as a social security, welfare or health policy issue, not a human rights or citizenship one" (Vanhala, 2009, p. 987). In the early 1990s in BC, when the NDP came into power again, social assistance programs became a public priority again despite federal efforts to reduce spending, such as capping the Canadian Assistance Plan spending eligibility of some provinces (Graham et al., 2009; Michael & Reitsma-Street, 2002; Prince 2001).

In 1996, CAP was abolished and replaced with the *Canada Health and Social Transfer* program (CHST) which some argue made welfare and disability reforms more difficult while others would attest that the CHST increased collaborative spending (Prince, 2001; Raphael, 2007; Townson, 2001). The 1990s marked yet another slash in the history of social policy advancements impacting marginalized peoples living on low income with disabilities,

As monetarism, deficit reduction, and government downsizing began to take hold in Canada, universal programs were increasingly challenged, whittled away, or subjected to deterioration in quality of services provided. Federal budget reductions simply shifted deficits to the provinces. (Frankman, 1998, p. 491)

The CHST essentially cut secured funding to the provinces at drastic rates, making the amount of funds the provinces could continuously depend on for social programs, health care, and education almost nonexistent (Cohen & Klein, 2011).

The *Guaranteed Available Income for Need Act* of 1972, which focused on reducing some of the apparent causes of systemic poverty, was later replaced by the *Social Assistance Act* of 1994. Demonstrating a reoccurring pattern within public policy, the short lived focus on meeting basic needs again shifted to renewed neoliberal outcomes. The *Social Assistance Act* paved the way for the *BC Benefits Act* and the *Disability Benefits Program Act*, which emphasized a greater focus on the 'welfare-to-work' model that marked much of the social policy efforts of the 1990s and onwards (Graham et al., 2009; Raphael, 2007; Strega et al., 2002). In 1996, British Columbians living on low income were subject to another policy change:

The modest Guaranteed Available Income for Need Act of 1972—notice the words guaranteed, income, and need—was replaced with the B.C. Benefits (Income Assistance) Act ... Eligibility was tightened for most applicants, especially youth, and more employment or training conditions were required. If eligible, a single person had to exist on \$510 per month in 2001. While rates for families with children and persons with disabilities were higher, all welfare rates remained far below commonly accepted standards of adequacy for necessities of dignified living. (Michael & Reitsma-Street, 2002, p. 4)

In 2002, the *Disability Benefits Program Act* (DBPA) of 1996, which provided disability assistance using Disability I (DBI) and Disability II (DBII) designations, was replaced by the *Employment and Assistance for Persons with Disabilities Act* (EAPWD) (BC Coalition of People with Disabilities, 2007; Klein & Long, 2003). Premier Gordon Campbell, of the Liberal party, began his dramatic assault on people with disabilities in BC through his aggressive efforts in January 2002 to “cut the Ministry of Human Resources (MHR) operating budget by \$581 million (or 30%) over three years (Graham et al., 2009, p. 16). People on social assistance, many trying to navigate the application process to hopefully receive disability assistance, were subject to extreme cost-cutting measures with nearly 107,000 people cited in 2005 to have been kicked off of assistance (MacLeod, 2005 August 18). Persons with Disabilities previously on DB I or DB II were subject to an extensive review process, and stress amongst people with disabilities on assistance were reported to have risen dramatically (Klein & Long, 2003). To illustrate present-day disability policy, the next section provides a brief synopsis of the current Person with Disability legislation and relating eligibility requirements.

### ***Current Policies on Person with Disability Assistance in British Columbia***

Individuals wanting to apply for the Community Volunteer Supplement (CVS) had to have received PWD designation, so it is important to understand these policies and processes. In addition, given that limited research has been conducted specifically on the CVS, PWD processes will be illustrated within this section as exemplary of the onerous processes people on PWD assistance must endure. In British Columbia, people with disabilities who do not have a significant source of income often have no choice but to turn to the provincial government for financial assistance to meet their basic needs. Although having undergone a number of name changes, the Ministry of Social Development and Social Innovation (MSDSI) of British Columbia has long been in charge of administering provincial Income Assistance (aka welfare),

Person with Disability (PWD) assistance, and Person with Persistent Multiple Barriers (PPMB) assistance. Prior to PWD and PPMB, disability assistance was provided under the umbrella of Disability I and Disability II designations. However, these designations were terminated when the *Disability Benefits Program Act* (DBPA) of 1996 was replaced in 2002 by the *Employment and Assistance for Persons with Disabilities Act* (EAPWD) (BC Coalition of People with Disabilities, 2007; Klein & Long, 2003).

People with disabilities living on Person with Disability (PWD) assistance in British Columbia frequently struggle with living well below the poverty line, limited resources, and ongoing systemic barriers (Goldberg & Stainton, 2008; Disability Without Poverty Network, 2012; Klein & Long, 2003). Under the current legislation, Person with Disability assistance provides individuals who meet the designation requirements with a maximum of \$906 per month to cover costs of shelter, food, and any other basic living costs (Ministry of Social Development and Social Innovation, 2007); a meager amount that many consider insufficient to meet even the most basic of needs:

For individuals relying on the Persons with Disability benefit and receiving only \$906 per month (\$10,872 annually), it is extremely difficult to make ends meet. An annual income of \$10,872 is also significantly below the Low Income Cut Offs (LICO) established by statistics Canada. (Disability Without Poverty Network, 2012, p. 5)

Despite being drastically below most poverty measures, it is the only option of public income support for many. Unfortunately, the criteria to be considered eligible for PWD designation (and the supplements that come with it) can be daunting. To be considered eligible for PWD designation, an individual must be determined to be “financially eligible” and “eligible under the PWD definition of disability” (BC Coalition for People with Disabilities, 2009, p. 3). To meet both requirements, an individual must fit a lengthy list of criteria. To be considered financially eligible, an individual must be 18 years of age or older and have a limited number of assets (single individuals can have \$3,000 in assets or less, while couples can have a maximum of \$5,000) (Ministry of Social Development and Social Innovation, 2012). In medical terms, an individual must have a mental or physical impairment that is expected to last at least two years, and be able to demonstrate that they are significantly restricted in their daily living activities and require assistance (BC Coalition for People with Disabilities, 2009; Ministry of Social Development and Social Innovation, 2012).

Although the new PWD designation, once obtained, promised an increase of benefits, supplements, and supports for British Columbians with disabilities, many critics argue that these miniscule benefits came at the price of increased gatekeeping measures (Klein & Long, 2003). With the onset of new disability assistance legislation in 2002, the people with disabilities were subjected to increased scrutiny, rather than increased supports. Following the adoption of the *Employment and Assistance for Persons with Disabilities Act* (EAPWD), 19,000 individuals who had already received disability designation under the prior legislation were subject to a “23 page, three-part functional reassessment form ... doctors and advocates have described it as the most complicated and time intensive assessment form they have ever encountered” (Murdoch, 2002, p.1). In fact, researchers found that by the end of the review process, some 62,000 individuals made up the \$5 million review, or witch hunt, which resulted in only 46 cases closed (Reitsma-Street & Wallace, 2004, p. 3). Meaning the implementation of the EAPWD Act resulted in 61,954 individuals being forced to unnecessarily complete a complicated application form, nearly double in size of the DBPA form, when they had already received disability designation under previous legislation (BC Coalition of People with Disabilities, 2007).

To even begin to appreciate the extent of this anxiety-inducing process, it is important to understand the EAPWD application for disability designation from the applicant’s perspective. The 23-page application form is composed of three sections. The applicant information section can be filled out by the applicant, if possible. The majority of the form is composed of the physician report, section two, and the assessor report. The assessor report can be completed by the same physician who completed section two, or another medical specialist such as a registered social worker, chiropractor, or psychologist (Ministry of Social Development and Social Innovation, 2012). Of course, the application assumes that an individual has a family doctor and/or designated medical professional who has some historical knowledge of their conditions (Morrow, Frischmuth, & Johnson, 2006). So extensive were the forms in detail that when originally introduced, many physicians refused to complete the forms until they could confirm that they would indeed be paid by the Ministry of Health for their time (Morrow, Frischmuth, & Johnson, 2006).

Research studies have shown that low socioeconomic status negatively impacts a person’s chance of being taken on by a family doctor; people who were considered economically wealthy were 50% more likely of being taken on by a family physician than applicants on

welfare (Olah, Gaisano, & Hwang, 2013). Exacerbating matters further, studies have shown a significant lack of primary physician care for individuals with chronic health issues, statistics that worsen significantly amongst marginalized communities (Crooks et al., 2010). With such limited resources within the medical profession in Canada, it is no wonder that physicians rarely spend the recommended 60-90 minutes suggested to complete the PWD application form:

Doctors are required to respond to a great many questions on the application and frequently do not provide comments in all of its sections. The form provides boxes to be checked and encourages a kind of shorthand which can put applicants at a disadvantage. Unless a physician consults an applicant about the impact of their disability on their daily life, they may miss important information because busy health professionals may not be familiar with a patient's day-to-day experience of living with a disability ... It is cumbersome for health care professionals and applicants. (BC Coalition of People with Disabilities, 2007, p. 16).

Moreover, the professionals supporting the applicant must be able to speak to the applicant's limitations in regards to detailed and extremely personal daily living activities such as: "preparing meals", "managing personal finances", "using public or personal transportation", "moving about indoors and outdoors", "performing personal hygiene", and "taking medications" (BC Coalition for People with Disabilities, 2009, p. 4). The actual number of daily living activities listed within the application form is much more extensive than the examples given above (Ministry of Social Development and Social Innovation, 2014). Such activities are typically outside the realm of most physicians' limited knowledge of their patients' daily lives.

Having established the rigorous processes endured by people with disabilities seeking PWD designation in British Columbia, the next section of this chapter will describe a specific benefit people on PWD could previously receive to support their volunteerism.

### ***The Community Volunteer Supplement***

Rigid policing of eligibility is not only limited to obtaining or maintaining PWD designation. Individuals on PWD can expect to experience the same scrutiny when trying to obtain or maintain benefits and supplements made eligible to them under the EAPWD Act and Regulations. Under the EAPWD legislation, PWD recipients are told they can receive nutritional allowances (intended to provide additional funds for nutritional needs resulting from disability), assistive devices, and supplements to support community involvement and independence, such

as the CVS (Ministry of Social Development and Social Innovation, 2013d). Supplements and other associated benefits are claimed to assist individuals with disabilities experience more equitable access to medical, community, and social supports, however individuals can expect an uphill battle if they hope to acquire any of the above benefits.

In Section 47 of the previous EAPWD Regulations, individuals receiving PWD assistance were said to be eligible for the Community Volunteer Supplement based on the following eligibility requirements:

The Minister may provide to or for a family unit that is eligible for disability assistance a supplement of up to \$100.00 for each calendar month for each recipient or dependent child who has reached 15 years of age for clothing, transportation or other expenses that are needed for that recipient or dependent child to participate in a community volunteer program. (Employment and Assistance Appeals Tribunal, 2011a, p. 7)

Ministry policy previously interpreted the legislation to state that individuals must be volunteering a minimum of ten hours per month, or less if medical reasons are confirmed by a physician (Employment and Assistance Appeals Tribunal, 2011a). Individuals interested in applying to receive the Community Volunteer Supplement had to bring a one-page form to their place of volunteer and have a supervisor or coordinator confirm their role as a volunteer. With significantly low PWD rates, the promise of an additional hundred dollars per month was a big benefit for many. The added benefit of receiving financial support to engage in the community, and to have funds to pay for the associated costs of such participation, was significant for many people on disability assistance.

The Community Volunteer Supplement, formerly referred to as the Community Volunteer Program (CVP), was in place prior to the 2002 EAPWD legislation. Few PWD recipients were aware of the program at the time (Goldberg & Stainton, 2008, p. 139). After a \$35-million-dollar insurgence of funds into an umbrella of Ministry programs referred to as the BC Employment Program, the CVP received a \$5-million-dollar boost (The Times, 2006 July 31, p. 1). Like many of the government's initiatives, the CVP was intended to encourage "people on PWD and PPMB benefits to seek paid work" (Cohen, M. et al., 2008, p. 16). Although targeted as a 'welfare to work' initiative, the CVP had unintentional side effects: supporting the civic participation of adults with disabilities in the province of BC. Of the limited literature available, statistics show that in September of 2000, only 3.5% of PWD recipients were active

participants in the Community Volunteer Program (Goldberg & Stainton, 2008, p. 141). Up until 2006, the number of individuals on the CVP continued to decline until, with a \$5-million-dollar insurgence, “the government announced that it would be increasing access to the CVP for an additional 2,500 persons with disabilities and persons with persistent multiple barriers to employment” (Goldberg & Stainton, 2008, p. 139). Individuals participating in the CVS program doubled, demonstrating that, “a rapid increase in accessing the CVP is a strong indication of the pent-up demand for this program and the need for the province to consider increasing support provided to this program” (Cohen, M. et al. 2008, p. 16). Such observations were but a foreshadowing of the challenges to come for recipients hoping to participate in the Community Volunteer Supplement program.

By 2009, client interest in the CVS program continued to grow. How could it not, given that individuals with disabilities were provided with the opportunity to receive \$100/month to volunteer in their communities? For many individuals, these funds helped offset the financial limitations that had previously prevented them from volunteering in their community. Moreover, the benefits of volunteerism are bountiful. One would argue even more so beneficial for individuals who are limited by financial circumstance and health conditions who are, as a result, subject to increased isolation, limited sense of social contribution, and limited experience-building opportunities (Miller et al., 2002; Bates & Davis, 2004). In this instance, volunteerism became an issue of equitable access for people with disabilities to have the same opportunity to civic participation as an able-bodied person.

Shortly after the popularity of the CVS program increased, so did issues of access. Although no literature speaks to when this practice started, at some point in time MSDSI staff created a policy to waitlist CVS applicants who met the legislated criteria to receive this supplement, resulting in a *de facto* denial of benefits. In doing so, the Ministry unlawfully created policy which superseded legislation, adding an additional criterion of eligibility: being subject to lengthy wait lists before being able to receive the CVS. In the case of the Community Volunteer Supplement, advocates reported that roughly 8,000 PWD recipients were being wait listed unjustly as a result of a Ministry policy that directly conflicted with provincial legislation (Clarke, 2011, July 06; Lavoie, 2011, July 07; Clarke, 2011, August 10). To be fully aware of the extent of this injustice, it is important to understand the math. If 8,000 individuals are wait listed for a \$100/month supplement, \$800,000 in CVS funding were withheld per month. CVS

applicants were required to continue volunteering to maintain their place on the waitlist (and, as noted above, Ministry policy stated individuals must volunteer a minimum of 10 hours per month) (Employment and Assistance Appeals Tribunal, 2011a). In this way, the government was effectively receiving 80,000 hours of free labour in the community while pocketing \$800,000 in benefits on the backs of the poor, every single month. Simple math shows that if we extrapolate these numbers, the provincial government gained 960,000 hours of free labour and roughly \$9.6 million annually in withheld CVS funds.

This injustice constituted the makings of a provincial scandal, yet the public was only vaguely aware of the existence of the CVS program. The first PWD recipients to appeal this benefit with the support of the Together Against Poverty Society were going down a path none had previously gone successfully (Clarke, 2011, August 10). Challenging the system in the best of times can be anxiety inducing, however one cannot imagine the experiences of being the first PWD recipients to draw attention to a provincial scandal.

### *Understanding the Appeals Process*

Public literature on the CVS hardly exists and obtaining details through requests for information to the Ministry have proven extremely difficult. The process of obtaining PWD designation is explored here as exemplary of navigating resistance within the disability assistance administrative appeals system. Individuals denied PWD assistance, or other benefits like the CVS, have a limited window to make their case if they want to make an appeal. Individuals have to submit a Request for Reconsideration and supporting documentation within 20 business days of receiving notice of their denial of benefits (Ministry of Social Development and Social Innovation, 2013f).

A Request for Reconsideration is a formal notice to the MSDSI that an individual raises objection to the MSDSI's denial of a benefit or designation. A Request for Reconsideration submission can include documentation or evidence that assists in arguing the individual's grounds for requesting the MSDSI reconsideration of their decision to deny the individual's application for benefits. It is important to critically examine Ministry processes to truly begin to understand the impact of disability policies in the daily lives of people on PWD assistance. For example, to be considered for PWD designation, an individual has to first be considered eligible for Income Assistance. If an individual has been denied PWD designation they are likely living

on the \$610 maximum allotted for single individuals on Income Assistance (Ministry of Social Development and Social Innovation, 2013a; 2013c; The Office of the Ombudsperson, 2009). Applicants can also be considered ineligible for Income Assistance for alternate reasons, such as if the individual turned down meaningful employment due to their disability (The Office of the Ombudsperson, 2009).

To begin the process of appealing a Ministry decision, an individual must go in person to their local Ministry office and meet with an Employment and Assistance Worker (EAW). The EAW will then provide a Request for Reconsideration form which details the Ministry's justification for denying PWD designation or other benefits. This process may sound simple, however many argue that it is a long and arduous process. One individual who tried to apply for PWD after being diagnosed with Fibromyalgia describes enduring "two years of standing in painful lines, being pushed through by security guards and having to re-explain her story to every intake worker" (Pope, 2013, June 18). Reflective of Foucault's theories of power relationships, the strain experienced by those wishing to exercise resistance via the appeals process demonstrates systemic inequity. According to Kelly Newhook, Executive Director of the Together Against Poverty Society, to meet with an EAW at the Ministry's office in Victoria, BC, an individual can expect "hours of waiting in line, and having to ask security guards permission to go to the bathroom" (Pope, 2013, June 18). Newhook's testimony foreshadows the narratives of participants interviewed in this study, one of whom recounted a similar experience:

And of course, when you visit the office you might end up waiting several hours. And then you might get kicked out. Come back the next day. (Participant)

A more in-depth exploration of participant experiences of inaccessibility are further explained later in Chapter Five.

If such demeaning gatekeeping does not deter an individual from hope, the Reconsideration process might. To complete a Request for Reconsideration form that may actually be approved, individuals must provide supporting documentation (that is, a letter of support or medical records) from their physician or other medical professionals. Individuals wanting to successfully appeal the Ministry's decision must provide detailed medical evidence contrary to the Ministry's justification for denial of benefits, and do so within 20 business days. In the case of the CVS, a doctor's note was often helpful to demonstrate that volunteering had positive effects on the individual's health or to justify why the individual's health condition

caused them to incur additional expenses while engaging in the community. As previously mentioned, this is extremely problematic for individuals without a family doctor or other designated medical professionals. If a person has a family doctor, the thought of returning with more requests following the completion of the 23-page PWD application form is not ideal:

This type of unreasonable requirement has concrete detrimental effects. Constant request for documentation require recipients to repeatedly approach their physicians to complete time consuming forms and re-send letters of medical opinion. This damages patient-doctor relationships, and, in our experience causes frustration among medical professionals. (BC Public Interest Advocacy Centre, 2005, p. 18)

People on disability assistance are all too familiar with having to make repeated requests for documentation of the same health conditions from their physicians or walk in clinics. To be able to apply for, or maintain, a benefit that may even remotely increase an individual's income, they must acquire medical documentation relating to that specific benefit.

In many instances, approval for particular supplements expires every 12 months, requiring individuals to request repeat documentation for conditions or symptoms previously acknowledged (BC Public Interest Advocacy Centre, 2005). Individuals awaiting PWD designation or desperately needed benefits, while living in poverty and enduring anxiety as they await the Ministry's decision are further subjected to being situated as an inconvenience to the few professional supports available to them. These issues are further complicated by experiences of discrimination at the hand of medical systems (Galabuzi, 2006; Kelm, 2011; Loppie, Reading & de Leeuw, 2014; McCue, 2015; Strong-Boag & Grace, 1999). In this way, the constructed reality of disablement intersects with biopolitical power structures, demonstrating that "one can never escape structure" (Davies, 1991, p. 52).

If an individual is able to gather a letter of support from their doctor or another medical professional, upon submitting their Request for Reconsideration they can expect to wait anywhere from three to six months before being informed of the Ministry's decision (The Office of the Ombudsperson, 2014). According to the MSDSI's statistics, the number of people in receipt of PWD assistance grew by 4,334 individuals from 2011 to 2012 (Ministry of Social Development and Social Innovation, 2013a). However, such a feat is not without a fight; the likelihood of being denied PWD designation, or any other benefit for that matter, is very high. According to the Office of the Ombudsperson of British Columbia, although 1,210 individuals

were later approved following reconsideration, the number of individuals who were initially denied PWD assistance and requested a reconsideration of this decision in 2011/12 was 1,714 (The Office of the Ombudsperson, 2014). These statistics exclude individuals who were denied PWD assistance and did not have the capacity or support to appeal, or missed the deadline to submit a Request for Reconsideration.

To put these numbers into context, nearly one third of the number of individuals applying for PWD designation were denied in 2011/12. Roughly 70% of the 1,714 individuals who requested reconsideration were later approved, which means 1,210 individuals were unnecessarily delayed in receiving benefits as a result of “a disproportionately high percentage of decisions to deny Persons with Disabilities (PWD) applications” (The Office of the Ombudsperson, 2014, p. 25). Making matters even more problematic, although legislation states the Ministry must make a decision within 10 business days (to a maximum of 20 in extenuating circumstances) of receiving a Request for Reconsideration package, this is often not the case (The Office of the Ombudsperson, 2014). If an individual is delayed in receiving the Ministry’s decision regarding their Request for Reconsideration, the individual is forced to do without benefits for an additional extended period of time.

If an individual is denied their Request for Reconsideration, they have seven business days upon receiving notice of their denial to file a Notice to Appeal form to the Employment and Assistance Appeals Tribunal (EAAT) Office, at which point the Tribunal will decide if the decision is eligible for review based on Section 16 of the *Employment and Assistance for Persons with Disabilities Act* (Employment and Assistance Appeal Tribunal, 2013). If the matter is considered appealable, a Tribunal Panel hearing is legally required to be scheduled within 15 business days where the individual (and an advocate or support person, if requested) can have the Ministry’s decision reviewed by the Tribunal Panel members (Employment and Assistance Appeal Tribunal, 2013; Khazamipour & Beda, 2013).

With the introduction of the EAPWD Act in 2002, the independent Income Assistance Appeal Board was eliminated and replaced with an Appeal Tribunal whose Panel members are appointed by the Minister of Social Development and Social Innovation (Michael & Reitsma-Street, 2002, p. 7; Klein & Long, 2003, p. 36). Prior to the introduction of the 2002 EAPWD Act, community-based appeal tribunals were “composed of one person they [the applicant] nominate, one person nominated by the Ministry, and a chair chosen by the two nominees” (Klein & Long,

2003, p. 36). This meant that, under the previous legislation, individuals had an equitable voice and representation in matters impacting their lives; this consideration was removed by the introduction of the 2002 EAPWD Act. Critics argue that by changing legislation to ensure the Ministry is responsible for the composition of the Tribunal Panel members, and by explicitly stating that people “who receive welfare or disability benefits are not eligible to serve as tribunal members [is] a blatant example of discrimination on the basis of income and class” (Klein & Long, 2003, p. 36).

It is hard to not perceive such actions as a direct assault on people with disabilities living in low income. To add further political salt to the wound, with the introduction of this new process,

Appointees to the Employment and Assistance Appeals Tribunal are now charged with the task of determining not only the correctness of the information presented but also its reasonableness ... [meaning] that appointees may be responsible for the medical interpretation of the form-a task they are likely not qualified to perform. (Klein & Long, 2003, p. 33)

As though making uneducated medical interpretations was not enough, the EAAT later decided that Tribunal Panels could be composed of only one member. In 2008, the EAAT implemented a new policy allowing panels to consist of only one member; where previous practice, and one would assume by the use of the prefix “tri,” dictated Tribunal Panels had to be composed of at least three members (Employment and Assistance Appeal Tribunal, 2010). The EAAT openly noted that the choice to reduce the number of Panel members was an effort to cut costs, justifying the move as a result of a 46% increase in applications for Tribunal Panel hearings in the year previous (MacLeod, 2010, February 01). One front line worker quoted by the Canadian Centre for Policy Alternatives in Vancouver, BC translated this decision into what it meant for individuals appealing PWD denials by way of Tribunal hearings:

Everyone who applied for disability was refused initially, virtually, and then the appeals were being won at a very high rate ... and so the government ... did an analysis and they discovered all these appeals were happening so they immediately changed the appeal process and made it narrower. (Morrow, Frischmuth, & Johnson, 2006, p. 19)

Such policies, coupled with provincial funding cuts to community and poverty law programs, subsequently resulted in bleak opportunities of successfully appealing Ministry decisions (Klein & Pulkingham, 2008; Wallace & Richards, 2008; Klein & Long, 2003). The BC Coalition of

People with Disabilities similarly echoes the sentiment that the appeals process is too complicated:

The regulations, time limits and procedures governing Reconsideration and Tribunals are extremely complicated. The rules governing Tribunals have become more legalistic ... Stressed, ill, confused individuals can find themselves denied the right to appeal because they have not understood what is required of them. They may have difficulty obtaining the necessary forms and information from the Ministry. (2007, p. 25)

The experiences of individuals attempting to navigate the appeals process speaks to the inequitable, and often unlawful nature of the reality for people with disabilities in this province.

In the 2011/12 EAAT Annual Report, 218 individuals appealed Ministry decisions to deny PWD designation to the EAAT and, although no reference is made to cases regarding the Community Volunteer Supplement, 110 “Other Supplement” appeals were made (Employment and Assistance Appeals Tribunal, 2012, p. 11). On the EAAT website where past Tribunal Panel decisions are published, CVS cases are deemed “other” so it can be inferred that at least some of the CVS appeals are represented within the annual report (Employment and Assistance Appeal Tribunal, 2013). This researcher made several requests to acquire a number of public records from both EAAT and MSDSI to provide further statistics on the CVS program; however, these requests were not sufficiently met. Using PWD designation applications as an indicator of the difficulty of the appeals process, if we compare EAAT’s numbers to the statistics previously discussed, we see that of the 1,714 individuals who requested reconsideration, 1,210 individuals were eventually approved for PWD designation (The Office of the Ombudsperson, 2014). Of the 504 individuals who had their Request for Reconsideration denied, 218 individuals brought their case to the Tribunal level. If less than half of the individuals who were denied at the Reconsideration level pursued further administrative review, this suggests how difficult the appeals process is for individuals with disabilities to endure. In a system that is riddled with barriers, it is understandable that many individuals in poverty do not trust the provincial government in its provision of benefits.

### ***Navigating the Barriers in Accessing the Community Volunteer Supplement***

In the case of the CVS, TAPS put a call out to the Minister of Social Development and Social Innovation (at that time, the Ministry of Social Development) in 2011 to fully fund the

CVS after a significant number of successful appeals regarding the practice of unlawfully wait listing CVS applicants. The Ministry responded by promising to immediately boost funding to the program; \$5 million was promised immediately, with an additional \$10 million pledged to address the near 8,000 individuals on the wait list (Clarke, 2011, August 10). However, the Minister released a statement announcing that the legislation for the CVS program would be repealed, clients would no longer be eligible for “back-pay” for the time they were on the wait list, and that “the appeal process for the CVS program no longer applies” (Clarke, 2011, August 10). Such actions may have felt as though drawing public attention to unjust administrative processes resulted in a sharp reprimand; losing the legislated protection that allowed individuals the right to appeal the wait listing of the CVS.

Exploring the physical process of being subject to lengthy line-ups, repeated visits to physicians, numerous forms and written testimony to obtain, punitive policy changes resulting from resistance, the cause of many individuals’ anxiety experienced when appealing Ministry decisions becomes more clearly understood.

Attempting to appeal denied benefits is a long and arduous process within the scope of provincial legislation. Within the context of this research, it is important to understand the varied and many ways in which people with disabilities are constricted in their opportunities to formally resist the very system that governs their lives. Challenging the system in any form can cause severe anxiety, fear of being cut off of benefits, particularly when provincial legislation governing PWD benefits presents with blatant administrative discrepancies (BC Coalition of People with Disabilities, 2007; Graham et al., 2009). In some cases, challenging the system can even contribute to suicide (Klein & Long, 2003; Murdoch, 2002; Graham et al., 2009). Individuals interacting with the MSDSI can expect to be “dehumanized, demoralized and shamed by a system they thought was created to help them” (Wallace, Klein, & Reitsma-Street, 2006, p. 43). Participants interviewed in this study echoed similar experiences that are explored further in Chapter Five, however one participant’s explanation of their experience at the Ministry office demonstrates the tone of these experiences:

It was so frustrating with the Ministry, as I always have the expectation of being denied first, expecting to have to fill out form after form, of being a number instead of a person. Feeling like I’m a huge burden to them, that we all are. You start to forget that they are

actually getting paid to do their jobs. They make you feel like they are giving you money from their personal bank account. (Participant)

The provincial disability system is meant to provide support and financial assistance to people living with disabilities in BC, yet, many PWD recipients are instead subject to the monitoring and policing of their impairments (Klein & Long, 2003; Saltes, 2013). Much of the *Employment and Assistance for Persons with Disabilities Act* and accompanying Regulation is centered on measuring and monitoring the severity of one's disabilities in order to be considered eligible for benefits (BC Public Interest Advocacy Centre, 2015; Klein & Long, 2003). Essentially, people with disabilities accessing PWD in BC must succumb to having their impairments observed, measured, and warranted merit (or not) to be considered deserving of an income and health supports (Teghtsoonian & Moss, 2008).

People living on PWD assistance struggle to exist within neoliberal gatekeeping, often have to fight for basic needs such as food and shelter, and deal with constant anxiety that they will be cut off of assistance (Graham et al., 2009; Klein & Long, 2003). Since 1995, the number of people receiving PWD assistance has increased from 22,167 individuals and families to 83,205 (Ministry of Social Development, 2013, p.3), and even more recent statistics show that 98,150 individuals currently receive PWD assistance (Disability Without Poverty Network, 2012, p. 1). Statistics Canada reported that "14.3 percent of the Canadian population identifies as a person with disabilities" and that "more women than men experience disability and the rate of disability increases with age" (Stienstra, 2012, p. 4). According to the Government of British Columbia, the total current population of BC amounts to roughly 4,581,978 which means PWD recipients comprise only 2.14% of the provincial population (BC Stats, 2013, Population Estimates). Estimates note that Aboriginal people are even more disproportionately represented amongst people with disabilities, with statistics finding that "the rate of disabilities among Aboriginal people is 32 per cent, which is twice the national average" (Durst et al., 2006). Newcomers and people of colour equally represent a higher proportion of people with disabilities, with an additional risk of being homelessness or precariously housed (Galabuzi, 2006; Raphael, 2007).

Navigating systems of support, within the oppressive and many locations amongst the margins, can be experienced as both exhausting and inequitable (Durst & Bluehardt, 2001). Strict legislation and policies ensures that obtaining or maintaining PWD assistance and other

benefits, like the CVS, to be extremely difficult. Social justice workers and governmental bodies need to be aware of the significant barriers faced by individuals through this process, the impact on the wellness of individuals appealing disability benefits, as well as the systemic issues present in denying benefits to people already struggling on the margins. People with disabilities need to have their experiences of resistance honored and voiced to the community, and changes need to be made to the systems that claim to provide support to people with disabilities in this province.

### ***Taking Up Space: On Resistance***

The concept of resistance surfaced in a myriad of ways within this research. Resistance, in the most basic sense, can be considered an intentional act of *pushing back* against a contrasting force, be it discourse, ideology, power, or oppression. The act of pushing back can occur, for example, through intentional action or discourse, in reflective practices aimed at creating new discourse over existing structures and relationships, or in the existence of covert denial of dominant ideologies.

The historical discounting of particular knowledges or experiences constitutes Foucault's concept of *subjugated knowledges*, referring to the "historical contents that have been buried or disguised" (1980, p. 81). Within the historical context of disability policy, people with disabilities have experienced relational power over the ways in which their disabilities were authored within policy and public discourse:

In a post-structuralist framework authority or agency can be thought of as the discursive constitution of a particular individual of having presence (rather than absence), that is having access to a subject position in which they have the right to be heard. (Davies, 1991, p. 51)

Particularly within the ways disability has been *counted* and *discounted* within disability policy, "state-defined disability" constitutes an oppressive arm of institutional powers through constructed disablement (Price & Sheldrick, 1999, p. 434-435). Disablement, as represented within public policy, constricts disability to the powers of state-regulated practices rather than as a personal experience layered with complexity. In speaking of power, Foucault emphasizes "where there is power, there is resistance" (1990, p. 95). As the previous sections demonstrate, the formalized avenues for resistance available to people with disabilities are extremely problematic. However, as demonstrated within this research, the various ways in which people

with disabilities have found ways to exercise resistance cannot be discounted. Present amongst the existence of power relationships, the concepts of agency and authorship are intrinsically tied to resistance (Davies, 1991; Foucault, 1990; Sawicki, 1991). Understanding the “multiplicity of points of resistance” within power relations serves to not only acknowledge the agency of people with disabilities, but constitutes an act of resistance in itself (Foucault, 1990, p. 95). The act of presenting authorship over one’s own narrative of disablement, particularly in response to disability policy, serves as a form of resistance.

Beyond the production of embodied selves by discursive processes, individuals are agents productive in conforming to, reiterating and contesting normative standards of ‘acceptable’ bodies ... Structure and agency, the economic, the cultural and the intimate gel together in patterns of negotiation and resistance. ... that there is always a need to resist. (Loja et al., 2013, p. 197)

The refusal to accept the subjugation of one’s knowledge, to exercise agency over one’s own authorship in resistance to the dominant discourse *takes up space* within externally constructed narratives.

Neoliberalism, relative to resistance, discounts the bodies of those perceived as medically, and thus economically, deficit within the capitalistic system. Within disability policy, the medicalized body immediately becomes discounted as a result of the neoliberal construction of validity. The medical gaze, as an institutional arm of neoliberalism, “plays a crucial role in invalidating bodies that do not conform to the norm” (Loja et al., 2013, p. 191). Neoliberalism ties the body to its economic functionality, reinforced by biomedical perspectives of disability, resulting in a hegemonic discounting of the disabled body. Neoliberalism utilizes a monetarily enforced, results-based distribution of entitlement; meaning that the right to resist will be afforded to those who can best climb the capitalist hierarchy (Dutta, 2012). The importance of resistance in response to the neoliberalism construction of worth over the concept of disablement is layered within the need for the ‘other’ to take up space, within history, within capitalism, within the current systems.

In a broad sense, the relative facets of resistance have been *bogarted* by the prioritization of masculine histories. Resistance, within the understanding of subjugated knowledge, is relevant to feminist thought in that the subtler forms of resistance have typically been dubbed as feminine, and thus discounted within history (Davies, 1991; Medina, 2011). Overt, more violent forms of resistance, such as that of soldiers in war, have been prioritized throughout history and

been considered as characteristically male. In this way, exploring the complex ways in which resistance occurs within the margins it itself constitutes a feminist act of pushing back. Feminist theorists have asserted resistance, agency, and authorship as integral in the effort to dismantle dominant, patriarchal systems:

The authority of maleness, of people in positions of power need to be reconceptualised as authority, with emphasis on authorship, the capacity to speak/write and be heard, to have voice, to articulate meanings from within the collective discourses and beyond them. (Davies, 1991, p. 52)

Oppressive systems have long sought to paint resistance from the margins as ‘hysteric’ and thus irrelevant. Butler (2013) attests that dominant systems of power seek to discount feminist acts of resistance and emphasize the vulnerability of the ‘other’ as this serves to make the “case for paternalistic protection” (p. 1). The tendency to frame the disabled or feminine body as a deficit is then cyclically fundamental to systemic paternalism and, therefore, resulting instances of resistance.

But what of internalized ableism? When a person on the margins unknowingly internalizes the dominant system’s constructed narrative over their community or cultural group, this constitutes internalized oppression (Hahn, 1997). But what of a person who knowingly adopts oppressive discourse for strategic purposes? At times, an individual intentionally adopts such discourse as an act of resistance by way of survival. Though this concept could be a thesis in itself, I would like to touch on the matter of adopted discourses within this section. Within this research, and I will explore more on this within the analysis chapters, participants identified instances where they, at times, adopted the neoliberal, ableist prioritization of the value of their ‘employability.’ As presented by participants, they were highly aware of the Ministry’s prioritization of benefits relevant to employability, so they often sought to highlight the ways in which the CVS was connected to enhancing employment opportunities to preserve the benefits experienced in relation to citizenship and economic enhancement. Within the context of resistance, the topic of internalized oppression and the reproduction of oppressive dialogue for survival purposes is extremely complicated (Campbell, 2010). What is important in the context of internalized ableism, especially in relation to this research, is not to conclude that the adoption of oppressive dialogue equates any form of validation for ableist thought. Instead, the adoption of externally and oppressively constructed ableist *truths* should be viewed as a means of resistance against the dominant rhetoric encountered daily by people with disabilities. To

*intentionally* adopt the rhetoric of the oppressor demonstrates, to some degree, an awareness of the oppressor's logic. Some would argue that the first step towards resistance involves this intentional awareness:

It is only when the oppressed find the oppressor out and become involved in the organized struggle for their liberation that they begin to believe in themselves. This discovery cannot be purely intellectual but must involve action; nor can it be limited to mere activism, but must include serious reflection: only then will it be a praxis. Critical and liberating dialogue, which presupposes action, must be carried on with the oppressed at whatever stage of their struggle for liberation. (Freire, 1970, p. 47)

It is my intent not to delve deeply into the concepts of internalized oppression, but to recognize the participants' sometimes strategic use of the neoliberal emphasis on employability as a means of resistance. In other instances, participants identified a desire to be identified within the dominant capitalistic systems as a recognized body of production, which is a complex and layered space that warrants further research. The strategic means utilized by people experiencing systemic oppression should be recognized as an act of negotiating and exercising agency in that, "agency is never freedom from discursive constitution of self, but the capacity to recognize that constitution and to resist, subvert, and change the discourse ... through which one is being constituted" (Davies, 1991, p. 51). In relation to the context of resistance, the use of the dominant discourse *against* the oppressor should be recognized as but one of the many ways people with disabilities find a way to exercise agency and resistance.

Throughout historical disability policy, the intentional absence of narratives of resistance within policy development has served to reinforce the need for oppressive, paternalistic decision making. In doing so, the agency of people with disabilities has been discounted within dominant discourse. Within feminism, the concept of agency equates authority and, thus, is important when considering the various ways in which the disability community has engaged in resistance:

To be a feminist, or a feminist theorist is itself to engage in the very act of choosing to speak, of discovering the possibility of authority, of using that speaking, that *authority*, of using that speaking, that *authority*, to bring about fundamental changes in the possible ways of being that are available to oneself and others. (Davies, 1991, p. 52)

By surfacing the existence of multiple resistances within the disability community, the intended erasure of agency sought by dominant systems is met with objection. The prioritization of the white, able bodied male is contested.

### *Summary*

This chapter has explored how post structural feminist notions of biopolitics can be utilized in exploring the policies and practices that impact people living on disability assistance in British Columbia. Given that feminism, critical disability theory, post-structuralism, and biopolitics overlap in many ways, exploring the ways in which the body is constructed within policy and theory relating to people with disabilities provides a theoretical foundation for this research. In regards to the construction of disablement, the intersection of assembled truths over the body draws on feminist, Foucauldian, and critical disability theory wherein the body is positioned as a governed space. Both subject to, and dependent on, the power relations that reinforce the systemic oppression of the disabled body, biopolitics is a significant facet of disability policy. Disability policy, argued by many as a vehicle for such power relations, has had many critics for its role in controlling the disabled body:

Insofar as the category of disability is constructed through such practices, it is --- and this is a point we would want to make about broken bodies in general --- as a condition that is en-gendered as feminine in terms of its implied dependency and passivity. Bearing in mind that docile bodies produced by disciplinary techniques are an effect in every instance of power/knowledge. (Price & Shildrick, 1999, p. 435)

The policies and legislation that have historically constructed the disabled body, reflective of neoliberalism's emphasis on the productive capacity of the body and the patriarchal prioritization of the white, male, abled body. The same systems have also served to subjugate the experiences and knowledges of people with disabilities throughout history. The government of the body has been coupled within productions of, and in consequence to, constructions of health and deservedness. In this way, the prevalence of biopolitically induced poverty is as much of a consequence and a condition necessary for the constructed body.

This chapter has given an overview of historical legislation impacting the lives of people with disabilities to contextualize the current regime of neoliberal policies that are characterized within the EAPWD legislation. Understanding how the policies and processes that have

historically impacted the lives of people with disabilities in Canada is important to understand in relation to present day disability policy. The erasure of the paternalistic and, often, inhumane treatment people with disabilities experienced from early Canadian disability policy highlights the cumulative oppressive factors that intersect with present day ableist policies. The ways in which the concepts of disablement were constructed via social policy throughout history is significant because people with disabilities have, throughout history, had to conform to externally constructed *truths* about their bodies in order to receive social benefits. Participants within this research spoke often about their experiences of paternalism and control when accessing disability assistance. Through exploring the various constructed realities of disablement throughout historical Canadian policy, the restrictive and prescriptive nature of present day PWD policy experienced by participants within this research is surfaced.

Furthermore, the power of, along with the need for, resistance amongst people with disabilities becomes that much more significant. Concepts of resistance, as pertinent to the relevant theories drawn upon within this research, are explored within this chapter. These concepts are connected to the historical erasure of people with disabilities and to the present day need to recognize the multiple and complex forms of resistance exercised by the disability community. The appeals process has been established to exemplify the rigorous processes people with disabilities must navigate in order to exercise resistance through formal institutional channels. What limited literature available on the CVS was examined in relation to the appeals process, and the policy changes impacting CVS recipients were outlined. Understanding how the CVS evolved as a benefit within disability policy provides a foundation from which to understand the participants' narratives of access and resistance.

## CHAPTER THREE

### Navigating the Research

The majority of people don't want to be on assistance, they don't want help. When people ask for help, it's because they have no other choice. (Participant)

This chapter explains how I approached the research and highlights the considerations that influenced choosing to draw on a post-structural feminist approach, referencing Foucault and disability theory. Details surrounding participant selection and recruitment processes are described, reflective of the methodological and theoretical approaches selected for this research. I then outline the format of the interviews and the chosen interview questions, reflective of the intent of each question. I also explain my approach to data analysis and identify relevant ethical considerations for this research.

#### *Methodology*

In exploring potential approaches for this research, it became apparent to me that the heart of the topic centers on the *agency* of people on disability assistance. One form of agency that was of interest here involves looking at the ways participants' exercised resistance in opposition to the systems that seek to maintain their location on the margins (Young, 1990). Though there are multiple and complex forms of agency and resistance exercised by people with disabilities, it was the participants' resistance against the Ministry that was of particular interest in this research. Interestingly, the participants highlighted other means of resistance and prioritized these as relevant in the interview and follow-up processes. The participants' expressions of resistance will be analyzed and discussed later in Chapter Four and Five.

The complex narratives of this study's participants juxtaposed with a critical analysis of policy was sought to create the breadth of this research. Characteristics and complexities of systems, institutional barriers, and the politics involved with being on disability assistance in British Columbia are surfaced by those who experience these issues firsthand. It is the occurrences of poverty and its subsequent effects, how people on disability assistance navigate these barriers, and the ways in which they make meaning within resistance to these barriers that

are explored in this research (Brown & Strega, 2005; Hesse-Biber, 2012; Reinharz, 1992; Young, 1990). In this way, a post structural feminist analysis best suited the objectives of this research in that feminist post structuralism argues greatly for the exploration of the agency exercised by the oppressed, and situates learning from within these complex spaces of resistance given that,

post-structural analysis seeks to transcend the individual-social divide and to find the ways in which the social worlds we inhabit, and the possibilities for existence within them, are actively spoken into existence by individuals and collectives. The individual in this way of thinking is not separate from the social landscape but complicated with it. (Hesse-Biber, 2012, p. 73)

Post structural feminist theory, influenced by Foucault, perceives the “world as a series of stories or texts that sustain the integration of power and oppression” (Olesen, 2011, p. 132). Post structuralist feminism, aligned with Foucault’s thoughts on power construction,

can be taken as a third feminism, historically following on from, but not replacing, liberal feminism and radical feminism ... feminist post-structuralism seeks to trouble the very categories male and female, to make visible the way they are constituted and to question their inevitability ... The central focus of feminist poststructuralist theorizing is on the processes of gendered *subjectification*. By subjectification we mean the historically specific processes whereby one is subjected to the discursive regimes and regulatory frameworks through which gendered individuals and their social contexts are also, and through the same processes, constructed. (Somekh & Lewis, 2005, p. 318)

Feminist theory has offered a critical means by which to examine the constructed body as a political site. Through its coupling with analyses of power, feminist post structuralism lends the foundation for this study’s examination of the ways in which power, resistance, and oppression are influenced by biopolitical constructions of the body (Butler, 1990; Foucault, 1980; 2004; Hesse-Biber, 2012; Reinharz, 1992). Feminist post structuralism “requires the researchers examine power and how it operates through discourse subjectivity. Through this examination, more effective means of resistance to inequity and injustice may be uncovered” (Brown & Strega, 2005, p. 200). By emphasizing the experiential narratives of people with disabilities, this study intends to prioritize the experiences of those accessing the system’s benefits as exemplary of the system (Prince, 2009).

My overall approach is situated where feminist post structuralism perceives the body as subject to externally constructed truths; where the body (and the way the body is defined) is

intertwined with institutional powers. I draw on feminist post structuralist notions of the constructed body that reject externally constructed truths and resulting definitions over one's body. I draw on Foucault's theories of power and truth to explore the ways in which the constructed body, referenced to critical disability theory's relating notions of 'wellness,' relate to receiving social benefits. I reference Foucault's notion of subjugated knowledge to recognize the resistance exercised by participants as indicative of systemic gaps, but also relevant to feminist and critical disability theory's notions of reclaiming space. I intentionally layer critical disability theory with notions of the constructed body in critiquing the medical view of disability and in resistance to paternalistic notions of citizenship and distribution of benefits. These perspectives overall provide the foundation for my research findings.

### *Participants*

For the purposes of this study, a person with disabilities included individuals who were over the age of 19 years, have a mental or physical disability (or disabilities), and are or were on provincial disability assistance between 2009-2012. Individuals who were wait listed for the CVS and who later appealed the Ministry's denial of this benefit were sought as participants in this research. As explained within Chapter Two, 2009-2012 was a pivotal time for CVS applicants who experienced wait listing, appeals processes, pledged provincial funding, and, later, broken government promises.

Individuals were not asked to "prove" the extent or the existence of their disabilities given that to be on PWD assistance, they endured a 28-page application form and had to provide very detailed medical testimony with the support of at least one physician. As such, their personal identification as a person with disabilities was sufficient for the intent of this research (Reinharz, 1992). Five individuals were interviewed who were: a) over the age of 19 years old, b) currently on provincial Person with Disability (PWD) assistance, and c) who were wait listed for the Community Volunteer Supplement and appealed a denial of this benefit during 2009-2012. Of the five individuals who were interviewed, three identified as women and two identified as men.

People who appealed the CVS were particularly of interest because it is valuable when examining policy to explore the experiences of individuals who personally navigated the enactment of that policy. To fully understand the benefits and downfalls of PWD policy in BC, it

is important to look to those who experience the issues firsthand. The intersection of ableism and constructs of the body, within a neoliberal system focus heavily on the value of the body as a means of production, and the participants' narratives of resistance offers a unique space from which to explore institutional power relations within disability policy.

### ***Recruitment***

A large text, plain language recruitment poster (see Appendix A) was distributed to community agencies traditionally accessed by people with disabilities on PWD assistance within the Greater Victoria area (i.e., the Together Against Poverty Society, the BC Coalition for People with Disabilities, Our Place). A recruitment script was provided to staff at these centers to ensure a verbal invitation to participate could be communicated to individuals whose visual, language, or literacy limitations may have prevented participation if recruitment occurred only through text (see appendix). Because the disability community is very much a *community*, referral through word of mouth was encouraged and accepted (i.e. snowball sampling) (Brown & Strega, 2005; Hesse-Biber, 2012; Reinharz, 1992). Of all the recruitment efforts undertaken for this research, most participants were referred by word of mouth within the disability community. Potential participants or any support person inquiring about participating in interviews for this study were provided with a plain language copy of the interview questions and consent form at the time of their inquiry. The researcher offered to read the documents over the phone if needed. Only after the potential participant was comfortable and familiar with the interview questions and consent procedures, were arrangements then made to conduct an interview (Brown & Strega, 2005; Hesse-Biber, 2012; Reinharz, 1992; Somekh & Lewis, 2005).

### ***Participant Authorship***

In order to protect participant privacy, I have not differentiated between participants in the analysis chapters of this thesis, nor did I request participants to identify themselves in anyway. However, I will share information about participants that they chose to identify within their interviews to respect the ways in which participants sought to contribute to their own narratives. Participants were asked to confirm the accuracy of the following information that is shared below:

Participant One spoke to her experiences as a single mother who has been a long standing activist in the disability and homeless community. Having been on social assistance in its varied forms for over three decades, Participant One offered valuable perspectives on the prevalence of ongoing barriers within the Ministry. She identified the contradictions between governmental claims to progress and the contrasting hypocrisies she experienced. Participant One was one of the first individuals to appeal the Ministry's practice to wait list CVS applicants.

Participant Two spoke to her mistrust of institutional systems, as the culminated experiences in accessing institutional supports in her life often resulted in penalization, barred access, and judgmental treatment. She spoke of a select number of people within her circles who assisted her to navigate the particularly strenuous appeals process, and talked about the complex interactions of how neoliberal gate-keeping impacted people with complex mental health issues. Participant Two spoke of the anxiety she felt in resisting the system, however identified a strong commitment to contribute to the overall progress of the disability community.

Participant Three identified as an Indigenous woman of unknown descent. She attributed her lack of cultural awareness to the oppressive governmental systems that sought to erase her families' identities as Aboriginal peoples. She talked about how this denied citizenship within her cultural community contributed to the passion she brought to standing up for the disability community. Participant Three spoke strongly of the collective power she felt the disability community has to contribute to change, to offer ideas for improvement, and to support each other. Participant Three often brought humor to her narrative, which she identified as an important coping mechanism to deal with the stigma she experienced as an Aboriginal woman with disabilities.

Participant Four chose to share minimal aspects of his identity on record. He identified an awareness of the people within the disability community who had been directly or indirectly penalized for speaking out; he emphasized, "don't bite the hand that feeds you." Participant Four talked about his struggle to build an identity without a career, yet felt barred by the judgments and lack of supports he received as a person with a disability. He offered insight on the ways in which the system should be changed to support the citizenship of people with disabilities within volunteerism, related specifically to the CVS, and within the employment sector.

Participant Five spoke of some important issues around the topics of volunteerism, some that went beyond the scope of this research. However, these issues are worth noting in that

Participant Five identified an indirect consequence of the Ministry removing CVS recipient's legislated eligibility protection; people with disabilities are at greater risk of enduring mistreatment as volunteers for fear of losing their CVS. Within the administration of volunteer focused programs, Participant Five suggested there should be systems in place to offer direction and ensure accountability measures are upheld. He noted that people with disabilities are vulnerable to mistreatment and have no protective measures available, in comparison to employed people protected by federal employment standards. Participant Five also highlighted that health benefits under PWD assistance are severely lacking, especially when considering the complexity of many PWD recipients' health issues.

The participants each offered unique and varied perspectives on navigating the CVS wait list and subsequent appeals processes, and each also identified key factors of intersectional considerations relating to disability policy overall.

### ***Interviews***

In this study, open-ended, semi-structured, face-to-face interviews were used in order to build rapport with participants and allow for authentic interaction (Hesse-Biber, 2012; Hesse-Biber & Leavy, 2011; Irvine, Drew, & Sainsbury, 2012). Open-ended interviews allowed for "the in-depth study of [people's] lives and the viewing of 'subjects' holistically within their environments" (Mason, 1997, p. 13). The participants were encouraged to engage as authentically as possible with the research (Hesse-Biber, 2012). Participants were supported to influence the logistics of the interviews (for example, location) and were encouraged to speak to their experiences of resistance as primary experts as system consumers. Participants were then asked to review the theming of the data, and quotes associated with their narratives.

Although telephone interviews might have been more convenient (as the researcher had to travel to conduct the interviews), telephone interviews were problematic given that it is difficult to be aware of and respond to nonverbal communication (Hesse-Biber, 2012; Opdenakker, 2006; Reinharz, 1992; Rubin & Rubin, 2005). The potential negative impacts of face-to-face interviewing, such as unintentional influence on the participant through body language, were reduced through the researcher's awareness of this potential impact and reflective journaling efforts (Hesse-Biber, 2012; Opdenakker, 2006; Reinharz, 1992). In addition, having worked as an advocate with people with disabilities, I was aware of the importance of

interjecting as little as possible during an interview or interaction, as this can be experienced as paternalistic or over-empathetic (Hesse-Biber, 2012; Opdenakker, 2006; Reinhartz, 1992; Rubin & Rubin, 2005). Prior to engaging in the interviews, I engaged in a self-reflective journaling process to surface ways in which I was biased towards the participant experiences (Hesse-Biber, 2012; Ortlipp, 2008). I reflected on the kind of prompt questions I might use during the interviews that would offer empathy and encourage elaboration, but would not guide the participant's response to be reflective of my beliefs or opinions. This process was incredibly helpful in surfacing the initial kinds of prompts or reactions I might have, analyzing them reflectively, and altering my approach based on these reflections (Hesse-Biber, 2012).

Participants who responded to recruitment notification or word of mouth referral were provided with a plain language copy of both the interview questions and consent form when they inquired about the study. Participants were offered a verbal explanation of all documents both over the phone and later at the time of the interview, as identified in the previous section. None of the participants presented any questions or concerns regarding the interview questions and consent form. Participants were invited to bring a support person with them (a support worker, friend, or family member) as long as that person agreed in writing to protect the participant's confidentiality (Hesse-Biber & Leavy, 2011; Reinhartz, 1992). Interviews were arranged directly with participants (and their chosen support person) at a time that was convenient to them (Creswell, 2012). Only one participant chose to bring a friend with them for support. Interviews were arranged to take place in a space that the participant was most comfortable with, for example, a meeting room located in a community agency that the participant frequents or in another public location (Hesse-Biber, 2012; Somekh & Lewis, 2005). I ensured that whichever location the participant chose, a semi-private space was used to conduct the interview to maintain the participant's privacy.

With participant consent, the interviews were audio recorded and the researcher took notes to ensure accuracy. If the participant did not consent to being recorded, the researcher was prepared to take interview notes in place of recording the interview; however, all participants consented to being recorded. At the end of the interview, the researcher read back the interview notes to ensure accuracy and to allow space for the participant to provide any additional information, clarification, or corrections desired. Interviews took place, as noted above, in a

semi-private space where the interview could not be overheard and the participant's privacy was maintained.

Of the five interviews conducted, the shortest interview was forty-five minutes and the longest interview was one hour and forty-five minutes. The average time of the interviews was approximately one hour.

### *Interview Questions*

The interview questions used in this study are noted below. The following table was an additional effort undertaken to remind myself the purpose of each question so that I could ensure my probing questions reflected my original research intentions. I brought a copy of the table to each interview and invited the participant to review it if they wished. None of the participants chose to review the table.

*Table 2: Interview Questions and Intentions*

<b>No.</b>	<b>Question</b>	<b>Intent</b>
<b>1</b>	Do you remember when you first heard about the CVS? What was your first impression of this benefit?	<i>-Participant to identify supplement, knowledge and experience of it in their own words</i>
<b>2</b>	What were your experiences with the Ministry (of Social Development) office when you first inquired or applied for the CVS?	<i>-Explore institutional power -Background to denial of benefit -Process -Interactions with staff (first contact)</i>
<b>3</b>	Do you remember how you found out you were denied for the CVS? What was your reaction to being denied this supplement?	<i>-Understand how participant made meaning out of experience -Space to voice experiences -Power imbalances</i>

4	How did this experience compare to your other interactions with the Ministry?	<p><i>-Experience within context of previous histories</i></p> <p><i>-Establish personal narrative</i></p>
5	Can you tell me about your experience of the appeals process? What emotions did you experience? How did the process impact you?	<p><i>-Elaborate on experience of appeal process from the appellant's perspective</i></p> <p><i>-Explore the emotional and potentially oppressive aspects of the appeal process</i></p>
6	Did you hear about the changes made to the CVS policy after you were denied the supplement? (if no, provide brief reminder). If so, what did you think when the government promised to fully fund the CVS program in 2011?	<p><i>-Explore potential feelings of empowerment, resistance, community, etc.</i></p>
7	How did you react when the government cancelled the CVS program?	<p><i>-Understand neoliberal policy from the experience of person affected</i></p>
8	Do you think the government could improve the CVS? Please explain.	<p><i>-Emphasize the individual as the expert in their own experience</i></p> <p><i>-Capacity to influence policy through expression</i></p>
9	Do you have any other thoughts on how you think disability assistance from the province could be improved?	<p><i>-Invite participant to speak critically about the system as a whole</i></p> <p><i>-Invite expression</i></p>
10	Do you have any other thoughts you would like to share with me today?	<p><i>-Ensure there is space for further expression</i></p>

### ***Data Analysis***

Prior to reviewing the interview data, I engaged in a form of pre-analysis preparation as encouraged by reflexive researchers across qualitative methodologies (Hesse-Biber, 2012; Ortlipp, 2008; Rubin & Rubin, 2005; Somekh & Lewis, 2005). To raise awareness of a researcher's perspectives, much of qualitative scholarship prescribes that the researcher engages in a reflective interview process with themselves (Rubin & Rubin, 2005). As noted previously, I engaged in personal journaling of my views and preconceptions to become more aware of how my perceptions might influence analysis (Hesse-Biber, 2012; Groenewald, 2004). This journaling was reviewed and critiqued, with an effort to surface existing biases, preconceptions, or social influences. At times, I shared excerpts and reflections within my personal circles to ask for external feedback. In addition, I intentionally returned to the literature throughout this process to surface what experiences outside of my own location might be absent in my considerations. In this way, I challenged myself to reflect on the different ways in which disability is further complicated by various intersections of oppression, such as racism, that are outside of my own personal narrative. This effort served to ground me prior to engaging in data analysis. Following this self-reflective process, audio recordings of the interviews were listened to repeatedly to ensure that the participants' voice and experience was central in the data analysis process.

I then transcribed the audio recordings and interview notes. Prior to theming the data, I invited each participant to review their transcribed narrative to confirm I had correctly captured their words. Several participants chose to clarify or elaborate on their narrative, and later, to give insight as to what they viewed were the important points of their interview. Engaging in a formative process collaboratively with some of the participants was extremely meaningful to me. Once the participants were satisfied with their contributions to this study, I began analyzing the data.

Qualitative analysis "involves organizing the data, conducting a preliminary read-through of the database, coding and organizing themes, representing the data [through tables, discussion, etc.], and forming an interpretation of them" (Creswell, 2012, p. 179). This process was followed as a means to structure my analysis of the data. I continually returned to the literature throughout this process, and would then periodically review the data to ensure the participants' voice remained the prioritized, guiding narrative (Reinharz, 1992).

From this analysis process, the following 11 dominant themes emerged:

- The perceived need for and benefit of the CVS
- Being wait listed
- Experiences of appealing the wait list
- Peer support as a means of resistance
- Withholding trust as resistance
- CVS experiences of the Ministry's broken promises
- The importance of the CVS as amplified due to severely low PWD rates
- The Ministry as an inaccessible system
- CVS eligibility and being penalized for illness
- Disability and stigma
- Paternalism and policing by the Ministry

The above list was shared with participants to ensure that they approved of the ways their narratives were analyzed. Sections of the participants' data that spoke to ways in which participants felt the Ministry could improve, or changes they sought from a systemic perspective, were used as the foundation for the recommendations made in Chapter Six. The participants' recommendations were pulled from the data and themed using the same approaches explained above. All individuals participating in this research were invited to read early drafts and the final version of this thesis (or have it read to them, if needed). In this way, participants retained ownership over their voice and exercised influence in the research process as a whole.

## *Ethics*

### *Participant Selection*

Fairness and equity approaches to inclusion in research participation were adhered to as outlined in Chapter 4 of the Canadian Tri-Council Panel on Research Ethics (Government of Canada, 2009). Participants were 19 years of age or older and voluntarily agreed to be part of the research study. Participants were chosen based on a selection criterion (see participant section above) and those who first responded to recruitment were selected to participate. For the purposes of this research, only individuals who were legally entitled to give consent were considered eligible to participate in this study. To be impacted by the CVS legislation during the prescribed time period, individuals had to possess the ability to give consent, without the

direction of a court appointed trustee, by the very criterion that made them eligible for CVS. The experiences of individuals who are not legally entitled to give consent are equally of value (if not more, in terms of research equity, as they have been underrepresented in consensual participation in research studies). However, due to the history of unethical research that has been conducted on individuals who were unable to provide informed consent, it would have been unethical to include such vulnerable populations without additional guidance and extensive ethical considerations (Cochran et al., 2006; Revie, 2006; Roman, 2009; van Heeswijk, 1994).

Too often, research has come at a cost to research participants, particularly if those participants are oppressed (Hesse-Biber, 2012). Since Canadians with disabilities are disproportionately marginalized, I sought to take additional considerations to ensure that participants involved in this study were not left with the all too common sentiment that “researchers are like mosquitoes; they suck your blood and leave” (Cochran et al., 2006, p. 22). A significant consideration within this research focused on protecting participant privacy. Participants were being asked to speak about experiences resisting the system that provides their source of income, therefore upholding participants’ privacy was of the utmost importance (Kaiser, 2009; Reinhartz, 1992; Young, 1990). With this in mind, limited participant demographical information is provided. In instances where participants identified their location within a particular demographic (or other distinguishing factors), I confirmed with the individual that they did in fact want such details on record for the purpose of their intended narrative. General identifying factors, such as the name of the participants’ volunteer agencies, were removed during the transcription phase. Participants were invited to review their transcribed interview to confirm for a final time that no identifying information remained and to ensure their words were captured correctly. Participants were also invited to speak with the researcher at any time after the interview to clarify or discuss any of their contributions to the research.

### *Compensation*

Participants interviewed were provided with a \$25 gift certificate as compensation for their time. Participants were invited to advise the researcher of which store they would prefer their gift certificate be from in order to respect the participant’s autonomy as much as possible. Participants were also compensated for any travel, childcare, or other accessibility expenses incurred as a result of participating.

Before starting the interviews, participants were advised that, should they choose to withdraw from the research at any time, they would receive their honorarium regardless. This was done in recognition of the fact that PWD assistance is insufficient to provide for basic needs, so the potential for economic coercion would be much higher if participants were not eligible to receive their honorarium if they chose to withdraw from the research. Of all the participants who consented to participate, none chose to withdrawal from the research.

### *Limitations*

Because this research sought people who had appealed the Community Volunteer Supplement, this research was limited in that its participants were already somewhat politicized by the sheer nature of their eligibility: people suitable to participate in this study had already engaged in some resistance of the system (Chouinard, 2010). As a result, this research was limited in that it excluded the experiences of people who may have resisted the system in means outside of CVS appeal, yet may have been subject to the same exclusion of benefits. However, it was the experiences of people engaging in this particular form of resistance that was the focus of this study. Instances of resistance, as identified by participants, are included in the discussion Chapters Four and Five of this study and offer an interesting foundation for further research in the area of resistance, particularly in relation to disability policy. Participant recommendations are highlighted in Chapter Six of this study.

Another potential limitation of this research results from efforts to maintain participant privacy (Kaiser, 2009). Because of the respectively modest number of participants, who are from the relatively small disability community of Victoria, the potential for participants to be identifiable was higher than in a larger city. Given that participants were being asked to speak to their resistance against the very system providing their income, demographic factors and the presence of intersectionality can only be spoken to in a limited way (Kaiser, 2009). This research is limited in the sense that it lacks a deeper investigation into the occurrences of othering and power relations, as it relates to racism and other forms of marginalization, as identifying such factors might significantly have risked the privacy of participants. In instances where participants felt their identification was pertinent to their narrative, I confirmed that they were aware of the risks relating to this identification so that the participant could make an informed decision.

This research may also be said to be limited given that I previously worked at the Together Against Poverty Agency and may have been biased towards the experiences of people on PWD assistance. However, as previously mentioned, I worked at being aware of this potential bias. In addition, such biases are reflective of the motivation many social science researchers experience that often lead them to a research topic that they are passionate about. Such motivations are not acknowledged in the more positivistic schools of thought that previously dominated the research field (Taylor, 1998; Papadimitriou, 2008).

### ***Summary***

Drawing on recruitment efforts and word of mouth referrals within the disability community in Victoria, BC, I sought participants who were over the age of nineteen, were able to give consent, and had been wait listed for the CVS. Using semi-structured interviews, I interviewed five individuals on disability assistance who had appealed the Ministry's practice to wait list CVS applicants. Ethical protocols and reflective journaling were key in guiding my approach to this research. A post structural feminist perspective, referenced to critical disability theory and Foucault, provided the theoretical foundation for this research. I engaged in a formative review process of the data, continuously returning to the literature, the interviews, and my research question as a means to approach data analysis. I frequently invited participants to provide feedback on their interviews, to review the ways in which I themed the data, and, later, to review the final draft of this thesis. A number of participants chose to contribute to the theming of the data and the final draft of this thesis. The engagement and contributions of participants throughout the research process was an extremely meaningful experience, for both myself and participants.

## CHAPTER FOUR

### Participant Experiences in Resistance

I was pissed off, but I mean the appeals process makes it a blessing because you can appeal. And I appealed. As long as the road is still open, then I'll travel that road. (Participant)

This chapter reports on the experiences of a small group of people on disability assistance in BC in resisting the Ministry practice to wait list Community Volunteer Supplement (CVS) applicants. The next chapter, in turn, discusses how these experiences connect to relations of power and processes of 'othering' by the government. Given the participants' concerns that the Ministry might identify them, this discussion does not differentiate between participants in order to avoid any opportunities where the participants could be identified through continuous narrative. Although this removes the opportunity to portray the uniqueness of each participant's experience, within the analysis sections of this thesis, participants' intentional identifications amongst the margins were highlighted within Chapter Three. Moreover, the participants' prioritizing of relevant factors remains central to the intent of this research, so the ways in which the participants felt certain factors to be relevant is respected in the organization of the discussion of this data.

In asking participants to reflect on their experiences accessing the CVS, it became apparent the CVS is not experienced in isolation of the participants' experiences of poverty, resistance, or community. Experiences of appealing the CVS wait list were identified as being intertwined with the participants' collective experiences with the Ministry, their ongoing distrust of the system as a whole, and their collective efforts to support others experiencing similar challenges.

#### ***Perceived Need for and Benefit of the Community Volunteer Supplement***

To understand the unjust denial of the CVS it is important to explore the narrative of participants' identified need for the CVS. Being able to personally speak to the importance of the CVS can be interpreted as a form of resistance in that the perspectives of the individuals who access this benefit are prioritized; pushing back against external narratives of disablement

exerted upon them from external systems. Within neoliberal constructions of power, institutional systems such as the MSDSI fail to recognize the various ways in which power is relational,

When power is understood as ‘productive,’ as a function of dynamic processes of interaction within regulated cultural and decision making situations, then it is possible to say that many widely dispersed persons are agents of power without ‘having’ it, or even being privileged. Without a structural understanding of power and domination as processes rather than patterns of distribution, the existence and nature of domination and oppression ... cannot be identified. (Young, 1990, p. 33)

Foucault (1994) emphasized that the oppressive nature of biopolitics positions the body as a means of production over which institutional powers assess, construct, and control the body’s perceived functionality. The practice of discounting experiential narratives within disability policy must firstly be resisted in that, “structures are constituted through practice and practice can always be turned against structure” (Davies, 1991, p. 52). In this way, it became an integral aspect of this research to give voice to the ways in which participants constructed their own narrative in relation to the CVS.

One of the participants interviewed spoke to the need for and benefit of the CVS from their perspective:

The CVS has been an instrumental tool in assisting me in my volunteering in the community by giving me a \$100 a month for things that are needed for my volunteering positions like maybe a brown bag lunch or something...bus tickets ... a cup of tea ... Anything that’s required for the job of volunteering that the Ministry won’t actually pay for.

The intent of the CVS program prior to being repealed, as outlined by the Ministry, was to provide “up to \$100 for each calendar month for clothing, transportation or other expenses that are needed by the eligible person to participate in a community volunteer program” (Ministry of Social Development and Social Innovation, 2011). Participants cited the specific and material ways in which the CVS helped them to cover the costs of basic needs associated with volunteering:

If they don’t get the CVS, how do they ... volunteer? There’s lots of street people, there’s lots of low income people that volunteer, that help out, that do things in different ways. So they need bus tickets. So the hundred dollars gets them to where they need to go.

I needed the supplement to be able to afford clothes to wear to go volunteer, to be able to get to my volunteer placement, and to be able to participate in events that were held at my volunteer ... Not being able to wear nice clothes, or having to wear old, ripped up clothes when you are volunteering ... really wears on your self-esteem.

Participants identified repeatedly that without the CVS, they would be unable to afford the basic items they needed to engage in their community:

It made things better for me so I could afford clothes.

I need to look presentable and thus, needed money for clothes, safety shoes, regular shoes.

I was able to have an extra income to help pay for groceries, clothes, shoes, and other daily items.

All of the participants interviewed began by defining the CVS in ways reflective of the Ministry's advertised intent for the program; however, participants soon began to explain their experience of the CVS with more complexity. Aspects of citizenship, mental health, and wellness were prioritized by participants as being the most important benefits of the CVS:

Volunteering gave me a sense of belonging and made me feel like I could help others ... it helped prevent or stop the isolation that was so damaging to my conditions. People don't understand how isolating it can be, and how much volunteering helps with that.

If the government's going to promise to pay them for volunteering, then they better have the money to talk ... Help to stop isolation. Help to stop abandonment issues. Prevention of health, mental health. Addictions. Give people something to do, they're not going to do drugs, they're not going to go steal, they're not going to go have a life of crime.

[Without the CVS] I would have still been living with being stuck inside all the time, not being able to eat a lot of food, not being able to interact with people, not turning the heat on ... not being a part of society at all ... [not volunteering] made me feel very secluded.

All participants highlighted the CVS as a key factor relating to citizenship. As explored within the context of disability policy, citizenship is "about the capacity to participate fully in all the institutions of society-not just those that fit the conventional definitions of the political, but also the social and cultural" (Pothier & Devlin, 2006, p. 1). People with disabilities have a right to participate fully in society and, therefore, people with disabilities should be the primary actors in identifying what factors, accommodations, and structural changes are required to achieve active

citizenship (Gilbert, Cochrane, & Greenwell, 2005; Pothier & Devlin, 2006; Prince, 2009). Participants' narratives of the benefits of the CVS were directly related to supporting their sense of belonging in society:

I was contributing to society by volunteering for an organization that meant a lot to me.

The people I've met ... I can stop and talk to on the streets if I see them and it gives me somewhere to go.

It supported my independence, and made me feel like something in the policy actually cared about supporting my independence.

It's a social aspect, right.

Participants clearly felt that the CVS assisted them in preventing mental health and depressive symptoms, and improving overall quality of life:

Prevention is an ounce of cure ... If you get enough people to volunteer, and give them incentives and all kinds of things, we're preventing them from being sick, we're preventing them from mental health issues, they're being social, they're getting out, they're doing ... we're using peer support with each other, we're helping each other out.

For me, that's my lifeline ... Like even when I'm depressed, I can at least phone people that I volunteer with and talk ... I can connect with someone and, and feel better. Like even depressed, I can feel a little better because the organization understands who I am and what I do for them, and can support me in my low moods.

You're not at home isolated ... Volunteering is such a big, big thing. It's *so* important for people. It's a community thing. When we're hit with a crisis, where do ya turn? Your community. You turn to your neighbour.

Volunteerism as facilitated by the CVS, when analyzed through the perspective of participants, not only positions citizenship as a progressive, preventative social measure, but further asserts citizenship as a basic right of people with disabilities (Raphael, 2007). The failure to recognize such basic aspects of citizenship echoes the personalization of poverty discussed previously. Moreover, the erasure of experiential narratives within disability policy constitutes the subjugation of the lived experience of disablement and relating aspects of citizenship (Foucault, 1990). Prince (2009) echoes the need to surface citizenship as a necessity, not a privilege:

Framing disability issues as matters of citizenship is potentially a powerful strategy for the disability movement. It challenges old images and stereotypical

beliefs about disability ... It offers a normative benchmark for evaluating existing services and benefits in terms of enabling or restricting the dignity and self-determination of persons with disabilities, and thus, by extension, advocating for reforms. (p. 16-17)

When citizenship, as facilitated by policies such as the CVS, is understood as a basic right enabling dignity, self-determination, and empowerment, the oppressive impact of withholding CVS from eligible participants is understood that much more.

In addition to the numerous social, civic, and emotional benefits of the CVS, participants were aware of the Ministry's neoliberal motivations to connect people on PWD assistance to employment-centered economic independence. As theorists have noted, neoliberalism has constructed an economically driven motivation for much of current disability policy:

Neo-liberal ideas have ushered in a new wave of policies in which the criteria for government disability entitlements still applies some version of the civic disability model of entitlement, that is, a biomedical formulation of disability ... this translates into paternalistic decision making policies programs and services. (Rioux & Valentine, 2006, p. 64)

The participants identified that, due to the restrictive nature of PWD policy, they were often afraid of stepping into employment for fear of losing their hard-earned PWD designation. Ministry policy states that individuals on PWD assistance retain "the right to participate in the labour force [as one is able] while maintaining the disability designation" (Ministry of Social Development and Social Innovation, 2013c). However, given the restrictive nature of PWD designation eligibility policy and processes cited in Chapter Two, it is understandable that participants were cautious of endeavoring employment for fear of being perceived as too 'able' for PWD benefits. With this in mind, participants cited the CVS as the perfect stepping stone to possible employment. Participants talked about how the CVS allowed them to gain meaningful experience, ease into the responsibilities of a working environment with reduced risk, and potentially trial solutions to any adverse impact resulting from engaging in continuous employment:

In my experience, volunteering is what gets me a job ... it gets me out of the house and makes me feel useful.

But that's one thing the volunteer really does is that it gets you a reference.

I thought it was great ... at the time I was looking for a paid job and I didn't have any references whatsoever, so I thought that would be a good start to get some references.

Participants needed to be able to build their confidence enough to try taking on responsibilities that are often in direct conflict with the kind of narrative they must emphasize in order to be eligible for PWD designation in the first place:

Slowly, getting used to the place, building up my self-esteem, it really took the edge off. Volunteering is a more low-pressure environment, especially when you aren't sure that you can manage without your disability cheque yet, and I probably wouldn't have taken the risk to jump into a job right away. It needed to feel safe.

What that hundred dollars symbolizes is more than just money, it means I can get back on my feet and that I can take the *emotional risk* it takes to try to get back on my feet. It makes me have a chance to grow, to feel good about myself, and to take care of myself while I am pushing myself out of my comfort zone.

Participants stated that, as a person with disabilities, they needed to be able to feel safe to explore what returning to work might actually look like. Participants demonstrated a significant awareness of the power relations present within the Ministry's prioritization of economic independence and the potential consequences risked by exploring employment within punitive social policies. Participants were often unsure of how their disabilities might be exacerbated by attempting to take on employment. The opportunity to access volunteerism and have autonomy over their own assessment of health and capacity was an empowering experience. Those participants who realized they could not manage the impacts of pursuing employment had been able to safely come to this self-assessment without gambling their PWD designation.

Given that much of the participants' experiences with the Ministry involve externally assigned narratives and definitions surrounding their health, it was important for participants to negotiate for the power to define their own experiences of their bodies (Foucault, 1994; 2004). One of the many problematic effects of neoliberal, biopolitical centric policy is its deficit-focused, capitalistic emphasis on the body (Hughes, 2009; Sawicki, 1991; Wendell, 1989). Particularly in relation to citizenship, "neo-liberalism promotes additional troubling notions of citizenship. The personal tragedy, charitable, and medical-oriented notions of citizenship converts Canadians with disabilities, respectively, into citizens with spoiled identities, as supplicants and as sick patients" (Prince, 2009, p. 24).

The participants' authorship over their own experiences of the CVS and facilitated empowerment can be recognized as resistance, as it presents a counter-narrative within a complex set of power relations whereby the Ministry typically retains sole authorship. Instead of the participants exercising autonomy as the authors of their own narratives relating to symptom management, ability, and employment, the Ministry retains authorship over what it means to be 'able' to work or in need of assistance (Chomsky & Foucault, 2013; Raoul, 2007). When participants explored the ways in which they could best mitigate their symptoms, build their confidence, and ease into the workplace without the threat of losing their PWD designation, several were able to transition into the workforce successfully:

I started volunteering ... and then I got casual employment ... Then, I was hired full time. It meant so much to me to work up to that, at a safe pace, with support and to not be risking my means of living [PWD].

I am now a full time employee there, and it was only through volunteering that I was able to afford the food, clothes, and everything I needed to get there and to eventually build up the confidence and resiliency I needed to be able to even believe I *could* work full time.

In this way, participants' experiences of accessing the CVS facilitated a more meaningful experience of citizenship. The CVS supported them to learn about how to manage their needs in relation to civic participation, and, for some, acted as a stepping stone to meaningful employment. Participants identified the importance of the CVS in order to attend to basic needs related to citizenship that were directly linked to the limitations they experienced as a person with a disability in an ableist world. Relating these experiences to the development of progressive social policy, inclusive efforts to value the experiential narratives of individuals as service consumers is integral:

Equality ... refers primarily to the full participation and inclusion of everyone in a society's major institutions, and the socially supported substantive opportunity for all to develop and exercise their capacities and realize their choices ... Policies that are universally formulated and thus blind to differences of race, culture, gender, age, or disability often perpetuate rather than undermine oppression. (Young, 1990, p. 173)

Participants speak to the benefit of the CVS not only as they experienced it, but also in relation to their experiential knowledge of Ministry objectives. Participants identified factors such as autonomy and low risk opportunities, which influenced their capacity to explore and define ways

in which they exercised power in relation to employment or community participation, offering important considerations for future policy development.

***Being Waitlisted: When Citizenship is Withheld***

When civic engagement and social interaction are barred through restrictive policy changes, a post-structuralist feminist analysis highlights the importance of exploring the experiential as powerful narratives of resistance in ways that are typically discounted within neoliberal society. As participants shared their experiences of being unjustly waitlisted for the CVS, they clearly identified that being denied the CVS felt like an intentional barricade to participants' citizenship. The Ministry began wait listing individuals who were eligible for the CVS by creating a policy that was in direct contradiction with provincially legislated eligibility requirements (Clarke, 2011; Lavoie, 2011). The Ministry's creation of a policy that superseded legislation resulting in a *de facto* denial of eligibility was experienced by participants as a very complex, intentional biopolitical assault:

[When I found out I was waitlisted] I felt like walking into their [the Ministry] office and kicking one of them in the nuts! Because I felt like everybody was getting theirs' right away and here I am having to wait and wait and wait and wait ... I'm starting to feel like a trained pet seal!

When I was denied for the CVS, it was so disappointing and frustrating. I was extremely triggered and anxious; it felt like getting a huge slap in the face.

Participants felt extremely emotive responses to being waitlisted:

I felt assaulted.

When I was turned down for the CVS, I was devastated.

I couldn't believe it; I was angry and anxious. I get very anxious and cannot concentrate or focus on what I need to do to assert myself regarding the MSD[SI]. The MSD[SI] is very triggering for me.

It just didn't show up on my cheque, which is really scary.

Participants experienced the waitlist as an intentional effort to exclude them from engaging in their communities:

I felt like I was being cut off from the world, like I was losing a lifeline. It had a huge impact on my sense of dignity and self-worth. That feeling of always

having to ask for help, it was a struggle to go through and wore on my self-esteem. It felt like being slapped in the face.

It is so stressful being denied, especially when you are already so nervous to go outside of your comfort zone, when you are managing trauma and triggers.

Thus, participants experienced the Ministry's refusal to acknowledge their eligibility for the CVS as withheld citizenship. When the ableist facade of neutrality is removed from institutional power relations, the truth, as identified by the participants, represents the painful reality of exclusionary and oppressive policies and practices that govern the lives of people with disabilities (Barnes & Mercer, 2005; Davies, 1991; Foucault, 1994; Jolly, 2003; Teghtsoonian, 2000; 2003).

Participants spoke of being waitlisted as a denial of recognition for the value of their contributions to society. In the most basic sense, by engaging in the CVS program, people with disabilities are supported in contributing at minimum ten hours of unpaid labour per month to the economic system when they otherwise might not have been able to do so. Participants felt they had adhered to the capitalistic valuing of contributing bodies, yet had still been denied. The CVS, as expressed by the participants, was seen as an acknowledgement of that contribution. The CVS marked the participants' place of belonging in a society in which they were typically excluded. Echoing the concepts of 'deserving' and 'undeserving' poor, participants felt they were deserving of the CVS and felt their contributions were being deemed as less valuable by the Ministry because of their status as people with disabilities:

I was a little angry, you know, because ... I believe that I needed it and I believed that I'm volunteering those ten hours.

I felt disappointment, sadness, anger, anxiety --- I felt like I wasn't worthy, valued, or considered a person who was a valued life and the right to be empowered.

It was devastating when they said I couldn't get it anymore.

These people are making judgments on people's lives, whether they deserve the CVS or whether they don't. If people are volunteering, they deserve to be appreciated, acknowledged and rewarded for volunteering.

These participants highlight one of the many consequences of disability policy existing within a neoliberal, patriarchal regime (Foucault, 1994; Knoll, 2009; Wendell, 1989). Participants spoke to their experiences of body politics, or biopolitics, in that the body, under the neoliberal facets

of capitalism, is perceived as valuable only in so far that it remains an effective means of production. One participant explained this experience with the following imagery:

When I see people on the bus with their briefcases and I think why can't I just fit in, why can't I just get a job? People don't see the emotional scars on the inside, especially people who work for the Ministry. People don't see how they break you down after a while. And that's why people start to give up and go living on the street because they just give up, they can't cope with that emotional crushing anymore. And they put up with *so* much.

Another participant identifies the challenges being a person with disabilities in a capitalistic society:

How do you feel there's any worth in yourself when you feel like nobody's giving you that worth, when you can't find a job, and you can't work with money? My skill is animals ... My skill is being loud and annoying and not belonging in society. And my skill is making my mom laugh when she's so depressed that she can't even lift her own head. So those are my skills and none of those apply to society.

When participants pushed back against the dominant narrative that they, as a person with disabilities, could in fact contribute as an economic body, their contributions were *still* devalued (Baxter, 2003; Butler, 1990; Chouinard, 2010; Hewitt, 1983; Jongbloed & Crichton, 1990).

Participants expressed their awareness of their value, as perceived by the Ministry, in relation to their contributions:

And I said, well I'm still working there [at volunteer placement]. And they said, well there's nothing we can do about it.

Well if you're disabled and you can't ... work, that it's great if you can make an extra \$800 a month, but if you can't find a job, it doesn't matter what you could make.

Regrettably, participants talked about how, though they experienced a range of emotive reactions to the Ministry's wait listing practice, they were not surprised by this abuse of power. All participants interviewed demonstrated that such unjust administration of benefits were unfortunately all too common. As one participant said, "Anger, frustration, pissed off, sadness; oh *here we go again* ..." Another said, "No, [they didn't say where I was on the waitlist] it was just you're on the waitlist. Often there's not much point asking the Ministry questions. They often don't give answers." Other participants' remarks illustrate this re-occurring power dynamic:

Lots of waiting. I'm used to waiting.

Really? It's like I'm on a waitlist once again? It's another waiting thing.

I was getting my cheques every month and then it just didn't show up on my cheque. So I phoned them ... and they said, once you're off it you can't go back on it.

I had been on it for a number of years I think. And then, I changed, I guess I changed volunteer work without telling them and they penalized me for that. So they took me off it and put me on the waitlist.

The participants' awareness of the functionality (or lack thereof) of the Ministry's services can be taken as a valuable indicator of the need for disability policy reforms. However, the participants' experiential knowledge of the system juxtaposed with the problematic structure of the current capitalistic emphasis within Ministry policy demonstrates the need to recognize the value of participant authorship over policy objectives.

Participants noted they were denied the right to know under what conditions they would be removed from the CVS waitlist or how long they could expect to remain on the waitlist:

It [the wait list] was for many months, that's for sure. But there was no indication of when it would end.

Saying ok, here's another experience, let's learn from this one and move on, let's fight the system again.

Given that this was a legislated benefit to which they were entitled, the Ministry's continual denial of the CVS further violated the rights of people with disabilities, creating what Agamben (2008) would call a "state of exception." In this way, the ways in which 'truth' is experienced as a recipient of inequitable exercises of institutional powers *over* the body (Foucault, 1997), demonstrates that,

The binaristic approach to disability engenders a process of 'othering' and categorization ... [and] at certain socio-political conjunctures, specific personal characteristics are understood as defects and, as a result, persons are *manufactured* as disabled. (Pothier & Devlin, 2006, p. 5)

Participant testimony of being denied citizenship via the inequitable administration of the CVS legislation constitutes the institutional enforcement of the manufactured disabled body. Coupled with the numerous processes and barriers experienced by participants to simply receive PWD designation, it is understandable that participants experienced the Ministry's unjust wait listing

policy as a predictable, personal assault. As one participant notes, “it felt like I was being objectified by them all the time, like there was always something and I would be denied and then denied again.” People with disabilities are all too often subjugated by systems of power, rather than respected as valuable contributors.

### *On Appealing the Waitlist*

Resisting the very system responsible for providing their means of living can be an anxiety inducing endeavor for any person, especially for a person further stigmatized and marginalized (Pope, 2013 June 18). Participants talked about their experiences resisting the Ministry’s unjust wait listing policy and many participants identified the appeals processes as too complicated to manage alone, often experiencing an exacerbation of health symptoms as a result of the stress experienced (BC Public Interest Advocacy Centre, 2015; Culbert, 2015 May 12; Pritchard & Sadrehashemi, 2015 June 02). One participant described, in detail, the complex interactions of symptoms and stress experienced as a result of being denied the CVS, seeking community support, and navigating their appeal:

It [appealing the CVS waitlist] was a long process. I was going through [symptoms] every week and so, had limited energy. I had to make sure that I had enough rest and had to talk myself into going to TAPS and wait and see the receptionist, book a time or wait to meet with a stranger [an advocate], in a place that had a lot of other anxious people sitting in the waiting room. And then share my frustration, disappointment, and fear of dealing with the MSD[SI]. I also had to be willing to trust the advocate and share personal information about my past/healing process and be willing to sign a release of information form so that she, then could speak with my doctor and various counsellors/psychologists.

Unfortunately, one can only assume such experiences are absent from consideration in the development of Ministry policy given the complexity of the current appeals process. Examining further participant experiences of resistance serves to highlight how exclusionary this system is in that it is structured to be inaccessible to the very population it is intended to serve:

I was denied CVS and had to go back to TAPS to have an advocate. [Advocate name] helped me to appeal my need for the CVS.

Having help through the appeals process is so important. Especially when the Ministry is asking for personal information or details about your condition or history.

I went looking for support to appeal and that was really important. I wouldn't have been able to manage that process on my own.

Participants clearly identify that their resistance, within the context of the administrative appeals process, is a particularly demanding experience that often times could not be navigated in isolation:

It [appeals process] was very draining.

I don't think I could've done it myself ... you get upset when you get denied and you can't think straight.

It's hard for people to be objective when you're in the situation so it's hard to write yourself a case scenario to fight an appeal when you don't know the words that you should be using and you don't know what the Ministry is looking for and you don't, you don't understand what kind of terminology ... what it involves.

Participants here highlight that their ability to exercise resistance is intertwined with the community of supports they depend on. Given that the appeals process is designed to be accessed by people with disabilities, the challenge and impact of appealing Ministry decisions, as noted above, should be taken as counterintuitive to the system's intent. The structural inaccessibility of the appeals process should be viewed as an intentional barrier to resistance. Ease of access in relation to the appeals process should be a significant priority within policy development. However, an onset of increasingly restrictive disability policy efforts has succeeded in making the avenues available for resistance extremely inaccessible (Goldberg & Stainton, 2008; Little & Marks, 2006; Michael & Reitsma-Street, 2002).

The collision of anxiety, frustration, and exhaustion, made the appeals process a complex undertaking for participants. Participants' emphasis on their community of support, both in relation to the community advocacy programs they depended on, and the support of their peers as described in the next section, is a significant consideration. Individuals with disabilities should not incur consequences when exercising their right to resist within the very systems that claim to provide assistance. The adverse factors of such systems should be analyzed more thoroughly to make systems supporting people with disabilities more accessible and less taxing.

### ***Peer Support as Resistance***

Participants identified a number of ways in which the community of people on PWD and Income Assistance shared knowledge and strategies amongst each other to increase their collective access to benefits. In this way, participants prioritized their coalesced identity and shared experiential knowledges as system consumers as a means of shared resistance. The varied and many ways participants supported each other in navigating the complex, inaccessible Ministry processes constitute an intentional act of dismantling the “regime of power” (Foucault, 1994, p. 329). As one participant noted, “I heard about it [the CVS] just because I went on disability and word of mouth and not-for-profit organizations who work with people around income assistance.” A different participant pointed out how they tried to distribute their knowledge as soon as they learned of the CVS: “Soon as I found out about the CVS, I told my volunteer agency, told other people I knew because I knew not many people knew about it.” Another participant explains how they learned about the CVS from the agency where they volunteered:

And my [family member] was shopping at [agency name] that I work at, now I work at, and he said that they’re looking for volunteers and I wasn’t doing anything at the time, I wasn’t working, so he gave me an application and I filled it out. So I started working there and the director said, ‘Are you on disability?’ And I said, ‘Yes.’ And she said, ‘Do you know you’re eligible for a Community Volunteer Supplement?’ So I took the form down to welfare and I filled it out.

Participants presented an alternate narrative that, despite an ongoing experience of neoliberal gatekeeping by the Ministry, peer support is a collective and powerful means of *talking back* to the existing narrative around disability created by Ministry policy and practices. As one participant explained, they shared their learning by contributing to the collective knowledge of their peers:

A neighbour of mine also had a hard time getting PWD status and so, I brought her to TAPS [Together Against Poverty Society]. Consequently, she was able to receive PWD status.

Other participants identified that they felt responsible for the collective wellbeing of one another, and talked about their efforts to contribute to the overall access to benefits amongst the disability community:

I actually hadn’t heard about it until I met [friend’s name], like became friends with him, and he told me about it so he got on the phone with the people because I was only getting my disability at the time. And so, it took a really long time

before I got a phone call back saying yes you qualify for this and ... I wish I had heard about it earlier.

I had a hard time asking for it because I wasn't sure what they would need from me, and as a person that has disabilities, my mom didn't know about it either ... [friend's name] just became friends with me and so trying to work that out all with all three of us together, it was very difficult trying to get people to understand that I did have disabilities because I do speak well.

I got it at 18, and one of my ex-boyfriends ... was on it so he helped me apply for that, so ... it helped. It helped big time. Because he was on persons with disability as well.

Even though participants expressed that they were often exhausted navigating poverty, health symptoms, and stigmatization, they felt an overwhelming need to contribute to the betterment of their peers' access to benefits. As one participant explained, "I see a lot of people hurting and it hurts me." Participants demonstrated a strong obligation to not only *take up space* within their community as knowledge holders, but to utilize their community's collective knowledge to create cleavages of resistance (Foucault, 1990a). As Butler (1990) notes, there is "an identity in difference," even within the most complex situations (p. 54-5). As Foucault explains, power relations typically occur not in large, cataclysmic events, but in "mobile and transitory points of resistance, producing cleavages in a society that shift about, fracturing unities and effecting regroupings, furrowing across individuals themselves, cutting them up and remolding them, marking off irreducible regions in them, in their bodies and minds" (Foucault, 1990a, p. 96). Foucault speaks to the micro moments of resistance that contribute to the collective sense of power amongst people with disabilities in that the shared value of experience serves to mobilize and shift the power relations, however minutely.

### ***Withholding Trust as Resistance***

Participants identified the Ministry not only as a system accessed for services, but as a structure which invoked a particular set of reactions that can be perceived as an almost guttural resistance. The participants strongly identified the ways in which they maintained a distrust of the Ministry, upholding their individual trust as a right that must be earned. Participants pushed back against the Ministry by carrying their cumulative knowledges and experiences into identifying the Ministry's unaccountability; in surfacing the ways in which the Ministry failed to support them as people with disabilities, the participants vocalized their

awareness of the Ministry's abuses of power. Such a collective demonstration of skepticism of a system that claims to provide assistance to people with disabilities should be considered a strong indicator of ineffective, oppressive institutional policy. In this way, given that so much of neoliberal policy centers on discounting and defining the disabled body, this research would like to highlight the body and mind's response to the Ministry as a form of resistance:

They [the Ministry] have no idea what it takes to phone them or to walk into that building, especially if you are appealing or disagreeing with them, and how triggering it can be.

As a woman, you are already objectified so much, you are already walking in [to the Ministry] feeling inferior. And then to have the Ministry objectify you, have the doctors and everyone else treat you poorly, the whole system is exhausting.

It's like dangling a steak in front of a really hungry dog, it's like one day we will turn, one day we will bite! It's just that I wish that they could be more positive with us because we try to be positive with them."

The presence of gendered experiences of objectification as expressed in the participants' narratives demonstrates that those accessing Ministry services maintain a cautious distance.

Participants talked about how solidified their mistrust truly is:

Well I don't have very much faith in the Ministry.

I don't necessarily see them as being as caring as they should be for the people that they're providing for.

Well it's hard to imagine the Ministry being helpful or caring [laughs], but there should be something in place because there's no support for volunteers on PWD.

Participants illustrated that there was also a pervading sense of permanence to their distrust of the Ministry:

No, it's pretty typical of the Ministry I believe. [*On the Ministry repealing the CVS legislation*].

It's pretty much the way the Ministry works I think anyways. [*On denials*].

Participant narratives speak to such a pervasive pessimism in the functionality of the Ministry that when progressive policies are announced, such as the Ministry's 2011 promise to fully fund the CVS program, one participant remained highly doubtful:

That they were going to reinstate it [the CVS]? Yep, I remembered that. I was skeptical. Very skeptical. And then, what happened? They didn't! They didn't fund it!

The participants talked about how the Ministry feels like a continuously failing, unpredictable system that embodies political hypocrisy in such a way that participants are left feeling distrustful, cautious, and scared:

Well, as always, dealing with social assistance is frequently confusing and quite scary. And that combination is particularly deadly. The confusion makes it more scary.

It's like you wake up in the morning and it's kinda like, 'Ok what's the fight of the day now?'

The Ministry has no idea what it is like to try to survive every day, especially with what some people have gone through.

The combined sense of not being able to trust the Ministry, a collective awareness of the Ministry's lack of empathy, and the sense of inevitable issues are summarized by one participant as a particularly impactful experience:

So it's more or less me just saying this is what other people deserve and if they don't work with us, we're going to have to work within ourselves and try to make things the best we can for ourselves. But sometimes it's not always like that. And to the government, it's like a storybook, but to us it's so realistic sometimes it hurts.

The participants' awareness of the Ministry's inconsistent administration of benefits presented as so severely hypocritical to one participant in particular, they were left questioning how the Ministry can really claim to be 'socially developing' people:

I think the system, the Ministry of Social Development and *Social Innovation* [laughs], they pay more money to change their name, and change the freakin' paperwork, letterhead, and the stamps, and the webpages, you know ... it's just like, really? Compare what really do we need? Really? What is the function of the Ministry of Social Development? Are we *socially developing* people or not? And if you're creating a name like social innovation, what does that mean? And why are you using that name? What is it doing for the people that you're serving?

The persistent presence of skepticism amongst participants, paired with their collective awareness of the Ministry's inequitable distribution of benefits, illustrates the harsh reality of being service consumers for people with disabilities all too clearly. Participants' experiences of

distrust speak volumes as to the effectiveness (or lack thereof) of the Ministry. When power is analyzed through resistance, rather than the systems that serve to rationalize existing power relations, participants' experiences of resistance construct an additional truth; the collective experiences of an inaccessible system that claims to support people with disabilities.

Foucault speaks to the need to critically analyze existing oppositions as a means of understanding power relations, but also to surface the ways in which subjects of power are further defined by the systems that oppress them by continually contributing to a perceived reality:

This form of power that applies itself to immediate everyday life categorizes the individual, marks him by his own individuality, attaches him to his own identity, imposes a law of truth on him that he must recognize and others have to recognize in him. It is a form of power that makes individuals subjects.

(Foucault, 1994, p. 331)

This concept of power, and its biopolitical constructed truths, are situated within the participants' experiences of resistance, we see how the Ministry's presented power as a dominating, fearful force in the lives of people with disabilities further subjugates them. Foucault goes on to say that there are two meanings of the word "subject: subject to someone else by control and dependence, and tied to his own identity by a conscience or self-knowledge. Both meanings suggest a form of power that subjugates and makes subject to" (1994, p. 331). In this way, participants' awareness of the Ministry's oppression acts as both a means of resistance to the externally imposed subjugation of power, yet serves to further marginalize PWD recipients in that resistance must often be *in reaction to* the system's power.

### ***Summary***

Participants exercised authorship over their need for and benefit of the CVS as a facet of supporting meaningful engagement within their community. Participants illustrated that, outside of the Ministry's intent for the CVS program, they experienced a wide range of benefits, such as the alleviation of mental health symptoms and a sense of community belonging. The participants' explanations of what facilitated wellness, engagement, and identity within the confines of a capitalistic system can be interpreted as a form of resistance, constituting an important counter-narrative against the Ministry, and often society's, ableist constructions. Freire

(1970) notes the importance of discourse within resistance in that, “critical and liberating dialogue, which presupposes action, must be carried on with the oppressed at whatever the stage of their struggle for liberation” (p. 47). Participants recognized the Ministry’s prioritization of capitalistic contribution and used this rhetoric as a means to justify a benefit. In shifting the discourse of what is named as disability, and resulting access to citizenship, the deconstruction of “the disciplinary process is laid bare” (Price & Shildrick, 1999, p. 435). Recognizing resistance within the assertion of the “person as author of their own multiple meanings” pushes back against the subjugation of knowledge and take up space within the externally constructed narratives that govern the lives of people with disabilities (Davies, 1991, p. 51).

Participants interviewed were unjustly waitlisted for the CVS and resisted the Ministry’s wait listing policy using the administrative appeals processes. Participants identified that they were all too familiar with being denied benefits, often without reason, and noted the CVS was no different. Anxiety, stress, and exhaustion were cited as some of the varied ways participants experienced the appeals processes, highlighting how an administrative practice entails so much more for people living on PWD assistance. As some participants emphasized, their experiences of the emotional and physical costs endured by navigating the appeals process and engaging in resistance are unaccounted for by the Ministry. Participant resistance, in the context of participant recognition of the multiple and layered cultures of power, demonstrates that:

Autonomy becomes the recognition that power and force presume sub-cultural counter-power and counter-force and that such sub-cultures can create new life forms, which disrupt the hegemonic forms, even potentially replacing them.  
Davies, 1991, p. 51)

The participants perceived the Ministry as being unaware of the extent to which PWD recipients are impacted by navigating such processes. In defining their experiences of navigating the appeals processes, the participants create a narrative of resistance and survival. The participants illustrated how their experiences of resisting the Ministry by way of peer support and through withholding trust constituted a means of resisting institutional powers. By taking up space within the authorship of resistance, such as within their community of peers, participants push back against the erasure of their experiences.

## CHAPTER FIVE

### **Relations of Power and Processes of ‘Othering’ by the Government**

Even just having to ask permission is quite a pain. It’s pretty demeaning all told.  
(Participant)

This chapter explores how the participant’s experiences of resistance connect to relations of power and processes of ‘othering’ by the BC government. Participants talked about the Ministry’s repeal of the CVS legislation after promising publicly to fully fund it, and how this was perceived as an intentional effort to remove the participants’ right to exercise resistance. Such direct efforts to remove rather than uphold opportunities to access benefits, further positioned participants amongst the margins. Participants’ experiences of systemic subjugation were complicated by the highly inadequate PWD benefit rates people with disabilities receive, showing that when people are forced to live drastically below the poverty line, every cent counts.

Participants understood the CVS as representative of larger experiences of withheld citizenship, injustice, and ableism enacted within the Ministry’s provision of services. They spoke of how the hypocritical inaccessibility of the Ministry, coupled with the perceived policing experienced by CVS recipients, served to constitute people with disabilities as the ‘others.’ Oppressive, stigmatized experiences of disablement were all too familiar for participants, as they talked about the prevalence of paternalism and ableism in multiple aspects of their lives. These themes are explored within this chapter as connective to the participants’ experiences of relations of power and processes of ‘othering’ by the government.

#### ***Broken Promises: Access Denied***

Given that the CVS facilitates the citizenship of people with disabilities, the Ministry’s efforts to restrict the CVS can only be interpreted as an intentional impediment to the community engagement of PWD recipients, with provincial policy acting as the vehicle of power (Foucault, 1994). From a post-structuralist feminist perspective, the inherently problematic marriage between economic liberalism and state distributed ‘freedoms’ cultivates the perfect recipe for resistance:

A state which abuses its power in the economic realm, and more generally in the realm of political life, violates basic rights, impairs essential freedoms, and thereby forfeits its own rights. A state cannot exercise its power legitimately if it violates the freedom of individuals; it forfeits its rights ... A state which violates the basic freedoms, the essential rights of citizens, is no longer representative of its citizens. (Foucault, 2004, p. 81)

One can only call the MSDSI actions an abuse of power, in that the Ministry publicly promised to fully fund the CVS program by \$5 million in the first year, with an additional \$10 million thereafter to address the 8,000 PWD recipients who were unjustly waitlisted (Clarke, 2011, August 10). Less than a year later, the Ministry announced the legislation supporting the CVS program would be repealed. This meant that individuals who had previously been able to appeal, the Ministry's practice of wait listing CVS applicants via the Employment and Assistance Appeals Tribunal, no longer had any recourse (Legal Aid, 2011; Ministry of Social Development and Social Innovation, 2011).

Having only just been told the CVS program would receive a multimillion dollar injection of funding and to instead lose the limited administrative protection offered under the now repealed legislation, reflects Foucault's explanation of strategies of power relations:

It is the way in which one seeks to have the advantage over others ... to designate the procedures used in a situation of confrontation to deprive the opponent of his means of combat and to reduce him to giving up the struggle; it is a question, therefore, of the means destined to obtain victory ... where the objective is to act on an adversary in such a way as to render the struggle impossible for him. (Foucault, 1994, p. 346)

Foucault's explanation of dominant strategies of power relations is painfully accurate when put next to participants' accounts of the Ministry's repeal of the CVS legislation; an effort that rendered the participants' means of resistance essentially futile. As one participant explained, "the Ministry basically dropped them [people on PWD] on their ass." Other participants spoke to their feelings in reaction to the Ministry's decision to deprive participants of this opportunity for resistance:

Pissed off [when CVS was repealed]. It's the stupidest thing they could have done. They're cutting their nose to spite their face.

[When CVS was repealed] That they're a bunch of fucking assholes! But that's my opinion ...

Disgusted.

Shocked --- couldn't believe it! Wondered why they would do that, that their cancellation of the program would make it difficult, once again, for an individual to survive on social assistance, to feel a sense of dignity, worthiness, hope and self-respect.

Participants explained the precariousness of their now uncertain eligibility for the CVS as another threat:

It's ambiguous now. There's policy, but there's no legislation in place to protect us.

It complicates things enormously. There's the danger that a bad volunteer experience means the end of my participation in the CVS entirely.

As one participant explained, the removal of the CVS legislation left yet another benefit up to the capricious discretion of Ministry workers:

Well it's frustrating now because my understanding is that the legislation has been withdrawn. So there's not that support, so apparently whenever issues come up regarding the CVS, workers can make somewhat arbitrary decisions ... So that part is an ongoing problem.

Coupled with the existing fragility of participants' income *insecurity*, the Ministry's repealing of the CVS legislation served to further aggravate the participants' sense of scarcity:

Stress. Stress. It's stress. You know, stress, it's not always a bad thing, you know ... like I don't believe it is, because it motivates me ... but it's motivating me to eliminate fear instead of motivating me for something positive. You know what I mean? It's motivating me to be fearful of losing the hundred [dollars] instead of motivating me to be positive and just keep being productive. Constantly. I'm micromanaging the CVS to make sure that it's, it's gonna stay.

For these participants, the Ministry's repeal of the CVS legislation speaks to the exertion of institutional powers that perpetuate the scarcity of resources, impede active citizenship, and perpetuate the constant stressors experienced by people forced to depend on an inadequate welfare system. Layered with the existing experiences of marginalization, participants' testimony of the ways in which the Ministry intentionally impeded their citizenship constitutes "perhaps the most dangerous form of oppression. A whole category of people is expelled from useful participation in social life and thus potentially subjected to severe material deprivation" (Young, 1990, p. 53).

***When It Isn't Enough to Live, Every Cent Counts***

Another reason the CVS was of significance was because the PWD rates are so low, meaning there was already not enough to have their basic needs met. The perpetual scarcity experienced by participants made the CVS all that much more important in facilitating their engagement in their community. Furthermore, the prevalence of systemically induced scarcity serves to ‘other’ people on disability assistance, effectively reducing their capacity for formalized resistance by way of material deprivation. Such institutional efforts to render people with disabilities *disabled* in every sense of the word should be viewed as systemic othering “masked in the production of a regulatory category” (Price & Shildrick, 1999, p. 435). As one participant pointed out, “it can be difficult to properly take care of myself, with the amount of money they give me.” Another noted that, “it’s [the CVS] a welcome benefit and unfortunately there is not enough of them.”

The participants’ collective awareness of the abjectness of poverty illustrates how issues of the CVS were experienced in relation to the barriers navigated on a daily basis, and the very real and damaging effects of neoliberal policies. As one participant notes, the lived experiences of people on disability assistance often means just trying to meet basic needs instead of achieving any kind of growth:

People can’t improve themselves or try to grow when they are going without food, proper clothing, transportation, everything. It makes the difference between thriving instead of surviving.

Participants spoke to the repeal of the CVS as yet another gap in an already severe reality of compounded deficiency within disability benefits:

Even with the volunteer subsidy ... it’s still not enough.

For me, it’s [the CVS] covering the fact that I don’t have enough money to take care of myself in the first place.

When I had to apply for PWD status, I was on social assistance and had to take meal supplements because the social assistance cheque was only \$485 a month. It was difficult to pay the bills (rent, phone bill, buy groceries, personal items, clothes, etc.) on that amount of money each month.

The familiarity of severe poverty for all of the participants interviewed was unfortunately all too real. The ways in which each of the participants described just truly how unobtainable basic needs are when surviving on PWD assistance offered insight into the realities of the systemic, othering consequences of oppressive social policies.

Though modest in amount, the additional funds the CVS provided to facilitate volunteerism also contributed to the participants' overall wellness. Participants noted that every cent assisted with covering the unreachable costs of the most basic needs, such as food and shelter:

When I was first only getting \$485 per month. I lost so much weight. The doctor gave me a letter saying I needed the nutritional supplement ... the doctor was really just trying to help me survive.

You're [the Ministry] doing the bare minimum to keep me barely alive. And functioning. The forty dollars in vitamin supplements I get to barely cover the vitamins that I buy ... It's not enough to buy the food.

The constant sense of never having enough was present amongst all participants. Participants expressed frustration over struggling to stretch every dollar, and then to have the Ministry reduce or restrict their eligibility for what few benefits actually helped increase their quality of life. As one participant explains, the restrictive nature of many of the Ministry's processes leaves many individuals to fall between the cracks:

They deny a lot of things ... I think that the problem is that the issues around disabilities are too concrete ... You have to fit into a box of five different symptoms ... so there's five criteria that you have to fit into [to be eligible for a monthly nutritional supplement] and I think those five criteria are too strict and too boxed in, because people's disabilities affect them in different ways and it should be a little broader, a little more flexible.

Restrictive gate-keeping efforts not only make Ministry benefits inaccessible; for many clients, the time spent navigating an appeal results in going without necessary supplements or supports throughout the duration of the often lengthy appeals process. Often, participants are seeking funds for desperately needed items, such as an emergency crisis grant or monthly nutritional supplement. Participants noted the overall sense of luck, rather than right, in relation to receiving their most basic needs. Seeking support for these basic needs are, as one participant aptly describes, a "hopeful gamble" considering Ministry processes; and luxuries, such as having disposable income to participate in social activities, are not even a realistic option. Participants' experiences highlighted here are not unique. As Raphael (2007) notes, "social activities in which low-income people reported not being involved were going out to restaurants, holding dinner parties, attending events with friends, inviting friends over, going out on dates, attending dances, going out for coffee, and buying gifts." (p. 153) Participants expressed that people on disability

assistance do not have enough money for their most basic needs, let alone preventative measures like accessing social supports. As one participant explains, “we don’t have the money to be social.”

Participants talked about sacrificing additional aspects of health and wellness, such as foregoing important mental health services because they could not afford the costs that the Ministry’s health coverage did not provide. Systemic othering by way of denying mental health-related supports serves as powerful vehicle from which to deny rights amongst the margins. As one participant stated, when their needs exceeded free community counselling services, the Ministry said that they would not be able to access the specialized mental health services they desperately needed because the additional expense was not considered a necessity:

A well-qualified counsellor, that’s over a hundred dollars an hour. The Ministry wouldn’t even cover that. That’s not even available to me ... It’s kind of crazy making in itself.

The deep and long term poverty in which people with disabilities must survive becomes a cyclical influence on worsening mental health symptoms. For individuals with complex mental health needs, accessing the necessary professional treatment needed becomes yet another addition to the list of things people on PWD are forced to consider a luxury. Roughly 70% of people with mental health related disabilities in Canada are dependent on social assistance (Canadian Mental Health Association, 2009). Coupled with the fact that there is an alarming and complex relationship between poverty and incidences of mental health symptoms (CMHA, 2009), the prevalence of barriers to suitable mental health services should be of significant concern for both health and social policy stakeholders.

Other participants noted that, because PWD rates are so low, rising costs of food, shelter and clothing, are a source of constant anxiety for people living in poverty, fearful of the smallest increase to their cost of living:

The costs of everything goes up every day, every year, every month, every moment.

They’ve [the landlord] also been raising the rent now ... And part of me feels like okay, yeah we’re living on enough now, but what happens when it gets past this point? Like we either don’t pay the rent and we eat, or we just pay the rent and we don’t eat at all.

When people on disability assistance live in significant poverty, they are forced to continuously focus on survival (Raphael, 2007; Wallace, Klein, & Reitsma-Street, 2006). The constant stress and anxiety of struggling to survive, balancing ever-increasing costs with personal health needs, treatment, or other attempts at preventative care (BC Coalition of People with Disabilities, 2007; BC Public Interest Advocacy Centre, 2005; Raphael, 2007) are further compounded by the Ministry's perspective on their poverty. The Ministry's perceived attitude will be explored later in this chapter. Here it is important to note the participants' pairing of their experiences of low income and the Ministry's lack of empathy, as one participant explained, served to further pour "salt on an open wound." Participants expressed that the impact of the Ministry's repeal of the CVS was worsened by their awareness of the Ministry's disconnected position of privilege:

I think they [the Ministry] could, well ... I think they could take a break from their regular lives and try and live on the amount of money that we live on from the day we get paid, to the time our money starts to run out. And then try and wait on canned food or have to go to the food bank and see what that's like.

Maybe they [the Ministry workers] need to stand in line at the food bank for hours patiently and have them give you only one bag of food ... but I'd like them to take that experience ... and see what it's like to feel that worthlessness and that emptiness for a while.

The disconnect participants note between the Ministry's reality and their own demonstrates a systemic othering through lived reality. Moreover, the continual denial to recognize the experiential knowledges of people with disabilities within the delivery of disability policy serves to further subjugate the knowledges of 'others'.

Participant testimony not only demonstrates the severity of poverty experienced by people living on PWD assistance in British Columbia, but also highlights how impactful withheld benefits truly are when there is never enough:

It's really tiring you know. Like when you're poor, and you already have things that you have to take care of. For me, it's a hustle every day. I thought I was out of that life, but really I still do the kinda hustle dance every day to maintain and to thrive and to support my family ... There is not enough money to live on. The things in life keep going up. The cost of living goes up. But the money that comes *in* doesn't go up. So it's really frustrating. And it's hard.

Throughout the participants' narratives, the effects of systematic othering of people with disabilities living in poverty is apparent in the presence of "exhaustion, depression and despair, anger and frustration, stress, thoughts of death, challenges to self-esteem and isolation" (Raphael,

2007, p. 151). As demonstrated in Chapter Two, such impacts are characteristic of the effects of navigating disability policy in British Columbia, particularly for individuals who further intersect with the feminization, colonization, and racialization of poverty.

As the Caledon Institute of Social Policy report notes, the PWD rates fall well below the poverty line regardless of which measure is used (Tweddle, Battle, & Torjman, 2014). When the normalized existence of abject poverty is viewed within the context of justice, the participants' accounts of deprivation command change:

Justice in modern industrial societies requires a societal commitment to meeting the basic needs of all persons whether or not they contribute to the social product. If persons suffer material deprivation of basic needs for food, shelter, health care, and so on, then they cannot pursue lives of satisfying work, social participation, and expression. (Young, 1990, p. 91)

The annual income of a single person on disability assistance in British Columbia amounts to a meager \$11,470, falling 58% or \$8,304 below the Low Income Cutoff (LICO) poverty line (Tweddle, Battle, & Torjman, 2014, p. 52). If the Market Measure Basket (MBM) is used, single persons on disability assistance in Vancouver, British Columbia will find their income to be only 60% of the MBM or \$7,634 short of the poverty line (Tweddle, Battle, & Torjman, 2014, p. 56). Looking at the average, after-tax incomes of the population of British Columbia shows that PWD rates are only 38% of the province's average income (Tweddle, Battle, & Torjman, 2014, p. 61). What can be concluded from these varied measures is that no matter the means of assessing PWD rates, people on disability assistance in British Columbia consistently live severely below the poverty line. With this in mind, the reduction or removal of what few benefits participants have left becomes all that much more significant. Participants' experiences highlight the various ways in which they are subject to systemic 'othering' at the hands of the Ministry by way of the neoliberal gate-keeping of individuals' access to benefits coupled with normalized abject poverty.

### ***Hypocritically Inaccessible***

The Ministry of Social Development and Social Innovation's purpose, as claimed by their most recent Service Plan, aims to provide "British Columbians in need with a system of supports to help them achieve their social and economic independence and secure a better tomorrow as

envisioned in the BC Strategic Plan” (Ministry of Social Development and Social Innovation, 2016b, p. 5). However, participants’ narratives starkly contrast the MSDSI’s proclaimed aims. Experiences of being wait listed for the CVS, and then later finding the legislation repealed, was unfortunately all too reflective of the overall inaccessibility of the Ministry. Unfortunately, the participants’ experiences of systemic inaccessibility are not contradictory to other PWD recipients’ experiences in that: “The social assistance system is frequently organized in such a way as to make receipt of assistance at best difficult, and at worse, degrading and humiliating” (Raphael, 2007, p. 194).

The deeply entrenched neoliberal ideologies present within provincial disability policies blames the poverty experienced on individuals on disability assistance, which serves to continually amplify the issues of access experienced by PWD recipients (BC Public Interest Advocacy Centre, 2015; Little & Marks, 2006; Raphael, 2007). Because the neoliberal gate-keeping efforts focus on the responsabilization (Teghtsoonian, 2009) and self-sufficiency of people with disabilities, rather than the quality of support experienced, complaints about barriers to access are often left unresolved (BC Public Interest Advocacy Centre, 2015; The Office of the Ombudsperson, 2009; 2014; Wallace, Klein, & Reitsma-Street, 2006).

Understanding systemic inaccessibility as a form of structural violence in the power relations (Foucault, 1994; Galtung, 1969; Young, 1990) of income assistance, highlights how the Ministry remains an impediment, rather than a support, in the lives of people with disabilities. People with disabilities and income assistance recipients talk about barriers in accessing services, either in person or on the telephone, receiving discriminatory treatment when accessing benefits, or being mishandled by security guards (The Office of the Ombudsperson, 2009; 2014). The complexity of the intersections of structuralized violence can be noted in numerous complaints to the Ombudsperson, where people on Income Assistance and PWD Assistance confirm,

The current service delivery scheme at the Ministry is ‘unjust, oppressive and improperly discriminatory ...’ The service delivery scheme is also discriminatory on the grounds of place of origin and race due to failures to properly implement the Ministry’s language interpretation policy, resulting in those who cannot communicate in English being shut out of receiving some Ministry services. (BC Public Interest Advocacy Centre, 2015, p. 40)

The participants’ awareness of the perceived inevitability of inaccessible services, their continuous perspectives of skepticism, and their accounts of the numerous barriers experienced

in accessing the Ministry highlight these power imbalances. Ways in which the Ministry remains a systemic force of structuralized violence are present in the following narratives by participants:

It's just hard to imagine things substantially better. It's just hard for my imagination to go there. These days, when you're dealing with the Ministry it's like they're in complete chaos because there's times when ... there's no guarantee that when you fax a document to them it will actually arrive. And even then, who knows where it will go ... Oh yeah, lots of crazy unpredictable things happen at the Ministry.

I don't know if they think that we don't have anything to do that we can just sit in the office and wait. It makes me really nervous when I go in there and there's always arguments. I try not to go in there.

Participants spoke of numerous issues of access that created significant barriers in seeking benefits or supports. The amount of time spent trying to get through to the Ministry's phone lines, as one participant noted, resulted in significant financial cost:

I've had bad instances with them [the Ministry] ... I had a cell phone at the time and I used all my minutes and stuff and had like an eighty-dollar bill just from dealing with welfare and being on hold forever.

In addition to waiting on the telephone to get through to Ministry staff, participants mentioned issues with how the Ministry requested contact from clients. As one participant indicates, sometimes the Ministry requested clients' attention through unusual, and often punitive, means:

One weird experience I've had, so say a worker wants to talk to you about something ... So instead of contacting me directly, they just didn't send me my cheque to force me to come in. Which is a very difficult situation because somebody might starve for a few days waiting because of that. I mean, that's just so cruel.

The same participant explains that by the time they figured out the Ministry expected them to go into the office, they would then experience significant delays in access:

And of course, when you visit the office you might end up waiting several hours. And then you might get kicked out. Come back the next day.

As I probed further into these issues of inaccessibility, I found that many participants suffered as a result of receiving contradictory or incorrect information:

I asked them a long time ago, can I get direct deposit or can you pay direct to my rent. They said we don't do that ... For five years, every month, it was a money order to go to my landlord and it was six dollars and fifty cents and then

I heard somebody say, yeah they can do that. So I call them up and they just say, yeah we can do that. Five years at six fifty a month!

Participants also identified that the Ministry's standards of accountability are more rigorously applied to PWD recipients than to the Ministry itself. One participant cites a haphazard attempt at accountability when a province wide violation of PWD recipients' privacy occurred:

They actually had a breach of privacy and it was in the papers ... Then they just kind of sent me a form letter with my cheque saying that, to call this number because there might be a breach of privacy ... And I couldn't phone because I was ill at the time.

Participants talked about ongoing issues in accessing the Ministry, and in having their time or personal information respected. The varied and numerous ways that participants spoke of the Ministry's overall inaccessibility was significant in this research in that it highlights how difficult it is for people on disability assistance to access the very system that claims to help them. Understanding the prevailing inaccessibility described by participants gives further context to the participants' previously cited waves of emotions, anxiety, and frustration. Coupled with the removal of the protection afforded to participants via legislated eligibility requirements, the Ministry's inaccessibility is yet another example of the inequitable power relations and experiences of othering experienced by people on PWD.

Within this understanding of the exclusion of people with disabilities from particular spaces, in this case volunteerism, through the direct and intentional denial of supports relating to active citizenship, the right to determine one's own narrative around health and illness becomes a desperate necessity.

### ***CVS and the Right to Be Ill***

Participants talked about how the ways in which they experienced illness as being suddenly burdened with the feared potential for institutional reprimand; being ill, or experiencing an increase in health symptoms meant that they would miss volunteering, threatening their eligibility for the CVS. Once the legislation supporting the CVS was repealed, those still in receipt of the benefit had no security afforded by legislated eligibility criterion. Those "grandfathered" into the CVS program had to adhere to volunteering a minimum of ten hours per month, as outlined in the Ministry's CVS program policy for fear of losing this important

benefit. As previously explained in Chapter Two, when the CVS legislation was repealed, those remaining recipients were left with no ability to appeal. In this way, surviving CVS recipients were left to the mercy of MSDSI staff to apply the sparsely remaining policy over any arising issues of eligibility. As such, the Ministry effectively created a process of othering by way of policy interpretation; participants were further ‘othered’ as a result of the systemic constructions of health and illness.

The right to be ill then becomes a contested space where one’s body is situated as a ticking time bomb where wellness is reinforced, yet again, as the ideal:

There have been a couple times in the past year where I’ve been ailing and so I had to not volunteer as much, so there’s the risk that I could just lose it ... for that reason.

Participants’ awareness of the potential economic consequences of illness were all too present in their narratives:

I did know somebody with [same health condition] that had to quit [volunteering] and got off the subsidy, and then she couldn’t get back on. So I think maybe if you quit and you’re ill, that’s another question.

I have to make sure that I’m, I’m making, keeping the records right of my days and my times, and I’m always ... I always have a worry in the back of my head that they’re gonna come up with like ‘well you were sick on that day.’ Like I always have a fear of making up the hours.

Participants expressed ongoing anxiety surrounding their symptoms potentially impacting their ability to volunteer for a minimum of ten hours per month. The threat of experiencing a denial of the CVS, one of the limited benefits that serve to facilitate active citizenship, was a great source of stress for the participants interviewed in this research. Many noted there should be a legitimate space for illness within the administration of the CVS:

If I got kicked off, I’d have to force myself to work, but then I’d probably get ill. But I’ve tried ... But I would get ill.

If you are ill [and work], you get maternity leave or sick leave ... It should just be like, if you’re ill, you’re ill.

Participants, without the protection of the CVS legislation, are subject to the Ministry’s often inconsistent application of the CVS program’s policy. If participants failed to volunteer for the

minimum ten hours per month, as per the provincial policy, they risked losing their CVS permanently (Ministry of Social Development and Social Innovation, 2016a).

By pairing the CVS eligibility of people with disabilities to the ideal of wellness, the Ministry has constructed ableist eligibility criterion, reinforcing the fact that “power, prestige, and privilege ... are distributed based on prevailing notions of ability and normalcy, thus downgrading the status of persons with disabilities” (Prince, 2009, p. 71). In this way, participants dreaded that any exacerbation of symptoms would impact their ability to volunteer for a minimum of ten hours per month. Such a pairing of health and eligibility constitutes a severe power imbalance between people with disabilities and the Ministry, steeped within ableist, biopolitical policing. Situating access to citizenship within one’s ability to be *well* serves to prioritize the able body, reinforcing the construction of the body as a site for singular economic production (Foucault, 1994; 2004).

From a feminist post-structuralist perspective of disability, such a pairing of eligibility and wellness further serves to politicize the body as a site of resistance (Butler, 1990). Participants felt more anxious about being denied eligibility for the CVS if their illness or symptoms were the result of what are commonly known as invisible disabilities, such as fibromyalgia or depression. As one participant notes, “the doctor won’t give you a note for what he can’t see. So if you have depression or something like that, good luck.” People with disabilities, particularly those with invisible disabilities should be acknowledged as the experts of their own experiences. When constructions of illness are externally imposed upon the concept of disablement as measured and enforced by the Ministry and other institutions, people with disabilities are further subjugated in that they are denied authorship over their own experience of disablement (Foucault, 1994). People with disabilities are then further confined within a constructed experience of the “other” and denied the agency within which to construct their own narratives around needs, ability, and disability.

### ***Disability and Stigma***

Participants talked about how the stigmatized ‘othering’ experienced at the hands of the Ministry was often layered with experiences of stigmatization they encountered in their daily lives: being devalued, suspected and blamed, and also excluded. Whether they were navigating health care systems, the community, social encounters, or the like, participants each identified

different and varied experiences of stigmatization as a result of their disabilities. The participants cited that the CVS was important partially because it afforded them the opportunity to *push back* against the stigmatized histories and offer a counter narrative. As one participant explained, “I was contributing to society by volunteering for an organization that meant a lot to me.”

The stigma experienced by participants was impactful in several ways. One participant explained, as a result of having invisible disabilities, “I don’t have a lot of friends.” Participants spoke of the emotional cost they experienced when they were subject to ableist attitudes. Participants often linked experiences in accessing disability assistance to the ableism of society as a whole, coupling their experiences of cumulative stigmatization in society to the Ministry’s systematic ‘othering,’ as a theme within this research. As one participant comments,

I don’t think anyone wants to be in a position where they are in need of social assistance and especially not disability assistance. Being a person with a disability or on social assistance is very stigmatized and many people are too proud or afraid to ask for help.

Within participant narratives, numerous accounts of experiences of ableism, discrimination, and systematic exclusion were presented. What follows are key examples of the ways in which the participants’ experience stigmatization in everyday encounters in an ableist society:

It is so difficult, draining, and demeaning to apply for disability assistance --- throughout the entire process you are objectified and feel disempowered --- as if you are at the mercy of the state ... and, in most cases, you are. [And] you already are dealing with so much.

To have to stand in line, talk to strangers, share private, sensitive information about yourself, try to think clearly, have all the information that MSD[SI] requires and advocate for your needs can be overwhelming, humiliating, traumatizing, frustrating, and draining.

Participants talked about how, being subject to the Ministry’s guidelines and documentation demands, they often felt disempowered. The Ministry’s eligibility requirements often meant that for participants to appeal Ministry denials or simply maintain their existing benefits, they were forced to repeatedly ask for documentation from their physicians, volunteer agencies, or other spaces occupied in the community. When resistance is tied so vehemently to documentation, people on disability assistance are forced to be the ‘documented’ subject, rather than the author, over their own health conditions. In this way, people on PWD are structurally made submissive within the power relationships they encounter as the very system claiming to support their

independence situates them as *dependent* on the systems and services they access. These systems and services then exercise power to document the very existence of PWD recipients as enough; that is to say, as disabled enough, as ill enough.

As people with disabilities on provincial PWD benefits, participants explained how they are dependent on the medical system to ‘legitimate’ their experiences of illness. Whether it be the need for medical professionals to document symptoms for the initial PWD application, nutritional or assistive needs, or to relating to an appeal, people on PWD assistance are constantly forced to depend on the medical system to document their existence (Wallace, 2009). In this way, the accountability processes of the Ministry served to ‘other’ people with disabilities as they sought to foster relationships with their medical supports. Participants expressed how strained these experiences were, particularly when medical professionals embodied some of the ableist attitudes that serve to disenfranchise people with disabilities:

They need to understand how hard it is to get on disability assistance, how nervous people are to go to their doctors.

My initial doctor ... didn’t believe the severity ... Another doctor treated me as if I was invisible, not worthy of being treated as an equal patient.

I had a hard time finding people or dentists who take our disability claims for some reason. A lot of people don’t take it. So I had to phone around forever to find a good dentist that understood everything.

One participant explained that they were severely impacted by the overall process of having their health conditions under administrative scrutiny when applying for PWD designation:

When I was applying for PWD, the process was so overwhelming and extremely triggering. Having to talk about all of the personal reasons and parts of my history ... that caused me to need PWD, the whole process just made me shut down. It physically hurt. I needed help to apply and get through that whole process.

For individuals with invisible disabilities, the experiences of being scrutinized by both the Ministry and the medical system can be exhausting:

The stigma I experienced while trying to differentiate between mental illness and mental injury was so strong, at times it was overwhelming.

A lot of people don’t understand mental illness, if it’s not visual, if you’re not in a wheelchair, people can’t see that.

Another participant, a person with a mental health condition, demanded equitable treatment:

Make us feel like valid citizens ... compared to the people that don't have mental illness.

Participants explained that it was not only the public scrutiny that often took its toll, but the assumption that they were satisfied with being excluded from many of the ableist means of cultivating an identity in a neoliberal society. In a society that values the economic functionality of one's body above all else, issues of poverty and access are often reframed to be the consequence of personal deficits, rather than societal barriers. The prevalence of the personalization of poverty can be considered a significant contributor to much of the stigma experienced by people with disabilities:

In addition to the burdens of living with material and social deprivation---and the stresses associated with these---people living in poverty must deal with the reality that others frequently blame them for their own situation. The belief that poverty is a result of moral failures on the part of those experiencing it can become internalized as feelings of guilt, shame, and failure. The experience of stigma adds to the profound issues that people in poverty must live with. (Raphael, 2007, p. 166)

One participant spoke in further detail as to the frustration they felt over having others assume they were happy not to work, when in fact they craved an opportunity to engage in employment:

It's very frustrating and it's very confusing [not being able to work]. Because I would like to be able to go and get an extra job and I would like to feel like I'm doing more with my life other than just secluding myself to my apartment.

Another explained, "How do you find a spot in society when you're in this situation?" The diminished respect experienced by participants as a result of their disabilities were numerous. Participants resented the ways in which they encountered ableism in their daily lives, and expressed a need for greater empathy from society as a whole:

You don't always necessarily get the most respect due to your looks or due to your abilities ... Sometimes people give me these really degrading looks and then they just attack you.

I'm risking my self-esteem, my ability to cope around other people ... it makes me feel like the biggest loser in the world and when people start attacking you for not being able to function as fast as they function. And one person actually started screaming at me.

The cost of asserting oneself as a person with disabilities in resistance to this stigma experienced was felt to be personally taxing, but absolutely necessary. As one participant explains,

You have to retain your dignity in order to demand respect from other people you must hold your position strong ... When you don't stand up for yourself, you feel walked all over your whole life. It causes you a lot of pain.

Participants identified that, as a result of their cumulative experiences of 'othering' in our ableist society, respect became that much more important to them. One participant notes,

Respect is a big deal to me because I've been disrespected from grade one all the way through.

Another participant identified that the community of people on disability assistance experience the ableist stigma in solidarity, in that they tried to draw on their community's collective strength to resist:

Someone got killed in front of the disability [office] ... And they [the Ministry] didn't even care, so all the homeless people and disabled people got together and protested for that person's acknowledgement.

One participant spoke powerfully about their desire to fight for existence:

It's like during that, when women had the revolution and the burning of the bras, when Black people were fighting for their rights, everybody was fighting for the same thing: freedom of being allowed to exist ... You're doing the same thing ... Trying to fight for our right to exist.

Participants spoke of the consistent stigmatization of disabilities, the absence of value for the ways in which they evoked strength, navigated symptoms, or exercised collective resistance. The absence of such experiences from social policy constitutes the systemic erasure of people with disabilities' lived experiences of disablement. In this way, the narrative of people with disabilities becomes *othered* through disability policy.

Participant experiences inherently reinforce the troubling reality that is embodied within our neoliberal, patriarchal society; institutional powers and the reinforcing dominant discourse continues to prioritize the white, able-bodied male as superior while all else are left amongst the margins (Young, 1990). As the participants identified, the Ministry constitutes but one of many means of marginalization for people with disabilities, which are further complicated by intersectional experiences of oppression. As Prince (2009) argues,

As a social group, persons with disabilities in Canada, are more likely to be marginalized than non-disabled Canadians; and there are consistent patterns of marginalization in the form of under-representation in employment, mass media, or political office or the over-representation of the disabled in welfare, non-standard work, and institutions. A critical need exists for improved and enhanced supports and services. Today, services and supports are fragmented, often unavailable or unaffordable, not portable across life transitions or place, and all too often disempowering or stigmatizing to those seeking a modicum of assistance to live in dignity and to be active citizens. (p. 212)

In this sense, the *other*, as exerted onto the bodies of people with disabilities, perpetuates an absence of the existence of rights, services, supports, and denies dignity, citizenship, and autonomy within the many spaces encountered by people with disabilities. The prevalence of stigmatization, as experienced by participants within this research, speaks to a need to further examine the ways in which power relations, discrimination, and systemic othering serve to further marginalize people with disabilities.

### ***Paternalistic Policing, Criminalized Poverty***

There has been a long standing history of paternalistic policing of people living on assistance in Canada, which is further reinforced by punitive policy measures and neoliberal perspectives highlighted within public discourse (Chunn & Gavigan, 2004; Glasbeek, 2006; Raphael, 2007; Swanson, 2001). The impact of such poor bashing is illustrated in the following participants' narratives:

It's not fair to keep me on such a low level of poverty when I'm doing my *damndest* to fucking get above and on top and be a striving, thriving part of the community. I don't get why the poor always have to be accountable for every fucking dollar we have.

I can't do mathematics. And they [the Ministry] said, 'Well if you can't do mathematics, what are you going to do with the money we give you? How are you going to take care of it, how are you going to monitor it?'

And yet they [the Ministry] have the right to say no, yes, no, yes, and *here's your allowance!* Almost like somebody saying, 'Here dance monkey dance!'

Participants experiences of an assumed identity of incompetence presents as challenging, yet comes as no surprise in comparison to the rhetoric enforced within fraud prevention policies. As one participant expressed, they were constantly resisting the Ministry's assumption of

incompetence as a result of their disability, “I’m very responsible in the first place!” Participants strongly identified the need for programs such as the CVS in that such policies gave space for an alternate narrative, one that recognized the value of civic contributions made by people with disabilities. By denying people with disabilities the right to have their contributions acknowledged, the Ministry effectively ‘othered’ participants as an ineffective cog in the capitalist machine. Additional effects were identified by participants as a result of being discounted with a neoliberal society. Participants advocated that their experiences of being recognized as contributors through social policy were made that much more important as such discourse served to contradict the consistently “heightened state presence which condemns and punishes the poor” (Chunn & Gavigan, 2004, p. 231). As the assumed-criminality of PWD and welfare recipients is perpetuated within policy, Foucault’s (1994) theories relating to power and the construction of truth are relevant in analyzing the ways in which institutional powers construct a narrative of the *never-deserving*:

This form of power that applies itself to immediate everyday life categorizes the individual, marks him by his own individuality, attaches him to his own identity, imposes a law of truth on him that he must recognize and others have to recognize in him. It is a form of power that makes individuals subjects ... subject to someone else by control and dependence, and tied to his own identity by a conscience or self-knowledge ... a form of power that subjugates and makes subject to. (p. 331)

In this way, people on disability assistance in the province of British Columbia are subject to power relations that result in a constructed narrative of assumed criminality, reinforced by programmatic surveillance efforts.

Moreover, participants explain how people on assistance are also subject to experiences of policed motherhood:

It’s just so ... demeaning is what it is. I mean, I asked for an emergency crisis food grant of forty dollars and was told that I’m a bad parent ... I cut the conversation short and I said, ‘I’m over 50, I don’t need to have a conversation with you, a man, whether I’m a good parent or not. So don’t give me the \$20 and I hope you sleep at night.

I don’t need to have somebody questioning my parenting ability.

They want to know why I am making those choices, and, but who are they to be asking me why I am making that choice ... that’s just demeaning and it’s unacceptable. It’s very unacceptable. And it’s really unprofessional.

Such testimony is not uncommon. Motherhood, amongst others, are but one of the many spaces where women experience gendered discrimination at the hands of ableist, institutional powers:

The capital required to establish credibility as a lover or parent requires the kind of physical ‘authenticity’ denied to disabled people by ableist norms and practices, assumptions about the kind of ‘clean and proper’ body ... that is a prerequisite for friendship, parenting and love and even everyday forms of social interaction. (Loja et al., 2013, p. 196)

Women have spoken out in many different spaces as to the paternalistic, often cruel experiences they have had in accessing provincial benefits (Chouinard, 2010; Reid, 2009; Strega et al., 2002; Teghtsoonian, 2003; Townson, 2000). Experiences of monitored motherhood are ever-present for Aboriginal women and women of colour. Numerous policies are aimed at policing the reproductive rights of marginalized women; policies that serve to scrutinize racialized motherhood, and other colonialist measures that prioritize able-bodied whiteness as the ultimate precursor of parenthood (Bannerji, 2000; Baxter, 1995; Raphael, 2007; Teghtsoonian, 2003; Thobani, 2007).

The experiences outlined by participants within this research echo similar occurrences of gendered and ableist oppression, in that accessing assistance will inevitably be dependent on the Ministry’s judgment of PWD recipients’ illness, parenthood, or innocence. One participant noted that, “you’re always kind of living under this fear umbrella.” Others spoke to the discriminatory assumption that anyone on disability assistance is manipulating the system dishonestly:

They think that people take advantage of everything that they give people ... Because ‘everybody scams welfare,’ which is such a fallacy, right?

It’s a lousy perception, but it’s a reality for a lot of people. It’s a reality for the government to think that people are scamming. I mean, people are scamming that are in the government you know. And they’re trying to put it off on the poor people.

Scrutiny of people with disabilities on PWD assistance is not unique. The assumed criminality of people receiving provincial assistance is prevalent within dominant political and public discourses:

The normative character of the ‘crime’ of welfare fraud is also revealed by the disparities that exist between welfare fraud regulation and other forms of economic misconduct. In almost every respect ‘tax evasion’ and ‘employee standards violations’ ... are viewed in a much less punitive and severe light in

terms of the moral culpability attached to the conduct, the range of detection and enforcement tools utilized and the penalties that follow up conviction. (Raphael, 2007, p. 323)

One participant clearly articulates the hypocrisy experienced by those living in poverty receiving assistance as a classist, ableist experience:

It's sad that we as a society who are *receiving* have to be accountable, and, and we have to always be prepared to be audited. We have to be prepared to keep all of our filing ok, because at any time somebody could say, 'Ok we're putting you under review for the CVS.' Which they do! The CVS is constantly monitored.

Another participant explained they are subject to greater scrutiny for their meager monthly benefits than many politicians must endure:

It's demeaning being on a system that you have to ask for everything and you have to account for things. Whereas, we're just now coming to a point where the government is ... the MLA's are saying, 'I guess we shouldn't have \$61 a day for lunch.' Jesus do you know what I could do with \$61 a day?!

Participants' awareness of people with disabilities being forced to be more accountable than the governmental leaders who oversee the administration of PWD benefits illuminates but one of the many hypocrisies embodied by social welfare policies.

Participants were extremely cognizant of the various ways in which the Ministry scrutinized them as PWD recipients. They talked about feeling frustrated with the level of surveillance they had to endure in order to access benefits. One participant noted, "it is certainly a drag being policed." Some of the participants explained that the monitoring they experienced felt personal, and seemed to embody a particular attitude or judgment against people with disabilities. According to one of the participants interviewed, the discriminatory attitude they experienced when accessing the Ministry felt unwarranted and insulting:

It's just demeaning. I think that, in my position, in my experience, I know what I'm doing. And I don't think that someone sitting behind a desk with a piece of paper with my name on it knows *anything* about me, knows anything about my journey, and has no right to make a decision on whether or not I deserve an extra dollar or I don't deserve an extra dollar.

Other participants echoed similar frustrations at the constant experience of judgment, restricted autonomy, and helplessness experienced when accessing benefits from the Ministry:

You're not in control of your life. You don't have any say. And if you have a say, you have to appeal it. Or you have to deny it. Or you have to *repeal* it. Or you have to convince. You know, like, you're always on guard.

Well someone else is in control of my money. Someone can tell me, 'No, you're not getting it.'

Awareness of the ongoing surveillance they were subjected to as a result of being a person reliant on disability assistance led to a heightened sense of being on guard. One participant explains the anxiety they experienced simply from seeing the Ministry logo on a letter in their mailbox:

As soon as you see a letter in your mailbox that's got the stamp 'Ministry' on it, you're just like 'Oh my god, what can it be?' It's just such a fear, all the time, of doing the wrong thing, under *their* ideas, not yours.

Having been unjustly wait listed for the CVS, only to later have their legislated protection repealed, participants were extremely cautious of the Ministry:

My heart pounds every time I talk to them. I'm very nervous to talk to them ...  
Having been kicked off the subsidy.

Participants perceived the security staff as an extension of the Ministry. Participants not only experienced scrutiny by the Ministry workers, but also by the security staff at the Ministry office. As one participant explains, she felt targeted because of their appearance as an Aboriginal woman with disabilities whenever she went to the Ministry office:

The security guards watch me like a hawk. They think I'm going to act out or do something just simply because of how I look.

The participants spoke of being treated roughly by the Ministry's security guards, an issue that should be considered troubling when the various conditions and experiences of people on PWD assistance are taken into consideration. The compounded experiences of discrimination, sexism, trauma, and other issues make unwanted physical contact all the more triggering. One participant elaborates on their negative experiences of interacting with the security staff at the Ministry office:

I said, 'Why don't you guys [the security guards] just do your thing and just acknowledge that I'm here ... just leave me alone. I'm not bothering you. I didn't start a fight with you ... And you're telling me to leave. I don't get it. And obviously you guys don't either. No one's telling you to leave. Right. Because you have a job here and you're being paid and I'm not ...

As the participant attempted to explain their intentions were anything but disruptive, the security guards still refused to accept the participant's explanation:

I told them that, that I'm not out to harm anybody. I'm just waiting for the offices to open so I can go upstairs and drop off paperwork that I need to get figured out. And they were really intent on wanting to tell me to leave or physically move me. So, I just held onto the railing and I said, 'Make me.'

Despite best efforts to avoid conflict with the security guards and simply see a Ministry worker, this participant was physically removed from the vicinity. In this way, the participant explains, they tried to exercise a non-violent form of resistance to the security guards' actions, however this resistance was not respected. The participant recalls trying to protest the security guards' physical approach:

You guys [Ministry security guards] also have no right to physically put your hands on me.

These efforts did not help; this participant was forced to leave and had to return the next day.

All of the participants interviewed expressed a frustration with having their existence acknowledged while the Ministry's abuses of power were simultaneously discounted. One of the most challenging aspects of being mistreated by the Ministry was that there was little hope of being able to share their concerns or improve the system. Participants talked about their experiences of being silenced by the Ministry:

There's no opportunity for real dialogue. I don't know what they think they're doing; it's not clear to me what Ministry workers think the effect they're having on us. There's no real way of letting them know. The Ministry's not set up to take that in.

That's the Ministry. If it's something that they really feel isn't appropriate, they don't feel ... it's suddenly not in their jurisdiction.

Another participant explained that the paternalistic attitudes of the Ministry workers often left them feeling like a burden:

It was so frustrating with the Ministry, as I always have the expectation of being denied first, expecting to have to fill out form after form, of being a number instead of a person. Feeling like I'm a huge burden to them, that we all are. You start to forget that they are actually getting paid to do their jobs. They make you feel like they are giving you money from their personal bank account.

As the interview with each participant progressed, I realized that the issue of poor policing and paternalistic attitudes were significant for the participants. Participants felt strongly that the Ministry was extremely hypocritical. The Ministry would assume participants were ‘scamming the system’ and rigorously scrutinized their actions, yet the Ministry denied them funds to contribute to their communities, efforts that facilitated an important counter-narrative.

Participants perceived the Ministry as having no sympathy for people living on disability assistance. One participant explained, “there’s nothing, when you’re dealing with a Ministry worker, to indicate that they’re interested or care that you’re being treated well or not.” Another participant’s testimony speaks to how the systematic policing is worsened by the Ministry’s lack of awareness of the participants’ experiences:

It’s really demeaning and frustrating. And I think that if any Ministry worker had to go through *anything* that *anybody* on welfare had to go through, they wouldn’t last five minutes.

Not unlike other testimonies of people with disabilities living in poverty (Baxter, 1995; Raphael, 2007), the participants explained their overall experiences of the cumulative effects of being policed, disrespected, and disregarded:

It’s always hard dealing with an organization where the underlying tone is one of disrespect. I don’t know what they think their tone is, but I experience it as disrespect.

I just wish the Ministry would look at people as human beings and I wish that policies were created with human beings in mind ... [pauses] I wish the reality of our lives was a little more apparent to them.

The collective experiences of frustration, exhaustion, and efforts of resistance speak to the unjust treatment of low income people with disabilities. The participants identified an increase in frustration over the ways in which the Ministry made assumptions about their capacity to contribute to society, as well as their accountability. The irony of being assumed guilty for welfare fraud, yet also being denied the CVS to contribute volunteer hours to their community was not lost on participants in this study.

Foucault (1994) speaks to the ways in which institutional power relations serve to create and perpetuate truths about people or groups as a means of subjectification; in that the people or group are *subject* to the consequences of the constructed truths as much as they are *subjected* to them. In this way, the Ministry can be understood to be an agent of power that serves to

perpetuate and reinforce the constructed truth of people with disabilities as deficits; requiring paternalistic management because they are assumed to be consistently out to ‘scam the system.’ The cruel reality of this fallacy is that people dependent on PWD or Income Assistance, across the country, are statistically very unlikely to be found guilty of ‘welfare fraud,’ despite significant efforts amongst government stakeholders to maintain rhetoric to the contrary:

If one considers the actual instances of criminal convictions for [welfare] fraud, the incidence is exceptionally low: convictions represented roughly 0.1% of the social assistance caseload ... notwithstanding more than 38,000 investigations being undertaken. The notion that fraud is rampant has been used to support a wide array of mechanisms to detect and deter fraud. (Raphael, 2007, p. 323)

When the reality of actual criminal convictions for fraud is understood, the justification for implementing such a wide variety of fraud prevention efforts is left unfounded. The paternalistic, stigmatized attitudes that people on disability assistance are left to navigate as they try to access benefits and supports are exhausting.

### ***Summary***

In various ways, participants experienced governmental power relations and processes of ‘othering’ as they interacted with the Ministry of Social Development and Social Innovation. These occurrences interconnected to their experiences of navigating the CVS. The participants strongly identified that the wait list, later repeal, and the current fragility of the CVS, coupled with the Ministry’s inaccessibility, was not experienced in isolation from other systemic power relations. The Ministry’s repeal of the CVS legislation was perceived as a direct attempt to intentionally limit the participants’ citizenship within a community where they already felt significantly limited due to ableism, poverty, discrimination, and exacerbated symptoms. The systematic reinforcement of participants as the ‘others’ should be recognized as a means to maintain the oppressed and deny alternate narratives of empowerment:

If one closely analyzes the reasons for which individuals’ entire existence was controlled by these institutions, one sees that, at bottom, it was not just a matter of appropriating ... but also of controlling, shaping, valorizing the individual’s body according to a particular system. (Foucault, 1994, p. 82)

The reality, then, of people with disabilities accessing PWD assistance should be viewed within the constructed confines of the ‘other’ and the structured compliance to an oppressive system.

Their experiences of stigma, paternalism, ableism, and further means of ‘othering’ were experienced cumulatively. With the numerous ways in which they were required to constantly document their illnesses, coupled with the prevalent assumption of criminality, participants were subject to paternalistic attitudes in order to meet their basic needs. The participants’ experiences speak to an exhausting, barriered, neoliberal system that is both inconsistent in its gate-keeping efforts and frequently inaccessible.

## CHAPTER SIX

### Experiential Recommendations and Supporting Policy

“I see big gaps.”-Participant

Throughout conducting this research, I was impressed at the volume of recommendations the participants were able to offer despite expressing a general pessimism towards possible Ministry improvements. This chapter, therefore, provides participant recommendations themed by overarching strategies that reference relevant policies and perspectives supported by the disability community and their allies. Participant recommendations can be categorized based on the following commonalities: reinstating the CVS, increasing benefits and rates to improve overall quality of life, improving system accessibility, utilizing the experiential knowledges of people with disabilities, and reforming the underlying ideological approach to the Ministry’s policy and service provision.

For decades, disability community activists and supporting allies have been calling for greater inclusion of people with disabilities when it comes to policy development (BC Public Interest Advocacy Centre, 2015; Prince, 2009; The Office of the Ombudsperson, 2009; 2014; Townson, 2000; Vanhala, 2009). Young (1990) goes on to explain that,

All persons should have the right and opportunity to participate in the deliberation and decision making of the institutions to which their actions contribute or which directly affect their actions. Such democratic structures should regulate decision making not only in government institutions, but in all institutions of collective life ... Democracy is both an element and a condition of social justice. (p. 91)

In this way, participation within the construction and application of public policy becomes a space for an expanded concept of citizenship, in that “contested citizenship allows for a redefinition of social relations in ways which aim to expand the boundaries of social justice to recognize the ‘other’” (Field, 2000, p. 1). Rioux & Valentine (2006) support the concept of contested citizenship when they explain that,

Citizenship is a messy concept, and therefore its boundaries are often contested. It constructs a system of inclusion and exclusion, defining boundaries between

who belongs and who does not, who enjoys the privileges (and duties) associated with membership and who is denied such privileges. (p. 54-55)

As people with disabilities in receipt of PWD assistance experience their citizenship subject to the Ministry's exercise of power, the participants' recommendations in this chapter can be viewed as an act of *pushing back* against ableist concepts of citizenship.

The relationship between the findings in this research and participant recommendations offer key areas for future policy development, and should be prioritized amongst relevant stakeholders:

Traditional approaches to the study of poverty and health have often not been particularly concerned with understanding poverty, nor with improving the health and well-being of those living in poverty. They have been more concerned with documenting the variables that predict the incidence of poverty, and identifying relationships between poverty and health...This research also rarely concerns itself with identifying and challenging existing power structures that create and maintain the policies that create poverty. (Raphael, 2007, p. 146)

Such perspectives cannot currently be found within existing Canadian disability policy, given that the opinions of individuals who experience the issues firsthand are not adequately prioritized. Emphasizing the experiential knowledges of people with disabilities within a neoliberal system would not be without its challenges, as the pessimism noted by some participants would attest. However, it is not until the knowledges of people with disabilities are valued within policy development will effective ideological changes truly begin. The valuable contributions of people with disabilities as service consumers should be a governing factor in all levels of policy development; an effort that would serve to redistribute the current imbalance of governmental power relations (Foucault, 1994; Young, 1990).

The following recommendations were gathered from the participants' direct recommendations, overall observations drawn from participant interviews, and relevant literature:

- **Reinstate the repealed CVS legislation, fully fund the program, and open the eligibility requirements to include both individuals on Income Assistance *and* PWD assistance in recognition of the invaluable benefits experienced by CVS recipients.**

All of the participants interviewed strongly expressed the need for the CVS to be reinstated within the legislation, and to be fully supported by the necessary funding originally promised by the Ministry in 2011. Participants identified that the benefits experienced by CVS supported volunteerism were widespread; noting increased citizenship, enhanced social supports, strengthened pathways to possible employment and/or further skill development, and decreased impact of mental health symptoms. Based on these observations, several of the participants interviewed felt the CVS should be available both to PWD recipients and to those on Income Assistance, as one participant advises:

Make it [the CVS] available to everyone on social assistance. Send out letters to everyone on social assistance about the CVS ... It is an effective way of empowering individuals towards becoming self-sufficient and thus, preventing a rise in socioeconomic costs.

Other participants note a progressive perspective on investing in human capital as they identify the long-term investments from supporting enhanced citizenship opportunities for people on social assistance:

If they can give more money than the hundred dollars a month, that would be great ... [but] I don't know how you put a dollar amount on the volunteer, you know. The money, there is no ... it's human beings we're dealing with, you can't put a dollar sign on human beings. The value of worth is grander than the dollar amount.

More money in the volunteer system. More funding would be good. Even if they can't raise the hundred dollars a month for people, get more people volunteering. Get more people out of the house.

Another participant explains in further detail the preventative benefits that will come from creating more programs like the CVS:

The government should put the [CVS] money back in there. I think that money should be there. I think that people should volunteer. It would prevent a lot of health issues and isolation and drug issues. There's a lot of good people out there that want to put back into the community because they have experience, and they want to help. And that's all they wanna do. You know, it's just, you get up with a purpose. And it's to help people.

Participants here offer what many would consider an adoption of the dominant discourse for a personal purpose, effectively utilizing the neoliberal rhetoric of the Ministry to 'sell' the Ministry on the importance of the CVS. Foucault (1994) speaks to this use awareness of the ways in

which existing systems of power function as a means to navigate systems when he talks about power relations. As the participants here have noted, the CVS represented a modest yet progressive policy that served to increase the overall income of participants, facilitated increased citizenship, and enhanced community access. In addition, from the participants' perspective, the CVS served to acknowledge the contributions of people with disabilities. The participants here have clearly recognized the Ministry's overall neoliberal priorities, and seek to use this in their favor. Such strategic use of dominant discourse should be considered an act of resistance in itself.

Furthermore, one of the many impacts of biopolitical, neoliberal policy is that the individual is reduced to their function within the capitalistic system (Foucault, 2004; Pothier & Devlin, 2006). In this context, the perceived functionality of able-bodied individuals is often privileged. Participants identified that the CVS was one of the few policies that recognized their contributions to their community, but that people with disabilities need to be supported in navigating the barriers experienced when accessing their community.

- **Increase available dental and medical benefits and supplements available to people on PWD assistance.**

Participants identified that the impact of the CVS wait listing and later repeal was amplified by the fact that there are already so few adequate benefits available to people on PWD. The participants identified that the limited means they have available to survive often meant that many necessities become luxuries when on PWD assistance. In the case of dental care, one participant describes living with severe pain while waiting for the next cycle of the Ministry's dental insurance coverage:

Maybe more for dental ... I had some run-ins with the dental thing where they said 'well, we can't cover this' and it was my wisdom teeth and it was just really, really painful. And I had to wait until the next year to get the new thing. Oh, that's what you could do! Right now you get a thousand dollars ... and if you don't spend it all that year, it just gets eliminated, so if maybe that money could transfer over to the next year. Because they just chop it off at the end of the year, so it would be nice to carry that over.

Another participant expressed similar issues with the Ministry's coverage for basic medical costs, such as optical care:

New glasses, those are ridiculous. Like two hundred bucks for new glasses, even with what they cover. More for glasses.

The amount of medical and health care expenses that are uninsured or only partially insured by Ministry funding, as the above participants testify, constitute completely unrealistic costs for individuals living on \$906 per month.

Increasing the funding and supports available to PWD recipients for basic needs would increase the participants' quality of life dramatically (BC Coalition of People with Disabilities, 2007; Pothier & Devlin, 2006; Raphael, 2007). The undue stress, anxiety, and frustrations experienced by people surviving on PWD assistance is unwarranted and detrimental to the wellbeing of people with disabilities. People surviving on PWD assistance should not find forgoing basic needs a normalized experience.

➤ **Raise the rates of PWD assistance to a livable amount.**

All of the participants interviewed in this research clearly identified that benefits like the CVS are that much more important because the rates of PWD assistance are so far below the poverty line. Participants talked about the adverse impacts experienced by being forced to choose between necessities, without sufficient nutrition and health needs, and consistently not have enough to make ends meet. As one participant explained, even if the CVS was fully reinstated for all potential applicants, they would still not have enough money to live on each month:

The CVS is a great thing; the Ministry help is a great thing. But the living wage?  
The money to live?

Another participant expressed a similar sentiment:

Everything's going up, but nothing is getting bigger being on the receiving end of it. It's great I get a hundred dollars, but groceries have gone up. The price of the bus tickets has gone up.

Participant narratives spoke repeatedly to the need to raise the rates:

Raise the rates. Raise the shelter portion in particular to match what the market value is of the renters' dollar.

I just wish that something would spark somewhere and you know, and the rates would raise a little bit.

Participants clearly articulated the need to increase the rates of PWD assistance, and many argued that the rates for Income Assistance needed to go up to a livable amount as well. As one participant explains, a significant number of people on PWD or Income Assistance regularly have to go without basic necessities:

Raise the amount of money a client receives on both social assistance and disability so that they can not only have their basic needs, but enough money to help alleviate the stress of having to cover extra costs: psychological services, some types of needed medication, clothing, shoes, to purchase healthy food items and supplements.

The ways in which people with disabilities living on PWD assistance are oppressed by neoliberal policies which restrict, rather than enhance, the quality of lives for people with disabilities are innumerable. As the participants expressed here, there is a compelling need to increase the rates of assistance provided to those living on PWD assistance. Knowingly withholding the most basic of services and supports, such as medication, clothing, or psychological services, is not reflective of the claimed mandate of service of the Ministry, nor does it serve to facilitate the independence of people with disabilities (Baxter, 1995; BC Coalition of People with Disabilities, 2007; BC Public Interest Advocacy Centre, 2015).

➤ **Make information regarding Ministry benefits and processes more accessible.**

Participants talked about experiencing ongoing challenges in accessing information about the benefits they are entitled to, and related eligibility restrictions. Participant experiences of barriers to access should be considered a significant limitation in measuring the effectiveness of current disability policy. Since most benefits are not legislatively retroactive, individuals cannot apply for retroactive benefits reflective of the onset of their *need*, but rather only when they are made aware of their *eligibility* and proceed to apply (Ministry of Social Development and Social Innovation, 2013e). In many ways, the Ministry makes no exceptions for individuals who were unaware of eligibility requirements. The Ministry's prevailing inaccessibility should be interpreted as institutional negligence in that many individuals go without basic needs due to health limitations, poverty, literacy barriers, or a variety of other causes, yet the Ministry maintains the same barriered practices that leave many individuals to fall between the cracks (BC

Public Interest Advocacy Centre, 2015). Most Ministry resources are text heavy, and are often only available online.

For individuals hoping to receive an explanation over the telephone, they may be sorely disappointed, as one participant points out the need for greater telephone access:

More people on the phones for one. Quite often when I phone it says, ‘due to higher call volumes you might not be able to get through today’ when it’s only 1:30 and they’re open until four.

As noted by many of the participants, people with disabilities often go without until they are made aware by someone else who has accessed a similar benefit or by a community non-profit. As one participant questioned, “What about the people who know nothing?” The relevant legislation governing the ways in which the Ministry administers PWD benefits, as reflected in Ministry policy, are noted by participants as being very inaccessible to most individuals living on PWD assistance. The constructed exclusion of people with disabilities from the very legislation, policies, and processes that govern their lives is an unethical hypocrisy. As one participant explains, there is a pressing need to ensure people with disabilities can access information sufficiently:

What does it [navigating Ministry rules] do to someone who’s already really down and with their disability? Who doesn’t understand? Who doesn’t comprehend the Ministry’s policy?

The same participant expressed concern for individuals who are limited in their ability to navigate the complex systems of information relating to PWD benefits as they explained further:

They don’t *tell* you the rules and regulations of stuff. I’m just lucky enough to have a copy of the rules ... I printed it off a long time ago, right. But still, the Ministry, it doesn’t tell me whether they, you know what their mood is for the day.

As noted by the above participant, increased access to information does not rectify issues of inequitable administration of benefits, however the participants’ practical recommendations to facilitate increased access to information should not be discounted. Another participant explained that simple efforts to enhance understanding of benefits would be of great assistance:

Need to inform people better of what they can be eligible for, like give them an info package or something when they first get assistance.

The participants here are not alone in their criticisms of the inaccessibility of the Ministry. Given that many PWD recipients must seek community advocacy supports to facilitate access to Ministry benefits, it seems quite contrary to the Ministry's mandate of promoting independence amongst its clients when third party assistance is required. Numerous recommendations and complaints can be found regarding similar issues around accessibility (BC Public Interest Advocacy Centre, 2015; The Office of the Ombudsperson, 2009; 2014). The Ministry has recently been criticized for the exact issues raised here by participants:

The increasing reliance on the centralized phone line with long wait times and arbitrary time limits for calls, an initial intake application which practically is only able to be completed online, together with the reduction in the availability of face to face services, results in barring or unreasonably delaying access to Ministry services for many. (BC Public Interest Advocacy Centre, 2015, p. 40)

Involving people with disabilities in the development of Ministry policy and processes would allow for further, tangible recommendations to be incorporated into everyday practice.

➤ **Utilize the strengths of people with disabilities within the Ministry**

Participants offered ideas as to how people on disability assistance could be employed for their experiential knowledge to facilitate better access for people newly applying for PWD benefits. Several participants offered suggestions around utilizing the CVS program as a platform to improve the Ministry's effectiveness. All of the participants interviewed connected their experiences of the Ministry's *de facto* policy to wait list CVS applicants as reflective of their general experiences of the Ministry as an inaccessible system overall. As one participant notes, drawing on willing volunteers could improve some of the challenges people experience when navigating the Ministry processes:

Volunteers are a crucial part of any organization. I don't know how the Ministry could obtain volunteers or train people to maybe assist in their workload, but I think that it would be a really cool solution to have people that are experiential in the Ministry issues be volunteers.

Such efforts would also serve to recognize the capacity of people with disabilities, as one participant declared, "a lot of people with illnesses, they do have skills." Such efforts might also

serve to reinforce the need for more inclusive, rather than ableist, practices (Young, 1990). As one participant explains, they have the skills needed:

Help people like me like, that have gone into their office, and I've constantly said if you can't do the job, I'll do it for you. I know how to do your job, I know how to write excel sheets ... I know how to word process, I know how to read, I know how to do things.

Participants identified that utilizing the experiential knowledge of people with disabilities would not, however, fix some of the broader issues with the Ministry:

Use volunteers in the government, use people, like I mean ... do something, help the problem, find a solution, don't just think you can hand me a hundred bucks to volunteer somewhere and think that's going to fix my problem, because it's not going to fix my problem and it's certainly not going to fix yours.

Participants here offer recommendations that are also reflective of larger, systemic issues of power imbalances, in that tangible solutions can be offered; what remains is a general sense of complex, institutional barriers steeped in neoliberalism. As one participant explains, it was difficult to think of recommendations when the challenge of unaccountability remains:

Nothing makes sense that the government does! They say one thing, do another. They're 'families first?' If you're families first, then families first. If you're 'housing first,' then housing first. Where's the housing? Where's the money for families?

The same participant emphasized that, though they could offer a multitude of suggestions, larger improvements to the Ministry's overall neoliberal assumptions first need to be rectified:

One big major point that makes me laugh is that it is supposed to be a short term income. Welfare is not supposed to be long term. Well let me tell you, in my life, it has been long term, forever. It has been this way for 30 some years. So what do you mean by short term? And if you look at all the people on welfare, you'll see none of them have been there for short term. So the idea of welfare as a short term, emergency thing, is not logical. It does not fit what the government thinks they're there for. Because I've been collecting it for over thirty years, so what do ya mean by short term? And if you look at the system, they're all there for a long time.

Participants identified ways in which they could draw on their experiential knowledge to assist individuals in accessing PWD benefits and also contribute to overall system improvements. The participants also talked about how there are still larger, systemic issues relating to the overall approach embodied by the Ministry.

- **Reform the Ministry of Social Development and Social Innovation to adopt a holistic, human-centered approach.**

The progressive approaches recommended here cannot be expected to flourish within a broken system. Participants noted the need for an overall change to the very ideological foundation from which PWD benefits are rooted. In the words of one participant:

It's hard to imagine them doing, I mean, when you ask questions about how the Ministry could be doing things better it's like well there's so many things I can't think of any of them. It's just so hard to imagine them treating people well.

The general pessimism of participants in regards to the Ministry should speak volumes to the desperate need for change. The need for such a shift in perspective is supported throughout the literature:

An alternative paradigm should focus upon the experience of people living in poverty, should be willing to consider structural issues in addition to individual ones, and should be more explicitly concerned with improving living conditions and creating a more equitable and just distribution of resources. (Raphael, 2007, p. 146-7)

Echoing Audre Lorde's (1984) rejection of the feasibility of seeking change within an oppressive regime, participants argued that a significant ideological shift amongst Ministry services is a necessary precursor to effective change. The need to focus on a progressive, multi-faceted approach to benefits for people on PWD, as one participant explained, is a must:

If there are socioeconomic services in place and accessible to help a person holistically heal and feel empowered to become self-sufficient ... that would be fantastic.

Another participant explained how assistance should be provided, focusing on the multiple areas of life that impact poverty:

They need things in place to help people with addictions and mental health issues, like a holistic wrap-around program that provides money to live, but also connects doctors, psychologists, housing, all of the mechanisms that empower a person.

Reinforcing the need for the same approach, another participant explains that if the Ministry truly wants to provide assistance for people living in low income and on PWD assistance, the Ministry's services should go beyond the bare minimum:

Short and long-term transition safe houses, various short and long-term counselling and detox services to help people with addictions and addressing their past, affordable housing, counselling services and organizations and programs. Social events. Empower individuals so that they may have their basic needs met plus, feel worthy, valued, respected, and know that their unique abilities are so that they may feel confident and excited about pursuing the appropriate socio economic avenues (education, training programs, volunteer services) to help them become contributors of society rather than the opposite.

The recurrence of suggestions relating to progressive, inter-disciplinary approaches to practice echo the sentiments of many leading academics and activists (Canadian Mental Health Association, 2009; Cohen et al., 2008; Disability Without Poverty Network, 2012; Prince, 2009; Raphael, 2007; Young, 1990). Participants have demonstrated firsthand narratives that justify the need for such changes; demands for progress that are supported by public advocacy claims, public interest reports, and Ombudsperson reports (BC Public Interest Advocacy Centre, 2015; Canadian Mental Health Association, 2009; Disability Without Poverty Network, 2012; Raphael, 2007; The Office of the Ombudsperson, 2009; 2014).

### ***Summary***

Participants' recommendations express a politic of critical reflection, of hope, and of greater engagement of people with disabilities as knowledge holders. The participants identify a number of ways the Ministry could improve specific benefits, improve the overall quality of life for people living on PWD assistance, and shift away from punitive, neoliberal policies to more progressive approaches. The public prioritization of people with disabilities as valued stakeholders in the development of social policy and the administration of public benefits is absolutely necessary (Young, 1990). Emphasizing the narratives and experiential knowledges of the individuals who experience the complexities of poverty first hand serves to resist ableist practices that discount the voices of people on disability assistance. The capacity of people with disabilities to contribute to effective change within public policy should not be discounted.

Within current disability policy in Canada, people on disability assistance are subject to paternalistic policing and rampant, biopolitical stigmatization, and institutionalized ableism. The narratives drawn upon in this research exemplify the disability community's capacity to contribute to, and be a catalyst for, progressive social change. The lived experiences of people with disabilities, their intersectional identities, and the ways in which they engage in active citizenship (or contested citizenship) should be considered an integral training component for relevant stakeholders. Employees who administer benefits and/or programs to people with disabilities or other marginalized populations should be required to engage in training specifically aimed at this sector, largely designed by people who experience the issues first hand.

## CHAPTER SEVEN

### Conclusion

It makes the difference between thriving instead of surviving. (Participant)

This thesis started as an effort to document the success of the disability community's efforts in impacting provincial disability policy. However, upon the Ministry's subsequent repeal of the CVS legislation, my intent turned towards documenting resistance amongst people with disabilities as they navigated structural barriers. As I started the interview process, I quickly realized that the concepts of resistance and systemic 'othering' were layered in the participants' narratives within a multiplicity of experience and knowledges. I realized that participants did not experience the CVS in isolation of other experiences. Nor did they experience the systemic issues of the Ministry as individual, but rather as cumulatively layered experiences of ableism, paternalism, and inequality.

Utilizing post-structuralist feminist theories, influenced by critical disability theory and Foucault, I explored the intersectionality of ableism, neoliberalism, and biopolitics as demonstrated within participant experiences of resistance in relation to the CVS. Post-structuralist, feminist theory recognizes the constructed body as a site for politicized resistance that intertwines with narratives of power and oppression that are echoed by Foucault's concepts of biopolitics (Butler, 1990; Foucault, 1980; 2004). People living on PWD assistance confront issues of unjust administration of legislated benefits, systemic gate-keeping, paternalistic policies, and ongoing legislated poverty-level rates of assistance. The CVS, as a case study, highlights some ways in which people with disabilities struggle to "survive instead of thrive" as one participant so aptly noted. The CVS was one of the few policies within a restrictive and residual welfare system that supported people with disabilities to engage in their communities in a meaningful way. When PWD recipients and their allies spoke out about the Ministry's practice to unjustly wait list eligible CVS applicants, people with disabilities celebrated a short-lived moment of collective empowerment. The Ministry had promised to fully fund the CVS program and remove all eligible applicants from the wait list. Unfortunately, not only did the Ministry fail to fully fund the program as promised, they instead repealed the legislation protecting existing

CVS recipients. Participants in this research identified various ways in which they resisted the Ministry's practice to unjustly wait list participants, as well as how these experiences were reflective of relations of power and processes of 'othering' by government.

A key finding is that participant encounters accessing the CVS are experienced in close connection to their experiences of poverty, resistance, and community. From a policy perspective, as a result of this finding, it is important to note the layered contextual character of participants' experiences in accessing and resisting the system. Participants highlighted their perceived need for and benefit of the CVS and their experiences in resisting the Ministry's practice to unjustly wait list CVS applicants through the appeals process. Participants identified a number of themes relevant to their experiences accessing the CVS. The need for, and benefit of, the CVS as experienced by participants was identified as significantly more complex than is depicted by Ministry policy. Several of the participants obtained meaningful employment as a result of their participation in the CVS program.

Participants identified the CVS as a means to facilitating enhanced citizenship, building an identity outside of the dominant capitalistic means, accessing peer support, preventing mental health symptoms and isolation, and as a potential stepping stone to further employment. They said they would not have pursued employment without using the CVS to 'trial' the workforce, as this would have otherwise risked their PWD designation. Within the participants' emphasis of their capitalistic capability highlights another key finding: further research should be conducted to explore the ways in which PWD recipients can, at times, adopt the priorities of the dominant system is often used as a means to an end, effectively redistributing the power balance. The participants' neoliberal emphasis would constitute what Foucault refers to as "infrapower," in that participants were able to not only recognize the "series of knowledges" governing systems and individuals, but were able to see the ideology *within* the means of production (Foucault, 1994, p. 87). In this way, participants demonstrated an awareness of how their experiences of the CVS even appeased the Ministry's neoliberal priorities. The participants were able to identify their own personal experiences of the benefit of the CVS, but also adopted the dominant discourse of the Ministry to effectively 'sell' the worth of the CVS within the confines of the neoliberal system.

Participants talked about ways in which they were impacted by the appeals process. These narratives should be of significance to policy stakeholders in considering the overall

impact of the appeals process on PWD recipients. Outside of the appeals process, participants exercised resistance against the Ministry in different ways. Participants' efforts to increase the collective knowledge of the disability community were a means of *pushing back* against a system they experienced as inaccessible. Sharing strategies to increase chances of being deemed 'eligible' for a benefit, and navigating application and appeals processes were notable sites of resistance. Referring peers to advocacy supports in the community was another method used by participants to alter inequitable power relations between the disability community and the Ministry. Participants also drew on sarcasm, skepticism, and other indicators of withholding trust as a means of exercising emotive resistance (Young, 1990). At times in one's life, and especially life at the margins, one must adopt dominant discourses in order to navigate systems of power, in this case, to access PWD benefits; individuals highlighted ways in which they 'fit' the Ministry's concept of disablement to qualify for benefits.

Participants talked about how the Ministry's removal of the CVS legislation shortly after promising to fully fund the program was experienced as a direct assault on citizenship. The participants linked the Ministry's repealing of the CVS legislation as representative of greater experiences of denied citizenship, unjust and inaccessible benefits, and institutionalized ableism; another key finding in this research. These negative experiences were exacerbated by the extremely low PWD rates. Participants spoke of having to choose between necessities, frequently going without even the most basic needs, even enduring pain in going without medication because of lack of funds or insurance restrictions. Participants described the exhausting reality of living in perpetual scarcity, leading any additional benefit or supplement to be a significant influence on their lives. Experiences of navigating the CVS were collectively layered within their experiences of poverty, resistance, and community.

The participants illustrated that the impacts of neoliberal, biopolitical policies are experienced in an overwhelming, assaultive, exhausting barrage. One of the numerous resulting challenges experienced by participants who remained in receipt of the no longer legislatively protected CVS was that any flare in health symptoms meant they potentially risked losing their CVS. The biopolitical precariousness felt by participants resulted in the creation of an additional eligibility criterion, whereby participants cited their wellness as being now tied to accessing supported citizenship. A key finding within this research surrounded the participants' articulation of the ways in which they experienced the biopolitics of the Ministry processes. Participants

identified a collective awareness of the Ministry's privileging of bodies that are more valued within capitalistic production and identified how the ability to contribute inherently devalued constructed illness. In this way, participants surfaced how present day disability policy serves to reinvigorate Elizabethan constructs of deserving and undeserving poor. Participants' experiences presented an account of how the Ministry's policies and processes served to construct disablement as the 'other.'

As people living with disabilities in an able-centric society, participants were subject to stigmatization from various quarters. Participants spoke of experiencing skepticism from physicians surrounding their disabilities. Such experiences are problematic considering the numerous ways in which people on PWD assistance are forced to depend on the medical profession to document and attest to their experiences of disablement. Moreover, participants were then, as a result of the Ministry's requirement for medical documentation, situated as the 'other' in their relationship with their medical supports. The Ministry's construction of what 'counted' as a disability served to deny individuals authorship over their own disabilities. These experiences were further embodied by the participants' accounts of paternalistic treatment by the Ministry, citing examples of having Ministry workers question their ability to count money or care for their child. The paternalization of poverty was present amongst the testimony of one participant in particular, when she recounted being questioned about her parenting by a male worker. Another participant emphasized that, as an Aboriginal woman on PWD, she was often subject to mistreatment based on how she looked. Other participants recounted how they continuously experienced poor policing and accusations of welfare fraud. The ways in which womanhood, parenting, and disability intersect within experiences of accessing provincial disability assistance attests to the need for further analysis of the various ways in which power and processes of othering permeates within disability policy, particularly for marginalized individuals.

Participants' narratives demonstrated the systemic prevalence of complex barriers, inaccessible and ableist systems, and normalized poverty that must be navigated by people with disabilities every day. In stark contrast to the participants' narratives, stands the Ministry's declared mandate as a "system of supports to help them [people with disabilities] achieve their social and economic independence and secure a better tomorrow" (Ministry of Social Development and Social Innovation, 2016b, p. 5). The juxtaposition of participants'

experiences of barriered citizenship, normalized poverty, stigmatized experiences of access, and overall *subjectification* at the hands of the Ministry should lay stark against its mandate as a sheer hypocrisy. As previously noted, the ways in which the Ministry knowingly upholds policies of legitimized poverty and systemic ‘othering’ of people with disabilities could be regarded as structuralized violence (Galtung, 1969). The Ministry constitutes a vehicle of power that serves to construct the concept of disablement for people in need of assistance. The Ministry’s approach to service delivery results in “serious barriers to access for a vulnerable group of people who are attempting to access critical services to meet their basic needs.” Additionally, “these barriers are also discriminatory in that particular groups of recipients, like those with mental illness or cognitive disabilities, have greater difficulty in accessing Ministry’s services” (BC Public Interest Advocacy Centre, 2015, p. 40).

In conducting this research, I often struggled to set boundaries around what was feasible within a graduate thesis and what was not. As I engaged in the interview process with participants, I was struck by the numerous topics that could, and *should*, inform provincial disability policy. Governmental bodies and social justice workers need to be aware of the lived experiences of people living on disability assistance. Health care workers and physicians need to be aware of the problematic pairing of income benefits, inaccessibility, and medicalized gatekeeping processes mentioned by participants. A broader recommendation relating to issues of access would involve examining the ethical issues of an institution obligated to provide for vulnerable or disadvantaged populations remaining severely barriered to the very people they are intending to serve. I recommend that additional research be taken up to explore PWD and Income Assistance recipients’ experiences and critiques of public policy, particularly in relation to welfare-to-work policies and workforce obligation. I also recommend that if individuals on assistance are subject to enforceable employment or welfare-to-work obligations, they should be entitled to use such obligations to shape the very system that governs them. For example, employing individuals on PWD assistance to contribute their knowledge as system navigators, in whatever means they are able, would recognize the assistance many individuals already provide to their peers and utilize the experiential knowledges of people on assistance. To build on the CVS, I also recommend that people with disabilities volunteering in the community be consulted by regional stakeholders regarding general barriers to community access. Additional work should be undertaken to explore the existence of precarious volunteerism, where individuals are

dependent on their role as a volunteer for financial reasons. Several of the participants spoke to their awareness of how people hoping to maintain their CVS were particularly vulnerable to mistreatment or subject to stagnating roles in their volunteer positions. Finally, additional research is recommended surrounding the impact Ministry expectations has on PWD recipients' relationship with the medical systems. The paternalistic policing of people on assistance often leads to medical professionals being called upon to lend credibility to people with disabilities, given that the existing system immediately discounts the credibility of people with disabilities. Participants talked about feeling that their relationships with their physicians were often strained as a result of the Ministry's expectations, an unjust impact that could lead to reduced access to primary care. Instead, opportunities to honor the individual who experiences their health issues as the expert should be prioritized. Self-assessment measures should be incorporated by physicians to reposition the patient as the most credible author of their own disablement.

The narratives shared with me by participants echoed much of my own experiences as a homeless, substance using queer woman with mental health issues. I felt a strong connection to the participants I interviewed, not only because I respected their contributions to trying to better issues of access for the disability community. I deeply felt the impact of how the services and supports available to them often determined whether or not they were able to thrive or simply survive. My experiences of accessing neoliberal systems, navigating scrutiny as a result of my status as a homeless teenager or, later, as a teenaged single mother on social assistance were unfortunately all too similar to many of the stories I heard throughout the research process. Engaging in this research was incredibly rewarding for me. In hearing participants' powerful stories of resistance, I gained a personal appreciation for the fact that many people living in poverty and on disability assistance possess the tools to change the system. I also noticed that, at times, participants sometimes utilized neoliberal rhetoric to justify the benefit of a particular policy, while at other times participants seemed to express a desire to be represented within the dominant capitalist means as a contributor. This contrast was especially curious to me, and I would enjoy exploring this place of friction further in future research. The oppressive nature of the systemic barriers faced by people on disability assistance surfaced for me an awareness of the multifaceted effects of oppressive disability policy. The external constructions over the disabled body, over motherhood, and over poverty that were surfaced by participants within this research named experiences that I had personally felt as well.

How the Ministry defines illness and wellness, by way of eligibility criterion and administrative scrutiny, determines what can be considered privilege, in contrast to a necessity, typifies neoliberal power relations. The ways in which participants *pushed back* against these externally constructed narratives were various and significant. The collective resistance exercised by the shared knowledges of people with disabilities within this research emphasizes that people with disabilities should be important stakeholders in the development of disability policy. I leave the final word to one of the participants:

I just wish the Ministry would look at people as human beings and I wish that policies were created with human beings in mind. I wish, (pauses) I wish the reality of our lives was a little more apparent to them.

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**APPENDIX*****Appendix A****Script*

Hello there,

I am writing in response to your inquiry about my research. You may have seen a poster recruiting participants for this research or you may have heard about it through word of mouth. Someone you know may have thought you would be a good person for me to interview. Please, let me tell you more about my research.

My name is Candace Witkowskyj and I am currently working on my Master's Degree in Studies in Policy and Practice. If you would like to find out more about the kind of research people in my program do, you can look at information on this website <http://web.uvic.ca/spp/> or please feel free to ask me more about it. I previously worked as an advocate at the Together Against Poverty Society and during my time there I helped many individuals to appeal the Ministry of Social Development's process of wait-listing people on disability assistance (PWD) for the Community Volunteer Supplement (CVS). Research shows that this is but one of many examples of the unjust denials that that people on disability assistance are forced to experience in British Columbia. I wish to explore how women on disability assistance who were denied or waitlisted for the CVS experienced this unjust policy and to give voice to their role in changing policy through resistance.

I hope that this research will impact how people perceive disability policy in British Columbia and also give voice to the risks people take when they choose to challenge the system. By exploring the ways in which women on disability assistance experienced an unjust policy and the difficult process of appeals they endured to challenge this process, I hope to make more known the reality of what it is to be on disability assistance in British Columbia. It is my hope that, with your contribution to this research, I might be able to inform policies on disability assistance to be more effective.

If you are interested in participating, I would like to invite you to take part in an interview. The interview should only take about an hour of your time. I will have a series of interview questions that I will ask you and I will also ask you to sign a form which consents to me using your answers in my research. I have included a copy of these questions and the consent form along with this letter for your review. I understand that this might be something hard to talk about, so all of the interviews will be confidential and your identity will be protected in the research. It is important that you know if you have told someone you are interested in this research, they may be able to identify you later as a participant. If you have previously talked about your experiences in a public way or if you have accessed the same resources as other participants, other participants may be able to identify you. I will make every effort to protect your privacy. Please ask me more questions about this if you have concerns.

You will also be able to see my final research paper and to make any changes to your contributions that you see fit, or to withdraw your input from the research overall. Reviewing your contributions and making any changes/edits you see fit should take no more than two hours' time. Overall, to participate in this study, it is expected it should take no more than 2-3 hours of your time in total. If you would like to participate, or if you have any further questions, please feel free to contact me through email or by telephone.

Thank you for your time.

## ***Appendix B***

### *Invitation to Participate*

Dear ... ,

My name is Candace Witkowskyj and I am currently a Studies in Policy and Practice Masters Student, studying at the University of Victoria. This letter is being given to you because someone you know has heard of my research and thinks that you may be interested in participating in research for my thesis.

My thesis research is on the experiences of women on provincial disability assistance (PWD) who have been denied/waitlisted and appealed for the Community Volunteer Supplement (CVS) during 2009-2011. My research explores barriers women on disability assistance experience accessing benefits like the CVS and hopes to give voice to the strength of those who have risked challenging this system. Much of my preliminary research has shown that people on disability assistance in British Columbia take a number of risks to their emotional and financial wellbeing when they resist systems like the Ministry of Social Development or other governmental bodies on which they must depend to survive.

If you have more questions about my research, please contact me. The interview should only take approximately one hour of your time. If you are interested in participating in the research I have a series of interview questions and a form that I will ask you to sign which gives me permission to use your answers in my research. I have included a copy of these here for your review. If you feel comfortable with these questions and with this form, I would like to schedule an interview with you at your convenience. Whatever answers you chose to share with me will be made anonymous and your identity will remain confidential. If you share with the person who gives you this letter that you are interested in this research, they may be able to identify you alter in my final thesis report. If you do not wish for this person to know of your participation, please do not share with them you have indicated interest in my research. You also should be aware that if you have previously talked about your experiences on CVS or PWD before or if you have accessed similar

resources as other participants in this study, you may be identifiable. I will make every effort to protect your privacy, but I am obliged to inform you of these potential limitations.

You will have a chance to look over your contributions to my thesis to make any changes you see necessary or to withdraw if you chose to. Reviewing your contributions to my thesis should take only 1-2 hours of your time. In total, if you participate in this study, it is expected that you will contribute likely only 2-3 hours in total of your time.

I hope that this research will benefit people on disability assistance in British Columbia by influencing policy, honoring the opinions of those who experience the issues first hand, and by creating a dialogue about barriers people experience when they are accessing benefits like the Community Volunteer Supplement.

Please feel free to contact me through email or by telephone if you have any questions at all or would be interested in participating in my research.

Thank you,

Candace Witkowskyj, BSW, MA Candidate

## *Appendix C*

### *Poster*

#### **Would you like to be part of a research project?**

I am interested in talking to women on Persons with Disability (PWD) assistance about their experiences.

#### **I am looking for women who:**

- Are 19 years of age or older
- Are on or were on PWD assistance in British Columbia
- Were waitlisted or denied for the Community Volunteer Supplement (CVS) during 2009-2011, and
- Appealed being denied or waitlisted for the CVS during this time period: 2009-2011

#### **I will ask you questions about your experiences:**

- Being on PWD assistance
- Being denied benefits
- Applying for the Community Volunteer Supplement
- Appealing the Ministry of Social Development's (aka welfare/disability office) decision to place you on the wait-list or to deny you this benefit

#### **I am:**

- A Masters Student doing research for my Master's thesis at the University of Victoria
- Not an employee or volunteer at any of the agencies where you may have seen this poster
- Interested in impacting disability policy in British Columbia

#### **If you are interested in being interviewed or would like to know more:**

- Please contact Candace Witkowskyj
- The interview should take only an hour of your time
- I will provide you with a copy of the questions I will ask ahead of time
- You will receive a small gift for participating in an interview

- You can bring a support person or friend with you to the interview if you like
- If you would like to be interviewed, I will send you a report after your interview (when I write my thesis). I will give you a report of how I will use what you told me during your interview. You will have a chance to make changes/edit how I use what you say. This should only take a maximum of 1-2 hours of your time.
- The total amount of time you will give if you participate should be 2-3 hours.

## ***Appendix D***

### *Consent Form*

#### Explanation of Consent

#### **Experiences of People on Disability Assistance in British Columbia: An Illegal Fettering of Legislative Authority Resulting in \$700,000 Without for Low Income Volunteers.**

I, Candace Witkowskyj, am a Masters Student at the University of Victoria working on a research project. I do not currently work or volunteer at any community service agencies in Victoria.

I am interested in talking to people on Person with Disability (PWD) assistance in British Columbia who were waitlisted for the Community Volunteer Supplement (CVS) and appealed being on the waitlist during 2009-2011.

#### **What will I be asking of you?**

I will be asking you to:

- Talk with your experiences on PWD assistance
- Tell me about the CVS, being on the waitlist, and appealing the waitlist
- To share anything you think is related or fits well into the discussion

I want to do this to better understand how people on PWD assistance:

- Experience provincial policy and legislation (the laws and practices of the disability office and their workers)
- What barriers and challenges do people experience when they access disability
- How people on disability assistance could be better supported

#### **How will I do the research?**

I will talk to you about the project a bit more. We will read over this form together. If you still feel comfortable, I will ask you some questions about the things I mentioned above. I sent these questions to you when you first contacted me.

I will ask the questions on the list I gave to you before. I might ask you to tell me more about something or to explain something you say. If at any time you feel uncomfortable you do not have to participate. You can refuse to answer any question you want. I will ask you questions, and then I will listen to your answers. There are no right or wrong answers.

If you agree, I will record this interview. I will also take notes.

After the interview is over, I will read you my notes. This way you can change your answer or tell me more if you want.

You can bring a person you trust to the meeting if you want. This person has to agree to respect your privacy. This means they agree to not share what is said in the meeting.

I will give you information about free counselling services and advocacy groups in your area. I am giving a copy of this list to all of my participants, just in case they feel they need it later. If you do not feel you will use this, you do not have to take it or you are welcome to recycle this information. Please let me know if you need any more information.

### **What will you do to protect my privacy?**

Your privacy may be limited because I am only interviewing 3-5 people. If other participants have accessed similar resources as you, if you have shared your experiences appealing CVS in a public way before (newspaper, other media, etc.), or if you attend the same community groups, other participants may be able to guess your identity. If you asked about this study or showed interest in this study at an agency or community resource you attend, they may be able to guess your identity. I will never identify you in the study, but please be aware that your privacy may be limited in these ways.

I will use the notes and the recording to write my thesis. When the meeting notes are typed up on the computer, I will change your name and remove details that might identify you, like where you volunteered or names of people you mention. That way, no one can tell who said what. I will keep any electronic copies in a file on my laptop. I will put a password on the file and I have a password on my laptop. Any paper copies of what you have said will be kept in a locked cabinet, in a locked room at my home. This way, no one can accidentally see any information about you.

There will be about 3-5 interviews in total. Everyone will be asked the same questions and given the same information.

I will write a final document, my thesis, on this information and relate what you and other participants have said to similar articles and papers. I will send all of the participants a copy of my final draft. I will ask the people I have interviewed to look at the sections where I have quoted you or referred to our interview. I can read this aloud to you as well. If you are okay with how I have used what you have said, I will present my thesis to my supervisors and other people at the University of Victoria. You are welcome to attend at this presentation. If you do choose to attend my presentation at the University (this is called my defense) you need to be aware that this may compromise your privacy. I will not identify you as a participant in any way however other people there may be able to guess you are one of the participants. As an alternative, I can record my defense (if permitted) and provide you with a copy of that recording. I may publish this information or share it in other ways later, like a report for a newsletter or at a conference.

### **What will happen if I change my mind about being in the research project?**

You can decide that you do not want to be a part of this project any time before your interview.

Even if I meet with you, you can still change your mind. After I have written a final draft of my thesis, I will send you a brief report on how I have used what you told me in my thesis, I will list any quotes used from our interview and paragraphs where I reference anything you told me in our interview. I will ask you to tell me when my thesis committee members have signed off on

my thesis (approved my thesis) if you are okay with what I have written about you and if you are okay with how I have quoted you. If you need help to do this, please let me know. You can stop anytime during recording your day and change your mind.

If you have changes to make to how I have quoted you or referenced what you have told me during our interview, you can tell me those changes or edits 1) over the phone, 2) in an email, or 3) you can write on the report I gave you and send it to me (by mail or email).

After I have shown you what I have written and you have agreed that you are okay with how I have used what you told me, I will not be able to remove your data from the study.

This is how you can let me know if you change your mind:

- At the interview, I will tell you when I think I will send you a copy of my draft thesis. A thesis is roughly 100 pages so it will take me some time to write this. To stop being a part of the study, you have to contact you have to tell me or email me
- Maybe you feel uncomfortable telling me directly that you changed your mind. Then you can contact my supervisor, Dr. Michael Prince. He can tell me that you have changed your mind, as long as you tell Michael or myself before the deadline I explained above. You can also contact the University of Victoria Human Research Ethics Office.

If you tell me at the time my thesis committee members sign off on my thesis that you do not want to be part of the study, this is what I will do:

- I will not keep copies of any information you have told me. It will be destroyed. I will either shred it or delete it
- I will not include any of the information you gave us in my thesis
- I will not tell anyone that you have changed your mind. If an agency or a friend of yours told you about my  
research, I will not tell them you changed your mind

**Who will get the final thesis?**

The University of Victoria will review and keep a copy of my thesis. This is part of earning my Master's Degree.

It might also go to other community agencies.

All data and the report will belong to myself and the University of Victoria.

**Who will benefit from this project?**

This project may help people on disability assistance. It might help other students and professionals in the community understand disability assistance better. Community agencies might benefit from hearing the opinions of people they are trying to help.

This project may help government policy makers. It might help them make policies and laws that are more supportive to people on PWD assistance.

*Written Consent*

Interview Date: \_\_\_\_\_

I \_\_\_\_\_ agree to take part in the research project titled  
**“Experiences of People on Disability Assistance in British Columbia: An Illegal Fettering of Legislative Authority Resulting in \$700,000 Without for Low Income Volunteers.”**

I understand that Candace Witkowskyj will meet with me, ask me the questions she sent me, and take notes. I understand that Candace might ask me questions to better understand what I say. I understand that the interview should only take about an hour. I understand that when Candace Witkowskyj provides me with a summary report of how she has used what I have written, this should take less than an hour to review. If I chose to make changes/edits, that may be additional time (likely no more than an additional hour). In total, I understand that I can expect to contribute likely 2-3 hours of my time to participate in this study.

If I say it is ok, my meeting will be recorded. If I agree, Candace will record our interview. If I say it is okay, Candace will use this recording in her thesis. I understand that other participants might be able to identify me if I have talked about my experiences on CVS or PWD assistance in a public way before or if other participants have accessed the same resources as me. I understand that if I told anyone at the agency/resource center where I saw the recruitment poster, staff who work at that agency/resource center may know I am participating in this study. I understand Candace will not confirm my identity to any agency, but that the agency may be aware of my participation because I indicated interest.

I can change my mind even after the interview. Candace will also give me a summary report listing how she has used what I have said. I can decide if I like how she has used what I have told her. On the bottom of the report Candace gives me, she will ask me to consent (verbally or in writing) to how she has used what I have told her, or to consent once she makes the changes/edits I request. I understand that if I request Candace to make changes to something and she doesn't, I can withdraw my consent. I will tell Candace or her supervisor Michael that I

change my mind at the time Candace's thesis committee has signed off on her thesis. If I do change my mind within these time frames, all my information will be destroyed.

### Consent Checklist

Interview Date: \_\_\_\_\_

I do

I do not

agree to be recorded (audio).

I do

I do not

agree to notes being taken.

I understand what this research is about. I agree to be a part of this research. I have been given a copy of this form. It has been read out loud to me.

Name of participant: \_\_\_\_\_

Signature of participant: \_\_\_\_\_ Date: \_\_\_\_\_

(ALTERNATIVELY) VERBAL CONSENT GIVEN: \_\_\_\_\_

RELATING AUDIO FILE NAME: \_\_\_\_\_

Signature of researcher: \_\_\_\_\_ Date: \_\_\_\_\_