

Uncertain subjects: Disabled women on B.C. income support

by

Sally Agnes Kimpson
Bachelor of Science in Nursing, University of Victoria, 1989
Master of Arts, University of Victoria, 1995

A Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of

Doctor of Philosophy

in Interdisciplinary Studies

© Sally Agnes Kimpson, 2015
University of Victoria

All rights reserved. This dissertation may not be reproduced in whole or in part, by photocopy or other means, without the permission of the author.

Supervisory Committee

Uncertain subjects: Disabled women on B.C. income support

by

Sally Agnes Kimpson

Bachelor of Science in Nursing, University of Victoria, 1989

Master of Arts, University of Victoria, 1995

Dr. Mary Ellen Purkis, Co-Supervisor
School of Nursing

Dr. Antoinette Oberg, Co-Supervisor
Department of Curriculum and Instruction

Dr. Carol McDonald, Departmental Member
School of Nursing

Dr. Katherine Teghtsoonian, Outside Member
Studies in Policy and Practice

Abstract

Supervisory Committee

Dr. Mary Ellen Purkis, Co-Supervisor
School of Nursing

Dr. Antoinette Oberg, Co-Supervisor
Department of Curriculum and Instruction

Dr. Carol McDonald, Departmental Member
School of Nursing

Dr. Katherine Teghtsoonian, Outside Member
Studies in Policy and Practice

With an explicit focus on how power is enacted and what this produces in the everyday lives of chronically ill women living on B.C. disability income support (BC Benefits), this research is located at the contested juxtaposition of what I refer to as three fields of possibility; feminism, poststructuralism and critical disability studies. Each of these fields suggests methodological, empirical and interpretive readings that enable me to produce different knowledge, differently, about disabled women's lives. Using verbatim narrative accounts from in-depth interviews focused on how each of four participants live their lives, take care of themselves, and make sense of and respond to the government policy and practices to which they are subject, reveals everyday, embodied practices of the self that constitute their subjectivities as disabled women. Together, these accounts along with critically interpretive reflections reveal/expose/make visible the lives of these women in response to exercises of power in ways that unseat, unsettle and disrupt taken-for-granted understandings of those who are disabled, female and poor.

Along with explicating power relations in the lives of disabled women and what these produce, I also link these critically to their health, socio-economic well-being and citizenship, while creating a disruptive reading that destabilizes common-sense notions about disabled women securing B.C. provincial income support benefits. Thus my research purposes and those of my disability activism are melded as these intersect within the (often-contested) borders of poststructural and social justice terrain. Despite public

claims by the B. C. government to foster the independence, participation in community and citizenship of disabled people in B.C., the intersection of government policy and practices and how they are read and taken up by the women, produce profound uncertainty in their lives, such that these women become uncertain subjects. Living poorly, they experience structural poverty, compromised well-being and “dis-citizenship” (Devlin & Pothier, 2006), all inconvenient facts reflecting a marked disjuncture between how government programs are publicly represented and their strategic effects.

Table of Contents

Supervisory Committee	ii
Abstract	iii
Table of Contents	v
Acknowledgements	vii
Dedication	xi
I begin here	1
What had I begun?	8
<i>Proceeding towards complexity: Weaving broad tapestries</i>	11
<i>Locating in field(s) of possibilities: Poststructuralism, feminism, and disability studies</i>	15
<i>(Fleshing out) women, bodies, disability</i>	21
<i>Disabling the social model</i>	33
<i>The subject(s) of bio-power</i>	43
The conduct of (the) research	52
<i>Imagining and recruiting participants</i>	61
<i>Why disabled women living with chronic illnesses?</i>	63
<i>Navigating interpretive labyrinths, finding egress</i>	71
Impossible stories	77
<i>Applying for benefits</i>	80
Laying bare the disciplinary process	101
<i>Im/personal campaigns</i>	111
<i>Translating difficulty, caring for self</i>	133
<i>(Close) Encounters with Ministry workers, and Alternative Means</i>	155
<i>Being caught: And a Faustian bargain?</i>	177
<i>Limiting changes, juggling limits</i>	190
Palimpsest: From the ground up (v. 4)	200
<i>No good subjects of resistance</i>	206
<i>Work without choice, fear and distrust, dependency</i>	210
<i>Be afraid, be very afraid</i>	213
<i>Dependency: An unintended consequence</i>	217
<i>Uncertain subjects</i>	224
Challenging Changes: The Disability Designation Review	228
<i>The unknown, known</i>	233
<i>Advocacy and The Review: Strategizing in the dark</i>	241
<i>(Mis)understanding The Review</i>	265
<i>Strategizing (and) The Review</i>	290
<i>Expediting The Review</i>	301
Pulling up short and thinking	314

<i>Unsettling well-being</i>	316
<i>The un/certainty of poverty</i>	322
<i>Poverty, revisited</i>	324
<i>Disabled citizen/subjects</i>	327
<i>Concerning ourselves with politics</i>	335
<i>Coda</i>	339
I end (it) here	343
References	346
Appendix A: Notes	362
Appendix B: Letter of Invitation and Informed Consent	366
Appendix C: Interview Guide	369
Appendix D: Context of The Review	370

Acknowledgments

Interestingly, writing appreciation for those who have accompanied me in/during this lengthy process seems a somewhat daunting task, not because I am at a loss for words (as if), nor because there were only a few of you. Quite the opposite, and along with the diverse (and special) roles each of you play in my life, therein lies the challenge.

Although I have space to name all of you, I may have to forgo written appreciation for each of your unique individual contributions to my life and/or studies.

Yet there are those who I would be remiss not to mention in this way.

I would first like to sincerely express how grateful I am to my four participants, Marion, Galya, Evelyne and Jocelyne for their participation in this research. Without their honesty, candour, passion and willingness to describe the difficult details of their lives, this dissertation would not be what it is.

Likewise, I have deep appreciation and respect for my committee members and their willingness to remain with me over time and through the vagaries of conducting doctoral research at mid-life while living with a chronic illness. Special thanks to my brilliant co-supervisors, Dr. Mary Ellen Purkis and Dr. Antoinette Oberg, for patiently and with exquisite timing and grace expertly encouraging, nudging, supporting, advocating, thinking, reflecting, discussing, understanding, accommodating, questioning, provoking, critiquing, and in uniquely flexible ways enabling me to proceed non-traditionally. To Dr. Katherine Teghtsoonian for your thoughtful and provocative engagement with me and my nascent understandings of feminist political theory during our directed study, and for continuing with me over time. And to Dr. Carol McDonald for generously volunteering to join my committee mid-degree, for reading my work with great heart, spirit and understanding, and for being there.

I am blessed with many longstanding, deep and nurturing friendships, which comprise different communities and means of support. All of you willingly join me in whatever enjoyment there is to be had when we spend time together, usually a lot. From these communities I wish to thank all of you.

From the early days of my doctoral studies, my interdisciplinary doctoral women's study group members (all now with earned doctorates), Wendy Donawa, Enid Elliott, Pat Rasmussen, Heather Hermanson and Joan Boyce, to whom I am deeply grateful for stimulating my intellect, supporting me in heartfelt ways and refusing the split. Latterly, thanks also to Carolyn Schellenberg and Connie Carter. And many thanks to Janet Sheppard and the members of the Thesis Completion Group for helping me to keep on track during the last two years. Deep gratitude and appreciation also goes to Connie Frey for nurturing my creativity.

Thanks to four people (two former graduate students I taught) who keep me intellectually, socially and politically engaged, nourished, and my wine glass full—Catherine van Mossel, Margaret Scaia, Lorelei Newton, and Karen Hurley—my life would be much diminished without each of you. Deep appreciation also goes to my dear friends Carmie Verdone and Susan Dempsey for walking closely beside me with great heart in our shared spiritual and embodied lives, and love of good food.

From my life pre-disability come some of my most enduring friendships. We have come a long way together and all of you live deeply in my heart, including my two close friends from high school, and nursing school at the Hospital for Sick Children, Sharon Broughton and Jane McDonald. A few years ago when I decided I wanted to have more fun in my life I turned again to friends I lived and played with years ago (and you didn't disappoint). Thanks to Pamela Ker, Jo-Anne Colquhoun & Tim Cooper, Doug Kelly (Isobel Doyle), Neil Smith (Deidre Björnson), and Susan Manchee, and from my earlier life in Rossland, BC, Raymond Gaudart and Jenny Baillie, for playfully reminding me who I am. Likewise to my dear friend, Denise Tarlier, old ski patrol pal and now nursing colleague. Appreciation also goes to Debbie Tippet, who has remained close (and immensely supportive) since our BSN days. Likewise to my quick-witted, cherished friend Martha Mackay, like me a former Torontonion who lived in Rossland and pursued a doctorate in nursing.

From those in the disability studies community from whom I have learned much and whose support and counsel deepens my ongoing understandings of being a woman living

with disability, a deep debt of gratitude is offered to Kari Krogh, Susan Mahipaul and Kirsty Liddiard.

A good life with disability means establishing trusted relationships with health care professionals and I am blessed to be connected with and cared for expertly by Louise Wood, Jim Tucker, David Attwell, Kavan Yu, Barbara Clearbridge, and Jacklin Houle.

I also wish to thank my sisters Jill Kimpson and Molly Charko for the gift of love they give me, especially valued as our family diminishes in size with the loss of our parents. And thanks to my stepmother Joan Kimpson for believing in me, Corey and Joe Kimpson for taking such good care of Dad in his declining years, and my stepfather, Warren Jackman (d. 2009) who recognized with generosity the financial disadvantage being disabled has placed on my life. To my cherished companion animals, Puck (d. 2012) and Fionn, whose warm bodies, joyful exuberance, and unconditional acceptance have been a tonic during difficult times.

Lastly (but not least), I offer untold appreciation, gratitude and respect to my beloved partner Greg Mittag, who knows deeply what it means to live with and be uniquely and wholeheartedly able to support a loved one living with a disabling chronic illness while pursuing a doctorate, which he has accepted willingly and with kindness, and for which I will be forever grateful.

This research was partially funded through the generous support of the following institutions, to which I am grateful:

Social Sciences and Humanities Research Council Doctoral Fellowship, University of Victoria President's Research Scholarship, the BC Health Research Foundation Studentship Grant, the Michael Smith Foundation for Health Research/BC Medical Services Foundation Doctoral Trainee Award, the Ord & Linda Anderson Interdisciplinary Scholarship, University of Victoria Interdisciplinary Fellowship, the Coast Capital Citizenship Award, University of Victoria Graduate Teaching Awards (2), Leslie and Kaye Jowett Memorial Scholarship (for disabled graduate students), Ray Hadfield Memorial Fellowship, Canadian Career Development Foundation Leadership Scholarship (Stu Conger Award), and The Hospital for Sick Children Alumnae Association Hilda Rolstin Memorial Award (first recipient).

Dedication

I dedicate this dissertation to two people in my life whose memory I cherish, and without whom this work would not have taken the shape it has.

To my father, Dennis Joseph Kimpson (1918-2014), who wisely fostered in me a love for the written word, a critical viewpoint, and the value of paying close attention.

To my dear friend and colleague, Dr. Tanis Doe (1967-2004), whose lively, unconventional spirit lives in this work deeply, for befriending, inspiring and mentoring me.

I begin here

Here, in my life with disability. A life that, reflected upon, reveals what interests me deeply about living with disability, deeply enough to spend a dozen and a half years studying the intersection of disabled women's lives with governing institutions. Simply put, the topic of this dissertation—the intersection of government policy in disabled women's everyday lives and what this produces—emerged from my own experiences of negotiating disability income support systems. This is not a disinterested account.

In early 1997, as I considered the possibility of pursuing a doctorate, I found myself immersed in a distressing set of circumstances that, at the time, left me feeling powerless, constrained and fearful. I had left my work as a registered nurse in 1982 due to a particularly aggressive form of rheumatoid arthritis, a chronic, progressively degenerative condition affecting my joints and connective tissue, characterized by unpredictable and fluctuating levels of pain, stiffness and fatigue, with destruction in most joints in my body and significant deformity in my hands and feet.

For 15 years I had been receiving a very small, fixed Long Term Disability (LTD) benefit from a well-known Canadian insurance company, bargained for as part of the very first contract between the British Columbia Nurses' Union (BCNU), of which I was member, and my previous employer. In 1996, I had begun a very part-time return to work after completing an undergraduate degree in Nursing in 1989, and a graduate degree in Counselling Psychology in 1995. During my university education I had continued to receive LTD benefits, in part because I had made convincing arguments before beginning both degrees to my vocational rehabilitation consultant (who makes recommendations to

the insurance company) for pursuing higher education as part of my rehabilitation, in terms of enhancing my future potential for securing gainful employment.

Re-entry into the workforce found me teaching an undergraduate course in Nursing, which did not provide me with enough income to support myself, but thankfully also did not exceed the highly restrictive limit on allowable employment earnings set out in the LTD contract. This offered me some relief, as I figured that with my education completed the insurance company would likely expect me to continue working and the teaching wages were sufficiently lower than the allowable earnings such that my LTD benefit would not be immediately withdrawn.

Or at least that is what I assumed. To be honest I was not sure what the insurance company expected of me during this period, or how long or how much work I might be allowed to do without jeopardizing my benefit. Second-guessing had become routine for me in my dealings with the insurance company, borne of mistrust and feeling at the mercy of those nameless individuals who made crucial decisions about whether I continued to meet their stringent criteria for being “disabled,” and thus eligible or not to receive benefits.

Losing the ‘security’ of the benefit—a misnomer because it was always subject to review by the insurance company—and everything to which it entitled me, including extended health benefits, was my biggest fear. I just could not see how I could wholly support myself, given the unpredictable and fluctuating condition I lived with, because I knew that I would need my health to be (relatively?) reliably stable in order to do so. Losing my benefit seemed a recipe for disaster. I imagined living in or near poverty, without extended health benefits, struggling to meet my rent, pay for medication, eating less

nutritious food, constantly scrambling to make ends meet, to survive, all the while the thing I would most need to depend on to be gainfully employed—my body and reasonably good health—deteriorating because working would have become an absolute necessity.

Teaching a large undergraduate course in Nursing for the first time was exhausting for me, and I began to reconsider whether I had the stamina to continue doing so. As a sessional lecturer I had not asked for a disability accommodation, nor was one offered. Doing the research for my graduate degree, as challenging as it had been, had never exhausted me in the way teaching did, because I could pace myself in ways that respected my physical limitations. It was at this point that I began thinking that doing a doctorate might be both a sensible and practical possibility, reasoning that it would provide me with the education needed for a research career. Completing my education would also enable me to maximize my potential, capitalize on my intellectual capacities and fulfil my dreams. I was also deeply concerned about my very constrained financial status and how to best improve it.

At least that is what I told myself. What I told my vocational rehabilitation consultant about doing a doctorate was that it would enable me to participate more fully in employment once completed, because I would have the qualifications needed to conduct research projects, a less physically demanding option than teaching. I was making the argument that I guessed would most appeal to the insurance company, that is, it would make good economic sense to have me attain the educational qualifications needed to secure gainful employment such that I would no longer require my disability benefit.

Despite my sense that approval from the insurance company to do a doctorate was a long shot, I was not prepared for my rehab consultant's response: the insurance company may view the return to school as hampering my ability to work. This was extremely distressing to me. I had spent the previous fall reading disability studies literature as a way of thinking about and getting clear on a topic that would sustain me during a doctoral program, which I was not certain was possible. During this period, I was also dealing with a seriously inflamed knee, characterized by joint thickening and pain, enough to immobilize me such that I declined another teaching appointment in Nursing. Once I arrived at a potential topic, the intersection of disabled women's lives and governing institutions, the possibility of doing a doctorate opened up and my spirits lifted immensely. Unexpectedly the inflammation began to resolve. It felt as if my energies and my life were in motion again after being so immobilized.

Yet learning that the insurance company might prevent me from returning to school left me angry, depressed, feeling defeated and constrained. The idea that it could exercise such power and control in my life sickened me. My knee began to thicken again. I asked myself why I should be kept from getting ahead, achieving my potential just because it did not fit into the insurance company's all-or-nothing definition of disabled. How could my dreams and aspirations be so at the mercy of a corporation (and by extension a disability plan bargained for by well-meaning nurses)?

Conversations with my rehab consultant about the possibility of returning to school focused on my efforts to downplay and minimize the time and energy required to return to school, for example, attending as a full-time student meant being registered for only three (3) units in any given session. I also stressed that in the past year I had only worked

very part time for five months out of twelve, and some of the remaining time could be put to good use advancing my education. Although supportive, she expressed caution, telling me the provider of the LTD benefit did not understand these nuances. I was hoping she would advance my case, while fearful of the insurance company's response.

It was the fear, immobilization and depression that finally got to me. I had no way of knowing whether the insurance company would approve my plan to pursue a doctorate. I felt trapped, both by their restrictions and by my inflamed knee. And I was angry, especially at being governed by the language of the LTD portion of the BCNU contract, which limited me and accounted for my life in ways that did not reflect what I was experiencing and hoping.

I spent most of my time strategizing ways to free myself. I could write the BCNU president so she would understand how the contract placed unreasonable restrictions on me. I could consult with the BC Coalition of People with Disabilities (BCCPD), an activist and advocacy organization, about finding a lawyer who might advance a class action suit against the BCNU for not bargaining for the LTD plan in good faith.

Considerable time was spent thinking about finding a way out of this impasse. But I knew engaging in any these strategies would likely tire me out, and I didn't really believe I could make a difference on my own, which further demoralized and angered me. The anger and fear were exhausting, and I began to see how unhealthy it was to continue responding this way. I simply didn't have the energy to engage in a campaign; I also knew that feeling trapped compromised my health. But what was I trapped by?

Reflecting on my situation, I began to see that I had *wholly* succumbed (subscribed) to a belief that the insurance company could control my life (and my future). I had

relinquished my own aspirations and the opportunity to honour my potential out of fear of losing my benefits. This shocking revelation was followed by another—I could resist this version of reality—and in fact doing so might release me from my powerlessness.

At first I thought I could tell the insurance company that I was attending school part-time, which I reasoned they would be most likely to accept, but I needed to be enrolled full time in order to apply for scholarships, because the income from my non-indexed LTD benefit left me living just below the poverty line. I wondered what game I would need to play. Go to school full-time, tell the insurance company I was attending part-time, and pray they didn't request documentation. This seemed too risky. But equally risky was returning to school full time without the insurance company's approval.

Ultimately, I opted for the latter and began the process of applying for full-time enrolment in a doctoral program, a process not unfettered by bureaucratic barriers. However, focusing my energies in this direction was freeing and I no longer felt immobilized. I was readily accepted into my program, something that both delighted and frightened me. A month into my coursework, my rehab consultant called to check in with me, registering considerable surprise when I told her what I was doing. I told her that central to my endeavours was “the principle of honouring my potential” despite the risk. I have no idea what she did with this information, but I have reached the end of my program unimpeded by the insurance company.

Even as I traversed this difficult terrain, I remarked in my journal how, given my interest in disabled women's lives, it was not surprising that this series of events was unfolding in my life. It enabled me to be engaged in my doctoral research before it began, based in the

detailed and intimate knowledge I had acquired about the disciplinary powers of institutions in my everyday life as a disabled woman. I began here.

What had I begun?

To re-search—search again and again—(for) ways to think and write about my deep, abiding interest in the intersections of disabled women’s embodied lives with governing institutions/organizations, and what these produce. I have been searching for ways that would do justice in/to the invisible lives of disabled women, but also ways of thinking and writing influenced by reflections on my own life with disability, which is imbricated with the lives of other disabled women subject to (and subjected by) institutional policy and practices. Put simply, the deeply personal interest central to this study is how power is exercised in disabled women’s lives and with what this might produce, i.e., the possible actions disabled women take and/or what they do in response to exercises of power.

In my everyday life as a woman with a disability, I have engaged the limits and possibilities made available to me within the confines of various institutional frameworks/practices to which I have been subject. The narrative that opens this dissertation reveals how I have exercised a certain level of risk in responding to one governing institution, an insurance company administering long-term disability benefits. I know from my encounters with other disabled women in regional and provincial activist settings however that, although my situation has been intermittently precarious and I always have latent fear of losing my benefits, I have not lived with some of the persistent fear and extreme difficulties, such as being homeless and uncared for experienced by those disabled women living with chronic illnesses who receive provincially-administered income support in British Columbia (B.C.).

In this dissertation my purpose is/I seek to explicate power relations in the lives of

chronically ill women who receive what disability activists and scholars call ‘last resort’ benefits, that is, disability income support administered by the provincial government of British Columbia. I am deeply curious about micro-practices of power and how they are enacted in these women’s lives (and on their bodies) and what is produced; in particular how these disabled women live their lives, how they make sense of the policies and practices to which they are subject, and what they do that makes them who they are as disabled women—everyday, embodied practices of the self that constitute their subjectivities.

My curiosity arises out of a desire for my work to benefit their lives in some small way, but also because I am aware of how close I have been to living the kind of precarious and uncertain lives they do and in turn might benefit from knowing what they know and do, as might we all. In this way their lives “have sedimented out in my own subjectivity” (St. Pierre, 2000, p. 259); my own life with disability does not remain unaffected upon encountering their lives, but rather is shaped by these encounters and I see how my life is both similar and different from theirs, and how I am perhaps well positioned to make visible what are (their) otherwise invisible lives.

Despite robust public claims to support British Columbians with disabilities and lofty intentions to foster their independence and participation as citizens in communities (Coleman, 2009), the B.C. government falls well short of these ideals, producing the opposite in the lives of disabled women receiving provincial disability income assistance wherein it is difficult, if not impossible for these disabled women to achieve social and economic well-being, and exercise citizenship in taken-for-granted ways. Through narrative accounts of disabled women’s everyday embodied lives I intend to show how

they (their subjectivities and their lives) are constituted in ways that produce uncertainty and further disable them, and how, in response, these women enact an uncertain, unsettled version of health.

Related to this purpose I also intend to reveal/expose/make visible the lives of the study participants in such a way that they and other disabled women *will recognize themselves and what they do* in response to institutional exercises of power. I intend to do this in ways that unseat, unsettle and disrupt taken-for-granted understandings of the lives of those who are disabled and female, and subject to structural poverty.

Thus, the purposes of the research are twofold: to explicate power relations in the lives of disabled women and what these produce, linking these to their health, socio-economic well-being and citizenship; and to create a disruptive reading that destabilizes common sense notions about chronically ill disabled women securing provincial income support benefits.

Living with disability requires that I respond daily (and often moment-to-moment) to the variety of physical symptoms I experience, but also to the ways I have been disciplined by medical, governmental (and insurance) bureaucratic imperatives and the legal frames and practices that shape them. I have been negotiating these murky waters fairly successfully. Doing so reveals how I am also positioned (and position myself) with respect to knowing and living with disability. It also produces an embodied, grounded, deeply reflexive reading of disability and disabled women's lives that informs how I think and write about each for the purposes of this study. Helen Meekosha (1998) reminds us that, "subjective stories and narratives of disabled women's experiences constitute valuable material demanding interpretation and analysis" (p. 163). By design,

the narrative accounts rendered here are both partial, perspectival and socially situated, that is, they reflect/comprise situated knowledge (Haraway, 1991) created with/in the lives of disabled women for specific purposes and audiences. The texts are plurivocal and open to multiple, fluid, and contextual readings; there is no master narrative represented here. As a researcher all I have is “talk and texts [representing] reality partially, selectively, and imperfectly” (Kohler Reissman, 1993, p. 15). Perhaps more importantly for this study these particular accounts are political in that they have the power to “produce new ways of seeing,” and are therefore “always...open to contestation” (Gannon & Davies, 2007, p. 72). They are not objective; rather they are socially and politically interested.

Proceeding towards complexity: Weaving broad tapestries

To say that ‘everything is political’ is to recognize the omnipresence of relations of force and...to set oneself the barely sketched task of unravelling this indefinite tangled skein. (Foucault, cited in Mills, 1997, p. 80)

Unravelling the “indefinite tangled skein” of power relations in disabled women’s lives requires me to identify and describe multiple interpretive strands, which reflect different ways of thinking about and making sense of various constitutive forces in the participants’ lives. As the unravelling proceeds, I rest at certain places to weave *in writing* methodological, empirical, and interpretive strands into “broad tapestries” (Schlesinger, 2005, p. D16). These textual tapestries inscribe “the thinking that writing produces” (St. Pierre, 1997, p. 178), which, along with reading and rewriting, constitute ways of proceeding in which I have engaged in order to study disabled women’s lives, using writing as a method of inquiry (Richardson, 2000).

Finding the threads in the skein “is not a process of finding independently existing objects or practices that can be named” (Davies, 1994, p. 46). When I create a text by describing what is there and/or interpreting it, or a narrative account, the objects and practices spoken or written about are constituted (in particular ways) by me. In this way “the constitutive act must become part of the picture of what is seen” and I must catch myself “in the act of seeing in particular ways” (p. 46). A concern with the material, embodied effects¹ of power relations guides me in the critical and self-reflexive task of interpretation, while concomitantly paying close and critical attention to the potential effects in my own life (and that of other disabled women) of the texts I am constructing in the writing/thinking process.

Writing (and rewriting) is a textual practice that both takes shape and shapes what can be said as the inquiry proceeds; in this study it is both vehicle and product. It is not just a means to convey ideas but is a practice that produces ideas. Julia Colyar (2009) is clear about the role of writing in qualitative research, “Writing *is* qualitative methodology... underlying and shaping the research approach” (p. 433). Being recursive, writing reflects “the unfinishedness of our work, the ways in which what we know as we write is constantly reshaping itself” (p. 433). It is an evolving process of discerning and refining.

¹ A note about the use of the term “effects” (as in effects of power relations/exercises of power). Foucault was clear about the use of this term in describing a non-causal relationship between exercises of power and what people do/ how people respond who are imbricated in/exposed to these. Tanya Murray Li (2007) asserts that interventions by government “are important because they have effects” (p. 276) specifically to “change things” (p. 276) (not always for the better). In this research “effects” constitute what is produced at the nexus/intersection of governmental exercises of power and women’s lives, and are multiple and unpredictable. The effects (conditions, responses, actions or non-actions and subjectivities, for example) produced are always possibilities (until revealed) because exercises of power intersecting with women’s embodied lives are always complex, situated and contingent.

I write in response to a vast array of experiences and texts—reflection on readings, my own writing, that of other authors, discursive encounters with participants, colleagues, supervisors, fellow activists, bodily sensations, dreams, difficulties with institutions, emotions, data collected and transcribed, data collection processes. Not all these writings appear here, but each textual encounter shapes the different ways I think about and approach my topic.

To weave is to create, to engage openly in a process of paying attention to the materials at hand and how they intertwine. To begin with I pay close attention to how I (am in relationship to) exercise(s of) power in my own life with disability. This process is generative and embodied. As a creative process it is analogous to living in a chronically ill body. I cannot order or control it (reliably), I cannot push it where it is unable (or unwilling) to go, I cannot hurry it, I do not know what comes next (it is unpredictable), and it requires me to attend to and be with what presents itself to me in the moment.

The world we know is not this ultimately simple configuration where events are reduced to accentuate their essential traits, their final meaning, or their initial and final value. On the contrary, it is a profusion of entangled events.
(Foucault, 1984, p. 89)

I have been guided in this unravelling/disentangling and weaving by how I have come to view my own life/everyday experiences of living with disability, and what it/these reveal about complex intersections with governing institutions. In this way, I use my embodied living with disability as a source of data; by paying attention to my own embodiment, insight (knowledge) about disabled women's lives is generated, rendering my experience epistemologically significant. Discerning the predominant quality of or conceptual element in the experience (e.g., resistance or dependence) is not the *whole* experience.

Ontologically, I assume multiplicity, and so consider other qualities or concepts that might also be in play, even though one element might predominate at any given point in time. This process enables me to articulate what is at stake as part of a liminal space of (researching) disabled women's lives, the space of refusing the split, the binaries.

Just as my life with disability and disability benefits is complex (and complicated) and messy so are the lives of my participants and I assume many other women living with disabling chronic illnesses. This complexity and messiness reveals the challenge; the question and the impossibility of representing their lives in some unitary way using a tidy realist tale. It is just this impossibility that provides the difficulty around which I have been circling that informs the shape of this text.

By situating my “experience of impossibility as an enabling site” (Lather, 2007, p. 16) for working through not knowing and other intellectual difficulties in writing, I signal another way I have been proceeding—“coming up against stuck place after stuck place as a way to keep moving in order to produce and learn from ruptures, failures, breaks, refusals” (Ellsworth 1997, pp. xi, 9). My life as a disabled woman informs what it is possible for me to say (as a researcher) about the lives of other disabled women. Mine has been an “interrupted and conflicted life, where energies are not [always] narrowly focused or permanently pointed toward a single ambition” (Bateson, 1990, p. 9). Yet it is a life with commitments, which by necessity need to be “continually refocused and redefined” (p. 9). Living with this kind of contingency and discontinuity is not unique to me, and like the disabled women's lives studied here uncertainty has been the hallmark of my experience as a researcher (and as a disabled woman) enabling me to see more clearly this quality in their lives and understand deeply how they live as uncertain subjects.

Locating in field(s) of possibilities: Poststructuralism, feminism, and disability studies

[It is important] that we work ourselves free—to the extent possible—of entrenched presuppositions and theoretical totalities, that we keep ourselves open to an ever-opening intellectual and political future by refusing the certainty that theories and their epistemic foundations always promise, that we opt for questions more than answers, that we love possibility and experiment more than we crave control. Whatever presses for closure, finality, absolute assurance presses also for an end to vitality—that is, for a kind of death. (McWhorter, 2005, p. xvi)

Earlier I referred to weaving broad tapestries from interpretive strands. What I refer to here is my use of different interpretive fields in which I locate myself to inform and shape the creation of textual tapestries that reflect readings/interpretations that explicate complex intersections in disabled women's lives with governing institutions, and what the women do in response. My choice of fields within which to locate myself is 'interested.' The fields are constituted not just through reading/writing how each is reflected and plays out in (and is shaped by) interpretations made of the lives of the disabled women studied here, but also as each resonates with my own experience of being a disabled woman with experience of living with income support. These fields "do not dictate what is to be seen or written, but open up new possibilities" (Davies, 2003, p. 15) or fields of possibilities produced through reading/writing as the inquiry proceeds.

Although these interpretive fields intersect and even overlap, I eschew the urge to create a unifying theoretical frame to guide interpretation. Despite proceeding in a way that locates me as a researcher (and my inquiry) within the interpretive fields of poststructural thought, feminism and disability studies, I catch myself in the illusion (and desire) that it is possible, indeed necessary for me to now clearly articulate a tidy little interpretive

framework (tapestry?) for the purpose of studying disabled women's lives. How seductive it would be to have each disparate element of a frame clearly described, and neatly (and directly) related to each other, problematic connections astutely articulated to reveal to readers how well thought-out, encompassing and definite (and definitive) my interpretive 'framework' is. But this would obscure complexity and the impossibility of knowing completely. Perhaps more importantly, to do so would obscure the ways I have been proceeding emerging from my awareness and acknowledgement of the complexity of my participants' lives and the impossibility of knowing in advance how to proceed to render these lives visible in ways that reflect the purposes I seek.

My understandings of each of these fields of possibility (and their utility for the study's purposes) emerged through an arduous process of engaging reflexively with the data, and each enables me in different ways to answer the question, "What can be said?" about these women's lives as they intersect with institutional practices. Together, drawing salient elements from these fields of interest in/form what Foucault (1998) calls doxology, a "description of the uses that might be made of a conceptual ensemble as a particular play of form on the ordering of the empirical" (p. 329). Each constitutes methodological, empirical and interpretive readings that enable me to produce different knowledge—to say different things and to say things differently—about disabled women's lives as these intersect with institutional exercises of power, and what these intersections might produce. Each also enables me "to produce [this] knowledge differently, thereby producing different ways of living in the world," and even opening the possibility of "different worlds that might, perhaps, not be so cruel to so many

people” (St. Pierre & Pillow, 2000, p. 1), especially disabled women living on provincial benefits.

I seek to unseat, to unsettle taken-for-granted understandings of the lives of those who are disabled and female and poor while acknowledging and respecting the difficulty of representing their complex, liminal, uncertain lives. Proceeding on shifting ground, not knowing—or more accurately “knowing too much and too little” (Lather, 2007, p. 11)—which interpretations ‘work,’ and when, and what each might produce constitutes something other than control and mastery. I can only know partially; the act of interpretation reveals only partial truths, at times incommensurable, leaving me wondering what precisely can be said about disabled women’s everyday lives that is justifiable and useful, about the complex ways their lives intersect with governing institutions. For myself this includes experiencing the “disruptive/blissful possibilities” (Davies, 2000, p. 143) that engaging in poststructuralist writing practices opens up. Working/writing poststructurally as a feminist enables me to “critique, interrupt, and reinscribe normative, hegemonic and exclusionary...practices” (St. Pierre & Pillow, 1997, p. 3) that diminish and narrow the lives of disabled women.

I seek also to blur and disrupt the abled/disabled binary, a hierarchical and oppositional mode of thinking disguised as natural, through the play of/with language and representation germane to poststructuralist writing, thus disrupting and troubling the relations of power that undergird stereotypes about disabled women (and their bodies) and that maintain the status quo and taken-for-granted understandings of their lives (Gannon & Davies, 2007). Research in/formed by poststructuralist thought concerns itself with “disrupting certainties and seeing possibilities other than ‘business as usual’ in the

cracks/silences opened by such disruption” (Laws, 2004, p. 119).

Thinking about using poststructuralist theory as a primary/central conceptual apparatus or interpretive ‘frame’ I might use to shape the interpretive process generates questions for me about how best to represent disabled women’s lives for the purposes I seek. Rather I choose to draw from the field of poststructuralism (and scholars using poststructuralist thought in both feminism and disability studies) in ways that serve the purposes I seek to achieve.

Poststructuralist theory does not provide a frame or lens through which to look at the data (nor is the data a lens on a world which is thought to exist independent of that data) but a way of drawing attention to aspects of text and talk [produced about and from women living with disabilities] otherwise not visible. I use poststructuralist theory as ... a way of unraveling old realities/perceptions and thus making way for new ones. (Davies, 2003, p. 15)

Thinking about frames as objects providing particular ways of viewing disabled women’s lives presumes that I can write about interpretive frames separately from using them and create interpretations through a linear process of ‘applying’ a particular frame to the data. But frames and interpretations are both produced in the discursive act of continuously reading and writing; ways of thinking about the phenomenon crystallize and become available only in the process of reading from interpretive fields alongside/along with the data/transcripts, not by being described or framed in advance of encounters with the data. This process is an example of how “the skills of attending to texts in poststructuralist ways are ones that must be struggled after continuously; they are not achievable as a repertoire of specific skills” (Davies, 2000, p. 143).

Indeed, Judith Meloy (1994) is clear about the difficulties engaging in such a process presents:

The processes of pulling together, sifting, organizing, and writing our thoughts are a challenge, because the coming together occurs in nonlinear, halting, and multiple ways. The task of choosing which strands to pursue, when to pursue them and how to pursue them, as well as how to organize them and write them (up) is a recurring and difficult one...The nearer your destination the more you're slip-sliding away. (p. 11)

Poststructuralist thought and my engagement with feminism and disability studies are particularly useful for asking and answering different kinds of questions about disabled women "who have been locked in painful categories and trapped on the wrong side of vicious binaries" (St. Pierre, 1997, p. 176) germane to humanism. Both feminism and poststructuralist thought also enable me to engage with my dual concern of working poststructurally while acknowledging the materiality of disabled women's lives, bodies, and practices.

Like Lather (2007), I am

persuaded by poststructural theory [and practice] that it is what seems impossible from the vantage point of our present regimes of meaning that is the between-space of any knowing that will make a difference in the expansion in social justice. (p. 16)

What interests me about poststructural, or post-foundational thought is that as I proceed I understand that everything is in play, in flux, including the texts I create and the embodied lives of disabled women, whose subjectivities are constituted within and through local and, more broadly, social and cultural practices and discourses allowing for

contradictions and resistances. Using Foucault's work as a "resource for thinking" (Gannon & Davies, 2007, p. 85) the version of power I subscribe to is one that it is unstable and productive (of subjects) and possibilities for agency are "contingent, limited and open to reconfiguration" (Gannon & Davies, 2007, p. 73). Butler's (1995) oft-quoted argument resonates here:

[T]o claim that the subject is constituted is not to claim that it is determined; on the contrary, the constituted character of the subject is the very precondition of its agency. For what is it that enables a purposive and significant reconfiguration of cultural and political relations, if not a relation that can be turned against itself, reworked, resisted? (p. 46).

Like myself as a researcher and as a disabled woman and activist the disabled women who participated in this study "learn to live in the middle of things, in the tension of conflict and confusion and possibility" and "become adept at making do with the messiness...and at finding agency within the ambiguity" (St. Pierre, 1997, p. 176) of their everyday practices.

I see now that despite the promise of its introductory title, this section has focused primarily on the uses of poststructural thought and writing practices for this research, only hinting at complicated (and contested) juxtapositions of the three interpretive fields in which I locate this work. I have not really located myself in an explicit way in disability studies or feminist thought, the two other 'fields of possibility' mostly because of the challenges I face articulating complex, interwoven (and somewhat uncomfortable, problematic, even risky) relationships between/among disability and feminism, feminism and poststructuralism, and disability and poststructuralism.

A possible strategy to proceed through this impasse is to “trace bodylines” (Somerville, 2004, p. 47) in part by engaging in particular kinds of embodied scholarship, but also to articulate how embodiment in/forms and re/figures this research. For what, if not bodies, and particularly disabled women’s bodies create problems (and even risk) for scholars in these fields? As Wanda Pillow (2003) reminds us, “Bodies are dangerous” (p. 145), specifically disabled women’s bodies that constitute contested terrain in each of the fields of possibilities in which I locate this study. I trace bodylines by beginning with writing my own corporeality, by unearthing experiences of my disabled “body at the scene of writing” (Somerville, 2004, p. 52) and how it might in/form how I locate myself (uncomfortably?) in each of the fields of possibilities, in ways that acknowledge disabled women’s corporeality as “the material condition of their subjectivity” (Grosz, 1995, p. 103). Bodies then are considered to be a “methodological site” (Pillow, 2003, p. 146) in this study from which to interpret the everyday (embodied) practices of disabled women as they respond in various ways to exercises of power in their lives subject to B.C. government income support policy and practices. Following Foucault, disabled women’s bodies are both “objects of power and sites of resistance” (p. 153), interrupting and decentering the study of power relations.

(Fleshing out) women, bodies, disability

A human being who is first of all an invalid is *all* body, therein lies his inhumanity and his debasement. In most cases he is little better than a carcass.

Thomas Mann, *The Magic Mountain*

Because disability is so strongly stigmatized and is countered by so few mitigating narratives, the literary traffic in metaphors often misrepresents or flattens the experience real people have of their own or other's disabilities.

Rosemarie Garland Thomson, *Extraordinary Bodies*

Disability itself is so important to all our lives, so crucial to any account of human embodiment.

Michael Bérubé, *Side Shows and Back Bends*

An excerpt from my research journal:

Can I know my body? Perhaps.

Mostly I know how it feels.

I sense its changes, sometimes minute, sometimes engulfing.

I inhabit this body. It inhabits me.

I am lying in bed, living with sensations which envelope me. I focus my attention inward, despite impulses to escape. I sense a deep soreness in my shoulders and upper arms, even just touching them gently. When I move my hands to pull the down comforter up over my shoulders, I notice one of my wrists stiffens as I try to grasp the soft fabric, and a short, sharp, shooting pain travels through my baby finger. In the area between my thigh and torso, in the front, the tendon feels as if it has been pulled past the point of stretching, and is recoiling in resistance. I woke up with this strained sensation, sleeping fitfully after a day of little exertion.

I breathe in and out consciously to relieve tension as my muscles contract around the pain, girding my body against the inner assault. I notice an easing with each warm breath as it passes softly over the skin near the nostrils. But release is fleeting and the tension returns to me as waves upon a shore. I am tired, but have been awake for less than an hour.

I know that most of what I wanted to do today will have to wait until these sensations ease, at least to the point where I can reliably focus elsewhere. And even then it is likely that my concerns will continue to be bodily; drawing a hot bath, making tea and something nourishing to eat, dressing, all performed with minimal effort so as not to stir up the dis-ease.

The phone rings and I ignore it, knowing I don't have the energy or spirit to speak with others. I have plenty to do, but know that bringing the phone or the computer to the bedroom, technological conveniences I could benefit from, will have to wait on my body.

Not every day is this way.

In this writing I refuse the split (Rockhill, 1986) of mind and body required when creating traditional academic texts and “the strictures of essentialism” (Somerville, 2004, p. 52) by engaging in the strategy of centering my body at the scene of writing. I am also recognizing that my body and the texts I produce about other disabled women’s embodied lives are culturally inscribed with/in power relations I seek to disrupt. My researcher’s body is also “productive of bodies and texts at the site of [my] academic work” (p. 57); writing (through) my experience of living in my chronically ill body I generate understandings of the different ways my own subjectivity (and possibly that of others) is constituted in ways that reflexively in/form the production of texts.

Poststructuralist feminist scholarship has a tendency to subscribe to the belief that there is “no outside of text” (Somerville, 2004, p. 49), exposing women’s bodies as contested terrain for those feminist poststructuralists who understand how bringing embodiment to our work enables the kind of multiplicity we seek, not exclusively through textual means. Staying with my disabled body in writing enables me to position myself variously, and to see how as Chouinard (cited in Dyck, 1996) suggests, power is exercised through

“multiple sites of experience and practice, in virtually every aspect of life” (p. 58). It also enables me to see that to challenge these exercises of power “requires reinventing ourselves . . . and our relations to others” (Dyck, 1996, p. 58).

Somerville (2004), writing about the “(dis)appearing body” (p. 49) in poststructural feminist scholarship, suggests methodological ways to bring the material, lived body into a discursive relation with contemporary body theory including the use of “naïve accounts of experience, using the body [at the scene of the writing] and unearthing bodily experiences in memory and diary” (p. 50). In the journal excerpt (above) I engaged briefly in these three practices in order to signal that this research is grounded in disabled women’s lived bodies, but also to acknowledge as I produce this research/writing that I continue to experience my (disabled, chronically ill) lived body, while simultaneously deconstructing that experience. In this sense my body is able to both interrupt and construct discourses/texts while (on occasion/when relevant) at the same time being (a) subject to (of) these texts.

In this dissertation, my lived body has been slowly transposed into a vehicle for understanding, something I seek to respect and understand, not defer, as the research has unfolded. By including the body—“that sad grey dishrag philosophers hang inside the door beneath the sink” (Zwicky, 1992, p. 142)—and especially my disabled body as a source of knowledge, I “...intervene in the production of knowledge. . . in ways that work out of the blood and spirit of [my life], rather than out of the consumerism that can pass for a life of the mind in academic theory” (Lather, 1991, p. 20). Telling truths about my body and life enables me to transgress boundaries of conventional academic discourse, to utter what is unspeakable (Mairs, 1996). Paying attention to my body (in

pain, immobility) and that of my participants has the potential to both disrupt and inform methodological practices (Pillow, 2000). Thus, using bodily experiences as ground for my thinking, analysis and activism is a deeply subversive and political move (Kimpson, 2000).

The focus on experience comes with a caution however. I recognize feminists' concerns regarding the use of knowledge generated from women's experiences in the context of poststructuralist thought that claims subjects are constituted as an effect of discourse. Nonetheless, Susan Strega (2004) urges "women and subjugated others cannot and must not completely abandon the knowledge of our experience" (p. 63). She also cautions that "positioning experience *as* knowledge" fails to account for different ways experience itself is constructed discursively; "we can only understand, apprehend or explain our experiences within discourses and subjectivities available to us" (p. 63). With this in mind articulating my experience of living in a chronically ill body requires that I reflect on how knowledge generated from this experience is constructed and "the place of these particular constructions of subjectivity, experience and knowledge in the broader pantheon of discursive power relations" (p 63). To situate my body as a source of writing that constitutes both my scholarly (and activist) practices and my subjectivity suggests that "a powerful alternative discourse seems possible: To write [and speak] from the body is to recreate the world" (Jones, 1985, p. 87).

In terms of "fleshing out" the topics of this section, Webster's Dictionary tells me that to "flesh" is to give substance to, to make something substantial. To what might I be giving substance and flesh? Feminism and disability studies that are, in the first case, either silent about disability and fail to make it a substantive concern, or in the latter case, treat

gender as an “add-on” and limit understandings of disability to the social model, thus obscuring the ways disabled women live in our bodies, many of them chronically ill.

It is not my intention to explain *why* feminism and disability studies fail to adequately theorize disabled women and their bodies, but rather to map (flesh?) out some of the ways bodies have been taken up or theorized in each of these inter/disciplines, and where I locate myself in that terrain.

Many parallels exist between the social meanings attributed to female bodies and those assigned to disabled bodies. Both the female and disabled body are cast as deviant and inferior; both are excluded from full participation in public as well as economic life; both are defined in opposition to a norm that is assumed to possess natural physical superiority. Indeed, the discursive equation of femaleness with disability is common... (Garland Thomson, 1997a, p. 19; Garland Thomson, 1997b, p. 279)

Garland Thomson starkly reminds us how female gendered embodiment and disabled embodiment are often conflated, with both being “deficient, subject to medicalization, normalization, state intervention and rendered the Other” (Meekosha, 1998, p. 170). Indeed Iris Marion Young’s (1990) exploration of constraints on/to feminine body comportment in contemporary Western societies strongly suggests that, “feminine embodiment is dis-abled” (Corker & Shakespeare, 2002, p. 11. See also Davis, 2002, p. 45 re: the feminization of disabled people). Feminists who challenge/critique Western patriarchal discourse that persistently equates feminine embodiment with disability fail to see how their critiques ignore differences among women, in particular how disabled women’s embodiment defines them as subordinate “according to norms that diminish and degrade them” (Corker & Shakespeare, 2002, p. 12). These feminists inadvertently (and

uncritically) participate in “the discursive practice of marking what is deemed aberrant while concealing what is privileged behind an assertion of normalcy” (Garland Thomson, 1997a, p. 20). Feminist assumptions about female empowerment drawing from liberal understandings of independence and autonomy based on the premise of “an abstract, disembodied subject of democracy” (p. 26) fail to account for the accommodations required by and particular needs of disabled women (and their bodies) in order to exercise independence and participate as equal citizens in democratic societies (See also Linton, 1998, p. 90 for the marginalized place of disabled women’s issues in women’s studies). Thus, (disabled and chronically ill) women’s bodies become contested terrain (Moss & Teghtsoonian, 2008) in feminist scholarship, enabling a textual escape for some (but not all) to more abstract and disembodied ground.

Yet weaving certain strands of feminist thought and disability studies that draw from poststructuralism is also potentially fruitful, and it is here I reside. In particular, I subscribe to those aspects of feminist thought applied to the study of disabled women’s lives that extend “beyond a narrow focus on gender...to undertake a broad socio-political critique of systemic, inequitable power relations based on social categories *grounded in the body*” [italics added] (Garland Thomson, 1997a, p. 21). Garland Thomson argues for methods to examine disability that draw from feminist aims of “politicizing the materiality of women’s bodies and rewriting the category of woman” (p. 21), that is, to theorize disability in ways similar to how feminism has theorized gender as culturally-mediated, individually-expressed, embodied, complex, even contradictory experiences and attributions. She imagines a feminist disability discourse that highlights individual differences, and draws from feminist standpoint theory in recognizing that an individual’s

social location, or situatedness, mediated through/by exercises of power is constitutive of her subjectivity.

Thus, a more thoroughgoing acknowledgement of physical diversity than typically included in feminist thought is required, one that is cautious of the risks Garland Thomson (1997a) believes to be embedded in the kind of social constructionism germane to the social model of disability of “neutralizing the significance” (p. 25) of embodied experiences, like physical pain and fatigue, or disabled women’s *embodied* struggles with environments (or even social policies) constructed in disabling ways. As she strongly asserts, “Disability, perhaps more than other difference demands a reckoning with the messiness of bodily variety” (Garland Thomson, 1997a, p. 23). Feminist poststructuralists writing/thinking about women’s bodies enable disability studies scholars to do so.

Acknowledging some feminists’ reluctance to connect women’s bodies with their social positions and subjectivities—“bodies in their material variety still wait to be thought” (Grosz, 1995, p. 31)—Elizabeth Grosz (1994) refigures the body, moving it to the center of analysis from the periphery and in doing so “conceive[s] of subjectivity in terms of the primacy of corporeality” (p. x). Like Grosz, I resist the binary of a “‘real’ material body on one hand and its various cultural and historical representations on the other” (p. x). I seek to conceive of bodies as socio-cultural entities “in the stuff of their corporeality” (Grosz, 1995, p. 31) by creating narrative accounts that refuse to reduce disabled women’s lives to biomedical discourse. These narratives also encompass the kinds of disruption and uncertainty embodied in living with chronic illness and disability, an uncertainty that arguably is “necessary to any understanding of health, disease and disability” (Price & Shildrick, 1998, p. 225). (See also Grills & Grills, 2008).

Disabled women's bodies are without doubt "colonized by the discursive practices...of biology and medicine" (Grosz, 1994, p. x), but more importantly are constituted by these and other (hegemonic) cultural and historical inscriptions as bodies "of a determinate type" (p. x)—defective, abnormal. It is this taken-for-granted conception of disabled women's "broken bodies" (Shildrick & Price, 1996) I seek to disrupt in ways that draw on disability as a "transgressive [category] that demands we rethink not simply the boundaries of the body, but ... between sameness and difference ... self and other ... a fluid and shifting set of conditions" (p. 93). In this sense the "pliable flesh" [of the body] is the unspecified raw material of social inscription" (Grosz, 1995, p. 32), producing particular kinds of subjects.

Yet the messiness and specificity of the corporeality of disabled women's bodies in all their variety absolutely must be acknowledged "if the notion of a radical and irreducible *difference* is to be understood with respect to [disabled women's] subjectivity" (Grosz, 1995, p. 32, italics in original), a difference both "inscribed on and experienced by and through" (p. 32) disabled women's bodies.

How does one write the disabled body? Current theories of the body are at a loss to say. Viewed in itself...a disabled body seems somehow *too much* a body, *too real*, too corporeal: it is a body that, so to speak, stands in its own way. From another angle, which is no less reductive, a disabled body appears to lack something essential...it seems *too little* a body: a body that is deficiently itself, not quite a body in the full sense of the word, *not real* enough... . (Porter, 1997, p. xiii)

Bodies interrupt theory, even theories about the body and disabled embodiment is always in excess of what we think we "know" about disabled women. Porter (1997) argues that

“body theory must begin by naming its own incomprehension in the face of disability in all its forms” (p. xiv). Given this, it is difficult to appropriate a unifying and/or synthesizing (or even robust) feminist theory of the body for the purposes of this study; rather, I consider disabled women’s bodies as fluid, shifting, unstable material sites of “information and practice, of regulation, power and resistance” (Pillow, 2000, p. 214). Paying close attention to their embodied practices reveals how their mutable bodies “bear the marks of our culture, practices, and policies” (p. 214) and what these re/produce, suggesting ways we might re/figure social practices.

It is also apparent to me that disabled women’s bodily discourse itself has the potential to interrupt/disrupt inscriptive practices, thus constituting disabled women as able to exercise agency in the moments the body is spoken (about)/into existence as a particular kind of body. Thus, as a researcher it becomes imperative to pay attention to the bodies (participants’, my own), bodily practices, and especially the bodily discourses we engage in during the interviews. To write disabled women’s bodies into this text in all their variety and messiness resists the sanctions (and oppression) of polite society and to some extent mainstream disability studies such that a disabled woman’s “deviant” body can be “radically transformed into a vehicle for redressing its normative cultural assignment as a dustbin of disavowal” (Snyder & Mitchell, 2001, p. 382; Shakespeare, 1994), thereby extending “a radical critique of corporeality” (Povinelli, 2001, p. x) proffered by disabled feminists, and other critical disability studies scholars. Given this, revealing disabled women’s own embodied perceptions and exercises of agency shows how these are “productive in conforming to, reiterating and contesting normative standards of acceptable bodies through which they are seen and known” (Zitzelberger, 2005, p. 400).

My location in disability studies then is both feminist and poststructural, necessary for understanding how disabled and chronically ill women's bodies (and lives) have been shaped and even disciplined through systemic patterns of power in our society, which as Foucault (cited in Davies, 2000, p. 39) reminds us “[reach] into the very grain of individuals, touches their bodies and inserts itself into their actions and attitudes, their discourses, learning processes and everyday lives.” Foucault also (1980a) refers to the “concrete nature of power” (as opposed to power as an abstraction) becoming visible for those “whose fight was located in the fine meshes of the web of power” (p. 116). For disabled women, the “concrete nature of power is materialized in [their] desires, in their bodies, and in social relations and institutional structures” (Gannon & Davies, 2007, p. 84).

Power operates directly on bodies by extricating knowledge from them useful for disciplinary purposes, including the academic disciplines. Grosz (1995) posits a kind of mutuality between disciplinary knowledge that requires interactions between bodies and exercises of power on one hand, and power that “requires knowledges of bodies...in order to remain effective and ‘in play’ ”(p. 32) on the other hand. The disciplinary regime of medicine for example (and attendant institutions), requires knowledge of bodies (and what is “normal”) in order to treat patients, thus exercising power not only to practice effectively but also to derive knowledge required for practice, inscribing bodies in particular ways.

An inscribed or marked body is not necessarily a passive one; our bodies produce inscriptions on others' bodies thus constituting the body as a living, acting, productive subject and one that can also become a site of resistance and struggle. In this way bodies,

“from which embodied knowledges emerge” (Moss & Teghtsoonian, 2008, p. 13) are understood as “simultaneously material and discursive” (p. 13) and “essential to accounts of power and critiques of knowledge” (Grosz, 1995, p. 32), such that embodied subjectivities are both produced and “are productive in shaping constructions and possibilities of embodiment...across social and material relations and practices” (Zitzelberger, 2005, p. 400).

Foucault’s work on the productive nature of power enables a shift in the focus of the study of power to the micro-level of bodies and their capacities and suggests that “power differentially *constitutes* particular kinds of body [sic] and empowers them to perform particular kinds of task [sic], thus constructing specific kinds of subjects” (Gatens, 1996, p. 66). Difference then does not so much arise from essential corporeal specificity but is constituted through societal “mechanisms by which bodies are recognized as different only in so far as they are constructed as possessing or lacking some socially privileged quality or qualities” (p. 73).

I acknowledge that a move further into poststructuralist territory risks leaving behind those disability activists focused primarily on political campaigns “as disability is opened up to its own complexity” (Corker & Shakespeare, 2002, 15), not the least being radical understandings of disabled bodies and how they are constituted. Like Corker & Shakespeare I subscribe to the hopeful notion that engaging poststructurally in my study of disabled women’s lives will both inform existing disability studies, but more importantly “contribute...to the development of inclusive societies” (p. 15), by exposing the kinds of differences disability makes (Michalko, 2002), both individually and collectively.

Disabling the social model

[We need] an analysis in which the biological and the historical are not consecutive to each other...but are bound together in an increasingly complex fashion in accordance with the development of modern technologies of power that take life as their objective. (Foucault, 1990, p. 152)

Considering the range of impairments under the disability umbrella; considering the different ways in which they impact on individuals and groups over their lifetime: considering the intersection of disability with other axes of inequality; and considering the challenge which impairment issues to notions of embodiment...it could be argued that disability is the ultimate postmodern concept. (Corker & Shakespeare, 2002, p. 15)

Emerging in the early 1980s, the disability rights movement in its rejection of models of disability that locate “the problem of disability” (Titchosky, 2003, p. 519) in our bodies, not the least being the (individual) biomedical model that views disability as deviation from biological norms, has served the disability movement well. It has done so by separating the impaired body from the “problems of social injustice [as] key to naming oppression” (Clare, 2001, p. 360) constituted by discrimination endemic in social systems that erect both physical and social barriers to participation. Indeed, for disability activists and disability studies scholars alike the social model of disability and its attendant critique of medical/individualistic/personal tragedy approaches have been very successful in “shifting debates about disability from biomedically-dominated agendas to discourses about politics and citizenship” (Hughes & Paterson, 1997, p. 325). The critical move of displacing “the problem of disability...from the individuated body” prompts inquiry about “forms of social life that enable some and disable others” (Povinelli, 2001, p. x). Even in the face of living with my own intensely personal bodily experiences of pain,

fatigue and immobility, I realize that my life has been restricted in particular ways because of the social, cultural and political meanings of disability, and practices based on those meanings.

However, in separating socially-constructed oppression from the body, in an effort “to place an analysis of disability beyond the influence of medical discourse” (Price & Shildrick, 1998, p. 227), a theoretical move that is potentially emancipatory (Hughes & Paterson, 1997), the disability rights movement and disability studies, by and large, sideline the disabled body as the locus of our material experience of disability and those relationships that connect our bodies with diverse aspects of our subjectivity. Disabled bodies as social and historical constructs and sites of meaning and agency are erased/made invisible, or at best strategically neglected (Snyder & Mitchell, 2001) as disability studies in its formulation of the social model of disability “explicitly sought to leave [the overscrutinized, overdiagnosed and overtreated impaired body] mercifully alone” (p. 374). On this model our relationships with our impaired bodies continue to be mediated by medicine (and “therapeutic” interventions), ignoring our *embodied* (not just social) relationships with policies and their effects (Hughes & Paterson, 1997).

Michael Oliver (1996), a prominent UK disability studies scholar, relying on the two mutually-exclusive terms of reference² undergirding the social model of disability, (socially constructed) *disability* and (embodied) *impairment*, has insisted that

² The definition of these two key concepts was originally created in the U.K. by Union of Physically Impaired Against Segregation (UPIAS), one of the earliest disability activist groups. Impairment and disability are defined as follows: “Impairment: Lacking part or all of a limb, or having a defective limb, organism or mechanism of the body. Disability: The disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities.” (UPIAS, 1976, pp. 3-4). Please note: Readers will be directed to longer, more detailed notes in Appendix A: Notes, along with specific page numbers.

“disablement *is* nothing to do with the body” (p. 35). The body of the social model subscribed to by Oliver, like the biomedical body, is one without history or meaning, “a pre-social, inert, physical object, separate from the self” recapitulating “the biomedical ‘faulty machine’ model of the body” (Hughes and Paterson, 1997, p. 329). Thus, the dualistic distinction between disability (processes of exclusion) and impairment (biological dysfunction) at the heart of the social model paradoxically both de-medicalizes disability while “conced[ing] the body to medicine,” with impairment being understood “in terms of medical discourse” (p. 326), which is an individualistic, de-contextualized model of disability (Marks, 1999). Yet oppression experienced by disabled people is embodied and socially lived, and impairment itself (as I argue above) is perhaps best viewed as socially constituted (Hughes, 2005).

Lennard Davis (2002) pushes this further when he suggests that disability and its doppelgänger, impairment, are both unstable categories, with disability being a category whose internal coherence is difficult to establish, a concept that “presents us with a malleable view of the human body and identity” (p. 26) The permeability of disability (anyone can become disabled), “an amorphous identity with porous boundaries” (p. 36) lends toward it being “the postmodern subject position” (p. 14).

The social and medical models of disability constitute “totalizing meta-historical narratives” (Corker & Shakespeare, 2002, p. 15) that fail to account for the complexity of disabled women’s embodied, social experiences of living with disability and the socially-situated knowledges they both draw on and produce in order to do so; disability as an “embodied relationship” (Marks, 1999, p. 611). Mairian Corker (writing in tandem with

Carol Thomas, 2002) is correct in suggesting that “masculinist, anti-experiential perspectives” (p. 23) dominate disability research using the social model.

These feminist disability studies scholars are not alone in their concern about imbalance with respect to disability studies scholars’ acknowledgment of the everyday materiality of bodies, along with concern about the political and social liabilities such discussions engender (Zitzelberger, 2005; Corker & French, 1999; Hughes, 1999; Corker, 1998, 1999; Hughes & Paterson, 1997; Shakespeare, 1994). If disabled (women’s) bodies are somewhat off the disability studies table the “innovative strategies [of disabled women] to negotiate living with(in) their bodies in their everyday social lives” (Zitzelberger, 2005, p. 390) run the risk of becoming secondary to discussions of disability, including those focused on changing the everyday living situations of disabled women/people.

Experiencing, reflecting upon and articulating the kinds of physical difficulties I live with raises questions for me about the adequacy of the social model of disability for making sense of and suggesting ways to act upon my situation and that of other women living with disabling chronic illnesses. How might social justice “liberate” me/us from embodied experiences of pain, fatigue and immobility? This is not to say these experiences are without value and should be completely eradicated. But more that they point to the problem of bodies, and in my case, the body in pain, the fatigued body, the body with stiff joints, the dis-eased body—*my* dis-eased body with all its uncertainties and vulnerabilities—for both feminist and disability theory and activism. Activists in both movements have ignored disabled women historically, although this is changing (Driedger & Owen, 2008).

The experience of living with a fluctuating (and often hidden) chronic

condition challenges the potential hegemony of the social model of disability, which assumes a fixed state of disability, acted upon by social practices, thus neglecting, eradicating, denying—making invisible—the embodied experience of chronic illness (Kimpson, 2000, p. 323).

Strong assertions about disability being exclusively socially constructed (Oliver, 1996), and what I perceive to be a rejection by many (mostly white, male) “healthy disabled” (Wendell, 2001, p. 19) scholars and activists of the idea that some disabled people might live in bodies that are impaired by chronic illness, leaves me feeling uncomfortable, and often excluded. I certainly recognize the political necessity of focusing on the ways disability is socially constructed as central to organizing an effective social justice movement. I also understand the dangers of identifying disability with illness, which “contributes to the medicalization of disability” and “fosters the myth that people with disabilities are globally incapacitated,” contributing to “the social devaluation of disabled people” (Wendell, 2001, p. 17), who do not want to be considered ill (Driedger & Owen, 2008). Yet, the focus on those who are disabled but not chronically ill— the healthy disabled—“a category with uncertain and fluctuating membership” (Wendell, 2001, p. 19), creates difficulties for me in terms of my identity as a disabled woman, leaving me wondering if I am indeed disabled or “just” chronically ill (and in need of, minimally, medical treatment, or cure), but not both. The uncertainties I live with as a disabled woman are central to how I personally understand disability, illness, health and well-being, but also how these inform my understandings as a researcher studying these phenomena in disabled women’s lives.

The question of how I understand health/illness/disability is important for this study if my concern is to “examine how regimes of truth about disabled bodies have been central to

their governance and control” (Tremain, 2002, p. 34). In particular I refer here to the “dividing practices” (Foucault, 1982, p. 777) of biomedical discourse that both objectify and separate us into those who are normal and those who deviate from normal, conflating disability with illness. But these dividing practices serve to categorize and manipulate subjects, thus working in concert with objectivization (as sane or insane, healthy or sick, for example) to individualize, socially segregate, exclude and manage disabled people (Tremain, 2002), to marginalize them, thus producing conditions for compromised health and well-being. The lives of the disabled women in this study are constituted in ways that produce uncertainty and further disable them, and in response, enact an uncertain, unsettled version of health.

Defining health in the context of disability is tricky and elusive, given that some of us occupy the territory of the healthy disabled, or “those whose physical conditions and functional limitations are relatively stable and predictable in the foreseeable future,” (Wendell, 2001, p. 19). Others live with chronic illness and are considered the unhealthy disabled, or what Cheri Register calls “the interminably ill” (Register, 1987, cited in Wendell, 2001, p. 21; See also Wendell, 2013, p. 163)—we experience periods of recurring acute illness (with potentially permanent loss of function), periods of debility interspersed with periods of relative ease, or we may have constantly-occurring symptoms (such as fatigue and pain). Most of us expect neither recovery nor cure, nor do most of us expect to die any time soon (Wendell, 1996; Wendell, 2001).

However, by focusing solely on bodily impairments as key to understanding the health or healthiness of disabled women, Wendell implies a false healthy/unhealthy dichotomy, while simultaneously problematizing the notion of the (disabled) body as “an essentially

unchanging unitary corpus” (Price & Shildrick, 1998, p. 233). The primacy of bodily impairments also risks foreclosing disability and health as constructs acted upon and produced by different societal arrangements and practices that are constitutive of bodies, in this case health as “a cultural fact in the broadest sense of the term, which is to say at once political, economic, and social” (Foucault, 1988, p. 175).

Foucault suggests that the materiality of the body “is a process negotiated through the discursive exercise of power/knowledge” (Price & Shildrick, 1998, p. 234), reminding us of the “radical instability” (p. 240) of embodiment as both a category and as something experienced/lived by disabled women. In this way bodily impairments, health/healthiness and the social construction of disability “are equally constructs held in place by the regulatory [and disciplinary] practices that both produce and govern *all* bodies” (Price & Shildrick, p. 234). If we understand embodiment as radically unstable, the episodic nature of chronic conditions means that these disabled women—and women live more frequently than men with long term disability and chronic, degenerative conditions (DesMeules, Turner, & Cho, 2003; Driedger & Owen, 2008; Fawcett, 2000)—live with the kind of uncertainty that requires that they “must continually renegotiate the relationship between body, self and socially constructed disability” (Meekosha, 1998, p. 175). Particularly relevant to this study is how women living with chronic illnesses in order to receive disability benefits must self-identify as disabled such that their illnesses (discursively) become disabilities, and they become disabled subjects. Yet Sharon Dale Stone (2008), arguing against the conflation of disability with illness, suggests that “applying for benefits sustain[s] disability as a health issue” (Stone, 2008, p. 214) based on the fact that applicants are too sick to be gainfully employed. Although the borders

between chronic illness and disability are artificially delineated for those applying for and receiving benefits, like Stone I see them as much more porous or even murky.

My own experience of living with a fluctuating condition, requiring (as do each of the participants) a responsive, multiple self, a self that constantly engages in the re/negotiations Meekosha refers to, again points to the appropriateness of poststructural thought to my inquiry into the uncertain lives of chronically ill disabled women, and their daily encounters with the “institutional production of [their] embodied subjectivities” (Snyder & Mitchell, 2001, p. 374). Like Shildrick and Price (1996), I view disability “as a fluid and shifting set of conditions” (p. 93), as Davis’ (2002) unstable category. Given this, I am seeking to unearth/reveal the constant negotiations exercised by my participants, not to resolve the impairment/socially constructed disability problem, but rather because exposing these negotiations points to a way through, what to pay attention to, in this case not just bodies or disciplinary forces but that which is unfolding in the fluid, shifting, liminal space in between, in all its uncertainty.

Hence, despite my location in disability studies, I believe that the social model of disability is inadequate to my aim of explicating how the embodied lives, practices and “fleshly concerns” (Thomas & Corker, 2002, p. 22) of the disabled women who are participants in this research are imbricated in disciplinary exercises of power and everyday social practices that are constitutive of their particular disabled subjectivities. Our impairments are part of our embodied subjectivities, which fluctuate as we are exposed to different communities (of sameness and difference) yet always “influenced, read and constructed” (Meekosha, 1998, p. 166) by our own experiences and broader

social, cultural, economic and political factors, reflecting my understanding of disability as fluid and shifting.

Shildrick & Price (1996), in their desire to disrupt notions of disability (and ability for that matter) and how these “constitute a disciplinary practice of the body” (p. 94), challenge taken-for-granted perceptions of disabled and able-bodied (or even health/illness) as permanent, fixed, internally homogenous and dichotomous oppositional categories constituting the ground of our embodied subjectivities. Indeed these scholars claim that “the body as abled/disabled has historicity [and is] constructed through a constant reiteration of set of norms...repetitive practice[s]”—discursive exercises of power—that both materialize, naturalize, and objectivize the body “as abled/disabled” (p. 94), these then being “provisional and insecure categories which can never be entirely separate” (p. 96).

Following Shildrick & Price’s (1996) lead I again call into question physical (and/or mental) impairments as a pre-discursive given (Tremain, 2002) upon which socially constructed disability is imposed; both impairment and disability are both constructs germane to disciplinary practices that regulate bodies, including the normative and normalizing effects of biomedicine, whose version of alterity focuses on “having too little or too much of a body” (Breckenridge & Voglar, 2001, p. 350). Foucault (1991) articulates the centrality of bodies as objects of knowledge, marked for/by exercises of power and disciplinary technologies, rendering them both docile and productive, and therefore of political and economic utility.

Given that this dissertation focuses on disciplinary practices in the everyday lives of disabled women, the constant negotiations they engage in as a response, and what these

produce, it is important to recognize that bodies serve as the “locus of the production of knowledge” in health sciences in such a way that “notions of health [and] physical ability [are not] pre-given qualities of the human body, but function both as norms and as practices of regulation and control that produce the bodies they govern” (Shildrick & Price, 1996, p. 99).

Disability and impairment, mutually incorporated/constituted (Paterson & Hughes, 1999; Marks, 1999), are then *both* social and embodied; disabled women’s lives, (and bodies) are situated in complex social networks and exposed to exercises of power such as that exercised with/in medical discourse that govern “which subjects [and bodies] can appear, where and in what capacity” (Mitchell & Snyder, 1997, p. 28). In fact locating poststructurally in disability studies (and feminism) enables me to explicate the various ways disabled women’s embodied lives “are both subjected to and exceed the limits of the state institutions that ensnare them” (p. 23), while exploring and revealing how their (disabled) subjectivities are constituted with/in and through contestation with the normative projections and investments of able-bodied citizens “in maintaining disability as alterity” (p. 23) and disabled subjects as “excludable” (Titchkosky, 2003, p. 518).

It is important to also acknowledge that the “socially constructed disabled body does not adequately account for...the subjective experience of impairment” (Meekosha, 1998, p. 174) such as “negotiating pain, spasticity, incontinence, and the iatrogenic effects of drugs and appliances” (p. 174). Nonetheless these kinds of subjective experiences are a “proper focus of social analysis” (p. 167) in the study of disabled women whose bodies and lives are subject to state regulation, surveillance and control via income support policies and programs. Indeed, the credo of the social model that having a disability

should not be conflated with being ill “contributes to the alienation” of chronically ill (and disabled) women for whom accommodation, access and social justice are requirements of everyday living (Devaney, 2008, p. 124).

The subject(s) of bio-power

A normalizing society is the historical outcome of a technology of power centred on life. (Foucault, 1990, p. 144).

Indeed, one might argue that disability is a product of modernist bio-power, that is, an effect of the medical management of people with impairments [in which] normalizing judgment constitutes impairment as a deficit of corporeal integrity and—simultaneously—as an invalid social position. (Hughes, 2005, p. 82, 83)

To define deviations from norms as deficits or impairments is the first step in making the subjects of this judgment into objects of knowledge and targets of power, substituting disciplinary tutelage for political accommodation. (Allen, 2005, p. 95)

This “beginning” now arrives at my consideration of Foucault’s work on bio-power and governmentality, which I appropriate in particular ways to in/form this study. Like McWhorter (2005) I believe that Foucault’s approach to power potentially provides us with novel ways to think critically about taken-for-granted phenomena, like disabled women’s lives, creating alternative “ways of resisting and possibly at times redirecting the forces that shape our lives” (p. xiv). Shildrick and Price (1996) commend Foucault’s approach to the episteme of the body and to power as a significant stepping-stone to a “feminist contestation of the politics of disability (p. 99). The application of Foucault’s ideas to critical work on disability has both widened and deepened over the past decade

or so; I both draw from and hopefully contribute meaningfully to these critical disability studies discourses drawing on his “call to question what has been regarded as natural, inevitable, ethical, and liberating” (Tremain, 2005, p. 2) in terms of the lives of disabled women receiving provincial government income support.

Income support programs (along with other institutions serving disabled people, like special education programs, home support, and rehabilitation services, for example) are part of an extensive state/societal apparatus erected during the past two centuries to “secure the well being of the general population [while causing] the contemporary disabled subject to emerge into discourse and social existence” (Tremain, 2005, p. 5).

These programs and the policies and regulations created to enact them are an example of bio-power—“the strategic tendency of relatively recent forms of power/knowledge [knowledge drawn from the human sciences, in particular] to work toward the ever more comprehensive management of life” (Allen, 1999, p. 103), in ways that divide, classify and order people around a norm (Tremain, 2005).

This exercise of power/knowledge individualizes people, and suggests “a form of power which subjugates and makes subject to” (Foucault, 1982, p. 781). Being a subject in this sense means we are subject to others who may exercise forms of control and on whom we may be dependent, but we are also our own subjects, tied to our identities in constraining (and perhaps liberating?) ways.

Bio-power and Foucault’s conceptualization of the subject are linked inextricably to his thinking about governmentality, which he viewed as an *activity*, specifically exercises of power in which certain actions modify others, or the “conduct of conduct.” In this sense, “to govern is to structure the possible field of action of others” (Foucault, 1982, p. 790),

not as we imagine power commonly understood as acting directly (and often coercively) on people and their lives. The exercise of power as conceived by Foucault reflects

the total structure of actions brought to bear upon possible actions: it incites, it seduces, it makes easier or more difficult; in the extreme it constrains or forbids absolutely; it is nevertheless always a way of acting upon an acting subject or acting subjects by virtue of their acting or being capable of action” (p.789).

In this sense Foucault links “practices bearing on the self to forms of power” (Rose, 1999, p. 151) that do not necessarily negate an individual’s vitality and capacities but rather shape us as subjects; thus “power...works through, not against, subjectivity” (p. 151). Foucault also imagines that coercion might be a tactic used as part of shaping the field of possible action of others. Lemke (2002) in his exploration of Foucault’s ideas about governmentality, tells us that the concept of government power “as guidance does not exclude...coercion, rather it is reformulated as a means of government among others” (p. 52). Foucault (1993) tells us that in his study of the knowledge of the subject (and power) he became aware of “techniques or technology of the self” (p. 203), and thus began to reconsider techniques of domination which had been his previous focus. He argued for the importance of taking into account both techniques of domination and those of the conduct of the self, suggesting that the “contact point” where these two are tied to each other “in a versatile equilibrium with complementarity and conflicts between techniques...is what we can call, I think, government” (p. 203-4).

Governmentality then, or “mentalities of government” consist(s) of that complex of strategies, calculations and tactics by which different authorities—political, economic, medical—seek to act in different ways upon the lives of subjects to achieve desirable

states, such as well-being, in part by “educating desires and configuring habits, aspirations, and beliefs” (Murray Li, 2007, p. 275). In doing so our capacities as subjects, citizens, individuals and selves are both targets of and resources for these authorities.³

Shelley Tremain, a Canadian disability studies scholar with a special interest in Foucault’s ideas stresses the importance of bio-power and governmentality (or governmental rationalities) to advance critical understandings of disabled people’s lives. She deftly critiques the social model of disability, proffering instead a Foucauldian approach to disability that suggests that governmental exercises of power into which disabled subjects are “inducted and divided from others produce the *illusion* that they have a pre-discursive, or natural antecedent (impairment)” (Tremain, 2005, p. 11), which obscures power relations that both constitute impairment and “the forms in which that discursive object will be materialized” (p. 11). The category of impairment then relates directly to disability, not in the additive way theorized by the social model of disability, but rather it “persists in order to legitimize the governmental practices” (p. 11) that constitute it to begin with, suggesting that the social model of disability “obscures the productive constraints of modern (bio-)power” (p. 11).

Other disability studies scholars (Whyte, 1995; Turner, 2000) critique Foucault’s work and its application to the lives of people with disabilities by focusing on its apparent

³ Historically disabled people have been objects of knowledge and domination simultaneously, housed in hospitals and asylums set aside for those considered unfit for participation in society. People with physical disabilities were often thought to be mentally “feeble” and were also incarcerated, and exposed to disciplinary tactics/techniques to ensure their security, and presumably that of the wider society. Given this history of being a designated group upon which harsh disciplinary tactics have been used, and the ways the discipline of medicine, for example, continues to shape and even discipline disabled people’s bodies and lives, I use both “governmentality” and “discipline” as conceptual tools. Governmentality is defined above. Discipline signifies the “interconnection of different techniques of rule” (Foucault, 1991, p. 80) and thus in my mind includes more coercive (and/or coercively-felt) tactics.

failure to adequately theorize disabled people's emancipation/emancipatory impulses, and that it is bereft of resources for improving disabled people lives. For example, Hughes' (2005) critique of Foucault's work focuses on its apparent preclusion of "consideration of the means by and through which some groups spring the trap" (p. 84) of their own history—that is, they resist modern forms of social control by establishing an emancipatory movement.

Somehow Hughes has (at best) misunderstood Foucault's conception of power, in particular the latter's provocative dictum that "where there is power, there is resistance" (Foucault, 1990, p. 95). Foucault (1982) also suggests a complicated interplay of freedom and power, such that "power is exercised only over free subjects and only insofar as they are free" (p. 790) to act. Resistance then never occurs outside relations of power. Points of resistance exist everywhere in networks of power; they constitute

a plurality of resistances...that are possible, necessary, improbable; others that are spontaneous, savage, solitary, concerted, rampant, or violent; still others that are quick to compromise, interested or sacrificial; by definition, they can only exist in the strategic field of power relations. (Foucault, 1990, p. 96).

Collectively, disabled people have mobilized historically along a number of points of resistance in order to alter disadvantaged circumstances, such as institutionalization, and physical, communication and transportation barriers. Foucault (1990) argues that "the strategic codification of these points of resistance [make] a revolution possible somewhat similar to the way in which the state relies on the institutional integration of power relationships" (p. 96) in order to manage citizen's lives.

I see resistance as multifaceted and unpredictable in effect, and have observed in my own life how I have simultaneously complied with *and* resisted institutional exercises of power as a way of fulfilling desires, for example, completing annual disability review forms in ways that provide (hopefully) the necessary information to maintain eligibility, while being strategic about which information to divulge. These local, targeted (and potentially risky) responses to power relations at work in my own life, similar to those of the participants in this study, constitute exercises of agency made possible within/shaped by existing power relations.

Foucault said there is a permanent provocation at the heart of the power relationship—“the recalcitrance of the will and the intransigence of freedom” (Foucault, 1982, p. 790), that is, the freedom to act, a necessary condition of the exercise of power. It is this aspect of power that intrigues me and the ways that the lives of the disabled women who participated in this study engage with the forces that seek to discipline them, ways that reveal how they are not entirely integrated into techniques that govern and administer them; rather their lives constantly escape these forces (Foucault, 1990) in myriad, unexpected ways. In the lives of these disabled women we witness how different kinds of resistance are generated within and by bio-politics, wherein the needs and imperatives of their lives serve as potential foci for (political) counter-demands, producing possibilities for the “strategic reversibility of power relations” (Gordon, 1991, p. 5) at the heart of disability activists’ aims.

Foucault’s study of power and its configurations in modern societies guide critical questions about what “has been done in the name of welfare, security, health and even liberation” (Allen, 2005, p. 98). Allen suggests that Foucault is not interested in

preserving an original individuality existing prior to the disciplinary machinations of sovereign states, rather he advises that we “try to *recuperate* some of the autonomy that is lost when we subject ourselves to forms of modern political rationality, especially economic efficiency and health” (Allen, 2005, p. 98). Efforts to recuperate autonomy are deeply familiar to those living with disabilities in the face of the disciplinary tactics of medicine and the state, the latter relying on medical discourse to determine eligibility for disability benefits and services. The repetitive (and potentially risky) ‘recuperative’ actions of disabled women reveal (their) subjugated knowledge, generated for/from responding to unpredictable embodied conditions as these intersect with their reading of policy, producing uncertainty/constituting them as uncertain subjects.

As Allen points out, Foucault’s understanding of knowledge upon which he bases his articulation of power/knowledge refers to “contingently prestigious discourse” (p. 101), yet Foucault also situates his work in an “*insurrection of subjugated knowledges*” (Italics added) (Foucault, 1980b, p. 81), or knowledge lacking formal prestige, in this case the kind of knowledge disabled women use to/produce about living on disability benefits.

Here knowledge is construed by Foucault according to its unsettling effect on prestigious discourse, that is, naïve, particular, local knowledge in the form of excluded or disqualified speech used as an insurrectionary tactic that “owes its force only to the harshness with which it is opposed by everything surrounding it” (Foucault, 1980b, p. 82). Foucault emphasised that through these subjugated knowledges “criticism performs its work” (p. 82); in this sense the lives of disabled women receiving income support constitute/enact/produce a critique of the disciplinary power relations with which they engage on a daily basis. Criticism here could be construed as a Foucauldian form of

resistance along “local and discontinuous points” (Shildrick & Price, 1996, p. 105).

The disabled women in this study find unlikely and sometimes risky ways to resist (and comply with) the disciplinary forces of the state and medicine reflecting micro-practices of subversion and sites of struggle, “not tied to the overthrow of systems or even to ideologies of emancipation” (Abu-Lughod, 1990, p, 41), raising critical questions about the nature of the forms of power and how disabled women are tied to them. In this way resistance can be used “as a diagnostic of power” (p. 48), bringing to light power relations in their lives, and where and how they are applied. Multiple points of resistance imply multiple (and interwoven) sites and forms of power; if we resist one aspect (or level) of power, for example at the local or micro level, we may be simultaneously caught up in other, systemic or macro, aspects/levels of power.

Katherine Teghtsoonian (2008) points out the importance of working in spaces between how we understand governmentality and “the insights that flow from critique” (p. 85). Doing so suggests/enables a focus on *what happens*, in this case in disabled women’s lives, and *how it happens* (p. 85). If the purpose of this study is to explicate how power is enacted in the everyday lives of disabled women living on B.C. provincial income support benefits and what this produces, then a research focus on how they live their lives, what they do and how they make sense of (and respond to) the policies and practices to which they are subject is required/essential. These everyday, embodied practices of the self constitute their subjectivities as disabled women. By making these practices visible I aim to unseat, unsettle and disrupt taken-for-granted understandings of the lives of those who are disabled and female and poor.

How the research was conducted is the subject of the next chapter; it also provides an

introduction to the narrative accounts that reveal the qualities/conditions of these women's lives imbricated with/in the disciplinary power of provincial government disability income support policy and programs.

The conduct of (the) research

From my own life with disability this dissertation emerged. I have been intrigued by the ways income support policy (of two separate institutions) has governed my life in so many ways, the opening narrative being but one example. As I was contemplating the possibility of pursuing a doctorate I read Susan Wendell's (1996) recently published book, *The Rejected Body: Feminist Philosophical Reflections on Disability*, and began a research journal (on my computer) as I read this important and insightful book. For me, keeping a research journal was a familiar practice; my MA thesis (Kimpson, 1995) had emerged directly from my research journal at the time.

Meloy (1994) reminds me that, "the journal is a way of imaging a stream that flows through (underneath?) and surrounds the territory of qualitative research" (p. 60). The current research journal has continued throughout and provides a space for me to not just record thoughts and reflections on my readings, encounters with interested others, and my research interviews, field notes and data but to make detailed notes, struggle with ideas and doubts and questions, remind myself where I am in my thinking/writing or at best sometimes just try and find myself in this complex and often contradictory process in which I have been engaged. But there is more. These journal entries also reflect personal aspirations, "whims, hunches...dreams, epiphanies, desolations, and doubts" (Donawa, 1999, p. 46), along with myriad passages describing physical difficulty and pain.

Embodied journal entries abound and more often than not provide an opening to my self as writer/researcher, or at least enable me to cache experiences whose meanings might have been obscure or nascent as they unfolded but subsequently become fertile sources for reflection and insight.

In this way, a research journal “can hold your heart” (Meloy, 1994, p. 60), but also provide a space in writing that enables close attention to (and interrogation of) the places I am positioned/position myself in life. Inspired by autobiographical writing practices focused on my deep-seated interest (from *inter esse*—to be in the midst of) in disabled women’s lives, practices fostered during study with curriculum theorist Antoinette Oberg, I see how my socially-significant topic emerged “from the swampy terrain of living practice, that fertile marsh where insight and creativity breed” (Oberg, Kimpson, Drew, Rasmussen, & Montgomery, 2003, p. 1) and how out of the “vast, living world” of possibility, “the creative act pulls . . . some more inclusive shape or progression” (Nachmanovitch, 1990, p. 106). I began here “enmeshed in the vital reciprocal relations that weave us into the web of inquiry of which our topic is a part instead of on the high ground of theory” (Oberg *et al*, 2003, p. 1) coming to see through attitudes of “openness, attentiveness . . . non-judgment and acceptance of . . . not knowing” (p. 26) the underlying patterns as they emerged in writing. In this case writing that established the conditions under which all that is related to my interest came into existence (p. 17), took shape, and has been “carried forward” (p. 25).

Jan 10, 1997

I’m not sure what’s got into me, and why, all of a sudden doing a Ph.D seems the thing to do next. Where might it take me? Although I don’t know exactly, I know it will open some doors for me (a door?). I spoke of this with my acupuncturist, and about how trapped I feel because of my disability pension—so little room to move. Not that my energy doesn’t limit me, it does plenty, but if it were to shift, I’d still be trapped in my pension.

So what about this Ph.D stuff? I feel like I’m being carried away, and seem to be going willingly. Truly, reading Wendell’s book got the wheels working and

I did ask to get clear on a topic. In fact, a year ago, and for most of this year, a topic wasn't clear. I wasn't sure I wanted to study my own experience again (at least not exactly the same way I did for the MA). However, the 'what to do with my illness' part of my MA thesis—that which wasn't easily accommodated (into it)—has generated lots of thinking, and a little writing. Part of it was about how I live with my illness while being a graduate student, but it was there as an important example of how it (or I with it) intersected with the institution (university) and health care system. It's how living with disability intersects with these that intrigues me.

This isn't just academic writing right now. As I read (and re-read) Wendell's book, and later this fall a journal piece by Margaret Fogg (about her experience setting up disability access at B.C. Women's), I realize I am not alone in my experience—others have written well about parallel experiences. Identifying with these disabled women has given me a great deal of permission to position myself as disabled or at least identify more strongly as a disabled person. Shed some of my own internalized 'able-ism.'

And then I realize that if there are three women having this experience (trying to work in institutions while living with energy-restricting disabilities), then there must be others. And if there are others who are struggling with discriminatory rules (borne out of ignorance, mostly), then there is need for change. And to first change situations, we need to make them visible. I have the ability to do that. I may not be able to walk to the corner store or ride my bike or work full-time, but I can do research into this troubling experience. And at the Ph.D level, I can/could be in a position to influence people with respect to this issue.

Influence indeed. Before beginning this degree, and throughout most of its duration I had taken up, along with a small group of disabled nurses locally, an activist role with respect to the British Columbia Nurse's Union (BCNU) and what we perceived as unjust aspects of the contract dealing with our Long Term Disability (LTD) benefits. Specifically, like

provincial disability benefits (and unlike Canada Pension Plan Disability (CPP-D) benefits), these LTD benefits were fixed, that is, they were not indexed to the cost of living, which meant those like myself who became work-disabled in the early eighties were now living well below the poverty line. In addition, although we had access to extended health and dental benefits, we had to pay our own monthly premiums in full out of our fixed income, along with our monthly Medical Services Plan (MSP) premiums, unlike working nurses for whom the employer wholly subsidized both MSP and extended/dental premiums. I relinquished my dental benefits early in my disablement because I could not afford the \$42 monthly premiums.

We made little progress in our campaign to index our LTD benefits over the fourteen (14) years I was involved, mostly because, as we understood it, the needs and concerns of working nurses pre-empted our needs as disabled nurses when it came to bargaining. Indexed LTD benefits got bargained away in place of better staffing ratios or salary increases or expanded benefits for working nurses. We felt like second-class citizens, aliens in the BCNU whose stated mission was the well-being of nurses. This seemed like a fertile site for a doctoral research project, but as I paid closer attention to the emotions I was expressing in writing about activist work on this issue I began to question this idea.

Feb 11/97

My fear is that the insurance company will block me in some way. I'm also aware that I have fears of being self-employed, and how much money I'll be able to earn, or for how long before 'they'—those who administer 'the plan'—decide I'm totally 'rehabilitated,' given the restrictive criteria for this. I feel so angry when I use their language. It's so limiting, and fails to account for important and subtle aspects of my quality of life. I am also angry at the

BCNU, and thought about what I might write the president about my situation while I was meditating this morning. I wonder if I should focus my research on disabled nurses on 'the plan'. Wouldn't that be a slap in the face? I could include several disabled nurses and use that data to write a paper challenging the BCNU. Plans, plans, plans. It's how constrained I feel that drives me—what happens in my body is a metaphor for my external reality—constricting and immobilizing me. I am deeply concerned about my financial status, and know that my intention to do a doctorate is driven in part by this fear. I sense many doors will open because of it, doors not open now. And the big door is getting off 'the plan', and I don't know if that's unrealistic or not. If only they wouldn't make it so difficult. If I could have unlimited employment earnings for an unlimited time (not just their measly 3 months—how did they decide 3 months was enough time to establish yourself in employment?), then I could see how it might be possible to get off the plan. Three months is nothing when you live with disability. Anything can happen in three months.

Fear and anger inhabited the stream flowing through my dreams of doing a doctorate, and as I sat with them and especially as I experienced the searing, caustic feeling of the anger, I realized researching disabled nurses' lives as they intersected with both institutions (the BCNU and the insurance company administering LTD benefits at the time, Great West Life) was unlikely to assuage my anger. Knowing that spending a half dozen (or more) years focusing my life and intellectual efforts on something that provoked anger in me seemed counterintuitive, and unhealthy. I began to think about other, less emotionally intense sites for the study.

In early 1998 I met and befriended Dr. Tanis Doe, an internationally-recognized disability activist and scholar, living locally (d. 2004). Based on a shared interest in the structural poverty with which disabled women live she and I collaborated on policy

research funded by Status of Women Canada focused on women nationally receiving federal CPP Disability Benefits (CPP-D) (Doe & Kimpson, 1999). Doing this research was invaluable in terms of helping me decide on a focus for the doctoral research and familiarizing myself with the issues, along with my own experiences as a disability activist in local, regional and provincial disability communities around issues of home support. Activism introduced me to many disabled women living on provincial disability benefits who were ineligible for CPP-D, and who, from what I could see were very economically disadvantaged. The idea of studying these women's lives as they intersect with governing institutions seemed right; over time I developed a research proposal focused on what I had construed as the "dis/abling effects of discourses" in the lives of women receiving provincial disability income support.

Despite the emergent design of this study certain elements of the original research proposal have remained constant, and given the shape-shifting effects of textual embeddedness and practices; others have not.

The purposes of the research remain: to explicate power relations in the lives of disabled women and what these produce, linking these to their health, socio-economic well-being and citizenship; and to create a disruptive reading that destabilizes taken-for-granted, common-sense notions about disabled women securing provincial income support benefits.

Here my purposes in this research and my activist life intersect within the (often-contested) borders of poststructural and social justice terrain. I draw from and employ poststructural philosophy and practices to think about/articulate exercises of power at play and show what these produce in disabled women's lives, and link these critically to

particular aspects of their lives that in part reflect (my) social justice concerns. As I proceed I remain aware of Foucault's continuing insistence "on showing how things could now be (and could have been) otherwise" (McHoul & Grace, 1993, p. 119), while stressing the importance of showing how "things weren't [aren't] as necessary as all that" (Foucault, 1991, p. 76). So despite my social justice commitments (broadly, socio-economic equality for disabled women), my intention and purposes are not to "prove" they are oppressed in various ways and thereby prescribe specific (social justice) remedies. Rather as Barry, Osborne and Rose (1996) suggest I aspire "to fragment the present" (p. 5) by unsettling and destabilizing the inevitability of commonplace understandings in disabled women's lives as lived at the time of the interviews, revealing gaps/fractures in these in ways that "allow a space for the work of freedom...as a practice of difference (p. 5). As previously mentioned, working/writing this way enables me to produce both different ways of seeing disabled women's lives, that is, producing different knowledge and knowledge differently, but keeping social justice commitments in mind as the work opens us to the possibility of reshaping these lives in ways that foster/produce equality and well-being.

As the study unfolded, the initially-proposed focus on discourses and what I had conceptualized as their dis/abling effects in these women's lives shifted away from a plan to expose, examine and critique particular discourses and discursive power relations in their lives showing how these produce both enabling and disabling effects in disabled women's lives. My intention was to engage each participant in an in-depth conversation about what it is (and has been) like for them to live with disability and income support. Drawing from Foucault's theory of discourse and its institutional effects I assumed the

language they used would reveal different ways they were embedded in the kinds of social relations made possible or disallowed by various discursive practices at work in their lives. Included in these are the discourses (and discursive practices) of medicine, state-administered income support, the disability rights movement, and feminism, to name a few. I imagined a critical focus on language and how women with disabilities use the language of these particular discourses in their descriptions of their day-to-day lives. The analysis and interpretation of the texts generated through in-depth, open-ended interviews were intended to expose and critique any taken-for-granted or common sense understandings embedded in the women's discourse and to reveal how through taking up various discourses in particular ways these women "as part of a wider network of power relations" (Weedon, 1997, p. 105) were being constituted and governed as individual embodied subjects.

Along with discourse, I proposed to pay close attention to how disabled women talk about and live in their bodies—practices of the self—what they *do* or in the language of governmentality how they *conduct* themselves in response to exercises of power. This focus apart from the specific emphasis on discourse held. During the interviews I asked each woman what she did in a day or what a "typical" day looked like as a way of prompting descriptions of how she conducted her daily routines and engaged in embodied practices. Tracing the body, its practices and exposures seemed particularly important in regards to the study of a gendered and embodied social issue (Pillow, 2000) like disability. I conceptualized the body and embodied practices as sites of information, of regulation, power and resistance, revealing how disabled women's bodies are produced/constituted as part of a wider network of power relations (Weedon, 1997).

Even without practicing (formal) discourse analysis, working poststructurally means I am always carefully attentive to language and how it potentially shapes disabled women's lives. My concern with using discourse analysis was reflective of my growing understanding of language as "an interactive, cultural phenomenon, not a transparent medium to be controlled by the researcher" (Alvesson & Skoldberg, 2000, p. 243) and my desire to both reflect and reproduce the "active, performative aspects of language" (p. 243). If one of my intentions/purposes is to make the writing as understandable as possible to women with disabilities then adding a formal discourse analysis layer to interpretation seemed counterintuitive.

I also considered our bodies to be the means through which we interpret our experience of the world, make meaning and through which we construct images of ourselves. As such I conceptualized bodies as "sites of imagination" (Gabel, 1999, p. 41) in these women's lives. By paying attention to how disabled women experience their bodies while negotiating power relations I hoped to reveal the different kinds of knowledge they generated about the experience. Of particular interest were the ways they used their bodies to make meaning and to engage their imaginative capacities, and as sites of resistance, including the effects of these on their health and social well-being. This intended focus on embodiment also held firm.

As the research unfolded and I engaged deeply in the interpretive work, the focus on discourse(s) (and the idea of using a formal discourse analysis technique) became less salient especially once I began textual engagement with the data, ironically. During this interpretive process I found myself focusing less on discourses and their effects. What I was actually doing in the reading/writing work of interpretation—focusing directly and

specifically on how power was being enacted in these disabled women's lives and what this produces—displaced discourse as the focus and I abandoned it as an analytical frame. But I am getting ahead of myself.

Imagining and recruiting participants

For the purposes of this study disabled women are those who live with chronic conditions including chronic but stable mental health/psychiatric disabilities, and who receive B.C. provincial disability benefits as their only official source of income. Disabled women are among Canada's poorest citizens and those disabled women who are single, Aboriginal, racialized, or are immigrants or refugees live in the deepest poverty. Women with disabilities are also more likely than their non-disabled counterparts to remain single, to be separated and/or divorced and to be single-parenting. Along with these factors their inability to work means they are also more likely to be receiving government-administered disability benefits (Rioux, 2006; Frazee, Gilmour, & Mykitiuk, 2006).

Women receiving provincial disability benefits are among the most economically and socially disadvantaged citizens in Canadian society, without the relative advantages of being beneficiaries of contributory schemes such as employer-sponsored long-term disability benefits or the federally-administered Canada Pension Plan (CPP-D), and “face the greatest likelihood of living in poverty” (Fawcett, 1996, p.147). In addition, as governments deploying “neoliberal strategies of rule” (Larner, 1996, p. 13; Teghtsoonian, 2003, p. 39) emphasize employment as a primary aim for those unable to participate fully in the labour force, including disabled women, these citizens are more likely to be stigmatized by society and increasingly discursively constructed as the “unworthy” poor (Bach & Rioux, 1996). Of course labour force participation does not guarantee gainful

employment as disabled women are more likely to be underemployed, underpaid and/or temporarily employed (Fawcett, 2000). For those without employment earnings, those ineligible for employment-based income support programs, and those who are unable to rely on social networks for financial support the only recourse is to apply for what disability activists and scholars call “last resort” benefits— provincial disability social assistance.

We know very little of the lives of those disabled women living on this kind of benefit; their lives are under-researched. This is unfortunate given well-established, robust associations between poverty and poor health, poverty and disability (and the profound disadvantages that accrue) and health inequalities related to gender and disability resulting in compromised well-being and quality of life (Raphael, 2007; Fawcett, 2000; DesMeules, Turner, & Cho, 2003).

The site of the research then is the everyday lives of disabled, chronically ill women living in community (i.e., not institutionalized) as they secure B.C. provincial income support or last resort benefits. Securing income support cannot be understood apart from its shaping effects in the everyday lives of these disabled women who require this source of income to survive. As part of surviving disabled women live with the material—bodily and economic—effects of being recipients of income support, and develop local, embodied knowledge enabling them to engage in various ways as they negotiate the parameters of income support policies according to their understanding or ‘reading’ of them. Thus, “securing income support” for the purposes of this study is not limited to chronically ill disabled women’s efforts to establish and maintain their disability benefits but encompasses every aspect of their everyday lives.

Why disabled women living with chronic illnesses?

Canadian women experience higher rates of chronic illness than men (Denton, Prus, & Walters, 2004; Driedger & Owen, 2008) and are more likely to be disabled because of the conditions with which they live. Chronic illness differs from acute, or short-term illness by length and persistence of symptoms. But this is not all. As Moss & Dyck (2002) suggest, being of longer duration fails to

capture chronic illness as a state of waxing and waning...uncertainty...indeterminacy...fluctuation. This capricious movement inherent in chronic illness sets up individuals to experience both vigor and lethargy, remissions and flare-ups, “good days” and “bad days”—sometimes months apart, sometimes within minutes of each other, sometimes in tandem. For most chronic illness, recurrence of sickness or of health is indeterminable...for the most part chronic illness is laced with uncertainty [enveloping] the everyday life of someone with chronic illness...so that each detail of life is awash with doubt. (p. 16)

It is just this unsettled, unpredictable and unreliable nature of chronic illness that challenges the social model of disability, in that the fluctuating nature of chronic illness reflects the important idea that chronically ill women can be both abled and disabled, even healthy and ill at the same time (Moss & Dyck, 2002). This instability also permeates these women’s everyday lives, the choices they make and their efforts to secure disability benefits. Indeed, length of illness is part of the eligibility criteria for all institutionally-administered disability benefits, including provincial last resort benefits. Again, women living with episodic conditions must be constantly negotiating and renegotiating relationships between their unreliable bodies, selves and socially-constructed disability (Meekosha, 1998) and these negotiations are always imbued with

and exercised within power relations. Exposing these negotiations and the power relations within which they take place is important in terms of making visible how chronically ill disabled women live their lives and how others might respond.

We live in a world that has difficulty with a person who is “ill,” or worse is “ill” but appears “well.” Women living with chronic illnesses often feel pressure to portray themselves as either “sick”—and appropriately fill their roles as persons with chronic conditions—or “not sick.” Chronic illness seems to mean chronic misery and unhappiness but it can also serve as a constant reminder to ourselves (and others) of the inability of science and medicine to protect us from disease, disability, and death (Wendell, 1996). In a society that idealizes bodily perfection we become the imperfect “Other” who could never come close to the ideal. In addition, “curiosity about medical diagnoses, physical appearance, and the sexual and other intimate aspects of disability is common: interest in the subjective experience is rare” (Wendell, 1996, p. 91).

I also expected that by making chronic illness part of my inclusion criteria that I would be inviting women with invisible disabilities into the study such as those living with depression or chronic fatigue, often considered “contested illnesses...dismissed as illegitimate” (Moss & Teghtsoonian, 2008, p. 7) or at best challenging or difficult within conventional biomedical contexts. Like the fluctuations of chronic illness that raise doubt (in participants and Ministry employees and citizens in general), invisibility creates another layer of uncertainty in the lives of those securing benefits. The embodied knowledge and expertise of those living with contested illnesses “[enjoy] far less privileged status...than conventionally accepted knowledges” (p. 11) with predictable (and unpredictable) effects. Disabled women whose bodies are not marked as such are

often considered unworthy of support or benefits—after all they do not *look* disabled, or even ill—and struggle to establish their eligibility. More often though they are ‘marked’ by poverty. They are truly on the margins, which beyond being an excluded location could also be considered “a space of radical openness,” (hooks, 1990, p. 145) where resisting closure on their own experience of chronic illness and disability constitutes a site of resistance and re-vision. Three of four participants live with invisible disabilities. For those participants with invisible disabilities, certain supports are denied to them compared to the participant with visible disabilities.

One of the other inclusion criteria for the study was that women recruited to participate had been on benefits *for at least two years* prior to the time of the initial interviews (conducted in late fall 2003). It was important to include this criterion for two reasons: 1) the participants would have lived on disability benefits such that they would have had time to establish a particular “form-of-life” (Agamben, cited in Ceci, Purkis and Bjornsdottir, 2013, p. 33) in response to provincial disability income support policy as this intersected with their fluctuating health conditions, and; 2) the participants would have undergone the province-wide Ministry⁴-initiated Disability Designation Review—colloquially referred to as The Review—of all provincial beneficiaries in 2002 (See Appendix D: Context of The Review for a detailed description of the political context of The Review).

⁴ I refer here to “the Ministry” rather than the full name of the Ministry whose mandate includes responsibility for disability income support programs. I do so because over the rather lengthy course of this research the Ministry has changed names numerous times, revealing interesting elements of the Ministry’s direction, investments and concomitant messaging to citizens. Ministry names since beginning the research are as follows: Ministry of Human Resources (2002); Ministry of Employment and Income Assistance (2008); Ministry of Housing and Social Development (2009); Ministry of Social Development and Social Innovation (2012 to current date).

The latter criteria was important because the Disability Designation Review represents an instance of formal surveillance of disabled women (and men) by the state, exemplifying “particular modes of disciplinary practice” (Shildrick & Price, 1996, p. 100), including coercion in this case. Although their daily lives are always inevitably circumscribed by provincial legislation and policies, the province-wide review of their disability status (renamed a “designation”) was an instance of a relatively recent, formalized intrusion of the state in the lives of these disabled women potentially threatening their eligibility for benefits (and security) in an overtly coercive way. To be clear, the women are not absolutely constrained by having their eligibility questioned—as acting subjects, they could always opt not to participate—but I do believe coercion is at work here, intended or otherwise. As such, I considered the participants’ experience of undergoing The Review a rich site for critically examining these kinds of power relations in their lives.

In addition, a new “designation” or category had been created by the Ministry in advance of The Review to account for those (previously designated as disabled) re-categorized as being “Persons with Persistent Multiple Barriers” (PPMB) to employment.⁵ I also invited women in this category to participate in the research as this re-categorization by the Ministry would (through an elaborate, detailed and onerous screening/eligibility process) disallow their full disability benefit (at the time, \$461.42 plus \$325 shelter maximum, \$786 total monthly) and reduce their monthly benefit substantially (\$282.92 plus \$325 shelter maximum, \$607)⁶. One of the participants (pseudonym, Jocelyne) was re-designated as PPMB during the Review.

⁵ See Appendix A, Note 1, p. 362 for a detailed description of this category, and further implications for participants.

⁶ The current monthly full disability benefit for a single person, last increased in 2007, is \$906 total.

Although four women readily volunteered to participate in the research, recruitment was not as straightforward as planned. As I was developing a plain language recruitment notice to be posted at local (and provincial) volunteer disability and disease-specific service organizations (for example, the Multiple Sclerosis Society), I had also begun to speak informally to others in the wider disability activist community locally of which I am a member, and in my wider friendship networks about my proposed research. Before I could post a recruitment notice, all four women from within these various networks volunteered to participate. I have given them pseudonyms—Marion, Galya, Evelyn, and Jocelyne. Unexpectedly, two of the participants emerged from the periphery of my friendship network; neither had ever previously revealed to me that they were disabled or living on provincial benefits. They had kept this aspect of their lives secret from myself and others in the shared networks to which we had previously belonged.

As mentioned, I designed the interviews as open ended as possible in order to engage individual participants in in-depth conversations about their experience of living on income-support. Open-ended questions focused on various aspects of their experience, including for example, the different strategies they used to initially secure income support, how they get by on a daily basis, the nature of their contacts with government officials, physicians and other professionals and their experience of having their eligibility reassessed via The Review. A second, follow-up interview was scheduled with participants to further clarify their descriptions, to ensure I had a good understanding of what they had shared with me and to continue our conversations and pursue relevant topics in more depth.

The interview process and intentions were described to participants at the initial telephone contact and in the follow-up Letter of Invitation and Informed Consent (See Appendix B). I had developed an interview guide that included several questions about the aspects of their lives that I hoped they would be willing to share with me. I made this guide available to participants in advance of the initial interview upon request (See Appendix C: Interview Guide).

All eight interviews were audio-taped and transcribed verbatim by me, the latter to enable me to become deeply familiar with each woman's account of her life. Galya and Evelyn opted not to have me interview them in their homes, at least for the first interview. These particular interviews were conducted in my home to ensure each woman's comfort and privacy; as I knew them from shared friendship networks both had visited me infrequently in the past in this setting. Evelyn invited me to conduct the follow-up interview in her private room in a temporary boarding house situation; Galya opted to have both interviews conducted in my home.

Respect and accommodation for the potential kinds of limitations women with disabilities might bring to a research project (e.g., compromised energy, limited time, mobility and communication issues) were essential. Issues of time connect to the different meanings of time (and energy) women with disabilities experience. It was important for me to remember and acknowledge that participants' energy and time would be taken away from life's other obligations, which I imagined would also be compromised because of disability-related factors. It was essential for me to take into account, in the planning stages and throughout the project, not only gendered (double day, caring for others), but also disability-related implications (caring for self, cost/effort to travel, fatigue) for

participating. In this sense, an important consideration was how this research accounted for the conditions of its own production, and provided appropriate accommodation for those conditions that produce barriers to participation.

Thus, it was important that I discuss with participants beforehand if they anticipated any inconvenience above and beyond the time anticipated for participating in the interviews, and reading written materials. It was also important that I be respectful of and negotiate with each participant in terms of ensuring that I was able to accommodate each woman's disability-related time and energy needs. No special accommodation (e.g. ASL translation, or large print text) was required by any of my participants even though I had taken pains to ensure that securing specific accommodations would not further inconvenience them by offering to organize these on their behalf and/or provide it myself if necessary. I ensured each participant that I would incur/subsidize any costs associated with whatever accommodation was necessary.

Given the disability-related implications for participating, I believed that the women should receive an honorarium for their participation, and because my studies were supported with a doctoral fellowship that included a research expense account I sought to secure this funding for the women. Here, financial remuneration ran into tricky waters. I applied for the honoraria but was clear with my funding organization that the participant's identities remain anonymous, an important consideration given provincial disability income support regulations (and surveillance) about receiving additional (unreported) income. This meant that the organization could have no avenue for tracing each recipient of the honoraria. Given how unorthodox this request was I had to advocate strenuously and provide solid rationale based in the purpose of the research for the

honoraria to be administered in this way. Typically the organization kept detailed records as to who received the honoraria and the amounts. By agreeing to categorize the money I gave them as honoraria rather than earned income, which by law would have to be reported to the Ministry (and I imagined set off a chain of challenging encounters with Ministry staff, and further surveillance) I was able to give each woman her honorarium (in cash) anonymously at the time of the first interview.

It was also important that I respect and accommodate my own disability-related limitations. This included building in as much rest as needed between interviews and ensuring I had the emotional supports needed to help me process what I anticipated to be exposure to difficult material. It was also important for me to be clear about my relative privilege as a disabled woman. Engaging in doctoral research as a disabled woman with other disabled women is a social practice imbued with power relations. As a disabled woman who has been an active participant in the disability community from which research participants were drawn I am aware that my status as an “insider” created unique challenges for the research. I share with participants the experience of being a disabled woman who has received disability income support providing me with unique knowledge unavailable to non-disabled researchers. Being an insider also signals the potential for making assumptions about the experience and missing or neglecting what may be unique or important in terms of these particular women engaged in this kind of research. Keen awareness of the negative potential of my own biases informed a critically self-reflexive stance about my own beliefs, intentions and actions, articulated in my research journal.

Navigating interpretive labyrinths, finding egress

I am now left with the question of how best to convey in writing (a linear form) the labyrinthine task of interpretation I engaged in for this research, with its iterative, spiral, creative, self-reflexive, textually-bounded nature. I can (and will) describe all that I did in sequence to create the interpretive texts, but this fails to capture the intense (and delicate, sensitive) thinking/writing/reading process needed to bring the participants' narratives to life. During this process I printed a little homily, a phrase used by one of my supervisors in one of our regular meetings, and pasted it on the wall beside my computer screen; it read

Describing and describing is a process of theorizing—layers of description that you keep producing until you see how this is working. Once the description is complete the analysis is done.

I was not entirely sure how to interpret this phrase, especially what a “complete” description might entail, but it seemed sufficient guidance for the writing and rewriting I was continuously engaged in.

So what did I do?

After each of the initial interviews, I wrote my impressions of the interview, reflecting on content and process, making notes about further topics for discussion or clarification.

Jocelyne's interview was particularly challenging; her energy was one of intense desperation and anger, and I had trouble understanding her due in part to language differences and staying centred. From my reflections on the interview:

November 11, 2003

I didn't know it at the time but in retrospect, to some degree I experienced her accounts as barrage of "facts" and emotions. This is partly related to my experience of her (and her desperation and dogged determination) but also I think because it raised emotions in me that I was either unaware of or unable to express in my efforts to stay focused during the interview. It is this mix of emotions that left me feeling assaulted or bruised or stunned/numb following the interview. Now, I sense sadness emerging from having witnessed a vibrant, intelligent professional woman being reduced to a minimal life, confined by her body, her physical space and government policies and practices. I also sense my own powerlessness (nothing like hers to be sure), anger, disgust and impotence even though I am potentially in a position to be able to do something. Perhaps I sense my own relative privilege as a disabled woman and ethically sense the responsibility I believe must accompany it. And sensing this, at the same time as being confronted by the difficulty and desperation and determination of this woman, I must quell my urge to roll up my sleeves, jump in and begin to help her tackle the problems she presents me with.

Interestingly, despite my cautions to myself about helping her with her problems, in this case a very time-limited situation (discovered late in the first interview) informing her of a Tribunal hearing about her re-designation as PPMB, I did take action on her behalf with her permission. I raised concerns after the interview (and my reflections) with my co-supervisors regarding the ethical dilemma I was presented with, and decided that offering circumscribed help was prudent. As a disability activist and scholar I had unique expertise that I believed could assist Jocelyne with her emergent problem. I could see from the documents she volunteered to show me (from the Ministry) at the first interview, including a recently-returned completed copy of the twenty-three page application form for benefits, in which she had written extensively in the margins of her

physician's statement (an absolute no-no), and from her somewhat mistaken understanding of the Tribunal process that she was in a precarious situation.

With Jocelyne's permission, I spoke to her advocate at the local disability advocacy group and together we strategized an approach to presenting Jocelyne's information at Tribunal given what I had discovered during the interview. Her advocate, a good friend of mine, had suggested Jocelyne volunteer for my study and knew from Jocelyne that she was a participant. I declined attendance at the hearing—the advocate would attend and speak on Jocelyne's behalf—but did spend considerable time in our second interview showing Jocelyne as best I could how to present herself (and her medical situation) textually to maximize the likelihood that she would be successful in re-instating her full disability benefit (and category). In the end, it was decided at Tribunal that her difficulties were directly related to a language barrier and she was allowed to reapply using a government-sponsored translator.

I was able to help her with the textual aspect of her problem in part because, before the interviews, I had spent considerable time familiarizing myself with and doing a critical, textual analysis of the new twenty-three page application form used first during the Disability Designation Review. At one point I thought I would include this document and the analysis in the dissertation, but as I proceeded, although related to the dissertation topic over time it did not seem directly relevant to the task at hand. I had also interviewed Jane Dyson (off the record), a seasoned advocate at the Vancouver-based B.C. Coalition of Persons with Disabilities (now Disability Alliance of B.C.) to clarify my understanding of (and facts about) the Disability Designation Review, in which her organization had played a major advocacy and activist role, with implications for my participants.

Throughout the research I kept a close eye on the Ministry website, including downloading numerous publicly-available documents and news releases, as a way of familiarizing myself with the changing administrative landscape and consequent disability policy and regulations. I also am a voting member of the B.C. Coalition of Persons with Disabilities and receive their quarterly-published journal, *Transitions*, which I was able to use for information about and understanding of province-wide community-based campaigns.

As I transcribed the interviews I kept notes in my research journal of aspects of the participants' lives that intrigued me or surprised me or seemed interesting to me. In writing self-reflexively I realized that "interesting" had meaning in the context of the research and my own interpretive practices; I saw that instances that revealed exercises of power in these women's lives and their responses were particularly interesting to me, and I began to identify these and write and rewrite (about) them in more depth, including an analytic element in which I would critically comment on what I saw the women doing using my understandings and experience of living with disability (and on benefits) and being an activist as a source of knowledge and critique.

During this period, I played with different elements of a theoretical 'frame' but had considerable difficulty incorporating these elements into the ongoing descriptive writing I was generating through my reading and re-reading of the data. So I set them aside all the while wondering if by doing so my work would be sufficiently robust theoretically (my use of 'framing' elements is articulated in the previous chapter). Nonetheless my methodological orientation in poststructuralist thought, feminism and disability studies, and to some extent my own embodied location as a disabled woman securing disability

benefits provided interpretive guidance in the form of the question, “What can be said?” about how power is exercised in these disabled women’s lives.

As I was creating these more interpretive texts about exercises of power, I was also engaged in another kind of writing about what I began to see/understand to be prominent (and repeated) qualities of the women’s lives evident in the narratives that follow and in my own introductory story. This process I consider to be one of culling and expanding, refining and discerning. Exploring the emerging qualities of the women’s lives through writing and rewriting and mapping I was able to elaborate them descriptively in a way that produced several different readings of the constantly-moving dynamics I saw in play in their lives (See *Palimpsest: From the ground up*, v. 4).

Describing these dynamics creates a web. Every thread is an explication of how the dynamics unfold or constellate in the lives of these women. Each thematic strand or story line originates in and is driven by an interpretation these women make about what is possible with respect to the institutions and regulations to which they are subject. Over time my persistent interest in exercises of power became focused on the dynamics reflected in the different ways these women organized/structured their everyday lives, that is, how they made strategic decisions about what to do or not do based on their readings or interpretation of what might be possible given the policy and regulations—the governing structures and processes—to which they are subject. Part of their reading of what might be possible was also constituted by what their physical or mental impairments allowed.

I was getting closer to the interpretive labyrinth’s edges/egress.

Reflecting on the data relating to the topics we had discussed during the interviews and drawing from the qualities of their lives and dynamics I had discerned and articulated in

writing I decided to construct narratives (or perhaps critical narratives) about each woman and her experience around three sets of circumstances in which exercises of power seemed germane: applying for and securing benefits; caring for herself, and; undergoing the Disability Designation Review. The next section(s) (*Impossible Stories*) serves as an introduction to these narratives which appear in three sections, first, Applying for Benefits, and, second, a grouping of five separate individually-titled narratives. The first narrative section is followed by critical reflection (*Laying bare the disciplinary process*), and the second grouping by critical, interpretive ‘readings’ constructed from the dynamics at play in their lives (*Palimpsest: From the ground up, v. 4*). The four narrative accounts of each participant’s experience of undergoing the Disability Designation Review are introduced in *Challenging Changes*. Each of these narratives is separately titled.

Impossible stories

Impossible stories, stories with No Entry signs on them, change our lives, and our minds, as often as the authorized versions, the stories we are expected to trust, upon which we are asked, or told, to build our judgments, and our lives. (Rushdie, 2000, p. 199)

We follow a narrative suspensefully, always reminded of the fragility of events, for things might have turned out differently. (Mattingly, 1998, p. 154)

The impossible stories presented in the next section (*Applying for benefits*, the five subsections following *Laying bare the disciplinary process*, and the four focused on each woman's experience of the Disability Designation Review) were constructed purposefully; I want to show readers what it is (and has been like) for the participants to live the lives they do in order to disrupt taken-for-granted 'authorized' versions of disabled women's lives. I did not think presenting carefully chosen shorter excerpts from the interviews/data interspersed with reflection, analysis and interpretation (to illustrate critical points or theorize) would convey the same depth or wholeness I was seeking. In fact, I did create a number of documents in this style before writing the stories as they exist, but this required that I wrote enough about the context such that readers would have a good sense of who each of these women were and how what they did might make sense to readers. This contextual writing often took a narrative form and these stories seemed important to pursue in depth; writing unbroken narratives focused around different aspects of each woman's life provides rich texture to their voices (Moss & Dyck, 2002). Stories really begin with endings; endings tell the narrator where to begin, what she ought to include and where to end the story (Mattingly, 2000). This is the "chronological

illusion” (Barthes, 1975, p. 251) of narrative that enables storytellers to speak/write with certainty about events despite knowing “life as lived opens onto an uncertain horizon” (Mattingly, 2000, p. 184). Of course, disabled women’s lives “as lived, as experienced and as told” may correspond, but as a researcher it is important that I “never assume the correspondence nor fail to make the distinction” (E. Bruner, 1984, p. 7). We who write about the uncertain, fluctuating moments of others’ lives (or even our own) are “storytelling tricksters,” (Mattingly, 2000, p. 184) shaping lives that may seem incoherent or lacking plot into something told rather than lived using more than knowledge, our “moral voice” (p. 185), to configure meaning.

Having said this, I have created narratives that as best I can closely reflect what my participants told me, in part because they presume I will do so, a salient point when the stories “concern the untoward, events that involve risk...danger, chance...[stories about] life in the breach” (Mattingly, 2000, p. 189). Yet even with attention to verisimilitude, as a writer I am keenly aware that narratives traffic in “human possibilities rather than settled certainties” (J. Bruner, 1986, p. 26); as such they are always open to alternative, and even unintended readings. Bruner reminds us that a story’s truth value is less important than the quality of verisimilitude—the idea that the story *could* be true (p. 21).

Readers are implicated through the relational act of reading and an effective or persuasive story engages readers actively in creating meaning. The story is not just about lives or events “but also *does* something” (Garro & Mattingly, 2000a, p. 11) if readers are willing. It is my hope that these stories also “have power as actions” (p. 11), that is, that they are powerful (and believable) stories—such that readers will come to care about

what matters to the participants—and perhaps are compelling enough to shape how these disabled women’s lives (and others like them) are thought about and acted upon.

Again, like my opening narrative these stories are not neutral. They are embedded in the contested and emergent social and political contexts of these women’s lives. The women recounted/configured their experiences (to me) in the interviews by and large in narrative form, “opening up a discursive space in which [they] can resist dominant subject positions by articulating the contradictory meanings in their experience” (Langellier, in Kohler Reissman, 2000, p. 133), a space that underlines the importance of stories in the study of women’s lives. If we understand stories to have both “persuasive and pragmatic possibilities” it requires us to “go beyond text to examine the social world in which a story is told, or even tellable” (Garro & Mattingly, 2000b, p. 263), thus anchoring the participants’ experiences “in a robust way” (Dreier, 2000, p. 254) in social and political structures and processes. Storytelling as “situated practice” (p. 256).

The narratives that follow are focused on the three topics mentioned above. The first grouping (all in one section, *Applying for benefits*) focuses on what unfolded as each of the women applied for benefits, and is presented without critical comment. A grouping of five additional narratives emerging from conversation about how each lives her everyday life follows a critical interpretive/analysis chapter (*Laying bare the disciplinary process*). Lastly, and then toward the end of the dissertation a grouping of four narratives about undergoing The Review are presented. In the latter two groupings interspersed with (often lengthy) verbatim quotes is my own critically reflexive writing which primarily provides context for the women’s stories, but also serves as an interpretive text that

situates aspects of each women's stories in different social and political structures and processes as I understand them.

Applying for benefits

Each of the participants had different circumstances, health problems and experiences applying for and securing B.C. provincial disability benefits. Jocelyne, Galya and Evelyn acquired disabilities (became chronically ill) as adults, Marion did so as a very young child. The former three live with invisible disabilities, Marion is visibly disabled. We begin with her story followed by the accounts of Jocelyne, Evelyn and Galya.

Marion is different from the other participants in that she has been disabled most of her life having developed juvenile rheumatoid arthritis as a pre-schooler. At the time of the interviews she was not middle-aged like the others but in her mid-thirties and up until just shortly before our interviews had lived with her parents all her life. She lives on her own in a subsidized two-bedroom universally-accessible ground floor unit in a mixed income housing development in a suburb of a major urban centre. Marion attended university as a young adult and earned a Bachelor of Arts degree while living with her parents. As someone who has lived with disability as a child, during her adolescence and into young adulthood she has developed unique expertise with respect to negotiating administrative systems. Marion has been receiving provincial disability benefits since 1985 when she turned 18.

Applying for benefits initially proved to be an unexpected challenge for her family in part because at the time they lived in a small resource-based community in British Columbia

whose Ministry workers had very limited knowledge and understanding of what constitutes a disability.

Marion: I actually had a heck of time getting on disability benefits because I first applied when I was 18 years old and I was living in [names town]. They turned me down initially because the [town's Ministry] office's only experience with people with disabilities in getting GAIN⁷—or disability benefits—was for people who lived in a group home and were severely mentally handicapped. And they actually turned me down and said, “You don't qualify.” And I actually at the time had limited experience of what disability benefits was. The only real reason it was so important was I was going to get my knees replaced, and I needed to be on it to access the medical benefits. And at \$1500 apiece for my knees because the pieces had to be specially made because of my age, I needed to be on the disability benefits. So I was a bit—kind of exasperated when they turned me down because *I* knew I was disabled. I had been disabled since I was three years old—all the documentation from the doctors—and I actually in the process went almost to the Tribunal [the Appeal Tribunal].

And so how long a period was this for you?

Marion: It was probably about six months. And it was terrifying because I was waiting to see if—there was a shortage of hospital beds, sort of like what's going on right now in a sense. And I was concerned that I might not have the coverage and might not have knee surgery. It was a big thing at that point.

And your parents didn't have you covered on their medical?

⁷ GAIN (Guaranteed Available Income for Need) paid monthly benefits to “handicapped” individuals between 1976-1996. Marion received this benefit for 11 years before the B.C. Benefits (Income Assistance) Act was assented to in 1996 (and repealed in 2001 at the assent of the Employment and Assistance for Persons with Disabilities Act, which took effect on September 30, 2002.) GAIN is a generic term Marion uses to refer to whatever disability benefit program she is speaking about at the time.

Marion: I wasn't covered at all on Mom and Dad's medical. Well my Dad wasn't working at the time. He used to be a forestry worker and they went bankrupt at the [forest products company he worked for]. And at the time my Mom had only started working as a casual for the school district, so she didn't really have any access to getting me on. I was kind of a bit put off though. One, because during the process of qualifying for GAIN they actually told my parents that they should split up and my Mom should collect welfare and then I would qualify for my knees to be covered, *if* I didn't get my GAIN—if I didn't qualify for GAIN that this was how my Mom should do it. And they actually told her that face to face.

Who told her that?

Marion: The [Ministry] financial assistance worker. That if I wanted to qualify—if she wanted to help me this is what she could do. And this was right after the employees had taken on the [forest products company]. And when they went bankrupt of course the employees lost their jobs and the money that they had put in to keep it staying afloat. So Dad wasn't working. Mom was only working part-time. And they said, "You should separate for a year, because that would be in the best interests of your daughter. And then you can suddenly, and spontaneously get back together again once you've got all these benefits from welfare." And my parents told them to drop dead basically. But I couldn't believe that—but in a way—I hate to say this—[names town] was more comfortable dealing with the welfare issues back then, than they were with the persons with disabilities. Unless you were in the group home. They seem to have that down pat, like what to do with mentally handicapped. But because I didn't fit that—what they were used to—I was totally breaking new ground. And they were clearly not comfortable with that and not experienced with it—that office. Maybe it would be different if it wasn't a small town. But that was their knowledge base and they were very forthright about telling my mom that this was the way to go, and seemed kind of put off that she wouldn't just go along with them.

But what happened was that my parents very wisely went to an upcoming politician who was a lawyer at the time, who heard about my situation because he had an office in [names town and lawyer]—and they went to see him and he said, “I’ll take your cause on.” He was actually looking for a lot of media attention. He was looking for profile—so he went to bat for me. He actually advocated on my behalf and essentially made the financial assistance workers there aware that disability constituted of more than mentally handicapped. And because I was physically handicapped that was well within the rules. So very shortly before my Tribunal they sent me a letter saying, “Never mind. You qualify.” But it was a bit stressful up to that point because they were kind of digging in and saying, “No no. No no. You don’t qualify.”

Jocelyne is a university-educated, middle-aged self-employed health care professional (physiotherapist specializing in mind/body approaches to *thallassotherapy*⁸) who emigrated from France and had been living in Canada for 27 years, six of them in B.C. at the time of the interviews. Since coming to Canada Jocelyne set up a clinic in Calgary, relinquished it, moved briefly back to France to institute a nationwide program then spent time in Monaco and Saudi Arabia using her expertise in various ways. Once these projects were completed she returned to Canada with her son (an adult living on his own at the time of the interviews) having divorced her husband.

When her health first began to fail she was on the cusp of a new self-generated project to set up a clinic in Montréal financed by an international consortium. It was her only possibility of employment at the time, but she was unable to begin negotiations because

⁸ *Thallassotherapy* is the medical use of the beneficial properties of the sea (which includes coastal climate, seawater, marine mud, seaweed, sand, and other substances extracted from the sea) in a preventative and remedial aim. (Retrieved Oct 1/2014 from <http://www.france-thalasso.com/?lang=en>)

she underwent consecutive abdominal surgeries (cholecystectomy and hysterectomy) a month apart that left her increasingly debilitated with muscle weakness and chronic pain. Eventually she was diagnosed in Montréal as having fibromyalgia, and diabetes. I am curious if she received disability benefits in Québec because she stayed in Montréal for four years after being diagnosed with fibromyalgia. Diabetes was diagnosed two years later.

Were you on disability benefits in Quebec?

Jocelyne: Ya.

So you decided to come here? [to the west coast]

Jocelyne: Ya. Because some doctor give me this advice too [about the weather] yes because I cannot go out, outside, you know. And is beginning too difficult. And when I came here I am afraid.

What are you afraid of?

Jocelyne: I am afraid because I think maybe I don't have money right away by disability. I ask at somebody to—my nurse—to take my bank account and for send to me from Montréal.

So you asked...you had a nurse in Montreal? Was she a community nurse?

Jocelyne: Mmm mmm.

And you asked her to send your money from Québec to B.C.?

Jocelyne: Mmm...mmm. For make sure I have for living. Until the authority here accept I can stay here. But at this point, at this time, you know I just make that for security. I never imagine is so difficult. I never imagine, I just think is maybe for one or two months, you know, but not is my way [meaning that it does not become her livelihood].

You were living on disability benefits in Québec and you knew that you were moving here. You hadn't got the disability benefits set up here yet in B.C.?

And so you were getting your disability benefit money sent to you in British Columbia after you came?

Jocelyne: After I came.

While you were applying for benefits here. Is that correct?

Jocelyne: Ya. But here they don't want me. I had very much difficulties, you know.

What kind of difficulties?

Jocelyne: Yes. And somebody said to me to going at association with *avocat* [advocate] of disability [names local non-profit disability advocacy service]. So I am going there and somebody help me. But one day this *avocat* is obliged to go in hospital for have a surgery on the knees. At this time my file *disparat* [disappeared] on *avocat* place.

Disappeared at the action committee.

Jocelyne: Mmm mmm. So I go and see the secretary of Anderson.

Of David Anderson? [Minister of Parliament at the time]

Jocelyne: Ya. And she speaks French. So I explain to her and she uh said to me where I can go for have some help to...for my disability.

You mean help to get benefits?

Jocelyne: Ya, a ministry somewhere.

An office?

Jocelyne: Ya. And it's so difficult you know.

So can you tell me what was difficult about it?

Jocelyne: Ya they don't want give me Disability 2.⁹

So you actually filled out the forms?

Jocelyne: Mm...mm.

And then you sent them off to the Ministry?

Jocelyne: Ya, they don't want accept to give me Disability 2, and I saw some other people. And finally, the priest on the church where I live here, take a phone and phone at the Ministry, and said "It's torture you give at this woman, because you know she is so sick and she cannot have the right medicine. And she cannot living and she is you know completely disappointed, you know, and she is very sick." And this man don't understand why I have difficulties, you know. So four days after I receive my Disability 2.

You were put on Disability 2 because your priest advocated for you?

Jocelyne: Mmm mmm.

And called the Ministry up?

Jocelyne: And said is torture.

And before that you were on Disability 1? So when you first applied you went on Disability 1?

Jocelyne: Here. Ya.

How long were you on Disability 1 for?

Jocelyne: I think two, three months, four months something.

⁹ Here Jocelyne uses the term Disability 2 (or DB2), which refers to the permanent disability designation instituted as part of the 1996-2002 B.C. Benefits (Income Assistance) Act, which provided income support for eligible people with disabilities on a long-term basis. The *temporary* disability designation (Disability 1 level) provided less income on a short-term basis for those with multiple barriers to employment, including mental illness, homelessness, substance abuse, and illiteracy. At the time of the interviews (2002), Jocelyne had been found ineligible for the newly-created Person with a Disability (PWD), which replaced the permanent category; she was deemed eligible for the Persons with Persistent Multiple Barriers (PPMB) category. The 'barriers' referred to in this category title are barriers to employment. Both Disability 1 and PPMB provide lower benefits than Disability 2 (or the current category, PWD).

And it wasn't enough for you?

Jocelyne: No. No. Definitely no.

Evelyn is also a middle-aged professional with undergraduate and graduate degrees in helping professions. She has two children in their twenties and was living on her own at the time of the interviews. At the point at which her chronic illness debilitated her completely Evelyn was self-employed, commuting two and a half days weekly to her workplace, a social services agency seventy (70) miles away. She also had a small private counselling practice and was single-parenting her children who were attending high school and living with her. She describes a two-year period of fluctuating illness during which she was exposed to a variety of environmental toxins, which she believes contributed to the development of chronic fatigue.

Evelyn: I remember being like pretty exhausted and then decided after—I think it was maybe a year—to move to Saltspring [Island] because I was getting really—I was getting sicker and sicker in Victoria and it felt like it was environmental.

Mmm mmm

Evelyn: Because during that time those three years—no two years before we moved, the DND — Department of National Defense— was doing their training for pilots to put out fires, and they would light garbage, toxic garbage, and then put it out with fire retardants. And I remember seeing the black smoke drifting towards Fernwood. But my lungs, I couldn't even ride my bike, my lungs were just burning. I know part of it was because I moved into a brand new building in the Co-op [housing] so that's when I started to feel sick.

So you think that it might have been the insulation or the paint or whatever?

Evelyn: Yah, the fumes from the glues, the carpet, everything. Off-gassing. And then on Saltspring I was not bad. I was commuting still to Victoria and that was OK because it was only like two days a week. We got a new ED [executive director]—that guy was really gnarly and abusive to the clients and to me. So I finally quit the job. And when I was looking for work I remember feeling OK. Then I started working in Duncan, with the Cowichan tribes. The work itself was you know exhausting and traumatic, lots of homicides and suicides and abuse and stuff. And I remember every day at lunch time, I would lock my office door and I would just throw myself on the couch and I would sleep.

And how many days were you working?

Evelyn: Five. And I was commuting from Saltspring. So then we moved back to Victoria before that job was over because my kids were really unhappy with the high school there. C. [her eldest child] got into the jazz program here. And then I remember—like we moved in about October—and I remember at around like December just going “I can’t. I can’t function.” And I was just like dead in my tracks, even though I was still working. I was doing private practice. I kind of like tried to end a lot of clients and then I totally crashed when a year later we moved to this other housing co-op, and it was totally mouldy in the basement, and that was when I got so sick I couldn’t even walk. For like four or five months I was pretty much bedridden.

Mmm mmm.

Evelyn: Then I was on EI—medical EI.

Do you know how long you were on that for?

Evelyn: It wasn’t that long. I don’t know. I was on EI and then it got switched to the medical benefits. And then I don’t know the dates but at some point it ran out. I remember now. In my case because my youngest child was under the age of 19, like 18, I went onto regular income assistance. I must have

though started seeing that I wasn't going to be getting better any time soon. And then at some point I don't know what point, I decided to start that process of applying for disability. So applying for Disability 2 was this whole thing of like getting a diagnosis. So I had to go to a psychologist, I mean a psychiatrist, to make sure I wasn't depressed.

Had you paid into CPP when you were working?

Evelyn: Yes I had.

What happened with that?

Evelyn: I didn't have enough hours? Or—

Length of time in the workforce.

Evelyn: Ya.

Those would have been the old CPP, rules which were much more liberal than the new CPP rules. It sounds like you didn't have enough working time to be eligible. Were you paying into some LTD?

Evelyn: No. But I was—like this was before, um—I was still working. I remember contemplating getting long term disability insurance and I never did. And then it wasn't that long after that I went "holy shit!" It was too late I think to go that route.

So how would you have done that [receive long term disability benefits] if you hadn't paid any premiums?

Evelyn: Oh well I would have started to pay. I didn't think I was sick at the time. When I thought, "oh that's an idea. Maybe I should get disability insurance" I was fine, more or less. Before the big crash.

And was it the big crash that it dawned on you that you needed to be getting disability insurance?

Evelyn: Ya. By that time both my kids had moved out of the house and I was I think, yeah, getting regular income assistance [welfare benefits], which of course isn't enough.

So your reason for getting disability insurance was to get more money? Was there more to that for you?

Evelyn: No. It was to try and pay for all my expenses, for seeing all these practitioners and trying to get my system back using supplements.

Can you just give me a sense of what might in your mind have been kind of difficult about that initial application process, and what might have surprised you about it at all? I just want to get a sense of what it was like for you to do that, especially not being well.

Evelyn: Ya. I ended up doing a lot of crying in offices with these strange men I had never seen before.

Who were the strange men?

Evelyn: Well I saw a neurologist—I don't remember his name. I saw another guy besides the psychiatrist, who was fairly nice. After about five minutes he said, "You're not depressed" and then he went on to give me some just kind of support around what I was going to do once I was better, which I could not relate to at all (laughs). But it was interesting.

At that point you were looking for a diagnosis?

Evelyn: Ya. I had to see—I remember there were three practitioners—a neurologist, a rheumatologist—to make sure it wasn't arthritis or lupus or any of those kinds of things.

Did you get a diagnosis?

Evelyn: Ya. Chronic fatigue and fibromyalgia.

Do you think that was accurate?

Evelyn: Yes.

And so that's what went onto your form.

Evelyn: Mmm mmm.

Did you take this form to these guys or just your GP?

Evelyn: I don't think I took a form to them. They wrote letters to my GP.

So those would have been included with the application.

Evelyn: Ya.

What did you actually write on the form? I have a copy of the old (application) form here and there are a couple of sections for the applicant, which basically asks, "What kind of costs do you incur?" Do you remember what you said in that section? What I'm trying to get at is did you get a sense that there is a way to be filling out this form so that you would get benefits?

Evelyn: Oh ya, just because I am a very paranoid, suspicious person (laughs). What was my sense of what I had to say? Well I don't think they cared about your expenses. That was my sense, that it was a kind of a token gesture, because they weren't going to give you any more money than they allotted to every Tom, Dick and Harry, as far as I can remember. I just remember feeling a lot of oh I don't know despair and anger when I did fill out my expenses versus how much they were going to give me.

Mm mm.

Evelyn: What else? I remember just kind of—well I have a really pretty sympathetic doctor, but I still felt like I was imposing on her because she had to do extra kind of work—I'm sure she billed for it. I guess maybe that, my sense of putting her out was more my own shame around feeling like I'm a burden on society (laughs gently). It felt kind of bogus because nobody but me can know what I'm experiencing, and even though these professionals seem to have a few little tests or tools or whatever that they used to say "Oh yah, that's what you have", I walked in there saying "this is what I have." It was kind of—I don't think they could care less. They were just jumping through hoops as well.

Meaning these three specialists.

Evelyn: Ya. I mean—maybe I'm digressing, but I remember the neurologist maybe guy saying, "Oh yah, you really need to exercise. You need to walk

around the block at least once a day.” And I just burst into tears. I could not make it from the sofa to the bathroom, and he’s telling me to go walk [around the block]. People just—still don’t get it. So it was kind of a weird kind of juxtaposition of getting to the appointments, having to drive, which was really beyond me.

What was beyond you about that?

Evelyn: It [the car] was probably a standard. And walking, just getting from the car to the office. I’m allergic to being in public places, more or less, so having to put up with all that. Being in an elevator.

I asked Evelyn why she might have been successful getting benefits.

Evelyn: Because my doctor probably—yah, she really put a lot into the application. It was sketchy because I didn’t really—those two syndromes don’t really fit into their black and white categories. I don’t quite know why I was successful. I think that um—yah, maybe I—OK now I am remembering maybe writing something to them.

What do you suppose it was you wanted to convey to them?

Evelyn: Um—well just the seriousness, the severity—the debilitating aspect of what I was living with. [long silence] I did do some research.

What kind?

Evelyn: I do remember going to TAPS (Together Against Poverty Society) and the Action Committee (for People with Disabilities) and getting some more—the bigger picture on what I needed to say and what some of my rights were.

And you found them helpful, at those community organizations?

Evelyn: Ya. I think I only did see someone once at TAPS ‘cause they were so busy. Ya it was good to touch in with someone. I was pretty much doing it in isolation.

Meaning you didn’t have any help with it. You were doing it on your own.

Evelyn: I didn't. Ya.

The volunteer at TAPS gave Evelyn a sense of what she needed to write on the original form.

Evelyn: My sense is that it was pretty much, "Don't worry. It is pretty much a basic—if you can prove that you have the need then you're going to get the extra money." I remember just being pretty confident about it. I mean it wasn't going to cover my costs but I could prove the need.

Did you have a sense that there was a way to fill out the form to maximize your chances of getting or continuing your benefits?

Evelyn: Probably 'cause I just—I can only say probably. I mean having—I'd been on income assistance years before so I kind of knew that it was sometimes a matter of a stroke in the wrong place and you're disqualified.

Galya is a middle-aged woman who, previous to emigrating to Canada with her then eight year old child as refugees from a Soviet bloc country had obtained a substantial education beginning with a degree in Education. While working toward her B.Ed. (or Soviet equivalent) she took some additional training and worked as a simultaneous translator but realized she always wanted to be a psychologist. During the two years spent as a high school languages teacher she was told that the most expedient way to become a psychologist was to complete her nursing education because nurses were among a group of preferred applicants in the tight competition for seats in the university psychology degree program she wished to take. After completing a three-year honours nursing program she worked at a surgical clinic, married and then moved with her husband to another communist country. There she taught languages (Russian, French, German, Spanish) sessionally for four years while taking neuropsychology and biology courses.

After this she taught biology in the science faculty while completing a B.Sc in Psychology and subsequently, just before emigrating to/becoming a refugee in Canada an MA in Clinical Psychology. At the time of her refugee claim she had been working overseas as a university professor in psychology.

Galya had been unsure whether or not her qualifications would be compatible with Canadian standards but because she had taken so many different courses during her education she thought this would not be a problem. She and her child stayed in Newfoundland for a year during which time she was informed that she should do some 'equivalency' education if she wanted to practice as a nurse, and once this was completed as long as she had Grade 12 English, which she got later, she could write the nursing registration exams. However, Galya moved to B.C. before doing so, and was told by the Registered Nurses Association of B.C. that she would not be able to practice as a nurse without repeating her education and getting an R.N. diploma or B.S.N. degree.

With this door closed she decided to take another Master's degree in psychology and applied successfully to a university program in B.C. . She believes her supervisor took a risk by accepting her into the program because the only Canadian education she had was Grade 12 English through Adult Basic Education. At the time she began experiencing symptoms Galya worked part-time as both a research and teaching assistant while taking graduate courses, which she completed but not her thesis.

Galya: But somehow Sally, little by little like—everything stopped making sense, anything, everything kind of became meaningless in a way. So I just got so depressed and I just found myself in bed sleeping 15 hours, 17 hours, sometimes overeating. But then I was—it's difficult to say if I was depressed or I wasn't. But if I was, as my therapist put it, "you weren't even aware you

were depressed.” But the leaving everything behind and starting again all the life circumstances, and raising my child, and having very, totally different status here than I used to have before.

Galya had been receiving disability benefits for three years when I interviewed her for the study. Previous to that she had lived for two years on a temporary benefit, which she sought after living with chronic depression for at least a year.

Galya: In my case depression expresses itself as total, total lack of energy, and also like very, very little motivation or none to even like pleasurable things, or necessary things like having a nice dress, or taking care of myself by having a nice bath. Like when I started to be depressed I could only take a shower just to not be dirty but—so when it started to be so difficult I still did not—I had this shame to admit that this is where I am at. And for a few months I think for—up to a year I was coping and uh—but I had to go to the ministry of social assistance and housing and ask them for some supports.

Income support?

Galya: Yes. Income support. It’s called—I don’t know if it exists now but it used be called Temporary Relief from Work [temporary welfare benefits, the lowest income support category]—that’s what I had from my doctor for two years. It had been, Sally, in comparison to where I am now with this disability pension. That had been worse.

And what was worse for you?

Galya: I mean worse in every regard. In one hand looked down even more than now.

And who looked down on you?

Galya: The social worker—of course I admit that it is also my own projection in a way but on another hand I certainly saw the suspicion, the disregard that I experienced again. Of course it is my experience I can only say. But I definitely saw differences between some of the workers. And uh—but also

the money. I had \$500 [monthly]. That's what I had. And one year—my particular situation was not common for other people—because one year, Sally, one year I and my daughter lived on that \$500 together. Because [names child] turned 18 and they said she—wasn't a dependent anymore.

Galya: But she was still in Grade 11 and for her to go to school as other kids—regular school—she would have to—she was not eligible for anything. They said clearly that she has to quit—she would have to quit school and look for work and then go to night school. Then she would have been eligible for that money. Not grade 11, sorry the last one—Grade 12. So because we came and she lost several years, that's why she was—and she turned 18. That was the most—I can't even explain how difficult it was in every regard. But then so I have been in that situation for a couple of years. And then I saw several people that had similar condition and they were qualified for disability. So I talked to my doctor and in my case I have really good doctor. I had a really good support as a doctor—I know her since we came here, [names daughter] and I. And she has known [names daughter] since she was 10, and myself and she is—she is in fact not really a common allopathic doctor—but on another hand she never suggested for me the disability benefits.

And she knew that you were depressed?

Galya: That was the diagnosis.

Like the temporary benefits were based on the fact that you had a diagnosis, right?

Galya: That's right. But nevertheless she never suggested anything. And when I saw all the other people—

—where did you see the other people?

Galya: Well for example, I just remember—I recall very clearly that I had done extensive reiki training—I am a reiki master—and *my* reiki master, she had the benefits and—of course I had been working the path of opening my mind but I couldn't contain myself not saying to myself, “well she seemed to

be like me or even less severely depressed.” So if she has it—and we happened to have the same doctor, just by chance—I said “well I can apply.” So I applied—I talked to my doctor and she said “yes I will fill it out for you.” So we fill it out and uh I got the benefits.

And do you remember filling out the form?

Galya: Everything. I remember.

Tell me what it was like for you to do that.

Galya: Well first of all I was very not sure that I’m going to get it. I was afraid that I’m not going to get it.

What made you feel that way?

Galya: It wasn’t very easy to answer because I—on the one hand I believe that we have enough resources on the Mother Earth for every single person. Nobody must starve or if someone needs—I believe in exchange and fair trade. So on the one hand I know that if I am not well, if I cannot—and I know I worked so hard before so why if I cannot do it now why can I not have support, on one hand? On the other hand it’s like I felt very embarrassed, and kind of ashamed. The sense was almost like begging. And I felt well yes I did work and I did study, but not in Canada really so almost like why Canada should provide? I was raised like “be strong”, “rely on yourself”. “Oh stop it, put it aside, people starving in Nicaragua” or whatever. So I kind of minimized in a way my situation and I thought maybe I shouldn’t apply, but then it was so hard to live on \$500 and be looked down as if I was a bum, a total bum. So I applied, but the first one was easier than second [the “second” referring to The Review] because the doctor was the one who filled it in the most of it. I just wrote my symptoms and my condition as I experienced it. And she filled it in her side of the story. And it went quite—I was surprised. I got it in three months.

Did you think it was going to take longer?

Galya: I thought it would.

How long did you think you were going to have to wait?

Galya: I thought maybe six months or maybe they would never respond. Because when I was not on disability benefits I tried to stay away. I never asked for any additional things. Like people say that “oh you can ask for \$100 of clothes or moving expenses.” I never did anything.

Why did you not ask for that other stuff?

Galya: Oh (sighs) I was embarrassed, I was ashamed, and also I run into several workers that like have this stare in the eyes that I interpreted as blank and totally not empathic. And questioning like someone—me as if I’m on trial or something. And I was also terrified Sally.

You were terrified of what?

Galya: It was stupid of me, but I was terrified they would cut me off totally. So I tried to stay away as much as I could.

So the less you involve yourself with the bureaucracy—with the workers—then the less chance that they might look closer or ask questions.

Galya: And say, “get away from us.”

“We don’t want you.”

Galya: Yes, exactly. That’s why it was. I suspect they were told, “Do not disclose any additional information for the clients.” I never saw them telling me, “This is what you can have.” Then I got this disability benefits. I remember I felt such a relief. I felt such a relief. But so—there was an acknowledgement that there is something in my condition. It’s not healthy enough to demand for me to work all the time right now. By the way even now I still have some hope, quite a lot of hope Sally, to still finish my school. To finish your master’s degree.

Galya: Yes, I do.

And you left that behind because of depression?

Galya: Definitely. I just—but meaninglessness—like nothing made sense plus no energy. No motivation. I could—I could sometimes walk, I have stairwell, I could just walk two or three stairs and I would just stand like this. And there is nothing in my head. And I would just stand there for a while. My cats would come to me and look at me, or sometimes I used to—I'm not there right now, but still sometimes to make a very small decision, like small decision—Do I go to buy bread? Or do I go to food bank? which was a major support for me all these years, Sally. It's embarrassing for me but it has been.

And this is true Sally. Everything is true. For example—it's almost embarrassing to say that, but this is very true [crying] there were times when I couldn't even take a shower for like three weeks. I couldn't get out of bed. And uh but I still never lost my appetite—but I never had binges. But in my case I always have eaten well. Like I grew up on a farm. I have taste for good—for vegetables. But I would just eat large, very large amounts, very large amounts. And I found myself not being able or motivated to connect with people at all.

And for how long at a time?

Galya: Oh fortunately I always had a contact with my doctor. So I would see her once a month. And fortunately I have been with [names therapist], with my therapist. And also I embraced the Buddhist teacher, [names teacher]. It's not that I stayed at home for four weeks without bathing. But uh—ya it happened a couple of times I would say. I would still go out. I would still—not pretend, but somehow shake myself off—up and um—but—it's interesting the most difficult thing for me was precisely bathing. Taking a bath. It was the hardest thing to do. Like looking after myself—I guess it was, life was—[sighs loudly] so hard. But I would be able to go to my therapy, to [names spiritual teacher] meetings.

So you got through this initial period somehow, but it was difficult.

Galya: Ya. I gradually fell into the depression. I gradually did. And when I found myself like totally not motivated towards anything—I only kept—the

only reading that motivated, the only reading that is still part of my life is astrology, related to my growth, my therapy and my teacher, my Buddhist readings. It doesn't make sense to me to read any novel no more. I used to enjoy that. Sometimes the energy, the lack of energy was so great that I didn't want to get out nowhere, but I still, Sally I could watch suspense movies, five and six and eight movies. And I found myself then, for example, very hard to go to bed. Each—I would just watch TV until 3 and 4 and 5, and then I couldn't sleep well and then I would sleep two days on the row. And the morning was the worst. I would get up and it just totally an empty day, nothing to live for. But I still had my daughter, so I had to also have some responsibility for her.

Laying bare the disciplinary process

Bearing in mind that the docile bodies produced by disciplinary techniques are an effect in every instance of power/knowledge, what is additionally striking about the shifting and heterogeneous set of conditions named as disability is that in its construction the disciplinary process is laid bare. (Shildrick & Price, 1996, p. 101)

In this section my intention is to begin laying bare the disciplinary processes the women in the study find themselves in the midst of/engaged with, that shape their lives in unexpected ways. The writing comprises critical reflections on the accounts at the heart of the previous narratives about applying for benefits but also fleshes out some of the contexts in which this particular process is experienced by all (and incidentally, all who apply for disability benefits). This section is not intended to be exhaustive but rather to provide different ways of thinking about particular aspects of the benefit application process and of the circumstances the women found themselves in at the point of applying. Later, (in *Palimpsest: From the ground up v.4*) I critically reflect on some of the dynamics central to disciplinary processes and what gets produced in their lives, following individual narratives about everyday life focused on how the women care for themselves and their bodies in the face of considerable constraint.

As it turns out applying for and securing benefits is not a simple, straightforward process for any of the participants wherein they visit a Ministry office, get an application form, see their doctor (or specialist) to have the form completed, deliver it back to the Ministry

office, and wait for approval.¹⁰ Although none of the participants mention or discuss the process in this elementary, impersonal way some version of these steps was taken by all during the application process. Despite the gate-keeping role of doctors in terms of getting benefits approved (by identifying and documenting disabling conditions), of the participants neither Marion nor Jocelyne mention medical approval although, like the others, they speak of the medical circumstances that prompted their application. Given that in contemporary society “it is incumbent upon the ‘good citizen’ to subject herself...to medical surveillance” (Stone, 2008, p. 207), all have sought (allopathic) medical treatment for their illnesses.

Both Galya and Evelyn spent time on basic social assistance (welfare), in Galya’s case welfare benefits designed (at the time) for those assessed as having temporary conditions preventing employment, before finally realizing they ought to apply for disability benefits. Some of this is likely a function of the slow (and often unsuccessful) process of getting a diagnosis that both of these women experienced in part due to fluctuating and invisible conditions (Lightman, Vick, Herd & Mitchell, 2009), but it is also well documented that many people live and work with significant health problems before realizing they cannot work any longer and have to leave the workforce due to disability (Fawcett, 1996). For some preserving “normality [is] rooted in maintaining employment”

¹⁰ Currently, the process for applying for benefits is even more onerous and complicated than it was when all the participants applied. The Ministry website outlines in detail what applicants are required to do: “1) Complete the **entire** online application process; 2) Conduct a work search (unless exempted) while awaiting an eligibility interview—New applicants who have **never** received assistance before must complete a five week work search [sic] [search]; Returning clients who **have** received assistance before must complete a three week work search; 3) Obtain a copy of the **Work Search Guidelines** and the **Work Search Activities Record**; 4) Attend an eligibility interview with Employment and Assistance Worker to determine your actual eligibility. A worker will make two attempts to contact you in order to set up an eligibility interview” (Retrieved October 1, 2014 from <https://www.iaselfserve.gov.bc.ca/Apply.aspx>).

(Moss & Dyck, 2002, p. 97); in this way economic factors borne of fear of losing their jobs play into decisions to remain in the workforce while chronically ill.

Disclosing illness to employers can be “a tricky process” (Moss & Dyck, 2002, p. 117) especially in the context of invisible conditions where visible proof of illness is absent/lacking or at best fluctuates, opening women’s bodies to scrutiny and potential loss of job security. Delaney & Bell (2008) also point out that maintaining “a façade of invulnerability...is a requirement of patriarchal systems” (p. 5); to show weakness may compromise any power or authority a woman may have cultivated in her workplace especially those working as professionals, as were Evelyn and Galya when they became ill. Arguably, another factor in deciding to leave employment is the presence/lack of disability-related supports in the workplace or reluctance to pursue these due to limited energy or resources or fear of scrutiny. In the face of their inability to continue employment Galya and Evelyn imply that being on social assistance was necessary in part because both still had children under 18 at home. In the face of limited energy and resources both women prioritized caring for their children over employment. This was not the case for Marion who does not have children and Jocelyne, whose son is a young adult living on his own (whom she declined to speak about at any length).

Applying for benefits often requires enlisting others beyond health care professionals in the process. Evelyn and Jocelyne sought out and relied on local, community-based non-profit disability service organizations to help them through the application process; Jocelyne also sought assistance through her federal Minister of Parliament’s (MP) office and her parish priest, who seemed the most effective as it turns out. Marion (and her parents) enlisted the support of a local B.C. Minister of the Legislative Assembly (MLA)

who was also a lawyer and willing to take on her cause, in this case a lack of understanding at her local Ministry office as to what constitutes eligibility for disability benefits despite being visibly disabled.

Evelyn comments on the fact that the application form at the time requested that she list her disability-related expenses and makes a judgment that providing this information is useless because she assumes it is unlikely to bring her more benefit income than others receive. She is correct in her judgment; all beneficiaries receive pre-determined standard benefits and housing allowances. Interestingly, the disability-related expenses element was dropped from the application form when the B.C. Liberals were elected (and changed the disability supports legislation and application form in 2002). In their judgment disability-related expenses were considered irrelevant assessment criteria because they were not medically-based, thus renewing the power and dominance of biomedicine (Moss & Teghtsoonian, 2008) and reinforcing disability as an individual failure unrelated to social or economic factors.

Socially-relevant criteria had been lobbied for by the disability community and included in the regulations in 1996 by the then NDP government after pressure from activist groups who had argued for more socially-based eligibility criteria (rather than exclusively medical criteria), including the inordinate costs associated with disability. These more progressive social model criteria included such important elements as requiring “unusual and continuous monthly expenditures for transportation or for special diets or for other unusual but essential and continuous needs” (British Columbia, 1996, p. 2). Here the NDP left-of-centre governing agenda is evident, although early in their mandate the NDP rescinded the \$100 allowable employment earnings (and restored it late in their mandate)

demonstrating ongoing “tensions between neoliberal and social justice commitments” (Teghtsoonian, 2003, p. 30) in the NDP approach to governing. Nonetheless, the costs-of-disability criteria were replaced (by the right-wing Liberal government in 2002) with biomedical criteria that specified the disability had to “directly and significantly restrict the person’s ability to perform daily living activities either continuously or periodically for extended periods, and as a result of those restrictions the person requires help performing those activities” (British Columbia, 2002a, p. 4).¹¹ Evelyn appeared not to know this history and shows distrust of the NDP government at the time in her response.

The disability studies and social policy literature is replete with writings about the effect of neoliberal regimes and the erosion of social welfare in Western democracies, in particular the tightening of eligibility criteria and reduction in supports for those living with disability (Bach & Rioux, 1996; Pulkingham & Ternowetsky, 1996; Rice & Prince, 2000; Krogh & Johnson, 2006; McColl & Jongbloed, 2006; Raphael, 2007; Lightman, *et al*, 2009; Prince, 2009). Not the least of these are the “pronounced and multiple” (Brodie, 1996, p. 126) impacts of restructuring on the lives of women, in particular how citizenship has been/is being redefined within the neoliberal order. Those women living on the margins, like disabled women, “who experience a variety of barriers to

¹¹ The B.C. Employment and Assistance for Persons with Disabilities Act, assented to May 30, 2002 (Bill 27) redefines disability (or a person with disabilities) as follows (subsection (2) and subsection (3)): “The minister may designate a person who has reached 18 years of age as a person with disabilities for the purposes of this Act if the minister is satisfied that the person has a severe mental or physical impairment that (a) in the opinion of a medical practitioner is likely to continue for at least 2 years, and (b) in the opinion of a prescribed professional (i) directly and significantly restricts the person’s ability to perform daily living activities either (A) continuously, or (B) periodically for extended periods, and (ii) as a result of those restrictions, the person requires help to perform those activities. (3) For the purposes of subsection (2), (a) a person who has a severed mental impairment includes a person with a mental disorder, and (b) a person requires help in relation to a daily living activity if, in order to perform it, the person requires (i) an assistive device, (ii) the significant help or supervision of another person, or (iii) the services of an assistance animal. (4) The minister may rescind a designation under subsection (2). (British Columbia, 2002a, p. 4).

participation in the paid labour force” have had their social and economic well-being “undermined by significant reductions in...supports available” (Teghtsoonian, 2003, p. 30) as part of neoliberal¹² governing agendas.

Of note for disabled women is the elision of the categories in which they are located—as deserving or worthy recipients of support—with those who are ‘employable’ and otherwise able-bodied and therefore undeserving or unworthy. These kinds of “adversative classifications (Lightman, *et al*, 2009, p. 3) historically associated with the Poor Laws established in England in the early 1600s neglect the embodied diversity amongst disabled women and the “social, attitudinal, ideological, architectural, and environmental dimensions at the heart of social model theorizing and social policy” (p. 3). Jocelyne, living with chronic conditions (chronic fatigue, fibromyalgia, ulcerative colitis and diabetes) typically characterized by invisibility and episodic symptoms is vulnerable to being institutionally classified as not disabled (and hence not worthy of full benefits) and ends up defending “the contested credibility of her volatile [body] and situation (Lightman, *et al*, 2009, p. 3) an experience she likens to torture. Put simply her embodied experience is initially “not disabling enough” (p. 14) to officially categorize her as a Person with a Disability. Yet as Marion’s experience suggests visibility of disability is not a guarantee of eligibility. Interestingly, Galya reflects on her

¹² A note about the use of the term neoliberal is salient here. Larner (1996) suggests neoliberalism is a term often used simplistically to describe “post-welfare state citizenship regimes...associated with a preference for a minimalist state” (p. 5). She argues convincingly, drawing from poststructural thought, in particular Foucault’s ideas around ‘power as productive,’ that neoliberalism as a contemporary political formation is ambiguous, complex and contingent in its effects. It follows that neoliberalism takes on different configurations, revealing “a complex and hybrid political imaginary” (p. 12). In her view (drawing from Nikolas Rose) “neoliberal strategies of rule” encourage us to view ourselves “as individual and active subjects [autonomously] responsible for enhancing [our own] well being” (p. 13). Teghtsoonian (2003) in her analysis of the dismantling of the B.C. Ministry of Women’s Equality in 2001 suggests that the B.C. government’s neoliberal agenda works through “discourses, policies and [various] strategies of rule” (p. 39), thereby governing “indirectly at a distance” (p. 31), a central understanding of this research.

unworthiness in an unexpected way relating it to her estimation of what the Canadian social welfare system owes her as a refugee who has made a limited contribution to this society compared to those born, raised, educated and employed here.

What is remarkable in the women's accounts is that the kind of exposure to Ministry scrutiny and risk they presumably undergo as part of the application process is barely noteworthy enough for them to mention beyond fears of not applying successfully.

Frazer *et al*, 2006 refer to this process (and ensuing reviews once eligibility is established) as “an institutionalized end to confidentiality”...[in which] “stringent legal protection of an individual's right to confidentiality of her medical information” (p. 237) yields to institutional imperatives such as enabling governments to gather information about and confirm an individual's health and financial status and information necessary “to detect and prevent deceit” (p. 237). The boundaries typically in place between the private and public sphere are redrawn for women applying for and living on disability benefits, and because they cannot approximate the norm of the independent, self-reliant citizen they are unable to “resist state intrusion [or] call on the state to protect their privacy,” which affects disabled women “particularly harshly” (p. 238). In this case the norm for disabled women is ongoing self-disclosure of private details as part of being subject to state control and surveillance to which they must comply.

Typically, provincial government disability income support programs require “fixed categorization” (Lightman, *et al*, 2009, p. 2), that is, you are either completely abled-bodied or completely disabled and unable to work (Jongbloed, 2003). But in living with chronic illness the women in the study “[reside] on the fluctuating borders of ability and disability” (p. 14) thereby eliding this kind of categorization. To do so “agitate[s] binary

organization” (p. 14) that is required by the state to determine eligibility and thus they live in bodies that are “politically unthinkable” (p. 14). Application forms with sections to be completed and checked off by both a health professional and the applicant, “inscriptively characterize bodies crudely as either disability eligible, or not” (p. 2). The women in the study would have to have portrayed themselves as sufficiently ‘disabled’ to meet eligibility criteria, a particularly challenging feat in the case of Galya, Evelyn and Jocelyne who live with invisible disabilities.

Nonetheless, without coercion each of the participants would have offered up/volunteered intimate details of her everyday life and bodily functions in order to be a successful applicant, “turning a critical gaze” (Shildrick & Price, 1996, p. 102) on her own body and life. Indeed, these authors suggest that by ‘confessing’ freely the women are made responsible for their own success in obtaining benefits and “thus all the more cautious and manageable” (p. 100). Galya speaks of being cautious with respect to encounters with Ministry staff for fear of losing benefits capriciously. Yet personal statements of illness or disability are not enough to secure benefits; these non-authoritative accounts must be verified and supplemented by health (care) professionals,¹³ who must complete the (now) lengthy application form focused on bodily functions, ability to perform activities of daily living with or without help (a key criterion for eligibility, even if no

¹³ As articulated in the Regulations, ‘Health professional’ means a person who is authorized under an enactment to practice the profession of (a) a medical practitioner, (b) a registered psychologist, (c) a registered nurse or registered psychiatric nurse, (d) an occupational therapist, (e) a physical therapist, or (f) a social worker” (Retrieved April 25, 2003, from http://www.qp.gov.bc.ca/statreg/stat/E/02041_01.htm).

The designation ‘health professionals’ was repealed and replaced by ‘prescribed professionals’ effective July 1, 2007. An online brochure for interested applicants lists prescribed professionals as: “medical practitioner, registered psychologist or certified school psychologist, nurse practitioner, registered nurse or registered psychiatric nurse, occupational therapist, physical therapist, social worker, chiropractor” (Retrieved October 14, 2014, from <http://www.eia.gov.bc.ca/publicat/pdf/PWD.pdf>)

help is present), and in the case of those with mental disabilities, emotional/psychological status. All these criteria are derived from biomedicine and traditional, positivist scientific understandings of normalcy.

Applying for benefits is an individualized process that ironically inserts applicants “into patterns of normalization that grossly restrict individuality” (Shildrick & Price, 1996, p. 101) by defining disability along rigidly-constructed parameters that serve official purposes. The process demands that the women produce themselves as embodied “disabled subjects” (p. 104) making normalizing judgments on their own bodies and lives. The application process constitutes (and enlists the women in) disciplinary practices/processes in which their individual bodies (and lives) are open to scrutiny and surveillance and by the expert knowledge of biomedicine and the state. As they apply for benefits they engage in self-regulating technologies of the self, a salient aspect of biopower.

In addition, the women are being disciplined by treating them in impersonal and demeaning ways including controlling information about programs or entitlements (Chouinard & Crooks, 2005) to extra supports (Galya), expecting families to restructure in order to meet requirements (Marion), categorizing them at lower income support levels that jeopardize their ability to survive (Jocelyne), and producing uncertainty and capriciousness as Ministry staff exercise power in encounters with applicants (Evelyn). Together these disciplinary practices produce barriers for the women in terms of self-advocacy “[forcing] them into...disabling relations with the state, which mean they have to struggle harder and longer” (p. 29) to acquire the supports and information they need.

Uncertainty is the hallmark of chronic illness; we question those things we previously took for granted—our own ability to maintain our health, our engagement in paid employment, hopes for our future, our relationships with others, and with institutions, healthcare and otherwise. Expert medical claims about cause of illness or diagnosis can also contribute to uncertainty especially if these differ with our experience and self-understandings (Grills & Grills, 2008). Evelyn in particular experiences this as she seeks a diagnosis she seems to already know. Like the other participants, a medically-recognized diagnosis is key to securing benefits, but in the case of many (often autoimmune) invisible disabilities establishing this may be challenging for women, raising another level of uncertainty (about health care professionals and their expertise) beyond the instability of living with chronic illness.

This is particularly the case when a physical illness is construed as a mental health issue, a more common practice when a woman demonstrates fatigue, anxiety and low spirits, experiences germane to women living with chronic illness. Evelyn experiences this in her search for a recognized diagnosis; she has to see a psychiatrist to rule out depression. The invisibility of her disability also contributes to being misunderstood by another specialist who suggests regular walking to improve her health, which she could do only with extreme difficulty.

Again, and going forward to the next set of stories, my focus and concern is to show what the women actually do and what they tell me they do, and even what they might not be doing that we would expect ourselves to do if we could imagine ourselves in similar circumstances. I have been interested in how these women live their everyday lives and the accounts of embodied practices that follow—how they care for their bodies and live

with ongoing chronic conditions—including encounters with Ministry officials and health care workers, and others whose purpose is to assist and support them, continue to reveal disciplinary processes at work in their lives. After the next grouping of five narrative accounts centered on their everyday lives, uninterrupted by lengthy critical comment, I reflect critically in the chapter entitled *Palimpsest: From the ground up (v. 4)* on the dynamics I discern at play in the various ways the women engage in the disciplinary processes they are in the midst and what is produced.

Im/personal campaigns

None of the participants except Marion receive home support services: Evelyn is in an unstable/precarious housing situation, including being intermittently homeless, sleeping in her car, and “couch surfing” (at the time of the interviews she was renting one of three bedrooms in a house); and neither Galya nor Jocelyne knew about the service or whether they might be eligible. However neither meet the regional health authority eligibility criteria as they do not require personal, physical care as Marion does. Marion receives regular home support services which began when she was living at home and her parents needed help to meet her physical needs; her services continued when she moved out of the family home a year previous to the interviews into a two-bedroom subsidized housing unit completely accessible to people with disabilities.

Home support provides assistance with activities of daily living that Marion is unable to perform independent of help due to deformity, chronic pain and stiffness, and mobility impairment. Marion uses a wheelchair and a walker and needs help transferring. She also has a car and is able to drive. Marion actually receives the upper limit of home support

services¹⁴ available from her regional health authority—120 hours monthly. Her home support workers perform personal care (there are several and she has little choice about who comes although she does attempt to influence scheduling, not always successfully) and are thus allowed by the health authority to also take care of Marion’s basic housekeeping needs.

I ask Marion about what happens typically in a day and what she gets help with. My intention in this section is to focus on the different kinds of interactions Marion has with various home support agencies and administrative bodies. In light of this, I summarize below the lengthy and detailed description she provided about her daily routine, presented here to show the kind and amount of help Marion needs to remain independent, and participate in community.

Marion rises on her own usually around 8:30 or 9:00 a.m. and immediately takes an anti-inflammatory (Entrophen®), glucosamine and an anti-hypertensive medication, which Marion says is because she has a prolapsed mitral valve. A cold breakfast, for example, fruit, cheese and crackers, is set out in the fridge for her by the home support worker the previous evening. Marion is unable to prepare food by herself but can get from the fridge whatever has been previously prepared for her as long as the food is prepared in such a

¹⁴ Home support services are funded by the province of B.C. through the Ministry of Health Services, but are administered locally through the community, or long-term care sector of the regional health authority. Services are provided by unionized workers through community-based home support agencies, which schedule visits. Eligibility for home support services is determined through a detailed physical (and/or mental) assessment by a long-term care assessor, usually a nurse, working in the community care sector. Physicians, hospital liaison nurses, community health nurses, home care nurses, OTs and PTs generally refer clients for services, or clients (and/or their families) can self-refer. Home support is a means-tested, subsidized service. People living on disability benefits are exempt from fees because their income is lower than the baseline rate used for calculating subsidy. Clients receiving “personal care”—help with bathing, dressing—are allowed homemaking services, such as cleaning and laundry, and meal preparation. Very few individuals receive housekeeping only as a result of a series of cutbacks to services to disabled and chronically ill people beginning in 1997 (including myself) affecting those who required help with laundry, vacuuming, washing floors, bathtubs, and preparing meals.

way that does not require a high degree of manual dexterity to eat. The first home support worker arrives at about 10:00 a.m. and helps Marion shower and dress. The shower is set up for people with disabilities such that she can roll her wheelchair in but needs help transferring to the shower bench and with washing (she showers 5 out of 7 days).

Marion's home support worker washes her hair every second day.

Ideally, three days weekly Marion goes to a local swimming pool with her worker who gets her wheelchair in and out of the car, helps with the transfers, handles payment at reception, helps her change out of her clothes into her bathing suit, gets a water wheelchair and helps her into the pool. After Marion exercises her hips and legs by walking for half an hour in the pool her worker helps her out of the pool and into the shower, and with showering, dressing and getting back into the car. When needed, Marion will stop at a grocery store for the worker to help her pick up whatever groceries she needs.

Once they arrive back at Marion's around 12:30 p.m., the worker takes care of the wet towels and bathing suit and gets Marion's lunch for her, usually something more substantial like soup and a sandwich. She also gets something out for Marion's dinner and prepares it and leaves it in the fridge or thaws out food to be cooked later (by either another worker or if necessary, Marion's mother, who lives nearby or a friend). The worker might do some housework for Marion at this point and usually leaves around 2:30. Marion may not have any home support come by until 9:00 p.m. so will get her already-prepared meal out of the fridge for dinner.

In the afternoon when she is on her own is often down time for Marion, a time when she experiences some low energy or fatigue. She does not take naps usually because these

interfere with her sleep at night but she will read or watch a comedy that she has recorded. Marion has a big leather reclining chair in the living room that allows her to put her feet up. She often drinks a cola at this time, which gives her an energy boost and then eats dinner around 4:30 p.m. and takes another dose of anti-inflammatory medications. Occasionally a worker will come by at the dinner hour to prepare a meal.

After dinner Marion will return phone calls from people who use the services of the many non-profit agencies she either volunteers with or works for, writes letters, spends time at her computer in her office (the second bedroom) or finishes reading. About 8:00 p.m. she watches about an hour of TV and the home support worker arrives at 9:00 p.m. to help her get ready for bed, which includes washing up, getting into her pyjamas, closing the blinds and preparing a bedtime snack for Marion like popcorn or fruit. The worker will also prepare Marion's breakfast for the next morning and leave it in the fridge. Marion takes another dose of anti-inflammatory drugs before bed and then routinely calls her parents at 10:00 p.m. to reassure them that she is doing alright.

Dealing with the home support agency (and community care) takes considerable time and energy and challenges Marion in ways most (non-disabled) people would not expect. At the point in her life when she decided to move from her parent's place to her current subsidized housing Marion was being pressured by community care to move to assisted living.

M: And I wanted to do this next step [move out of her family home]. But they were really elbowing. And the reason they were elbowing was because they were originally trying to push me towards going to assisted living, and we had a long chat and I said, "Not in this lifetime thank you very much," in a nice kind of way but really "Are you out of your friggin' mind?" Anyways,

and we had nice little chat about what I thought about those places and how much that would be totally against *me* and my character.

Marion is a disability activist and advocate with a longstanding connection to local and provincial disability organizations. As such she values her independence highly and coupled with her belief that disabled people should receive the supports they need to exercise independence, a move to an assisted living facility is seen by her as ludicrous and not all reflective of her values and beliefs about who she is as a disabled woman who exercises her independence as much as possible (and needs appropriate and sufficient support to do that).

I ask Marion about the efforts by the health authority to convince her to move to an assisted living residence:

M: Yah—well they phoned me up out of the blue—long term care did—this lady said she had been contracted to help my case manager and she wanted to come over and talk to me and she didn't say what it was about. And I thought that's kind of strange. So I phoned up and I actually got my case manager and she said, "Marion you know I've quit. I don't have my position anymore." And I know that for a long time she used to phone me and tell me things off the record and say she was advocating for people, but she was getting a lot of flack from higher up. So I was talking to her and she said to me candidly, she said, "Marion you better be ready because they're not just coming to talk to you. They're coming to push you into assisted living." And I went, "Pardon?" And she said, "Well they've been told that they have to earmark so many young disabled people from our caseload for the units that are being built. And that's why she is coming Friday." So she said, "You better have your information prepared because that's exactly what she wants."

Marion knows the community care system well from her own personal experience and from being an activist and advocate for others such that she is not just alert to anomalies, she also does not hesitate to contact the authorities to inquire about this unusual set of circumstances. Marion has a case manager, a nurse she tells me later who has been an ally for her (and other disabled people) who has been willing to reveal insider information at considerable risk to herself professionally. With the information provided by the case manager, Marion mounts a campaign to convince the health authority otherwise.

M: So I was really appreciative that she told me, because I didn't you know—know. And sure enough the lady came and she was all very sweet. I've since found out that if she [referred] a certain number of people, she got a bonus because of it. But that's a little bit of insider knowledge.

How did you find that out?

M: From somebody else in her Ministry that leaked it to me. She was contracted by VIHA [the health authority) to do this—

Assisted living thing.

M: Yah. To help. She's not publicly saying she's connected with that program [assisted living]. But she got—she's the person in that department that is interim now for assisted living—she got a bonus because of it. And that makes sense to me because when she came she was very rah! rah! rah! about assisted living.

Marion is well-positioned politically. Her informants go beyond the local community care office where her case manager works to at least one person in the Ministry of Health whose portfolio includes long-term care. I later learn she also has contacts in the Ministry governing disability benefit programs willing to speak off the record to her. Being so well

informed and connected does not exempt Marion from the kinds of arbitrary decisions that threaten her independence, which she guards vehemently, but does help her to strategize in the face of and to resist these kinds of institutional pressures (to re-categorize and relocate her).

What kinds of things was she saying?

M: Oh she was saying that they're going to do these great new buildings and there is going to be—it's going to be a community and that we're going to be able to have all these meals together in a day. And the place is going to be all accessible. Anyways—and I had made a list and so I went through it with her and I said to her, "You know I have a water bed. A water bed is huge to my independent living because the heat really helps me. Where do you think that's going to fit into an assisted living complex?" That was the first thing. The second thing is I said, "You know I go to physio twice a week. I go to swimming three times a week. Out of those hours that I would be getting from a homemaker working in the assisted living complex is that going to be facilitated during the course of the week? Because I doubt very much in the course of those hours that I am going to be able to take a worker away from all those other people to go and do my swimming and my physio. And if you try and tell me that that is not going to be part of my program, then I will have every doctor on my health care team on your back. Because they know that this is proven to be effective." And then the third thing was that I had said to them that—I had about eight things—me being in a bedroom and then eating with all these other people that I didn't need social stimulation. I was involved with twenty different non-profits all over BC and that was not an issue for me. But if you put me in a bedroom like that where you know where—with all due respect some of the people in there are going to be dementia and not exactly highly communicative and very ill—that's not going to be an upper for me. Now why would that be appealing to me? And um then I had said to her you know that I had a friend for years that lived in

Nigel House¹⁵ and I said I used to go see her all the time and she was a very high functioning lady with CP [cerebral palsy], and I said, “Not one of those times did I ever see her thriving in that kind of environment. That environment sucked the life out of her because it was not stimulating. It was not thriving. And I don’t think she benefited one iota from being there.” And I said, “In the 45 minutes that you have talked to me in this house, do you see what benefit that would have for someone like me? Any benefit at all?” And she just looked at me and said, “I see your point.”

Not only has the point been taken, but Marion has also backed up her argument with a threat to enlist her medical allies—her physicians—in her campaign to stay out of assisted living. Given the medical hierarchy, this woman contracted to move a quota of younger disabled adults to assisted living would have taken this threat seriously knowing that any decision she might make could be overruled by Marion’s medical team. Marion cannot know how influential her clearly-articulated arguments were in (once again) staving off this particular instance of organizational pressure to alter the life she has created. Nonetheless she takes credit, while understanding that the issue at this point relegated to the administrative back burner is unlikely to go away.

Marion knows what she needs in terms of help with activities of daily living to maintain her well-being and the quality of her life. Anything less would compromise these. Before the subsidized unit was offered to her she had been living at home with help from her mother and home support workers (weekdays only). When she was offered the subsidized housing Marion was adamant that she would need the maximum hours available and would not make the move unless this was guaranteed.

¹⁵ Nigel House is a Vancouver Island non-profit society providing supportive community-based services to adults (18-55) who have physical disabilities. Nigel House also provides housing in group home settings.

M: I do know when I said I would take this place I said to them, and I was very forthright, “If I take this place you have to give me no less than 120 hours per month, because there is no way I can live on my own without it. Are we clear on this? You’re not going to cut me after I get there?” And they said, “No. No. No.” So I said, “OK.” But I also know it was very highly rumoured to me in long-term care that had I said no to this place the next step would be to cut my hours because they would say I could rely on my parents more. And that’s a huge issue with me because both my parents are aging. They both work full-time and they have their own health issues. And that was the last thing I wanted to do. That was the whole point of getting home care at the house [her parent’s house when she lived there] was so there was less reliance on them. And both of them have bad backs and it just wasn’t a good situation.

Despite the uncertainty inherent in the situation Marion makes her decision based on community care’s stated agreement to provide her with the maximum number of hours, which she knows are essential to living independently. Yet there is no certainty for Marion because in the background the regional health authority is constantly manoeuvring in ways that threaten her hard won and precarious independence. Marion successfully fends off the contractor seeking to move her to assisted living and before that manages to secure the maximum number of hours needed to enable her to live on her own, but there is no guarantee they will not return and try again. She knows this and is constantly vigilant, ready to muster her forces when needed in the face of the health authority’s impetus to manage her differently.

I ask Marion about her relationship with the home support agency and the long-term care assessors from the region.

M: They've been decent but they still every once and a while bring up the issue of CISIL [Choices in Support of Independent Living]¹⁶ now as a way of you know, shuffling me off to a different budget. And the first time was right when I moved here and I said, "Come on. You've got to be kidding. I've just moved out [from her family home]. I've got enough stuff on my plate." But they phoned me up just recently saying they wanted to come talk to me again.

About CISIL?

M: They didn't say what. And I stalled them for about a month.

How did you do that?

M: I said I really hadn't been feeling well lately. You know, "I'm not sleeping well. Do we have to do this—is it really important? Do you have to...?" And I just love it when they say this because it is such a bunch of bullshit, "Oh we're just coming for a friendly visit. I guess we could postpone it for a couple of months." And I thought "friendly visit"? When is it ever a "friendly visit"? It is usually, "What can we cut from you?"

Before the dust settles from her previous campaign to avoid assisted living and her recent move to her own place, Marion is approached again by the health authority to (re)consider moving to the CISIL program. She understands the politics behind an otherwise simple suggestion to pay her a visit and is skeptical of the case manager's

¹⁶ CISIL (Choice in Supports for Independent Living) is a home support program begun during the previous NDP government's tenure and was designed as a pilot project in response to the Independent Living Community and their concerns about how restrictive home support services are in terms of what services they provide for younger people with disabilities wanting to participate in society. From the 2010 Ministry of Health Services (HSERV) website: "Choice in Supports for Independent Living (CSIL) is an alternative for eligible home support clients. CSIL was developed to give British Columbians with daily personal care needs more flexibility in managing their home support services. CSIL is a 'self-managed model of care'. Clients receive funds directly for the purchase of home support services. They assume full responsibility for the management, co-ordination and financial accountability of their services, including recruiting, hiring, training, scheduling and supervising home support workers" (Retrieved January 20, 2010 from <http://www.health.gov.bc.ca/hcc/csil.html>). But CISIL has problems (as Marion articulates), not the least being the daunting work of being disabled and running your own business. A review of the CISIL program was conducted in 2006 by HSERV in conjunction with a review of the Payment to Family Members Policy, which was amended in July 2007. Changes were made to CISIL because of the review "to ensure the program is responsive to client needs and to confirm that policy and operational frameworks remain relevant" (Retrieved January 20, 2010 from <http://www.health.gov.bc.ca/hcc/csil.html>).

entreaties. She is critically aware of the economic rationale behind the pressure for her to move to CISIL. Marion senses she can resist actively for a short period without repercussions but knows it is really only a temporary solution to the pressure. She has sensible reasons for not changing the delivery mode of her home support services, reasons embedded in her determination to maintain the quality of her life and her independence. These are less important to managers from community care administration whose priorities appear to be meeting financial targets. None of this is lost on Marion.

And their attempt to convince you to go on CISIL is an attempt to get you off their rolls?

M: Yah. And it's something I don't want to do for a lot of reasons.

Like?

M: Some of the reasons why I don't want to do it are the fact that when I came here, because I was having more hours than I did at Mom and Dad's I went through two months of going through a lot of workers. Some ugly workers, some really good workers, and some mediocre workers. And it was through that that I came up with list of about 14 people that I really like. Well, I have now built relationships with those people where they know me on good days and bad days. And there's enough of those people that it is easy to fill a shift when I book. And I was very clear about the fact that when I moved that my hours would not be the same [as they had been previously]—five days a week—because I would have a life and I was going to have to juggle some days needing a night shift more than a dinner shift. So I book a week ahead for like the week's hours. So they have a week to book them. And typically the hours are very similar but some—typically in a thirty day period I cannot have five days a week [consecutively] where I have a dinner and night shift or I am way over my hours...so sometimes I make a choice between night shift and dinner shift, which is 5-6. And 9-10 for the night

time. And it usually works out very well, but if I went to CISIL I would not have these girls I have now who know me.

Marion has had to endure, figure out/calculate and manage different aspects of home support as part of ensuring she has the help she needs on a daily basis. Through sheer hard work and effort she has established relationships with a workers who now know her well enough such that she can trust them to care for her even when her level of need fluctuates. Marion also has done this with enough workers that she is unlikely to be sent a worker who is unfamiliar with her needs, although this is always a possibility. Having enough trusted workers who know Marion well also means less work for the home support scheduler, something that perhaps Marion calculates will work in her favour, because there is a roster of people who can work with her from which to draw when booking. Booking her workers a week in advance means Marion has to plan her weekly activities and the supports she needs to engage in them ahead of time, which may be inconvenient, but also provides her with some flexibility in terms of timing daily activities. Well-established relationships with workers is only one reason she gives for refusing CISIL; if she went on the CISIL program she would have to go through the same process of finding eligible workers, interviewing them, hiring them and getting to know them, along with doing all the weekly (or even daily) work of booking them (currently she just phones in the hours she needs to the home support scheduler).

And for CISIL you would have to hire someone out of the community?

M: Yah. And they—there's several things. One is they tend to be inexperienced girls because you pay them less, a lot less than these girls are getting from the agency. And the agency girls don't want to work for CISIL because you don't get paid as much. You can't really blame them. Number

two, you have to build up all these people which I am not really sure I have the energy or the time for now. And if someone is sick or someone bails, it's your call to fix that. That's a lot when you're not feeling well yourself. I just don't know really if I want that headache. They basically have promoted it to me about how I can book the hours with the girls myself and I don't have to go through the agency. And yes that would be a plus.

But the agency knows you. The person on the other end of the phone knows you—

M: Yah. But it is good to take out the middle man—so there is no agency—just me and the worker. Because there are a lot of times when I could actually do my scheduling faster than they do. So I appreciate that. And I also appreciate the fact that you have more flexibility in terms of what you can do with your worker [with CISIL]. But the reality for me is that I have that flexibility now, in true fashion.

Marion sees the value CISIL provides in not having to deal with the home support agency and the kind of flexibility it might provide for her in terms of the activities she could engage in with her support worker (rather than living with the possibility of being limited to restrictive home support agency rules), but she experiences enough flexibility in the way she is managing her home support hours despite restrictions. I ask her to talk about those restrictions, and what kind of flexibility she experiences with workers.

M: I mean for the most part I am not getting slapped on the hand too much. And if there are things they're not really fussy about, well then I just do them with certain workers who are not going to publicly talk to the office about it later.

What kinds of things would those be? Could you give me an example?

M: I've been pretty fortunate—because my care plan is actually in my bathroom and it's—got everything. But I know that for some clients they

won't let them do any housecleaning. They've never told me that personally. Apparently if you don't get any personal care, then you don't get any housecleaning at all. But because they help me get dressed and they help me shower, then they can tidy up a little bit—vacuum and stuff. And like for some people they won't do that. And I know for some people—and it's very strange—some people they're not allowed to go out of the house at all. Like they're not allowed to drive them in their car—anywhere. And I don't know if it's because I drive and they accompany me if that's the difference because it's my insurance. Or it's the fact that I got it OK'd by a doctor for me to go to physio with my worker to help me out with the walker, which I can't lift. Or to go with me to the pool to help me into the pool—that they don't make as big of a deal for me to go and do errands. Because they're already out with me. Do you know what I mean?

Yah.

M: How do you nitpick about whether you stop at the grocery store on the way home or...you know? But some people [workers] I know they're really fussy about that kind of thing.

Care plans for home support clients are worked out in advance with/by the long-term care assessor. Patients' support needs are assessed and communicated to the home support agency that delivers services. The "care plan" is essentially a notice posted by the home support agency in a prominent location in the client's home—in this case in Marion's bathroom—so that each worker knows what supports she should provide (and those she is not allowed to provide). Marion receives housecleaning as per policy but expresses uncertainty about having the worker travel in her car, signalling that Marion is always vulnerable to decisions about particular services that can be removed without her consent.

So have you been kind of slapped on the hand about anything?

M: I haven't been slapped on the hand about this stuff in terms of what they're doing. Sometimes—one time—they gave me a bit of a lecture about the fact that I was taking one of my workers to a disability event. This was quite a long time ago. And they almost made me not go to this event because they weren't going to send the worker. They said it wasn't acceptable. But after that I went through my occupational therapist at long term care and I said, "Excuse me but how do I get out of the car if someone is not with me? I can't push the wheelchair and I can't transfer to the walker. Like what do you want me to do sit in the car all day?" Like hello! This person is my enabling factor, you know. And we're not doing this five to seven days a week. We're doing this twice a month, once a month. And she just said, "Oh well. That's fine. Just don't make a point of—when you're booking—don't make a point of saying you're gallivanting all over place." And I thought as if I'm gallivanting seven days a week you know. My thing to everyone I talk to is this is enabling me to have a quality of life. Isn't it more important that I'm not focusing on my disability, feeling awful, sitting at the house, that I am getting out and trying to be active, doing things to feel better?

Interestingly, Marion's independence is revealed here in her phrasing "I was taking one of my workers" to the community event rather than the worker taking her. Even though her OT suggests how to approach the scheduler in the future, she underestimates/fails to acknowledge Marion's astute ability to be strategic when it comes to getting the supports she needs.

I suggest that she is doing more than trying to be active and doing things to personally feel better.

And things that are by and large to help other people.

M: Yah. Yes. Exactly. So there was that one time that I was sort of lectured. And the other that I was kind of lectured was—I had to change the time or

something because it just happened that it didn't work out, and they got a little bit snippy with the fact that they wanted me to have regular times every single day of the week. And not change. And I kind of resented that because I'm not someone who stays at home all the time. But they treat you like you should just be happy sometimes if someone comes. And this wasn't the homemaker's attitude. This was the like the management at the home support agency office.

So you should be grateful that somebody actually comes here and spends some time with you?

M: Yah. It's like I'm home all day and what does it matter if they show up? Shouldn't I be happy with that? And my mom actually had a conversation once with the head administrator and she sort of got quite heated on the phone. And she said, "My daughter has things to do. And she has a life. And her life is not her disability. And she does not sit here 24 hours a day waiting for someone to come visit. Someone is here to help her so she can enjoy doing these things which help other people and help herself and it gets her out of the house so it keeps her mobile. It's better than her seizing up sitting down on the couch all day." And she just sort of vented at this woman for about three minutes. And I never actually had it said to me again. But I'm not that naïve enough to think they don't still have that attitude. And I'm really clear when I try new workers out that if I get a worker who is—I had one worker who came here and held my hand for one hour straight. And she was only booked for an hour. The first thing she said when she opened the door was, "Oh my god." She said, "How awful for you. You're so young and you're so disabled and it just must be horrible for you. And how do you cope with this?" And I remember thinking, how long is she here for? And she did three things in an hour and they were really tiny things like getting me my pills—set up. Cutting some cheese up and putting it in the fridge. And like, I don't know, something silly like watering my plants or something. And I remember thinking, this is painful because she had enough trouble doing those three things. What would it be like when I'm having a day when I drop

everything or I'm really sore. And I need to be productive on those days too. I need to feel like I'm getting something done despite the pain, because that's how I feel better. And I thought I was actually having a good day until she held my hand. And then I thought, I'm having a really hard time staying patient because I could really smack you right now because this is obviously something that works on your other clients but it's really—like it was not genuine at all. I don't need this. I'm just not this person. And so she left quickly. And I phoned the office the next day and got a hold of the nurse who used to be one of my workers. And I said, "L. this just cannot be. I cannot handle this." And she said, "Well what happened?" And so I told her and she goes, "Oh please. I just don't see how that would work with you." And I said, "No." So there have been—I try very quickly to screen those people out.

Marion is ever-vigilant with respect to the quality of workers that are scheduled to take care of her especially those who are unhelpful. She is suspicious of attitudes toward her as a disabled person held by home support and health authority administrators that undermine her sense of herself as independent and undeserving of pity. Even on bad days she endeavours to engage in the work she does and its value in terms of her well-being. Unskilled workers are thus disabling because they create barriers to Marion in terms of her pursuing her personal aspirations. She is also keenly aware of the risks involved in having the kind of (unstable and even unskilled) workers who typically work for CISIL clients and at the time the uncertainty around the CISIL program itself.

M: But the thing with CISIL is you do get a lot of people who are going to school, young girls or young people in particular who want the extra money but they're not very secure. Like they can leave very quickly if they want and they can leave you in a state of trying to find someone to fill in. And I don't want to be in that situation and I need the people who are experienced, especially with transferring on days when I'm really bad. And I don't have a

lot of comfort that people at CISIL are going to be able to do that. Some may and some may not. There's a lot of uncertainty. It's very risky and it is a pilot project after all [at the time of the interviews it was still a pilot project]. And they keep threatening to cut the budget for that. So if it doesn't last then you end up having to go back to the agency again. And by that time who knows where all these people are that I've gotten used to and have a great working relationship with?

Marion is not having as much success in her campaign to resist the pressure to move to CISIL as she did with the assisted living campaign, and knows that the issue is not going to go away easily. She has important reasons for refusing to go on the program, but questions whether these reasons will be sufficient for her to resist effectively over time in the face of repeated attempts to move her to the program.

M: But trying to then tell them that in a way that they will let go of it is going to be difficult, because they're pushing it. It doesn't come from the same budget and that's the whole reason that they want to elbow me into it. The last time I said, "I really appreciate all the information you gave me but I've looked at it and I don't think it's a good option for me and I'm not interested in it." That's what I said last time. And they said, "We'll talk to you in six months." My big concern with saying that though is their next step saying, "Well if you're not going to do that option, we're going to cut you back on your hours for here." And that would be huge for me only because a hundred and twenty a month when you live alone is bare minimum. I work at it every month to make sure I don't go over. I do without shifts some days because you have to really budget when you are going to need it more than other days. So—they told me that I would actually get more hours [with CISIL]. That's their promotional tour—is that you actually get more hours. But you see you're paying your worker next to nothing. And that's why you're getting the quality of workers you're getting. You're getting workers that will work for barely minimum wage. And if I were to do CISIL I would be putting x

amount of hours a month into taking care of my little business basically. And I just don't think I could do that and still have the energy for—it's like a cost, do you know what I mean? I don't need another cost. Just having that would be a drain.

CISIL is framed as an “option” but that is not entirely reflective of its rationale; it is considered a cost reduction (or at the very least a cost shift) for the system, one that ought to be pursued enthusiastically. Despite the pressure to manoeuvre Marion into the CISIL box she respectfully declines this “option” but does not trust the health authority to respect her wishes. She lives with fear and uncertainty that they will force her into the program (and create pressure for her to look at other “options”) by cutting back her existing hours, which are really the bare minimum she needs to maintain her independence and which she rations closely to ensure she stays within the limits. The health authority's argument that Marion would get more hours if she were on the CISIL program feeds into her fear that her hours might be reduced because she knows she is vulnerable in this regard. Any reduction in hours intrinsically threatens everything she has worked so hard to establish and maintain. Yet Marion knows that the health authority will continue to use the “reasonable” offer of more hours to persuade her to go on CISIL and that she runs the risk of being deemed “unreasonable” if she refuses this opportunity, especially when more hours would (in theory) enable more flexibility and hence increased independence. She knows she would be powerless if the health authority were to co-opt the value that she as a disabled woman places on independence in their campaign to enlist her in the CISIL program. Her independence is on shaky ground. Marion also assumes that going on CISIL will rob her of the energy she currently has (as a result of the home support she receives) because she believes she would be spending

that energy on managing her CISIL business. She views it primarily as costing not benefiting her. Her views about CISIL are not imagined; she has heard of the difficulties many people had with it from her peers in the disability community.

I am curious as to what effect she thinks she might be having on the woman from the health authority who has been trying to move her to assisted living or CISIL.

Do you think Marion the fact that you—at least from what I know of you—are able to mount a fairly good argument against some of these initiatives, because really you come from a place of self-respect and are able to say “no, no my life is just fine if you guys would all more or less get in line instead of pestering me”—do you think because of the way you are makes them realize that things need to be different?

M: Well yes and no. I think I educated her.

How so?

Because—not that I—I mean she left here and she was just spouting, “Oh you’re so inspirational. You’re so wonderful” the whole way out to her car. And I think she genuinely meant that. I think that I made an impact. I think that I educated her to the issues that she just did not see, you know. So that kind of stirred her pot up a bit about the fact that, “Oh yeah. I can see that this person is not a good fit into this hole.” [assisted living] But I don’t think there was enough to make her see that she should stop her campaign. And in fact this is the same lady who is campaigning for CISIL. So I don’t know if she really—like this is now my long-term care case manager—I mean it’s every six months she’s doing this, it’s not every week—I don’t know if she gets it completely because she is not really enabling me. She’s just changing her focus.

Her tactics.

M: Yah. But I get farther because I am able to make an argument. There is no question about that. I mean because I am making a good—what’s the word?—I know ahead of time, I am prepared, I am informed and I’m making sense with what I say, clearly I get farther than people who can’t communicate their own needs and who are too sick or too ill to do that.

Marion is realistic about the effect she might be having on the case manager in terms of altering her approach to Marion’s situation. She sees that the woman is willing to learn what kinds of things are important to Marion and the ways she acts on her value of independence and needs help to do so. But she also sees that having that knowledge does not guarantee that someone will act differently or stop her campaign especially if, as Marion suggests, she receives a bonus for successfully moving a client to assisted living or CISIL. From her advocacy work and being part of the disability community Marion knows how well positioned she is with respect to other people with disabilities in terms of advancing her cause and getting what she needs but she also knows her “place” with respect to the authorities.

We discuss the possibility of challenging this case manager about her persistence in trying to get Marion to accept another living arrangement.

M: In all honesty I would much rather her leave feeling good about me than leave with a bad impression of me. Because that is going to get me farther. And it did, because two weeks later [after the first visit to persuade her to move to assisted living, while she was still living at home] she remembered me and I got this apartment and it could have gone to somebody else. But the flip side of that is that there is for me a safe area in terms of pushing the envelope, but how much do you feel comfortable pushing it? Because you don’t want it to come back and slap you in the face. And that’s the problem is you don’t really know how much your protected rights will be protected if

you did stand up. So I am somewhat cautious about how much to do that. Although I feel definitely my rights are that and it should be black and white. I mean what's the big deal?

Marion values diplomacy for its salutary effects and is appropriately cautious about overtly resisting or advancing her position too strongly. She senses the punitive aspect of dealing with bureaucracies and is uncertain as to what extent her rights would be protected if she were to claim them overtly (or more overtly). It is not clear what rights Marion is referring to here. In the health care system the only rights that apply are the Charter of Rights and Freedoms. The purview of the health care system is not the rights of marginalized or designated groups *per se*. Unfortunately Marion's argument about home support enabling her participation in community and independence could be viewed as a weak one if it is exclusively rights-based; when dealing with a ministry that focuses on health a better argument is that their services promote a disabled person's health. I wonder what Marion thinks might be at the centre of the campaign to relocate her.

It seems that the fact the care manager keeps missing that you're actually OK seems to indicate that this is being driven by the institution.

M: Oh totally. It has nothing to do with me. It's all part of a grand plan. But I know it really comes down to nothing to do with my well-being. It comes down to budget. And they're looking to cut. That's really the whole focus is cut, cut, cut. And so I'm not taking it personally in that regard because it is impersonal. But the part of it that is tough is that—it's personal to me 'cause it's my life. And why shouldn't it be? So I'm not going to fit into a slot that I'm not going to fit into. So that's the real challenge. It really is kind of a juggling act and it's getting worse like that. Like the latest I've heard [about home support] is that they are now going to go after people like me who have

high hours and try and cut them anyway they can. ‘Cause they started with people who have low hours and now they’re going to the opposite side of the spectrum. But the big challenge is that you really wouldn’t be able to live on your own if you had less than 120 hours. I mean that’s really 4 hours a day for 30 days. So I work it so that I do without some days, when I have friends over, or really shuffle it around so that I have a few more hours some days. But you really got to work it or you would be hooped. And I don’t know what they—how they think you could do it with less. But they seem to want to go that way.

Translating difficulty, caring for self

In this presentation of the data, I include more context and comment because I spent considerable time in the interviews trying to make sense/translate not often that successfully what it was Jocelyne was saying due to language differences; I believe readers could benefit from similar translation and more contextual details.

Difficulty is the hallmark of Jocelyne’s life on many fronts and I found interviewing her challenging because of language differences and the intense emotions she conveyed as she spoke, often in a complaining tone and with desperation. From time to time I also detected a sense (a sigh?) of resignation as she spoke where she expresses a sense of it all being too much to bear, but she has to. At one point she sighed and said in a soft voice, “And it’s so difficult. You know?” When she said this it felt both like a bid for understanding and a plea for me to help change her reality and I often felt like she was on a mission to tell me about every single difficulty she faced to ensure I had the correct information to convey to those who might make her life different.

Some of the difficulty she experiences arises because of her understandings, or misunderstandings of how government works and her (unmet) expectations of what the Ministry can and should provide for her as a disabled person. Jocelyne has to constantly make sense of how government works, often with very little and ultimately partial information like a giant jigsaw puzzle in which she has to not just “see” each piece (for what it might be) but somehow relate it to the whole. She does not always accomplish this successfully.

At the time of the interviews, I discovered (as I was about to leave—she had not mentioned this during the interview) that Jocelyne was in the midst of an appeal process with the Ministry, which had determined during The Review that she was not eligible for the designation requested (Person with a Disability, or PWD). She had been re-categorized as a Person with Persistent Multiple Barriers (PPMB)¹⁷ leaving her with a substantially reduced income (by \$200 monthly). Jocelyne was having considerable difficulty with the appeal process despite help from a local disability advocate and especially with the reduced income. What is noteworthy is that she personalizes the

¹⁷ The Persons with Persistent Multiple Barriers (PPMB) category recognizes individuals who are unable to achieve financial independence because of specific barriers to employment. Persons with Persistent Multiple Barriers are individuals who have received assistance for 12 of the last 15 months, and meet the following criteria;

- Have severe multiple barriers to employment;
- Have taken all reasonable steps to overcome their barriers; and
- Have a medical condition (excluding addictions) that has lasted for at least one year, is likely to continue or reoccur frequently for at least two years and which seriously impedes their ability to search for, accept or continue employment; or,
- Have a medical condition (excluding addictions) that has lasted for at least one year, is likely to continue or reoccur frequently for at least two years and which, by itself, precludes their ability to search for, accept or continue employment.

PPMB clients are not subject to time limits. The monthly Support Rate is \$283 and the monthly Maximum Shelter Rate is \$375. The total monthly benefit is \$658. (Retrieved March 4, 2010 from <http://www.hsd.gov.bc.ca/factsheets/2004/ppmb.htm>)

See Appendix A, Note 1, p. 362 for more detail about conditions for eligibility for PPMB.

rejection of the government—“they don’t want me” and “they don’t want to give me Disability 2” [actually PWD]. I suspect this phrasing primarily reflects her difficulties with English, not because she actually sees her relationship with government this way (although this is also possible). Nonetheless, by using this phrasing Jocelyne conveys a more capricious, arbitrary, and even confusing decision than expected. The way she refers to government throughout the interviews implies that if the Ministry could just be aware of and understand the difficulties with which she lives a reasonable course of action (a logical outcome) would be that they would unequivocally *want* to give her the benefits.

Jocelyne lives in non-subsidized housing. She does this because she needs to live in a geographical location where she believes the air is clean with the result that most of her disability benefit is spent on housing. She also has a mature cat that she is not willing to give up and that is not allowed in most subsidized housing.

J: Because you know I am obliged to living here because I cannot living in town, because I cannot breathe. Because I have another problem. I have parathyroid problem. And it is for that you know I have uh difficulties to breathe and I need more oxygen sometime, you know. And if I am on uh downtown on city it is very difficult, you know. Yah. And I have pain on my chest after a few time. I cannot go often downtown, you know.

Jocelyne also cannot afford to have a phone, and understands, perhaps because of information she received from a neighbourhood house volunteer (incorrectly, likely again because of language differences), that if she has a social worker that person can do whatever it takes for her to get a phone. But even getting a social worker eludes her. Jocelyne has great difficulty attending appointments because of the unpredictability of

her physical health, which is by and large not good and because she cannot be reliably contacted via phone.

Why do you think you might need a social worker?

J: I need a social worker because I have no enough money for pay my telephone, example. And I am very sick, I repeat again. Because you know if you don't have a phone at this time you know is very...you feel very bad.

Meaning?

J: Specifically when you have problem with your heart, you know. So I cannot phone in hospital or at anybody. I have no phone. So I cannot have help, support for my condition, physical condition, you know. So very often you know I feel I going to dead.

You're going to die?

J: Die, yah. And that's it, you know...uh hmm. I pray. Because I need to have focus on other things, because believe me, is difficult.

Jocelyne has a crucial reason for needing a phone—she experiences heart problems that leave her feeling as if she is going to die and has no access to help when feeling this way. This is not the only time I hear her utter the phrase “I feel I going to dead”; she repeats it throughout the interview. At one point she shows me an ECG readout from the hospital during an admission for what she says was a heart attack. I get a sense that her health is not just unstable or chronic but that she (frequently?) also experiences symptoms that suddenly threaten her life, all the more frightening because she has no way of accessing immediate help.

I am intrigued by her focus on getting back on the higher level of disability benefits. I mirror her use of the terms for the previous government's categories so as not to confuse her unnecessarily.

What was the difference between Disability 1 and Disability 2 for you?

J: The money.

So more money.

J: Yah. That's it.

How much more?

J: Uh...two hundred, maybe.

Two hundred a month?

Yuh.

And medication?

J: It is very difficult for me, because medication here is only chemical medication, and I cannot support.

You mean you can't take that?

J: Ya. Because my *metabolisme* cannot support you know. Many, many medicine give me...make me sick with my liver or stomach or intestine, you know. Because I am very fragile. I have pain everywhere. Because I have two *hepatit* before.

Hepatitis?

J: *Oui*. Hepatitis. I have twice. And so now I have this *diabete* so that is another hormone problem. I have my hysterectomy, so that is another hormone problem, and I don't have gall bladder, so that again give you...disturb you. And I have problem on my intestine and that is hormone too, you know. So I have *big* hormone problem and the doctor here don't know. He don't have knowledge for that. If he has some knowledge for that during the life of these people I think he don't care very much for study a little bit more, because specifically on this kind and this way, you know the hormone disease, you need to study every day.

My question about subsidized medications has led us into very different ground than expected, not an unusual feature of our interviews. I certainly did not expect the answer I got, which in retrospect I probably should have seen coming given Jocelyne's background as a practitioner in alternative therapies and the large collection of plastic bottles on the table containing nutritional supplements.

J: But uh...But I have some doctor said 'the French doctor is cuckoo.' I have some [meaning another] doctor said he don't want to see me because my case is too difficult. I have some other doctor said to me 'Is better if you go back to east.' And I said 'I am not from east. I am from France.' So he says, 'Why you are here?' I am here since 27 years, you know. And I came here with *monnaie*, and I came here with knowledge, and I came here for built this country with other people. And I am very happy to participate with the growing of this country, you know. And now I am very disappointed for sure.

Jocelyne seemed very emphatic as she spoke, especially as she listed the different hormone problems she lives with and even dropping her palm loudly on the table at the end of each "I came here..." phrase emphasizing how strongly she feels about her intentions for coming and contributions to Canada. She tells me that she has seen a French doctor because he speaks her language but he is not a specialist. But clearly another physician she has seen does not agree with the French doctor's treatment. She has been told her case is too difficult to manage and another physician has suggested she should return to Quebec. The rationale for this treatment appears to be the complexity of her health and how unmanageable it appears to be.

I wonder if she experiences it the same way. Her understanding of her health is that she has an underlying hormone problem that is manifesting in different systems. Somehow she must be managing the complexity of living in a body whose regulatory systems are so

completely compromised and also managing the complexity of living with/in a health care system that she experiences as compromised in its ability to meet her medical needs.

I ask her what she does in a day as a way of unearthing how she manages.

J: So what I do in a day? Hmm. So I cannot sleep very much because I—
comment dirage?—je ne fait pas d'insomnie.

You have insomnia? (I am only able to translate the French word for insomnia)

J: No.

You don't have insomnia.

J: No. I don't have that problem. I have too much pain—*douleur*—too much pain. Too strong. And uh...incredible. Because this pain is the pain *hormone*. And you know for woman can understand maybe a little bit better because when we are period some people have very much pain. But imagine you have pain only with hormone on ovary, but if you have pain with complex with *diabete* and everything, everything. All is incredible, you know. And I think if I am not on cancer now is because I have some knowledge for take care of myself. And all money I have, all...and if somebody want give me a gift or something it is only for buy my medicine. For me is medicine. For other people is *simplement* food, but is not right, you know, because you know uh...we do medicine with natural product basically. And after we can synthesize molecule for do it.

What kind of molecule? (I misunderstand her pronunciation of the word “synthesize”)

J: We can make other medicine with uh *synthetique* molecule you know, for *therapie*... . When you find one product to make...I don't know. Example. You have calcitonin? OK. Calcitonin is from *synthetique* [synthetic]. And this is from salmon. But this [shows pill container] is *synthetique* medicine. OK. So this is chemical. I cannot support.

You can't take that.

J: But I try. Because the doctor here cannot do anything other for me. And I said I want try OK, for your pleasure. You know. But I think I going to dead.

It's going to kill you.

J: Yah. This medicine I can show you [synthetic calcitonin] cost more of \$100.

More than \$100?

J: Ya. And is not cover.

Not covered?

J: No.

Why is it not covered?

J: I don't know. And I am obliged to pay this and I am allergic. So and if I take...if I ask for have you know natural medicine it don't...is not same price because you know is ...uh...you can have for \$30 or \$35. Some is a little bit more [lifting up and showing me vitamin/supplement containers sitting on the table]. But you know...the government accept to pay this kind of product [synthetic] because is...uh...because is lobbying of pharmacist. Make lot of pressure on the government. And the government people over there know nothing. OK? You know, the MP [means her provincial MLA] here is from policeman, you know. What he can know about? Another one is same, you know. On the government here you have many people responsible of many thing and know nothing. Any knowledge for nothing, you know. And Campbell...what is Campbell? [the Premier of B.C. at the time] Campbell is business for...*comment appel ça?*

He is a businessman.

J: Yah. A business man for...um...for the...sell house and something like that. He's nothing you know.

In this exchange focused more sharply on how she manages her health and the constraints she experiences, Jocelyne reveals her experiences with the medication she is prescribed by her physician *vis à vis* her existing knowledge about non-synthetic or biological medicinals, which she considers simply to be food or nutritional supplements. Jocelyne attributes her current experience as cancer-free to knowing how to take care of herself well implying that she is also able to do so. She does so in part by spending all her available money (beyond rent and food, I assume) on natural products. Here, she provides me with her knowledge of how synthetically-produced medicinals are developed from their biological counterparts using similar molecular structures. Jocelyne gives the example of calcitonin, apparently found in salmon but manufactured synthetically by pharmaceutical companies and sold at inflated (and exorbitant) costs.

Despite this knowledge, Jocelyne obliges her physician whose therapeutic resources are apparently exhausted and purchases the \$100 synthetic medication to which she is allergic, and perhaps has had a frightening reaction (“I think I going to dead”). The medication is not subsidized by government so she pays for it out of pocket without reimbursement and discovers she cannot tolerate it. Again, she learns that purchasing and using natural products is best for her not just for her health but (because they are less expensive than prescription meds) also for the health of her fragile financial situation.

With her doctors treating her conditions as unmanageable, Jocelyne is more or less on her own—especially given her financial resources—to find treatments that are effective and she can afford. Her use of the English word “support” (as in “I cannot support synthetic medications”) also applies to her economic situation. Her body cannot support the conventional medicines she is prescribed and she cannot support the cost of buying them.

Indeed, she can barely support (financially) her requirement for alternative treatments, although this choice is less likely to cause an adverse or toxic reaction.

Jocelyne also comments on the political aspects of her dilemma, making links between what products are available, which are subsidized and those who have particular interests in this being the case. She also critiques the knowledge of politicians/what politicians know specifically how inappropriate what they *do* know is for dealing with people like her. In her estimation politicians, who she believes are ill-suited to the task are directly responsible for her well-being.

Again I bring her back to talking about the details of her everyday life and what she does in a day.

Can you tell me a little bit more about your day?

J: Ya. So you know, ya...I don't sleep very much. I sleep only four hours, five."

So what time would you get up?

J: Oh you know is depend at what time I might go to bed. But you know usually I get up...is depend. Is depend on my pain. Sometime I cannot sleep. Nothing. So I get up at four o'clock in the morning, mostly.

And what do you do?

J: I pray.

So do you sit to do that? Or do you...?

J: Oh yes, I am obliged to stay in my bed.

You stay in your bed to pray.

J: I want to explain to you exactly what I do OK? So when I open my eyes, you know, after some sleep, first thing I do is exercise in the bed, because I

am on a warm place, and I beginning to stretch my body inside on the bed, you know. And after that you know I get up and I continue to stretch my body, you know for...because if I don't do that I am on the wheelchair since a long time believe me.

(I misunderstand her here) Do you have a wheelchair?

J: No. And I have no money for buy anything. And I have a *vibromasseur*, this (points to electric vibrator) you know?

Vibrating massage.

J: Ya. So I do massage on me. Everywhere, everywhere. Hands, feet, legs, arms, you know, and back. And after that I take shower, warm shower, OK? And if I have some cream I can put some cream. That is better.

What kind of cream?

J: I have two...if it's perfect for me I can...I need to have cream for moisturizing because I am *diabete*. But I need to have special cream to help—*comment dire?*—circulation. But superficial circulation. That helps little bit you know for...you know you can see here I have some *édeme* (swelling). But if I have cream I don't have this.

So you have a shower and put cream on when you have it.

J: Ya. This one is for cellulite you know, but I use not for cellulite. I use because (speaking French) it helps the surface circulation. And if is perfect I can...I need to have massage—for lymphatic massage. Yes. Because you know with my case I cannot support strong massage.”

So you don't have that kind of massage?

J: No. I have nothing. No help. Nothing of nothing and very often I am here and I am obliged to take aspirin and Tylenol®. That's all I have for pain. Can you imagine that, you know? That's all I have and because I am allergic to Tylenol 3® I cannot take this too you know. And I want medicine for keep my brain safe because it is only *that* I have now.

So do you take aspirin and Tylenol® on a regular basis?

J: Oh ya.

What time of day do you usually take it?

I try to don't take too much because I take strong and I take twice on the same time. Twice aspirin... two aspirin and two Tylenol® in the morning and at night. And sometimes I am obliged during the day. Sometimes.

In recounting a typical day, it becomes clear how much of Jocelyne's energy, time and focus is spent attending to, caring for and managing various aspects of her health. I hear intimate details about her relationship with her body—what she can and cannot do, what bodily experiences she responds to as part of her routine, in particular the omnipresent experience of pain, which keeps her from sleeping at night and the need to ameliorate this and other effects of the illnesses with which she lives.

There is an intimacy to this account of Jocelyne's daily ablutions; to me she is speaking of how she relates to her body and she spends considerable time in the morning being with her body in various ways for different purposes. These are not just routine activities for her. They are a necessary part of her daily life, necessary for her to engage with life beyond just attending to her body. If she can't get moving it is likely she does very little.

In recounting how she manages pain pharmaceutically, Jocelyne reveals something very important. She is not willing to forfeit her mind by taking medication that has psychoactive properties and affects it negatively like the codeine in Tylenol 3®. By telling me that her brain is *all* she has now she implies that her brain is all that functions normally for her and it is too precious to willingly alter. In Jocelyne's case the intact mind is not a replacement for a broken body; it is an ally.

I regret I did not ask her more about prayer, like how she prays or how long she prays or what it brings to her, but we move very quickly into a conversation in the realm of spirit.

So after your shower what do you do?”

J: I make my coffee. And usually I eat porridge and mostly I read philosophy book.

What kind of philosophy?

J: Oh...(pauses)...is difficult...to explain. (Asks to have the tape off briefly, then goes and gets a stack of thick books). So, you know I cannot work. So I am obliged to find something for interest my spirit. But you know now I have time and I cannot do anything so I am obliged to do something. Because if I do nothing—if I open my mouth and I looking outside I think is better if I dead. Because I don't want to stay on this life, you know if I cannot do anything. So for beginning when I am more sick, because I am therapist of body and little bit with *equilibre* for...for *mentale* [for body/mind equilibrium] for my client, you know. So after when I cannot work, I am looking a little bit more with spiritual view because at this point my knowledge is not hundred percent. So I beginning to looking with this way. So I am beginning to buy...is a book same to *la Torah*. OK? So I beginning with that, you know because I have never time before for do it, you know. And uh I am very interested. And after that I bought Bible, and after that I bought another book for Qu'ran. Muslim. Because when I am young...*avant*...before I work on this—*thallasotherapie* (her therapeutic practice)—I do other way to...I have *licence*—you understand *licence*...degree? For sociology on this, Arabic people. Muslim. So ya. So is for that too you know I take a Qu'ran. So I read, and I meditate what I read, you know, for try more as possible what's mean. Because very often you know is same to parable. Do you understand parable?

Yes. A tale, a story.

J: Yah. So it is not easy always to understand what he mean. So I need to study, really, you know. So between the Torah and Bible, example, you have always little bit more so you can compare and you can understand better after. So that is very interested. And after that I beginning to read a book for more...uh with people have more experience with both experience—*mentale*, with *spiritualité* and body ... program.

The mind and the body, is that what you mean?

J: Yah, because is very *approche* of my... experience too.

Your experience of the mind and the body.

We actually got tangled up at this point in our discussion because I did not understand initially what Jocelyne was trying to tell me about what she believes are the differences between Eastern and Western approaches to illness. She understands that in Eastern approaches the underlying spiritual dis-ease is explored, whereas in the West we start with and focus on what is wrong with the body and neglect the spirit. Jocelyne then tells me that in her thalassotherapy practice she incorporated both approaches in ways that would be acceptable to Europeans.

J: So for touch the brain (mind/spirit) in Europe we need touch body first. So is for that I give special massage *underwater*, with special way for touch body strongly, but with no pain, for go to spirit. And with this kind of treatment we have lots of result. For that I try to explain to you why I am so interesting, you know with spiritual way now because I cannot work physically. So I study spiritually. I think one day maybe I can do something for help somebody with another way.

This other way.

J: Yes. Because my point is I want to do something you know. That's all.

Jocelyne's belief that her body is not amenable to "development," meaning it cannot be enhanced reliably or improved significantly buttresses her focus on mind/spirit. She does not seem to make a distinction between these in speaking about them. Jocelyne knows/sees that she is unable to work, but is not willing to just do nothing (as if doing "nothing" is a possibility). Indeed, she believes that if she does not do something, in this case engage her mind/spirit, she would be better off dead. But how she phrases this is interesting. Jocelyne uses the word "cannot" implying that she is unable to do anything but in the same sentence she uses this 'not being able' as the impetus or rationale for feeling obligated/compelled in some way to actually do something (despite the fact that she "cannot"). Jocelyne's use of the phrase "cannot do anything" signals that she is unable to engage in paid work/employment for which she believes she needs an intact body. In order for her life to have meaning in the absence of paid employment she feels compelled to do something other than that to keep her spirits up, to engage her spiritual life.

Given the nature of her illness and how physically confining it is and given her extant personal and professional interest in the connections between mind, spirit and body, Jocelyne is deepening her knowledge and understanding of three of the world's great spiritual traditions—Judaism, Christianity, and Islam. She studies the central texts of these traditions—reading, comparing, meditating/reflecting on her reading and her understandings of them—to try and get at the meanings she believes lie within. Despite its effacement, she values her life and her potential for growth and learning, and enacts these values in her reading.

This move toward the spiritual fits with her inclinations as an alternative health care practitioner, and her informal study of religions. Jocelyne tells me that she has had significant influence on therapeutic practices in France by bringing some of the ideas about the spiritual into her practice. In this way she remains true to her interests in the spiritual aspects of the healing arts, which she is now practicing in her own life but in a very limited way because of her poor economic circumstances. She hopes that at some point in the future she can use this approach to help someone else who might be suffering. Emphatically, she tells me that the bottom line is that she aspires to help others, not just be a sick person living on disability benefits.

I refocus our conversation on her daily activities.

J: So usually I study all morning and I eat. And what I eat only buckwheat, *galettes*.

Uh huh. You eat buckwheat?

J: *Galettes*.

What do you do with the buckwheat?

J: I show you. (gets thin buckwheat pancakes stacked on top of one another wrapped in a towel out of fridge)

Oh you eat buckwheat cakes!

J: It's not cakes. It's just a *galette*.

Like a pancake.

J: Very thin.

You make those yourself?

J: Yes. And I eat that mostly always.

When do you make those?

J: Oh, usually once a week.

So how many do you make at a time?

J: One hour.

It takes an hour.

J: Mmm mmm. That's all.

So you eat buckwheat pancakes, *galettes*.

J: Mmm mmm. And um...one tomato, sometime. Little bit *salade*. But no *salade* and tomato because that is too expensive. I can eat only one tomato or part of *salade* because...I'm not *stupide* but, you know, one *salade* at \$2.50 is very expensive, you know so I need to make three. I go example for take uh you know some fruit or something. So I eat mostly banana and apple, you know. Because I am diabetic I cannot eat very much. I have problem with my intestine and so I cannot eat very much with that too. So I am very limited to eat. And is for that I try to have *diète*. But the government don't understand what is *diète*. You know *diète* is *equilibre* of what we put on the mouth.

Diet is what?

J: *Diète* is *equilibre* of product—*equilibre*? (seeking my comprehension)

Equilibrium?

J: ...of product that you need to have for your system, for your body.

Oh, a balance of products.

J: Voilà! *Ce ça une diète*.

But government doesn't understand that.

J: He...don't understand what is *diète*, you know. So I cannot believe, you know... (Emphatically) I think is same to one hundred years ago in Europe you know we have no better treatment. Here is medicine of emergency. Is not...*comment dire*? Preventive.

So what kind of diet do you think the government wants you to eat?

J: I don't know. I have no idea. Because always when I ask to have some more *monnaie* for I can have my supplement he refuse all...always, you know. So I cannot eat.

Jocelyne knows what constitutes a healthy diet for her and what she needs to manage the conditions with which she lives, but because of her limited income and the refusal of the Ministry to provide her with the money for supplements she has requested she is forced to choose either to eat less (of) or not eat those things that she believes support her health. Jocelyne attributes the problem wholly to government suggesting that government does not understand what a good diet is (a balance of nutrients necessary for good health), implying that government does not allow her (and other disabled people) to have food that is nourishing and healthy. Jocelyne furthers her criticism by linking this treatment of disabled people to what she understands to be the focus of the current health care system in B.C.; acute care not preventive care. Later she tells me that monthly she receives a \$40 nutritional supplement because she has two illnesses—diabetes and colitis—that can be at least partially managed/treated nutritionally.¹⁸

And then what do you do in your day after you eat?

J: Usually I try to have a *raison* for go somewhere for going out. A little bit. So...not everyday because I cannot. But one hour out you know...something. I cannot walk very much. I cannot. But for that I take a bus. Just for change for my mind, because I cannot stay always inside, you know, so I'm obliged to do something. Just for take, I take a bus. You know usually I take my time you know. I take my time for everything because you know uh I am alone. I have no pressure with anybody and I manage myself with what I am, if I am suffering a lot more or less. I do with my composition is not always same.

¹⁸ Please see Appendix A, Note 2, pp. 362-364 for a detailed description of the Nutritional Supplement policy, and eligibility criteria.

Because sometimes I eat, sometimes I cannot, so maybe I eat a little salad only and maybe I go on balcony and I watch the sky.

And the ocean. You can see the ocean?

J: Ya that's good for me living here because I cannot go anywhere. We have a nice little park over there but I cannot go because is too difficult for me to walk. I cannot. And I like to go in a swimming pool too but I cannot go because uh you know, I don't know. If you have too much, if I cannot dry my hair then I am afraid to have a cold. Because I am fragile. So I take care of me always. I am obliged you know and is for that I don't go very often—I don't go downtown very often for example because it too many people and I don't want to keep bad things.

Get bad things.

J: Ya because when you are sick like that you are fragile.

Jocelyne paces herself and daily makes decisions about what she is able to do given her energy and pain levels. What she is able to do does not always align with her desires and routinely she must put these (rather simple) desires in abeyance, limiting what she does and where she goes. Mostly she remains in her apartment. Jocelyne watches the news on TV (her rent includes cable) and she is particularly interested in CPAC, the Canadian parliamentary channel to further her education about Canadian politics, building on what she tells me is her keen and longstanding interest in politics.

J: I watch TV for politic, you know. And I watch TV for news. And sometime when you have interesting debate, you know I looking that and I make my dinner. And again I go to my book.

So you read again?

J: Yes, you know. Or I sometime I write.

And what do you write?

J: Comment of my book.

Comments. Notes. You take notes.

J: Notes, you know. And if I have some *monnaie* I like to paint, but I have no *monnaie* for buy paint, you know. You can see you have a frame here (pointing to the next room) with nothing inside. I like to paint something but I cannot. I have no *monnaie* for buy anything.

You can't buy canvas. What would you say was...?

(Jocelyne doesn't appear to hear me fumbling with a question)

J: But you know my pain is too much. Specifically during the night because is hormone. I know the government don't know the hormone work on night. But is true. In the...so during the day I have pain too, but is not so much, you know. So that I can talk to you. But someday I cannot. Nothing, nothing. I cannot read.

So what do you do?

J: Nothing.

Do you lie down?

J: I am on my bed. I thinking about what I read the day before. That's it. I cannot do nothing, believe me. Some time is impossible. It is impossible for me to have plan-ification for every day. To plan. I cannot. Every day. If I take an appointment with doctor and somebody other, I am obliged to have one day between. I cannot take every day. No no. Because I tried to have that and I cannot.

Jocelyne suggests that her knowledge of bodily processes, especially her own in this case is not shared by government. Her experience of pain is invisible, particularly when it is hormonally triggered and happens during the night. She is also invisible to government (and others) when pain is intense enough that she cannot function and cannot even read.

Then, she lies on her bed and reflects on what she read the day before. Her reading again sustains her even when she is unable to carry out her daily routine.

Jocelyne's monthly PPMB benefit is \$607, which along with her nutritional supplement brings her monthly amount to \$647. Her monthly rent is \$645. I am interested in how she survives and if she gets any help.

So how do you survive?

J: I have a friend give me what I have.

What sort of things?

J: Some fruit, some milk, better soya milk because I cannot take...[cow's milk?] ya. And now I have two dollar on top of my rent. And I don't have any money for buy my medicine for *diabete*. And my *avocat* ask for I have \$42 a month on top for my *diabete only*, just for my *diabete* pills and he said no.

Who said no?

J: The government.

So how did you find that out? Did they write the government or call up on a phone or...?

J: My advocate write so many time, and always is no.

So you couldn't get your prescription?"

J: I cannot have my prescription because I need to pay \$40 on top and I have no money for pay. So my *avocat* is obliged to looking everywhere always each month for I have my medical *diabète* cause I go to dead if I don't have.

What else does your advocate do?

J: She ask me—'cause I can show you my bed. I have very much pain all the time. So I don't have a good bed. So my advocate see that because I don't know I can ask [for] one. But when I go sometime and the woman give me the form... .

J: This form, the Request for Reconsideration form? (she has shown me a number of forms and correspondence from the Ministry)

J: Ya. This woman she said to me “you can ask us for new bed because we can give you new bed.’ And I said, “Really?” I am very happy. And I said that to my advocate, and she said yes and she ask, and they say no.

They say no for the new bed.

J: And she ask for I have some help from my bank because now I have problem with my bank. No help.

With your...doing your banking? (nods) No help.

J: No.

So you don’t get any help?

J: No. So. What I feel...I feel...*humiliation* and humiliation and humiliation.

Over and over again.

J: And completely...You know what? I feel I living on...uh...*comment dire?* On fascist government. He want the kill old people and he want kill the sick people.

It’s kind of like a slow death, eh?

J: Yah. And you know. With this way you don’t need to have official torture. You know, but for me on *democracie* you are not official torture. But here is existing because I feel the government torture at me since four years. Because they refuse to give me social worker for four years.

Even with an advocate Jocelyne is unable to successfully access or secure what she needs, including the help she needs in her daily life. She receives no home support, so all the personal activities she engages in are performed on her own independent of help at a pace reflective of her physical limitations. Securing additional benefits is a prominent focus of her energies but she has to be able to get up, feed herself, wash, get dressed, get

to the bus stop, ride the bus and attend appointments, no small feat when you are unwell and in pain, and desperate. Her experience is one of being repeatedly humiliated: having to ask for even basic necessities like money to pay for the non-deductible amount of her diabetic medication, being told she could have a new bed and then being refused, again and again. Her desire for a social worker, a person she believes could solve many of her problems with government is thwarted. Out of frustration Jocelyne offers a searing critique of government, accusing it of being fascist and weeding out those who are most vulnerable—the sick and the elderly.

(Close) Encounters with Ministry workers, and Alternative Means

Evelyn and I had been discussing her experience of applying for benefits initially and I had asked her if there was anything about the process that surprised her.

E: Well, I mean one thing still surprises me. The office that I have to go to is quite a drive. I would not want to have to do it taking the bus. That would be ridiculous. And then...the woman comes out [Evelyn calls her full name out loudly]. It's like "oh my god."

Yelling your name out.

E: Ya. No privacy.

For those people receiving provincial disability benefits in the region where the participants live the Ministry of Employment and Assistance (MEA) [now Ministry of Social Development and Social Innovation] offices were previously centrally located in the downtown area of the largest regional urban centre, but in 2000 were relocated along with restructuring of services to a small plaza north of the city. Other participants also

complained of the inconvenience of this location including the fact that those living in surrounding communities require three buses to get to the MEA offices.

Evelyn lives with seriously compromised energy due to CFS and ME; a decision to travel the extra distance is not taken lightly. Fortunately she has a vehicle, although elsewhere she reveals that when she is at her worst physically she is unable to drive and therefore immobilized. For those who have to use precious energy and/or travel long distances to get to the MEA offices this location is not just inconvenient, it requires energy, time, effort and planning, which constitute the work of being disabled and poor.

Once she gets to the MEA offices there is no guarantee that Evelyn will be treated with dignity and respect. She expresses dismay at having her full name called out loudly by the office staff—not an unusual practice apparently—into a waiting room where presumably there are others awaiting services. Evelyn is particularly sensitive to this in part because of her professional practice as a social worker/therapist where confidentiality is strictly adhered to. Ministry staff strip her of her privacy, removing any anonymity she might wish to protect; an impersonal act in a public space experienced as highly personal and invasive of her privacy. Evelyn does not contest this violation for she knows that it could expose her to the risk of inviting further infringements on her person or reprisals. Even so her privacy is not an unalloyed privilege with which she lives; Evelyn is not absolutely protected from (over)exposure because encounters with Ministry employees typically require routine detailed disclosure of highly personal aspects of her life.

Evelyn expresses surprise at both these circumstances—the inconvenient location and the public removal of her privacy—not unlike any reasonable person who expects public

services to be oriented toward those they serve. Here I refer to the most physically and economically vulnerable citizens who are not positioned to either speak back without fear of reprisal, or to afford alternate transportation such as taxis enabling them to travel with less effort. Like her able-bodied counterparts Evelyn's expectations (and subsequent surprise) reflect her reading/understanding of (or subscription to) an official version of program delivery in which government and public servants deliver services as intended, respectfully, conveniently, and oriented towards the needs of client/citizens.

But Evelyn also understands that the worker she actually sees in the Ministry office and how she gets treated are a matter of chance ("I've been lucky though."), suggesting a capricious, unreliable element in this bureaucratic process. Evelyn never knows which worker she will see and she cannot reliably predict how each will treat her or handle her file.

E: Yah. I've been lucky though. I mean I think I've had only had three workers, they've all been fairly decent people. Like really by the books. But this one woman I know—when I had to all of a sudden do a year annual review a year after I first went on benefits. I hadn't been paying attention to things going in and out of my bank. Like money that my mother was giving me to help me survive. It was on my bank statement. You have to show two months—at that point anyways—I think it was two months of your bank statements.

That was part of the yearly review?

E: Ya.

Evelyn has had the 'good fortune' of meeting with three Ministry workers who have acted decently toward her apparently following protocol closely, or at least not exercising power indiscriminately or unfairly. Yet she goes on to tell me about a worker who both

treated her well and did *not* follow protocol apparently, at least not how Evelyn understands it should be in this instance (as necessarily punitive), suggesting that workers proceeding “by the books” might not always be to her advantage.

Evelyn does not anticipate that her file would be reviewed in the year following successfully applying for disability benefits and experiences this event as startling and unexpected. If she was given the information initially that she was going to be reviewed annually she has perhaps forgotten. But Evelyn has also not received from the Ministry any advance notice of this process nor a specific date or range of dates when she can expect it to occur, leaving her to second guess when it might happen. Some of this might be a result of her precarious housing situation and not receiving mail at a regular location or not picking it up routinely, or not paying attention as was the case with the deposits in her bank account.

The potential costs of not being informed, or alternately not being vigilant become apparent to Evelyn because she has been depositing in her bank account the monthly cheques received from her mother to offset the poverty with which she lives without reporting the income to the Ministry. All additional income, earned or otherwise, must be reported to the Ministry, and if it is not “allowable” income measures are taken to ensure that clients receive no more than they are allowed, including reimbursing the Ministry any “overpayment” of benefits they have received during the period they received the additional income.

At the time, the Ministry required clients to present at least two months of their most recent bank statements as part of the annual review of their files (currently it is three months). Interestingly, this financial surveillance is the full extent of the Ministry annual

review unlike the private sector, particularly insurance companies that administer long-term disability benefits, which primarily require yearly physician verification of physical or mental impairment and a personal statement of ongoing disability and questions about volunteer, educational and work-related activities. Nor does the CPP Disability program ask for bank statements, requiring only documentation similar to insurance companies but not on a regular basis. The latter could be attributed to the permanent category of disability created as part of the CPP program and what has been considered the most stringent criteria nationally for eligibility (Doe & Kimpson, 1999).

Economics (specifically accounting) is at the centre of this provincial public sector process that focuses on client bank account statements and whether or not they reveal any unauthorized income and by extension unauthorized activities. The client must simultaneously reveal and therefore account for her financial situation and whatever income-generating activities she may have undertaken in the months preceding the review. This type of surveillance requires clients to disclose personal banking information with an implied threat of losing their benefits if they fail to comply, thus exposing themselves to risk. Here a lack of trust in clients to comply with the regulations is revealed, which undermines the trust disabled women like Evelyn have with regard to how the Ministry responds to them.

Knowing the policy and that she cannot escape the situation in which she finds herself, with documented evidence of a transgression Evelyn decides to tell the Ministry worker about receiving the extra money from mother. By choosing to tell the worker 'the truth' Evelyn signals that she always has the option to falsify her story but likely makes a judgment in this situation that the evidence is against her. She guesses that she is

potentially in trouble and that the best strategy is to be truthful and see where it takes her.

I ask her how much she was receiving from her mother.

How much was your mom giving you? Do you mind me asking?

E: I think she was giving me \$500 a month. And I didn't declare it. I didn't tell them about it.

It wasn't earned income?

E: No. But you're supposed to declare any income. So she [the worker] was like, "What is this?"

So what did you say?

E: I told her the truth. She said, "Well I guess you didn't really understand." She was very nice.

What was it that she thought you didn't understand?

E: That I was supposed to declare that. Like I think then, I don't know—I know now you're allowed to make \$300.

It's actually \$400 [through employment].

E: Four hundred?

Ya. I'll get you a copy of the policy so you'll know for sure.

E: I know! It's so crazy!

Evelyn has a general awareness of policy regarding additional income—she is “supposed to” declare income, implying punishment if not complied with—but is incorrect about the actual allowable earnings amount from employment at the time, which actually does not apply in this situation because the money she was receiving was a gift. Despite not knowing what the consequences might be for not declaring the additional income Evelyn willingly receives the money from her mother and takes her chances.

Once the worker gives Evelyn some latitude, treating it as a case of ignorance, Evelyn engages in a strategy that works to her advantage. She does not reveal to the worker that she knows about the general reporting policy and thus colludes in the worker's estimation that Evelyn did not understand the rules with respect to declaring income. However the worker does not further illuminate Evelyn as to the allowable amount she can receive as a gift, nor does Evelyn ask possibly signaling that she might be considering receiving further gifts and inadvertently inviting more surveillance. In fact when she exclaims, "It's so crazy," Evelyn points to how difficult it is for clients to know the policies in detail when they keep changing and Ministry workers do not reliably inform clients of what they are authorized to do or have. That information is found elsewhere, if you know where to look.

So how did you find out that you're allowed to get \$300. Did your worker tell you that?

E: No, I think—it was really surprising—I remember going to either Together Against Poverty or to the Disability Action Committee. And finding out, getting a list of all the things I *was* eligible for. And then at the interview, at the end of it I went, "Oh by the way...". She [the Ministry worker] was just about to send me on my way and this is it, run off and have a great life. She didn't say, "Oh, you can get a food allowance. You can get this ferry thing, you can get the fuel tax rebate, a bus pass," like all these things. She didn't tell me any of it until the end of the interview.

When you confronted her with it? With the information you got from the committee or TAPS.

E: Ya. I mean I didn't confront her, I just said, "I heard it through the grapevine." And it's still like that. 'Cause I just had an annual review about three weeks ago. Yah this year again (shocked tone of voice) she didn't tell

me any of the extra things I was eligible for. None of it. I didn't realize but after the first year you have to reapply for the \$40 extra for—if you have the special diet, which I do have. I hadn't been getting it the whole time, except for that one year. You have to reapply every year.

You have to reapply every year for the supplementary benefits you get?

E: Yah. I think so. It's stupid

Do you get any other supplementary benefits?

E: No. I don't even really know what they are anymore.

Again Evelyn is surprised. She expects to learn from her worker what she is eligible for but it takes a visit to a non-profit society serving the disabled and poor to get an accurate list. After the review of her bank statements—apparently the only purpose of the meeting—is complete Evelyn draws the list to the attention of the worker hoping she will verify or confirm or augment the information received from the non-profit society. Despite the fact that Evelyn has previously shown an interest in knowing what she is eligible for, at her next annual review the same worker neglects to provide her with information. Evelyn was unaware that she had to apply yearly for a \$40 monthly supplementary benefit to offset the cost of a special diet she required and so she went without it. Evelyn does not say so but reapplying for the supplementary benefit yearly requires a visit to a physician to verify medical need for the special diet she requires something that she may not always have the energy to do.

Despite the profound fatigue and bodily pain she lives with, Evelyn has to work hard to keep her knowledge of policy current, including the work of gathering and bringing pertinent information about eligible services, products and services to Ministry staff who she believes should be providing this information to her. The Ministry worker was about

to dismiss her when Evelyn interrupted the process to bring her concerns forward. And there is more work to be done if she wishes to secure the \$40 monthly supplementary benefit; a visit to the Ministry office to get the appropriate form and a visit to her physician to deliver the form and request verification of her continued medical need. Presumably the physician would mail in the completed form but this is not always the case, requiring another visit to the physician to retrieve the form so it can be mailed or alternately delivered in person to Ministry offices.

In her efforts to take care of her body she trades off having the supplements she needs for conserving energy she does not have, all part of the difficult, full-time work of survival. Given the extent of the work involved in the face of compromised energy it makes sense that Evelyn no longer knows what she is eligible for because not knowing also means preserving energy otherwise used to secure the benefits.

Disability benefits are always insecure because workers have the discretion/authority to either allow or disallow income received without authorization.

E: When I was caught getting that extra money and not declaring it, she was really nice about it, and she kind of played around with her computer screen thing, somehow.

And what do you suppose she was doing?

E: I think she was adding it in. Because I think—ya she had to put a copy of my bank statement into the file.

The two months of the bank statement?

E: Ya. I think she changed some numbers on her computer. Yah. I think—I don't know when—I've been repaying them for some overpayment that they

made that was their mistake, but they charged me. Like I've been repaying that \$20 a month for a couple of years.

How much of an overpayment was that?

E: I'm not sure. I probably have it in some file somewhere.

And you're still paying that?

E: Ya.

Although this particular unauthorized income situation worked out well, Evelyn cannot escape the fact that this series of events/process may have gone very differently signaling again the uncertainty inherent in encounters with Ministry workers, notwithstanding Evelyn's financial transgression. In fact all the participants expressed the opinion that contact with Ministry workers be avoided at all costs precisely because of the unpredictability of worker response. These disabled women believe their eligibility status is at risk in any given encounter with officials or minimally they will be financially penalized for some transgression they may have (inadvertently) made. They never know when or how a judgment will be made against them. Even if their eligibility status is not directly at risk Ministry decisions about seeking penalty for overpayment are made in unpredictable and seemingly arbitrary ways; Evelyn is 'forgiven' her current transgression but continues to repay the Ministry \$20 monthly for a previous "overpayment." Presumably this money is taken at source from her monthly benefit amount.

Evelyn is caught between a rock and a hard place. Like the others she relies on the Ministry to provide supports for her and believes that she should be well looked after. She continues to subscribe to these beliefs and expectations, opting-in/subscribing to the

promise of support and care. But when her worker does not provide information she needs about supplementary benefits, Evelyn's expectations are unfulfilled giving her cause to distrust that she is going to be looked after the way the Ministry says it will let alone as well as it ought to (or Evelyn believes it ought to). In addition she is subject to different forms of surveillance and knows that punishment/reprisal is a potential outcome of transgressing the rules. Yet she experiences a worker who is flexible with respect to her unauthorized income, but Evelyn knows this flexibility is discretionary, arbitrary, random, uncertain. Uncertainty only serves to keep her necessarily wary and untrusting of contact with workers but ultimately reliant on them to provide the benefits and supports she needs.

Though Evelyn's transgression with respect to her unauthorized income is challenging in terms of dealing with the Ministry, as a threat it is not as constant in the way issues around housing constitute in her life. When I ask Evelyn what it has been like to be living on disability benefits and how it has affected her health she responds by telling me she chose to spend three summers in a row being homeless.

E: So in order to buy car insurance or some extra things I chose [*sighs heavily*] to for three summers to be homeless. So I wasn't paying rent, so I could save up that rent money so I could have some extra money to buy supplements and to get extra treatments and just kind of have a little—but I don't have any of that left now at this time of year [*early winter*].

So, when you say homeless, where were you actually living? Were you taking care of people's homes or...?

E: Um—well, the first year [*chuckles*] I lived in my trailer on Salt Spring.

So that wasn't a home? Or...?

Well I was paying rent, but it was this tiny little trailer that didn't have running water or electricity or anything. But that summer it was OK because I was getting all my amalgams out. And I wanted to do it on Salt Spring because I have a dentist there. And then the second summer—

Can I just ask, was that dental work paid for by government?

E: No.

You had to pay yourself to have your amalgams removed?

E: Ya, and um my—somebody helped me out with that—um—[*loses train of thought*].

So you were talking about living in your trailer, and—that you were homeless for three years or three summers—

E: Three months. Well, I think—maybe—May, June, July, August, I don't know. I think I remember even June was really cold a lot. So I would kind of like sometimes be there or couch-surfed until the weather warmed up.

So that trailer was something—you bought that trailer?

E: Ya.

And then you paid rent to put it on somebody's land?

E: Ya. But it was only \$100 a month.

But if it was cold then you couldn't actually stay there?

E: No.

So you would sleep on people's couches?

E: Ya.

And you had a vehicle, right?

E: Ya.

So some of your money went into that?

E: Ya. I can't remember what I did the second summer... I stayed with family for the first month, for June. I stayed with my oldest child. And then for part of June and July I stayed with my youngest. It's so stressful not having a home. I've moved sixteen times since I left our place in 1992 [when her marriage ended]. Ya. It's like so—so wrong. For anybody. Especially for somebody with chronic fatigue or fibromyalgia. Like every time I moved I would throw out my back, and I would have incredible, like more body pain than usual. And I am exhausted for like another month. It's just like so bad. And most of your moving is just because of wanting to be able to afford the treatments that you've chosen?

E: Ya.

Evelyn has what could be considered unorthodox, and even creative strategies she applies to her housing needs but it is unclear if, despite her intentions, her approach is supportive of her health. Later she tells me the next summer she tried to work on an organic farm for board but her body could not handle staying in a tent and presumably engaging in demanding physical labour. There is a clear trade-off to the decisions she makes around housing; she saves money on rent which she can use to pay for unsubsidized treatments and products that support her health, but she ends up in physically challenging situations not the least being the physical act of moving more or less constantly. I am interested in how she juggles her housing situation with respect to her relationship with the Ministry.

So how often would you see your case worker?

E: Once a year.

And that has to do with the review—the yearly financial review?

Ya, so like last summer, my cheque was arriving at this house where—it was really, like I was taking a big risk.

Why?

E: Because I didn't know who was living there. I was living there—like I moved into that house a while back at the time a friend was leaving an abusive relationship. She came and stayed. She ended up staying. I asked her to leave. She didn't leave. She ended up buying the house, evicting me. And then she immediately left town and rented it out to some kids, you know school, university kids. And I knew them. It was just a total fluke. So my cheques kept arriving there. But then they moved out and then she came back and she returned my mail to the Ministry. And I didn't know that because I was out of town. So they caught—you know they started getting pretty suspicious, and so I'm owing them money from that fiasco. I saw my worker about this and at first she wasn't very suspicious. Then she asked me some pretty scary questions and I was like shaking.

What kind of questions?

E: Well why didn't you tell us that you had moved?

Right.

E: Why was this mail returned? We—you know have to look into this.

Meaning?

E: Well she didn't.

So this was how many months of cheques did your friend send back?

E: She sent back two.

Right. And you had gone where?

To the Interior.

And did you go there to work or just to live?

E: Just to live. So I had a friend checking on my mail.

And you were hoping that friend would pick the mail up at your old place and send it to you, right?

E: Ya. But you know this woman got the mail and sent it back probably that same morning.

And so you didn't want to tell the Ministry you were moving to the Interior, and have your cheques sent there?

E: No.

How come?

E: Because I wasn't paying rent there, and you have to be—you have to have a rent receipt and a tenancy agreement from the Ministry of Attorney General's office, blah, blah, blah.

So you—in order to get the money that you get—your housing allowance, you—

E: You have to show utility bills.

And have you ever had to show all that stuff?

E: Oh ya.

That happens also in your annual review?

E: No. It happens every time I move.

Oh. And if you tell them.

E: Right. If I tell them.

So if you tell them, they want to see that you've rented a new place and what your rent is going to be, and what your utilities are.

E: Mm...mm.

In an effort to save energy taken up dealing with bureaucratic requirements (which she may not meet) Evelyn makes a strategic decision to take the risk of not informing the Ministry each time she moves. Unfortunately in one instance this strategy backfires, for which she tells me she is still paying. It is not clear to me if this is actually the

“overpayment” previously mentioned but it is clear her strategy has required the consent and active engagement of trusted others willing to assume responsibility for following through on agreed-upon actions. In this way she tests the limits of housing policy/regulations, which she exceeds at her peril. Evelyn subverts the rules around housing when she guesses correctly that she can live elsewhere as long as she appears to meet Ministry housing requirements, but this strategy is not always successful and so when two of her cheques are returned to the Ministry she has to account for her whereabouts and make amends. Presumably the return of the cheques to the Ministry by the landlady covers an overpayment made to Evelyn while she was temporarily ineligible for benefits because of violating housing policy. This may be why the worker did not look into this situation despite telling Evelyn she would do so. Telling me her life feels like it is not her own, Evelyn feels constrained by Ministry housing policy, which does not allow her the mobility she needs and desires. I ask about her current housing situation and if that is challenging in any way.

E: Where I live the owner lives in the house so they [the Ministry] won't pay my damage deposit because legally it is seen as a “hotel.”

Tell me that again. I'm missing something.

E: The Ministry won't pay my damage deposit because where I live now the owner lives there as well, and so legally it is seen as a hotel. And they don't pay if you live in a hotel. Or your not supposed—I don't know.

Well aren't you just renting room from somebody?

E: Mm...mm.

And is it board too? Or just room?

E: Just room.

Why is that a hotel? That's bizarre.

E: Mm... mm.

And so you haven't done anything about finding out about that or fighting it?

E: No. I doubt I'd win and I don't have the energy.

By renting a room in a house in which the owner lives, Evelyn inadvertently encounters restrictive Ministry regulations/policy about damage deposits that she could not have anticipated or known in advance without being previously informed about it, something Ministry workers are unlikely to do. In this way she reveals a source of her mistrust of government and how it intersects with her compromised energy; in the interests of her health she chooses to comply.

Evelyn's somewhat unorthodox, creative and risky approach to housing reflects the stakes she contends with in her efforts to survive as best she can on her own terms. I wonder if these qualities are reflected in taking care of herself.

I would like to know what you actually do to maintain your health. It's not so much what you spend your money on, but what do you actually do for yourself to maintain your health?

E: Well, like yesterday I tried not to do anything.

Mm...mm. So how successful were you?

E: Not very.

So what did you end up doing?

E: Well, like I moved into this [rooming] house just at the beginning of November. And I really wasn't thinking but I was so desperate and it was kind of affordable and it was nice and I knew the person. But I didn't get it. Like I am so spaced out or in denial or whatever. To get to the first level is up this huge flight of stairs, and then to get to my bedroom is up another flight of

stairs. I am like realizing I am getting really tired from just doing nothing, just staying home. That I'm gonna—OK, I'm going to bring a kettle up to my bedroom, and some tea, and maybe... [*loses train of thought*].

How many other people in the house?

E: Two.

Mm...mm. Tell me about what it is you do for yourself—I mean apart from not doing anything? You must have a dietary regimen of some kind. Can you talk about that?

E: Ya.

And you must do different kinds of treatments, right?

E: Ya.

If you give me a typical day maybe then that might—[*shakes head*] No? No typical days?

E: No. Not really.

Every day is different.

E: I see my GP once a week for a B12 shot.

Is that covered?

E: The B12 itself isn't covered.

So how do you buy that? Do you use the money that the government gives you?

E: Ya. Mm...mm.

Do you get anything back on that?

E: Nope.

You don't claim it on Pharmacare? How much does it cost?

E: I think it's about \$13 and lasts about a month.

So you go to your doctor once a week?

E: Mm mm.

That takes a lot of energy.

E: Ya. And I choose to climb the stairs because I'm allergic to the elevator.

What floor is she on?

E: I'm allergic to the f—g stairwell too. Um—she's on the third floor and she used to be on the main floor when she was in her house and then she moved from her house. I take Western herbs from her.

Western herbs. Is that like a brand or—what?

E: It's like not Chinese herbs.

OK. So which herbs do you take?

E: I could bring the list but there is a long list.

So what do those do for you?

E: Well—I take a formula for menopause. I take a formula for pain. And then I have—a formula for nerves.

And so does she prescribe those?

E: Yes—

And do you buy those from her?

E: I mean I tell her what I want basically and she kind of adds to it.

And where do you get those?

E: She sells them.

Do you think they're working?

E: (pauses) Ya. I think they—I mean I'm better than I was.

Better meaning?

E: Um. I'm a lot better than a lot of other people I know too that have the same thing.

So how are you better than—you've got somebody else in mind. So how are you better than that person?

E: I have more energy. I can go for like a bodywork treatment, like chiropractic or acupressure and they can work fairly deeply. As long as I have an Epsom salts bath afterward then I'm not in pain. Like I had a treatment yesterday. I'm fine. It really helped me.

So you have acupuncture—uh acupressure how often?

E: I do a trade with this woman. For counselling. It's kind of like every two or three weeks. And then I do it—I just started doing a trade with another woman. For massage. Because my coverage under B.C. Medical, it's—now I've used it up for the year to see my chiropractor.

Right, so that's ten visits, right?

E: Mm...mm.

So chiropractic, massage, acupressure—those three kinds of body work. Any other kind of body work?

E: [*shakes head*] Um—I do yoga.

Do you do yoga regularly?

E: Mm...mm. Kind of twice a day. I have to.

What times a day do you do it usually?

E: In the morning and at night. And sometimes in the middle of the night because I wake up and my body is just like—fucked.

What do mean “fucked”?

E: Really stiff, really sore.

Sore and stiff. Is that generalized or is it localized in some kind of way?

E: Well I definitely have my weak spots.

Which are?

E: My neck and my shoulders. My lower back. This side of my ribs.

In the front of your chest like?

E: Ya. So yoga. Lots of hydrotherapy.

So where do you do your hydrotherapy?

E: At home.

In the tub?

E: Ya.

Is that just having nice hot baths?

E: Epsom salts. Once a month I put in apple cider vinegar and baking soda, like large quantities. Once a month I put in three bottles of hydrogen peroxide to—

What does that do?

E: Oxygenate myself.

How did you learn about that?

E: From a book by Susan Lark called “Chronic Fatigue”.

Is it a good one?

E: Ya. Pretty good.

Evelyn, like Jocelyne, and to some extent Galya, has chosen to treat her disabling medical condition using mostly alternative therapies but has to be creative in accessing those services and products that are either not subsidized, or whose yearly limits have expired. She is able to barter with other professionals by offering counselling services in exchange for body work that she needs on a regular basis to reduce pain and increase mobility (and energy). In part by necessity but also because they align with her understanding of how the conditions with which she lives ought to be treated (and lived

with), many of Evelyn's self-care practices are simple, basic, non-toxic or invasive, requiring very little expense. Knowing she has environmental sensitivities I wonder about her diet and naively assume she purchases everything she eats, which reveals another unorthodox, creative and risky practice of caring for herself.

E: Um—I'm on a candida diet. I eat everything organic I possible can.

And where do you usually buy that food?

E: Here and there. I grow it. I wildcraft [harvesting wild edible plants, like miner's lettuce and nettles] it. I go dumpster diving.

So what are you looking for in dumpsters?

E: Whatever.

Just give me an example of something.

E: Well. Um—[names small health food store in a local neighbourhood].

They throw out a lot of produce.

Oh do they?

E: Ya. Into their compost. [names another larger health food store]—twice a year their freezers break down. Not that I have my scout anymore—I used to have this friend who'd go almost every night. We filled up three station wagons full—butter, yogurt, tempeh. You name it from that freezer. Their fridge.

It's hard to believe that there is that much waste.

E: I know. It's scary. And then [names organic wholesale distributor].

I know where it is.

E: Ya. If you want to jump in the dumpster and sort through broken glass and old computers and garbage, there is food in there. It's amazing. Big sacks of rice.

And why are they throwing that out? Why are they throwing a sack of rice out?

E: I don't know. Got a little hole in it.

So what is that like for you?

E: I don't usually get in the dumpster. I go with someone.

You go with someone else—and you have a station wagon, right? So you can transport all the goods.

E: Mm...mm.

So don't you get worried that someone might see you doing it, like the police or whatever [*shakes head*] oh nobody cares?

E: They were locking their dumpster at [names wholesale company again], and my friend who owns [a popular artisan bakery] called them and said "Stop locking your dumpster. My friends eat out of your dumpster."

Right. "And if you don't I won't order goods from you."

E: Right. Exactly. Ya. So it worked.

Being caught: And a Faustian bargain?

Galya was completing a second master's degree at a Western Canadian university at the time of the onset of her mental impairment, chronic depression. As a student employed seasonally and part-time as a research assistant she had no access to employer-sponsored disability benefits or would not have qualified for CPP Disability benefits. In fact at the time of disablement she had a large student loan on which she and her daughter lived. At the time of the interviews her daughter was a young adult living on her own. Galya continues to pay the Ministry \$10 monthly for paying off the student loan whose large

monthly payments she could not afford when she withdrew from her program and became eligible for disability benefits.

Galya's chronic depression fluctuates. She also lives with high blood pressure, chronic bronchitis and chronic back problems that significantly limit her energy and what can be done physically in a day. I find myself curious as to whether or not Galya continues to experience the depth of depression she did at the time she applied for benefits and what she might do to alleviate it or mitigate its effects. I ask Galya if the kind of depression she experienced at the beginning is behind her now or if she still experiences it from time to time.

I would like to learn a little bit about—with respect to your health—your psychological and physical health. You've been telling me about the worst. Is that something that is behind you now? Or is that always potentially there for you? Or do you still experience it from time to time?

G: Well that's a very good question. I must say that also over the years—OK. My therapy never ended. I tried to see different psychiatrists and none of them was helpful.

How were they not helpful?

G: I found all of them—and my doctor referred me to all possible people who could take new patients—I found them so absolutely not empathic, but even worse. I found them almost using me and my time to talk about how they became psychiatrists, or how they can help me, or what their life looks like. It's unbelievable. I even said to one person, "you know the medical plan is paying to you to talk about yourself." So they were just patronizing, classifying and just making all kind of judgments. It was just totally insane.

Galya requires ongoing therapy to help her deal with the effects of depression. In part because of the poverty in which she lives and her doctor's referral practices she seeks

therapy offered by psychiatrists who are subsidized in B.C. through the Medical Services Plan. Ironically, despite being a trained psychologist (and a thesis short of a graduate degree in counselling) Galya cannot utilize the services of either psychologists or counsellor/therapists because these professionals are by and large unsubsidized in B.C., unless they are working in publicly-funded institutional settings. Their services are beyond the means of people living in community receiving provincial disability benefits who are not connected to institutions providing psychological services beyond psychiatry.

Galya has a level of self-awareness commensurate with her qualifications. She also knows what it means both personally and professionally to be helpful. Despite seeing a number of psychiatrists she does not receive the compassionate, non-judgmental, respectful care she needs and expects. In frustration she even speaks back to one of the psychiatrists who is wasting her time. Despite the fact that the services of psychiatrists are affordable Galya opts not to further expose herself to the “insanity” of their treatment of her.

Not only do the psychiatric services she tries fail her, the conventional anti-depressants she is prescribed have unintended adverse effects; she becomes depressed physically and mentally and aggressive in interactions with others. Galya has a high degree of self-awareness and a committed spiritual practice. These serve her well in terms of knowing what side effects she is not willing to live with. Contrary to her doctor’s recommendation she discontinues the anti-depressants that are impairing her quality of life risking the possibility of the return of debilitating depression. She is resourceful though in her search for alternatives.

Galya tells me about an alternative approach to depression that she subscribes to given her unsatisfactory experience with conventional psychiatry. She returns to see a mental health practitioner whom she had seen when she arrived in B.C. before beginning her graduate program and previous to developing depression. Although an unusual practice for some, seeing a mental health practitioner on a regular basis even in times of good mental health would make sense given her already well-established personal and professional orientation toward psychological health.

G: But then I had known since I came I found—it's interesting—I found long time ago, this Dr. Hoffer [a psychiatrist specializing in orthomolecular medicine, i.e., megavitamin therapy, d. 2009]. Back then I went to see him and we talked and he gave me autographed book of his. I still have it. But then I went into my therapy and I went into school and I let him go and his approach. But now since a few years ago I start—I went back to him. And I went on his vitamin plans religiously Sally. And I think it is really making a difference. The niacin I'm taking huge doses. I'm taking folic acid huge doses and I'm taking all other thing—salmon oil, primrose oil and Vitamin E in clear base in large doses. Vitamin C in large doses. And also I researched and I talked to him and he agreed that this age for a woman it would be very beneficial to have wild yam cream, which is progesterone. And I'm taking some other things. Because I must say I tried anti-depressants through the years. I still was in school when I started the first symptoms. I took Prozac® for four months and the first three months was great. I went back to my old self I would say, but then it became worse. Because I started to be aggressive in a way, aggressive, more aggressive which I didn't like walking my spiritual path. And then it just became numbing. I started to sleep 15 hours a day, nothing else. So I stopped and we tried some other anti-depressant. My doctor probably thinks I didn't give them a longer try, but after five, six, seven days I felt like it's not me. I never really depended on antidepressants.

But with this vitamin plan and now I've been on this plan solidly for two years, I've seen improvements.

And are you able to get extra money from the government for these supplements?

G: No.

The kind and number of supplements Galya is taking raises questions for me. As a disabled woman who takes some of these supplements in part covered by my extended medical benefits (which Galya has only partially), I know how expensive these can be, potentially well beyond her means. Later Galya tells me the niacin and folic acid are subsidized by the Ministry via a nutritional supplement allowance for vitamins and minerals (up to \$40 monthly is allowed for vitamin and mineral supplements).

How would Galya know about these supplements? Galya indicates later that Ministry workers are generally not forthcoming with this information unless asked, if you even know to ask. Even though the Ministry website lists the available supplements (in the Regulations, but you have to know to look there for this information), Galya has no computer (and rudimentary computer skills) with which to access the Ministry website. She relies on others in the community. As Evelyn previously suggested, Galya gets this information 'through the grapevine,' via TAPS (Together Against Poverty Society, a local antipoverty group) and the local disability advocacy centre, two non-profit agencies serving the poor and disabled in the region. Her doctor also provides some of the information but it is hard to discern from what she tells me what exactly she learns from her physician.

After learning about the supplements, procuring them is no mean feat. Galya has to engage in the energy and time-consuming work necessary to find out what she needs to know, plan and then execute that plan to secure them. Despite seriously compromised energy and shortness of breath associated with chronic bronchitis Galya would have to travel via public transit (for her two buses) to Ministry offices to get the form for this request, make an appointment with her doctor, travel to and from the appointment (again two buses) via public transit and make sure the required forms were completed and delivered. Once the forms (completed by the doctor) reach the Ministry there are detailed regulations governing approval for which the applicant has to wait. Despite this, receiving financial help with this expense is worth Galya's effort and presumably continues to be worth it because those applying for these kinds of supplements must reapply to the Ministry on an annual basis to ensure they remain eligible for them, as Evelyn discovered.

I also wonder what Galya might be giving up, or expending more energy to do because of the expense of purchasing the non-subsidized supplements (beyond niacin and folic acid) her chosen alternative to Prozac®, a medication which is completely subsidized. I suspect there are some very real effects on her health trying to get the medications she needs, which prompts the question:

How would you say living on disability benefits affects your health?

G: Well Sally I tell you that when I was approved the first time I was relieved. With the changes that are happening right now I'm alarmed, very alarmed.

And which changes are those?

G: I'm talking about privatization of health care, talking about political changes and I'm talking like when I got this \$700 instead of \$500 and been

looked a little bit less as a bum it was kind of encouraging. But then now I don't feel—I am very discouraged.

And you're discouraged about?

G: I tell you very discouraged. On one hand—when I had my bronchitis—by the way that is the outcome of depression as well. It is very, very clearly psychosomatic. I had difficulties with my daughter and I just got so sick. I went to see the doctor—my doctor was away but I took one antibiotic and it didn't really help. So I had to take another antibiotic and the doctor—he is a very good doctor—I know him, he lives close by my house and I couldn't get to my doctor who was back, but it was so far away and I don't have transportation. So he said to me “I would go with this antibiotic. Otherwise you would just poison your system and I don't think it would help.” So I went to pick up the antibiotic and it's not covered no more. It's a very new antibiotic. It's very potent towards specific bacterial condition and it's not covered. It's \$78 and I went back to the doctor, and he said to me, “Well I don't know. I can prescribe some other one that is covered. But I would go with this one because this one is the only one that I think will help.” So I— from \$300 that I have to live on after I pay the rent and the utility I had to buy that. So I bought it.

Galya is astutely aware of the marginalizing social effects of living on welfare versus disability benefits and how she felt better emotionally when her disability status was approved and she began receiving the increased benefit (\$786, at the time). But she is also aware of how political decisions affect her outlook, her mental and physical health. As an example Galya describes the kind of dilemma she faces due to the delisting of a potent antibiotic needed to relieve bronchitis; either reduce her income by almost a third and either do without things she needs to live on (or work harder to get them through donation) or do without the antibiotic (or take a subsidized one) and run the risk of

continuing to be ill with bronchitis, and perhaps even getting worse. This is not unlike the dilemma she faces with respect to either taking the Prozac® or treating her depression nutritionally. For Galya, getting the most appropriate treatment is infinitely more expensive than she can afford but she is willing to make substantial sacrifices in order to have it. What might she be going without or doing more of to do so? Fresh food, extra trips (despite compromised energy) to the food bank and other charitable organizations, intensified efforts to find cheaper products and household goods—toilet paper, cleaning products, toothpaste, shampoo.

So did it help?

G: It helped. Immediately it helped quite a bit. The symptoms felt better. But it didn't—antibiotic you know is an intervention, an acute intervention mechanism. But then I need to have my—by the way, niacin and folic acid I have covered, but the rest I have to pay from my own pocket. And there is none as it stands now supplements—I talked to my doctor. The supplements are not available to people unless they have cancer or life-threatening disease, like AIDS.

Galya knows (after all she was educated as a nurse) that prevention is as important as what might be needed in an acute episode, and perhaps even more so. She believes the supplements she takes help prevent the reoccurrence of immobilizing depression and asks her doctor if these can also be subsidized, but is told by her doctor that it is not possible unless she is in a special category of people who, unlike herself, are eligible for subsidized nutritional supplements (vitamins and minerals), because they have life-threatening illnesses¹⁹.

¹⁹ Please see Appendix A, Note 3, p. 364 for a description of the regulation regarding the eligibility criteria for the Life-Threatening Health Need supplement.

This category is included in the Regulations. What this regulation/policy allows is access to a long list of health supplements including both dietary and nutritional supplements (these are two different categories), overriding the Regulation that states a person cannot receive both a nutritional and dietary supplement. Separate from “nutritional supplements” the Ministry provides various “dietary supplements” (or subsidies) ranging from \$10 monthly for a restricted sodium diet to \$50 for those living with cystic fibrosis. Officially, according to the Regulations, people receiving the former are restricted from receiving the latter.

Interestingly, despite the Regulation against receiving both supplements and the fact that Galya is not technically in the life-threatening illness category, Galya’s doctor seems to have made a convincing case with the Ministry to allow her to receive both kinds of supplements indicating some flexibility in terms of decision making at the Ministry level. Along with the nutritional supplements (niacin and folic acid) she receives the dietary supplement (\$20) for a low sodium diet needed to help control her high blood pressure. But she does not receive the nutritional supplement she desires for the high doses of Vitamin C, Vitamin E, salmon oil, primrose oil and wild yam cream she is prescribed by Dr. Hoffer.

Were you going to apply for supplementary benefits?

G: I applied. They told me that it doesn’t exist. I get my diet—\$20.

You get \$20 for diet?

G: For diet—high blood pressure low sodium diet. So it is \$20. My doctor advised me several things and I went there and talked to the worker recently. This is the only one of very few workers who is empathic and intelligent. And even she is guarded because it seems like they are encouraged not to disclose anything at all.

Meaning about what’s available?

G: Exactly. About what's available. But I asked her if I have had everything already that is available and she told me that yes. So how does it affect my health? It's scary. I think I have anxiety that it will be less and less and less available things. I have anger Sally that, for example, I love theatre, I love music. I'm not able to go to even to the museum. The gap between someone who has money and someone who is on disability benefits—yes, it's enough not to die out of hunger *if* we have subsidized housing. If I didn't have subsidized housing I probably would have less than \$200 for everything, like a hundred something. So using food banks one can just survive. I don't remember even how many years ago I bought any clothes. All my clothes are from the donation or St. Vincent de Paul. Of course because I'm depressed it doesn't really bother me, but sometimes it does. Because as I said when I go to the bank, and if it is not my bank where people know me and they feel like I'm a neighbour, if it's a different bank, I see the difference in treatment. I feel anxiety so I'm sure that it is unsettling emotionally and mentally.

Living in poverty with limited access (and the threat of further restriction) to those products and social activities that support her mental health and exposure to discrimination, Galya experiences anxiety and anger, and feelings of worthlessness, emotions that undermine her health and compromise her quality of life. Repeatedly in the interviews she expresses her desire to escape the circumstances of her life and the fears and hopelessness these generate. Growing up in a Communist country Galya would have had the experience of being treated similar to others (barring any transgressions) and given the extreme disadvantage and privation she currently experiences compared to others, the impulse to be positioned similar to others is likely compelling for her.

G: And I'm afraid. And that's why I would like to go to a convent. [here she refers to a Buddhist convent]. At least to be with people who are like me and who—who knows? I am looking there for like-minded people and a likeness

of the situation. So just being where there is nowhere I am not the worst, or the most sick or the less privileged or I am just like everybody else. I just don't see any life behind the tunnel. It's like the saying the light at the end of the tunnel is turned off permanently. So uh—another thing—I'm torn. On one hand I would like to get better. On another I'm afraid if I get better I will lose it. [her disability benefit] And this is very terrible. (crying)

Galya's desire for good health and well-being is thwarted by (her reading of) policy. Even an improvement in health is paradoxically life-threatening to Galya because for her getting better signals the potential loss of benefits, which she cannot imagine doing without. Here, she reveals her mistrust of government and her understanding of policy as punitive. She is unable to fulfill her desire for a future that is different from her current circumstances.

So you're caught.

G: Yes. And if I want to get back to school for a semester, I have to get the funding from somewhere else—the person is not allowed to be on disability benefits and go to school. So. It's hard.

Galya believes that the Ministry will not fund a return to school by providing tuition and books despite the fact she has only a thesis to write to complete her graduate degree. However she suggests that if she were to receive funding from another source she would consider returning regardless of her understanding that going to school (actually university) is not allowed while receiving disability benefits. A monthly initiative supplement (\$50) is available for a six-month period, with a possible six-month extension approved by the Ministry²⁰. At the time of the interviews neither Galya nor I are aware of

²⁰ Please see Appendix A, Note 4, pp. 364-365 for a description of the related Training Initiative Supplement and criteria for eligibility.

this supplement, nor does Galya tell me whether she has been approached by the Ministry requiring her to develop an employment plan. Presumably the training supplement is available to those participating in an approved (and/or mandated, more commonly) employment plan. I ask her if it is possible to put together an employment plan that includes completing her degree while receiving benefits.

G: Well uh I will see. If the school becomes a priority I will see. But when I was last semester at school I was—I couldn't get student loan. One terrible thing Sally, that when I started school, I didn't know that with my uh notes—how you call notes? [she means grades]—I could have asked for scholarships. I didn't know about scholarships, nothing. So I went into debt, and so when I didn't get my student loan for the last semester I went to social services and they gave me loan, which I'm still paying now.

How much do you pay?

G: \$10 a month. But it will be still for like 15 years or something. So yes there is this sense of being caught between getting well and losing the benefits. This is the very main thing, Sally, this desire to get better and fear to lose it if I get better. Although I meditate every day on enhancing my health. I do meditation—chi gong meditation conserving my health and working with my mind. I work with a lesson in the Course in Miracles. In the morning. But there is part of my psyche that is caught in that old —“Don't. Stay where you are. Otherwise you will be on the street, under the bridge.”

Galya engages in spiritual (self-care) practices that reflect a strong desire to improve physically and mentally in the face of strong doubts about the possible consequences—losing her benefit, becoming a street person, living under the bridge where local homeless people congregate. In comparison maintaining her current health status (but not getting better) and continuing to receive benefits and to be subject to the constraints of policy

seem a less risky option than increasing her efforts to get better and losing her benefits—a kind of Faustian bargain. It is also entirely possible that she will never be able to regain her health for a variety of reasons, including the chronicity of her medical conditions, along with the constraints and difficulty she faces just surviving. But regaining her health is Galya's aspiration as is retaining her eligibility for benefits (or being able, however restricted, to support herself). She is caught between competing aspirations whose outcomes are structured in part by the poverty with which she lives, the everyday struggle of caring for self with limited (access to) resources, how she takes up disability benefits policy and how programs are administered by the Ministry. Although Galya attributes her inertia/dependency to vestiges of her psychological constitution she also subscribes to a reading of disability benefit policy that tells her that if she were to regain her health she will lose her benefit (and become homeless).

And this is your fear?

G: That is my greatest fear. Because I know that—I'm not a good liar and I know it's just uh—that is my greatest fear. I couldn't lie at all. [about getting better] And I think—I said to my doctor last week “I am depressed”—I don't think I am depressed right now—before it was not true but I said, “right now I don't think I am in a rut because I am depressed. I am depressed because I am in a rut.” I think maybe I'm just not on the right place. I think—I felt depressed, depression came over me because what I was doing was not my life lesson and who knows? I don't know. It sure has been difficult. It sure has been not very manageable. But now I don't have much. I used to have a very strong will. I don't think I do have it. Again, like the commitment [to her education] and the will are not something that I have anymore.

Galya implies that the continuation of her benefits is dependent in part on her truthfulness in an implied battle between herself as an individual and the Ministry. The fact that her

doctor plays a central role in ensuring she has the benefits she needs is not mentioned. Galya seeks spiritual and/or existential reasons for the onset of depression but these are not satisfying or sufficiently explanatory for her. More importantly, Galya's fears demoralize her as does living with relentless difficulty; these efface her will, her spirit, conditions directly counter to becoming better.

Limiting changes, juggling limits

I suggest to Marion that she must have seen a lot of changes given that she has been receiving benefits for almost 20 years. She speaks about the most recent changes to access to allied health services and medications instituted by the Liberal government newly-elected in 2001.

M: I've seen a lot of changes in the benefits and also in the offices and the staff. The biggest change with the benefits, which is really, really hard on people like myself and other people with disabilities are the changes to the medical. Because for a long time there they would cover so many of each, and extra appointments [with physio and massage, for example]. And now with the changes where they only cover—I think it's ten—but of one [modality].

Meaning the massage or whatever.

M: Yah or naturopath, or chiropractic, or physio. It really—podiatry—it limits unbelievably people's choices to get medical help. And even the cutbacks to medication now—like for example I take Entrophen® but I can't take the generic kind of Entrophen®. If I could take the generic they would cover it. If I can't take the generic, which I can't, I have to every six months, regardless of the fact that I've been on this pill for like 18 bloody years, I

have to go through my specialist, get a special form filled out—a special authorization form—to get them to approve the Entrophen®, which I have been on since I was seven years old—to get them to approve it every year. Because they don't really like to do that because they like you to take the cheapie brands. That's been the most hurtful is those—and also changes in cutting out pills specifically. Like some pills are just totally not covered at all.

Are you affected by that?

M: I haven't been so much, but there's the grey area in the sense that some of the ones that before weren't covered in terms of my medical—they would still sometimes give you like a cheque to cover certain over-the-counter things like stool softeners, or certain vitamins that I would take, or creams and things like that. I would sometimes get that in the past. Now, forget it. You wouldn't get any extra coverage as far as that goes.

Marion understands the changes to subsidized allied health services such as physiotherapy and massage as meaning she can only have ten visits a year of one modality, rather than several of each as before. This is actually not the case. For those receiving income assistance of any kind or from a First Nation ten visits are fully subsidized and not limited to one modality but are now limited in terms of how many visits are fully subsidized in a year (ten). Previously as Marion indicates, British Columbians on income assistance or from a First Nation could see any allied health professionals (chiropractor, massage therapist, naturopath, physiotherapist, and podiatrist) up to twelve (12) visits *each* yearly, and pay a nominal fee. Later (below) when she speaks of the specific impact of these changes on her health and ability to participate in paid employment she seems to understand the changes correctly, that is she is now limited to ten (10) subsidized visits total yearly and can choose from a variety of practitioners as needed.

Marion also directly experiences changes in B.C. Pharmacare policy that de-listed many common proprietary (brand name) medications replacing them with their generic counterparts. This change does not result in the desired effect for Marion or government for that matter, that is, a simple matter of Marion being prescribed the generic drug, which she then would take regularly. It requires considerable effort on her part and cost in terms of time and energy to see her specialist yearly to ensure she is able to have her regular anti-inflammatory medication subsidized. In this case the government incurs the unexpected cost of paying the medical specialist and civil servants to complete and process the special authorization form. Marion also points to some previous flexibility in terms of the Ministry reimbursing her for over-the-counter products she might use, which means she now has to pay for these from her very limited income.

Marion tells me that she works part-time with a non-profit society as a trained advocate. I ask if she feels any pressure from government especially given that the Liberal government increased the earnings exemption to \$400 monthly.²¹

²¹ The earnings exemption in B.C. has had a chequered past (pardon the pun). Earnings exemptions allow people with disabilities to earn a monthly amount from paid employment while retaining their disability assistance. The government claws back from the monthly assistance benefit any employment earnings over and above the allowed exemption. According to the Ministry, “[t]hese exempted earnings can help defer some work expenses as individuals move toward greater self-reliance and independence through employment” (British Columbia, 2002c, p. 3). The flat-rate earnings exemption of \$100 monthly (for single people receiving disability benefits) was available under B.C.’s former GAIN (Guaranteed Available Income for Need) program until 1996, when the NDP government at the time made reforms to B.C. Benefits (as income assistance was called 1996-2001) “to refocus resources on skills training programs under Youth Works and Welfare to Work” (British Columbia, 1999, p. 1). The reforms included (ironically considering its purpose) rescinding the earnings exemption. The NDP government restored the \$100 earnings exemption in late 1999 citing it as “providing an incentive for people to seek and keep part-time employment” (British Columbia, 1999, p. 1). Flat-rate earnings exemptions have since been found to be a disincentive to work (Feres, 2007). Nonetheless, the Liberal government increased the earnings exemptions for single people receiving income assistance as follows: in 2001 to \$200, in 2002 to \$300, in 2003 to \$400, in 2006 to \$500, and in 2012 to \$800.

M: I'm still leery right now about making the extra income per month, because I would like to make more. But I know for a fact that if you make \$400 a month, which I could frankly use for paying for these medical things that they're not paying for now—you know like physio and massage and podiatry and everything else. The reality of it is that if you start making that money every month—and I think they are going to lean on you hard to be doing that more often, getting off the GAIN. And there's no way I could do that and live you know with my expenses. I mean I don't even know how you would pay rent. I could not live in my own place if I was not living here in subsidized housing because the rent alone, never mind groceries would be what?—it would be more than my GAIN cheque a month. I'm making \$790 or \$760 something like that—\$700 and change.²² Well you try finding a place to rent for that kind of money. And that's not groceries. Or gas payments or car insurance. So there is just no way.

So with the extra money you do make you're predominantly buying medication and other certain medical services?

M: Yup. Exactly. Almost exclusively.

And would you say that in order to work you need more of that? Or is it more or less the same?

M: Well I have to have it to complement doing the work.

What kind of work is it?

M: I do uh it's working part-time for a non-profit—one of the nice things is the nature of my job is very flexible. I do so many hours a month and I do a lot of PR. I do speeches. I do phone work. I do computer work. But I can change the nature of what I do on that day depending on how I feel. But the

²² Marion's monthly Support Allowance at the time of the interviews was 461.42, plus a monthly "Shelter Maximum" of \$325, totalling \$786. Currently the Support Rate is 531.42 plus a Shelter Maximum of \$375, totalling 906.42 monthly. Along with the increase of the earnings exemption to \$500, the monthly disability assistance rate was increased in 2006 by \$70 monthly (to \$856 in total), prompting the Ministry to make the claim that this was "the highest rate increase in B.C.'s history, providing the third highest rate of assistance available in Canada for persons with disabilities" (British Columbia, 2006, p. 1).

flip side of that is that pain is part of my life. So if I didn't have the physio and I didn't have the massage, there would be a lot less computer work I could do. There would be a lot less going out-and-about making contacts that I could do because without physio I just wouldn't be able to move. So I've got to have it. One facilitates the other.

Most people with disabilities want to engage in some kind of paid employment. Marion is no exception. She has post-secondary education and is putting it to good use through the part-time work she does with various province-wide non-profit organizations serving disabled people. Marion has found the kind of work that enables her to participate in paid employment in ways that do not compromise her health (or ability to work). Yet she wants to work more in part so she can increase her income enough to pay for the health services and products she needs to participate in employment, now no longer subsidized by the B.C. government.

Despite her desire (and ability) to work more and regardless of the advantages it would provide her, Marion limits herself with respect to paid employment using the earnings exemption as a kind of bellwether indicating what limits she has to set on her earnings. She believes that if she were to earn the monthly maximum allowable earnings exemption (\$400) this would send a signal to the Ministry triggering a campaign to 'encourage' her to keep earning that amount in a more consistent way. Marion fears what would be for her a logical outcome of this kind of campaign—having her benefits disallowed—forcing her to rely solely on earned income to live, with the resulting domino effect in terms of her ability to live independently and to participate in paid employment. Given that a portion of the income she earns is necessarily spent on the health-related items she needs to participate in employment Marion would need to earn

substantially more just to cover the products and services that enable her to work, never mind her basic living expenses. Relying solely on earned income is a challenging, even daunting proposition for someone like Marion living with an unpredictable chronic condition especially if a portion of that income would necessarily be used to purchase products needed to support work.

You need the physio and massage in order to do the work.

M: Yah, yah. It's really important. And quite honestly, I'm still not going as much as I could be to these medical appointments because the cost impact of that. You know when you only have so much money to go around, I tend to do more physio because it is all over my body, and a few times massage, than do it the other way around because of its significance for functioning.

Although the massage is definitely good for pain relief. And it helps me sleep. So it's kind of a—but it's a big thing. But the flip side of that is that you risk if you are bringing in the money all the time. Then they look at you and say, "Can't you go out and make more? Why do you need the GAIN?"

Marion has always got one eye on her limited income and thus sets limits in terms of what health care services she uses and what kind. She knows her body well and what benefits she receives from each modality and chooses accordingly. Although the treatments enable her to work she does not trust the Ministry to allow her to earn the maximum exemption without repercussions. Marion is vigilant about how much she allows herself to earn, believing this will prevent the Ministry from pushing her towards working more or disallowing her benefits. Her fears are not imagined; her contacts at the province's most prominent disability advocacy group urge caution with respect to the earnings exemptions.

Can I just ask how much extra you're actually making?

M: I make \$200 extra a month. And potentially I'd like to make more. Like I would like to go out and sort of find the same kind of thing with another non-profit. But the tough part is—the Coalition (British Columbia Coalition of People with Disabilities) is already saying to people “Be careful” because they [the Ministry] are already leaning on people who have done this. But as an advocate I told people candidly that I wouldn't be going out and making \$400 a month. Because I could then see them turning around and saying “Well if you can make \$400, then you can make \$600 or \$800 and why do you need to be on DB2 [the permanent category of disability assistance 1996-2002, formerly GAIN] anymore?” And I could see that really happening. So I've told people to be very, very cautious about that. And people who have also got full-time work they [the Ministry] have said to them, “Oh you'll keep your medical benefits” and once they go off GAIN, they're actually trying to renege on the medical benefits.²³

So if you get full-time work and you're disabled they're saying that you can still keep your medical benefits?

M: You're supposed to be able to.

But the government is trying to claw those back.

M: That's right, they're renegeing on that. And that's a huge issue for people who might have liked to have tried that [working] and need the security.

Quite honestly \$200 extra a month, meaning \$400 total would give me a lot

²³ Here Marion refers to the continuation of medical benefits for persons with disabilities (PWDs) when engaging in paid employment such that they are no longer eligible for disability benefits. The intention of this policy is that it “assures persons with disabilities that their efforts will be supported regardless of their ability to become independent through employment” (British Columbia, 2002c, p. 3). From the Ministry website: “Continued Medical Benefits. While receiving disability assistance, persons with disabilities are eligible for basic and enhanced medical benefits, including medical, dental, optical and other medical equipment and supplies. When a person with a disability leaves BC Employment and Assistance for a job, he or she continues to be eligible for enhanced health benefits” (British Columbia, 2002c, p. 3). Interestingly the Ministry in the quote below uses the phrase “leaves BC Employment and Assistance for a job” signalling that beneficiaries belong/to (or are at least subjects of) the Ministry, not their clients/consumers.

more freedom in terms of medical stuff, but if it's going to cost me in terms of just having the income I need to live here, I can't do that.

Marion's mistrust of government is palpable. In her mind, pressure from the Ministry to force those earning the full exemption to earn more and/or be off benefits is real and she acts on this understanding in her own life but also in her role as an advocate, cautioning others to be careful about earnings from employment. Marion deeply senses how precarious her situation is and responds accordingly; her hard-won independence is not worth jeopardizing. So she limits herself, a difficult choice considering her desire to work more.

Marion's positioning as an advocate means she hears about how intended policies are not working the way they were intended in this case the continuation of enhanced medical benefits. This serves to deepen her mistrust and suspicion of government to actually follow through on what they promise to disabled persons and potentially undermines any plans she might have in the future for increasing her engagement in employment. Marion absolutely needs her medical benefits in order to work and to remain independent and if these are not guaranteed upon a return to work it is unlikely she will consider doing so. Her life is a fine-tuned balancing act.

M: So I really juggle a lot.

'Juggle' meaning?

M: I choose to do what I can do the most in a given month. Budgeting is a huge skill. I mean right now I'm inclined to go to more physio because it does all over the body. Less massage—I mean sometimes when I'm feeling better, maybe in the summertime I might go to less physio and more massage—

The massage being more expensive, or...?

M: Um I have a good relationship with my physio, so I get it for \$32 each time, which is pretty reasonable considering what they could charge. And he usually gives me extra time so I don't, you know—it's about \$35 for a massage, just slightly more. But the problem is, is that I am not getting the stretching, and I'm not getting the exercises that I can't do on my own—at massage. And typically you get about two areas at massage. They don't usually want to treat more than that. Just 'cause that's their protocol. Well that's great for me but how do you choose one day what hurts more than the other spot? Do you know what I mean?

Yah right!

M: So it's challenging. And usually the more affordable one for me would be to go for half an hour, but because I am so tight by the time the half an hour comes we're just starting to get to pain relief. So I need that hour, which means that I am paying—what is it? It's a little bit cheaper for the hour—I think it is \$65 for an hour. That's still—when you're only making \$200 extra a month, where are you taking that out of? I tend to be really good with my grocery shopping. I take a lot of sales and I'm thrifty and try not to buy things unless I really need them. But it's got to come from somewhere.

The thirty-two dollars Marion pays for physio (\$35 for massage) reflects the rate at the time for the part of the treatment extending beyond the basic twenty minutes subsidized by the Medical Services Plan (MSP). People requesting more than twenty minutes paid the difference between what the MSP paid (it depended on the number of areas being treated as prescribed by a doctor) and the therapist's rate. Marion refers to the number of areas being treated as part of massage therapists' protocol but the protocol (and fees) are set by MSP and anything above the basic amount she has to pay for. [currently I pay \$95/hr for massage].

Beyond the careful attention to income and expenses, what Marion has to juggle is getting the treatment she needs (and can afford) on any given day in response to unpredictable fluctuations in pain and stiffness. Marion budgets for medical expenses but also budgets what can be done during any given treatment. She knows well the benefits of passive movement in physio to stretch stiff joints but also values and needs the benefits of massage for pain relief in terms of reducing exhaustion. But the limit she has set on earnings makes it very difficult for her to have both physio and massage without having to short change herself in terms of other needs.

So a lot of what you're talking about is how you have a certain budget for medical expenses in a month.

M: Yah, yah.

And you're trying to keep within—and make decisions within that amount?

M: Yah. Exactly.

Palimpsest: From the ground up (v. 4)

Politics is also down there, in the strategic field of small things. (Cruikshank, 1999, p. 124)

A rich phenomenon with inherent ambiguities calls for a characterization that preserves those shady edges, rather than being drowned in the pretense that there is a formulaic and sharp delineation waiting to be unearthed that will exactly separate out all the sheep from the goats. (Sen, 2005, p. xiv)

Much of the writing in this chapter pre-dates everything written thus far in the dissertation, appearing first in my research journal and then, over time, as several documents different in content and structure from what I bring forward here. This chapter's substantive writing (not the form) emerged during a lengthy, in-depth phase of dwelling with the interview data; reading, re-reading, writing and rewriting from the ground of each woman's life centered around the question, "How do each of these women organize/live their lives in response to the interpretations they make about what they believe is possible, particularly in relation to those governing structures to which they are subject, and with what effects?" This process enabled me to: a) generate critical reflections on disciplinary processes at work in the participants' lives; b) identify particular qualities manifested in their lives as *effects* produced through these exercises of power and what ought to be said about the patterns I saw, and; c) articulate the dynamics they reflected. Ultimately, this text in its various forms reflexively in/formed how I structured the participant narratives you have just read, which were in part designed to *show* these qualities and dynamics and power relations at work. You are reading the latest (and last?) version of From the Ground Up, including its form, which came to life in layers each revealing something of what came before—a palimpsest.

As I dwelled with the raw interview data and engaged in a reflexive, generative writing process, I circled around a number of related questions posed as I sought to make sense of their lives (and the dynamics at play):

What do these women know/believe about Ministry policy, and the regulations? How do these interpretations organize/guide their actions? What is each woman telling me about the Ministry and what she thinks of it—how she reads the Ministry—and what it will and won't allow, and what she thinks she can and cannot do in any given situation? And how does that govern her actions? And (importantly) to what effect(s)? Similarly, how does each woman's reading of her bodily experience and/or mental state govern her actions? And how do these bodily readings (and actions) intersect/collide with those she makes of Ministry policy? Again, to what effect(s)?

What began to be revealed were certain dynamics at work in the women's everyday lives as I understood them critically. I knew from my own experience that there is rarely a direct, straightforward relationship between government income support policy (and programs) and the actions of those whose lives are governed by these policies. Indeed, citizens are encouraged to be active in ways that governments can engage our "self-activating capacities as individuals" (Rose, 1996, p. 165) thus shaping our social commitments to self and others, in this way governing "at a distance" (p. 165) (See also Li, 2007). Yet this "new regime of the self" (p. 165) potentially excludes women such as the study participants, who live marginally (and are economically, socially and politically marginalized) and to some extent are "controlled by older, harsher [and more direct] ways" (p. 166) of disciplining citizens. In spite of this the women in the study participate as actively as they can in their own unique versions of the "free exercise of personal choice" (p. 165), engendering a life of "responsible selfhood" (p. 168) while living with

and responding to the effects produced by governing at a distance. Posed again and again, the questions enabled me to both see and say what is at work in the interactions between the Ministry (and related government institutions) and the women, and what these produce, including unintended consequences.

In this chapter I describe dynamics emerging from critical understandings of what is at stake in the participants' lives including the strategic practices of compliance and resistance, followed by a description of some of the effects constituting the qualities of the participants' everyday lives that are most persistent and troubling. By engaging in the kind of critical analysis presented here my intention is to bring to light and clarify some of the ways the B.C. disability benefit program 'works' in the everyday lives of disabled women. I do this in part "by presenting 'inconvenient facts' reflecting the disjunction between how such programs represent themselves and their objectives and strategic effects" (Dean, 2010, p. 87). Indeed, by contesting or even attempting to reconfigure how we think about governance, "we call into question the very fabric of our forms of life" (p. 80), and if these women's lives are any indication this fabric is at best hanging by threads.

As part of the fabric of the participants' lives various patterns become established in response to their persistent readings of how government operates, revealed in the narrative accounts. These are not imaginary perceptions; these readings make sense to the women given their inclinations, experiences, aspirations, desires, all aspects constitutive of their subjectivities. Their readings are idiosyncratic and particular to each woman and, importantly, may not consistently position them well. Paradoxically, the patterns may be different but the narratives reveal commonalities in their lives. This is not a nod to

humanism in an otherwise poststructural work; each woman's life is unique to her and the participants are very different from each other in so many ways. Yet similar effects are produced in lives structured by disability income support policy in ways that tie them together despite being isolated from each other. In this way exercises of power work through them uniquely while producing a kind of common ground that serves as a possible field from which they choose to act (or not).

Differing patterns and their underlying similarities constitute the constantly-moving dynamics revealed in my reading of the texts generated by the interviews, exposing the myriad ways policy is lived in the everyday. The women are perpetually being organized and/or organizing themselves but they never get completely 'organized' due to the messiness and unpredictability of their everyday lives, raising important questions about how commonality is produced despite the evident uniqueness of each woman and the particularity of their lives. There appears to be no endpoint in/to all this organizing, although it produces effects; these are my concern.

What Ministry policy and regulations prescribe and what the women do in response is not seamless; between these there is a gap, a chasm of possibilities. Inhabiting this space (and time) are the women's readings, which mediate between policy and their actions.

Multiple factors are at play in these readings; Ministry policy and regulations, possible actions and consequences, and the women's own subjectivity, desires and aspirations, including their embodied experiences and mental states. Here we see how "power works through, and not against, subjectivity" (Rose, 1996, p. 151). Indeed, contemporary practices of government "have come to rely upon the agency of the governed themselves" (Dean, 2010, p. 82). Again, Foucault's (1982) idea that "to govern is to structure the

possible field of action of others” (p. 790) comes into play here, especially as we consider how the women as subjects “capable of action” (p. 789) or agency are being acted upon by policies that structure how they *themselves* act upon their own readings/understandings of possible actions to be taken.

What I am referring to here and what the narrative accounts preceding this chapter reveal is how *bio-power* is exercised in these women’s lives producing particular kinds of selves/subjectivities. Bio-power signifies a constructive approach for managing populations by concentrating power on life and in particular on individual bodies, making them docile (or more to the point, useful) in such ways that they can be “subjected, used, transformed, and improved” (Foucault, 1991, p. 136). Denise Gastaldo (1997) reminds us that bio-power is “not a set of mechanisms that guarantee control of citizens by the state” but rather “a subtle, constant and ubiquitous power over life” linking “individual bodies to the social body” (p. 115) and ideally as individuals participating in and constituting a (healthy) society.

Drawing from both traditional and alternative knowledge bases and each woman’s own attitudes, beliefs and capacities each of the participants has acquired an ability, or “*habitus*” (Burkitt, 2002, p. 225) to discern and enact the best ways to care diligently for herself, her body, and her life in ways that make sense given the exercise of biopower to which they are subject as these intersect with individual hopes, aspirations and capacities. Each woman chooses “particular forms of practical actions...appropriate to the situation” (p. 225) she finds herself in and applies them as best she can, assuming responsibility for her well-being. In these ways each woman becomes “the doctor of oneself” (Foucault, 1997, p. 235) enacting “a discourse of ability and health” (Anderson, 2005, p. 255) that

currently governs disabled people's lives (and arguably able-bodied people) in contemporary society. What this belies is how compromised, under-resourced and ill-equipped these disabled women are to be the wholly "autonomous, independent, and self-reliant" (Nettleton, 1997, p. 212) subjects required for the 'healthy' functioning of an advanced liberal democracy such as exists in the province of B.C.

Who is this "self" being shaped through government exercises of power? Nikolas Rose (1996) tells us

The self is to be a subjective being, it is to aspire to autonomy, it is to strive for personal fulfillment...it is to interpret its reality and destiny as a matter of individual responsibility, it is to find meaning in existence by shaping its life through acts of choice. (p. 151)

Using a variety of "technologies of the self" (Foucault, 1997, p. 225) primarily through their own means (in highly straitened economic circumstances), sometimes with the help of others (particularly in Marion's situation of receiving help with personal care of her body and activities of daily living), each performs "a certain number of operations on their bodies, and souls, thoughts, conduct and ways of being" (p. 225). Each strives toward her own embodied version of well-being seeking to meet everyday needs and desires, again constituting a terrain upon which it is possible for her to act.

It is also a territory in which governments act/intervene and exercise "a form of power that produces and relies upon [the active participation] of subjects rather than absolute subjugation"—again, biopower—which "operates to invest citizens with a set of goals and self-understandings [giving them] an investment in participating voluntarily in programs...and institutions set up to 'help' " (Cruikshank, 1999, p. 41). Experts (and

their knowledge and tactics) and agencies, including physicians, therapists, community-based volunteer social services and Ministry workers constitute “the ensemble” Foucault (1992) refers to that enables “the exercise of this very specific albeit complex form of power” (p. 102), both *voluntary and coercive*, in the lives of the disabled women who participated in this study, acting on their actions “rather than procuring their apathy” (Cruikshank, 1999, p. 38).

Cruikshank (1999) reminds us that women receiving state-administered income support “are not excluded or controlled” by [exercises of] power so much as constituted and put into action by power (p. 41). Each of the participants participates in her (own) governance by subscribing to, taking up and strategically acting upon her own unique interpretations/readings of policy and what they understand/believe to be possible/allowed or not, given the policy and given their fluctuating health status. These strategic moves/actions produce a variety of effects in their everyday lives. In this sense government does not govern as directly as it might appear; it does so indirectly with the participation, willing/aware or otherwise of individuals. What government expects of its subjects may align with their desires and aspirations but it may also not, and this too produces effects.

No good subjects of resistance

The personal narrative that opens the dissertation reveals how I had made a strategic decision regarding how to proceed with respect to my desire to begin the doctorate, given my reading of the negative response of the vocational rehabilitation consultant hired by the insurance company. My decision also included a reading of my body/mind and how

immobilized I felt emotionally and experienced physically due to an inflamed weight-bearing joint.

Given that insurance company policy was often opaque, I never knew if my reading would achieve my goals; these too/two being constituted by the exercise of biopower in which I was participating. I had become used to second-guessing before acting and then waiting (in fear of retribution) to see if I had guessed right, never really knowing what exactly might constitute a correct guess even when the outcome favoured me. This kind of uncertainty made it more difficult for me to know/read the actual policy about returning to school to complete my education; I knew that to some extent decisions in this regard would be mediated by my vocational rehab consultant and I had no idea what kind of influence I might have with her, or she with the insurance company. In a nod to compliance, I told my rehab consultant what I thought the insurance company might like to hear (in terms of my intentions to pursue the doctorate) but went ahead with the risky (and perhaps resistant) decision to register for full-time studies and (strategically) not actively inform the company until I was asked, taking a chance.

My own experience enabled me to see how the women in my study also both comply with and resist the rules/policy strategically. Given this and what the participants told me about their lives and strategies I subscribe to the view that “acquiescence and rebellion are not antithetical but can take place in the same breath” (Cruikshank, 1999, p. 41). The impetus to live their lives according to their own impulses, aspirations and desires intertwines and even collides with the material (poverty, impaired bodies) and socio-political constraints with which they live. Despite overwhelming evidence that the women’s everyday lives are characterized by relentlessly responding to barriers and

constraints, by complying and resisting strategically (often simultaneously) they position themselves agentially, that is, they enact whatever agency and exercise whatever power is available to them. If “agency is spoken into existence at any [given] moment” (Davies, 1991, p. 52) then by “speaking back” (as we see Marion do when the Case Manager attempts to convince her to move to assisted living), typically seen as a form of resistance, the women position themselves strategically so that they can actually get some of the things they need. If it holds that “[e]very power relationship implies... a strategy of struggle” (Foucault, 1982, p. 794) then each of these women show us how a life in which every move must be strategized is a life under siege, a life of struggle.

In response to their interpretation of what is possible (or not) often in the face of opaque policy or details omitted—and only discovered when they either stumble into clarity inadvertently, or mistakenly exceed the rules—these women make strategic decisions about what to do or not do given their readings of the possibilities, including possible consequences. A woman may have keen knowledge and accurate understandings of government policy and what is required of her and her first inclination is to comply, but for strategic reasons she may not entirely comply with the rules, in which case she is simultaneously resisting. Complying/resisting is contingent on each woman’s judgment of what is at stake in any given decision and response and is often subtle. How then are we to understand resistance (and compliance) as exercised by the participants?

Although Foucault (1990) suggests that “where there is power, there is resistance” (p. 95), Gordon (1980) questions what it is for

people to reject or refuse, or on the other hand in some manner to consent to, acquiesce in, or accept the subjection of themselves or of others...it becomes

apparent that the binary division between resistance and non-resistance is an unreal one...account must be taken of resistances whose strategy is one of evasion or defence ...there is no good subject of resistance. (p. 257).

Here Gordon signals the indivisible nature of resistance and compliance and suggests unconventional strategies as kinds of resistance. I am not entirely sure I understand correctly Gordon's last line, which I take to mean that resistance as a phenomenon takes forms that may on the surface not look like what is commonly understood to be resistance. Hence there is no typical form of resistance (or compliance for that matter)—no good subject of resistance/compliance to study—they are all unique, idiosyncratic, individual, contingent, as the women's responses to being governed demonstrate.

Sometimes the women read their situation as being much safer to follow the rules as they understand them. But in Evelyn's case, for example, the rules do not fit for her or meet her needs around housing; they prevent her from moving around freely to find appropriate lodging, without requiring time-consuming and potentially risky contact with Ministry officials. The rules require that she deal with Ministry officials, in particular filling out various forms and getting approval for the shelter allowance every time she moves. But doing so constitutes a risk to her health/well-being by having to stay in unsuitable housing longer than she can tolerate given her environmental sensitivities, and using limited energy to comply with administrative requirements. Again her well-being is compromised by constantly having to respond to the rules around housing. Evelyn (as are all beneficiaries) is required to have a fixed address and therefore cannot legitimately change her housing situation/address arbitrarily, nor can she be couch-surfing or sleeping in her car to escape an unsuitable housing situation. She also cannot move to another

region of the province (something she has done) without informing the Ministry. In some cases the women judge that the possibility of losing or compromising their health/well-being outweighs the risk of being penalized for non-compliance. And so, in order to protect their health, like Evelyn (who intermittently chooses to have unstable housing and risk punitive measures by the Ministry) they do not always comply with the rules.

Work without choice, fear and distrust, dependency

What effects are produced in these women's lives through exercises of power? And how do these affect the quality of their lives? The most persistent effects—the ones that surfaced in complicated and compelling ways in the women's everyday lives, as the narratives reveal, constellated around the “work” of being disabled, unrelenting fear of losing benefits, complicated by tangible distrust of government (imbricated with distrust by government that beneficiaries will not comply with the regulations, The Review being an extreme example), and the production of dependency. These qualities form a web emerging from complex dynamics at play in the participants' responses to exercises of power and from each woman's readings of what is possible in any given situation.

With respect to the (unpaid) work of being disabled, all four women expend an inordinate amount of time, effort and energy in securing supports or otherwise responding to government, including in Marion's case resisting the intrusion of the state with respect to her relative independence. Disability activists and scholars are deeply familiar with this dynamic of expending already-depleted energy to secure benefits and supports, which constitutes a kind of (unpaid) “work without choice” (Krogh & Johnson, 2006, p. 170). The unpaid work of living with disability is necessary to navigate social programs,

receive support from various systems, including health care and medical services, non-profit, community-based agencies, and care for self. In some instances this work requires “immediate attention without consideration of negative personal health or lifestyle consequences” (p. 170). This kind of immediacy is particularly evident as each of the women faced *The Review*, read by all as an emergent situation requiring immediate attention and also shows up in my interviews with Jocelyne who is facing an imminent Tribunal hearing to challenge a recent negative decision regarding her eligibility for full benefits.

The hard work of surviving permeates and structures their everyday lives in ways that leaves little energy left over for regeneration and recreation, yet they also demonstrate creativity, resourcefulness and generosity in going about their everyday lives and organizing them given the structural poverty and other constraints with which they live. Jocelyne creatively engages in caring for her body with limited resources in ways that align with her values and beliefs about health and well-being and expresses a strong desire to help others spiritually. Galya is resourceful in finding effective alternatives to prescribed (and fully funded) antidepressants. Marion has useful contacts in the health authority and Ministry, which she does not hesitate to enlist to support her desire to remain independent, and Evelyn creatively engages her imagination and limited resources to find organic food, alternative treatments (bartering) and environmentally safe housing. Despite these edifying activities, surviving for each of the women is like a full-time job—the unpaid and externally unrewarding work of being disabled and poor, engaged in with limited physical and social resources.

Another aspect of the work of being disabled (and receiving disability benefits) arises out of the challenges of knowing for certain what is allowed (and/or provided by government); not knowing means the women spend considerable time and energy attempting to discover this information. When they do find out what they are allowed or eligible for, like the nutritional supplement, they have to exert more effort to obtain it (complete forms, get medical approval, wait for a decision). Also they never know whether they will continue to be eligible for the supplement going forward and/or repeat the same process yearly as the Regulations require. In this case, the possibility of accessing much-needed additional supports and benefits creates uncertainty and another layer of work they can ill afford to engage in.

Time and effort required to second-guess government is also work without choice as it takes away from energy that each woman would otherwise have to contribute directly to her health/well-being. Yet, securing additional benefits like nutritional supplements, reflects a kind of agentic positioning on the women's part, with two possible effects; the women experience a sense of empowerment (if they are successful) because they actually achieve a goal and receive supports that they might not have otherwise have (and cannot independently afford), which could improve their quality of life, while enabling a minimal kind of participation in the society in which they are living. On the other hand securing supplemental benefits requires energy reserves that are seriously compromised due to fatigue accompanying the chronic conditions with which they live. In this way the effect of government policy is *disabling*, in that all the work to secure supplemental supports exacerbates the disability that government intends to remediate or compensate for.

Be afraid, be very afraid

The threat of having eligibility for benefits disallowed is a tool of coercion exercised by the B.C. government with embodied effects. All of the women who participated in the study live in constant fear of losing their disability benefits and are ever-vigilant regarding threats to their income support; they experience complex embodied reactions to the perceived threat of losing benefits. Galya, for example, clearly articulates the fear, immobilization and depression she lives with in response to this very tangible threat. Fear of losing benefits was also a key finding in research focused on women receiving CPP-D benefits (Doe & Kimpson, 1999)

The B.C. government reserves the right to change the definition of disability for official purposes at any time. With the previous Disability Benefits Program Act (1996-2001) (British Columbia, 1996) and regulations, people with disabilities could be designated as ‘permanently disabled,’ which created a kind of stability in terms of their eligibility. With a change of government in 2001 the (new) Minister of Human Resources announced plans to move the Ministry from “a culture of entitlement to a culture of employment and self-sufficiency” (Coell, 2002, no page). This cultural shift was to be accomplished by means of a “new income assistance system that supports individuals and families in achieving their social and economic potential [emphasizing] self-reliance and participation” (British Columbia, 2002a, p. 5). To enact this the government announced plans to eliminate the Disability Benefits Program Act and institute the new Employment and Assistance for Persons with Disabilities Act (along with the new Employment and Assistance Act governing those receiving welfare, or basic assistance). This moved people with disabilities back into the general welfare system by virtue of being governed

by the second part of the Act designed to govern those receiving basic welfare benefits, a move viewed as regressive by disability activists (and scholars). (See Kneebone & Grynishak, 2011).

The new Employment and Assistance for Persons with Disabilities Act (2002) (British Columbia, 2003a) rescinded the permanent disability status and most people in the disability community have been aware that this status no longer exists. At the point where the new Act was proposed the B.C. Coalition of People with Disabilities (now Disability Alliance of B.C.) argued that a permanent disability status was crucial “given the diverse nature of disability” (B.C. Coalition of People with Disabilities, 2001, p. 2) as “sporadic or cyclical, recurrent or permanent” (p. 2) and without permanent status the “fear of losing disability benefits will discourage [beneficiaries] from seeking work” (p. 2).

Disabled people receiving income support need to be assured they have some stability in terms of their benefits, which goes with a permanent status should any trial of employment be unsuccessful due to recurrence of episodic conditions, for example.

Currently disability status and eligibility for benefits are provisional producing uncertainty in the women’s lives and undermining their well-being. Here the government has done something untrustworthy that confirms the women’s judgment of it as capricious and unreliable, which is to remove the permanent disability status. With the new Act the government removed what little certainty people with permanent (or prolonged, severe) conditions had preventing them from gainful employment. Activists suggest this was designed to ‘scare’ or otherwise coerce/manipulate disabled people into the paid labour force or employment training. None of the women in the study respond by seeking work or training and demonstrate that this move by government to remove the

permanent category clearly produces unintended effects, indeed the opposite effect, which is to further deepen economic dependency.

Although there was no longer any permanent status to be removed at the time of Jocelyne's interview, she was experiencing very high levels of distress due to a decision arising from the province-wide Disability Designation Review²⁴ in 2002 to disallow her full (formerly permanent) benefits and place her in an welfare employment category, with a substantial reduction in her monthly allowance such that, after her rent was paid she was left with less than fifty dollars monthly on which to live. When I interviewed her she was desperate, highly anxious and deeply fearful that she would not be able to survive for very long and told me that she also experienced an exacerbation of her bowel condition and fibromyalgia and had a mild heart attack, which she related directly to the change in her disability category.

Women also know that their eligibility status is at risk in any given encounter with Ministry officials during which the women are vulnerable to exposure, some of it enforced/coerced. When the women are forced to expose themselves during these encounters or textual ones that require them to complete forms, they live with the uncertainty that the personal information they provide might produce unpredictable, problematic consequences either in the present, during the next encounter with officials, or sometime further into the future (or in between). They never know if/when/how that

²⁴ With the new Act governing welfare and disability, using newly-developed criteria reflective of the new definition of disability for official purposes the Liberals reviewed (or more accurately, reassessed the eligibility of) every single person in B.C. receiving provincial disability benefits in 2002, at the time approximately sixty-two thousand (62,000) British Columbians living with disability and/or disabling chronic conditions. All of the participants engaged in the review process, ultimately successfully, with Jocelyne being placed in an employment category, with significantly reduced monthly income. Over a year-long period she fought hard to be re-categorized as a Person with a Disability, eligible to receive full benefits; she was doing so at the time of the interviews.

information might be used bureaucratically in ways that disrupt their already precarious lives. In response the women have learned (some more effectively than others) to act strategically by managing as best they can their personal information, only answering questions asked and not volunteering any further information, an instance of simultaneously complying and resisting.

The women are also frightened of contact with officials because they never know if they will be listened to/heard, understood or respected. Information they believe crucial to survival or at least improving their well-being is often not forthcoming, or employs bureaucratic language difficult to understand/decipher. Also, contact is to be avoided at all costs because the women never know if Ministry officials will arbitrarily decide to disallow benefits. Here the effects are evident; this form of self-regulation, which arguably keeps them from asking for services that might be costly to government, has deeply delimiting effects, creating narrowness in their lives and compromising their well-being. The women also reveal in the narratives that their knowledge of the rules/policy by which they are governed is partial, leaving them feeling insecure, uncertain and fearful in encounters with Ministry officials and distrusting of government.

Yet distrust is a two way street. Part of the tactics or techniques of government whose purpose is the welfare of those unable to work due to disabling conditions includes surveillance of those receiving benefits, which implies fiscal responsibility, but more importantly for the participants distrust on the part of government. The women are well aware of being controlled in this way and read the government as not trusting them to follow the rules. They believe that one of the primary functions of government with respect to their benefits is to set the regulations and through different forms of

surveillance ensure the rules are followed; they experience this done in capricious, exacting and occasionally punitive ways. Evelyn and Galya are repaying the B.C. government a small (but unaffordable) sum monthly (indefinitely) for mistakes made, or in Galya's case for the student loan repaid on her behalf by the Ministry when when she became disabled.

Dependency: An unintended consequence

Pervasive fear, distrust and dependency are closely comingled and intersect in particular ways with embodiment. Both fear and mistrust have the potential to immobilize the women (emotionally and physically) and the fear of losing supports reinforces their economic dependency. Living in unreliable bodies and unstable health means they are unable to depend on their bodies for economic stability or security and thus become ever more dependent on income support.

A stated value of the B.C. government with respect to disabled people is independence, which the Minister of Housing and Social Development (the name given at the time to the ministry governing welfare programs) (Coleman, 2009) clearly articulated as

we want to ensure low income earners and people dealing with addictions, mental illnesses and disabilities have access to supports when and where they need them most so they can become independent and participate more fully in their communities. (p. 3)

According to Strelieff (2004) (the B.C. Auditor General) the goal of the new legislation introduced by the Liberal government is “to promote greater independence for people with disabilities, security of income, enhanced well being and participation in

community” (p. 1). However, exercises of power in these women’s lives produce what is clearly an unintended consequence, that is, a particularly pervasive and insidious kind of dependence, an inconvenient fact (Dean, 2010) revealing the disjunction between Ministry objectives and ideals and the women’s lives.

The provincial government defines in advance the parameters of legitimate involvement in the question of how disability is defined, accommodated and compensated for.

Enactment of regulations governing the disability benefits program seems discretionary from the women’s viewpoint when they experience what appear to be arbitrary changes to the amount and kind of supports and services they receive, which directly affect each woman’s health/ability to care for herself/potential to be independent. We see this in Marion’s case with a provincial government decision (in the interests of austerity) to markedly decrease the number of physiotherapy and massage treatments allowed and the kind of medications subsidized; likewise the delisting (from subsidy) of a potent antibiotic that could treat Galya’s bronchitis effectively.

Like many disabled people, Evelyn and Galya are leery of re-entering the paid workforce (and Marion of working/earning more than she does) for fear of losing benefits (Jocelyne is not in a position to consider paid employment despite, ironically, being moved to an employment category) even in the face of a recent (and substantial, at the time) increase in allowable employment earnings by the B.C. government. To do so would be to face a high degree of risk. The imagined neoliberal path out of poverty (workfare) becomes complicated as it intersects with disability and government’s stated intention to foster the independence of disabled people through its programs and services. Although independence is a key aspiration of many disabled people, the version espoused by the

B.C. government appears to imply economic independence (from government) given the language used in its publications. Nonetheless, by allowing some earned income while retaining benefits the B.C. government is subscribing to what some activists and scholars consider ‘disability positive’ policy.

Yet, this policy has unintended consequences/effects as Marion’s example demonstrates; her persistent distrust of government in the face of additional disability-related financial needs related to engaging in paid employment makes earning the maximum allowable earned income a risky venture for her. A good example of how compliance and resistance often co-exist, she reads the Ministry as untrustworthy and chooses to earn a minimal amount (\$200 monthly instead of the \$400 maximum, at the time) in her part-time employment in order (she believes) to reduce Ministry surveillance and possible review (and denial) of her eligibility for benefits. This is a stark example of how economic dependency is produced. Even with an employer who is willing to be flexible and accommodate her disability-related employment needs (never a guarantee for disabled people upon a return to work and certainly not mandated by governments), Marion is cautious so much so that in her volunteer position as a community disability advocate she urges caution to others she supports about “pushing the limits,” that is, earning the maximum allowable employment income. Here the government program to allow earned income to a maximum (without clawing back the disability benefit) designed to “operationalize the self-governing capacities of the governed in the pursuit of governmental objectives” (Dean, 2010, p. 83) goes awry. Marion has a desire, even an aspiration to improve her situation but her reading of risk undermines that aspiration and

any traditional economic means of improving (get a better job, more pay) she may engage in are effaced.

The dynamics of power relations at work in these women's lives are complicated and pervasive. Each of the women relies on government to provide supports and believes strongly that the provincial government *should* be looking after them (better), given it is the last resort for all of them in the face of disabling chronic illnesses that prevent paid employment. In this way they opt in to a system they believe is going to support them to establish and assist in maintaining their well-being. Upon discovering this is not the case they are then given cause to distrust that the Ministry is going to look after them in the ways it suggests it will let alone as well as it ought to (or the women believe it ought to). Economic dependence combined with distrust constitutes a double bind—the women do not just opt in, they are necessarily hooked in—and due to the capriciousness of Ministry practices as they experience and read them, cannot take anything for granted.

Constantly vigilant, they pay very close attention to what the Ministry does or allows or conversely does not do or allow; vigilance is a primary activity in their daily lives in order to ensure they strategize in the most effective ways they know how in order to ensure continuation of their benefits. Paying attention all the time means the women are attuned to where to look and find resources (and better information) otherwise not immediately evident; they know what to look (and look out) for. In many ways they are (politically) astute subjects and perhaps not as docile as the Ministry may wish in practice.

Second-guessing is also a persistent practice in/of everyday life because Ministry officials may make certain rules and responsibilities clear to beneficiaries but often

neglect to specify clearly the exemptions/exceptions to the rules, or provide no rationale for changes to rules. Nor do Ministry officials inform beneficiaries when rules are changed; these changes are often discovered by the women inadvertently. Here government exercises power capriciously producing fear, uncertainty and distrust in beneficiaries lives; these women absolutely depend on the disability benefit and related programs/supports to survive so are forced to expend energy and time discerning what the Ministry intends or allows, with embodied effects, not the least being fatigue and increased anxiety.

What might appear on the surface to be a causal relationship with respect to exacerbated symptoms and occasionally coercive bureaucratic processes is more complicated than it first appears. Peter Freund (1982) describes a “specific relationship between civilized social control, social domination and the ability of the body-mind system to efficiently and effectively manage its internal affairs” (p. 10). In particular, he specifies what he calls “ ‘civilized’ forms of control that sustain relationships of domination” (p. 21) and links these to health effects. These forms of control include “those that inhibit the presentation of self or invalidate the individual, and those that regulate time, bodily expression and social information in such a way as to render individuals powerless” (p. 21). Significantly, Freund links these forms of social control with the body’s ability to maintain health. He suggests that we can become desensitized to our body experience and the messages it sends us; these are necessary for maintaining health. It becomes “difficult for our bodies to mobilize healing resources such as the ability to relax” (p. 21) or let go. The daily challenges of responding to being governed and what that produces includes

embodied difficulties, particularly the challenge of maintaining health made visible in the preceding participant narratives.

What is pertinent with respect to the women in my study are the ways Ministry exercises power reflecting a form of social control that provides limited information to individuals (and groups), with particular effects. Freund (1982) calls them “informational troubles” (p. 118) related to “...uncertainty about information important to one’s security [that] creates physiological consequences in the individual, which may, in the long run, adversely affect the person’s health” (p. 118). Asymmetrical access to information generic to hierarchical structures such as government generates informational troubles, which as an instrument of social control extends beyond knowledge monopoly to include the use of language. Freund (1982) asserts that bureaucratic language is often strategically ambiguous, allowing “those in power the maximum flexibility, the avoidance of definite commitments, and the veiling of the coercive or unpleasant nature of certain decisions” (p. 122). What it produces is anxiety, distrust and uncertainty in these disabled women’s lives.

The participants’ experience of economic dependence reveals itself in unsettling ways. The women are consigned to poverty preventing them from purchasing the kind of goods and services more affluent citizens take for granted. From their day-to-day efforts to manage while living in poverty they know that their monthly benefit is not adequate to live on, which produces a view of government that is negative, unsupportive and untrustworthy. Their reading is stark; the government does not value us enough to provide us with sufficient income to foster our well-being. If this reading holds, it implies (and makes sense that the women would think) that the government also does not value

them enough to be more open/transparent, provide pertinent information or to ensure reliability in terms of services and supports.

Distrust of government persists despite evidence to the contrary (occasional flexible workers/officials). Ironically, the untrustworthiness of government is an operating assumption that the women believe they have to adhere to in order to survive. How so? By subscribing to this view/assumption they necessarily position themselves on the defensive, always at a minimum level, always struggling, always having to expend depleted energy just to get by every day. To do otherwise would constitute exposure to unnecessary risk. Consequently these disabled women cannot take anything for granted; second-guessing in any given situation with government is a requirement, all part of paying close attention to government tactics to ensure they do not fall through the cracks, are not punished arbitrarily or have their benefits disallowed.

A more insidious source of distrust of government (and the Ministry in particular) has to do with the women's fundamental belief that they ought to be taken care of better than they are, that government is in the business of fostering their well-being (if Ministry publications are to be believed). Each of the participants is suspicious of any claims by government that it will do what it says it will do or even the values it publicly espouses. How could they believe otherwise when they sense they are not being taken care of in the way they believe they ought to be or government cannot be relied on to do what it says it is going to do?

The distrust in this case seems critical (and precarious) because it arises within/from a situation where the women are reliant (and economically dependent) primarily on the Ministry (or the Minister, as the Regulations articulate) to look after them. Always trying

to second guess and even outwit government, the women organize their daily lives in ways designed to ensure how they are responded to is not altered by the Ministry in fear of withdrawal of supports or ineligibility for benefits. Mostly they engage in a daily balancing act in which their everyday lives are organized such that they are able to take full advantage of everything government is willing to give them or allows (that they are aware of) but are careful not to overstep their bounds/push the limits and risk being exposed and lose their supports.

These disabled women have no alternative. In this sense government has a tight grip on them, a kind of stranglehold on their lives; it provides for the women minimally in the face of no other options (these are 'last resort' benefits after all). Even in the context of palpable distrust of government actions and intentions they have to respond in the ways they do in order to survive based on their various readings of the situations they encounter. In this sense they are enlisted in the stranglehold and cannot see ways to break free of it without losing their health, well-being, their lives. Again this is not entirely a one-way exercise of power by government. What the women believe (about government as unreliable, untrustworthy and uncaring) and how they respond to that belief/understanding/reading is also constitutive of this stranglehold over their lives.

Uncertain subjects

Terms such as empowerment, agency, activity and resistance, as much as dependency, passivity and subordination, are key aspects of our contemporary vocabulary of rule and are constituted in relation to definite regimes of government and power relations. In order to work, governing often concerns the formation of the subjectivities through which it can work [or be seen to be working]. (Dean, 2010, p. 87)

The persistence and pervasiveness of uncertainty in these women's lives is revealed in the narratives that precede this chapter (and in a heightened way in participant narratives comprising the forthcoming section focused on the province-wide Disability Designation Review in 2002/3). Uncertainty is at work constantly in their lives, is multi-faceted, embodied and constituted as a particularly unsettling aspect of their subjectivity. Living with chronic illness means their day-to-day fluctuating embodied impairments make it impossible to know from one day to the next what their bodies will enable them to do, thus producing profound uncertainty. Uncertainty is not just germane to actions taken by the Ministry or how the women read these actions; it is also central to what on any given day they decide is possible once they have taken a reading of the ability of their own bodies.

Beyond being a characterization of a familiar and constant mental/emotional register, uncertainty actually acts as a descriptor for these women's relationships with their bodies. In other words it reaches all the way down to the core of their lives and permeates every single dimension, embodying a certain kind of 'that beyond which you cannot go' which extends into every aspect of their lives. Indeed uncertainty is a central aspect of their subjectivity; these women (and their lives) are uncertain subjects.

Cruikshank (1999) asserts that governing is concerned with the production of certain kinds of subjectivity obtained/taken up by citizens in the context of ubiquitous power relations, raising two important and related questions: Firstly, what kind of subjectivity does the Ministry intend to produce? Secondly, given the accounts of the women's lives rendered here what gets produced? If independence, income security, enhanced well-being and a more robust participation in community—a more active citizenship—is the

object then the production of uncertain subjects is another unintended consequence of governing disabled citizens receiving B.C. provincial disability benefits (in ways that produce uncertainty). The idea that “subjectivity is both enabled and constrained by relations of power” (p. 2) is powerfully evident in these women’s lives.

A different understanding of uncertainty is also potentially revealed if we accept the notion that these women (and their lives) are under siege. To be under siege in a situation in which the opponent acts in predictable ways enables individuals (or groups) to strategize and develop effective resistance. When uncertainty is the ground for your engagement it is much more subtle, permeating all your actions. In response to being under siege, by engaging agentially in resistance/compliance strategies the women are disadvantaged/disabled by never really knowing whether they are making the right moves constituting another kind of uncertainty in their lives.

Given the capricious and to some extent secretive (or at least not transparent/obscured) actions of the Ministry, the women never know if their readings of any given policy or what is possible is accurate, inconsequential or risky. When they act on those readings they are uncertain if the strategies they enact are going to be effective *until they have enacted them*. Ironically, uncertainty is again produced/reinforced after the women enact the strategies effectively because they may not know what actions (or non-actions) actually worked. They also live with considerable uncertainty as to the longevity and durability of their strategies, producing the energy-draining activity of always second-guessing.

With so much uncertainty permeating their everyday lives the women exercise resistance to exposing themselves to greater uncertainty but can never be certain these tactics are

successful. Their reading of government as untrustworthy, for example, although it augments the uncertainty with which they live, to some degree serves their purposes; it protects them from a naïve reading that might jeopardize their claim to benefits and expose them to the kind of uncertainty they fear most—not having their benefits and dropping out of the safety net they rely on to survive, such as it is.

The next chapter introduces what I referred to earlier (p. 65) as a coercive enactment of policy by the B.C. government in 2002, and provides rationale for including it in the dissertation. It also alerts readers to a shift in my approach to presenting participant narratives, and critical reflections/interpretations emerging from their accounts of The Review.

Challenging Changes: The Disability Designation Review

Government, if one likes, has become more multiple, diffuse, facilitative and empowering. It is also, however, strangely more disciplinary, stringent and punitive. (Dean, 2010, p. 200)

Qualifying for disability supports or services most typically involves demonstrating one's embodied reflection of one of the many conceptions of disability at work in any particular department, agency or ministry. (Titchkosky, 2006 p. 59)

This chapter serves as an introduction to the four participant narratives that follow focused on each woman's experience of the 2002 B.C. province-wide administrative review of all those receiving provincial disability benefits, called the Disability Designation Review, but colloquially referred to as The Review, and provides rationale for its inclusion in the dissertation. It also presents critical reflection on the narrative accounts that follow generated from the transcript data of each of the participants' unique experience of this review. These narratives are focused on how the women contended with and were implicated with/in the Disability Designation Review process.

In 2002, the then new Liberal government in an expressly neoliberal strategy of rule set about to change the Act governing welfare and disability income support policy and programs, in particular revising and narrowing eligibility requirements. In doing so, using newly-developed criteria (See Appendix D: Context of the Review) the Liberals proposed to review (or more accurately reassess the eligibility of) every single person in B.C. receiving provincial disability benefits, at the time approximately sixty-two thousand (62,000) British Columbians living with disability and/or disabling chronic conditions. Ultimately, the Disability Designation Review became controversial for a number of

reasons, not the least being what was a large fiscal expenditure by the Ministry (\$4,869,000, the bulk of which went to physicians' fees) with miniscule savings resulting, and characteristically neoliberal "politics of stealth" used to introduce the changes, wherein significant changes were enacted almost immediately "without prior warning, consultation or [substantial] media scrutiny" (Brodie, 1996, p. 131). Subsequently, in 2004 responding to pressure from advocacy groups and the general public the B.C. government requested that the Auditor General audit the process.

A detailed description of the background and context of The Review, and aspects of The Review (process) relevant to the study participants' experience of it, including (the role/participation of) advocacy, activism and critique from well-organized community-based advocacy and activist groups, along with relevant elements of the Auditor-General's report (Strelieff, 2004) appear in Appendix D: Context of the Review. This appended document contains detail about the history and political context of The Review and the ensuing administrative processes and was written to provide relevant background too detailed or lengthy to be included in footnotes. It can be read as a whole or referred to for specific information as needed or when directed.

As I was developing the research proposal, I was aware the new government was planning to change the Act governing disability benefits and related programs and learned of The Review just as I was thinking about recruiting participants. From my contacts in the disability community I knew The Review process had been experienced with considerable difficulty by those being reviewed and decided to include participants' experience of The Review in the study, in particular to reveal how these disabled women underwent being reviewed and the effects in their everyday lives. As mentioned in *The*

Conduct (of) the Research in my Information and Informed Consent letter I stipulated that each participant should have been receiving provincial disability benefits for at least two years, which meant they would have undergone the Disability Designation Review. Four narrative accounts follow this chapter, one from each of the participants describing her particular experience of The Review. I begin with Marion's account primarily because she has a substantially (and significantly) different experience of The Review, from which she was ostensibly exempted. She also participates actively in local and provincial advocacy focused on the issues and concerns arising from The Review of those directly affected by it, providing some context for understanding the other women's narrative accounts.

My purposes in including The Review in the dissertation are multiple. Primarily, drawing from the transcript data I wish to show/present the constitutive effects of a unique exercise of more "stringent, disciplinary and punitive" (Dean, 2010, p. 200) government/bureaucratic power in these women's lives. This overt intrusion and surveillance by the state, which produced significant disruption in these women's already precarious and uncertain lives makes visible intensified difficulties in their everyday lives beyond the official (Auditor General's) version that grossly minimized The Review's effect on those disabled people being reviewed. The Review crystallizes the rationality governing disability and brings a different kind of practicality to the participants' lives. Again they are required to act in the world in embodied ways but not entirely in ways they do to keep their daily lives together; it adds a specific burden and strategic challenge. My intention is to expose how such an exercise of disciplinary power by the state affects these women whose lives are already so limited, constrained and narrowed.

I also want to reveal how the women negotiated this coercive, state-initiated process, including their encounters with physicians, exposing the ways physicians and the power of medical knowledge are implicated in these disabled women's lives and bodies and what that produces. I also want to show how they took care of themselves during this unexpected, unbidden disruption in their everyday lives, including their reliance on community-based advocacy organizations during this time, revealing both each woman's vulnerability and their strengths. It is also my intention to describe and explicate some of the embodied effects of this disciplinary process drawing from what the participants articulated about their experience of The Review during the interviews.

Originally I planned to include in the dissertation a critically interpretive/analytic chapter similar to the *Palimpsest* chapter *after* the narrative accounts of the participants' experiences of The Review. These narrative accounts, like those previously presented and then reflected upon and interpreted in *Palimpsest* were constructed to show how each of the women responded to having her disability status formally questioned in a coercive and threatening manner and what that produces. As I re-read their accounts in preparation for crafting critical reflections here, it became apparent to me that the analysis and interpretation rendered and the dynamics and patterns articulated in *Palimpsest* apply ever more forcefully to the women and their lives during this unusually unsettling and deeply uncertain period of time. I focus particularly on how each participant negotiated the confusing minefield represented by The Review revealing how the persistent dynamics at play in their "normal" everyday lives (described in *Palimpsest*) are also evident during this period.

Therefore, it is important to reiterate that the dynamics and patterns produced with/in exercises of power and described in *Palimpsest* are repeated in these narrative accounts. Yet because of the emergent nature of the events as they unfolded, the immediacy of the threat of losing benefits considerably in excess of that lived with on an everyday basis and the almost complete lack of information from the Ministry (and government) about the review process, the intensity of the dynamics is deepened, in particular the mistrust of government and fear of losing benefits. Vigilance is heightened and uncertainty greatly intensified. With very little (and often confusing) information communicated by government to beneficiaries (and advocates) or explanation for official actions taken, second-guessing takes on even more strategic importance. What is at stake becomes increasingly urgent in ways not consistently seen in their accounts of everyday life.

What is remarkable about their experience of The Review is in fact revealed in their everyday experience; the urgency of the situation and coercive nature of The Review could be expected to produce the dynamics articulated in the previous chapter but it is everyday life that has exposed these dynamics that then become heightened and intensified during The Review. Each woman's (differing) ability to strategize in order to survive is put to the test, perhaps the ultimate test reflecting their deepest fears of having their benefits threatened and in their minds, arbitrarily taken away.

Rather than reiterating the precise analysis that was produced in *Palimpsest* (and applies here), in this chapter I will reflect critically here on several particular aspects of the participants' experience of The Review that I wish to make visible but that are also applicable in their everyday lives. Unlike previously where the narratives preceded the analysis, reflecting critically in advance of the narratives will provide a different context

for reading the participants' accounts, one in which readers are already aware of the dynamics at play in the women's lives, perhaps altering their reading. In doing so the narrative accounts of *The Review* to some extent stand on their own. To illuminate points in my reflections I will refer to particular aspects of individual narrative accounts that follow but will not present excerpts here. Readers are invited to carry these interpretive reflections (and the analysis from *Palimpsest*) forward into their reading, informing them differently as they proceed.

The unknown, known

Whether we recognize it or not, each of us is poised between two existential terrors, that of remaining unknown and unseen, our anguish and our joys without witness, and that of being known so completely we are left undefended. (Harrison, 2006, p.11)

For all of the participants, receiving news that their eligibility for disability benefits are under review uniformly produces intensified anxiety and fear. Undefended in the face of renewed government surveillance this news came to most recipients of disability benefits (and all the participants) via a form letter telling them only that their eligibility for benefits was under review and an application form would follow in the mail.²⁵ Each woman reads this move by government as a situation of heightened danger (of losing their benefits) bringing to the surface the kind of economic dependency each lives with. Evelyn specifically reveals she is afraid of contact with Ministry personnel because it raises the possibility that an arbitrary decision will be made during an encounter upon which she has no influence, that is, her eligibility will be denied and she will lose her

²⁵ I did not see a copy of the letter; none of the participants retained a copy for me to read, but all uniformly described it as perfunctory and impersonal (and threatening).

benefits. The response to the threat of losing benefits is described by each woman in various ways using such language as “afraid” “agitated” “terrified” “panicky” “worry” “shock” “traumatized.” More commonly, all the participants repeatedly name increased “stress” as significant during this period, which for two of them lasted five months (Evelyn) or longer (Jocelyne).

For women who are already mistrusting of government, not being provided with sufficient information or explanation about The Review in particular (merely that their eligibility would be reviewed and an application form was to follow), produces deeper suspicion and mistrust of government (motives). Additionally, they read this process as not being valued or respected enough by government to be communicated with in open, transparent ways. Both Evelyn and Galya view the whole process as a “trap” they are caught in set out to winnow out supposedly unworthy beneficiaries, producing confusion and self-doubt about their disability status and feeling victimized.

Each of the women in her own way very quickly concludes that she has to discern how to transit this difficult, challenging period and each strategizes the best she can, including seeking much-needed assistance from local advocates and physicians (although the latter are not uniformly helpful). Evelyn for example, in a somewhat risky, subversive move decides to call a Ministry staff person (she gets the phone number from a community-based advocate) in which she poses as an Assessor seeking advice about how to approach completing the Assessor section of an applicant’s form. Her intention here is to glean as much information as she can about what the Ministry reviewers are looking for so she can use this knowledge to her benefit whilst completing her application form. She is able to pull this manoeuvre off in part because she is a professional social worker herself.

Interestingly, the Ministry worker she speaks to cautions her about accepting the veracity of any applicant's verbatim descriptions of impairment/disability especially if she (as an Assessor) has not had much previous contact with the individual. Here "the limits of reliability of non-authoritarian discourse" (Shildrick & Price, 1996, p. 102) are exposed; the applicant's own report is considered questionable and must be supplemented by medical professionals' statements. Mistrust of applicants by government is also exposed in this account.

Day-to-day activities comprising 'work without pay' become more than a way of life, rather an absolute (and exhausting) necessity in the face of The Review. Using precious time and energy (and creativity) to demystify the process while continuously second-guessing is central to each woman's survival during this time. At the outset, none of the women are confident they will be successful, again deepening uncertainty in already substantially uncertain lives and (re)producing the women as uncertain subjects.

I am struck by how the heightened, immediate threat of losing disability benefits that The Review signifies is intensified and sustained by the lack of information all the women have with respect to every aspect of The Review. Most surprisingly is how despite her deep connections to local and provincial advocacy groups, Marion who presumably would be "in the know" was (along with other advocates) equally disenfranchised during this time. Again, not having adequate or appropriate information necessary for negotiating Ministry programs produces significant difficulty in each woman's everyday life. The Review increases the difficulty to a much more challenging level, with particular effects, including embodied effects.

Although all the participants tell me they have increased anxiety and stress during this period only two of the participants describe embodied physical effects directly attributed to undergoing The Review. I did not ask participants specifically about how they experienced their bodies during The Review. Nonetheless, Galya tells me she has incredible difficulty both emotionally and physically, including significantly increased blood pressure and feeling traumatized, dissociated and agitated, embodied psychological effects. Jocelyne tells me her bowel problems were exacerbated due to the shock of learning from her doctor that her benefits may not be in place in the future. She also tells me that further along in the process she has had a mild heart attack, exacerbated muscle/fibromyalgia problems and feels tortured. Readers are reminded of Freund's (1982) concern about how embodied effects are produced by interactions between individuals and bureaucratic systems, in particular the idea of "informational troubles" (p. 118). What is pertinent with respect to the women in my study and particularly with respect to The Review, is how this exercise of power reflects a form of social control that relies on providing very limited information to individuals (and groups) with particular effects.

The daily challenges of responding to being governed in the ways the participants are and what that produces includes embodied difficulties, particularly the challenge of maintaining health made visible in the preceding narratives and intensified during The Review. I know from my own decades-long experience of being reviewed yearly by the insurance company to confirm eligibility for benefits that my anxiety levels always increased substantially, my sleep patterns were altered and energy levels sagged during what was annually a four-to-six week period of waiting for a decision, a relatively small

length of time compared to the wait for Evelyn and Jocelyne. Year-to-year I never really knew what personal, intimate information about my body, my health or activities was sufficient to enable continuation of benefits and the opaque language of the form gave nothing away. Both complying and resisting simultaneously, my strategy was always to just answer the questions factually, never provide information not asked for, maximize my impairments and their effect on my ability to work and minimize my strengths. Even being consistently successful over time I never really knew what I wrote that “worked,” if anything. Fortunately, my doctor was always unequivocal and completed the form leaving no doubt about my inability to work at a substantially gainful occupation. I suspect his responses carried significantly more weight than my non-authoritative ones.

All of the participants struggled with the second section of the form that provides space for them to respond to two personal questions,²⁶ in terms of its meaning and intent and the focus and scope of the written response they imagine was expected. Evelyn in particular struggled with composing her responses, with three revisions over several months exposing her to considerable self-doubt about what language to use and how to portray herself as disabled and whether she is even disabled (enough) to meet the requirements of the (regulatory) category of disability, all the while cognizant of her relatively powerless location in this exercise of power. She finds the medical language

²⁶ The second section of the form, Section B, entitled Disabling Condition and appearing after the basic Personal Information section (name, contact information and date of birth) consists of two blank lined sections, designed to provide applicants with the opportunity to describe their disability and the impact on their lives. Applicants are not required to complete this particular section, in which case a determination will be made solely on the Physician and Assessor sections of the form. In the first part of Section B, applicants are asked to describe their disability (no further instructions are given). Similarly, in the second part, applicants are asked how their disability affects their lives and their ability to take care of themselves. The latter is particularly significant because this aspect of disability is a crucial part of the 2002 Act’s definition of disability, which states that as a result of restrictions in one’s ability to perform activities of daily living “the person requires help to perform those activities” (British Columbia, 2003, p. 4-5).

and criteria of the rest of the form both helpful and a hindrance to her cause; she is discursively adept with medical descriptions but questions whether this ability portrays her as less disabled. Like all the participants, being constituted “through the constant reiteration of a set of [able-bodied] norms” (Shildrick & Price, 1996, p. 94) that categorize her as meeting (or not) the official criteria for eligibility for disability benefits, Evelyn’s body as disabled and subjectivity as a disabled woman are also under threat during this precarious time. Like the others Evelyn is being disciplined to extend the gaze of medicine returning it to herself in ways that invite self-regulation, in this way “becoming complicit in the process of constituting herself as an embodied subject” (p. 108) in line with how disability is defined for official purposes, an overt exercise of bio-power. Given that many women with disabilities live in “deep poverty” and are totally reliant on government income support “they are particularly vulnerable not only to restrictions and cutbacks but also...harsh interpretations of the legislation and regulations governing eligibility by...bureaucratic decision makers” (Frazee, *et al*, 2006, p. 238) who administer benefits. Exposure to government is germane to living on income support; The Review, an instance of harsh interpretation of legislation heightens the risk (and uncertainty) beyond that of everyday exposure.

The production of uncertainty imbricates with the unpredictability Evelyn experiences of living with a chronic, in this case invisible, fluctuating physical condition, which defies medical and welfare systems that “constitute the body, whether marked by impairment or not, as stable and predictable” (Shildrick & Price, 1996, p. 98) producing a difficult challenge for her. The newly-developed application form “rigidly constructs and controls the definitional parameters of what constitutes disability” (p. 102) so that Evelyn and

other applicants are “obliged to take personal responsibility in turning a critical gaze upon their own bodies [implying that] disability is a fixed and unchanging state which pre-exists its observation” (p. 102) or is at least “predictably changeable” (p. 108) to which applicants’ (impaired) bodies must comply. Evelyn is caught in a different way than previously articulated in *Palimpsest*. She must ensure the fluctuating, unpredictable nature of her condition is clearly conveyed as disabling using a form that neglects to include this aspect of chronic illness in its request for intimate details of each woman’s life and ability to complete activities of daily living with or without help. Evelyn must produce herself as a certain (but not uncertain) kind of disabled subject, one who “constructs her very selfhood” (p. 104) through engaging in “a normalizing judgment on her own modes of being” (p. 104) whose effect is self-doubt and uncertainty.

Some of this uncertainty is alleviated in encounters with physicians, in particular for Evelyn and Galya. As best as they have been able to each has cultivated a long-term, trusting relationship with their general practitioners and Galya with a specialist, which by and large serve both of them well during The Review process. This is not the case for Jocelyne whose relationship with her primary physician seems unstable and not entirely supportive. Realizing how important this is to her successful application she works hard to find a supportive and understanding physician, not entirely successfully as it turns out.

The discipline of medicine (and allied disciplines) is highly valued by government, which relies on the knowledge medicine generates (from the study of people’s bodies/minds) to determine which aspects of a person’s body and life beyond/in excess of socially-constructed normative standards are used to constitute the categories that produce an official version of disability. The definition of disability for official purposes relies on an

objective determination and verification of impairment (ambiguously referred to on the B.C. application form as ‘disability’) by a physician, demonstrating a firm “adherence to the medical model of disability” (Frazee, *et al*, 2006, p. 240. See also Stone, 1984). As previously discussed, this view of disability reflects a fixed abnormality located in the individual and her impairment, rather than a fluctuating, embodied experience produced in the matrix of different physical, social and economic contexts (and power relations) that potentially limit participation and the ability to take care of herself. The application form itself positions medical “professional discourse and judgement alone [as] authoritative” (p. 241) in particular the section to be completed by the physician, which displays a list of diagnostic categories with official code numbers. The remainder of the form serves as a functional assessment tool based on normative constructions of activities of daily living, leaving little room for descriptive comments or explanation of categories chosen as representative of the applicants’ lives, and potentially perpetuating the conflation of illness with (socially constructed) disability (Rioux & Daly, 2006).

All the participants are cognizant of the “cognitive and social authority of medicine” (Wendell, 1996, p. 117), in particular its disciplinary power in their lives and how it positions each of the women and their descriptions of their bodies as less valid or legitimate for the purposes of determining eligibility for benefits. One aspect of Evelyn’s encounter with her physician reveals the exercise of disciplinary power starkly when her physician refuses to check off an item in such a way that would reflect a level of disability Evelyn believes she experiences, potentially denying her access to benefits. Evelyn speaks back but her physician exercises her authority in this situation, despite Evelyn’s common sense claim that she only sees her physician occasionally and therefore

she could not know what Evelyn's life is like on a daily basis. This encounter in which Evelyn's own knowledge is disregarded validates findings by Canadian researchers and disabled women's organizations that health care providers know very little about how disabled women live their lives or the impact of their impairments on their everyday lives (Odette, 1993; Masuda, 1999; Morrow, 2000). It also undermines her trust in her physician.

Each of the women's verbatim accounts of her experience of The Review that follow is interspersed with my own short descriptions, commentary or explanation (when needed) and critical understandings of what is being said and done by the participants.

Advocacy and The Review: Strategizing in the dark

During our second interview, Marion and I discussed her experience of The Review in which she participated both as a person with a disability and as an advocate. Marion is uniquely positioned as a trained disability advocate in the community in which she lives and has worked closely, directly and frequently with advocates at the B.C. Coalition of People with Disabilities, no more so than during The Review. This positioning provided valuable insights into The Review process and opened up the possibility of viewing it not just from the perspective of a disabled person, but from that of a person actively advocating for those who were having difficulty with The Review process. Galya, Jocelyne and Evelyn all sought help from disability advocates as part of their experience of The Review and Marion's comments provide context for their experiences.

As an advocate Marion has access to Ministry workers via phone, that is, she did not hesitate to call up and ask pertinent questions about aspects of The Review (or other

Ministry policy) in order that she had the correct information for those disabled people calling her for assistance. Often this information was partial making it difficult for her to advocate effectively. Advocates typically had trouble getting information from government through formal channels because it was repeatedly withheld as the new Act and regulations were developed and The Review application form and process were being created and instituted. While the advocacy Marion engaged in provides insider insight and background to The Review process, her own experience of The Review also contrasts starkly with that of the other three participants.

As a result of initial file reviews²⁷ at the Ministry, Marion was placed in that group of “former disability recipients [who] had their eligibility status confirmed without having to provide additional proof of their disability” (Strelieff, 2004, p. 27), that is, she was exempted from The Review. Marion does not receive any explanation from the Ministry as to why she was exempted. She attributes her stroke of luck to having a visible disability, one requiring ongoing government-administered physical supports but actually does not really know why she was exempted; she is just guessing. But this may be an astute guess on her part.

Marion’s sense that having a visible disability, one requiring assistive devices (as she elaborates on later), exempted her from this process is not entirely off the mark. I have not seen the guidelines used by Ministry staff to conduct the initial in-house review, but the

²⁷ The Ministry undertook an in-house review of files of all disability income support recipients in order to separate out those they ascertained already met the new criteria for eligibility status, from those who did not (and would subsequently need to complete the newly-developed 23-page application form). The new criteria added a clause that stated that as a result in restrictions in the ability to perform activities of daily living the applicant required help to perform those activities. This latter clause referring to help with activities of daily living was not part of the previous criteria under the old Act. Nonetheless, I am only guessing that the new criteria were applied because it is not entirely clear what parameters were considered during this extensive internal review. In the end 43,227 out of 61,932 disability income support recipients were exempted from the reapplication process.

Auditor General's report provides some basis, however partial, for decisions made by Ministry staff about eligibility. Of those not being required to reapply for benefits, the Auditor General lists the following kinds of physical and mental disabilities and/or diagnoses that exempted clients might be living with: "developmental disabilities, paraplegia, total blindness, profound deafness, double amputation, quadriplegia, Alzheimer's, ALS and similar conditions, muscular dystrophy, cystic fibrosis, severe mental disorders (e.g., schizophrenia, bipolar disorder), and wasting syndromes (e.g., AIDS)" (Strelieff, p. 27, 2004). Presumably those other mentally disabled recipients who were required to reapply (before the government exempted them. See Appendix D), like Galya, were not judged during the initial Ministry in-house review as being severely mentally disabled. Like Marion, who has severe rheumatoid arthritis (a chronic physically disabling condition not mentioned in the Auditor General's list, nor is multiple sclerosis) requiring supports, many of these clients would also require extensive aids, supports and assistive devices in order to moderate the effect of their conditions on their ability to care for themselves. For most of them, securing these devices would require frequent contact with Ministry workers, something likely easily determined and verifiable as part of the initial review.

Nonetheless until Marion received the letter saying she was exempted she lived with the same kinds of intense fears as the other participants. Also during this period she was on the 'front lines' receiving desperate calls from distraught disabled people about their benefits being threatened and the difficulty they were experiencing completing the new 23-page application form that none of them were in the least familiar with and as it turns out neither were the advocates initially. Unlike Marion none of the other participants in

the study are visibly disabled nor do any of them receive any government-administered physical supports; all of them were required to reapply for their benefits as part of The Review.

At the time of the Review, through her regular advocacy work helping people access one-of-a-kind devices, like wheelchairs or other mobility aids to promote quality of life and independence, Marion was in contact with many disabled people who had received the initial letter and application form. I asked her about this contact.

M: So you can imagine if these were coming out in the mail—these letters saying you had to fill out the form and you know you have to reapply, you're [as an advocate] not just getting "I'd like a cup holder" [for your wheelchair or stationary chair] you're having someone vent on you because they're feeling rather sort of "Oh my god! What is happening to me?" So I get a—that's how I get a lot of calls.

They're frightened.

M: Exactly.

Marion was part of the activist disability community who mobilized previous to and during The Review mostly under the auspices of the BCCPD, who developed and organized different ways of responding both to individuals affected by The Review and to government. Marion and others like her at the Coalition and around the province were working at two levels as advocates: helping individuals having difficulty with the application process be strategic about how they complete the application, and with how they engage in that process. There was also continuous development and execution of strategy by the Coalition and other advocacy groups, including disease-specific non-

profits like the Arthritis Society regarding how to influence government about the changes being proposed and instituted very rapidly (over a three month period).

M: Part of what happened during that time is we did letter campaigns to government with the B.C. Coalition, we used their website forever. We were printing things out, we were talking to people—but what happened was the advocates—because it was happening so fast—everything was changing so quickly that what was happening today wouldn't be happening tomorrow. For example—in the mental health community—a lot of the people got a letter stating that they had to go out and find work. Even before the actual process of reapplication came. It was about two months before the long form application went out to them.

When did that come out?

M: I think—I'm not sure the actual—it was early fall [2002]. But say two months prior to that at least—and I wasn't aware of this, but they got a letter stating that they were going to have to go through this reapplication form and they were qualified to find work in terms of having skills they could use, and basically because they didn't have a visual [visible] disability—it was very discriminatorily laid out—that they should go out and look for work. And—
Would these be DB2s or DB1s? [the two categories of recipients at the time, with DB2 being the “permanently disabled” category, and DB1 being “temporarily disabled”].

M: I think mostly all these were DB1 people that would now probably qualify for Multiple Barriers—not the DB2. I haven't actually—I wanted to get a copy of the letter, but nobody in the Ministry would give it to me. And the people who had mental health concerns, some of them were so stunned by the letter some of them quite honestly ripped them up. But I'm sure there are a few floating around at some point. But what happened is that some of those people did go out and find work, which the Ministry loved, because they cut

them off immediately and it saved them less people to have to re-qualify, right?

Mm...mm. Right.

M: So that then saved them money. Some people in the mental health community committed suicide right away.²⁸

Here or in Vancouver?

M: I think there was four that I know of here in the Victoria area within the first three weeks, because they were so desperate when they were getting this letter and their financial security had been so much around having sustainability with some kind of income coming in that it—you know getting this letter out of the blue their schizophrenia and everything just kind of went through the roof. But what happened in the whole process of going from the employment letter to the—getting the form—is some people in the mental health community immediately went to have the form filled out.²⁹

They went and had someone help them with it?

M: Well they started to actually set up an appointment and actually get somebody to help them fill it out. Because what happened with these people is that they didn't have people [physicians] they went to on a regular basis. So they didn't have a good relationship with them, and all of sudden they had this 23-page form that had to be filled out specifically, and they didn't know what had to be put down, or what didn't have to be put down, or who to get to fill it out. In the middle of them doing this the Ministry of Human Resources

²⁸ In a search online I was only able to find one documented suicide, that is, one person who committed suicide and left a note relating it to the pressures of The Review. (See http://edocs.lib.sfu.ca/projects/chodarr/carnegie_newsletters/2002-12-01.pdf#page=19)

This information was contained in a local Vancouver newsletter serving poverty activists (and people living in poverty in the downtown Eastside). Marion is an insider in the disability advocacy community and would have information about the status of disabled people under review not readily available to the public. Of course, insider information does not guarantee veracity.

²⁹ This was the case for Galya. Her fears drove her to act quickly and complete the process as soon as possible.

came along and told our Activity Centre rep that I think it was a certain number—I have no idea how they determined this number it was bizarre—were going to be exempted from having to do the forms at all.

So who do you think in the Ministry said that to them?

M: Well I know for sure that the co-ordinator at [the activity centre] was told by a staff rep at our local Ministry of Human Resources office. And they were told that on this particular day—it was like a Wednesday three o'clock that this many mental health patients—I think it was like 4000—all over the province—were going to be exempted. And the only way that um you would find out if you were exempted was to phone your local office. And if you didn't phone you wouldn't find out.³⁰

So how would you know to phone the local office?

M: Well ya! (sarcastically)

Like most disability advocates trained by and working in community along with or under the auspices of the B.C. Coalition of People with Disabilities, Marion understands the strategic importance of forming supportive relationships with physicians who can be relied on to unequivocally verify disability status when necessary. It is possible that doctors were also caught off guard by the new application form and new requirements from them. Therefore educating clients about what the Ministry was looking for so they in turn could then optimally influence or direct their physicians was a key strategic move taken by advocates to ensure each response was as effective as possible. Also the Coalition provided detailed Help Sheets on its website and at their offices about how to complete the form and supported applicants directly with the process. All this was organized in a very short time, a month or so, with the help of volunteers like Marion in

³⁰ This was not entirely the case, as Galya did actually receive a letter informing her of her exemption, and did not need to call the Ministry to determine this.

various communities around the province. This was in addition to lobbying government throughout the process including lobbying to exempt the mentally disabled, who were having particular difficulty with the reapplication process.

M: What happened was that the mental health advocate from the BCCPD, and myself—we didn't find out about these [mental health clients] exemptions until probably a week before they were given out because the Ministry changed its mind as the process was starting. So we had been giving out information to people—B.C. Coalition printed this big document about how to help doctors fill out this form with specifics—because the whole point was trying to get everybody—but specifically people with invisible disabilities to be very, very—you know, if you do it once [for example, spend a whole day in bed] put it on a form. You have to be very blatant. Otherwise it is going to disqualify you. So we were really pushing that because we had to. So there was a lot of stress and anxiety, especially with mental health people. Like there were several people there that day that said, “Like should I go on the assumption that I'm not going to be exempt and go through the process of actually getting this filled out? What should I do?” Like we were coaching that day—the mental health advocate and I—to have people to bring a blank form already filled out [in rough, by the patient] to the doctor and go through it with them so that you proofread it before the doctor fills it out. So essentially the doctor is just filling it out again so that they felt confident knowing what was going in. And again there was a lot of anxiety because these people didn't see what was written until it was sent.

But the doctor was supposed to give the form back to them and they were supposed to send it. So they would get the form back and...what if the doctor says something that is not true?

M: Well that—ya. And in terms of just their ability to communicate about their own health issues. In a way it was like a team kind of approach—they didn't have to do it at a time when they were under pressure, under stress.

They could do it while they were sitting at home and then just bring the notes in with them if they didn't have an advocate. But the challenges with the changes happening constantly was the fact that the mental health advocate and I and everybody else, if you didn't sort of stay on it every day you really didn't know what was going on. And this piece about suddenly exempting the mental health community. Was that because they were going to do that all along? Or was that because for four weeks the B.C. Coalition campaigned about the fact that they [government] had not listened to them at their meetings before this whole process was decided upon?

Although it could be said that the lobbying of the Coalition and professional groups about the particular difficulty mentally disabled clients were experiencing was the catalyst for the decision late fall to exempt this group of clients from the Review process, Marion reveals that even those directly involved in lobbying did not know what actually precipitated this government retreat/decision.

M.: But there was a lot of lobbying about this mental health issue and how these people were the most vulnerable and were going to have quite a bit of challenges with filling out the form, getting a specialist—because you know it can be up and down. So I find it interesting the timing of the exemption.

What do you find interesting about that?

M: I find it very suspect that it happened right after the start of the public campaign. It seems to me that it was done in a way that they were hoping the public would say, "That's an improvement."

Right. So it would look good on the government to be responding to the activists.

M: Ya. I think they wanted to give the general public a little something that for people who didn't know what it is like to live with a disability and the income issue, they would think, "Oh that's good they're helping some

people.” And then they wouldn’t complain about it any more and they would go back to their daily lives. It wouldn’t be an issue. And in some ways that did happen—because it became less newsworthy. But that’s not to say it became any less an issue.

In the absence of meaningful government consultation with advocates in the disability community disability advocates like Marion tried to make sense of what the government was doing in terms of many aspects of The Review. Limited communication from government about such things as how The Review would unfold and what was expected in terms of completing the reapplication form hampered advocates’ ability to effectively advise those undergoing review. A lot of sense making was done in communication with other advocates either in local communities and others around the province without knowing how accurate their hunches were. Consultations with the disability community were organized by the Coalition in order to apprise disabled people and their local advocates of whatever information they had gleaned in order that applicants were more likely to apply successfully.

Marion questions government’s decision to leave advocacy organizations in the dark. Is it purely administrative (and appearing ineptly so)? Or is it Machiavellian—designed to make it more difficult for advocates to advise people in ways that would maximize their chances of successfully reapplying, and thus winnow out those deemed undeserving (or lacking competence to read and complete the form in strategic ways)? In these ways Marion (and her advocate cohorts) are continuously working out their relationships with government as both advocates and as people with disabilities.

M.: So that was happening pretty constantly with the—you know I was looking at the website, I was phoning the other advocates. I mean you had to

because otherwise you were giving people the wrong information. It wasn't that you were trying to. It was just that I don't think they [government] knew what they were doing. And I think it was very political the fact that they did not give the advocates the information. That they made them work to find all this stuff. And as they [the advocates] were going through it. Because they did not enable us so then we could not enable other people. So there was this period of shock and then it went into anger and then it went into, "Oh my god! What do I do? I have this timeline where I have to get this stuff done. And I don't know where to start and who will help me." And so we lost a lot of time ourselves—

Just trying to bring yourselves up to speed.

M.: Oh sure. Because it happened so quickly and there was no consultation. There was no warning. There was no, "This is how you appeal." I mean the whole appeal process changed at the same time too you know.

Physicians were paid \$200 by government for each form they completed.³¹ According to Marion, if a person filled out the form wrong the first time, it would be difficult to overturn any decision made, because the form that was submitted was considered the official version. If you wanted a second form completed you would have to pay the physician's fees yourself.

So why might you want it filled out another time?

M.: Well because for example the mental health people who don't go to see their doctor very often and possibly didn't specify in specifics how often they have these attacks or the person with the invisible disability who you know

³¹ Physicians have five pages to complete on the Application form, one page being a coded diagnostic checklist; Assessors have eight pages to complete, including two pages allowing descriptive text. Most physicians serve as Assessors too. Physicians receive \$200, Assessors receive \$75 for completing their portion of the form despite the larger task. In 2007, the government expanded the prescribed practitioners along with physicians who could serve as Assessors. See Footnote 13, p. 108 for changes to authorized professionals.

tries to say everything is not so bad, then they get it filled out and it doesn't sound as strong as it needs to be. And then they find out after going to these community consultations, "Oh that's going to hurt your chances and you need to..." And then they think "Oh crap I should have"—

And then they've already sent the form.

M.: Exactly. And there was a lot of that. And the other thing is people who for example had multiple disabilities, who, for whatever reason started filling out the form but possibly didn't get someone who was accredited, and the Ministry would not accept that person filling out the form. And there was a lot of stress because people don't have someone who has seen them for any length of time. And some of those questions were very specific and very personal, and if you have seen this person twice how are they going to know really what that was all about?

We discussed what Marion understood in terms of how decisions were made at the Ministry level. She used second-hand information to make sense of how Ministry workers made the decisions to distinguish between those to be reviewed and those exempted from The Review like herself, but also talked directly to Ministry workers who were forthcoming about the process of dividing disabled people into the two groups. Knowing that this was done was not comforting to her but it answered her questions about this process, and presumably enabled her to provide an answer to those she was advocating who might question why they were placed in one category or another.

It also raises questions about how disability is defined for official purposes. Using a scooter or a wheelchair means you require assistive devices to carry out activities of daily living. During the internal review this was considered 'evidence' that a person is disabled according to the new criteria, which uses the ability to take care of one's self unaided as the litmus test of ability/disability. Using any kind of aids, including physical supports

like home support services or guide dogs is presumably indicative of eligibility for disability benefits for official purposes, a dividing practice excluding certain kinds of disabled people. Marion uses both a scooter and a wheelchair depending on need and has regular, daily home support services. She obtained these mobility aids through medical supports funding through the health ministry; home support services are delivered by the regional health authority. These supports and devices, along with the physical changes of RA she displays expose her as visibly disabled, not something that applies to the other three participants, who were not exempted during the internal review.

M.: I heard—this is scary—but I heard in terms of the categories that they decided who qualified and who didn't based on if you had gone through the Ministry at all I think it was in the past two or three years for any kind of medical equipment. So if you had got a scooter or a wheelchair or something then they automatically decided you were disabled. But if you didn't then you weren't disabled enough.

To be a disabled person.

M.: (Laughs) Ya. And yet it was just ridiculous because I spoke to one Ministry of Human Resources person and that's what she told me. I find that just ridiculous because there is so much about disability that the medical equipment is just one part of that. But I was told by a Human Resources worker who was not too happy about the whole process that they got huge big pack of files, and they were basically told to go through them. And if there was no medical kind of help that the Human Resources had given the person—I think it was [in the past] two years she said—then they were put in the long form file. And if they had they were put in the letter file.

The letter file being where you were placed?

M.: Ya. And I was also told, which I find very sad, that they didn't consider fibromyalgia—anything like an invisible disability—enough not to work.

That you weren't disabled in the government's definition anymore. We were told that even the Multiple Barriers people [typically people living with invisible disabilities] are apparently going to be put through some employment program. As a person who qualified I find that discriminatory. Because it seems to me there should have been a lot more criteria and it should have been a lot less discretionary and a lot more fixed in terms of what they were looking for. If they were really going to divide us then there should have been some pretty clear specifics about the definition of disability. And where I have huge problems is they totally discredit your doctor's definition. And as a community person, never mind as someone with a disability, I figure if you qualify for disabled status through your doctor, why are they questioning this? Why is there the need to redo this?

So if your doctor believes you are disabled and are a disabled person then that should be enough?

M.: Mm mm. Oh definitely because I think in terms of just what—I mean know just from hearing from and talking with other people what they go through to get that classification. And even the ownership of just calling yourself disabled after that, that should be enough. I mean these people with their professional expertise in human resources, which frankly there is not a whole heck of a lot there—in terms of medical background. I really just don't think they have the right or the knowledge to be making those kinds of decisions.

Disability is now something—they tell us whether we have a disability and it's really not dependent on what your doctor says. That's only one part of it. The other part is—they say how well can you take care of yourself?—but really it's about whether you are getting goods and services [e.g., medical equipment or home support] for your disability.

M.: That's right. And how much of those goods and services. And also there are two issues in terms of that. One is the fact that I heard from a Human Resources staff member that they were told outright to, "Get rid of x number

amount of case files.” And that it’s a budget issue basically. And that this separation process is just not because they were cleaning house type of thing. This is because they want to save money and this is what it is all about. It is not for the betterment of people going out to find them work. It’s not about it would improve their health. No way darn it! This is about numbers and budgets. And I was told that by three different people in three different Human Resources offices—we were talking about the cuts and I was saying, “You know as an advocate I am getting an awful lot of calls from people who are feeling very helpless and who really feel like their life is on the line because you know I see they have really very genuine health needs. And I don’t know what to tell these people as someone who goes through it every day. I just don’t know what to tell them.” And I was just kind of like, “Help me, help me understand.” And they basically—two of them were almost in tears on the phone with me and they said, “We don’t really have any choice Marion. We are being told to cut x number of cases from our files and to save the government this amount of money.”³²

Were these managers?

M.: No. These were financial assistance workers—front line workers. All three of them actually were. And I said, “Why do you have to do this? Why now? If clearly these people qualified at one point—they have doctor certification—why does this reassessment have to take place?” They said, “It’s a budget issue. We’re being told that we have to follow the rules or our ass is on the line.” They were pretty blatant about that. And the whole issue around categorization came up. And I said you know, “I know people who

³² This comment is interesting in light of the Auditor General’s assertions about this aspect of the internal review. The Ministry expected that approximately ten percent of disabled clients would be deemed ineligible as a result of the review. Presumably these would be clients determined to be not disabled/ineligible as part of the initial internal review, that is, clients who did not initially meet the new criteria and would have had to undergo reapplication. Despite these Ministry expectations, and in contradiction to what Marion learned from a Ministry “staff person”, the Auditor General asserts that, “the ministry was also careful not to tell reviewers that it was expecting to rescind disability status from a targeted number of recipients” (Strelhoff, 2004, p. 27). It is not clear from this wording whether or not there was a targeted number, but Marion’s conversations with workers reveals they understood this to be the case, and that reducing the case numbers was a budget issue.

have arthritis who are the walking disabled—more so than me—those people got the long form and I got the short form. And I said, “That doesn’t make any sense to me. Why is that? How did you determine who gets the long form and who gets the short form?” and I said, “Granted the people who got the short form and the letter are bloody relieved right now, but as a community person I kind of like to explain why you get this and someone else gets something else, at least to make them understand what is going on.” And the woman said to me on the phone, “The only thing I know is that this person got a walker through the Ministry, you got a scooter, you got this, so therefore you have medical needs so we don’t see you as terribly mobile. So we’re not going to push the work strategy on you.” But everybody else they’re going to push their new employment strategy—let’s get everybody back to work as a way of getting them off the system.³³ And that was her total—her complete answer to that. And I remember thinking I have so many people phone me who don’t want to fill out forms and letters. And here we are in a system where in order to qualify for help you have to just load it on the line to say you need help getting out of bed and everything else. And if you don’t you don’t qualify. And for people who want to take pride in having some kind of independence, which they fight for, it’s really hard to say to them, “You have to do this, you have to put this in—”

You have to portray yourself as very physically dependent.

M.: Ya, or you don’t qualify. It’s just—it’s very twisted. And for me it was one of these things where when I got the letter and found out I qualified. I was sitting there thinking to myself you know as a community advocate OK I’m happy for me that I don’t have to go through this. But sad because when you make the decision that you’re going to get the walker, the scooter it’s a hard decision to make because it means having taken your own responsibility

³³ None of the other participants in the study reported being asked to participate in employment, presumably because they had all been receiving permanent benefits as DB2 clients at the time of the Review. Ironically, despite being exempted from The Review, Marion received a letter informing her that she was being referred (mistakenly as it turns out) to an employment program, which she challenges successfully.

for your mobility away from you and you're having to use more tools, more stuff. It's a big thing. It's more dependency, right? And you know I like to sort of focus on independence and the same thing with the non-profits [Marion does work for a non-profit focused on helping people with chronic conditions be more independent]. And yet in a way people who did focus on the independence thing it's coming back to bite them—you know what I am saying?

I asked Marion about the process she went through personally with respect to the Review, specifically when she received a letter and how she experienced it.

M.: I got mine—I think—I got it the first month. It was quite ominous because on my cheque it said “Message coming” or something like that. And I remember phoning a friend going, “What the hell does that mean?” She goes, “I don't know, but it sounds ominous.” And then I think I got mine at the end of October. And it just says you qualify blah, blah, blah.

So you didn't really know from when the Act was passed what was going to happen to you?

M.: No I kept thinking I was going to get a letter at some point. But I didn't know if the letter would have the [Review] form or just the letter.

Did you know there was a form being developed?

M.: I did know there was a form that other people had got, because I was receiving—they must have started getting them at the end of September—because I was already receiving calls from people saying, “Oh my god! I've got this 23-page form—and I don't know where to start and it's asking me all these personal questions and I don't know if I want to fill it out.” And, “How much information do I have to give?” And I thought oh god, it sounds like quite the form, but I never actually saw what it looked like or got it personally and at that point the Coalition didn't have a copy of it yet. And so I thought they were probably in the same boat as all of us in the sense that they could

hear it but they didn't have anything tangible to work with. So there was like this learning curve.

And it wasn't posted on the Ministry website?

M.: No. Not at all. Not at all. In fact there was just—I think Human Resources at the time only had this rather ominous statement posted on their website saying they were going to—how was it worded?—“We're going through a transitional time where qualifications for disability status are being reviewed.” Something like that. And we were thinking well that's comforting, you know. Like what does that mean? And I remember being terrified because I remember thinking well how disabled do you have to be? And like what hoop do you have to jump through to actually keep your status?

I was concerned initially when the form thing happened—initially, because about a month before I got my letter saying I qualified, they sent me a letter saying they were going to refer my case to a—what was it?—to *Destinations* something or other,³⁴ because they thought that I might want to get part-time employment through them. And it was like a job placement kind of thing. And I got that before I got my letter. And I thought oh my god what the hell is going on down there?

Who said that to you?

M.: Well I actually got a letter in the mail from Social Services [the Ministry] saying they had transferred my file to this *Destinations* something or other and somebody would be phoning me. So I phoned them up—I sort of played dumb—

You phoned the Ministry?

³⁴ *Destinations* is a private employment service contracted by the B.C. government to help welfare clients with job searches. They “develop and deliver employment programs aimed at helping individuals who are marginalized from the labour force to become employable and independent.” (See http://www.gthiringsolutions.ca/govt_partnering.shtml)

M.: No. *Destinations*. I phoned them up and I said, “Oh what’s going on?” I said, “I got this message that I should follow up with you. And my file is going to be sent to you” blah, blah, blah. And I said, “You know I’m on DB2 and I have severe arthritis and I’m already working part-time and I claim that with the Ministry.” So I said, “There’s just no way I could be working more part time you know.” And she said, “I don’t know why they even sent your file here. It’s supposed to be people that were only DB1 that got sent here.”

So they were sending files off to a job placement agency.

M.: Ya.

Are they allowed to do that?

M.: I don’t think it was legal because I actually phoned the [Ministry] office and my worker had changed. And I thought well I’m going to confront you, you little so and so. So I phoned up and said, “I think there must be some confusion. My name’s Marion and I’m on DB2 and I have severe rheumatoid arthritis” and blah blah blah. And I said, “I just got this letter saying my file had been sent”, and the lady goes, “Oh ya, oh ya.” And then she sort of sounded like a church mouse that had just got stuck in an orange. She went “Nnnh, you’re not DB1? Oh!” like four times. And I’m like, “No. I’m DB2”. And I said, “I’ve been working part-time. I’ve been working part time for years.” “Ya. That’s right,” she said. And then there’s like quiet again. And then all of a sudden I hear, “That shouldn’t have happened. That was a mistake.” Click. On the phone. And I thought have a nice day too lady. And that made me nervous because OK now what’s going to happen? What’s coming? When I got the letter next month I was relieved. But it tells me that they were doing that to people who were DB1 probably before or around the same time that they got that letter with the long form.

But how can they send somebody's personal file to an employment agency without notifying them?³⁵

M.: I think it was a bit illegal frankly. Like when I called her she was very like quick...abrupt didn't want to talk to me on the phone. I think quite frankly I embarrassed them. Because I think honestly they were very surprised that someone would phone back and confront them on it. I mean I did it nicely. I just thought if you're going to play me I want to know all the rules you know. And I don't want anything surprised over my head. And if it's wrong information I want it cleared up quickly before it is passed on to ten other people. Because I know how these things get out of hand. But that did make me nervous initially because I thought, "Why are they sending me for more work?" You know. I do the part-time because that's all I can do. And I go swimming three times a week and I go to physio twice a week and that is pretty damned important to my mobility. And so I do kind of what works in combination. I enjoy that, but at the same time basically—this doesn't make any sense, but do you think I'm not disabled? So when I called them on it—I think they were kind of getting on a roll—the system and I wouldn't be at all surprised if —oh DB2 let's see how many we can get off and oh well I just made an oops and if you don't call me on it we'll just transfer you right out of the system and get you work too. I mean it was totally ironic about the part-time thing, because my part-time positions started through a Human Resources program and yet they didn't know about it. Now how ironic is that when this program was initiated by *them*, and they don't realize? Like you know. How stupid can you be?

I asked Marion to make some observations about The Review process as a community advocate.

³⁵ This is a naïve question on my part. As part of its contract with the Ministry, this company would have legitimate access to files of clients the Ministry deemed eligible for employment services.

M.: People had no idea how they determined who got what form and how they were going to be determined as to who qualified and or not qualify. It became easier when they put specifics down—

What kind of specifics?

M.: Well I have to have somebody cut up my food. I have to have somebody help me dress. I have to have somebody help me with personal care. A lot of people didn't want to spill the beans about all the intimate particulars of their life. I mean they don't want to share that they need personal care. They don't want to share that they have them cut up their food, or they need to be rolled over on the bed or whatever else. You name it. Catheter care. You name it. It is a violation of your human rights to have to disclose this to get a service—something that should have been—basically you qualified for years before that and now wanting you to prove it all over again. It's very demeaning.

And that information would have been in the first section of the form where they get to write about themselves?

M.: Ya. But some people didn't want to go into that detail. They didn't use those kind of words. If you had problems with spelling or literacy you were hooped on those forms. There was a lot of that out in the community. Not just from the mental health community but people with learning disabilities and—it was a big problem. The rules for exemptions about who could qualify and who couldn't qualify for exemptions like I said even the advocates didn't know. It was like constantly changing. Um calls for advocates went through the roof. The Coalition could not keep up with the demand of the phone calls. And I wonder if that had something to do with them [the Ministry] extending the deadline of when these long forms had to be in. Because people just couldn't—it's hard because those people needed help. But the problem was because it was always changing some people then waited longer to fill out the form because why do it wrong the first time and have to pay again? And the flip side was that it was very intensive, that whole process.

Meaning what?

M.: Draining for everybody involved and very stressful. Because as an advocate you didn't want to be the one that you know didn't have the right information and ended up screwing up somebody's form. You know like their lives were kind of on that line with that form. It was pretty—pressure tactic. The other thing like I said before there was definitely some mental health suicides, pretty desperate, pretty fast after the first “go to work” letter. And you had to phone your worker to see if you qualified for the exemption and by the time that happened the doctor might have been paid for the form. You might have already had it filled out. I mentioned that to you. Very much extreme fear. Helplessness. More sickness. General chronic health problems from just the compounding stress—not knowing when they were going to find out. During that time there was so many changes with office staff [at the Ministry]. People had changed jobs or were let go because they were losing their numbers. I mean all those things are really traumatic when you're trying to get a straight answer. And one day you have worker 105 and the next day you have worker 109 and—how do they really know you? And you don't know if these people are the ones that are deciding if you had medical equipment or not. And I mentioned it was a long time to wait to see if you qualify. And in the meantime you know what has the stress of that done to you, done to your body?

After receiving an advance letter in September most people received their twenty-three page form in October, which was originally due at the Ministry offices in January 2003 but was extended to March 2003 under pressure from community groups. Most people were notified of their status by the June 2003 or before, depending on when their application form was received and reviewed at the Ministry.

M.: So it was a long time for people who have chronic health conditions who they say stress affects dramatically, to put that on people for that long of time with that kind of momentous decision—I think that was political too. ‘Cause I

think they were hoping that at some point people would just go out and find work or some work.

But when you're sicker, how can you do that?

M.: I know and that's the catch-22. But I think their thinking was that if they left them hanging that people would think I better go find something because what happens if I'm cut off? Right?

So it's a catch-22.

M.: So they would dwindle down the numbers even more and that makes them look better. And in fact as a community advocate it just annoyed the hell out of me when you hear Murray Coell [a former social worker, the Liberal Minister of Human Resources at the time] talk because he just talked about how, "Oh no we never cut anybody off who didn't really need it you know." And how they saved so much money and the Coalition—you can get copies of this—sent me several bulletins to say that the Deputy Minister of Human Resources got a mega-bonus to her personal pay cheque because of the money that that Ministry saved with cutting people off benefits³⁶. And they have—the Coalition has records of this because they sent notices out to all the advocates—it was a whopping big bonus this woman got, pocketed at our expense, clearly. And I actually took that to some of the people in the medical community and said, "This is what they are not advertising on TV. This is not a newsworthy story. The fact that they are saving money is, but the fact that they're redirecting it to their own"—and they were just furious with these people.

³⁶ It is not clear to me if she is referring here to disabled clients being cut off or those on basic welfare benefits, whose eligibility would have changed with a new welfare Act in 2002, different from the new Act governing people with disabilities. In the end The Review did not save any money. In fact it was very costly. Initial Ministry estimates about the numbers of ineligible clients identified during the review were 6,200 or more. Only 400 cases were ultimately deemed ineligible, and of those only 46 had their cases closed. Presumably the remainder were reclassified into a welfare category, most likely PPMB. The total cost of the Review was \$4,869,000 (Strelhoff, 2004), or approximately \$100,000 per person who was declared ineligible, enough to fund 500 people on full benefits for a year.

I don't think there is any kind of sensibility to our issues. The government is very pro-business and that's where their allegiance is to. It's not even pro-union now because they've pissed off the unions. So ya it's one of these things where unfortunately I don't see that changing, I see it only getting worse. Where at least with the NDP their focus and support of social programs was consistent. I'm not saying the previous act was altogether fabulous, but it was *way* better. And you know clearly there just isn't that intent here. And one of the challenges is that if people get help now it's more because of patronage, because they know someone rather than collective in terms of a group of people. It's a real challenge to actually keep your ass covered and to keep yourself kind of uh in an equitable state. It really is a personal kind of thing that you—I've told people repeatedly, "You have to stay vigilant. Otherwise you're going to lose just about all your supports." Because it's just one big change. And I don't think the welfare thing is going to be the end of it. I think again it's going to be another sort of change in the process and go through a few more months and then they'll find something else and it will probably be that way as long as we have a Liberal government.

It's kind of ad hoc in some kind of way, except for the overarching principle, which is save money.

M.: Yup. Well, so they say. I mean when you think about where the money is—and these bonuses it's hard to—it's hard to kind of feel respectful of that. I mean if they were saving money sometimes I would cut them a bit of slack—not that I agree with how they did it, but I kind of say, "Oh well OK." But this is really repugnant, because people are benefiting at other people's expense. And it's the people's expense who are already in the lowest form of the income bracket and the people that are in the high income bracket are bringing in another \$12,000. I mean it's repugnant.

Marion's disgust and mistrust of government is starkly evident in these accounts and as an advocate she is positioned not just to know more than other beneficiaries—although

uncertainty and second-guessing prevail—but to be able to influence others in terms of how to remain vigilant as much as possible as a strategy for protecting their benefits and supports. Interestingly, her viewpoint about the government economizing could be read as balanced—as long as they are saving money in what she suggests (but does not specify) are ‘legitimate’ ways, presumably finding people receiving benefits who are ineligible—she is willing to back off in her criticism.

Where government crosses a line in her opinion and operates unjustly occurs when she learns Ministry staff receive bonuses for reaching quotas in their efforts to disallow benefits. Her insider knowledge and strong social justice orientation enables this reading in part. What she misses (or does not include) is that some disabled people became ineligible for disability benefits when they did not meet the new criteria for eligibility instituted as part of the new Act. Their situations may have changed little, if at all; what changed was the definition of disability for official purposes and thus the eligibility criteria.

(Mis)understanding The Review

Like most aspects of her life, Jocelyne’s experience of The Review was complicated and fraught with difficulty, resulting in a largely unsustainable outcome rectified over a long, stressful period of dealing with physicians, Ministry staff, advocates and a Tribunal appeal. Like many other applicants Jocelyne does not have a well-established or supportive relationship with a physician, crucial for securing benefits. She also misunderstood the intent of the twenty-three page application document (but not The Review), which was by and large designed as a functional assessment. Jocelyne

approached the review process with a faulty strategy, treating it primarily as a medical issue, insisting on the primacy of having her diagnoses itemized and thoroughly documented by her physician and depicting herself as independent and wholly able to care for herself. She either did not know or failed to grasp that conveying that she was (more or less) able to engage independently in activities of daily living precluded a successful application. In addition, Jocelyne's simplistic understanding of what she sees as a direct link between not being able to work and disability income support did not serve her well during this process because this assumption intensified her negative emotions, diverting her from attending to what was needed to be successful. Interestingly, the ability to work was (and is) not questioned on the The Review application form and currently for determining eligibility, that is, no information about this aspect of an applicant's life was/is required or sought. Finally, language barriers made this process lengthy and arduous for Jocelyne but ultimately provided compelling rationale for her lack of success, something the government ultimately was willing to consider in her efforts to have Ministry decisions reversed.

Again, during the interview it was challenging for me to stay centered and attentive to what Jocelyne was saying because of the emotional intensity with which she spoke. The interview was also difficult (and sometimes frustrating), in part because of the language barrier but also because she was not completely engaged in our conversations. Rather with a sense of urgency she seemed very focused on telling me what she wanted me to know about this process, providing me with detailed information. Due to her insistence the details I sought were not always forthcoming, nor was a coherent narrative always evident.

Interestingly, although Jocelyne received The Review letter in the fall 2002, she did not receive the application form until mid-December along with the extended March 15, 2003 deadline. At the point where she submitted the completed form, she was told by the Ministry worker that her physician had not completed it properly and instructed her to complete another one (it was not clear to me what was improper about the first Review application form). The completed second Review form was submitted in late April 2003 and a decision was made in mid-May. At that point Jocelyne was informed by the Ministry that she was categorized as a Person with Multiple Barriers to Employment (PPMB)³⁷, which meant she would receive \$200 less monthly having previously been a DB2 client. She was distraught about this decision and struggled to reverse it, ultimately seeking the help of a local disability advocate.

At the time of the first interview, unbeknownst to me until I was just about to leave, Jocelyne had been preparing for a second Tribunal hearing about her case. Over the previous year she (and the physicians she chose to represent her) had completed two 23-page application forms, a 20-page Request for Reconsideration form and, with assistance from her advocate, Jocelyne had prepared for and undergone her first Tribunal hearing. All had been rejected, leaving her in the PPMB category at the time of the interviews. Interestingly the second application form went missing at the Ministry, which angered her immensely. At her second Tribunal hearing, seven months after the initial decision, it

³⁷ Of the almost 62,000 reviewed, Jocelyne was likely included in the 40 claimants who reapplied after losing their status, and were subsequently granted disability status, as reported in the Auditor General's 2004 report (Strelieff, 2004). Another 316 had "begun receiving other forms of government assistance" (p. 6), although the kinds were not specified. It is also conceivable that Jocelyne might have been in this grouping if it includes PPMB, which was not specified by the Auditor General. Please see Appendix A, Note 1, p. 362 for further description of the PPMB category and the Employability Screen it uses.

was decided that she should submit another application *in French* as the language barrier was recognized as the primary problem.

We first talked about her relationship with her physician. During the Tribunal process her advocate requested her files from the Ministry so she had copies of her documents to which she referred during our conversation and later showed me to help me comprehend her situation.

What is your doctor like? Do you have a good...

J: He don't care. He don't care.

Do you have a good relationship with your doctor?

J: Not bad. But he don't care about nothing.

He doesn't care about you?

J: No!

Did he fill out the 23-page form for you?

J: Oh the first one, ya. But...I am very surprised with what he does, you know, he...

What did he do?

J: He is same to he didn't know me.

He does the same as if he doesn't know you?

J: Ya, very much. Ya. *This* doctor I'm talking to you. [points repeatedly on a copy of the application form] is supposed to give me my shot of calcium. OK, but this doctor you imagine you know. This doctor give me my shot of calcium for a few years now and he don't talking about that on my file.

He doesn't mention that on your file.

J: No, no, nothing. He just put I have *diabète*, and he said I have chronic fatigue, and he don't want write I have problem with my intestine.

With ulcerative colitis. He didn't put that in there?

J: No. And he said fibromyalgie.

Jocelyne mentions this to me because she believes strongly that the fact that her physician neglected to include that she lives with ulcerative colitis and that she requires regular calcium shots due to parathyroid insufficiency (and other conditions she refers to when she elaborates on this oversight below) is the reason she was re-categorized. She wholly attributes her rejection to physician error—in this case forgetting to list two of her conditions—and once these were added she thought she would be successful. I try to refocus the interview on The Review process.

So can I ask you what happened when you got the letter?

J: You know what? This doctor what I see—my family doctor—give me shot of calcium first time he said last December. I remember date because you know is 13 of December because I didn't receive my paper [the Review application form] at this time.

Oh you didn't?

J: No.

When did you get it?

J: Just a few days after.

In December. So you got the...did you get the letter in September?

J: Uh...yes but I don't care because I don't understand. [laughs] So at this time I don't care.

So you weren't upset about getting the letter?

J: No. I think, OK. I don't understand very much you know. For beginning you know I think I can do it little bit. [complete the application]

You thought that you could do it?

J: Ya. First time I trust completely because I never imagine I have problem.

This makes sense because Jocelyne applied successfully for full disability benefit in 1997 and had been receiving income support in the permanent designation (DB2) since then without cause for concern. At the time of The Review she believed her claim was intact. After all, her physical condition remained poor and perhaps had even deteriorated since initially securing benefits. Jocelyne was unaware that the newly-elected Liberal government had changed the eligibility criteria substantially. She also did not anticipate having trouble with her physician who she recognizes as crucial to her successful negotiation of The Review process, a practitioner she ended up with after a series of misunderstandings and acute health episodes. Unfortunately, when she goes to see him this physician inadvertently raises her fears about continued income support.

So when you saw the form what did you think?

J: The first shock is when the doctor said to me in December, and he laughing, and he said, "Maybe you don't have any help next year."

What kind of help?

J: And I said why? What? And he said to me, "For your disability," and he said, "but don't worry probably you can have because you have *fibromyalgie*." And he give me shock because I don't understand completely at this time, but little bit, you know I am afraid, and that provoked to me another crisis on my intestine.

So was he saying that he thought you weren't going to need any help? [I miss here briefly that the "help" she is referring to is disability benefits]

J: He think is funny.

He was making a joke.

J: Ya. He think is funny, but not.

[Jocelyne shows a document to me] When you got the form—right? Which one is this?

J: [Does not let me read it at this point] Ya, but, yes but I explain to you because you know is difficult.

Did you make a copy of the review form?

J: Ya. Every copy. [shuffling through papers] But you know I want explain something. Because he don't do exactly what you need to do. OK? First I try to explain in English. I ask at somebody for translate my little letter [her section of the application form]. Because I think is uh the doctor can complete, so I just want...

So did someone help you translate?

J: Ya.

Where did you find that person?

J: At a church. [There is a French Catholic church in the city in which she lives, which she attends when she can]. So this...the translate explain little bit my pain, you know. But I think the doctor can complete, but probably don't looking that.

You don't think he looked at that [the translation].

J: No. No. So...and a few days after...

And did you take this to your doctor's office after you completed this piece?

J: Ya. I give him.

Did you talk to him too? At that time?

J: At that time I have appointment for my thing.

For your what?

J: Because when he talked to me [before] he gave me shock. I have problem with my intestine. A few days after I receive that [the 23-page application form]. On the same time, a few days after, I need to see him because I have

problem with my intestine. So I said to him, “Look I have problem with my intestine, I have colitis, and this time is very strong.” And I don’t talk him...I don’t said he give me shock. But you know is. But he said to me, “You have nothing.” So at this time I am obliged to go back to see the other doctor [she saw a French-speaking doctor at a walk-in clinic on several occasions]—first one—speak French to explain to him, “Look I have this problem.” So he give me medicine. But this time it take me three months for recovered. And I am obliged to treat myself for clean inside. It is very difficult and I cannot eat and I drink a lot of oil and oh. I think I going to dead sometime because you know when I have problem with my intestine, it is because I have problem with my parathyroid and because my system don’t metabolism the calcium.

Jocelyne makes a direct connection between the flare up of her ulcerative colitis and learning from her doctor that it is possible that, despite his reassurances, she might not have benefits in the coming year. Four days later she receives the 23-page review form for completion. Although this is likely the second shock she receives (after the doctor’s comments about losing benefits), Jocelyne doesn’t elaborate about how she experienced receiving the form. I know from my own experience that receiving a document that threatens your security at the same time as you are dealing with an acute episode is a bit like being kicked when you are down, utterly besieged, inside and out. Jocelyne needs treatment for the flare-up and again goes to see her physician but he denies she has anything wrong with her. She successfully seeks treatment from another physician who gives her medication, but she attributes her recovery from this episode three months later to her own ministrations. I omitted transcript data here that describes her detailed use of castor oil to resolve the problem by cleaning out her intestines so she can absorb/metabolize calcium better.

Jocelyne wisely gets someone from her church to translate her portion of the application, which she hopes will provide information for her physician about the pain with which she lives, but she doubts her physician even looked at the translation. It is not clear to me at what point in this process she actually gives the application form to her doctor for him to complete the Physician Section, but she wants me to see how incomplete his assessment is as written.

J: So you can see...you know what he write?

He writes [reading from form], "Diabetes, fibromyalgia, and chronic fatigue."

J: That's all.

But he doesn't write ulcerative colitis?

J: No. And parathyroid.

Or parathyroid. Right.

J: No. And you know you can see the parathyroid what he does...what's happened this parathyroid you know. You can read.

Yes. You put this in there?

J: Ya.

Looking at her copy of the form, in particular the section completed by this particular physician, I can see Jocelyne has inserted in her own handwriting "parathyroid" in the margins of the Physician's Section. As someone who has completed disability insurance review forms yearly for decades, as has my own physician I would never think of altering anything my doctor might put on the form. If I thought something was missing or incorrect I would point it out to him and ask him to change it. I would do this because I believe that notations made by me in the margins are unlikely to be taken seriously by reviewers. Jocelyne seems to think that by including this omitted information and

including the type of specialists she has seen in the past as she elaborates (below), she can somehow influence the reviewers. She wants to make sure all relevant information is included despite the fact that it is done in such a way that it has the potential to be treated as irrelevant at best, or illegitimate. I wonder if Jocelyne has sought the help of another professional to complete the Assessor portion of the form.

Did you get another health professional to fill out the form or your doctor?

J: Just the doctor. Ya... I just doctor for the first one. And when I go for give my file... That is from Montréal for *fibromyalgie* and the doctor said I am specialist with *cardiologie* and *physiatre*.

So these are people you would be followed by?

J: Ya. Ya. And you know...look since 1996.

Since 1996. Fibromyalgia, ya. So you put all these things in there for them?

J: Ya. And look you can see (reading from the Montréal doctor's notes, which were included in her submission) "*Douleur generalizé*, [pain, generalized pain] *enfaiblesse muscular* [muscle weakness]. So that on '91.

'91 or '97? (looking more closely at document). Oh '91. You're right. And what did you think...hope would happen by including all this material from Montréal?

J: You know the first doctor can read French so...but the second one cannot.

So did you hope...what did you hope by adding all these extra things to your file?

J: For prove. For give more information and you know for more...is right.

Correct information?

J: Exactly. And I suppose to living on a country bilingual specifically on a government way, I give lots of comment in French, but it never took.

Meaning they don't understand it?

J: Don't read. They don't try to read. Is impossible. But you know, when I do the first application—for 20 page—I write here...

What did your doctor...? [Reading physicians comments from document]

“Disabling chronic fatigue. Unable to perform any meaningful remunerating employment due to incapacitating fatigue. Chronic pain felt in many parts of the body contributes to her inability to function. Diabetes, well-controlled on medication.” So did your doctor fill out the whole form?

J: Ya he do that you know. But I don't know...he's refused.

So the government refused your claim?

J: Mmm...mmm.

And then what did they do?

J: *Remarque*. [shows me more comments from physician]

“She cannot walk far and requires transport. She is unable to carry for example groceries or laundry except for short distances.” So the government refused this right?

J: Ya.

So what did they do? Did they put you on...?

J: They said, “No you cannot qualify.”

You don't qualify. Did you qualify for anything?

J: Yes, just for [speaking French].

What do you qualify for? [she points to document] Persons with Persistent Multiple Barriers?

J: Ya, *c'est ça*.

Jocelyne's monthly benefit in the PPMB designation is \$605 monthly. She receives a dietary supplement allowance of \$42 because she has two illnesses that can be at least partially managed/treated nutritionally—diabetes and colitis—which brings her monthly

benefit amount to \$647. Her monthly rent is \$645. Jocelyne uses her dietary supplement for housing. I ask her how she survives and she tells me a friend gives her food. I am curious about what happened when she learned she would be living with approximately \$200 less monthly.

So when you found out that they put you in this category, what did you do?

J: I go to disability place. [local disability advocacy committee] And I give my file—23 page. And I don't know who I see...somebody there. It's a woman.

At this point, because the documents are at hand, I am interested in what the Ministry communicated to her about this change in her status.

Can I please look at the letter from the government that tells you that you don't have a claim? Do you mind if I take a look at that? I just want to see what...they wrote you a letter and said "no".

J: Ya. [Looking for letter in file, which she hands to me]

It says (reading from letter), "Upon reconsideration of the information provided, the Ministry has determined that you are not eligible for the designation requested (Person With Disability designation). Enclosed is a copy of the Employment and Assistance Reconsideration Decision Form in confirming this decision and the reasons why you were found ineligible. Also enclosed is a copy of the Notice of Appeal to the Employment and Assistance Appeal Tribunal Form. If you wish to appeal this reconsideration decision you must advise the Ministry by completing the enclosed Appeal Tribunal Form and returning it within seven business days of receiving the reconsideration decision to the Employment and Assistance Tribunal. Appeals will not be considered if they are received beyond this seven day period."

You had seven days? You had a week to do that?

J: Ya. So give me very much stress always, always.

Our conversation reverts to discussing the process of having the original Review application form completed by her doctor, and what happened subsequently.

J: So when he do that you know, he write—I am not with him so he don't ask me any question.

Right. So you just leave the form?

J: Yes. And the—and when he give me back I don't looking after you know because I—trust him and I think is OK, probably and he do well. So I give that immediately at the place where I need to go for payment.

The government office?

J: Ya. And at this place I saw—I talking uh this lady talking with me the week before and she looked this paper and she said to me, “Oh I think it is not right for you.” And she gave me another 23-page.

So she looked at your first form and didn't think—

J: Is well.

Meaning it wasn't filled out properly? Is that what you mean?

J: Ya.

By your doctor do you mean? Or by you?

J: She give me another 23 page for I give at another doctor. She said to me, “You need to see another doctor because I think is not—”

He hasn't done it right?

J: Ya—“for your situation” she said to me. So I am surprised but at this time I don't speak English same to now. Is a little bit better. So at this time I go back to see the first doctor I saw when I came [here] because this man speak French. But I—I am not supposed to see this man because this man have

emergency clinic. But he said, “OK” and this man do the first time for I have disability when I came.

Oh when you first came he filled out the form for you to get Disability 2.

J: Exactly. So I go back to see him and I give him the 23 page. You know you can see this man. So I give him the 23 page. [has file on table in front of her]

Is that in here?

J: No because the government didn’t take it. I give but they take out. Don’t want include inside.

So they used the one that you had done originally?

J: Mm mm.

Later I learn more about this sequence of events and her understanding of why she was instructed to complete another form. As it turns out I never get clear as to whether she was required to complete a second application form at this point or had gone to the French-speaking doctor to help her complete the 20 page Request for Reconsideration form.

This is the Employment and Assistance Request for Reconsideration [completed by the French-speaking physician].

J: And I show you what he write, he write here. [Pointing to page]

[Reading handwritten doctor’s notes] “Fibromyalgia, chronic fatigue, diabetes, recurrent colitis as diagnosed by previous physician.” Right.

J: Ya. Because this one don’t said that.

So what has happened now?

J: And... [hands me more to read aloud]

[Reading aloud handwritten physician notes] “Patient states she tires easily, cannot walk for... [here J. has crossed out his estimate of how far she can

walk and inserted her own information, which is undecipherable] or carry more than five to ten pounds for any length of time.”

J: And I change this because is not *real*. I carry two pounds and have pain after.

So what happened? [pointing for me to read on]. “This patient feels discriminated against because she is French-speaking and unable to get her point across in English. It is very difficult to determine the emotional overlay of her conditions.”

J: Yes, because when you saw one doctor, ten doctor and all said to you always no, he don’t want...da da da. Look at this.

[Reading from notes] “Patient states she is too tired to do housecleaning, request help in housecleaning once a week. Uses a basket with wheels to transport items and to stabilize her walking any distance.” So what happened after you...this went to the government? [looks blankly] You don’t know?

J: Refuse.

Refused again?

J: Refused again, always, always, always. So after that I take *avocat* and again, no, no, no. And now I have two dollar on top of my rent. And I don’t have any money for buy my medicine for *diabète*. And my *avocat* ask for I have \$42 a month on top for my *diabète only*, for my *diabète* pills and he said no.

Who said no?

J: The government. And you know what? The second twenty page...

The second...this [pointing to document] reconsideration form [nods] for the doctor.

J: They receive that...

They got that May 15, 2003.

J: OK. But is not include on my file

It's not included on your file?

J: Take out.

They took it out of your file?

J: Ya.

How do you know that?

J: Because is not here.

That's your file?

J: That is my file from the Ministry.

So what did you do with this file? How did you use this file?

J: It is all my file, and 20 page and everything you know we give to the government for they know what about me.

Right. [skimming documents]. So these are what your doctors are saying, but what does the government say about you? [points to document, then I read] "Diet allowance". So the diet allowance was refused. Is that correct?

J: They refuse everything. Ya they refuse everything. So you know I try to give that example because we go to tribunal. So when we go to tribunal I give that at everybody for they understand. I have somebody to translate little bit, you know.

So you have all this written out for the tribunal.

J: For tribunal. I give that [showing me documents that were given to tribunal members].

What was it like for you to go to the tribunal? How did they respond to you?

J: And note you know always this doctor said I need to have help with cleaning and I cannot work and that is on February OK. And I put a paper since 1991. I put this file.

So you were trying to show them that you had these things for a long time.

J: Exactly. And this is from the hospital on 1991 [in Montreal] for ulcerative colitis. And here [points to text, which I then read from]

Stricture.

J: I have. And he said you can see *spasmicité important de sigmoid*.

Significant spasm in sigmoid.

J: So that. And this is *physiatre. Institute physiatre de Quebec*. He explain why I have, he said I have *fibromyalgie* too. And he explain what problem I have with my spine.

Jocelyne is unaware that the medical information, in particular a list of diagnoses is only one small aspect of the information the application form requires from physicians.

Evidence sufficient to establish a severe mental or physical *impairment* (not just a diagnosis) must also be provided, along with evidence that establishes that the impairment directly and significantly restricts daily living activities. If, as Jocelyne's physician indicated, a person's functional skills are not severely impacted (being able to carry 5-10lbs or walking with a basket "for any distance" does not constitute significant restriction) it is unlikely that person will be successful in their claim.

The application form focuses largely on the applicant's ability to perform activities of living independent (or not) of different modes of assistance, thus establishing the need for

help with daily living activities is crucial to a successful application³⁸. Jocelyne links not being able to work with being deserving of income support but interestingly the

³⁸ One of my professional activities as a Registered Nurse in B.C. has been to act as an Assessor for individuals who have had difficulty previously applying for provincial disability benefits. I have become

application form requires no information about whether or not an applicant is able to perform any work.

Jocelyne also seeks resolution with government based on her enduring belief that politicians, when appealed to, will act on their constituent's behalf to rectify an unfair situation. She writes to her federal Minister of Parliament reasoning that he is a physician, so will understand her situation (and also mistakenly, assumes he will be bilingual). He is unable to help her directly but contacts her local provincial MLA who subsequently writes to Jocelyne suggesting that she contact his office "to obtain more information and discuss your concerns." She calls his office to set up an appointment but for reasons not clear to me Jocelyne is unsuccessful securing a meeting with him.

Then Jocelyne tells me that she contacted the local office of B.C. Housing in 2002 and is told her name is not on file which surprises her. She then believes that she is not eligible for subsidized housing because her name is not on file when she thought it was. Later she discovers when she receives her entire file from the Ministry requested by her advocate, that the Request for Reconsideration form that she had sent to them and was noted as being received May 15, 2003 was also not on her file. She sees these two incidents as part of a pattern that are typical of bureaucracies, a person's information is not really fully considered and believes it is a matter of deciding yes or no in a very simple perfunctory way, like an objective test that requires yes or no/true or false answers, no more.

familiar with the 23-page application form, and in my work have made an educated guess about what Ministry staff are looking for and how to present it such that applicants are successful. I have also become familiar with the Request for Reconsideration Form, and have seen Ministry correspondence sent to clients articulating detailed rationale for denial of their claims. I was unfamiliar with the latter documents at the time of my interviews with Jocelyne, so didn't pay closer attention to the documents she allowed me to read (nor was there time allotted to do so), but before the interviews I had conducted a critical discourse analysis of the application form as part of my studies to familiarize myself with this document.

I wonder what Jocelyne imagines happens with her application(s).

What do you think? They don't seem to pay any attention to the medical information.

Ya, exactly.

How do you think they make a decision?

J: I think is only so *simplement de fonctionnaire*.

It's simply...uh...what does *fonctionnaire* mean?

J: It's a...*comment appel ça?* Um...people work for administration.

They work for the administration and...

So these are just functionaries in the bureaucracy.

J: Exactly! And they say "Oh. This is OK. No."

Right. So just making decisions, like a true or false test, yes or no.

J: Exactly. So *c'est la même chose*. It's the same thing. But you know what?

Last June I have stroke.

You had a stroke?

J: Yes. I have heart attack because this case make me so much stress. So you imagine now I have problem with my heart. On top of everything I have disease with my muscles. So now I have more problems with my muscle. I have my problem in June. And I am alone. I have no phone. So really I feel torture.

You feel tortured and humiliated.

J: Because I have no help.

[Hands me a letter]. So the cheque was...you were cut off before you went to the Tribunal. They cut it off a week before?

J: Ya. Before the decision. And you know I have five letter of different people to explain yes he can see me...my health and condition is more bad

each year. And nobody want listen, nothing. I think maybe nobody read nothing. They just take the decision. Three...four years ago they don't want me and probably have something on the computer "don't give anything to this person" because always I go, always is no. So that is very discrimination.

At the time of my second research interview with Jocelyne, she had attended her second Tribunal hearing where a decision had been made to allow her to submit a completely new application entirely in French. She had already begun working on the Assessor section of the application form in pencil, which I learned later was in preparation for meeting and being assessed by a non-physician Assessor. This professional was referred to Jocelyne by her advocate who had used this particular assessor with other clients. Jocelyne was tentatively completing this section without understanding that she needed to convey to the Ministry that because of her physical conditions she required substantial help and was not wholly independent, despite her determination to see (and inadvertently portray) herself this way. I suspect her advocate instructed her to fill out this portion of the form in rough to cue the Assessor as to how to complete this section focused on the ability to perform activities of daily living and whether or not help was needed doing so. Given the kind of responses Jocelyne was penciling in, which she showed me almost immediately upon my arrival at the second interview reflected a more activist role on my part. At the outset I did not initially realize it had been decided to have an Assessor not her physician complete this section of the form, as had been done previously.

You know what is important? Is your doctor needs to put here that you need assistance [looking at form]—these need to be checked off—these ones here because the fact that he's put that you're independent in these categories [in previous forms], the government says you're not disabled.

J: Ya, ya.

This is wrong.

J: Ya is stupid because you know because—you know the doctor I can see every doctor is really fed up to do the paper. They don't want you know so you do that two minutes very fast, he don't want do that is because so many people—I don't know but he don't want do it.

Again she tells me (at length) that people making decisions about her eligibility know nothing of her life and are merely bureaucratic functionaries, and this is wrong.

I know. You're right they shouldn't be making decisions based on little boxes. But that's how they are doing it. They're making decisions based on which little boxes are checked off. And when it says "Independent" and it's checked off, then the government looks at this and says you're not disabled.

J: Ya but is not—yes, I understand but *cette un mal* (?) for the government because the government don't want—uh—don't want to help people. That's it.

That's a bad thing.

J: Ya is for that they make this way for the equation and for everything you know. Because you know if you are doctor and you can see what I have immediately you know I can't work for sure. I'm going to dead.

They're not asking anywhere in this whether you can work. They're asking whether you need help with everyday life. And you *do* need help with everyday life—

J: Yes.

But you need to convince your doctor that you need help. Right?

J: Ya. But what you can do?—I am so tired, and I feel go to dead. That's it you know.

You feel like you're just going to die.

J: Ya, that's it. And it's true. So what I can do? And every day almost you know I need to go somewhere and pick up one letter office and go another place—I am sick. For me is incredible. I have no—I am not strong enough for demonstrate—I am sick. And is very difficult for *mentale* to support these—
comment?—refus—

Refusal?

J: Ya. Is very difficult you know because I am honest. I want to go to work. For sure I do everything as possible for do it.

I read from the decision of the Request for Reconsideration in May to try and show Jocelyne again what the criteria are for being designated as disabled.

January 14 you submitted your PWD application. April 16 denial. May 15 Request for Reconsideration. May 26 completed its review of your request. “Was unable to conclude there was a severe mental or physical impairment. Unable to conclude that the impairment significantly restricts your ability to perform daily living activities. Unable to conclude that you require significant help or supervision.” Do you see that?

J: No I don't understand what this is.

What this is—these are the three criteria for getting full benefits. Right? You have to be able to show that you have a severe physical impairment. They say you didn't do that. You have to show that your impairment restricts your ability to perform daily living activities, and you have to show that you require significant help or supervision of another person to perform daily living activities. Those three things you have to show.

I realize Jocelyne is not comprehending what I am saying about the criteria and I see she has been ticking off each category as being able to complete tasks independently. The Tribunal's decision that she can reapply (and complete the application form again) in French provides another opportunity for Jocelyne, but it is clear to me that even in French

this strategy is unlikely to be successful. I reiterate the point about needing help as a way of demonstrating she meets the new criteria.

So it's really important that not only do you document your illness but that you in very minute detail tell them what you need help with. So for instance—in the morning, “I need help getting out of bed. I need someone to come and cook my breakfast. I need someone”—you're not going to get the help, but you need to say that you need the help. “I need someone to help me in and out of the shower or the bath. I need someone to help me get dressed.” You need to document every little thing. Right? “I need help with shopping. I need help with banking. I need help with every little thing.”

J: Really?

Yep. That's how you do it. Look I'll show you. Now look, see these—right here—Daily Living Activities—well you do need help.

J: Yes sure.

Never put “Independent.” Put I need either “Periodic assistance”—

J: Never here? [pointing to “Independent” column]

No. See shopping. Who filled these out? [she ticked off the Independent column for all]. Did you?

J: [nods]

OK. Carrying purchase home? You know what? I would move that one to here. You see what you're trying to do is—you're trying to—that you have to show them, you have to imagine this is your very worst day, very worst day right? The worst day you could ever have, and then you answer.

J: Oh, I see. Because you know example sometime I cannot—I am obliged to stay always all day in the bed.

So you—OK so here is your very worst day.

J: All day in the bed.

So dressing—

J: No, no. I cannot dress. I do nothing when I am bad.

OK. Would you dress if you had some help?

J: No, I stay in bed.

OK you need to answer their question. Right? So you could also say here
“Takes significantly longer than usual.” Right?

J: Ya.

So you take significantly longer to get dressed, right? Grooming, right?
Bathing. You know so—so what you’re trying to do is you’re trying to show
them that you may not get the help but you could certainly use the help, right?

J: Mm mm. I understand what you mean, ya.

Because you’re ill enough. Because there are days when you could use help
with absolutely everything.

J: It’s very strange for me. Because it’s a—because I am very independent,
mentally.

I know. But physically no.

J: Ya. And uh one day I know I cannot do one thing for long time. Some day I
stay for one week, and I cannot do anything. But I stay home because you
know I manage my life for I have enough for food and roof.

OK. So don’t tell them that you manage your life.

J: Do you understand what I mean?

Of course you have to because you don’t have help.

J: I don’t want, you know.

But it doesn’t matter if you have it or if you want it—

J: Ya. But do you understand what I—

Absolutely—I don't want help usually, but sometimes I could use some, right?

J: Ya.

But I'm like you. I prepare the meals—I don't cook everyday—

J: Ya. *Voilà*.

—because I am too sore right?

J: Exactly.

So that's exactly it.

J: You know when I take my shower it give me pain. You can imagine. Maybe you too, you know, so you understand what I say. I take shower it give me pain.

It's important to say that, but it's not as important to say that as it is to say this, because they actually don't care whether you have pain.

J: So is for that when the doctor see me you know I am always you know dressed and makeup and everything and he think I am well.

He thinks you're doing fine. No. You're not doing fine. Right?

J: No, no.

Right. So you're not doing fine. That needs to be reflected here.

J: OK.

Knowing her advocate well, a prominent and skilled disabled local activist, I suspect the kind of strategy I am urging her to use has already been suggested to Jocelyne. However, the fact that she has begun filling out the form portraying herself as able to engage in activities of living independently tells me the message had not been completely comprehended by her. In this encounter I assume the role of advocate and unlike my experience with her throughout the first interview, she actually begins to recognize that I

am also for the most part invisibly disabled and have insider knowledge to share with her about completing benefit application forms.

Her own self-understanding as being able to care for herself independent of help and the importance of having this aspect of her subjectivity reflected in the application form, along with bureaucratic bumbling, language barriers and insensitive physicians have undermined Jocelyne's efforts to have her benefits reinstated promptly after being re-designated during The Review as ineligible for full disability benefits. Fraught with difficulty and confusion, it has taken the better part of a year for this process to unfold, during which time her chronic conditions are exacerbated and she develops a heart condition enough at least to end up in Emergency with chest pain. Yet out of desperation she persists and because deep down she believes she is disabled enough to qualify for full benefits.

Strategizing (and) The Review

Evelyn's experience of The Review began when she received the letter from the Ministry informing her that she was being reviewed. A month later she received the application form. When she saw the letter she remembers feeling anxiety.

E: Well, there's always anxiety when you see the letter, you know, anything in the mail from them because it could mean—who knows of course what, but—

What's your fear?

E: One assumes the worst somehow. That you have to go in and talk to someone.

And...what's scary about talking to somebody.

E: Um, well—I'm really lucky because the woman I have *now* is nice, but you never know who you're going to get actually. They change the workers at random it seems.

So what is it about going to talk to somebody that raises your anxiety?

E: Well they just have a lot of power and any kind of decision that is made is unilateral. And then to have to go into some kind of process of rev—not review but appeal seems horrific and pretty stressful and time-consuming. Um—ya, I guess just because—me personally having to move around so much it's just been really stressful to have to deal with it, but things are different now. But when I got the letter I think I was I was in a pretty stable situation. It's just kind of an authority, punitive, hierarchical system that seems to be out to get you.

At the time of the Review Evelyn was involved as a volunteer with the local Anti-Poverty Coalition (APOV):

E: APOV was direct action where people would go into Ministry offices and occupy them and not leave until they got to talk to the supervisor and negotiated something on behalf of the claimant.

Evelyn eschewed occupying Ministry offices because she was concerned about getting arrested and having that jeopardize her benefits, but she did volunteer to support activist campaigns. She got going right away responding to The Review once she had received both the letter and application form, which she took with her to her physician. I asked Evelyn about her first impressions of the form.

E: It was really puzzling, confusing. I couldn't quite figure it out, just from looking at it. Um what the differences, you know, there were three sections

and what they were—there was a lot of repetitive questions, questions that seemed similar enough that I wasn't getting why they were asking for three different kinds of takes from—you know different perspectives from different practitioners. But ya, I was pretty suspicious that they were somehow you know creating this trap. Somehow if you didn't have the right strategy you would get caught and then chucked out.

And so given your suspicions, how did you decide to approach the whole thing?

E: Well initially just at the first part itself I wrote a description of my disability—that took a while.

How long did that take?

E: Two months I think probably until I was finished.

Did you write several drafts?

E: Ya, I did. Probably three.

And each one of those drafts would be different along what kind of lines?

E: I think it actually was more like adding in more concrete examples. And then worrying—oh I'm going way—I'm saying too much and a disabled person shouldn't own a computer, shouldn't be able to type, shouldn't be able to think, shouldn't be able to organize their thoughts in some kind of a coherent fashion [laughs loudly]—talk about paranoid! Ya like am I appearing too able-bodied, or able-minded here? Am I saying too much? Are they going to get fed up? Are they even going to read this? And it was only two pages, but I was still like, “Oh OK I've got to edit it. I've got to take stuff out. It's too much.” And then it's sounding too scientific—the first part, the medical like when I told it straight out. They are going to think I'm way too smart.

And then?

E: Then they won't give me my money. *My* money [laughs]. *The* money. So ya it was back and forth and a lot of like doubting about how I was sounding—and whether or not I was sounding too cocky or too confident. Like I have a right to this money and goddammit—you know like that kind of thing that maybe was coming though a bit.

So you settled on a final draft. And why did you limit it to two pages?

E: Um, I didn't think they wanted to read more than that. [Yawns loudly]

Where did that idea come from?

E: I don't know. Probably like the two page resumé, you know.

Evelyn had help completing her form. Before she finished completing her section of the application form she left it with her doctor, who completed the Physician and Assessor sections and then they looked at the form together. Once her physician had completed her sections, Evelyn took the form to an advocate at the Open Door (a local non-profit shelter and advocacy society for the poor and homeless) who gave her tips on how to answer questions throughout the form. Evelyn's description of her disability ended up being two pages long, despite the fact that the form only provides space on one page to answer two questions.³⁹ I asked Evelyn what she was thinking about when she completed this aspect of the form.

³⁹ The two questions applicants are asked to answer are: "Please describe your disability" and "How does your disability affect your life and your ability to take care of yourself?" Applicants are not required to complete this section if they so choose. The latter is particularly significant because this aspect of disability is a crucial part of the 2002 Act's new definition of disability, which states that as a result of restrictions in one's ability to perform activities of daily living "the person requires help to perform those activities" (British Columbia, 2003c, p. 4-5). It is unlikely that the three participants that completed this section were aware of the change in the definition of disability for official purposes, or understood the significance of this clause, although over time community-based advocates deciphered the importance of requiring help in taking care of self and were stressing this aspect be clearly articulated by applicants. Of course requiring even a small amount of assistance does not mean a person receives it. Other than Marion, who is visibly disabled and receives daily assistance, none of the other participants received assistance with activities of daily living although all could have used some. In this way they (and others like them) were in danger of reading this as not requiring assistance, a description that might jeopardize their eligibility.

E: I was thinking about what they wanted to hear.

And what did you think that was?

E: Well I guess that there were—it was like—well I explained as if they had no idea what chronic fatigue and fibromyalgia was. I explained what it was, what it is I mean from kind of a medical standpoint. So I took that from some of the literature I had gathered over the years. And then for the second part—how it affects my functioning—

Your life and your ability to take care of yourself—

E: Ya, then I just got a bit more personal and gave them a few anecdotes.

Like—?

E: Well like um how it was affecting my self-esteem in terms of my family, and that my sister who works as a vocational rehab worker for the province told me that like—earlier on I guess in the disease that I was actually walking slowly to get attention. And she's trained to work with people with disabilities. And that my corporate lawyer brother told me I should just get a job at McDonald's if I can't handle the stress of working as a professional. I gave that kind of detail sometimes of how people don't get it and how it is an invisible situation and how that's really confusing—for me.

Can you just say a little bit about how it's confusing?

E: Well because sometimes I actually do feel OK, and then I'm out in public and people say, "You're looking good" and I'm feeling alright and then I say, "Well ya" and then I start doubting that there is anything wrong with me. Or I'm out in public and I feel really bad, and people say, "Oh you look really good." And then I'm like, "Well I feel horrible" so there is something wrong with me because you think I look good. I don't know—it's just so unpredictable. I can't figure out what causes any of the symptoms hardly, so I can't really just take a pill as if—if it was something really definite like a migraine headache then I would know what it was I'd know that basically it was going to go away in a couple of hours or something.

What else were you trying to convey to them?

E: That it affects all areas of my life.

Not just your ability to make breakfast kind of thing?

E: Mm mm. Just the unpredictability of it makes it impossible to make plans. And then if I do and I cancel them people start thinking that I'm unreliable. Ya. That's hard on my self-esteem too. Like even this morning I said I would do some—a volunteer thing and I couldn't do it. And the person said, "Well we really need someone who we can depend on," and this is just a volunteer situation where you're supposed to have more flexibility as opposed to a job. And they are saying, "Sorry. We don't want your help." And that was a result of—I'd gone to the dentist the day before and the next day I had a huge reaction to the freezing, I guess.

Did you actually comment on your ability to take care of yourself in your response?

E: Well I think I basically said you know the quality of life that I have is a lot less than I want it to be. I *can* take care of myself but it takes three times longer than it used to and there's a lot of things I never get around to and—I gave them an example of...I often have big fines at the library because I can't get out to the library. Um and I'm allergic to the library and so when I go in there it's just in and out. But—so I didn't really—I don't think I said that isn't any way to judge if a person's disabled or not because it isn't, but I think I was indicating that I can take care of myself, but then I didn't want to sound too independent because they would have deemed that I was not eligible.

When I interviewed Evelyn about her experience of The Review, we had a copy of the application form and were able to refer to it to discuss how she completed the form. She talks about the difficulty fitting her condition into the various categories on The Review form. The advocate she works with suggests that Evelyn actually get her doctor to change some of her answers on the "multiple choice" aspects of the form.

So where was the adjustment that the advocate suggested? Was it on these kinds of forms—the functional skills?

E: Ya. More on the piece where you had multiple choice kind of things.

Like this, “What are the person’s limitations in lifting?”

E: Mm mm. Ya. You have to fit into their way of thinking about it. Ya like I can climb 5+ steps unaided, but it may take me three times longer on certain days. I think we only chose one answer, because we didn’t want to confuse them. Ya. And then again it’s “unaided” [“on a flat surface”] ya. OK well sometimes I can walk more than four blocks. I can walk thirty thousand blocks unaided but how long is it going to take me? Uh—and then we agreed on this one—I can’t sit for—I can only sit for less than one hour. And it was actually on—she said, “Always write a comment. Always write in the comments line.”

So always write in the comments would mean what?

E: Just clarification or re-enforcing what you’ve already stated.

Originally Evelyn’s doctor had not added any comments but agreed to do so when Evelyn took the form back to her after seeing the advocate [this is fairly typical of physicians, in my experience. They neglect to add descriptive examples in the space provided]. One aspect of the form asks if you need help on either a continuous or periodic basis around such activities as heavy lifting, which Evelyn needs continuously, meaning whenever she has to lift anything. The advocate advises Evelyn to make sure her doctor indicates that she needs assistance with all the activities of daily living listed on the form on a continuous basis at least half the time. But like Galya and Jocelyne when completing the section about the kinds of assistance she needs she realizes the answers are all hypothetical because usually she gets no assistance, which means most activities take considerably longer. The criteria are presented in the application form in a way that

reveals that certain aspects of Evelyn's functional impairments (and Galya and Jocelyne's) can be attributed to not having help, which could be considered an unintended consequence of defining disability in the way the government has chosen to do, linking it to the need for help with activities of daily living.

E: It would be nice to have significant help and it would make my life normal. I don't have it and I don't require it, but she suggested that I put it in there at some point. I seem to remember that the advocate said, "You really should be in this column (looking at the form) most of the time—continuous assistance." But my doctor she was in this column here—"Takes significantly longer than typical."

What about this section? Meals, paying rent and bills, medications, transportation?

E: And again I was in this column—"Takes significantly longer." So I was a bit nervous about that.

What were you nervous about?

E: Well just that it wouldn't hold any weight.

Why do you think it might not hold weight?

E: Well because—well I guess you know they would then assume if you can do it, but it just takes longer, like you can be working and supporting yourself somehow. I don't know what kind of work would allow you to move slowly.

The Assessor section of the form could have been completed by one of a list of health care professionals, but a physician would suffice to complete all sections of the form.

Evelyn's physician also completed the Assessor portion of the form, but Evelyn worried that the reviewers might think she was not really that disabled because she was not seeing an Occupational or Physiotherapist, or that with the same person filling out both the Physician and Assessor portion that no new information was being provided, which

Evelyn thought they might be looking for. The advice of the advocate to write comments wherever possible displeased her physician and Evelyn was concerned because she thought her GP was only getting \$50 (physicians could actually bill \$200 for completing the form, Assessors \$75), given that Evelyn saw her several times to discuss each item. There is a section on the form about cognitive and emotional functioning, which created some difficulty for Evelyn.

E: Some of that was hard too because I haven't really disclosed my emotional life to my doctor because I didn't want to. So some of it was a surprise to her—"Oh well I didn't realize you were going through that."

And what—what do you mean? Do you feel like saying anything about it?

E: Well like depression or—ya. I don't know I guess if someone is treating my—I know this is dualistic but—my body, my physical health—I get these mixed messages this New Age thing—"Oh you've just got a broken heart that's why you have a pain in your chest." Well no. And she's [Evelyn's GP] like that a bit. Even though I'm not asking for it. So I just kind of vomit and say, "No thanks."

I asked Evelyn if she felt trivialized when her doctor interprets her symptoms in this way.

E: Ya it kind of tries to simplify it or reduce it to, "Oh well it's just your emotions." And so I feel like I've educated her *a lot* about the issues around power and privilege and the assumptions that people make when they are able-bodied and healthy. They just don't need to grasp what it is like for someone like me. Ya plus I kind of felt like I was pretty vulnerable—like I was depending on her. She had so much power in this situation. If she refused to check "poor" instead of "satisfactory" you know—and I'm trying to argue my case—she wasn't that bad but there were certain places where she would just—she would kind of shut down almost and she would just say, "Well, no. I think it is satisfactory." Do you realize what this means to me? You live in a

nice house in Oak Bay. You've got a husband, you've got your health. You're a doctor. If I have too many "satisfactories" I may not have my measly little cheque coming in. You know and how many times am I going to say that before I start going, "Oh fuck this shit." I just—I'm being mistreated by my own doctor, my ally is betraying me. Ya it was pretty scary.

How would she respond to that kind of challenge?

E: Well she would just become very logical and rational and say, "Well I see you once a week and I've observed this and this." And I would say, "Well you don't see me the rest of the time, and here I am telling you...". And part of me is going, "Well wait a minute, am I just lying? Am I exaggerating because I really need to get this secured?" So there was sometimes that I was exaggerating—I think?—you know and I would start judging myself as being untruthful.

But what do you mean by exaggerating?

E: Well what is "satisfactory" and what is "poor", you know? And if I'm checking the "poor" box then that's a lot, that's better for me, that's in my favour. But then it's almost like this whole self-perpetuating thing, well if say "poor me" and I have "poor" whatever, then is that going to you know create that?

In your life.

E: Ya. Is that going to exacerbate it or...? Am I going to start believing this?

It becomes part of your identity.

E: Ya. And I'll never get out of this. And I guess you know just the whole thing that is there a lot for me too is—I'll just mention it—is that I think about people who are *really* disabled.

Meaning?

E: Like they're in a wheelchair. And then I'm taking money away from them if I get it and somehow they don't. And throughout the whole time I kept

thinking to myself I should be out there volunteering at the Open Door or somewhere, helping people fill out these forms. But I couldn't. I don't know. I didn't.

Because you were disabled, right?

E: Ya, ya. And being around other people in distress I've realized is not good for me. I've done it and I can't overdo it anymore. But it was still that pressure I put that on myself throughout the whole frigging five months or something, worrying about all these other people who didn't have the right information and were going to fall through the cracks.

[phone rings, Evelyn answers and when she hangs up makes a comment about how some people look one way but act another]

Well appearances aren't always what they seem; I mean that's partly what you're saying where you are with your doctor.

E: Ya and the level of education. The *potential* that I have and that I have fulfilled in the past. It's just this whole warped and warping mechanism that I can fall into around some of this isn't true or that there is something wrong with me that I've ended up in this predicament.

Right. And the warping is something that you do in your own mind?

E: Ya. With the help of Big Brother.

How does Big Brother help you with that?

E: Well just that's the covert/overt way people are treated that don't produce in this society.

Evelyn deals with some of her uncertainty about not knowing how decisions about being eligible for benefits are made by asking an advocate how she can find out what the Ministry reviewers want to know. The advocate provides her with a phone number at the Ministry and suggests Evelyn try calling. She engages in a unique and potentially risky strategy.

E.: So I phoned and it took me a while on hold and I guess when I was on hold I came up with this strategy. So when the guy came on the phone he said, “Oh hello and what’s your name and blah, blah, and where do you work?” And I lied and told him I was an advocate and that I worked at the Upper Room or the Open Door, and he said, he went on and started telling me how—what they wanted to hear.

And what did he say?

E: He was so disparaging about the clients—“If you—before they come, if you know they are coming, you should watch out the window and see if they are actually like walking quickly or maybe they are even skipping down the sidewalk and then when they open your door and they start limping, you want to be watching out for non-verbal and assessing them not just from what they are saying but...”. Ya. “Are they”—I wish I had written it down—“are they carrying a heavy backpack with them?”

He’s giving this information to you as an advocate?

E: Yah as if I’m an Assessor.

The Ministry person tells Evelyn, who he thinks is an Assessor that applicants should have a lot of documentation from practitioners other than those required because she (as an Assessor) might not know applicants very well and cannot just decide what to include based on what they say about their condition.

Expediting The Review

Like most disabled people under review, Galya received a letter first informing her that she was going to be reviewed and that a detailed application form would follow. The form arrived shortly after the letter.

When did you receive the letter?

G: I received it some time in October. Late October. And they were saying that it [the form] has to be submitted by the end of March [this was the extension date, determined in mid-November. At the time of she received the letter, the original mid-January deadline would have been in effect].

What did you actually think and feel when you first saw that form?

G: It terrified me.

And what was terrifying about it?

G: What I remember very vividly what I felt. I felt at first when I first open it I felt terrified, but I thought this is a trap. This is really almost a no-win situation for many, many people. Am I going to be one of those people? I felt panicky. I said will I be able to...?—I wasn't sure if I would be able to fill it out. And then I thought I will write everything out and ask my doctor to help me. But I'm lucky I have her. Not everyone has a [names physician].

Exactly.

G: So I thought it was—also I made a judgement that, it's not written out with benign attitude. It's almost like—not a good will—yah I thought it just set up for people to be sifted away from the right to receive assistance. But I was—Sally, I felt panicky. I was terrified, so I looked at all these pages and read and oh my God! So then I went to my physician—she is such a good support for me and she knows me as I said for a long, long time. So she filled it in and then I took it to [names another physician who served as Assessor] and he filled his part.

What about your section? I'm wondering how long it took you actually to write your piece. And that includes different drafts—like how long did it take you?

G: The first draft definitely—the one that I brought to my doctor—not less than two hours. Three hours probably.

And did you think about it for a while, like a week or a few days, what you might say?

G: No I was so terrified to—I said—I had this paranoia Sally—I said if I send it first who knows? Maybe they will—it happens—they take first twenty people or two hundred and the rest will be just shuffled so I better send it right now. So I thought I should be sending immediately. I got the letter for example in the afternoon mail. The next morning I went to Social Services [the Ministry office, two bus rides away]. I picked the form and that very day I made an appointment with [names physician] for the next day. And then the whole afternoon and evening I worked on it. And then the next day already with her. So it took me less than a week to do everything. And I submitted it right away, in two weeks after I received it.

In October?

G: In October. I submitted it immediately. And guess what, Sally?

What?

G: I send it off and three days later I got the letter that said for me I didn't have to do a review.

Despite her close contact with local disability advocacy groups, Galya was unaware of the lobbying by disability advocacy groups and professional associations to influence the government to exempt people with mental disabilities because of the enormous emotional stress they were experiencing due to increased fear of losing benefits. At the time of the initial letter and during the period she was completing the form, Galya would not have known that she would be receiving a letter exempting her from The Review. I tell her that she would have received the exemption letter even if she had not completed the form in such a timely fashion.

G: That's what I thought. Because I definitely knew that they wouldn't already have reviewed me or anything. But you know it was so much—I felt so much anxiety.

When you received the letter? Or when you were filling out the form?

G: When I was filling it out. So I'm saying that on one hand I felt—when I got the second letter of course I felt relieved, but on the other hand I felt angry. [speaks in an angry tone] What is going on? I just—my energy was so angry. But as I said I felt mixed emotions—relieved, but also angry. The letter—too bad I don't have it—it felt, it came across as very unpersonal and not apologetic in any way. It's like well we ask you to do that. Now we don't ask you to do that anymore.

We changed our minds.

G: We changed our minds. Exactly. So it just disrespect for people. Looking at people—I felt as if I was related to as if I was a number somewhere or some piece of a pawn.

They could just do anything they wanted really.

G: Ya.

You did all that work right? [ya] including filling out your portion and making sure [physician] did and getting it to [the Assessor, also a physician]—all the things that you had to do, it just was for nothing.

G: Inhumane. Like—victimized. I don't want to be a victim. You know Sally interestingly enough, for me completing this form was not just physically difficult, it was very difficult emotionally. It was very much in a state of panic really until I finish it and I send it. Then I still had tension. My blood pressure went up too—because I get sometimes high blood pressure.

I asked Galya what she might have imagined would happen with her form once she had sent it to the Ministry.

G: I was very hopeful that I was going to get the disability because it was uh—[names physician] she's very, she knows the system. She knows that at this time in my life I needed that. So she stood in her integrity but she—like she didn't manipulate it or falsify anything. But she knows the language and

the way to write. Because part of—because my part I wrote it out on a normal piece of paper and came to her with a tentative draft. Then I talked to her—

About what you had written?

G: About how clearly it was written and exactly what style and language.

And she suggested changes in stylistics and corrected several things.

What kinds of things?

G: For example, I wrote several personal things about myself, how I *feel* about something. And she said, “Nobody will care about your feelings. You have to really put them in a language that stays with symptomatology more than the state of the person.”

Right. Your subjective experience doesn’t really count for much. It’s kind of more the objective symptoms that you have.

G: That’s right. She also suggested to add some things

What kinds of things?

G: Uh. Let’s see. For example she stated that I was at that time specifically—I had tremendous difficulties to bathe myself. And she moved it, she said, “This is good to put at the beginning” and to state in clear words in a way I have such depressive state in the mornings that I cannot even go and bathe myself. And I have not done this and this for three weeks. And so once she reviewed—some of the things, for example that I feel very sad, and I feel like I don’t belong nowhere. Some of the things she said I shouldn’t be putting there. It should have been shortened. So after that I just sat in her office and I wrote it out—

Oh you did. Right on the form?

G: Yes, because the client it seems like is supposed to write first. So I rewrote it and then I left it with her and she filled out her part. Very professionally.

And she said she will phone me when she finishes it, in few days—three, four days. She phoned me—her receptionist phoned me. I went to pick it up.

Galya was able to advance a previously-scheduled appointment with her other physician, the psychoneuroimmunologist who would be completing the Assessor section of the form, and took the partially-completed form to him for completion. A week later she returned to his office to pick up the completed form.

G: After he finished it, I picked it up and I went to social services—the office [north of the city] for disabled people. And they have in the office, they have a machine—it's free for the clients. We can make any copy of documents. So I made a copy there. And I had my envelope and I gave it to them and I said, "Can I trust you that you're not going to lose it?" And the woman was kind of friendly and said, "Well 100% nobody can guarantee but I'm going to put it right now in the mail." So that's what she did.

I asked Galya how clear it was to her what the government was actually looking for in terms of information about her disability in the review form. Galya would have not have known about the new aspect of the definition of disability for official purposes, the ability to care for self. In her advice to Galya about what language to use, what to include and where and how to describe her situation her physician clearly had some understanding of how the Ministry might read Galya's form and advised her accordingly. With the exemption letter Galya was freed from worrying about whether her strategies/tactics had been successful, but along with feeling disrespected in this process she remained in the dark as to whether she would have received her disability designation upon review of her application.

I assumed that Galya must have read all three sections of the form before completing her own.

G: I did. I read everything.

And so what kind of sense did you make of those sections when you read them? Can you recall?

G: Mm mm. Yah. Well I remember that, for example, when they ask here the client “Describe your disability” and “How does your disability affect your life and your ability to take care of yourself?” Those two questions I didn’t have problems with.

You felt able to do that.

G: Ya, and it made sense to me. It made sense to me.

What made sense to you about that?

G: That if I am applying for economical support I’m asked to disclose what is the reason for me to do that and how is my life stands right now in such a way that I am not able to support myself on my own. So that the first part—describe what I am sick with—but also how does that affect your life and how you can—on another hand your ability to take care of yourself—it’s a little bit um. It’s almost—it really says to me that unless you cannot take care of yourself you are not allowed to have any support. And that is harsh. That is harsh. But I didn’t like that, I would say. I didn’t like that.

So what’s harsh about that in your mind?

G: Mm mm. Well, I think that sometimes a person can—sometimes a person can take care of themselves alright, or appear to be taking care of themselves. People can cope with life yet be not able to work regularly and that is not included there.

What is not?

G: There is no room here for people who are able to cope with life and not able to work at the same time. This, those two questions—they are really set up for me in such a way that say you have to be totally unable to take care of yourself. You have to be *dis*-abled. That’s why it’s disability. That’s the part that is hard I think. Because if someone is in a disaster situation where they cannot work at all, but I have—I don’t have split personality disorder, but I

have what? A façade all my life even in the most miserable situation many people wouldn't even know that, because I have a belief system that people are not the cause of my misery. Why should they suffer? There is some kind of pride or self-respect in a way not to be a mess when it is not appropriate. So I when I mostly get—when I am very, very depressed—I mostly withdraw and people just don't really know about it.

They don't see you so they don't know—

G: Yes. So as bad as it went at some point, I never have felt before but life lost all meaning. Was no meaning at all. Nothing made any sense. So when we don't have meaning in life then it is just like—what to live for? So that was kind of exposing oneself a little bit—this question, “how does your disability affect your life and your ability to take care of yourself.” Your ability to take care of yourself I wouldn't leave it. I would just—if it was “how does your disability affect your life and your ability to work?”

You think it should have read “your ability to work.”

G: To work, yes. Not to take care of yourself. Because they are levels, layers. And definitely I know people who cannot work for several years but they still look after themselves.

Right. So you think the distinction of being able to take care of yourself is an arbitrary one and is stringent.

G: It is. It is very (sighs) it is really—say if you are not capable to live on your own without outside physical support you will not get it.

That's what it implies.

G: That's what it implies, yes.

So in response to what it implies, so then did you paint a picture of yourself as—

G: As they wanted me to paint it.

As not being able to take care of yourself?

G: That's right. Although it's true. But it's not true uh, well it is [sighs loudly]. It is true. But I said to my doctor, "if I write all these things, do you think—I'm afraid I will be locked up in a facility. I don't want to go to that."

So what you're pointing to is this kind of tension between describing your life as it is and some of the potential implications of that—I mean being hospitalized for one, right? [mm mm] —and basically telling the truth about your life. There's this kind of tension where if you paint this really dire, terrible picture something might happen [yes] that wouldn't be good. [yes] But on the other hand if you paint a picture of you doing well then you won't have your disability support. So you're in this kind of in-between place—

G: Caught.

Caught, yes. And—in filling out the form the way you did you have read it in a particular way and then based on your own interpretation or reading of what is required of you, then you have completed the form in a way that you would hope paints a picture or depicts you as a person needing help with taking care of yourself, at least enough that warrants them supporting you financially.

G: That's very accurate. That's very accurate.

So I'm just wondering if there was anything about the other two sections that might have informed your own response.

G: Yes. I remember very well that for example, this section where they say "Are there any significant deficits with cognitive and emotional function?" I utilized some of their terms, like motivation, emotional disturbances, attention span. Yes. I use it because it really—well I said "they are looking for it and I do have this symptoms" and so I just uh use it, yes. [reading from form] Management of finances. Management of finances—I was not able to manage my finances.

So you included some of these elements in your own personal statement?

G: Yes. I brought their—

Using their language?

G: Changing it a little bit. I wouldn't say I cannot manage my finances. I would say um, "I have difficulties to distribute my money adequately."

Right, but same idea—this element is included.

G: Absolutely.

I was interested in what the waiting period (albeit truncated) was like for Galya and how not knowing one way or another affected her daily life.

G: In my case I guess I was so traumatized by the application those three days I kind of like post-traumatic—I was disassociated. True. It's just like—if it was longer I may have had some more apprehension thinking, "oh they are not saying that to me." But because it was short and I just put it forward and I was pleased with how—all three of us how we filled it in. So it was kind of—I don't think I thought of it much at that time. Although there was always at the back of my head there was always zoom like zoom "what if they still will not approve you?" there was that little tiny zzzzz [buzzing kind of] mm mm. And I'm sure I think if it was longer period to wait it would have become stronger. Because me having here no family at all—it's scary, looking sometimes at people on the street.

So it would have immobilized you in some way?

G: Oh, I would have been much more traumatized. So even though I felt angry when I got the letter I still as I say I felt very relieved.

It's really the period of not knowing went from when you got the initial letter and then the form to the point where you got the second letter. That period was as you were saying when your blood pressure went up.

G: Ya. Drastically.

And did you notice any thing else about your life that was different during that period?

G: I was kind of agitated. I was agitated. Like I share with you that I don't have this manic phase, unfortunately [laughs]—

Then you would get all sorts of things done, right?

G: Yes. I just spoke to someone and she just moves mountains. I never have that. I used to be pretty stable. I always thought of myself as monotone person. All my life I could have tasks and I could have worked hard towards it on an ongoing basis—but when I got this letter and when I got—and I picked up the form, I was just agitated. Usually, normally I am not agitated. I was honestly—I was sleeping and eating or wherever I would go, whatever I would do, whatever chore I would needed to be done, it was always in my mind and what do I do? And how do I do? Who do I ask more? At one point, by the way, at one point I was downtown—I forgot to tell you—and I passed by this street church, Open Door, I happen to know the minister. He's awesome person. I don't remember now where I came across him but he had a workshop for whoever was to come about his form.

Oh did he?

G: He did. So showed up. I went. It was since I got the form until I gave it to [my doctor] maybe three days. Because in that period I went to the workshop that was there. And the minister was there and another fellow—I think he was lawyer and the minister, they were talking and telling us basically not to be totally terrified. That is the reality now and we have to deal with it. And they offered help to people who didn't have a physician or whatever. They also said that they had social worker there who could be a second person, social worker. And then—that was good workshop.

What did you learn? Can you remember?

G: It consoled me a little emotionally. I was in such a state of agitation and having those people who said, “don't panic” they will deal with this anyway and if you have the disability you have to put it right there and we will be

behind you and most likely that you will get it. So the assurance was very important. That was very good.

So in that workshop were they giving people pointers or tips on how to fill out their portion of the form? Do you remember?

G: They mainly said that if you don't know how to write it come to us and we will help.

Right. So they weren't like giving you a list of things. [no] They were—it was just kind of a general “don't worry there is someone here for you that can help you with this process.”

G: That's right. And if—they said if you have a doctor talk with the doctor. And probably that is now I realize, probably that helped me to think it over better and write it over and go to [names physician]. Because I don't want to lean even on [her] much. But certainly I did that and that was very helpful.

I was interested in what sense Galya might have after having completed the form of the government's general purpose or intention for The Review.

G: Well I could be paranoid but the government just want to get rid of people who are not uh—just get rid of many people who are on assistance. And they want to reduce it to a very small amount of people who are totally not able to take care of themselves. We are not talking about work as I said taking care of themselves physically and mentally. And only those will be getting support and the rest. It just seems like they want the disabled people to disappear from the face of the earth. It's scary because Canada still is the best place in the world, I believe strongly. But the politics we have now in B.C. it's not humane. Because when anything is built on the suffering of one child as they say, one person, it is not alright. And this country is so rich. Somebody told me it all comes from taxes. It's scary and—but you know I must say something. You know I was so embarrassed and ashamed before I made a decision to ask for disability, for several years when I was not—when I was

on temporary relief from work—\$500 and no, nothing—I was very embarrassed and ashamed. But then as time progressed I didn't feel ashamed. Like right now I don't feel ashamed.

So how do you feel right now that's different?

G: I just feel that anyone who is not well in the human society must be given support and help. So I just feel that I deserve it.

Pulling up short and thinking

The point here, I think, is not to feel bad about the injustice or the suffering in the world; nor is it to read this...so that you will know what to do to change whatever is wrong. The point is to pull up short before the possibility that what you thought might be true might not be, that what you thought was normal or natural might be the product of political struggle, and to start—from just that place—to *think*, which means to question, to critique, to experiment, to wonder, to imagine, to try. (McWhorter, 2005, p. xvii).

Perhaps what McWhorter refers to with respect to my work is pulling up short and *thinking/writing* guided by two closely connected questions emerging from what has been revealed here about disabled women's lives: What does my approach enable me to say about disabled women's lives? and, What will I want to have said, in light of this approach as it intersects with my social justice commitments (as articulated in my purposes, p. 57)? I imagined this chapter as a "discussion" chapter taking shape around my concerns for the health, socio-economic well-being, and citizenship of the women whose lives are made visible in this study. It may appear here as a disjuncture, discontinuous with what precedes it; this is not my intention. This chapter serves to situate these concerns in ways that I take them up critically to open readers to possibilities at work/play in these women's uncertain lives.

Throughout the research, as I engaged with my participants and what they told me about their lives and then moved to interpreting these accounts, I have been continuously struck not just by the kind of deprivation they live with, and how much they have to struggle and strategize in response to disciplinary powers that shape their everyday lives, but by how they manage to keep going, to have lives worth living despite the uncertainties of

chronic illness and the insecurity and privation of poverty. It is not my intent to valorize them here, rather I wish to bring into relief the embodied effects produced in their everyday lives through power relations germane to income support policies and programs, in particular how the pervasive and all-encompassing conditions of structural poverty (an effect of government exercises of power) shapes so much of what they do, how they respond and how they care for their bodies and health.

In my life with disability and limited income support systems (tied to my previous paid employment) I have struggled economically and done without and lived with heightened anxiety and uncertainty about the stability of my benefits, but over time I have had advantages that have enabled me to pursue chosen aspirations like completing my education (while receiving generous scholarships). I have also been in the position of being able to take care of my body and life with support and in ways beyond the means of the women in this study whose income fails to compensate for the additional costs of disability, providing me with the energy needed to have a deep, enriched intellectual, social, political and cultural life while allowing me the space and time I need to rest and rejuvenate. These have enabled me to enjoy good health and live well, or experience well-being, while living with a disabling chronic illness, something the women in my study aspire to but do not achieve.

In this chapter I wish to bring different ways of thinking/writing to bear on poverty and well-being (and its corollary, health) and citizenship in the lives of disabled women. I recognize these aspects are mutually productive and there are myriad and multi-layered possibilities for how they intersect; my interest is in how they might offer different ways of understanding the women's lives with disability depicted here. As I reconsider the

participants' lives with respect to poverty, well-being and citizenship the possibilities for understanding how power is enacted in/through their everyday embodied lives and what it produces, as explicated in this research, deepens (or is expanded). In so doing I further expose the unintended consequences (or the inevitable excesses) (Murray Li, 2007) produced as the Ministry puts into practice its stated intentions of improving disabled people's lives by fostering their independence and participation in community, revealing how "governing programs operate imperfectly (Teghtsoonian, 2008, p. 72). In the context of the Liberal neoliberal policy agenda the version of independence referred to here is less reflective of ideal versions of disabled persons' social citizenship than the imperative of economic independence such that these disabled 'good citizens' recognize the limits of state provision and increasingly assume the obligation to be more self-reliant (Hillyard Little, 1999; Brodie, 1996) despite being positioned poorly to do so, thus producing a limited version of community participation. What is revealed more keenly is how conditions associated with structural poverty are also productive of the uncertain, unsettled version of health/well-being the women live with and how they enact an eroded version of citizenship, such that good health and robust well-being are difficult to achieve and sustain. These are the uncertain subjects of this chapter.

Unsettling well-being

Earlier I discussed the difficulty of defining health in the context of being a woman living with a disabling chronic illness. My concern here is less in creating an objective, biomedical definition of health that might apply to the women in my study and more focused on different ways that their health is constituted through the social, political, economic and cultural forces that shape their everyday lives (Inhorn, 2006), reflecting

effects produced through power relations on their embodied experiences of health. This pursuit leads me to a differently imagined way of thinking about health, that is, well-being.

Even though the health promotion literature considers poverty “one of the strongest determinants of health” (Raphael, 2007, p. 5) and particularly inequalities in health, like being female and disabled means being more susceptible than others in Canada to living in poverty, this deterministic social model of health is limiting in some of the same ways as the social model of disability. In holding social processes and structures wholly responsible for health and well-being it fails to take into account the complex interaction between the different ways the women in this study are being positioned (as poor). Of equal importance is how the women also live/take up positions as “creative [and embodied] agents acting on and shaping” (Popay, Williams, Thomas & Gatrell, 2003, p. 396) the material deprivation with/in which they live and the embodied effects on their health/well-being, as demonstrated in their narrative accounts. Popay, Williams, Thomas & Gatrell (2003) suggest that the local and personal knowledge/expertise and subjectivity of those living in poverty articulated in narrative form has “theoretical significance for our understanding of...health inequalities” (p. 386) in the context of the complex “relationship between individual human agency and wider social structures” (p. 399), thus challenging predominantly modernist approaches embedded in the social determinants model.

The narrative accounts presented here connect the local and embodied knowledges of each of the women with their experiences of powerful social structures and processes that

shape and govern embodied ways of everyday life, exposing the unsettled version of health each lives with.

Bodies that depart from the norm—bodies marked by some condition of impairment—disrupt the rules. Striking their own “bond with the natural order” (Rich, 1976) these bodies disrupt the metaphors of science, infuse static notions of health with deeper, richer meanings, and challenge law makers and policy makers who seek to create conditions of justice for all. (Frazee, Gilmour, & Mykitiuk, 2006, p. 224)

Difficulties defining health given the complexities described above prompt me to consider well-being as a more robust way of understanding the quality of the participants’ lives, one that takes into account aspects of living with/in “the unwieldy humanness” of disabled women’s bodies beyond normatively-constructed biomedical versions of health (and disability) (Frazee, Gilmour, & Mykitiuk, 2006, p. 224). I subscribe to the World Health Organization’s version of health as a resource for everyday living (WHO, 1946) although I eschew the idea that good health is a static reflection of well-being, or an end unto itself. Health and well-being are often used interchangeably, but are not actually the same. Health is a corollary of well-being, a component of and contributor to the experience of well-being but not all of it.

The version of well-being at the centre of the claims I am making draws from the work of critical disability studies scholar Marcia Rioux and others (Rioux, Bach & Muszynski, 1993; Hay, 1993; Rioux, 1994) whose understandings of well-being go beyond ideas about health to include not just elements such as the identification and pursuit of an individual’s aspirations, but those social, political, and economic conditions that enable women with disabilities to enact well-being, including having basic needs met,

experiencing personal and economic security, participation and inclusion in social life and exercising citizenship rights. Rioux (1994) also suggests that the meaning of equality ought to include well-being and vice versa, with the outcome being “equality of well-being” (p. 127) in particular for people with disabilities. On this view equality of well-being takes into account not just individual embodied differences “in the achievement of social well-being” (p. 143) but also the important idea that “the conditions and means of participation may vary” (p. 143) from person to person and entail accommodation particular to individuals “in the distributive paradigm of social justice” (p. 143).

Citizenship is understood to be a contributor to well-being, in particular those aspects of citizenship (social rights) that govern entitlements to citizens such as levels of economic security, enabling disabled women to live “according to prevailing standards of living” (Hay, 1993, p. 23) and to participate in society.

For the women in this study, the ability to make freely-chosen plans for their lives in line with their capacities and desires—to be self-determining above and beyond just strategizing to survive—is both substantially thwarted and truncated. Surviving in the ways they do primarily means just getting through any given day, expending valuable energy just to access the basic necessities of life and engaging in such critical and difficult decisions about whether to purchase either expensive medication or food, or forfeit secure housing in order to purchase alternative health treatments, all the while caring for and living in bodies that make everyday activities challenging (and sometimes impossible). Having personal plans for the future, even the near future could be seen as hubristic given what the participants face on a daily basis. For example, even though Galya dreams of returning to school to complete her degree, following through on this

aspiration is inconceivable to her given not just her current circumstances; a way out of the poverty and the unsettled health seems wholly unattainable. These thwarted aspirations deeply affect her experience of well-being, leaving her trapped and arguably unfulfilled. Even Marion who has presumably acted on aspirations to serve the disability community by engaging in valuable part-time work with other disabled people understands that increasing her current activities is dangerous in terms of the stability of her benefit and not worth the risk.

Decisions about how to live their lives and who they may become are made in the context of various social relationships with close (and close by) others, within communities of support and interest, and within institutional encounters. Hay (1993) suggest that along with self-determination, “mutual recognition” is a key component of well-being such that individuals “recognize themselves as respected persons from the vantage point of others” (p. 11) with whom they are in relationship and recognize others as valuable and worthy of respect, in the context of a society that values diversity. With respect to this aspect of well-being, all the participants experience diminished and compromised respect in particular in encounters with Ministry workers, but also with physicians and beyond to encounters in everyday social situations. Galya recounts being differently treated in an unfamiliar banking institution and believes how she appears (wearing second-hand clothes which are all she can afford) contributes to her experience of being devalued. Evelyn remarks about the “surprise” of having her identity suddenly revealed to others waiting in Ministry offices.

Having a secure, reliable, adequate source of income such that basic needs are met, along with compensation for the additional expenses germane to living with a disabling chronic

illness contributes greatly to the kind of personal security from which individuals can imagine and plan a desired future. The kinds of fears, uncertainty and insecurity about losing their benefits and worry about how to meet basic needs contributes to the participants' social and personal vulnerability, eroding their well-being.

Rioux, Bach & Muszynski (2003) posit that well-being ought to be enjoyed equally by all members of society such that our aspirational pursuits and values are enabled and protected, requiring the equitable "distribution of certain goods or conditions that contribute to and make possible well-being" (p. 99). With respect to the well-being of disabled people equality and resource allocation are implicated in each other; how resources are allocated reflects societal and legal understandings of equality and vice versa (Rioux, 1994). Disabled women living on income support live with "substantive inequality" (Doe & Kimpson, 1999, p. 45); their everyday lives are shaped by decisions made by government about "criteria concerning appropriate recipients of social assistance or support, and the nature of legal entitlements and citizenship rights" (Rioux, 1994, p. 127), shaping how disability itself is understood for official purposes, but also in the public consciousness. A "critical victory for neoliberalism" (Brodie, 1996, p. 131) has been the alteration of public expectations about citizenship entitlement, the collective provision of social needs" (p. 131) and "the progressive hollowing out of the welfare state" (p. 130), significantly eroding the well-being of disabled women. (See also Larner, 2000, p. 9).

The un/certainty of poverty

The reallocation of resources in B.C. that constitute the material conditions that might enable the women in this study to experience well-being falls well short of their need for physical and economic security, exposing the inequitable distribution of resources for those who are disabled, and producing the kind of impoverishment and economic vulnerability (and related fear) the women live with. These women are among the poorest British Columbians.

B.C. disability benefits are means-tested, a situation in which the government establishes its authority to closely examine a person's financial assets and to determine the level at which those assets are deemed excessive. It sets stringent limits and polices them on the actual level of economic 'stability' of any disabled person who is either applying for or receiving benefits. The regulations are clear (and extensive) about various categories of unauthorized income not exempt from either claw back or penalty. Although Evelyn was the only participant to speak about direct dealings with the Ministry around unauthorized income, which to her surprise and good fortune unexpectedly worked in her favour, Marion is also aware of the limits of allowable earned income and the potential for penalty should she exceed it, both revealing anxiety and fear directly concerned with the stability of their income support. Evelyn also refers to the annual review of three months of claimant bank accounts, which most claimants are subject to, presumably to establish that she is not receiving any unauthorized income beyond her benefit amount, nor has cash assets in excess of the allowable amount. Surveillance of this kind produces fears, mistrust and uncertainties that erode the participants' capacity for and experience of well-being.

The experience of poverty is the experience of deprivation...[an] inability to meet basic needs and participate in a range of everyday activities [that] is a source of constant stress and worry. (Raphael, 2007, p. 165)

Relatively little research exists conveying the everyday experience of being female and disabled and living in poverty in Canada, to which this research makes an important contribution. Much of the existing research focuses on able-bodied, lone female parents' experiences of poverty in different provinces, but two B.C.-based feminist participatory action studies include some participants women living with chronic illnesses (Ocean, 2005; Reid, 2004), all receiving provincial welfare or disability benefits. The qualities experienced by the women in these studies include exhaustion, anger and frustration, unrelenting stress, depression and despair, isolation, and experiences of worthlessness, along with deterioration in physical well-being.

In this study, the four participants' accounts mirror these qualities and expose the struggles, the material and social deprivation, the disadvantage and the inequities they live with; their stories bring to life and deepen our understanding of what it is like to live as person who is disabled, female and poor. They are positioned in such a way economically and socially to be unable to partake in and enjoy amenities they cannot afford such as cultural activities, like the symphony that Galya longs to hear, visiting the museum, dining out, or forms of recreation requiring a fee. Although I did not ask about other aspects of social life, none spoke of having fun with friends (or about friends they may have) or even the possibility of more intimate personal relations with others of the same or opposite sex.

Poverty, revisited

Poverty, in particular the kind of structural poverty (du Toit, 2005) the women in my study live with significantly constrains these disabled women's lives. According to du Toit, the idea of structural poverty takes into account how poor people are positioned (unequally) in society in terms of their access to resources and the kinds of (unequal) social relations they encounter and are vulnerable to. This is not simply a matter of social or economic inclusion or exclusion, the latter a popular motif when describing those living in poverty. du Toit reminds us that dichotomizing these and assuming that inclusion is "necessarily beneficial" (p. 16) fails to account for a more complex version of social and economic positioning such that "the problem is not that poor people have simply been excluded from particular institutions, resources or larger processes but that they have been *included* on inequitable or invidious terms" (p. 16), a dynamic he describes as "disabling" (p. 19).

Nowhere is this dynamic more evident than with The Review, wherein the women in the study are enlisted in a process that positions them inequitably with respect to decisions being made on their behalf about their economic security. Interactions between my participants and Ministry officials and to some extent with doctors also starkly reveal this inequity in social positioning and its disabling effects. Nonetheless, how the women engage in exercises of power while responding to poverty as lived also produces the possibility of acting strategically/enacting agency, however effective (or not) in changing structural poverty and power relations that position them inequitably and compromise their well-being. We see this in the participants' active connections to community-based

networks designed to help them negotiate institutional barriers to health and other resources.

Farmer (2005) similarly posits that poverty is an instance of inequality of power, such that those who are economically disadvantaged and marginalized are also politically so. This political inequality positions those who are poor to enact impoverished versions of health and well-being and citizenship, given that their “greatest task is to try to survive” (p. 6). Using a human rights approach Farmer also argues that the social and economic inequality the poor are consigned to comprise structural violence, a kind of “cloaked violence” (p. 8, citing Héritier, 1996) operating in the everyday lives of those who are economically and socially marginalized. We see this in the myriad ways the women are denied services or are given meager compensation for chronic conditions requiring nutritional supports, or are unable to afford nutritious food, or have to strategize in the face of bureaucratic pressure to comply with imperatives to relocate to less costly and complicated (for the system) living arrangements, or learn suddenly required medications are no longer subsidized.

When he suggests that poverty ought to be considered socially “in relation to issues of morality and economy, but perhaps is best understood in terms of governance and the ‘forms of life’ [or conduct of life]...promoted by it” (Dean, 1992, p. 218), Dean points to the importance of my participants’ accounts of deprivation and struggle in their everyday lives and of how these accounts/lives are shaped by governing institutions. The disabled women’s lives described herein reveal how their responses to exercises of governmental power in/form lives constrained not just by the ways government enacts power, but by all-encompassing economic deprivation and impaired access to sufficient social and

practical resources needed to meet the basic necessities of life, and to participate in society in ways most British Columbians do, apart from struggling to survive. The poverty the women live with is not then an individual failure but rather a failure of government to provide adequately for these women who are unable to provide for themselves in a substantially gainful way. Yet it is a failure each woman is required to live with, individually. The description of the Faustian bargain both Galya and Marion make, opting for “dependency in exchange for ‘security’ [or insecure security], choosing ‘risk management’ in the present” (du Toit, 2005, p. 14) rather than investing in an imagined (and perhaps unimaginable) future, captures “the desperation...and complexity of these choices [and] slippery slopes” (p. 14) they face, producing eroded well-being.

Disabled women are generally exempt from the discourse of responsibility (for their impoverished lives) that other welfare recipients are targeted with (although, those living with mental disabilities, especially those compounded by substance misuse are often stigmatized this way) (Reid & Tom, 2006). Yet those disabled women who, like the participants, live with chronic illnesses are subjected to a version that potentially holds them responsible for not improving their health enough to return to work and ideally free themselves from poverty. After all this is the message implicit in the province’s stated intentions for disabled people receiving income assistance in B.C. In its strategic plan, vision statements, and Ministry service plans, the government has set vague, but lofty goals for the well-being of disabled citizens, a primary concern of this Ministry. Recall (p. 214, this document) that the Minister at the time proclaimed the government’s intention to provide timely access to supports for people with disabilities in order that

they “can become independent and participate more fully in their communities”

(Coleman, 2009, p. 3)

What is (necessarily?) absent from this proclamation is how, through public policy decisions determining how economic and social resources are distributed unequally the province of B.C. is complicit in legislating/structuring poverty, which both sets the material and social conditions for and produces the versions of health/well-being and citizenship we see the participants enacting. In effect this kind of structural poverty is another exercise of bio-power such that the women’s bodies and lives are being governed in ways that significantly deprive, constrain and disadvantage them. Put simply, they are living poorly.

Disabled citizen/subjects

To be candid, I’ve never felt too easy with the idea of citizenship. Even the word sounds so upright, so sure of itself, so disembodied. Can we rescue the word, infuse it with meanings of vulnerability and imperfection? What do you, my fellow citizens, think? (Frazee, 2003, p. 13)

If the women in this study are indeed living poorly, how might they be enacting (whatever versions of) citizenship (are available to them) and how might that shape their well-being? My concern here is with that aspect of citizenship usually referred to as social citizenship which conveys a particular status on disabled women, but is also a *practice* that governs their position and participation in communities of interest and support; it is often associated with benefits and entitlements, disability income support programs being one concrete example (Devlin & Pothier, 2006; Prince, 2009). Most importantly, the material supports the participants receive and the structural poverty

with/in which they live shape their ability to be independent and participate in community. Most of the women's citizenship practices are focused on meeting basic needs as best they can given their impoverishment and engaging in social interactions (and exercises of power) towards that end. In these women's lives, citizenship as an aspect of social well-being is deeply compromised. How the participants enact social citizenship reflects relations of power that both produce (and rely on?) the exercises of agency (compliance/resistance) in which the women in the study engage, shaping their very limited participation in community and eroding their well-being, to which citizenship is a contributor.

The participants strive towards well-being in their own ways, most of which reflect basic survival, thus constituting a terrain upon/in which it is possible to act (or enact whatever versions of well-being are available to them). It is also a territory "where government might intervene" (Cruikshank, 1999, p. 40) producing the subjectivity of the women as particular kinds of citizens and revealing the exercise of bio-power in their lives, investing them with the 'ability' to participate "voluntarily in programs...and institutions set up to 'help' them" (p. 41). For Galya, Evelyn and Jocelyne the enactment of their social citizenship on a daily basis is primarily relegated to this kind of participation and more coercively while undergoing The Review. Everyday reliance on community-based social support services, like the local food bank, St. Vincent de Paul, the Action Committee for People with Disabilities, and Together Against Poverty shapes their social citizenship in ways that orient it towards fulfilling material and other needs. Although the women may experience being part of a community (of need), it is always as supplicants.

Despite downward social mobility associated with acquired disability status, the women in the study are being disciplined to be active, responsible citizens who minimize claims (Meekosha & Dowse, 1997) on the B.C. government. Active citizenship characterized by independence and community participation favours the ‘duties’ and neglects the ‘rights’ aspect of a disabled woman’s citizenship. Marion’s life and activities most closely approximate normative versions of social citizenship than the other participants; she is a young, disabled woman living independently from her parents with home support, working part-time and volunteering as a disability advocate in the community. Yet this ‘independence’ is under constant threat as the health authority pressures her to move to assisted living, thus reducing the financial burden on government and complexity of managing her supports. She resists her ‘duty’ to do so, arguing from a social model of disability perspective that her ability to participate in community, an aspect of her social citizenship and her well-being, is contingent on the kind of independence she has established for herself, even with minimal home support. Being poor means she is unable to purchase further supports that would arguably enhance her ability to be more independent and socially engaged and less exposed to coercive moves by the health authority.

Michael Prince (2009) refers to Canadians with disabilities as “absent citizens” (p.1), but this way of thinking assumes a binary—that there also citizens, presumably those who are white, male, able-bodied and fully-employed (and contributing to the economy)—that ‘show up’ or are otherwise ‘present’ in the public imagination, or perhaps are more able to make their presence known. Meekosha & Dowse (1997) argue that the disabled citizen is “a contradiction in terms” (p. 50), which discursively suggests something contested

with respect to the juxtaposition of being disabled and being a citizen (Prince, 2008).

What is being contested from this disabled woman's point of view is negative and devaluing societal attitudes and beliefs that disabled women "are passive citizens reflecting a source of increasing demand for services" (Meekosha & Dowse, 1997, p. 50) in the context of neoliberal austerity measures, with questionable contributions to society.

Although they may be by and large socially isolated and invisible, the women in this study are not absent from citizenship. Rather like other disabled people they live with the effects of significant material and social disadvantages produced by "deep economic, social, political, legal, and cultural inequality...unequal citizenship, a regime of dis-citizenship" (Devlin & Pothier, 2006, p. 1), or "disabling citizenship" (p. 2). Cruikshank (1999) reminds us that income support programs "are not modes of governance that cancel out citizenship....They are modes of government that work upon the capacities of citizens to act on their own behalf" (pp. 38-39). When notions of citizenship are tied to ambiguous and contested concepts like independence and participation and community they (and the women in this study) move into uncertain territory.

If citizenship is already ordered currently such that non-disabled women are "genderless citizens" (Brodie, 1996, p. 138), disabled women then inhabit spaces "that hover stateless, somewhere between the public and private spheres, while they remain a burden in both" (Meekosha & Dowse, 1997, p. 55). Although Das and Addlakha (2001) suggest that "the domestic sphere...is always on the verge of becoming the political" (p. 512), for the disabled women subject to income support policy in this study there is continuous leakage between the domestic and the political spheres. They are mutually productive of each other in such a way that, for example, care of their bodies in various ways is now

considered “a requirement of citizenship” (Davis, 2002, p. 27); by assuming responsibility for their own self-care they can become “enterprising individuals” (Rose, 1998, p. 150) who ‘choose’ to work on themselves in ways that foster citizenship that is meant to be “active and individualistic rather than passive and dependent” (p. 165). Responsibilization (Teghtsoonian, 2008) of this sort is particularly problematic in the lives of these disabled women.

Paradoxically, the women in this study have been left to make lives/live on their own/care for their bodies, a particularly onerous version of independence, while being caught in the web of economic dependency and poverty germane to living on income support. What/whose versions of participation and independence are being privileged in normative versions of citizenship? And what might be underpinning them such that citizenship for the women in this study is disabling, making them uncertain citizen subjects?

I explore these questions by returning to the problem of disabled women’s inequitable inclusion, in particular drawing from Titchkosky’s (2003) powerful idea that

To know *how* disability is produced as a problem in need of a remedy, to know how, for example disability is given shape as an excluded population in need of programs enabling inclusion, is to come to know how and why disability matters. (p. 518).

By constituting disability as a problem and operating programs like income support to remediate the problem of disability, people with disabilities “are made to matter as excluded and marginalized” (Titchkosky, 2003, p. 518) citizens that then need to be included (or be seen to be included). The B.C. government subscribes to the biomedical

understanding of disability arising from individual biological abnormality, which in turn is understood to create negative personal consequences for disabled individuals, in particular a “lack of participatory citizenship” (p. 520) that presumably (and ideally) is remediated through income support and related programs that target these individuals.

Yet “understanding disability as a biological-matter-gone-wrong is a conception that does not readily fit with any conception of the ‘citizenry’ ” (Titchkosky, 2003, p. 522), or at least those imagined citizens who do not biologically depart from (unexamined, unquestioned) conceptions of normalcy. The assumption underlying the B.C. government’s intentions that the disabled women in this study, for example, could potentially achieve independence and participation in community both supports taken-for-granted constructions of the able, employed (or employable) normal male citizen for whom “employment is a key obligation of citizenship” (Teghtsoonian, 2008, p. 72) while excluding (or invidiously including) these women, who inconsistently and not always successfully (fail to?) “fit into and embody that which is regarded as the normal order of daily life” (p. 529).

Explicating what kind of citizen subjects the participants are enacting or producing/reproducing produces a critique of all-too-common idealized narratives or discourses of triumph (over the adversity and personal tragedy of disability) and the way government programs, often colluding with these are oriented, as in, “We’re going to help you out and then you’re going to rise above/overcome all your personal difficulties, become independent, and participate in community.” Moreover, “all citizens should want to participate so as to maximize their independence and enhance their well-being” (Titchkosky, 2003, p. 534). Disability then is a robust site within the context of the

neoliberal strategies of rule for this kind of heroic individual with a body and a life that can be ‘worked on,’ and thereby helped to conquer the personal tragedy and individual problem that is disability, and approximate normalcy. Here discourses of normalcy “unconnected to differential embodiment” (p. 530) work to produce the participants’ subjectivity as inadequate citizens whose citizenship is disabled. Normalcy and what constitutes a normal life are left unquestioned, obscuring how these in/form how disability is embodied and lived by the participants and leaving them feeling as if their lives do not matter.

The women I interviewed do not even come close to approximating any ‘normal’ version of citizenship; in many ways their lives demonstrate the failure of the B.C. income support programs to enable them to reliably replicate (or participate successfully in) this heroic tale of triumph over the tragedy of disability. Despite their impulse to/desire for normalcy (and energy spent approximating it in various ways), what is materially available to them produces lives narrowed and tightly constrained. Yet by engaging in embodied (and often challenging) practices of everyday living they undertake the work of making a life for themselves. This raises the question of how the experience of having to approach government (and community-based organizations) for services to aid in making those lives, fractures their own coherent stories of being *able* to live/make their lives, however constrained. We can clearly see this juxtaposition in the life of Jocelyne as she interprets the questions on The Review form about being able to care for herself as questions about her capacity for independence, which she values and believes she is capable of, but answering in this way in the context of applying for benefits produces unintended consequences, not what she requires to exercise her fragile independence.

Titchkosky (2003) reminds us that the “processes of life governments are primarily concerned with are those surrounding ‘employment,’ i.e., a life ‘able’ to make a living” (p. 532), thus the disabled women in my study whose faulty bodies (and for Galya) minds/emotions impair their ability to work and participate in community are potentially normal workers and community participants who are not either working or participating, and can presumably re-enter this highly desirable terrain with (minimal) financial assistance. In addition, both chronic illness and disability pose a threat to contemporary social order because they both “represent...deviance from socially acceptable levels of [economic] productivity” (Devaney, 2008, p. 123). Chronically ill women living our lives during those times when we are unwell are assigned little if any societal value (Devaney, 2008). The “unquestioned ability to participate, to work” (Titchosky, 2003, p. 532) is invested in the so-called normal citizen while “people with disabilities are invested with abnormalcy” (p. 532); all citizens are constituted as potential economic contributors with disabled citizens “devalued and depicted as an expense” (p. 533). Yet we see how the women in the study are making lives and making their lives work, however successfully, even while being excluded from making a (substantially gainful) living.

...what if instead of stigmatising the unacceptable in order to supplant it by the acceptable, one were to call into question the very rationality which grounds the establishment of a regime of acceptability and the programmatic logic whereby the ‘unacceptable’ is regularly restored to the ‘acceptability’ of a norm? (Gordon, 1980, p. 257-258)

Disability challenges how normalcy is understood and in doing so challenges how we understand and enact citizenship. From a disability perspective binaries like inclusion/exclusion and rights/responsibilities are inappropriate “because they contain

within them unspoken assumptions that social relations are carried out by able-bodied individuals free to contest or follow civil mores” (Meekosha & Dowse, 1997, p. 52).

What then are the possibilities for conceiving of (writing and thinking through) embodied living with disability in ways that do not have to approximate/require normalcy? As the everyday lives of the women in this study reveal, both living and making a life with disability are both ordinary and extraordinary. Deeply embodied they are “continually and constantly intertwined with flux, change, variation and vulnerability” (Titchkosky, 2003, p. 534), resisting categorization. Their ordinariness as part of what it is like to be human disrupts normal/abnormal binaries, but they are caught in a liminal space situated between the embodied ‘abnormalities’ they live with and their desire to be included “in an abstract version” (p. 537) of normal, disembodied citizenship subscribed to and promulgated by the B.C. government. Thus their lives with disability are thoroughly invested with a “cultural contradiction” (p. 537) potentially excluding them further from being the citizens they imagine, undermining their well-being and producing disabled citizen subjects.

Concerning ourselves with politics

We are going to be governed whether we like it or not; it is up to us to see to it that we are governed no worse than is absolutely necessary. We must therefore concern ourselves with politics...to mitigate as far as possible the damage done by the madness of our rulers. (Pierre Elliott Trudeau, in George Elliot Clarke, 2006, p. 89)

As I have proceeded in this writing I have been continuously circling around an aspect of being a disabled citizen that relates directly to the lives of the women in this study and

that troubles me. When I articulate this concern as a question like, “What is society’s obligation to disabled people?” it does not entirely ring true for me, and prompts further questions. Who are “the rulers” whose madness politics might mitigate? More importantly, why might it be (disabled or other) citizens’ responsibility to mitigate this madness?

This study concerns itself with the intersection of disabled women’s lives with provincial government income support policy and programs, which implies there are three subjects (of scrutiny)—the women (and their lives), the provincial government, and the relationship (of power) between them. But the women live in contemporary society, albeit on the margins. This living-in-society prompts me to question how other citizens might be implicated in the lives of these women in ways that enable the marginalization and uncertainty produced through government exercises of power with which these disabled women live. Making visible the poverty and struggles of disabled women living on “last resort” benefits thoroughly challenges our beliefs and values as citizens about supporting economically and socially marginalized Canadians. In particular, the lives of the women in this study provoke questions about the kinds of thresholds we as citizens set (or permit governments to set) below which we/citizens will not tolerate policies that produce the kind of poverty and income inequality, unsettled/uncertain health and well-being, and disabled citizenship these disabled women live with. But we do in fact tolerate *disabling* income support policies developed and enacted on our behalf. How so?

Is it a matter of willful ignorance imbricated with how people separate/distance themselves from those who are different, as in, “*They* are being taken care of so I do not need to concern myself with it/them?” Or “*They* are not working or contributing to

society so a minimum benefit is appropriate; besides the government only has so much money to go around.” Or even scapegoating and individualizing as in, “If we/the government is taking care of them and *they* are struggling or in poor health, then it must be something they are doing or not doing.” Perhaps it is also related to how invisible the women (and other disabled people are) in part because of living with invisible chronic illnesses but also because of the effaced nature of their participation in communities even when visibly disabled. Non-disabled citizens in this province going about their daily lives rarely encounter (or have meaningful encounters with) impoverished disabled people like the women in this study, unless they are employed or volunteer in organizations set up to ‘help.’

As an undergraduate and graduate student (and an instructor) I never met anyone living on B.C disability income support studying at the university. This makes sense because higher education is beyond the financial means of B.C. benefit recipients and any student loan they might apply for would exceed allowable income/assets. A “monthly incentive supplement” (British Columbia, 2003c, p. 37) of \$50 is available to those wanting to participate in “vocational self-improvement” or any program preparing the recipient for employment. It comes with a stipulation that “the recipient does a minimum of 20 hours of work experience” in the month prior to receiving the supplement. None of the women in the study would qualify for this supplement.⁴⁰

What is being done for/to recipients of B.C. Benefits in this province reflects what we are willing to do for them or allow government to do on our behalf, which raises questions

⁴⁰ Please see Appendix A, Note 4, pp. 364-365 for details of the related Training Initiative Supplement, which cannot be provided while receiving the Monthly Incentive Supplement.

about tolerance. In her complex study of tolerance in the liberal democracy that is the U.S., Wendy Brown (2006) argues that tolerance is “an effective instrument of contemporary biopower” (p. 38) which produces and positions subject/citizens, marking them/their bodies “as undesirable or marginal, as liminal civil subjects or even liminal humans” (p. 28) all the while “appearing only as a genial, neighborly value” (p. 38). Thus “contemporary tolerance takes shape as a normative discourse” (p. 45) depositing difference into that which is tolerated, “reinscribing the marginalization” (p. 45) of individuals already on the margins and iterating the normalcy (and privilege) of those who practice tolerance. Imbued with power, the practice of tolerance as “respect for human difference” (p. 19) (as long as different ‘Others’ make no political/economic demands that might alter/disturb the status quo) also takes shape as a substitute for social justice or equality, depoliticizing difference, while neutralizing any political claims different ‘Others’ might make.

Interestingly, Brown does not take up disability or the position of disabled people in her study, a major oversight, but reading her work with a critical disability lens enables me to translate and apply some of her ideas to my questions about how society ought to treat disabled people and suggest ways able-bodied citizens might be complicit in their marginalization and disadvantage. After all, disabled bodies/minds are quintessentially marked as deviating from the norm and the taken-for-granted, normative understanding is that their disabled bodies are central to the problems with which the women in the study live, for example. A generous version of tolerance, one that aligns with the individualized personal tragedy model of disability is that these women unexpectedly and tragically became disabled through no fault of their own and though different from able-bodied

citizens they ought to receive some form of support. The assumption being made is that this support is enough and even if there is evidence to the contrary this is tolerated in part because *they* are not us; the claims of disabled people are not the primary concern of the non-disabled citizenry who may respect differences, to a point. Political and economic claims of disabled people for social justice, and more to the point, the institution of a living wage potentially encroaches on the privileges of non-disabled citizens and challenges their capacity for tolerance.

Being unfamiliar with the lives of those who are subject to income support policy reflects a critical aspect of tolerance and the different (and unequal) positioning of those whose circumstances are tolerated (by others) and those exercising tolerance. Yet if we know little or nothing of the lives of those who receive B.C. Benefits other than they are being taken care of we position ourselves in ways that abdicate responsibility for their well-being.

Coda

Given the span of time during which this project has taken shape, including the research interviews conducted in late 2003 and early 2004, readers may wonder what, if anything, might have changed in the participants' lives. Given my community contact with disabled people locally, and ongoing with two of my participants, I believe the answer is "not much." Rather than provide details about my participants that are beyond the intention and ethical obligations of this work, I choose a somewhat different way of "concerning myself with politics." Here, briefly, I bring to readers' attention certain aspects that are particularly relevant to this study of relatively recent efforts (2014) of the B.C.

government to assess the efficacy of the disability assistance program, as reported by the Auditor General.

The Auditor General's report (Jones, 2014) had three objectives that were focused on determining: a) whether services are accessible; b) whether the Ministry can “demonstrate that its eligibility decisions and payments...are accurate and timely” (p. 17); and c) whether the Ministry “can demonstrate whether or not it is contributing to improved outcomes for... clients” (p. 17).⁴¹ Findings concerned with the latter two objectives are particularly relevant to this study, and the question of what has changed over time. Elsewhere I have described monetary changes, like employment earnings exemptions being increased to \$800/month, and how in 2007 the assistance rates for single individuals were increased to \$906 monthly, which includes the maximum shelter amount of \$375.

What I found particularly interesting (and relevant to this study) about the findings from the Auditor General's 2014 report were twofold: 1) those concerned with his conclusion that “Risks are not being fully managed to ensure benefits are being provided only to eligible individuals...” (Jones, 2014, p. 7); and 2) those focused on the inability of the Ministry “to demonstrate that the program is contributing to the lives of clients” (p. 7), both articulated in the following statement:

The ministry has a number of systems and processes in place to assess the financial eligibility of its clients and to proactively monitor, detect and recover overpayments. However, the ministry's system and processes for determining initial and ongoing eligibility for the PWD designation can be

⁴¹ Interestingly this audit followed (but is reportedly independent from) a public consultation, known as the White Paper, focused on how B.C. could increase accessibility and decrease barriers for people with disabilities. In the Auditor's report published on the B.C. government website, the current premier (Christy Clark) asserts that “Our government has set a vision for B.C. to become the most progressive jurisdiction in Canada for people with disabilities” (British Columbia, 2015, p. 2).

improved. The audit found that there is a risk that some individuals may be in receipt of PWD benefits that do not qualify. In addition, there is a risk that clients whose condition has worsened are not receiving services that they would benefit from...Ministry information provided indicates that given the level of assistance provided, some clients' basic needs may not be met. In terms of tracking the health and social outcomes of the disability assistance program, the ministry has developed some preliminary indicators but has not fully evaluated the results. (Jones, 2014, p. 7).

Given the Auditor General's mandate, recommendations emerging from these two particular findings are focused on instituting primarily quantitative administrative mechanisms to measure and rectify the gaps identified in service. However they reveal somewhat contradictory impulses, given the focus of my research on the disciplinary effects of governmental exercises of power. In the case of questions about eligibility, the Auditor General recommends "a risk-based approach for reviewing initial and ongoing eligibility" (Jones, 2014, p. 9), raising the spectre of increased surveillance and unwanted government intrusion in the lives of disabled women receiving benefits. Presumably "risk-based" refers to the need to undertake this recommended review process in ways that are cost-effective for the Ministry, given findings from the previous Auditor General report (Streliaoff, 2004) into the Disability Designation Review that a sampling of files ought to have been reviewed initially to see what percentage of clients might not have continued to be eligible, rather than engaging in a costly review of everyone in the province receiving benefits.

Most important for this research is any move by government to institute ongoing review of eligibility (rather than just annual review of financial eligibility) is likely to have

deleterious effects in the lives of disabled women. In contrast, a move to establish parameters for determining whether or not clients' basic needs are being met and that track health and social outcomes seems to indicate concerns shared by this researcher for the well-being of disabled women in B.C. Whether these will be acted upon, and potential effects, remain to be seen.

I end (it) here

June 10, 2015

A week ago my official relationship with the government of Canada with respect to income support based on my disability status ended. Canada Pension Plan-Disability (CPP-D) had sent me monthly disability benefits since becoming disabled and unable to work at my job as a Labour and Delivery nurse in 1982, terminating this month as it must for those who reach my age. My relationship with the insurance company that carried and disbursed my long-term disability benefits (from which my basic CPP-D benefits were clawed back) ended over five years ago when I took early “retirement.”

I am free. I no longer need to look over my shoulder in fear of losing my benefits, nor worry if I am complying with policies in ways that would jeopardize my income support. I can earn as much money as I like at paid employment and not worry about clawbacks. I can do whatever work I want and pursue higher education without consulting with the government or the insurance company to have it approved.

I never imagined the doctorate would take so long, but perhaps at the beginning I did not factor in the oft-quoted phrase from the 1986 National Film Board film about five Canadian disabled women’s lives, “The impossible takes a little longer.” But this makes sense given the unpredictable, fluctuating nature of the chronic condition with which I live, and how it requires daily energy, attention, care and rest in order to take care of all I am responsible for. To have a life. When something pressing arises—the death of a parent, exacerbation of symptoms—my attention and energy necessarily go elsewhere undermining my ability to remain focused on my writing.

I also did not imagine that being a doctoral student while living with a disabling chronic illness would become a way of life, lived together, (an) *ensemble*, each in/forming the other. The women in this study are denied the privilege I have had to return to school, to (over time, not without struggle) negotiate a supportive and effective disability accommodation at the university, to benefit from the financial support of scholarship, to be as active as possible in the broad academic community, to deepen my understanding (and hopefully others') of how power is exercised and lived in disabled women's lives. To write.

The doubts and uncertainties I have lived with have shaped this academic journey, along with the uncertain, unpredictable embodied experiences germane to living with chronic illness and the administrative challenges (and power relations) of disability, but also 'natural' doubts about the quality of the dissertation/writing. Even now I wonder if I have met the standards expected of doctoral work and especially the kind of interpretive work I have undertaken. Judith Meloy (1994) suggests "thought-provoking" (p. 44) questions centered around six criteria focused on how quality might be assessed in qualitative research, which I bring forward to readers (in abridged form) here to make their own judgments of the quality and merit of this study. I also draw from my own intentions for the research, along with Alvesson & Skoldberg's (2000) criteria and combine them as follows:

Verité: Does the work ring true? Is it consistent with accepted knowledge in the field, and if not, does it address why? Is it intellectually honest and authentic? Does it unseat, unsettle, disrupt taken-for-granted understandings of the embodied lives of those who are disabled, female and poor? Are the

ways power is enacted in these disabled women's lives and how these lives are shaped by it sufficiently explicated?

Rigor: Is there sufficient depth of intellect, rather than superficial or simplistic reasoning? Does it depart from fixed forms of subjectivity?

Vitality: Is it important, meaningful? Does it have a sense of vibrancy, intensity, excitement of discovery? Is the voice/persona of the researcher appropriate? Do metaphors, images communicate powerfully?

Integrity: Is the work structurally sound? Does it hang together? Is the design of the research appropriate?

Utility: How relevant is it? Does it contribute to the fields from which it emerges? Does it open new departures for action?

Aesthetics: Is it enriching, pleasing to anticipate and experience? Does it prompt insight for readers? Does it touch readers' spirit in some way?

(Meloy, 1994, pp. 44-45; Alvesson & Sköldbberg, 2000, p. 274)

I leave these questions with readers, not to limit or summarize the quality and value of this dissertation, but to stimulate conversation and discussion, opening us to the (unseen) possibilities this research enables.

References

- Abu-Lughod, L. (1990). The romance of resistance: Tracing transformations of power through Bedouin women. *American Ethnologist*, 17, (1), 41-55.
- Allen, B. (1999). Disabling knowledge. In G. B. Madison & M. Fairbairn (Eds.), *The ethics of postmodernity: Current trends in continental thought* (pp. 89-103). Evanston, ILL: Northwestern University Press.
- Allen, B. (2005). Foucault's nominalism. In S. Tremain (Ed.), *Foucault and the government of disability* (pp. 93-107). Ann Arbor, MI: University of Michigan Press.
- Alvesson, M., & Sköldbberg, K. (2000). *Reflexive methodology: New vistas for qualitative research*. London, UK: SAGE Publications.
- Anderson, C. A. (2005). Real and ideal spaces of disability in American stadiums and arenas. In S. Tremain (Ed.), *Foucault and the government of disability* (pp. 245-260). Ann Arbor, MI: University of Michigan Press.
- Bach, M., & Rioux, M. (1996). Social policy, devolution, and disability: Back to notions of the worthy poor? In J. Pulkinham & G. Ternowetsky (Eds.), *Remaking Canadian social policy: Social security in the late 1990s* (pp. 317-326). Halifax, NS: Fernwood.
- Barry, A., Osborne, T., & Rose, N. (1996). Introduction. In A. Barry, T. Osborne & N. Rose (Eds.), *Foucault and political reason: Liberalism, neo-liberalism, and rationalities of government*. (pp. 1-18). Chicago, ILL: University of Chicago Press.
- Barthes, R. (1975). An introduction to the structural analysis of narrative. *New Literary History*, 6 (2), 237-272.
- Bateson, M. C. (1990). *Composing a life*. NY: Penguin Books.
- Breckenridge, C. A., & Vogler, C. (2001). The critical limits of embodiment: Disability's criticism. *Public Culture*, 13 (3), 349-357. (Special Issue: Disability Criticism)
- British Columbia (1996). *Disability Benefits Program Act [RSBC 1996] Chapter 97*. Victoria, BC: Queen's Printer. (Retrieved October 6, 2003 from http://www.qp.gov.bc.ca/stateg/stat/D/96097_01.htm)
- British Columbia (1999a). *BC Benefits: the first three years*. Victoria, BC: Ministry of Human Resources.
- British Columbia (1999b) *News Release: Government restores earnings exemption*, November 19, 1999. Victoria, BC: Ministry of Social Development and Economic Security.

- British Columbia (2001a). *Welfare to work, Phase 2, Provincial and Territorial Updates*. Victoria, B.C: Ministry of Human Resources. (Retrieved March 2, 2015 from <http://publish.uwo.ca/~pomfret/wtw/html/provsum/bc2.html>)
- British Columbia (2001b). *Core services review: presentation to Cabinet, November 7, 2001*. Victoria, BC: Ministry of Human Resources. (Retrieved March 2, 2015 from http://www.llbc.leg.bc.ca/public/pubdocs/bcdocs/347634/november_7_2001/hr_core_review_nov_6.pdf)
- British Columbia (2002a). *2001/02 Annual report: A new era update*. Victoria, BC: Ministry of Human Resources. (Retrieved July 24, 2003 from http://www.bcbudget.gov.bc.ca/Annual_Reports/2001_2002/hr.pdf)
- British Columbia (2002b). *B.C. Employment and Assistance Shelter and Support Rates effective July 1, 2002*. Victoria, B. C.: Ministry of Human Resources. (Retrieved July 24, 2003 from http://www.mhr.gov.bc.ca/publicat/bcea/bcben_rates.htm)
- British Columbia (2002c), *Employment Strategy for Persons with Disabilities, April, 2002*. Victoria, BC: Ministry of Employment and Income Assistance. (Retrieved July 24, 2003 from <http://www.mhr.gov.bc.ca/PUBLICAT/DB/EmployStrat.pdf>)
- British Columbia (2003a). *Employment and Assistance for Persons with Disabilities Act [SBC 2002] Chapter 41*. Victoria, BC: Queen's Printer. (Retrieved April 25, 2003 from http://qp.gov.bc.ca/statreg/stat/E/02041_01.htm)
- British Columbia (2003b). *Employment and Assistance for Persons with Disabilities Regulations*. Victoria, BC: Ministry of Human Resources. (Retrieved July 24, 2003 from <http://www.mhr.gov.bc.ca/PUBLIC/VOL1/pdf/3-5pol.pdf>)
- British Columbia (2006), Ministry of Employment and Income Assistance *News Release: Higher income possible for those most in need*, February 2, 2006. Victoria, BC: Author.
- British Columbia (2014). *Disability consultation report: Moving towards an accessible B.C. A reflection of the voices of British Columbians heard during the disability white paper consultation*. Victoria, BC: Ministry of Social Development and Social Innovation.(Retrieved September 9, 2015 from <http://www2.gov.bc.ca/assets/gov/government/about-the-bc-government/accessible-bc/disability-consultation/disability-consultation-report/disability-consultation-report-largetype-accessible.pdf>)
- British Columbia Coalition of People with Disabilities (December, 2001). *The Disability Benefits Program Act: A necessary starting point*. (Submitted to the B.C. Core Services Review Committee). Vancouver, BC: Author.
- British Columbia Coalition of People with Disabilities (2002, May/June/July). Analysis of changes to disability benefits legislation. *Transition*, 12-14. Vancouver, BC: Author.

- British Columbia Coalition of People with Disabilities (2003, March). Changes to disability benefits legislation. *Transition*, 6-7. Vancouver, BC: Author.
- Brodie, J. (1996). Restructuring and the new citizenship. In I. Bakker (Ed.), *Rethinking restructuring: Gender and change in Canada* (pp. 126-140). Toronto, ON: University of Toronto Press.
- Bruner, E. (1984). Introduction: The opening up of anthropology. In E. Bruner (Ed.), *Text, play and story* (pp. 1-16). Prospect, ILL: Waveland Press.
- Bruner, J. (1986). *Actual minds, possible worlds*. Cambridge, MASS: Harvard University Press.
- Burkitt, I. (2002). Technologies of the self: Habitus and capacities. *Journal for the Theory of Social Behaviour*, 32 (2), 219-37.
- Butler, J. (1995). Contingent foundations: Feminism and the question of "postmodernism." In S. Benhabib, J. Butler, D. Cornell, & N. Fraser (Eds.), *Feminist contentions: A philosophical exchange* (pp. 35-57). NY: Routledge.
- Cameron, S. (December 2002). The disability review process is deeply flawed, and is making people sick with anxiety and stress: Three provincial associations protest review process. *Carnegie Newsletter*, 4.
- Chouinard, V., & Crooks, V. A. (2005). 'Because *they* have all the power and I have none: State restructuring of income and employment supports in disabled women's lives in Ontario, Canada. *Disability & Society*, 20 (1), 19-32.
- Clare, E. (2001). Stolen bodies, reclaimed bodies: Disability and queerness. *Public Culture*, 13 (3), 359-365.
- Clarke, G. E. (2006, April). Poetic rule: Liberty is a work of art. *The Walrus*, 3 (3), 89-91.
- Ceci, C., Purkis, M. E., & Björnsdóttir, K. (2013). Theorizing accommodation in supportive home care for older people. *Journal of Aging Studies*, 27, 30-37.
- Coell, M. (2002). Message from the Minister. In British Columbia, Ministry of Human Resources, *2001/02 Annual report: A new era update*. Victoria, BC: Ministry of Human Resources. (Retrieved July 24, 2003 from http://www.bcbudget.gov.bc.ca/Annual_Reports/2001_2002/hr.pdf)
- Coleman, R. (2009). *2009/10-2011/12 B. C. Ministry of Housing and Social Development Service Plan Update*. Victoria, BC: Province of British Columbia. (Retrieved June 8, 2010 from http://www.bcbudget.gov.bc.ca/2009_Sept_Update/sp/pdf/ministry/hsd.pdf)
- Colyar, J. (2009). Becoming writing, becoming writers, *Qualitative Inquiry* 15 (2), 421-426.

- Corker, M. (1998) Disability discourse in a postmodern world. In T. Shakespeare (Ed.) *The disability reader: Social science perspectives* (pp. 221–233). London: Cassell.
- Corker, M. (1999) Differences, confluences and foundations: The limits to “accurate” theoretical representation of disabled people’s experiences? *Disability & Society*, 14(5), 627–642.
- Corker, M. & French, S. (Eds.). (1999). *Disability discourse*. Philadelphia, PA: Open University Press.
- Corker, M. & Shakespeare, T. (2002). Mapping the terrain. In M. Corker & T. Shakespeare (Eds.), *Disability/postmodernity: Embodying disability theory* (pp. 1-17). London: Continuum.
- Cruikshank, B. (1999). *The will to empower: Democratic citizens and other subjects*. Ithaca, NY: Cornell University Press.
- Das, V., & Adlakha, R. (2001). Disability and domestic citizenship: Voice, gender, and the making of the subject. *Public Culture*, 13 (3), 511-531.
- Davies, B. (1991). The concept of agency: A feminist poststructural analysis. *Postmodern Critical Theorizing*, 30, 42-53.
- Davies, B. (1994). *Poststructuralist theory and classroom practice*. Geelong, Australia: Deakin University Press.
- Davies, B. (2000). *A body of writing 1990-1999*. Walnut Creek, CA: Altamira Press.
- Davies, B. (2003). *Shards of glass: Children reading and writing beyond gendered identities*. Cresskill, NJ: Hampton Press.
- Davis, L. (2002). *Bending over backwards: Disability, dismodernism, and other difficult positions*. New York: NYU Press.
- Dean, M. (1992). A genealogy of the government of poverty. *Economy and Society*, 21 (3), 215-251.
- Dean, M. (2010). *Governmentality: Power and rule in modern society* (2nd ed.). London: SAGE Publications.
- Delaney, M., & Bell, S. (2008) The complexities of negotiating power under conditions of chronic illness. In D. Driedger & M. Owen (Eds.), *Dissonant disabilities: Women with chronic illnesses explore their lives* (pp. 29-40). Toronto, ON: Canadian Scholars’ Press/Women’s Press.
- Denton, M., & Walters, V. (1999). Gender differences in structural and behavioural determinants of health: An analysis of the social production of health. *Social Science & Medicine*, 48, (9), 1221-1235.

- Denton, M., Prus, S., & Walters, V. (2004). Gender differences in health: A Canadian study of the psychosocial, structural and behavioural determinants of health. *Social Science & Medicine*, 58 (12), 2585-2600.
- DesMeules, M., Turner, L., & Cho, R. (2003). Morbidity experiences and disability among Canadian women, In M. DesMeules, L. Turner, & R. Cho, *Women's health surveillance report: A multi-dimensional look at the health of Canadian women*. Ottawa, ON: Health Canada, Canadian Population Health Initiative.
- Devaney, J. (2008). There always seems to be excuses: A grad student's narrative of autoimmunity. In D. Driedger & M. Owen (Eds.), *Dissonant disabilities: Women with chronic illnesses explore their lives* (pp.121-129). Toronto, ON: Canadian Scholars Press/Women's Press.
- Devlin, R., & Pothier, D. (2006). Introduction: Toward a critical theory of dis-citizenship. In D. Pothier & R. Devlin (Eds.), *Critical disability theory: Essays in philosophy, politics, policy, and law* (pp. 1-24). Vancouver, BC: UBC Press.
- Doe, T. & Kimpson, S. (1999). *Enabling income: CPP Disability Benefits and women with disabilities*. Ottawa, ON: Status of Women Canada.
- Donawa, M. W. (1999). *A rebel band of friends: Understanding through women's narratives of friendship, identity, and moral agency*. Unpublished Ph.D. dissertation. Victoria, BC: University of Victoria.
- Dreier, O. (2000). Psychotherapy in clients' trajectories across contexts. In C. Mattingly & L. C. Garro (Eds.), *Narrative and the cultural construction of illness and healing* (pp. 237-258). Berkeley, CA: University of California Press.
- Driedger, D., & Owen M. (Eds.), *Dissonant disabilities: Women with chronic illnesses explore their lives*. Toronto, ON: Canadian Scholars' Press/Women's Press.
- du Toit, A. (2005). *Chronic and structural poverty in South Africa: Challenges for action and research, CPRC Working Paper 56*. Manchester, UK: Chronic Poverty Research Centre.
- Dyck, I. (1996). Whose body? Whose voice? *Atlantis*, 21 (1), 54-62.
- Ellsworth, E. (1997). *Teaching positions*. NY: Teachers College Press.
- Fawcett, G. (1996). *Living with disability in Canada: An economic portrait*. Ottawa, ON: HRDC.
- Fawcett, G. (2000). *Bringing down the barriers: The labour market and women with disabilities in Ontario*. Ottawa: Canadian Council on Social Development.

- Feres, K. (2007). *Earnings exemptions for disability in BC: Effects on social enterprises and their employees*. Unpublished Master's thesis. Vancouver, BC: Simon Fraser University.
- Foucault, M. (1980a). Truth and power. In M. Foucault (C. Gordon, Ed.), *Power/knowledge: Selected interviews & other writings 1972-1977* (pp. 109-133). NY: Pantheon Books.
- Foucault, M. (1980b). Two lectures. In M. Foucault (C. Gordon, Ed.), *Power/knowledge: Selected interviews & other writings 1972-1977* (pp. 78-108). NY: Pantheon Books.
- Foucault, M. (1982). The subject and power. *Critical Inquiry*, 8 (4), 777-795.
- Foucault, M. (1984). Nietzsche, genealogy, history. In P. Rabinow (Ed.), *The Foucault reader* (pp. 76-100). NY: Pantheon Books.
- Foucault, M. (1988). Social security. In L. D. Kritzman (Ed.), *Politics, philosophy, culture: Interviews and other writings of Michel Foucault, 1977-1984* (pp. 159-177). New York: Routledge.
- Foucault, M. (1990). *The history of sexuality Volume 1: An introduction* (R. Hurley, Trans.). NY: Vintage Books.
- Foucault, M. (1991). Questions of method. In G. Burchell, C. Gordon, & P. Miller (Eds.), *The Foucault effect: Studies in governmentality* (pp. 73-86). Chicago: University of Chicago.
- Foucault, M. (1991/1979). *Discipline and punish: The birth of the prison* (A. Sheridan, Trans.). NY: Vintage Books
- Foucault, M. (1992). Governmentality. In G. Burchell, C. Gordon, & P. Miller (Eds.), *The Foucault effect: Studies in governmentality* (pp. 87-104). Chicago: University of Chicago.
- Foucault, M. (1993). About the beginning of the hermeneutics of the self: Two lectures at Dartmouth. *Political Theory*, 21(2), 198-227.
- Foucault, M. (1997). Technologies of the self. In P. Rabinow (Ed.), *Ethics: Subjectivity and truth*. (pp. 223-251). NY: The New Press.
- Foucault, M. (1998). *Aesthetics, method, and epistemology: Essential works of Foucault 1954-1984*. (James D. Faubion, Ed.). NY: New Press.
- Fraze, C. (2003, March). Our citizenship is on the rocks. *Transition*, 10-13.
- Fraze, C., Gilmour, J., & Mykitiuk, R. (2006). Now you see her, now you don't: How law shapes disabled women's experience of exposure, surveillance, and assessment

in the clinical encounter. In D. Pothier & R. Devlin (Eds.), *Critical disability theory: Essays in philosophy, politics, policy, and law* (pp. 223-247). Vancouver, BC: UBC Press.

- Freund, P. E. S. (1982). *The civilized body: Social domination, control, and health*. Philadelphia, PA: Temple University Press.
- Gabel, S. (1999). Depressed and disabled: Some discursive problems with mental illness. In M. Corker and S. French (Eds.), *Disability discourse* (pp. 38-46). Buckingham, UK: Open University Press.
- Gannon, S., & Davies, B. (2007). Postmodern, poststructural, and critical theories. In S. Nagy Hesse-Biber (Ed.), *Handbook of feminist research: Theory and praxis* (pp. 71-106). Thousand Oaks, CA: Sage.
- Garland Thomson, R. (1997a). *Extraordinary bodies: Figuring physical disability in American culture and literature*. NY: Columbia University Press.
- Garland Thomson, R. (1997b). Feminist theory, the body, and the disabled figure. In L.J. Davis (Ed.), *The disability studies reader* (pp. 278-292). NY: Routledge.
- Garro, L. C., & Mattingly, C. (2000a). Narrative as construct and construction. In C. Mattingly & L. C. Garro (Eds.), *Narrative and the cultural construction of illness and healing* (pp. 1-49). Berkeley, CA: University of California Press.
- Garro, L. C., & Mattingly, C. (2000b). Narrative turns. In C. Mattingly & L. C. Garro (Eds.), *Narrative and the cultural construction of illness and healing* (pp. 259-269). Berkeley, CA: University of California Press.
- Gastaldo, D. (1997). Is health education good for you? Re-thinking health education through the concept of bio-power. In A. Petersen & R. Bunton (Eds.), *Foucault, health and medicine* (pp. 113-133). London: Routledge.
- Gatens, M. (1996). *Imaginary bodies: Ethics, power, corporeality*. London: Routledge.
- Gordon, C. (1980). Afterword. In C. Gordon (Ed.), *Power/knowledge: Selected interviews and other writings 1972-1977* (pp. 229-259). NY: Pantheon Books.
- Gordon, C. (1991). Governmental rationality: An introduction. In G. Burchell, C. Gordon, & P. Miller (Eds.), *The Foucault effect: Studies in governmentality* (pp. 1-51). Chicago, ILL: University of Chicago Press.
- Grills, S., & Grills, S. (2008). The social construction of doubt: Women's accounts of uncertainty and chronic illness. In D. Driedger & M. Owen (Eds.), *Dissonant disabilities: Women with chronic illnesses explore their lives* (pp. 53-62). Toronto, ON: Canadian Scholars Press/Women's Press.

- Grosz, E. (1994). *Volatile bodies: Toward a corporeal feminism*. Bloomington, IN: Indiana University Press.
- Grosz, E. (1995). *Space, time and perversion: The politics of bodies*. NY: Routledge.
- Hankivsky, O., & Cormier, R. (2009). *Intersectionality: Moving women's health research and policy forward*. Vancouver, BC: Women's Health Research Network.
- Haraway, D. (1991) *Simians, cyborgs and women: The reinvention of nature*. London: Free Association Books.
- Hay, D. I. (1993). *Well-being: A conceptual framework and three literature reviews*. Vancouver, BC: SPARC of B.C.
- Hillyard Little, M. (1999). The limits of Canadian democracy: The citizenship rights of poor women. *Canadian Review of Social Policy*, 43, 59-76.
- Harrison, K. (2006). "What's left unsaid." Review of Annie G. Rogers' *The Unsayable: The Hidden Language of Trauma*. *The New York Times Book Review*, Sunday, August 13, 2006, p. 11.
- hooks, b. (1990). Choosing the margin as a space of radical openness. In b. hooks, *Yearning: race, gender, and cultural politics* (pp. 145-153). Toronto: Between the Lines.
- Hughes, B. (1999) The constitution of impairment: Modernity and the aesthetic of oppression. *Disability & Society*, 14(2), 155–172.
- Hughes, B. (2005). What can a Foucauldian analysis contribute to disability theory? In S. Tremain (Ed.), *Foucault and the government of disability* (pp. 78-92). Ann Arbor, MI: University of Michigan Press.
- Hughes, B., & Paterson, K. (1997). The social model of disability and the disappearing body: Towards a sociology of impairment. *Disability & Society*, 12 (3), 325-340.
- Inhorn, M. C. (2006). Defining women's health: A dozen messages from more than 150 ethnographies. *Medical Anthropology Quarterly*, 20 (3), 345-378.
- Jones, A. R. (1985). Writing the body: toward an understanding of *l'écriture féminine*. In J. Newton & D. Rosenfelt (Eds.), *Feminist criticism and social change: Sex, class and race in literature and culture* (pp. 86-101). NY: Methuen.
- Jones, R. (2014). *An audit of program access, integrity and results*. Victoria, BC: Office of the Auditor General. (Retrieved May 12, 2015 from http://www.bcauditor.com/sites/default/files/publications/2014/report_18/report/OAG%20Disability%20Assistance-FINAL.pdf)

- Jongbloed, L. (2003). Disability policy in Canada: An overview. *Journal of Disability Policy Studies, 13*, (4), 203-209.
- Kimpson, S. A. (1995). *Stepping off the road: A narrative (of) inquiry*. Unpublished MA thesis. Victoria, BC: University of Victoria.
- Kimpson, S. A. (2000). Embodied activism: Constructing a transgressive self. *Disability Studies Quarterly, 20* (3), 319-325.
- Kneebone, R., & Grynishak, O. (2011). Income support for persons with disabilities. *University of Calgary School of Public Policy Research Papers 4* (11), 1-21.
- Kohler Riessman, C. (1993). Narrative analysis. *Qualitative Research Methods, v. 30*. Newbury Park, CA: SAGE Publications.
- Kohler Reissman, C. (2000). "Even if we don't have children [we] can live": Stigma and infertility in south India. In C. Mattingly & L. C. Garro (Eds.), *Narrative and the cultural construction of illness and healing* (pp.128-152). Berkeley, CA: University of California Press.
- Krogh, K., & Johnson, J. (2006). A life without living: Challenging medical and economic reductionism in home support policy for people with disabilities. In D. Pothier & R. Devlin (Eds.), *Critical disability theory: Essays in philosophy, politics, policy, and law* (pp. 151-176). Vancouver, BC: UBC Press.
- Larner, W. (2000). Neo-liberalism: Policy, ideology, governmentality. *Studies in Political Economy, 63*, 5-25.
- Lather, P. (1991). *Getting smart: Feminist research and pedagogy with/in the postmodern*. NY: Routledge.
- Lather, P. (2007). *Getting lost: Feminist efforts toward a double(d) science*. Albany NY: SUNY Press.
- Laws, C. (2004). Poststructuralist writing at work. *International Journal of Qualitative Studies in Education, 17* (1), 113-127.
- Lemke, T. (2002). Foucault, governmentality and critique. *Rethinking Marxism, 14* (3), 51-64.
- Li, T. (2007). *The will to improve: Governmentality, development, and the practice of politics*. Durham, NC: Duke University Press.
- Lightman, E., Vick, A., Herd, D., & Mitchell, A. (2009). 'Not disabled enough': Episodic disabilities and the Ontario Disability Support Program. *Disability Studies Quarterly, 29* (3), 1-9.
- Linton, S. (1998). *Claiming disability: Knowledge and identity*. NY: NYU Press.

- Loxton, R. (2001, October/November/December). New definition a landmark victory. *Transition*, 30. Vancouver, BC: BC Coalition of People with Disabilities.
- Mairs, N. (1996). *Carnal acts: Essays*. Boston: Beacon Press.
- Marks, D. (1999). Dimensions of oppression: Theorizing the embodied subject. *Disability & Society*, 14 (5), 611-626.
- Masuda, S. (1999). *Women with disabilities: We know what we need to be healthy!* Vancouver, BC: B.C. Centre of Excellence for Women's Health and DAWN Canada.
- Mattingly, C. (1998). *Healing dramas and clinical plots: The narrative structure of experience*. Cambridge, UK: Cambridge University Press.
- Mattingly, C. (2000). Emergent narratives. In C. Mattingly & L. C. Garro (Eds.), *Narrative and the cultural construction of illness and healing* (pp. 181-211). Berkeley, CA: University of California Press.
- McCull, M. A., & Jongbloed, L. (Eds.) (2006). *Disability and social policy in Canada* (2nd ed). Concord, ON: Captus Press.
- McGregor, T. (2003). Persistent and multiple cuts: A look at continuing changes to the "definition of disability." *Transition*, 8-9. Vancouver, BC: B.C. Coalition of People with Disabilities.
- McHoul, A., & Grace, W. (1993). *A Foucault primer: Discourse, power and the subject*. Melbourne, AUS: Melbourne University Press.
- McIntyre, M. (2002, May/June/July). A major step back for people with disabilities. *Transition*, 11. Vancouver, BC: B.C. Coalition of People with Disabilities.
- McWhorter, L. (2005). Foreword. In S. Tremain (Ed.), *Foucault and the government of disability* (pp. xiii-xvii). Ann Arbor, MI: University of Michigan Press.
- Meekosha, H. (1998). Body battles: Bodies, gender and disability. In T. Shakespeare (Ed.), *The disability reader: Social science perspectives* (pp. 163-180). London: Cassell.
- Meekosha, H., & Dowse, L. (1997). Enabling citizenship: Gender, disability and citizenship in Australia. *Feminist Review*, 57 (Autumn), 49-72.
- Meloy, J. M. (1994). *Writing the qualitative dissertation: Understanding by doing*. Hillsdale, NJ: Lawrence Erlbaum.
- Michalko, R. (2002). *The difference that disability makes*. Philadelphia: Temple University Press.

- Mills, S. (1997). *Discourse*. London: Routledge.
- Mitchell, D. T., & Snyder, S. L. (1997). Introduction: Disability studies and the double bind of representation. In D. T. Mitchell & S. L. Snyder (Eds.), *The body and physical difference: Discourses of disability* (pp. 1-33). Ann Arbor: University of Michigan Press.
- Morrow, M. (2000). *The challenges of change: Midlife needs of women with disabilities*. Vancouver, BC: B.C. Centre of Excellence for Women's Health and DAWN Canada.
- Moss, P., & Dyck, I. (2002). *Women, body, illness: Space and identity in the everyday lives of women with chronic illness*. Lanham, MD: Rowman & Littlefield.
- Moss, P., & Teghtsoonian, K. (Eds.). (2008). *Contested illnesses: processes and practices*. Toronto, ON: University of Toronto Press.
- Murray Li, T. (2007). Governmentality. *Anthropoligica*, 9 (2), 275-281.
- Nachmanovitch, S. (1990). *Free play: Improvisation in life and art*. Los Angeles, CA: Penguin-Tarcher.
- Nettleton, S. (1997). Governing the risky self: How to become healthy, wealthy and wise. In A. Petersen & R. Bunton (Eds.), *Foucault, health and medicine* (pp. 207-222). London: Routledge.
- Oberg, A., Kimpson, S., Drew, D., Rasmussen, P., & Montgomery, P. (2003). *A way of proceeding in inquiry: The emergence of a research topic from the midst of autobiographical writing*. Unpublished paper presented at Provoking Curriculum/Canadian Association of Curriculum Studies, University of British Columbia, Vancouver, BC, February 28-Mar 1, 2003.
- Ocean, C. (2005). *Policies of exclusion, poverty and health*. Duncan, BC: Wellbeing through Inclusion Socially and Economically Society.
- Odette, F. (1993). *Staying healthy in the nineties: Women with disabilities talk about healthcare*. Toronto, ON: DAWN Toronto.
- Oliver, M. (1996). *Understanding disability: From theory to practice*. London: Macmillan Press.
- Paterson, K., & Hughes, B. (1999). Disability studies and phenomenology: The carnal politics of everyday life. *Disability & Society*, 14 (5), 597-610.
- Pillow, W. S. (2000). Exposed methodology: The body as deconstructive practice. In E.A. St. Pierre & W. Pillow (Eds.), *Working the ruins: Feminist poststructural theory and methods in education* (pp. 199-219). NY: Routledge.

- Pillow, W. (2003). 'Bodies are dangerous': Using feminist genealogy as policy studies methodology. *Journal of Education Policy*, 18 (2), 145-159.
- Popay, J., Williams, G., Thomas, C., & Gatrell, A. (2003). Theorizing inequalities in health: The place of lay knowledge. In R. Hofrichter (Ed.), *Health and social justice: politics, ideology, and inequity in the distribution of disease* (pp. 385-409). San Francisco CA: Jossey-Bass.
- Porter, J. I. (1997). Foreword. In D. T. Mitchell & S. L. Snyder (Eds.), *The body and physical difference: Discourses of disability* (pp. xiii-xiv). Ann Arbor: University of Michigan Press.
- Pothier, D., & Devlin, R. (Eds.) (2006). *Critical disability theory: Essays in philosophy, politics, policy, and law*. Vancouver, BC: UBC Press.
- Povinelli, E. A. (2001). Editor's note. *Public Culture*, 13 (3), ix-xi. (Special Issue: Disability Criticism)
- Price, J., & Shildrick, M. (1998). Uncertain thoughts on the dis/abled body. In M. Shildrick & J. Price (Eds.), *Vital signs: Feminist reconfigurations of the biological body* (pp. 224-249). Edinburgh: Edinburgh University Press.
- Prince, M. J. (2008). Claiming a disability benefit as contesting social citizenship. In P. Moss & K. Teghtsoonian (Eds.), *Contesting illness: Processes and practices* (pp. 28-46). Toronto, ON: University of Toronto Press.
- Prince, M. J. (2009). *Absent citizens: Disability politics and policy in Canada*. Toronto, ON: University of Toronto Press.
- Pulkingham, J., & Ternowetsky, G. (1996). The changing landscape of social policy and the Canadian welfare state. In J. Pulkingham & G. Ternowetsky (Eds.), *Remaking Canadian social policy: Social security in the late 1990s* (pp. 1-29). Halifax, NS: Fernwood Publishing.
- Raphael, D. (2003). A society in decline: The political, economic, and social determinants of health inequalities in the United States. In R. Hofrichter (Ed.), *Health and social justice: Politics, ideology, and inequity in the distribution of disease* (pp. 59-88). San Francisco, CA: Jossey-Bass.
- Raphael, D. (2007). *Poverty and policy in Canada: Implications for health and quality of life*. Toronto, ON: Canadian Scholars' Press.
- Reid, C. (2004). *The wounds of exclusion: Poverty, women's health, and social justice*. Walnut Creek, CA: Left Coast Press.
- Reid, C., & Tom, A. (2006). Poor women's discourses of legitimacy, poverty and health. *Gender & Society*, 20 (3), 402-421.

- Rice, J. J., & Prince, M. J. (2000). *Changing politics of Canadian social policy*. Toronto, ON: University of Toronto Press.
- Richardson, L. (2000). Writing: A method of inquiry. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed.) (pp. 923-949). Thousand Oaks, CA: Sage Publications.
- Rioux, M. (1994). Towards a concept of equality of well-being: Overcoming the social and legal construction of inequality. *Canadian Journal of Law & Jurisprudence*, *Vol. VII* (1), 127-147.
- Rioux, M. (2006). The right to health—Human rights approaches to health. In D. Raphael, T. Bryant & M. Rioux (Eds.), *Staying alive: critical perspectives on health, illness, and health care* (pp. 85-114). Toronto, ON: Canadian Scholars' Press.
- Rioux, M., Bach, M., & Muszynski, L. (1993). Well-being, society & institutional development. A literature review. In D. I. Hay, *Well-being: A conceptual framework and three literature reviews* (pp. 97-125). Vancouver, BC: SPARC of BC.
- Rioux, M., & Daly, T. (2006). Constructing illness and disability. In D. Raphael, T. Bryant & M. Rioux (Eds.), *Staying alive: critical perspectives on health, illness, and health care* (pp. 305-324). Toronto, ON: Canadian Scholars' Press.
- Rockhill, K. (1987). The chaos of subjectivity in the ordered halls of academe. *Canadian Woman Studies*, *8* (4), 12-17.
- Rose, N. (1996). Governing enterprising individuals. In N. Rose, *Inventing our selves: Psychology, power, personhood* (pp. 150-168). Cambridge: Cambridge University Press.
- Rose, N. (1996). *Inventing our selves: Psychology, power, personhood*. Cambridge: Cambridge University Press.
- Rushdie, Salman (2000). *The ground beneath her feet*. Toronto: Vintage Canada.
- Schlesinger, J. (2005). Europe out of the ashes. Review of Postwar: A history of Europe since 1945 (Tony Judt, author). *The Globe & Mail*, Saturday, December 31, 2005.
- Sen, A. (2005). Foreword. In P. Farmer, *Pathologies of power: Health, human rights, and the new war on the poor* (pp. xi-xvii). Berkeley, CA: University of California Press.
- Shakespeare, T. (1994) Cultural representation of disabled people: Dustbins for disavowal? *Disability & Society*, *9*(3), 283–299.
- Shildrick, M., & Price, J. (1996). Breaking the boundaries of the broken body. *Body & Society*, *2* (4), 93-113.

- Snyder, S. L., & Mitchell, D. T. (2001). Re-engaging the body: Disability studies and the resistance to embodiment. *Public Culture*, 13 (3), 367-389.
- Somerville, M. (2004). Tracing bodylines: The body in feminist poststructuralist research. *International Journal of Qualitative Studies in Education*, 17 (1), 47-63.
- Stone, D. (1984). *The disabled state*. Philadelphia, PA: Temple University Press.
- Stone, S. D. (2008). Resisting an illness label: Disability, impairment, and illness. In P. Moss & K. Teghtsoonian (Eds.), *Contesting illness: Processes and practices* (pp.201-217). Toronto, ON: University of Toronto Press.
- St. Pierre, E. A. (1997). Methodology in the fold and the irruption of transgressive data. *Qualitative Studies in Education*, 10 (2), 175-189.
- St. Pierre, E. A. (2000). Nomadic inquiry in smooth spaces of the field: A preface. In E.A. St. Pierre & W. Pillow (Eds.), *Working the ruins: Feminist poststructural theory and methods in education* (pp. 258-283). NY: Routledge.
- St. Pierre, E. A., & Pillow, W. S. (2000). Introduction: Inquiry among the ruins. In E.A. St. Pierre & W. Pillow (Eds.), *Working the ruins: Feminist poststructural theory and methods in education* (pp. 1-24). NY: Routledge.
- Strega, S. (2004). *The case of the missing perpetrator: A cross-national investigation of child welfare policy, practice and discourse in cases where men beat mothers*. Unpublished doctoral dissertation. University of Southampton. Southampton, UK.
- Streliaoff, W. (2004). *Audit of the government's review of eligibility for disability assistance*. Victoria, BC: Office of the Auditor General.
- Teghtsoonian, K. (2003). W(h)ither women's equality? Neoliberalism, institutional change and public policy in British Columbia. *Policy & Society*, 2 (1), 26-47.
- Teghtsoonian, K. (2008). Managing workplace depression: Contesting the contours of emerging policy in the workplace. In P. Moss & K. Teghtsoonian (Eds.), *Contesting illness: Processes and practices* (pp. 69-89). Toronto, ON: University of Toronto Press.
- The Arthritis Society, BC and Yukon Division (2002). *Media Release: Employment and Assistance for Persons with Disability Act*. Vancouver, BC: Author.
- Thomas, C., & Corker, M. (2002). A journey around the social model. In M. Corker & T. Shakespeare (Eds.), *Disability/postmodernity: Embodying disability theory* (pp. 18-31). London: Continuum.
- Titchkosky, T. (2003). Governing embodiment: Technologies of constituting citizens with disabilities. *Canadian Journal of Sociology*, 28 (4), 517-542.

- Titchkosky, T. (2006). Policy, disability, reciprocity? In M. A. McColl & L. Jongbloed (Eds.), *Disability and social policy in Canada* (2nd ed.) (pp. 54-72). Concord, ON: Captus University Publications.
- Titchkosky, T. (2007). *Reading & writing disability differently: The textured life of embodiment*. Toronto, ON: University of Toronto Press.
- Tremain, S. (2002). On the subject of impairment. In M. Corker & T. Shakespeare (Eds.), *Disability/postmodernity: Embodying disability theory* (pp. 32-47). London: Continuum Press.
- Tremain, S. (2005). Foucault, governmentality, and critical disability theory: An introduction. In S. Tremain (Ed.), *Foucault and the government of disability* (pp. 1-26). Ann Arbor, MI: University of Michigan Press.
- Turner, B. S. (2000). Disability and the sociology of the body. In G. Albrecht, K. D. Seelman & M. Bury (Eds.), *Handbook of disability studies* (pp. 252-266). Thousand Oaks, CA: Sage.
- UPIAS (1976). *Fundamental principles of disability*. London: Union of Physically Impaired Against Segregation.
- Vrlak, A. (2002, March/April). Disability benefits program act: A necessary starting point, *Transition*, 8-10. Vancouver, BC: BC Coalition of People with Disabilities.
- Weedon, C. (1997). *Feminist practice and poststructuralist theory* (2nd ed.). Oxford, UK: Blackwell Publishers.
- Wendell, S. (1989). Toward a feminist theory of disability. *Hypatia*, 4 (2), 104-123.
- Wendell, S. (1996). *The rejected body: Feminist philosophical reflections on disability*. New York, NY: Routledge.
- Wendell, S. (2001). Unhealthy disabled: Treating chronic illnesses as disabilities. *Hypatia*, 14 (4), 17-33.
- Wendell, S. (2013). Unhealthy disabled: Treating chronic illnesses as disabilities. In L. Davis (Ed.), *The disability studies reader* (4th ed.) (pp. 161-173). New York: Routledge.
- WHO (1946). *Health*. Geneva, CH: World Health Organization (Retrieved May 22, 2015 from <http://www.who.int/trade/glossary/story046/en/>).
- Whyte, S. R. (1995). Disability between discourse and experience. In B. Ingstad & S. R. Whyte (Eds.), *Disability and culture* (pp. 267-292). Berkeley, CA: University of California Press.
- Young, I. M. (1999). *Throwing like a girl*. Bloomington, IN: Indiana University Press.

Zitzelberger, H. (2005). (In)visibility: Accounts of embodiment of women with physical disabilities and differences. *Disability & Society*, 20 (4), 389-403.

Zwicky, J. (1992). *Lyric philosophy*. Toronto, ON: University of Toronto Press.

Appendix A: Notes

Note 1:

The new PPMB designation replaced the previous Disability Benefits Level 1 (DB1) category, but changed the requirement such that eligibility was based on having received income assistance (welfare) for 12 consecutive months of the previous 15 prior to applying for the increased (PWD) rate. Previously, eligibility for DB1 was based on having a medical condition that would be likely to last for at least 6 months.

In order to be eligible for PPMB the medical condition has to have continued for at least a year and be likely to continue for at least 2 more years. Also eligibility for PPMB focuses on an individual's ability to work and includes an Employability Screen, which asks questions about level of education, language skills, and time spent on income assistance. A minimum of 15 of a possible 21 points must be scored to pass the screen. The Screen asks no questions about the applicant's medical condition. People who fail to score 15 points may still qualify for PPMB based on information provided by a physician on a Medical Report, which asks the physician to list possible workplace accommodations that may lessen the person's employment barriers. But these applicants must prove their medical condition *precludes* their ability to work or seek work. People who score 15 must have a medical condition that *seriously impedes* their ability to work or seek work. (BCCPD, 2003, 6-7; McGregor, 2003, p. 9). As far as I know Jocelyne was never asked to complete the Employability Screen.

Note 2:

The regulations governing the nutritional supplement follow. The regulations governing the dietary supplement are similarly extensive. From the Employment and Assistance for Persons with Disabilities Regulation, Part 5, Division 4, Section 67 (British Columbia, 2003b):

Nutritional supplement

67 (1) The minister may provide a nutritional supplement in accordance with section 7 [*monthly nutritional supplement*] of Schedule C to or for a person with disabilities in a family unit who receives disability assistance under (a) section 2 [*monthly support*]

allowance], 4 [*monthly shelter allowance*], 6 [*people receiving room and board*] or 9 [*people in emergency shelters*] of Schedule A, or (b) section 8 [*people receiving special care*] of Schedule A, if the special care facility is an alcohol or drug treatment center if the minister is satisfied that all of the following conditions are met: (c) the minister receives a completed request in the form specified by the minister in which a medical practitioner or nurse practitioner has confirmed that

(i) the person with disabilities to whom the request relates is being treated by the medical practitioner or nurse practitioner for a chronic, progressive deterioration of health on account of a severe medical condition, (B.C. Reg. 317/2008)

(ii) as a direct result of the chronic, progressive deterioration of health, the person displays one or more of the following symptoms:

(A) malnutrition;

(B) underweight status;

(C) significant weight change;

(D) muscle mass loss;

(E) bone density loss;

(F) neurological degeneration;

(G) significant deterioration of an organ;

(H) moderate to severe immune suppression,

(iii) for the purpose of alleviating a symptom referred to in subparagraph (ii), the person requires one or more of the items set out in section 7 of Schedule C and specified in the request, and

(iv) failure to obtain the items referred to in subparagraph (iii) will result in imminent danger to the person's life;

(d) the person is not receiving a supplement under section 2 (3) [*general health supplement*] of Schedule C;

(e) the person is not receiving a supplement under subsection (3) or section 66 [*diet supplements*];

(f) the person complies with any requirement of the minister under subsection (2);

(g) the person's family unit does not have any resources available to pay for the items for which the supplement may be provided.

(2) In order to determine or confirm the need or continuing need of a person for whom a supplement is provided under subsection (1), the minister may at any time require that the person obtain a medical opinion from a medical practitioner other than the medical practitioner referred to in subsection (1) (c).

(3) The minister may provide a nutritional supplement for a period of 3 calendar months to or for a family unit if the supplement is provided to or for a recipient of disability assistance or a dependent child of a recipient of disability assistance if

(a) the recipient or dependent child is not receiving a supplement under subsection (1) of this section or section 2 (3) of Schedule C, and

(b) a medical practitioner or nurse practitioner confirms in writing that the recipient or dependent child has an acute short term need for caloric supplementation to a regular dietary intake to prevent critical weight loss while recovering from (B.C. Reg. 317/2008)

(i) surgery,

(ii) a severe injury,

(iii) a serious disease, or

(iv) side effects of medical treatment.

Monthly nutritional supplement

7 The amount of a nutritional supplement that may be provided under section 67 [nutritional supplement] of this regulation is the sum of the amounts for those of the following items specified as required in the request under section 67 (1) (c):

(a) for additional nutritional items that are part of a caloric supplementation to a regular dietary intake, \$165 each month;(b) for bottled water for a person suffering moderate to severe immune suppression, \$20 each month; (c) for vitamins and minerals, \$40 each month. (Retrieved January 5, 2010 from <http://www.hsd.gov.bc.ca/PUBLICAT/VOL1/Part3/3-5.htm#c>).

From the Employment and Assistance for Persons with Disabilities Regulations, Part 5, Division 4, Section 69:

Note 3:

Supplement for persons facing Life-Threatening Health Need

The minister may provide any health supplement set out in Schedule C [health supplements, above] to a family unit that includes a person with disabilities, if the health supplement is provided to or for a person in the family unit who is otherwise not eligible for the health supplement under this regulation, and if

- (a) the person faces a life-threatening health need and there are no resources available to the person's family unit with which to meet that need, and (b) the minister determines that the health supplement is necessary to meet that need.

(Retrieved December 9, 2009 from

http://www.health.gov.bc.ca/pharmacare/outgoing/palliative_patientinfo.pdf)

Note 4:

A monthly training initiative supplement (\$50) is available for a six-month period, with a possible six-month extension approved by the Ministry.

Training initiative supplement

49 (1) The minister may provide a training initiative supplement to or for a family unit that is eligible for disability assistance of \$50 each month towards the expenses of a recipient or a dependant in the family unit of participating in a training initiative program established under section 8 of the Act. [See below]

(2) Only 6 monthly payments may be made under this section in respect of a recipient or

dependent over any period of 36 consecutive months, beginning with the month the recipient first receives the supplement, unless more payments are authorized under subsection (3).

(3) The minister may authorize up to 6 more monthly payments, if satisfied that the person participating in the training initiative program would, because of the nature of the person's disability, benefit from more participation.

(4) No supplement may be provided under this section in respect of a person for whom a supplement is being provided under section 47 [*community volunteer supplement*] or section 48 [*monthly incentive supplement*].

From Section 8 (British Columbia, 2003a):

Employment plan

9 (1) For a family unit to be eligible for disability assistance or hardship assistance, each applicant or recipient in the family unit, when required to do so by the minister, must (a) enter into an employment plan, and (b) comply with the conditions in the employment plan.

(2) A dependent youth, when required to do so by the minister, must (a) enter into an employment plan, and (b) comply with the conditions in the employment plan.

(3) The minister may specify the conditions in an employment plan including, without limitation, a condition requiring the applicant, recipient or dependent youth to participate in a specific employment-related program that, in the minister's opinion, will assist the applicant, recipient or dependent youth to (a) find employment, or (b) become more employable.

(4) If an employment plan includes a condition requiring an applicant, a recipient or a dependent youth to participate in a specific employment-related program, that condition is not met if the person (a) fails to demonstrate reasonable efforts to participate in the program, or (b) ceases, except for medical reasons, to participate in the program.

(5) If a dependent youth fails comply with subsection (2), the minister may reduce the amount of disability assistance or hardship assistance provided to or for the family unit by the prescribed amount for the prescribed period.

(6) The minister may amend, suspend or cancel an employment plan.

(7) A decision under this section is final and conclusive and is not open to review by a court on any ground or to appeal under section 16 (3) [*reconsideration and appeal rights*].

(Retrieved January 12, 2010 from <http://www.hsd.gov.bc.ca/PUBLICAT/VOL1/Part3/3-4.HTM#section8>)

Appendix B: Letter of Invitation and Informed Consent

[Date]

Dear _____ :

You are being invited to participate in a study entitled “Income support and the health of disabled women: The dis/abling effects of discourses.” This research is being conducted by Sally Kimpson, an Interdisciplinary Doctoral (Ph.D) Candidate in Education and Nursing at the University of Victoria. You may contact me if you have further questions once you have read the information that follows. I can be reached at (250) 595-7655 or skimpson@uvic.ca. Please reverse telephone charges if you are calling long distance.

As a graduate student, I am required to conduct research as part of the requirements for completion of my degree. This research is being conducted under the supervision of Dr. Antoinette Oberg and Dr. Mary Ellen Purkis. You may contact Dr. Oberg at (250) 721-7807 or aoberg@uvic.ca . Dr. Purkis can be reached via phone at (250) 721-7953 or mepurkis@uvic.ca .

As a disabled woman, I have been keenly interested in the different ways disabled women negotiate the influence of government in their everyday lives. The purpose of this research project is to examine and reveal the language of provincial government disability income support policy and programs, and how the use of this language affects the lives of disabled women in powerful ways. Before I engage in interviews with disabled women, I will be conducting a close, critical examination of the language used in various B.C. government documents to reveal taken-for-granted assumptions about disability and disabled women. The interviews I will be conducting with you and other disabled women are designed to reveal important elements of how you speak about, and how you engage with and make meaning of these programs in your everyday life with disability, and how all of this affects your health.

Research of this type is important because we know very little about how disabled women actually experience living on income support, and especially how disability income support policy is enacted in the everyday lives of disabled women, including the health effects of such policy. I am hoping that this research and your contributions to it will influence not only people who design and administer income support programs for disabled people, but also that it will provide important information for disabled women in their everyday lives, and for those who practice with them professionally.

You are being invited to participate in this study as a disabled woman living in community with a chronic physical or chronic, but stable mental condition. You also currently receive B.C. provincial disability benefits as your sole formal source of income and have done so for at least the past two years, and you participated in the recent (September 2002-March 2003) Disability Designation Review. The potential benefits of participating in this study include having an opportunity to bring your experience with income support to light, and have it valued; making a contribution to society in a way that enhances the health and lives of disabled women; and generating knowledge that has the

potential to influence government and the practice of professionals who work with disabled women.

If you agree to participate in this research, I will travel to a location specified by you, at a time convenient for you to engage in an in-depth, guided audio-taped interview about your experience of securing and living on income support lasting up to 1.5 hours, depending on your energy levels. Alternatively, several shorter interviews may be scheduled, if necessary, to accommodate your disability. A follow-up interview will be scheduled when we meet, and will be of a length that accommodates your disability. Additionally, I will provide you with a copy of the interview transcripts and the draft analysis of the data, if you so desire. You will receive a copy of the finished dissertation.

Participation may cause some inconvenience to you, including the time and energy required for both the initial and the follow-up interviews. If special accommodation is necessary (e.g., ASL translation, large print texts), please let me know, and I will ensure that arranging this specific accommodation does not further inconvenience you. To the best of my ability, I will arrange whatever specific accommodation you need, and will ensure that you do not incur any additional accommodation-related or other expenses resulting from your participation in the research. There are some potential risks to you by participating in this study. I recognize that in-depth discussions about living on income support may bring up difficult emotions for you. As an experienced nurse and counsellor, I have well-developed skills and abilities in terms of providing support for participants when difficult emotions arise, and if necessary, will work with you to secure appropriate informal or professional supports.

Your participation in this research *must be completely voluntary*. If you do decide to participate, you may withdraw from the study at any time without any consequences or explanation if you find it too emotionally risky or uncomfortable to continue. If you decide to withdraw from the study at any time, your data will be handled according to your wishes. You would have several options: allowing me to maintain the relevant material and use it for the analysis; having all taped and/or transcribed interview material pertaining to you returned; or having me destroy this material. In order to assure that you are continuing to give consent to participate in this research during follow-up interviews, I will ask you again about your willingness to continue involvement or not. You will also be reminded that participating in the review of the transcriptions or data analysis is entirely up to you.

As a way to compensate you for the time you have volunteered in order to participate in this research, you will be offered an honorarium of \$50.00. It is important for you to know that it is unethical to provide undue compensation or inducements to research participants and, if you agree to be a participant in this study, this form of compensation to you must not be coercive.

In terms of protecting your anonymity, your name and any identifying characteristics will be removed from the interview transcripts, and will not appear in the analysis, the dissertation or any subsequent reports written or presented about this research. If you

wish, you can choose a pseudonym or code name, or I will designate one for use during data analysis or in any subsequent written materials. Where specifics about your physical or mental condition are important to the analysis, I will seek your approval before including these details.

Your confidentiality and the confidentiality of the data will be protected by ensuring that personal information is removed from the data and replaced with a code name during transcription of the interviews, which I will do myself. I will be the only person with access to the code list. My dissertation co-supervisors will have access to the transcribed data. In order to protect your anonymity and the confidentiality of the information you provide, all personal and research information, including this consent form will be kept, along with the audio-tapes and transcriptions, in a locked file when not in active use. These materials will be completely destroyed five years after the University of Victoria has accepted my dissertation. Interview transcripts will be destroyed by shredding and electronic file deletion, and the audio-tapes will be erased.

I will analyze the data using discourse analysis, a research method that focuses in a critical way on how language both constitutes and is reproduced in both social institutions and practices, and in a disabled woman's everyday life and encounters with these institutional practices. As part of the analysis, I will use some direct quotes from our interviews to illustrate critical points. It is anticipated that the results of this study will be shared with others as part of the dissertation, and as part of scholarly, lay and professional writing and presentations I will undertake, for both the general public, scholarly community, and, if invited, policy analysts and other government employees.

In addition to being able to contact the researcher and/or my supervisors at the above phone numbers and email addresses, you may verify the ethical approval of this research, or raise any concerns you might have by contacting the Associate Vice-President, Research at the University of Victoria (250) 472-4362.

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researcher.

Name of Participant

Signature

Date

A copy of this consent will be left with you, and a copy will be taken by the researcher.

Appendix C: Interview Guide

The following questions will serve to guide the initial interviews. Each grouping of questions broadly represents a different topical area to be explored in conversation. I will use prompts as appropriate to keep the conversation moving, and will request examples from each woman's experience as needed. Clarifying questions will be asked to ensure specificity. Participants will lead the conversation by discussing whatever comes to mind and will not be encouraged to move in any specific direction beyond the general topic areas.

1. What has been your experience of living on disability income support? Please tell me, if you can what a typical day is like for you. How do you get by on a daily basis?
2. Please tell me about what it was like for you to go through the process of applying for support initially. Since when have you been receiving benefits? At what point with respect to your condition did you decide to apply for benefits? What kind of help, if any, did you ask for and receive to facilitate the process? What surprised you the most about applying for benefits? What were the most difficult aspects of applying for support? Why do you think you were successful?
3. How has living on income support influenced your health? What kinds of things do you do to be healthy?
4. What was it like for you to have to participate in the recent reassessment of your eligibility for benefits? How did you respond to receiving the government letter informing you that you were going to be reassessed? How did you respond to receiving the reassessment form? Who did you have contact with, if anyone, to help you out with the reassessment process?
5. What is the nature of your contacts with government employees? Your physician?

Appendix D: Context of The Review

[Please note this section has its own *Endnotes* using Roman numerals in the text to alert readers to the notes, which appear at the end of the document. References cited appear in the References]

Successive governments in British Columbia have sought to change the way social programs are delivered. Relevant to this study, in January 1996 the provincial New Democratic Party (NDP) government “launched a renewal of our social safety net called B.C. Benefits” (British Columbia, 1999a, p. 1). This was not a renewal geared toward expanding (or at least not dismantling) social security programs, which might have aligned with NDP social policy historically. Despite the NDP’s historic left-of-centre governing agenda, the intention and focus of the new B.C. Benefits set of programs was primarily to reform social welfare policy in ways that aligned with neo-liberal methods of adjusting to the “the new, global economy” (p. 1) specifically, welfare-to-work, or workfare. It tailored benefits to meet the specific needs of various subgroups in the welfare caseload, including people with disabilities (British Columbia, 2001a).

The B.C. Benefits policy and programs directly relevant to disabled people in B.C. were instituted by repealing the previous GAIN (Guaranteed Available Income for Need) Act, and enacting the Disability Benefits Program Act in 1996 (See British Columbia, 1996). In an apparently socially progressive move, the new Disability Benefits Program Act “transferred income support and other benefits for people with disabilities from the welfare system, to a separate system designed to meet the needs of this group” (British Columbia, 1999a, p. 14). When the GAIN Act was repealed and the new B.C. Benefits Act was instituted, an individual designated as a “handicapped person” under the GAIN

Act was automatically re-designated as “a person with disabilities” for the purposes of receiving benefits and allowances under the new Disability Benefits Program Act.

Disabled people receiving (or eligible for) disability benefits were not entirely subject to this new alignment with neo-liberal workfare policies. Despite tightening eligibility for and conditions of receiving welfare, aspects of the B.C. Benefits program designed to support people with disabilities were progressive compared to the welfare program and aligned with some of the stated interests of disability activists. The Disability Benefits Program Act changed the definition of disability for official purposes in several ways, abandoning the previous definition of “handicapped” and making the new definition the most progressive (and according to advocates the most reflective of the social model of disability) in Canada.ⁱ The Disability Benefits Program Act also included a progressively-worded Preambleⁱⁱ that asserted the values held by British Columbians regarding the social safety net, the importance of treating people with disabilities fairly and the intent of disability benefits programs.

One significant feature of the Disability Benefits Program Act that made it broader and more inclusive was to recognize that disability status was permanent. Doing so ostensibly removed disabled people from the general welfare system, which “is designed to provide short term assistance to those facing temporary problems, such as illness, unemployment, or family breakdown” (B.C. Coalition of People with Disabilities, 2001, p. 3). It also recognized the diverse nature of disability as possibly sporadic or cyclical, congenital or acquired, intellectual, mental, or physical (BCCPD, 2001). Individuals with fluctuating conditions, for example, may be able to work for short periods but then might need to

return to full or partial benefits for a period. According to the BC Coalition of People with Disabilities (2001),

unless they are accorded permanent status, the fear of losing their disability benefits will discourage them from seeking work. With the assurance that there is a stable, reliable place they can return to should there be a recurrence of their disability, they can focus on a strategic plan, including education and training, for achieving self-sufficiency. Without this assurance, their energies will be spent on basic survival. (p. 2)

Reflective of the new permanent status the government created a fast-track or rapid reinstatement component that enabled disabled clients who left the system for employment to re-enter it if necessary without having to re-qualify for benefits.

Community activists, such as the BCCPD, together with representatives from the BC Association for Community Living and the BC Division of the Canadian Mental Health Association welcomed the establishment of the permanent disability status (and other changes, see below), for which they had lobbied long and hard (Loxton, 2001). In their opinion

by removing the stigmatizing term “permanently unemployable,” the Act...takes into account the diversity of the disability community, and provides protection for those who are either temporarily or permanently unable to work so they can live with dignity and security. (Vrlak, 2002, p. 10)

The issue of permanent status is crucial for people with disabilities, in particular those living with fluctuating conditions, as do all my participants. Permanent status provides a measure of security in otherwise insecure lives. It also ensures that those who are able to work for short periods but may need to return again to full or partial benefits are enabled

to do so. Otherwise, fear of losing disability benefits discourages people with disabilities from seeking paid employment (Vrlak, 2002).

The second feature, one that is the most directly responsive to the social construction (model) of disability, was that the definition of disability for official purposes recognized the extraordinary costs incurred by people with disabilities as a function of living with impairments and incorporated them as part of the criteria for receiving benefits. This aspect of the definition of disability was clearly articulated in the Act, that is, a person with disabilities is an individual “who, as a direct result of a severe mental or physical impairment, requires unusual and continuous monthly expenditures for transportation or for special diets or for other unusual but essential and continuous needs” (British Columbia, 1996, p. 2).

Not all the reforms made in 1996 were progressive. The B.C. Ministry of Social Development and Economic Security rescinded the \$100 monthly earnings exemption, which had allowed disabled people to earn some income and retain their benefits. Earnings exemptions are generally viewed by disabled people and activists as financial support for disabled people to begin engaging in paid work without having their benefits clawed back or their claim disallowed and are thus considered progressive policy, although not proven to be uniformly effective (Feres, 2007). Under pressure from the disability community, the NDP government did restore the \$100 monthly earnings exemption in late 1999 citing it as “providing an incentive for people to seek and keep part-time employment” (British Columbia, 1999b, p. 1).

Unfortunately the new legislation supportive of disabled people was itself not permanent. In May 2001, the NDP government was voted out and the B.C. Liberal Party assumed

control of government. In November of that transition year the (new) Minister of Human Resources, a social worker by profession, announced plans to move the Ministry from “a culture of entitlement to a culture of employment and self-sufficiency” (Coell, 2002, no page). This cultural shift was to be accomplished by means of a “new income assistance system that supports individuals and families in achieving their social and economic potential [emphasizing] self-reliance and participation” (British Columbia, 2002a, p. 5). To enact this, the government announced plans to eliminate the Disability Benefits Program Act and institute the new Employment and Assistance for Persons with Disabilities Act (along with the new Employment and Assistance Act governing those receiving welfare, or basic assistance). This moved people with disabilities back into the general welfare system by virtue of being governed by the second part of the Act designed to administer those receiving basic welfare benefits, a move viewed as regressive by disability activists (and scholars). (See Kneebone & Grynishak, 2011).

According to Auditor General Wayne Strelieff, who later (in 2004) completed an audit of the government’s review of disabled people receiving benefits to determine eligibility, the proposed new Employment and Assistance for Persons with Disabilities Act was designed to “address several weaknesses...in the previous legislation and administrative processes” (Strelieff, 2004, p. 12). The Liberal government and Ministry officials considered the progressive aspects of the previous legislation (described above) to be “deficient,” and proposed to eliminate both the ‘extraordinary costs’ criteria for assessing eligibility and the permanent disability status. The argument used to support elimination of the “unusual and continuous expenditures” criteria was that this particular measure was “inconsistent with human rights case law, where the level of impairment of a

person's ability to carry out the normal functions of life is the focus" (p. 12) for determining disability status. This rationale upholds the primacy of the medical model of disability bulwarking the human rights case law referred to. In doing so it fails to recognize the importance of the social model of disability, subscribed to by disability activists who have fought strenuously for its inclusion in income support (and other) policies directly affecting the lives of disabled people.

As for the permanent disability status, the new government considered it "a weakness" of the previous legislation, because "there was no ongoing requirement to review [a person's status]" (Strelieff, 2004, p. 12).ⁱⁱⁱ Also factored into the rationale for the new legislation and administrative changes were Treasury Board concerns (since 1988) about "the rapid increase of program costs," and concerned responses to "ministry research [that] showed that indiscriminately granting disability status to clients who really should not qualify increases their dependence on assistance. Not granting this status to such clients reduces their dependence without harming their health" (p. 12).

Two categories of assistance were proposed: temporary and continuous. Those on "temporary assistance," were primarily receiving basic assistance (welfare), but also included disabled clients receiving additional medical benefits; all of these people were considered employable. People with disabilities on temporary assistance would most likely be temporarily and/or part-time engaged in employment and would be receiving a partial benefit and medical supports or would be disabled clients just receiving medical supports. Those on "continuous assistance" were disabled people "not expected to achieve independence through employment" (British Columbia, 2001b, p. 11). Two sub-categories were created for those in this category: those who have severe disability with

added medical supports, and those with persistent multiple barriers to employment (not specified), or PPMB. This latter group would receive a substantially decreased monthly benefit (\$608 instead of \$786).

Activists, in particular those working at the B.C. Coalition of People with Disabilities were alarmed by the government's plan. In their submission to the provincial government Core Services Review Committee (BCCPD, 2001) late in 2001, they argued strongly for retaining the existing Act and programs for which they had worked so hard and which they considered to be a starting point towards breaking down barriers faced by people with disabilities in terms of becoming contributing members of society. According to the Auditor General, the Ministry did recognize "the importance of consulting with key stakeholders," but limited these to "affected ministries and professional organizations" (Strelieff, 2004, p. 5). Without providing any further detail the Auditor General pronounced the Ministry's consultations with community-based advocacy groups as "less effective" (p. 5). This was a gross understatement.

On November 7, 2001 Minister Coell announced plans to rescind the Disability Benefits Program Act in place at the time. Over the next few months, the BCCPD met with Minister Coell and his senior staff to express concerns about the government's plans to institute a new act governing the lives of people with disabilities in B.C. . The Minister expressed a commitment "to continued dialogue with [BCCPD] before any implementation of changes to the existing legislation" (McIntyre, 2002, p. 11). The Coalition began a campaign to defend the existing Act in particular the definition of disability in early 2002 with support from 450 groups. In February 2002, The Arthritis Society (BC and Yukon Division) also lobbied Minister Coell to create a consultation

process to allow for input about the proposed legislation but received no response by the end of April of that year. Subsequently, The Arthritis Society issued a media release urging the Minister “to delay consideration of the new Employment and Assistance for Persons with Disabilities Act; and for the minister to develop, with The Arthritis Society...a consultative process that involves community stakeholders and individuals with disabilities” (The Arthritis Society, 2002, p. 1). [TAS did not respond to my request for information about what Ministry response there was, if any, to their recommendations]

The Coalition was under the impression that the Minister understood clearly that the community wanted a separate Act similar to the existing Disability Benefits Program Act. From their point of view, “he did not indicate there would be any changes to the definition of disability” (McIntyre, 2002, p. 11) but in a meeting with senior Ministry staff in early April 2002 the Coalition was presented “with a draft document of a new definition of a person with a disability to be contained in a new Act” about which the Coalition “expressed...grave concern” (p. 11). At that meeting Ministry staff reassured Coalition members that changes would not be implemented without further meetings and because of this the Coalition agreed to continue dialogue, with a meeting set for two weeks away. But no further meeting or consultation occurred.

Coalition members were shocked when on April 15, 2002 the newly drafted Act went to the Legislature for first reading (there were only two Opposition party members at the time) “with a radically changed definition of disability” (McIntyre, 2002, p. 11) and removal of the former Preamble. The Ministry had promised the B.C. Coalition of People with Disabilities first response to the proposed Act and the Regulations once developed,

but the Act was drafted and went to the Legislature without meaningful consultation with the BCCPD. In mid-April, “under pressure from the disability community...the government...made an amendment to the Act at Second Reading [reverting] back to the 18 years qualifying age, rather than 19 years of age it had originally proposed” (BCCPD, 2002, p. 14). This was an important victory because parents or guardians of disabled minors receive supports and services up until age eighteen when the disabled person would have to apply for provincial disability benefits, if otherwise unsupported financially. Raising the age to nineteen would have created a year-long gap without supports for these individuals and families.

The Coalition then tried to stop the proclamation of the Act with a petition to Cabinet. Three hundred community groups signed onto this campaign, ultimately unsuccessfully. The Coalition also issued “community alerts” and engaged the media in the campaign to no avail. (Jane Dyson, personal communication, January 2004). Despite well-organized opposition from disability activists, who feared the removal of the recognition of the particular needs of disabled people in the new Act and a stated (but broken) commitment by the Minister to continued dialogue before any changes were made, the new legislation governing disability benefits, The Employment and Assistance for Persons with Disabilities Act (EAPWD) was proclaimed in September 2002.

According to the Liberal government, “the goal of the new legislation [was] to promote greater independence for people with disabilities, security of income, enhanced well-being and participation in the community” (Strelieff, 2004, p. 1). Despite these laudable goals, the new Act radically changed the definition of disability for official purposes and redefined other aspects of eligibility criteria in ways that according to advocates, would

“make it significantly more difficult for people to qualify for benefits” (McIntyre, 2002, p. 11) in the future. Although there were many changes to eligibility requirements along with changes to the appeal system, by removing the permanent status the EAPWD Act made each person’s disability status subject to review. And that is precisely what happened next, affecting disabled people throughout BC who were receiving benefits at the time.

The Disability Designation Review, Redux

The Minister was invested through the Act with the power to remove any person receiving disability benefits including those who may qualify in the future. A new category was created as part of the Act (Person with a Disability, or PWD) based on more restrictive criteria^{iv} and a decision was made to embark on a fast-track review of the disability status of all those who were currently receiving permanent benefits (previously known as Disability Benefit 2, or DB2 clients) under the old Act to ensure they met the criteria for the new PWD category. In fact, because of the changes in the new Act the Minister was “*required* to review benefit recipients approved under the former legislation (previously referred to as Disability Benefit 2 clients) to determine their eligibility under the revised criteria” (Italics added) (Strelieff, 2004, p. 11). A person’s disability designation could be cancelled by the Minister, “if [the person’s] situation does not meet the requirements of the Act” (p. 11). In the Auditor General’s words, “A key assumption of the ministry... was that a large number of recipients would fail to qualify, thereby losing their disability status [with] significant cost savings to government and taxpayers” (p. 3).^v

Not all people receiving DB2 were required to re-apply for benefits, including the study participant Marion, as she describes in her account of undergoing The Review. Using existing information on file in the spring and summer of 2002 the Ministry undertook a preliminary internal review of files to determine eligibility under the new Act. Of the 61,932 former clients reviewed, 43,227 “had their eligibility status confirmed without having to provide additional proof of their disability” (Strelieff, 2004, p. 27), leaving a further 18,705 clients who had “insufficient information on their files to enable the Ministry to determine eligibility” (p. 15). What this meant for these approximately 19,000 people with disabilities (including the participants in this study) who were receiving benefits under the previous permanent designation (DB2) was that they were forced to participate in a reapplication process in order to retain their benefits. This came to be known colloquially as The Review.

After the new Act was proclaimed in September 2002, the Ministry began sending out letters to the latter (un-exempted) disabled clients informing them that the Ministry did not have enough information to determine their eligibility for the new PWD category. A request was made to complete the new Persons with Disability Designation Review form, a completely new (and daunting) twenty-three (23) page form, which in many cases disabled clients received a week after the letter. They were required to complete the form, including getting a physician and a qualified assessor to complete their respective sections and submit it before the January 15, 2003 deadline.

The Ministry assumed “that the review would identify a large number of ineligible people” (Strelieff, 2004, p. 17) but did not adequately test this assumption before sending the letters, with the unfortunate effect of creating extremely high levels of anxiety for

disabled clients whose lives were already precarious and extremely challenging. Those living with mental illness were particularly upset about the letter and about getting The Review form (new to clients and advocates) completed in a timely fashion. Advocates were receiving overwhelming numbers of calls from this group of disabled people, distraught and desperate for help, including threats of suicide (Jane Dyson, personal communication, 2004).

At this point the Coalition developed the first “Help Sheet” designed to educate people regarding how to deal with the reassessment. The Coalition was also trying to get people exempted from The Review process through organizing and lobbying efforts. In October, a mentally disabled man, Arne Ristveldt committed suicide, leaving a note explaining that he could not deal with the reassessment (Jane Dyson, personal communication, 2004). On October 17, 2002, three professional groups (B.C. Society of Occupational Therapists, Physiotherapy Association of B.C., and the B.C. Association of Social Workers) whose members were eligible to complete the new Assessor portion of the form, wrote a letter to the Minister stating that it was unrealistic to expect people with disabilities, especially those with mental disabilities to complete the form by the deadline. On the front lines they were seeing how The Review process was creating heightened anxiety, turmoil, pain, and fear.^{vi} Their mentally disabled clients especially were becoming sicker due to worry about completing The Review form and had difficulty managing symptoms. The professional groups expressed their non-support for The Review process and requested a meeting with the Minister. They were granted consultation with Ministry officials (not the Minister) but it did not result in any changes to The Review process. Subsequently these professional groups called for a press

conference for November 21, 2002 at the office of the Coalition with the intention to publicly call on the Minister to make changes to The Review process, including a change to the January 2003 deadline (Cameron, 2002).

Just before the press conference, the Ministry sent a fax to the above-named professional organizations announcing two significant changes to The Review process, as follows:

- 1) of those with a primary diagnosis of mental illness (5629 clients), 4726 would be exempted from the Review^{vii}, and;
- 2) the Ministry extended the deadline for submission of the completed review form by two months to March 15, 2003.

These changes were welcomed by the professional and advocacy groups, but the more significant changes sought by the Coalition to the definition of disability were not forthcoming and continue to be lobbied for to this day.

All of the participants in the study were caught in the web of The Review in different ways that an account such as has been presented here obscures. Upon reading the Auditor General's report of his audit of The Review, requested by members of the public, the Leader of the Opposition and the Coalition (Strelioff, 2004), I was struck by how the language of his report described a process in stark contrast to that experienced by my study participants, and of others in the community I spoke to as part of my own activist work. In particular, his conclusion that stated simply, "the review also increased anxiety among its disabled clients" (Strelioff, 2004. p. 2) seemed a gross understatement to me, given what I my participants told me about their lives during The Review process.

To illustrate the disjuncture between the language of Mr. Strelloff's report and the experience of disabled people, I have relied on the women's own words in their previous narrative accounts to show how each experienced The Review and what it produced in their lives.

Endnotes

ⁱIn the Disability Benefits Program Act (1996), the definition of disability for official purposes was as follows:

“person with disabilities” means a person who at the time this section comes into force was a handicapped person under the *Guaranteed Available Income for Need Act* or a person

- a) who is 18 years of age or older,
- b) who, as a direct result of a severe mental or physical impairment,
 - (i) requires extensive assistance or supervision in order to perform daily living tasks within a reasonable time, or
 - (ii) requires unusual and continuous monthly expenditures for transportation or for special diets or for other unusual but essential and continuous needs, and
- c) who has confirmation from a medical practitioner that the impairment referred to in paragraph (b) exists and
 - (i) is likely to continue for at least 2 years, or
 - (ii) is likely to continue for at least one year and is likely to recur. (British Columbia, 1996, p. 2)

ⁱⁱ The Preamble in full was worded as follows: WHEREAS British Columbians are committed to preserving a social safety net that is responsive to changing and economic circumstances;

AND WHEREAS people with disabilities will be treated with fairness, dignity and sensitivity to their diverse needs as individuals;

AND WHEREAS disability benefits programs support the inclusion and integration of people with disabilities into the mainstream of the community and the enhancement of their quality of life;

AND WHEREAS disability benefits programs encourage communication and joint problem solving among people with disabilities, their families, friends, advocates, ministry staff and service providers;

AND WHEREAS disability benefits programs should be financially and administratively accountable, effective, efficient and well coordinated. (British Columbia, 1996, p. 1)

ⁱⁱⁱ Ironically, the only annual review done by the Ministry under the new regulations is to review clients' bank statements over the previous three months. Annual review of disability status was not reported by any of my participants, and does not appear in the regulations created to administer the new Act. A recent (2014) review of the disability assistance system by the Auditor General indicates that “the Ministry's system and processes for determining initial and ongoing eligibility for the PWD designation can be improved” (Jones, 2014, p. 7). This statement suggests measures to review medical status in an ongoing way ought to be instituted. Given the kinds of difficulties the participants describe as part of The Review, a decision to engage in this kind of heightened surveillance of clients, would likely have undesirable effects for beneficiaries.

-
- ^{iv} See p. 105 for definition of disability under the new Act (Employment and Assistance for People with Disabilities Act, assented to May 30, 2002).
- ^v In the end, 98.2% of existing clients had their designations confirmed or were exempted from the review; 400 clients or 0.6% of those reviewed were found ineligible, and of these 40 reapplied and were granted disability status, and the remaining 314 clients were eligible to receive other forms of government assistance. The review cost the BC government and taxpayers \$4,869,000 (Strelieff, 2004). Please see Footnotes 24, 25 and 33 (in main text) for further details about review numbers.
- ^{vi} Interestingly, in the Ministry's response to the Auditor General's remarks that the review created increased anxiety among disabled clients (Strelieff, 2004) the Ministry blamed "certain stakeholder groups [who] opposed the review and dropped out of the process" stating that "the Ministry believes the subsequent actions of some of these groups contributed to higher client anxiety" (Strelieff, 2004, p. 41). Although the ministry held meetings with advocacy groups "to discuss the application form's development and the timing of the review" (p. 26), the Coalition and the Canadian Mental Health Association did not consider the Ministry to be "consulting in good faith because it had already made key commitments (to the time frame and the 23-page form). The Coalition strenuously opposed both the eligibility review and changes to the Disability Benefits Program and legislation and subsequently dropped out of the process. The Coalition provided as much hands-on support as they could for clients needing help with the form and posted numerous Bulletins and Help Sheets on their website to assist those around the province undergoing review.
- ^{vii} The Auditor General provides some background detail about this change: "According to the ministry, after it had received and adjudicated 903 completed forms from these recipients—all confirming their eligibility status—it decided to exempt the remaining individuals from having to complete the form" (Strelieff, 2004, p. 19). Nothing in his report attributed this change to lobbying and pressure by professional groups.