<u>The Community Support Worker of the 1980s, as She was Imagined: A Genealogy</u>

By

Pamela Cambiazo
Bachelor of Fine Arts, University of Victoria, 1989

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in the School of Social Work

Supervisory Committee

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Dr. Donna Jeffery, Social Work
Supervisor

Dr. Mehmoona Moosa-Mitha, Social Work
Departmental Member

Abstract

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Supervisor

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Departmental Member

I am a community support worker who supports people with intellectual disabilities to *live full lives with dignity* in the community. This is a role that can trace its heritage to the 1980s when large institutions in BC closed in favour of community group homes. Current scholarship suggests that the requisite *full lives* promised at the time the institutions closed have not materialized in the years since. Further, this scholarship suggests that it is the community support worker who has failed to deliver on important social goals. As a worker I can attest that I do at times feel unsettled in my work, like my mere presence is problematic, as if I fail by showing up. Based on the premise that I can learn about the worker of present by looking at how she was first imagined, in this genealogical study I explore how the community support worker of the 1980s was produced in archival documents of groups involved in the development of community group homes after the closure of Woodlands in New Westminster, BC. My findings suggest that the community support worker role served many interests, and that her purpose was not solely trained to the social needs of the people she supported. A confluence of economic rationalities, family concerns, and regulatory demands shaped her as an invisible domestic idealized as a temporary solution to a problem that was expected to dissipate through the increased

independence of people with disabilities, and the participation of a welcoming community that steps up to help when needed. The ongoing presence of the worker calls into question her original mandate.

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Acknowledgments

Sometime in the past four years I saw a message stencilled onto the side of a building in Vancouver: *Just you, Just me, Just us.* It is a message that suggests that justice is made in the very intimate meeting of individuals. During the process of writing this thesis there was a large collection of individuals who met me and helped me have the courage to speak up and show up as a community support worker, as a researcher, and as a person trying to sort out who we are to one another.

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Dedication

This thesis is dedicated to the contemporary community
support worker, in particular to my co-workers,
Wanda Chamberlain, Simon Kemal, Tara Skerratt,
and Ursula Konik

I see you.

Chapter 1: Introduction

When Cheryl died I went to her funeral with a few of the other women, my co-workers, who had also supported her in her home. As the small casket was being placed in the hearse, Cheryl's sister spontaneously reached in and plucked some of the white roses off the top of the casket, one for each girl in the family. We stood there, the women who for years had prepared Cheryl's breakfast, helped her fix her hair, and had dried carefully under her breasts after her bath, so that she wouldn't get a rash. We stood there as the little girls circled around, each holding a white rose. I didn't need a rose, or want one; I just noticed that I didn't have one.

I am a community support worker and I spend my days supporting people with intellectual disabilities to live in "communities where every person lives with dignity and enjoys a full life."[1] While this seems straightforward enough in contemporary terms, the role I play and where I perform it is a relatively recent phenomenon that can be traced to the 1980s. The spirit of *living a full life with dignity* that emerged at that time is still heralded as the benchmark for services to people with disabilities. Yet scholarship suggests that despite the closure of large institutions in favour of community living, people with intellectual disabilities continue to live relatively segregated and isolated lives within their communities. This lack of community inclusion is attributed to many factors such as restricted budgets for care, a plethora of institutional practices that limit opportunities, and inadequately trained or prepared community support workers (Mansell, 2006; McConkey & Collins, 2010; Hastings, 2010; Mitchell & Welshman, 2006; Burrell & Trip, 2010). Given our presence in the day to day lives of people who live simulations of ordinary lives (i.e. day programs rather than jobs) I doubt that it would be a surprise to many workers to hear that community inclusion for people with disabilities, as it was envisioned, has not been

realized. The notion that workers are implicated would also not be unexpected. This inspired me to wonder; at the time when large institutions were closing and people with disabilities were moving into the community, what *were* the expectations of workers, what did workers have to do in order to be successful in their role?

The story of the community living movement is well known to most support workers in the Greater Vancouver area. It is taught in community college programs and disseminated by service agencies when orienting new employees; it is a story that workers are invited to be a part of. Training for my current job included a memorable afternoon when the mothers of "supported individuals" came to tell the story of closing the institution, and to share their dreams of a new life for their child in the community. This story included the heroism of parents and advocates who chained themselves to the gate at one of the institutions when some people were going to be transferred to extended care hospitals instead of community homes. These mothers championed the rights of people with the most serious impairments, such as those who were living in the back wards of the institutions. When asked by the Minister of Human Resources "who exactly they wanted to take out [of the institution] they…shouted 'Everybody! Everybody!'" (Panitch, 2008, p. 66). Families and advocates had the courage to move forward even when, according to one mother, they were told that if the institutions closed the people who moved to community residences would die.

These stories, wrapped in hopes, desires, and dreams for a better life for loved ones, are emblematic of universal rights and freedoms. They are also historically situated and shaped by the social conditions from which they emerge. The 1980s were in many ways a successful time for people with disabilities in Canada. Due to the efforts of disability

activists, disability was included as a category in section 15 of the Canadian Charter of Rights and Freedoms, giving people with disabilities legal protection from discrimination. The Supreme Court of Canada ruling on the Eve case was a triumph on two counts, first because a woman with an intellectual disability won the right not to be sterilized against her will, and second because the testimony of people with intellectual disabilities was admissible in the courts (Panitch, 2008). The closure of large institutions in British Columbia is also an important success of these times. In the context of these successes, workers are invited to join a movement whose goals represent the rights of people with disabilities to lives of independence, self-determination, and inclusion.

Over the years the supporting role of workers has been labeled in many ways: We are called staff, friends, health care workers, counsellors, personal assistants, home care workers, caregivers, advocates, community support workers, dependency workers, rented strangers[2], helpers, and home support workers. We work in group homes, day modules, in supported employment centres, sheltered workshops, "coffee houses," in the community, at Special Olympics, in semi-independent living residences and, in the rainy season we have spent countless hours circling inside shopping malls with the people we support. What we are called, the spaces where we work, and the descriptions of our jobs all change according to commonly held ideas of the presumed identities and abilities of the people we support. As conceptions of the identities of people with intellectual disabilities change, notions of what they (can) expect from life change as well. If we think they are animals, as has been suggested by some moral philosophers (Carlson, 2010), then we become zookeepers; if we think they are children, then we become parents; if we think they are adult persons with

political and social rights, then we, presumably, become workers who can help them live a life that expresses this personhood.

But the complexity of providing support to people with intellectual disabilities is not only connected to identity. From almost my first day on the job I recognized tension in the fact that the place where I worked was both someone's home *and* a place of employment. It "made sense" to me that this place must be considered a home *before* a job site, and yet, it is *also* a job site, and this has important implications for who I am when I am there. What *is* this liminal position I hold? Not family or friend, and given the intimacy of supportive relationships that sometimes span decades, we are not simply staff either. As a companion I am kind, patient, and friend-like, and as a worker I must meet organizational and accreditation standards. The space itself is ambivalent, a well-kept and nicely decorated middle-classed home, but with cupboards filled with binders, material safety data sheets on hand, and licensing agents dropping by unannounced. As a worker, I must be committed to the values of community living that proclaim normal lives filled with passion, independence, choice, and freedom, but I have a central role in containing, regulating, and documenting this freedom (Burnell & Trip, 2010). In order to accommodate this paradox, my role is informally idealized as an invisible one. My overt presence is an affront to the narrative of independence that the community living movement of the 1980s sought to instil on behalf of people with intellectual disabilities. In order to be a *good* worker I must be here and not be here at the same time.

There is a paragraph written by disability activist and advocate Bob Perske (n.d), that I found in many of the boxes of archives, from many different sources. Its ubiquity

suggests that it represents an important theme in the community living movement, the

theme that being surrounded by people who are paid to be with you is harmful.

What if all the people in your life were paid to be there?

> We have only begun to sense the tragic wounds some mentally retarded
> persons may feel when it dawns on them that the only people relating with
> them – outside of relatives – are paid to do so. If you or I came to such a sad
> realization about ourselves, it would rip at our souls to even talk about it.
> Chances are some of us would cover it up with one noise, awkward bluff after
> another, and chances are, some professionals seeing us acting this way,
> would say we had "maladaptive behaviour." Think about what it would feel
> like to have even one person come up to us and without pay, develop a
> reliable, long-term relationship with us because he or she wanted to…to
> literally accept us as we are. Then think of the unspeakable feelings we
> might possess if - when others were "talking down" to us and "putting us in
> our place" - that kind person could be counted on to defend us and stick up
> for us as well! Most of us do have a person like that in our lives. But will the
> day ever come when retarded citizens will have them too?
>
> Bob Perske (n.d.)
> (from the archives of The Mission Association for Community Living)

While this quote is likely from the late 1970s, it reflects the sentiments, albeit more

sentimentally, of those found in the *current* strategic plan from Community Living British

Columbia (2013), the crown corporation administrating services to people with intellectual

disabilities. This strategic plan calls for an increase in "natural support roles" (p. 25), the

unpaid informal supports provided by friends, family, and neighbours. While the content of

this "echo" is interesting, it is more the fact of it that I find thought provoking. How do

threads from the past draw forward into the present, and how does recognizing them help

us to see that "the present is not and need not be taken as inevitable or absolute"

(Chambon, 1999)?

Resting on the premise that I can understand something about the present by exploring the past, in this thesis I approach the past at two levels. First, I interrogate the social and historical conditions that gave rise to a confluence of desires, policies, and assumptions leading to the need for a new kind of worker in the 1980s; and second, I collect and analyze archives from this time in order to understand how this worker was produced as a particular subject at the time when she was needed. The questions that guide this research are:

- o At the time when the community support role was first created in the 1980s, what was the worker supposed to do, and who did she need to be to be successful in this role?

- o How was she produced as a particular subject at the time she was first needed?

In the next section I provide a very brief historical overview of residential supports for British Columbians with intellectual disabilities by way of historically situating my research. In this overview I mark some of the changes that are important to this research, noting particularly the closure of Woodlands. As the closure of Woodlands is a landmark in changes to services for people with disabilities, I chose it as the entry point for this research. My analysis is based on archives from groups and individuals that contributed to discussions about how people moving from this institution would be supported in the community.

Residential Care for Intellectually Disabled British Columbians

Residential care[3] for people with intellectual disabilities has historically been provided in the home by families (i.e. mothers), or by paid attendants in one institution or another, from asylum to "school." In British Columbia, The Provincial Hospital for the

Insane (PHI) opened in New Westminster in 1878 and housed people with mental illnesses, those who were frail, elders, and people with intellectual disabilities. Over the decades the types of residents and therapeutic goals of the hospital changed. When a new facility for people with mental illnesses was built in the 1930s, children and adults with intellectual disabilities became the primary population of PHI (Adolph, 1996). In 1950, the PHI was renamed "The Woodlands School," and the goals of the institution were established as care, instruction, training, and education. The staff, working along a continuum of custodial care, medical services, and formalized recreational programming, was comprised of nurses, teachers, activity workers, health care workers, and ward assistants (Adolph, 1996). The people living in these institutions led highly structured, institutional lives, without the opportunity to meet anyone other than fellow inmates, institutional staff, volunteers, or family who came to visit. Like people with intellectual disabilities elsewhere, they were segregated physically, socially, and symbolically from the communities they had been born into (Wolfensberger & Thomas, 1998).

The events leading up to the "community living movement" in British Columbia occurred within the context of larger social movements in Europe, the USA, and other parts of Canada (Scheerenberger, 1984; Trent, 1994; Panitch, 2008). According to British Columbian parent and advocacy group literature, the local movement began as a series of negotiations in the 1970s between the Minister of Social Services and a group that became the Woodlands Parents Group. At first these negotiations were for better care within the institution, but they soon became a powerful lobby for institutions to close (Panitch, 2008). Beginning in the late 1970s, people began moving out of Woodlands into the community, but it was not until 1981 that BC Minister of Human Resources, Bill Vander Zalm, confirmed

that all of the large institutions in British Columbia would close. In 1996 the last people

moved out of Woodlands and power was cut to the center block of the institution, the first

building to be erected on that site, and the last one to close (Adolph, 1996).

The importance of parent and advocacy group leadership in lobbying the

government during the decade leading up to this exodus of people from Woodlands into

the community cannot be overstated. This activism, which educated and motivated policy

makers and parents alike, was deeply informed by the work of disability advocates Gunnar

Dywar and Wolf Wolfensberger, who promoted normalization as the organizational and

moral high ground for disability services. Normalization theory originated in Scandinavia

with Neils E. Bank-Mikkelsen and Bengt Nirje, and was brought to North America by

Wolfensberger (1972) and disseminated through his widely read book, *The Principle of

Normalization in Human Services*. Normalization theory advocates the least restrictive

environment and supports for people with intellectual disabilities, an idea that stands in

stark contrast to life within institutions. Wolfensberger promoted lives for people with

disabilities that resembled, as much as possible, the lives of average citizens. He was

particularly concerned that people with disabilities would experience the normative

cadence of the day, week, and year, participate in the public economic life, and be

integrated into the social life of the community.

The advent of community living represents an important change in the way that

people with disabilities were thought about, what they could expect from life, and how

their community would meet them. It was by all measures a huge step forward into a new

and improved order (Panitch, 2008). However, as Michel Foucault suggests, "there is no

order that is unproblematic and that can be taken for granted" (O'Farrell, 2005, p. 57). This

is as true for the community living movement as for any other example. Foucault is interested in "how the traces left behind by the past are organized" (O'Farrell, 2005, p. 56). For example, while the community living movement helped hundreds of people move out of the confines of life limiting and at times dangerous institutions, it did so while bringing many of the confining institutional practices out with them.

This failure to truly loose the bonds of control over people with disabilities rests squarely in the purview of ableism, a foundational ordering principle (O'Farrell, 2005) that exists beneath the institution, the community living movement, and the category of disability itself. The concept of ableism has been the focus of many scholars including Fiona Kumari-Campbell (2009) who suggests that ableism is:

> A network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as perfect, species-typical and therefore essential and fully human. Disability then is cast as a diminished state of being human. (Campbell, 2001, cited in Campbell, 2009, p. 5)

Linton (1998b) adds that, within ableist ontology, "people with disabilities as a group are inferior to non-disabled people"(p. 9 cited in Campbell, 2009, p. 6). However, Campbell (2009) argues that it is not simply a comparative relationship, but a constitutive one; "it is not possible to have the concept of *difference* without ableism" (p. 6), and further, that "inscribing certain bodies in terms of deficiency and essential inadequacy privileges a particular understanding of normalcy that is commensurate with the interests of dominant groups" (p. 11). Within the community living movement, in particular through the deployment of Wolfensberger's (1972) normalization theory, it is clear that "the negative response to biological and intellectual difference in modernity is strongly influenced by the

tendency embedded in the 'civilizing process' to incrementally deride the value of physical and intellectual difference and promote a sanitised norm of human behaviour and appearance (Elias, 2000)" (Hughes, 2012, p. 17). Ableism is the territory in which the community living movement was built.

While Woodlands has closed, the lives of people with disabilities and their families continue to be governed institutionally. Community Living British Columbia (CLBC), the Crown Corporation that has administrated services to adults with developmental disabilities since 2004, assesses and qualifies people for services, and issues contracts (generally to agencies) to provide these services. CLBC literature focuses on the importance of person-centered planning, family consultation, and individualized services with particular attention to issues of quality of life (Community Living British Columbia, n.d.). While Hastings (2010) notes that many researchers insist that "the quality of the work that paid support staff carry out within services for individuals with intellectual disability is clearly crucial to achieving positive quality of life outcomes for service users" (p. 207), current CLBC literature suggests that paid staff are less crucial to quality, privileging instead the presence of "family members, friends, and neighbours [who] often play natural support roles which enhance quality of life" (CLBC, 2013, p. 25). I suggest that this tension between the presence of staff in the context of enduring political and philosophical preference for people with disabilities to be supported by informal helpers is a conundrum at the heart of the community living movement.

> *My point is not that everything is bad, but that everything is dangerous, which is not exactly the same as bad. If everything is dangerous, then we always have something to do.*
>
> Michel Foucault, 1983

Introducing the Research

      This thesis is structured in six chapters. The introductory chapter is followed by a

description of the epistemological foundation, methodology, and methods. To approach my

research question I used a genealogy, a historically situated research methodology that

taps normative and critical readings of texts, practices, geographies, and events. A

genealogy is guided by a problem in the present, from which we trace back the historical

and social conditions that deliver us, contingently, to this particular and problematic

present (Koopman, 2010).

      Chapter Three outlines the *conditions of possibility*: the events, ideas, and social

movements that contributed knowledge, moral frameworks, and political initiative to the

project of closing institutions in favour of providing homes in the community. This chapter

is divided into two sections. First I look at social and historical conditions relating to

disability, such as institutional care, the parent/advocacy movement, normalization theory,

the social model of disability and corresponding disability movement. In the second

section I look at social and historical conditions that are more general, noting care as a

feminized and devalued practice that generally happens in private spaces. I provide an

overview of the political and economic landscape in British Columbia at the time the

announcement was made to close the institutions. I also discuss briefly how notions of

community have been theorized and consider some implications for the community living

movement. Together these movements, issues, and ideas represent the *conditions of*

possibility; the epistemic landscape from which desires and interests produced the

imagined paradigmatic community support worker.

My analysis, which I detail in Chapter Four, focuses on archival documents circa 1983 – 1989 from four distinct sources: parent and advocacy groups; the Ministry of Social Development and Housing; the British Columbia Government Employees Union; and three agencies providing residential supports to people with disabilities. Structured along the themes *support, community,* and *worker*, the analysis generated six core findings that speak directly to how the community support worker was imagined at the moment she was needed. The worker of the community living movement cannot be extracted from the institutional legacy that followed her into the community though practices, reporting, and governance. Added to this, her identity is navigated through a series of metaphors and archetypes, from bridge, to mother, to systems.

In Chapter Five I discuss these findings and review them in relation to the conditions of possibility, which I outlined in Chapter Three. I look at the findings and draw some conclusions about the worker, who I suggest was imagined as invisible and temporary. Within the constraints of how workers were imagined I look at how the worker might exercise her agency, suggesting that the care relationship itself may, at times, represent a form of refuge for the institutional demands made of both workers and the people they support. Finally, I consider the current conditions and prevailing perspectives about support workers today. In Chapter Six I offer a brief reflection on taking up this project from my perspective as a community support worker, and share a wish list for further research.

Chapter 2: A Genealogical Approach to Curiosity

"History is a nightmare from which I am trying to awake."
James Joyce, Ulysses

A methodology is a guide we use to exercise our curiosity, but it is not an inert guide; it acts upon us. Its actions come in the form of questions that challenge or contain assumptions about the big questions of life: Who are we? How do we become who we are? What is knowledge? How do we know something to be true? Each methodology contains its own code for approaching these questions, and this code determines what kinds of questions can be asked, what kinds of questions that it makes sense to ask, and how we know when we have satisfied our inquiry. For this research I used a Foucauldian genealogy, a methodology that takes history as its platform to explore the contingent emergence of that which is taken as natural or inevitable (Koopman, 2010). The value of this genealogical process was that it gave me the opportunity to dig down in history, ostensibly to learn something about how the community support worker was produced at the time she was first needed, but no less importantly, to get a sense of how the past comes to bear on my everyday work-life and on my identity as worker. A genealogy is a critical practice that we can engage to "make the past no longer present"(O'Farrell, 2005, p. 72).

When using any particular methodology we take up the epistemic assumptions that create it and are encoded within it. A Foucauldian genealogy is necessarily grounded in poststructuralism, but for this project I used a feminist poststructural lens as I explored the data. These choices shaped the research question, how I gathered and read the data, how I

approached the analysis and discussion, and how I evaluated the research. In the first part

of this chapter I describe these theoretical underpinnings and define some of the main

concepts. Following this, I introduce some of the core elements of a Foucauldian genealogy,

noting its suitability for this research project. In the second part of the chapter I outline my

methods, provide a brief overview of some of the historical conditions I discuss in the

literature, and introduce the data and my analysis process. I finish by talking about the

criteria for evaluating this research.

Feminist Poststructuralism

The epistemological foundation of a research project governs how claims are made,

what counts as knowledge, and the political commitments of the project. The epistemic

framework for this thesis is feminist poststructuralism, a hybrid of two 20th century

theories concerned with how power is exercised to govern actions, identity, and social

organization (St. Pierre, 2000; Weedon, 1987). Using a feminist poststructural framework I

analyzed how workers were produced and governed at the level of their identity through

job descriptions, publicly distributed information about community living, parent and

advocacy newsletters, and staff training materials.

Feminism combined with poststructuralism gave me access to many points of

analysis. I used a feminist lens to think about the ways that group homes function as both

public institutions and private homes; a dynamic that creates a central tension for workers

in terms of their roles and identities. Further, notions of "home" mask the fact that workers

are employees and that what they are doing is "work." I noted the ways in which workers

were invited to participate in their own production as devalued workers. Weedon (1987)

suggests that yoking feminism to poststructuralism gives the feminist researcher access to

an analysis of the discursive strategies that structure identity and social spaces, an analysis

that is fruitful for understanding how people choose to occupy and remain in subordinated

roles. Feminist epistemology also privileges my experience and identity as a worker,

allowing me to transparently discuss the ways I engaged the research question from the

standpoint of a worker. It is a standpoint that often complicated the research process for

me. My own impulse to stay in the shadows as a worker was challenged by the necessity of

showing up as a researcher and in meeting the commitment of the research to "see" the

worker of the 1980s.

The idea that identity can be produced through texts challenges assumptions of

liberal humanism, particularly assumptions that language is a transparent vehicle for

meaning, and subjectivity is stable and essential (St. Pierre, 2000). Given that

poststructuralism is a social and philosophical theory that sets itself against the tenets of

liberal humanism, it is important to touch on some of its basic assumptions. Liberal

humanism is recognizable as the guiding ideology of Western modernity; it structures our

institutions, our political organization, privileges knowledge produced through scientific

reason, and asserts the self as an essential, self-conscious arbiter of experience (Mann,

2010). The ideal modern liberal subject is separated from history and nature, existing as a

universal, persisting, moral, and self-conscious subject capable of making reasoned choices

in response to life (Mansfield, 2000). Liberal humanism occupies an important place in this

research as it provides the ideological framework for the goals and assumptions of the

community living movement. Like many other social movements of the time (i.e. the

women's movement, the civil rights movement and the gay rights movement), the disability

rights movement was informed by demands for justice, autonomy, self-determination, rights, and choice (Shakespeare & Watson, 2001). Liberal humanism takes progress in human affairs for granted, asserting that growth and improvement are the telos of social and natural life (St. Pierre, 2000). We recognize these ideals as cornerstones of liberal humanism and in popular terms their realization represents the hallmark of a civilized society. Based on this ideology, change *equals* progress.

In this ideological context, the rise of the community living movement represented unquestionable progress. The changes that initiated and carried the community living movement forward were imbued with assumptions of a march toward civility and an attainment of social justice. However, from the perspective of poststructuralism, this represents *one* way to tell the story. Poststructuralism rejects modernity's grand narrative of progress, asserting instead a landscape of contingency, a "series of lurches from one system of classification and representation to another" (Mills, 1997, p. 53). Accounting for contingency (which I discuss in more detail later in connection with the Foucauldian genealogy), exposes how the community support worker emerged in such a way that who she would be and what she would do appeared necessary. Shaking the foundations of naturalness and necessity is the political muscle of feminist poststructuralism (Weedon, 1987). Using a feminist poststructural analysis it is possible to see the story of the community living movement and the emergence of the worker *as* a story, told in ways that advantage some and disadvantage others. In aid of understanding where this particular story came from it is important to recognize how language and discourse work to produce subjectivity (Weedon, 1987).

Subjectivity. The pursuit of the community support worker as a particular subject is at the heart of this research project. Subjectivity is a highly contested concept, and a core concern of philosophy, politics, and social theory. Within humanism the subject is presumed to be a "conscious, stable, unified, rational, coherent, knowing, autonomous and ahistoric individual" (St. Pierre, 2000, p. 500). O'Farrell (2005) suggests that the subject is "a philosophical category which describes an entity which is able to choose courses of action" (p. 110); others have described subjectivity as the locus of experience (Weedon, 1987). Nick Mansfield (2000) proposes four types of subjectivity: the *subject of grammar*, the "I" in a sentence; the *political-legal subject*, also sometimes referred to as the legal person; the *philosophical subject*, understood to be the "ground of truth and knowledge" (p. 4); and finally, the "subject as a *human* person" (p. 4, emphasis added), which is connected to our understanding of being a human who can *experience* life. All of these ideas about subjectivity are found in the data, but I used a Foucauldian understanding of subjectivity to focus my analysis.

For Foucault subjectivity represents a way of organizing knowledge that informs how we come to identify as various subjects throughout our lives (O'Farrell, 2005). He invites us to explore the following types of questions in relation to our identity: "How are we constituted as subjects of knowledge? How are we constituted as subjects who exercise or submit to power relations" (Carlson, 2010, p. 15)? Foucault proposes an ontology in which subjects are produced and reproduced through the exercise of power and knowledge; he was particularly interested in "how the self was constituted through practices and institutions" (Chambon, 1999. p. 54). Following this premise, I based my analysis on policy priorities, job descriptions, public education materials, training manuals

and newsletters. As anticipated, this approach did not produce a singular and coherent worker/subject, but a multifarious collection of workers captured in one job title. This composite worker was produced through the tasks she performed, through statements about her character, by the spaces where she worked, and importantly, in relation to the subjectivity of the person she supported. This is not to say that the worker is without agency, which I discuss in Chapter Six, only that she was implored to participate in the community living project in ways that constrained her subjectivity through a collection of very instrumental definitions of a caregiver.

Contestations of subjectivity are central to the community living movement. In a sense it is a social movement that began with a focus on subjectivity through the recuperation of people with disabilities from *object* to *citizen*. People with intellectual disabilities had historically been considered less than human; the community living movement contributed significantly to helping these people claim their humanity through assertions of social and civil rights, and demands for access to opportunity. This shift necessarily resonated to those providing support through "institutional activities [that] simultaneously create clients and workers, as two sides of the same coin" (Chambon, 1999, p. 68). As the subjectivity of the people being supported changed, the goals of support and the spaces where this support was provided also changed. The worker of the community living movement was produced as the subject that it "made sense" to have in order to fulfill these new goals within these new spaces. Despite attributions of her naturalness, this worker did not emerge from anything essential about her, but from the demands and desires that produced her.

Disciplined through discourses that shape her as a worker that resembled a mother, or simply a service, the prime directive of the worker was to protect the subjectivity of her charge, a subjectivity that achieved its value through apparent independence and autonomy. If we refer back to the idea that a subject is "able to choose a course of action," the subjectivity of worker becomes ephemeral. Her own agency was enmeshed with that of the person she supported. Added to this, the language used in job descriptions to speak about the worker produced her as a particular subject. It is, in part, through language that the community support worker came to understand herself as a particular worker, a self-understanding that contributed to how she was disciplined at the level of her identity, to be or act in prescribed ways.

Language. Within humanism, language is the transparent means of describing reality; language reflects reality and meanings are intrinsic. A poststructural theory of language asserts, "there is no intrinsic order to the world itself other than the ordering which we impose on it through our linguistic description of it" (Mills, 1997, p. 47). This has important implications for research based on the examination of texts; I did not read the texts as descriptions, but as propositions. When the Ministry of Social Services and Housing (1987a) pamphlets speak about the group home staff, they are speaking about a hypothetical worker, they are speaking about the worker who is required, and they are speaking about the worker that they hope for. As they are speaking, a particular worker simmers into existence in the imagination of the community, parents, advocates, neighbours, and in the mind of the worker herself. Language is productive.

Language structures systems of meanings and values that constitute social and political environments, it is for this reason that feminist poststructuralism recognizes

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language as a site of political struggle (Weedon, 1987). In this research attending to language was paramount as I looked at how the worker was produced in and by texts. Given that language structures identity, normalcy, and common sense (Mills, 1997) this necessitated reaching beyond a naïve view of duties described in job descriptions. In attending to the language used to describe these duties I was able to recognize the ways that "common sense" was evoked as a placeholder for ideology or rationalizations that masked the movement of power. For example, workers were expected to support a *normal* lifestyle for the people they supported, one that conformed to the *lifestyle* of the neighbourhood. The house was to be kept to *acceptable standards*, and people were to be supported to dress *in style*. All of these values are embedded in the assumption that "everyone knows" what they mean, but within these values there is a layer of coercion that the worker was subject to, and that she was required to impose on the person she supported (Weedon, 1987). Connected to the productivity of language, next I look at discourse, which is another concept central to a feminist poststructural analysis.

Discourse. Within the parlance of liberal humanism, the term *discourse* was originally used in linguistics or rhetoric to describe a reasoned argument (O'Farrell, 2005). Its meaning can also include something akin to a conversation, or a collection of statements that stand for a body of knowledge (Chambon, 1999). From a poststructural perspective, discourse is a series of statements or texts recognizable as discourse by the "systemacity of the ideas, opinions, concepts, ways of thinking and behaving which are formed within a particular context, and because of the *effects* of those ways of thinking and behaving" (Mills, 1997, p. 15, emphasis added). Discourses are not descriptions of an idea or concept, rather they "structure both our sense of reality and our notion of our own identity" (Mills, 1997, p.

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13). Discourses shape our understanding of phenomena according to orders that are socially and historically situated (Weedon, 1987). For example, medical discourse that produces the category of intellectual disability relies on medical and social science in order to establish a baseline for human normalcy. Discourses have their own materiality, and people who have atypical ways of expressing their humanity have tragically experienced the effects of discourses that produce a "discrepancy…[that] spoils [their] social identity" (Goffman, 1963, p. 19).

In relation to discourse, the terms *production* and *constitution* are used in particular ways in this thesis. When I speak of the *production* of a particular subject I am indicating that the individual is being acted on by a composite of power and knowledge (or, knowledge that is authoritative) that *produces* the individual as a particular subject. In the same way, we say that particular discourses have the capacity to *constitute* individuals as particular subjects. Individuals, in relation to one another, can be co-constitutive in that their relationship is in some sense defining and they become a certain type of subject within the relationship that they might not otherwise be (Chambon, 1999), much like a patient is simply a sick person until he is tended by a nurse and *becomes* a patient.

While having a certain solidity as "objects in the world," (O'Farrell, 2005, p. 78) discourses must also be recognized as fluid, historically situated, and subject to change (Mills, 1997). The commitment of a feminist poststructural epistemology is to advance research that attends to the effects of discourse, to challenge, counter and resist discourses that are repressive or harmful. This necessitates a process that attends to language, to tone, to how we are invited to play out scripts that are devaluing or demeaning; it is a political project. The quality of our attention is critical, as this attention makes way for new

orders informed by new discursive structures, which in turn rise out of the historical and social conditions in which they are forged (Mills, 1997).

A Foucauldian Genealogy

A genealogy is a historical and critical practice used to articulate certain types of problems that represent challenges in the present (Koopman, 2010). The types of problems a genealogy best addresses are submerged problems, ones that are difficult to pin point, that "condition us without our fully understanding why or how…that swirl around the heart of who we are" (Koopman, 2010, pp. 1-2). My own sense of unsettledness in my role as a community support worker is a good example of a type of problem a genealogy is used to explore. Predicated on a relationship between the present and the past, a genealogy is often called "a history of the present" (O'Farrell, 2005, p. 71). It is an excavation that "privileges the present as a site of inquiry" (Koopman, 2010, p. 2) and looks to the past to explore how "an unproblematic set of practices which were accepted without question becomes a problem" (O'Farrell, 2005, p. 70, quoting FS: 74).

Using methods akin to historical criticism, a genealogist troubles these submerged problems through staging an inquiry into the historical conditions that make it possible for the present to appear natural or necessary. By exposing the chaos and contingency that lay beneath socially produced necessities that compellingly govern us through our identity and desires, a genealogy allows us to challenge notions of inevitability (Koopman, 2010). In using this methodology I was able to look at the social and historical conditions that existed at the time the need for the community support worker arose, and see how she was produced through a confluence of ideas, fears, dreams, and rationalities.

Research Methods

In the introductory chapter I reflected on my experiences as a worker: Who do I feel I am asked to be? What is strange about a home also being a place of work? Why do I feel as if I fail just by showing up? In sorting out my own sense of "not being able to win for trying," I asked, at the time when the community support role was first created in the 1980s, what *was* the worker supposed to do, and who *did she need to be* to be successful in this role? How was she produced as a particular subject at the time she was first needed? What kind of worker did society need? I began by looking at the social and historical conditions that existed at the time the community support worker role was created. These conditions represent the *conditions of possibility*, the contingencies through which a particular worker becomes necessary.

Based on literature that lays out the conditions of possibility, I considered who had the authority to speak about this worker, to make demands of her, to say who she should be and what she would do? I decided to search for data from parent and advocacy groups, the Ministry of Social Services and Housing, the British Columbia Government Employees Union, and not-for-profit services agencies. I combed through boxes of archives looking for materials that spoke to my research question, and selected data that evoked an image of a worker, a placeholder, or a functionary. I found her described as a gesture, as the fulfillment of desires, through the spaces where she worked, and in her implied absence. My analysis was structured along the themes *support, worker*, and *community*. I looked for the way the *worker* was spoken about, how ideas about the priorities of *support* were revisited in the community, and I looked at the *community* as a social space. Structuring the analysis along these themes made demands on the data, forcing juxtapositions between

documents that illuminated relationships between the different sources of data, and provided a complex view of how the worker was imagined.

An Introduction to the Conditions of Possibility. To begin my inquiry into the conditions of possibility, I drew a circle around the time when Woodlands closed. Woodlands was the first large institution of its kind in British Columbia. Originally called The Provincial Hospital for the Insane, in 1950 it became the Woodlands School, changing the focus of its mandate to become a residence for children and adults with intellectual disabilities (Adolph, 1996). With the graduated closure of Woodlands, beginning slowly in the late 1970s and more actively in the 1980s, the need for alternative supports for people with intellectual disabilities was created. What were some of the ideas and events of that time that came to play in producing this new worker?

I decided to focus on the social movements, social theories, and political circumstances that created the conditions for the community living movement to begin, and correspondingly, the community support worker to emerge. Within a genealogy, these ideas and events represent the conditions of possibility. My criterion in selecting which conditions to explore was that *collectively* these categories would provide a historical context for the data and help me understand popular ideas about care and support for people with intellectual disabilities. Finally, I looked for literature that would provide an overview of local political and social issues of the day, issues that might come to play on how the community support worker would be imagined.

I divided these conditions into two categories. First I looked at disability-related topics, which include: the medical model of disability and critique of institutions; the parent's movement; the disability movement and accompanying social model of disability

theory; and the contribution of Wolfensberger's (1972) normalization theory. These topics

contain important information about how people with intellectual disabilities had

traditionally been supported, and how ideas about support were changing radically. In

these disability-related conditions of possibility the rationale for deinstitutionalization is

clearly explicated; we get a good picture of what the stakes were for people with

disabilities, families, and the state as the large institutions were closing. While basic human

rights were an issue for people with intellectual disabilities, the community living project

would exceed this through challenges to the state and the community to recognize people

with intellectual disabilities as citizens. The implication for workers was that support was

not simply providing assistance with "activities of daily living." Workers would instead be

part of a historic emancipatory project to free people with disabilities from the institution.

Community support work would *be* social justice work.

     In the second category I looked at politics in British Columbia circa 1983, a time that

marks a transition in the province toward neoliberalism, a burgeoning economic and

political rationale noted, in part, for privatizing social services. I also discussed more

generally the complexities of dependency and care labour, particularly in relation to gender

and gendered spaces. I considered how changes in the opportunities for women outside

the home did little to value the care work that still needed to be attended to. Finally, I

introduced *the community* as an unexamined partner in the community living project. This

literature helps underline the vulnerability of the worker in the context of care as gendered

work, the loss of union representation for many workers, and the privatization of public

services. An example of this vulnerability is found in the rise of neoliberal sensibilities in

the early 1980s that destabilized the compensation for care work. The rights of people

with disabilities to service were placed in direct competition with workers' rights for fair compensation. While this literature does not exhaust the conditions of possibility for the production of the community support worker, it does provide an orientation to the social and historical context for the data.

An Introduction to the Data. I collected archival data from four distinct sources: parent and advocacy groups, the Ministry of Social Services and Housing, service agencies, and the British Columbia Government Employees Union (see Appendix for an inventory of the data). These sources were selected based on their authority to speak to the issue of who would care for people in the community and, more practically, whether I had access to the archives. In the end, given an *abundance* of data, I was inspired by Foucault's approach to "focus on prescriptive and programmatic texts that create the impression of a perfect order" (O'Farrell, 2005, p. 77). I chose texts that made recommendations or provided guidelines for "ideal" support, that talked about the kinds of services workers would provide and the goals of these services, and that spoke directly to workers about their job. These criteria were narrow enough to speak directly to my research question and broad enough to capture the complexities surrounding the support worker's emergence. Below I introduce the four sources of data, and include a short description of the documents that I used for my analysis. All of the documents I selected are generic, contain no personal information, and were either circulated widely to members of organizations and their affiliates, or were publicly distributed.

The BC Government Employees Union. At the time of institutional downsizing and closures at Glendale (Victoria), Tranquille (Kamloops), Woodlands (New Westminster), and Riverview (New Westminster), there was labour conflict between the provincial

government and the British Columbia Government Employees Union. Thousands of union

sector jobs in the institutions shifted to privatized jobs in the community. This was a

daunting prospect for the union and it found itself in the unenviable position of *seeming to*

advocate keeping people in institutions in order to protect the jobs of unionized workers.

This confusion over the union's position in relation to deinstitutionalization is easily

identified in the 1984 policy statement that I selected for this research. While favouring

the closure of large institutions, the union was fully invested in the idea of establishing

small institutions, group homes, staffed by unionized workers. This policy statement is

important to this research for its straightforward acceptance of the institution and

institutional practices. No other source of documents, or materials is so unabashedly

committed to the institution. The Union, in fact, seems to miss the nuanced argument

about community living as a social justice movement, instead focusing on it as a movement

about scale. For the Union, community living means many small institutions rather than

one big one. The main argument the Union makes in this policy statement addresses the

privatization of services.

      The Ministry of Social Services and Housing. I selected two brochures published

in 1987 by the Ministry of Social Services and Housing that were directed to the general

public. These pamphlets describe publicly provided services for people with disabilities of

all ages, and community living services for adults. Read as the state's position on

community living, these documents were valuable in helping me understand how the state

planned to approach publicly funded, privately delivered support in the community, what

they thought workers would do, and how they understood the community as a social space.

The worker produced in these documents was an important element in the public relations

aspect of opening group homes in suburban and urban neighbourhoods, as the state made promises to the community that the presence and actions of workers would keep. These documents were helpful in exploring not only the production of the worker, but also the production of the community as a reluctant participant in the community living project. As well, the state was not only promoting community living, it was also promoting privatization.

Family and advocacy groups. The influence of family advocacy in the advent of community living was paramount; it was families who pressured government first to improve the institutions and then to close them. For this research I drew primarily on a series of newsletters published by the Woodlands Parents Group that were directed to other families as *family-to-family* communication that advocated community living. At the outset of the community living movement a small group of families was highly involved in staff recruitment and selection, and they had high expectations for workers. These materials were incredibly valuable due to their openness in describing the desires of parents for better lives for their children. These desires play a central role in shaping the person and practices of the community support worker. Other important contributions from families were made through the Western Family-to Family Association, in particular documents that are communications from parents to workers.

Service agencies. Agencies in the Lower Mainland serving people with intellectual disabilities and their families first emerged in the1950s. They provided educational and respite support for families with children with disabilities, and sheltered workshops for adults. In the 1980s, at the start of wide-scale deinstitutionalization, many agencies shifted their mandate to include long-term residential services for adults with disabilities. I

contacted many of these agencies and received a range of documents from the Community

Living Society, Spectrum Society for Community Living, and the Mission Association for

Community Living. Kelly's (2010) research suggests "organisational mandates and

philosophies shape support provision interactions in multiple ways" (p. 114) and for this

reason my selection included agency mandates and mission statements, along with training

materials and job descriptions. In its entirety this category of data was particularly rich, as

these documents spoke very directly about and to the community support worker.

Through job descriptions that outline duties from housekeeping to teaching, there were

many workers produced by these documents.

A Foucauldian Discourse Analysis. Having discussed feminist

poststructuralism as the epistemological commitment of the research, provided an

overview of the Foucauldian genealogy, and introduced the data, I will now identify my

approach to the analysis within this methodological framework. This framework made

particular demands on the analytic process. In the use of historical materials I was

committed to a process that made assumptions about the past as a constituting presence in

the conditions of possibility, the data, and in the world of the contemporary worker. It is a

framework that attends to the discursive strategies of spaces and practices, the tone of

communication (persuasive, imploring, formal), and to the constitution of subjectivity

through discourse. Finally, it contains the political commitments of feminist

poststructuralism to expose and challenge social structures and institutions that are

oppressive or exploitative. Within this methodological framework I engaged a Foucauldian

discourse analysis in order to explore how a particular worker was called out in the data.

A Foucauldian discourse analysis can be conceptualized as an approach more than as a particular process or method (Carabine, 2001). It is an approach that arises from an *invitation to engage with* the data, rather than a *procedure that is applied* to it. This idea underlines the participation of the researcher, not as someone who stands outside the data as an observer, but as an engaged participant whose attention adds content to the analysis. My identity as a support worker was inseparable from the lens I brought to the analysis and I could recognize myself "being spoken into existence" (Davies, 2005, p. 41). One of the challenges of being enmeshed in the data was that it was hard for me to see the implied, unspoken, or common sense content of the documents as such. Texts that from the "outside" of the community living movement would be considered strange made perfect sense to me as an "insider." For example, instructions for staff not to park near the house to avoid bothering the neighbours (Western Family-to-Family. n.d. 2, p. 1) might seem strange to someone who assumes that they have a right to park near where they work. While this instruction irritated me, it made sense to me, and in fact I routinely park where I will avoid inconveniencing neighbours who live next to the group home where I work. Despite the promise of the Foucauldian discourse analysis to make the "familiar unfamiliar and [make] visible what we take for granted" (Chambon, 1999. p. 54), it was a constant struggle for me to read the documents outside of the way that they make sense to me in my everyday experience as a worker.

There are many ways of approaching a discourse analysis. In general terms a discourse analysis is concerned with language, patterns of language and how meaning is negotiated in language (Taylor, 2001), but it is not simply a matter of identifying discourse as a stable and persisting formation. A discourse analysis traces discourses as they form

and reform in history, exposing the ways that discourses of one time challenge or join with those they supplant (Mills, 1997). A discourse analysis also takes note of the effects of discourse, exploring how they materialize as practices, subjectivity, and social institutions (Chambon, 1999; Weedon, 1987). Foucault's approach creatively includes the analysis of discourse produced through texts, in and through choices around language and tone, architecture, gestures, practices, programs, and images (Carabine, 2001).

This attention to a wide-range of discursive structures distinguishes a Foucauldian discourse analysis, making it an excellent tool for the detailed analysis of complex relations that existed between parents, the Ministry of Social Services and Housing, the union, services agencies, people with disabilities, and the community support worker. In addition to looking at statements that are implied or expressed in the data, the Foucauldian discourse analysis draws in the discourses that are produced by the social spaces evoked in the documents, the home, the community, and the institution. It calls attention to detailed lists of housekeeping duties that sit alongside detailed lists for teaching skills, it shows the complex ways in which the worker would be expected to be present and absent at the same time.

My Approach to the Analysis. To begin my analysis I read through the documents from each data source separately. Applying a critical lens to seemingly familiar or common sense statements, I looked at how language was used, noted word choices, tone, and how the sequence of instructions implied a hierarchy of importance. I tried to imagine the worker who was being produced by these words, statements, and priorities:

- o How do these texts work to create a particular worker? What kind of worker?

- What responses might the texts inspire from workers?

- What are the discourses that these texts evoke, and how might they enter into a dialogue with other similar or contrasting discourses? (For example, how are discourses of femininity evoked through the use of the 'family metaphor'?)

- What are the disciplinary effects of discourses that position the community support worker as a foil for the institutional worker?

- Are there any contradictions, or counter-narratives in the texts with regard to the identity of the worker?

- How are support and the goals of support spoken about?

- How is the community spoken about? What are the qualities attributed to it as a social space?

- How do the themes, statements, and apparent desires in the documents echo the historical, social, or ideological materials I looked at in the literature?

Through the process of isolating statements that explicitly or implicitly responded to my questions, I was able to group these statements into themes. This process yielded two things. First, I was able to recognize the original statements for their discursive effects, noting how they were used to shape and discipline the worker. Second, in each category of data a distinct story emerged. For example, the worker produced by the documents from parents was a decidedly domestic worker, while the one produced by state documents was more akin to a public relations worker, and sometimes the worker disappeared within the more general category of "services."

Having explored the data along the axes of the different sources of data, I then structured the analysis thematically along the lines of *worker, support*, and *community*. By organizing the analysis this way I was able to complicate the thematic findings by combining the different data categories, and setting them in conversation with one another.

This provided me with additional insights into the complex and contradictory role and identity of the community support worker. Through this process I was able to see her production as a composite of *many* interests and desires, and as the contingent production of the historical and social context in which she was required.

  My Role as a Researcher: A Reflexive Process. As I embarked on the analysis, I sat with the stacks of documents I selected as representative samples from a larger volume of materials. I sat, as if they were separate from me, and I would look *at* them. However, this would not be the case, as through the process of reading the documents I came to recognize that my presence as a support worker represented a fifth source of data. But with this source of data it was not going to be possible to "set aside some of the materials." I would, in my entirety, be an integral part of this analysis. I was challenged when my identity as a self-respecting "good worker" was, in the context of the data, required to be invisible and subservient. And at other times, when the data simply did not reflect any part of my understanding of what it is to be a support worker, I tried to distance myself from this worker who was being produced along a sloppy continuum of the ideal and the incompetent. Back and forth, good person or bad person, selfless or selfish, caring and controlling; these binaries flickered through the data. In noticing the stories this told about workers, my identity became a negotiable element. As a way of participating in the conversation about my own production I have included some vignettes as chapter headings. These are stories from my experience as a worker or they are stories told to me by other workers when I shared my research with them. Engagement with the data, in tandem with my own experiences and the stories of my co-workers invited me to set aside

the either/or of my identity in this project: I am both the researcher and the support worker, and in both cases I am a woman who has, since childhood, been naturalized to care.

Discussion: a Return to the Present. The final part of this research project is a discussion of the findings. This discussion represents an important step as it closes the circular aspect of the genealogy: present to past, and back to the present again. The purpose of the discussion is to look at the findings in relation to the conditions of possibility, reflecting on the worker as contingent rather than inevitable, and noting *how* she was formed. For example, I could see that through the confluence of contingencies, such as ablesim (the pathology of disability), chance events (global oil crisis precipitating restraint legislation), and the passion of mother-love (the Woodlands Parents Group) the conditions were laid for a particular worker. The discussion, importantly, brings the findings to bear on current discourse about paid support and the community support worker. As a final step in the process, I reflect on the present in relation to the contemporary community support worker and consider the intervention that this research invites.

Evaluating the Research: Assessment and Limitations

In terms of validity this research can be evaluated along several axes, as outlined by Sarah Tracy (2010). Is my topic worthy? Timely? Is the research sincere: Does it reflect a willingness to engage with the data that is transparent and open? Does the research "provide readers with a vicarious experience" (Tracy, 2005, p. 845)? Have I given my readers a sense of the worker of the 1980s and insight into some of the complexities of her role? Is my research multi-vocal? Does it include disparate voices and interests that speak

to the production of the community support worker (Tracy, 2005)? Koopman (2010)

suggests that the measure or value in a genealogy is largely reflexive, that is to say, did it

meet its purpose? These questions represent the central criteria I used to establish the

rigour of this research.

Given current initiatives to shift services for people with intellectual disabilities

away from group homes, which are now referred to as "staffed residential settings" in

literature from the crown corporation that administrates funding (CLBC, 2013, p.25), it is

an excellent time to consider the role of paid support workers in the lives of people with

disabilities. Increasingly privatized services make individuals with disabilities, their

families, and workers more vulnerable to bearing the risks and responsibilities for

supports that are better met through a collective public response (Scourfield, 2007; Fine,

2005). In focusing on the worker, this research helps to show the origins of the

rationalizations for these current initiatives. Through using data that represents disparate

views and interests, these rationalizations attain solidity from which to make claims about

how these interests produced the role of support and the person of the worker. Through

reviewing the data and findings, the reader is able to get a sense of what it was like to be a

community support worker of the 1980s and what were some of the demands she

experienced at the level of her subjectivity.

Tracy (2010) points to the importance of sincerity, which is particularly salient to

this project given my role as a support worker. My experiences as a worker initiated this

study and these experiences were a constant companion to the analytic process. While the

questions that guided this research were limited to looking at the production of a

community support worker thirty years ago, I hoped to draw a connection between this

worker and the contemporary worker in order to gain some insights into the experiences

of workers in the present. My awareness of this connection was largely borne out in

noticing how hard it has been for me, as a representative worker, to *see* the worker of the

1980s. As a measure of the value of this research, I have reflected on and discussed with

my co-workers our impulse to stay in the shadows in our work, and to recognize this

impulse, not as necessary or natural, but as produced.

According to Koopman (2010), who suggests that the validity of a research project is

claimed through the realization of its purpose, the findings in this thesis mark the

achievement of its purpose. However, the notion of this reflexivity has the potential to cast

the genealogy as a wholly subjective undertaking (Koopman, 2010). We might even simply

call the findings a fiction or *another* way of telling the story. Yet, there is some rigour

attached to this method that allows us to make claims with confidence; "a history of the

present is not simply a diagnosis" (Koopman, 2010, p. 72), rather it is meant to inspire or

provoke change in the present. A genealogy illumines what seems to be a solid, inevitable

object, and exposes it as a multiplicity of desire, contingency, and socially produced

necessity. This fragile contingency, or the sense that things might have been otherwise,

opens up possibilities in the present to choose again. In other words, a genealogy invites us

to hold with less sureness a view that is problematic. The value of this research, then, is the

degree to which it reaches beyond itself in order to recognize the present as a proposition.

In terms of the limitations of this research, in drawing on institutional and

organizational documents, contributions from support worker are absent, as are the voices

of people with intellectual disabilities who receive support. This is due, in part, to the

design of the research, and particularly the choice of methodology. A second limitation is

that this research is confined to paid caregivers. As mentioned in the introductory chapter,
throughout the history of British Columbia many adults have been cared for in family
homes by their family members[4]. I recognize that looking specifically at the closure of one
institution and the adjacent policy pertaining to paid care for the people who moved into
the community does not explicitly include the experiences or participation of family or
informal caregivers who were not involved with the institution and its closure.

A Note about Ethics

People with disabilities represent half of the care relationship and are the focus of
the social movement at the center of this study, I necessarily refer to them constantly. I am
aware of the danger of objectifying or misrepresenting people with disabilities in this study
and was mindful of terms of reference, language, and labels. In some of the literature and
archives derisive terms are used when referring to people with intellectual disabilities, i.e.
"the retarded." I occasionally include these labels, only as they are reference points that
are indicative of their time. As noted earlier, the category of disability is built on the
tabletop of ableism and the ableist gaze informs the data. Despite attention to this, my
analysis makes assumptions about ability and disability as solid categories. Speaking to
dependency, as I do, also requires caution. Discourses of independence and dependence
can be used to reify some identities or ways of being as less valued than others. I have
made every attempt to be mindful of these issues.

Conclusion

In this chapter I introduced the epistemological foundation for this research,
feminist poststructuralism, a theoretical framework that sets itself against the core tenets

of liberal humanism. Within poststructuralism, the *subject* is discursively and socially

produced, rather than essential, *language* is not a reflection or description of meaning, it

creates meaning, and *discourse* is more than a collection of statements, it is an object

imbued with authority often recognized through its effects. These concepts are central to

this research as they act as guides to read the texts. I also described the methodology. A

genealogy is a historically based critical practice that articulates problems that are difficult

to define. Through exploring historical *conditions of possibility* that give rise to certain

ideas or orders that produce these problems, a genealogy is able to address necessity, not

as a fact, but in terms of social and ideological mechanisms. A genealogy has an ethical

commitment to increase awareness of how the apparent necessity of the present has

emerged contingently, thereby exposing the fragility of the present. This awareness

creates the opportunity for an informed, strategic intervention in the present (Koopman,

2010).

In the second section of the chapter I outlined the research methods. Beginning

with the literature I identified the *conditions of possibility* that made the emergence of a

particular worker possible. For example: What did people need to think or believe for the

worker to be produced as she was? What were some of the social and political factors that

came to bear on her production? I introduced the data, archival materials that tell the story

of this new worker from the perspective of four sources: parents, the state, the union, and

service agencies. Using a Foucauldian discourse analysis, a process informed by a

poststructural conception of language, discourse, and subjectivity, I was able to complicate

the view of the worker through the categories: worker, support and community. The final

step in the research design was to discuss the findings, to hold them up against the

conditions from which they emerged, and to consider their implications in terms of an

intervention in the present. In the next chapter I introduce the *conditions of possibility*, the

social and historical conditions surrounding the community living movement of the 1980s.

Chapter 3: From Contingency to Necessity

When the center block of Woodlands was demolished recently, there was a ceremony, and survivors of Woodlands, their families, and advocates came to watch the building be destroyed. In the crowd there was also a woman who had worked at Woodlands as a care aid almost thirty years ago. She told me she saw one of the fellows she used to care for. She said she remembered him from when he was little, and on the nights when he had trouble sleeping she used to go to the ward, take him out of his crib, and rock him to sleep.

The purpose of this chapter, in the language of a genealogy, is to introduce the *conditions of possibility*. These conditions are issues, events, social movements, and theories that have a solidity to them. As products and effects of discourse they are "objects in the world" (O'Farrell, 2005, p. 78). However, it is important to also read them as delineations of thought. The conditions of possibility set limits on how it was possible to think about disability, care, and labour during a particular time in history. Limits come in the form of how objects and subjects are spoken about, the language that is used, the problems that are articulated, and how they are solved. For example, we can notice when dependency is framed as a particular type of problem.

For this research I selected events, social movements and theories, and political issues in circulation leading up to and including the time when the large institutions were closed in British Columbia and the residents moved to small community-based group homes. These conditions shaped how support in the community would be envisioned; they functioned both to constrain and inspire the ideas of those who would be thinking about how community services would be realized. Importantly, they laid the groundwork for

how the community support worker was imagined in the data that I analyze in Chapter Four.

This chapter is divided into two sections. The first section focuses on conditions relating to disability: the medical model of disability and the advancing critique of institutions; the disabled family and the parent advocacy movement; the disability movement and development of a social model of disability; and the promulgation of Wolf Wolfensberger's (1972) normalization theory. In the second section, I look at some of the social and political issues that had an impact on community care for people with intellectual disabilities. I discuss care labour in the context of ongoing dependency and caregiving as the gendered practice of the lower classes. I note the introduction of restraint legislation in British Columbia, circa 1983, which marks the advent of neoliberalism as a burgeoning economic and political rationale in the province. Finally, I offer a short introduction to some ideas about *community* as a social and political space.

Part One: Disability

Historically, people with intellectual disabilities have been segregated from mainstream society for their own good, for the safety of society, for the sake of their families, for treatment, for education, and for care (Simmons, 1982; Trent, 1994). Care, whether provided by family, neighbours, volunteers, or paid workers, has shifted between activities akin to mothering, nursing, teaching, and wrangling, and has taken place in both private homes and public institutions. In these contexts, the *content* of care has fluctuated, depending on ideas about intellectual disability. At times care has been provided based on the assumption that people with intellectual disabilities are incurable, untreatable, and

uneducable (Trent, 1994). At other times care has included basic education and vocational training (Trent, 1994). However, "care" could also include brutal discipline and isolation (McCallum, 2001). The prejudice and violence that people with intellectual disabilities have been, and in some instances continue to be, subjected to in the name of "care" cannot be overstated. The social response to intellectual disability has often been cruelty in the form of segregation, physical abuse, forced sterilization, loss of privacy, denial of education, restraint and confinement, and assaults on personal dignity (Trent, 1994; Carlson, 2010; Wolfensberger, 1972). It was the staff in institutions that perpetrated much of this cruelty, often as a routine part of their job (Goffman, 1961; Jones, 1975; Trent, 1994; McCallum, 2001).

Social movements circa the 1950s and 1960s denoted a new era for many social identity groups that had experienced discrimination, including people with physical and intellectual disabilities. For people with disabilities, this era is sometimes referred to as the Reform Era (Wolfensberger & Thomas, 1998) and is marked by significant contributions from parent activists lobbying for state-funded education and institutional reform. By the 1970s, American and Canadian state service providers were adopting Wolf Wolfenberger's (1972) normalization theory, a theory which envisioned lives for people with intellectual disabilities that resembled, as much as possible, the lives of all other citizens. In aid of this, normalization theory guided service administrators and support workers to support people with disabilities to exhibit "personal behaviours and characteristics which are as culturally normative as possible" (Wolfensberger, 1972, p. 28). In the United Kingdom a social model of disability was developed. This theory asserts that people are not disabled by their impairments, but by social structures and institutions that fail to meet their needs.

Activists have used the social model of disability to advance systemic reforms within social and legal frameworks (Shakespeare & Watson, 2002). Leading up to the community living movement of the 1980s, parent activism, normalization theory, and disability activism had a profound influence on what constituted "care" for people with intellectual disabilities, and taken together, they had an impact on the public imagination. Talk of rights and inclusion turned the tide away from institutions toward care that would be available to people in the community.[5] Moving away from the institution was more than simply looking for a better option; community living was a vehement rejection of large institutions.

The Institution. Institutions have been an undeniably tragic reality at the center of supports for people with intellectual disabilities (Trent, 1994). Historically, and in places where they are still used, institutions function in three ways: they protect people with disabilities from society; they protect society from people with disabilities; and they relieve the burden on families to provide care (Simmons, 1982). From their inception, institutions in North America were overcrowded and underfunded, but in the 1960s and 1970s a series of critiques emerged in academic and public arenas attacking these conditions (Trent, 1994). Leading this critique was the publication of *Asylums,* by sociologist Irving Goffman (1961). Goffman identifies the asylum (such as long-stay mental hospitals or prisons) as a "total institution" (p. 4), an environment that usurps every aspect of a person's life and sense of identity. Goffman's indictment of the institution was followed by the infamous 1966 *Look* magazine photographic essay, *Christmas in Purgatory,* by Burton Blatt and Fred Kaplan. This graphic review of conditions in the institution showed "neglect, filth, and pervasive boredom" (Trent, 1994, p. 256), and elicited the "largest reader response in the history of the magazine" (Trent, 1994, p. 255). In 1972, journalist Geraldo Rivera reported

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atrocities at Willowbrook Institution on Long Island. This exposé showed naked people

crowded into dormitories that "smelled like a poorly kept kennel" (Trent, 1984, p. 258

citing Rivera, 1972, p. 78). Discussions about institutional reform had been ongoing since

the 1940s, but with the publication of the photographs in *Look* magazine and Rivera's

reportage, public opinion now shifted to the conviction that institutions had to close (Trent,

1994). This conviction echoed all the way to the west coast of Canada, and in 1978 British

Columbia Minister of Social Services, Bill Vander Zalm, stood in the legislature to offer his

assessment of the situation:

> I visited Woodlands School. I found, despite what has been said by some
> opposition members, that this building had received little attention. The beds
> were six to eight inches apart, little steel cots; the hallways had maybe
> received a coat of paint, but the play rooms were small, the facilities were
> limited. If that situation had existed in any normal hospital providing for any
> of us here, we would have been screaming all the way from here to Come-by-
> Chance, Newfoundland. We would not have stood for it. We would have seen
> protests. This ministry immediately set out to say: "Hey, those people also
> deserve a break." They deserve some of the opportunities provided us. They
> must share in the resources and wealth that we're creating in this province.
> Let's give them a chance to live in the community as near a normal life as
> possible. (Hansard, 1978, p. 342)

At the same time institutions were coming under scrutiny and evaluation, so was the

performance and character of the staff working at these institutions.

Workers in the institution. For as long as there have been institutions there have

been workers. At various times in history much of the work in institutions has been done

by religious orders, conscientious objectors, unwed mothers, and by the inmates/patients

themselves (Trent, 1994; Carlson, 2010). Trent (1994) strongly acknowledges that the

institution "did not ensure the all care was good care. Much of it clearly was not" (p. 128-129), however he allows that

> ...most [care attendants] were there to care as best they could for people who, they believed, needed care either because of their inability to care for themselves, because no one else would care for them, or because their behaviour or potential behaviour made them threats to the social fabric. (p. 129)

Goffman's (1961) assessment of staff is more critical. He describes the work of staff in the "total institution" (p. 4) as "*people-work*" (Goffman, 1961, p. 74, emphasis in original) through which the inmates are "worked upon...in the direction of some ideal standard" (p. 74). Institutions "usually present themselves to the public as rational organizations designed consciously, through and through, as effective machines for producing a few officially avowed and officially approved ends" (p. 74), however, "much of the time [they] seem to function merely as storage dumps for inmates" (p. 74). The dissonance between what the institution says it *is*, and what it actually *does*, is a contradiction that complicates the work of staff. Goffman (1961) identifies three instances of this complication, as seen from the perspective of the institution and the staff.

The first complication is the status and relationships that the inmate has in, and with, the outside world. Staff is aware that the institution must respect some of the rights of the inmates *qua* persons, but this "awareness" often comes through interventions from the family of an inmate. Not governed by the discipline of the institutions, families make special demands on behalf of the inmate, ones the inmate has been conditioned not to ask for himself. The second complicating factor in the work of staff is the need to provide humane standards while maintaining institutional efficiency. This presents a dilemma to

staff who must "choose" between meeting unique needs or institutional needs. This dilemma is played out at the level of objects through the use of uniforms for inmates rather than personal clothing in order to streamline laundry services, and at the level of the body, by shaving heads to combat lice and simplify grooming, removing the teeth of inmates who bite, and removing the wombs of "promiscuous" (Goffman, 1961, p. 79) female inmates. The third complication is the problem of staff developing affection for inmates, which interferes with their ability to carry out certain duties, such as maintaining discipline. The danger in forming these affections, according to Goffman (1961), is that the inmate will begin to "appear human" (p. 81) to the staff, and when required to instil hardships or privations on inmates, "sympathetic staff will suffer"(p. 81). Goffman (1961) paints a grim portrait of the institutional worker as a core constituent in the intentional and systematic dehumanization of people living in institutions.

Kathleen Jones (1975) studies hospital care for people with intellectual disabilities in the United Kingdom, focusing in particular on the back wards, which were residential wards for people whose needs had been assessed as all encompassing. She uses the term "back ward syndrome" to describe the prevalence of staff inertia and disrespect toward the people they care for, and toward the work itself. Jones (1975) concludes that the main factor in back ward syndrome is the staff view of patients as insensitive, unable to meaningfully discriminate, and un-teachable (Jones, 1975). Accepting the medical view of the patient's condition as "severe subnormal" (p.105), the staffs' belief that patients cannot learn leads to disrespectful treatment, such as referring to the ward as a "farmyard" (p. 104). These staff express frustration, claiming that they do not have any specific techniques for training or teaching in circumstances where full recovery is not the goal. In

lieu of resources that would provide staff with the ability to work more productively with the patients, staff depend on routine to move them mechanically through the day. Jones (1975) reports that this becomes a cycle of inertia; the more staff depend on routine to get their job done the less inspired they are to look outside of these routines.

Like Goffman (1961), Jones (1975) identifies personal feelings between staff and patients as a complicating factor of support. She explores the "family-linked metaphor" (p. 108) used by hospital staff to make sense of their work on a hospital ward where people are not cured. Jones suggests that the family-linked metaphor may be "the best model for staff-patients interaction that many staff have" (p. 108) in terms of meeting the ongoing dependency of patients. It is a metaphor that elicits impulses to provide comfort, safety, and "a warm and happy atmosphere" (p. 108), and it is a metaphor that appeals to the humanity of the staff and patient alike. However, Jones suggests that the family metaphor fails to deliver the compassionate approach that it seems to promise, in several important ways.

In taking on a parenting role, staff exercise a "diffuse authority" (Jones, 1975, p. 108) over every aspect of the patient's life. Apart from the stress that this is likely to evoke for the patient, it also creates tensions between staff and the *real* parents when they compete for authority over the patient's care. Another way the family link metaphor fails is in the area of discipline. Where parents (in 1975) might use corporeal punishment to discipline their child, obviously this practice should not transfer to the ward, and yet it did (Jones 1975). Another complicating issue is that in families parents often try to have the same rules for everyone to prevent the dynamic of favouritism, but on the ward, *one rule for everyone* meant some patients were denied access to care that would have benefited them

(Jones, 1975). Finally, in relation to earlier comments on the low expectations of staff, in families the children mature. The notion of "nurses as mothers and fathers is strained at several points by the fact that patients on the 'back wards' do not mature like children" (Jones, 1975, p. 109) and this is sometimes met with a "violent rejection of the (family) model and the adoption of a more derogatory one [Jones quoting staff]: 'A lot of them can't talk, the same as animals can't'" (p. 109). According to Jones (1975), the family-linked model, while holding some promise for more affectionate and humane treatment of people with disabilities, ultimately contributed to back ward syndrome, by providing some staff with (another) rationale for abusing their patients physically and emotionally. However, this must be seen in the context of an ableist gaze that privileges some developmental trajectories over others. Connected to this, we can see the use of the family-linked metaphor as a way of coping with this gaze. Nonetheless, ongoing dependency stresses the metaphor, and a situation that might have offered a humane (if paternalistic) approach degenerates.

Taken as a composite, the worker produced by Goffman (1961) and Jones (1975) is opportunistically cruel, institutionalized in the sense of prioritizing the needs of the institution over inmate/patient needs, demoralized through institutional routinization, and dehumanized by her own responses within the institutional paradigm. Any efforts or impulses that would allow her to recognize the humanity of the people she supports, or reclaim her own humanity, such as feeling friendly toward the people she supports or performing a family-like role (while problematic, as noted), are discouraged by institutions and families alike. Some scholars are willing to see staff as pawns of the institution, suggesting that within institutions, "attendants, like inmates, became institutionalized as

their personal identities became subsumed by their…involvement in the institution" (Trent, 1994, p. 128), and further, that *institutional practices* dehumanize both the patient and the staff (Jones, 1975). But even within these somewhat more generous evaluations, many of the actions and attitudes of staff are impossible to reconcile as *caregiving*.

  Workers at Woodlands. *The Need to Know* is an administrative review prepared by British Columbia ombudsperson Dulcie McCallum (2001). In this review McCallum details her findings from an investigation of documents pertaining to abuses at Woodlands between 1975 and 1992. Her findings make it clear that administrators at Woodlands were aware of the potential for abuse, that abuse was happening, and that staff were perpetrating abuse with relative impunity. McCallum (2001) states that it is not her intention to cast aspersion on all the people who ever worked at Woodlands, nonetheless, her report *is* an indictment of workers at the institution, of the administration, and of institutionalization itself. This indictment takes the form of recognizing both the systemic and the extraordinary abuse that took place under the auspices of "care." Systemic practices of abuse included sterilization without consent, the routine use of restraints, and confinement in isolation rooms. The abuse perpetrated by individual staff included sexual assault and physical violence, such as "slapping, striking, restraining, isolating, grabbing by the hair or limbs, dragging, pushing onto table, kicking and shoving, very cold showers, and very hot baths resulting in burns to the skin" (p. 18). The safety and security of residents was also compromised by the fact that the "general milieu seems to have been an unwelcoming place for families" which limited the oversight and intervention of concerned families or personal networks (McCallum, 2001).

McCallum (2001) finds in Woodlands a culture of tolerating abuse that was endemic. She reports that the "substandard treatment of residents by staff was repeated over time with no evidence of remorse on the part of the employees involved" (p. 22) and that staff "denied, minimized or excused their abusive conduct" (p. 22). The administration and police were rarely involved, and amongst staff there was a "code of silence" (p. 21) that was only broken if "the laziness and overly unacceptable personality were already annoying other co-workers who added their abusive behaviour to the litany of complaints" (p. 21). A barbeque pit for staff use, built in the mid-1970s, from the gravestones of residents, has since become an icon of staff attitudes of dehumanization, cruelty, and disrespect toward the residents at Woodlands.

McCallum (2001) makes it clear that parents were alarmed about the abuse that was occurring and were proactive in asking for it to be addressed. The Woodlands Parent Group submitted a policy document "highlighting the immediate needs of the residents" to the Ministry, that outlined priorities for stopping abuse, and protocols for following up on complaints (McCallum, 2001). This same group would be instrumental in the development of community-based services, and continued to advocate for safeguards in the form of oversight and monitoring in group homes. They were also particularly committed to ensuring that staff understood their absolute responsibility to provide respectful care, and that any form of abuse would not be tolerated. This concern shaped the values training that staff received at one of the service agencies that was started by these parents. Some of the materials from this training are included in the data for this research.

The Medical Model of Disability. Institutionalization only makes sense within a medical model of disability. The institution _needs_ the medical model of disability, but the

medical model of disability does not need an institution per se, rather it *creates* an institution wherever it is invoked. The medical model of disability is predicated on the medical model of the body as understood through allopathic (Western) medicine, a view of the body as a machine with mechanical, chemical, and electrical functions. Within this model, doctors proceed along a trajectory of diagnosis, treatment, and cure.

The medical model of *disability* locates disability *within* the body and mind of the person. The person is disabled by their embodied physical or mental attributes or symptoms, and their life takes on tragic proportions; they are a subject of science, and an object of pity (Shakespeare & Watson, 2001). The medical model of disability gains its authority through specialized medical knowledge that is the purview of professionals. Through this model professionals have historically governed people with disabilities and their families in ways that presented a diagnosis/treatment/care triad that offered very few options. On the one hand, through a medical diagnosis, parents and children could qualify for state resources, but it was often the case that these resources only came in the form of institutionalizing the child (Brockley, 2004). In the next section I look at parents of disabled children as they tried to gain some control over the implications of their child's medical diagnosis.

A Family with a Disability. Historically children with disabilities have been thought of in various disparaging ways: as sinners, holy innocents, unteachable, or a public menace (Trent, 1994). The families of disabled children were also captured by these discourses and as a result the whole family often suffered stigma and shame. However, "in the years after WWll, parents...both benefited from and contributed to a radical change in public discourse about who the mentally retarded were and what it meant to be mentally

retarded" (Castles, 2004, p. 352). These changes ranged from the rising authority of

medical expertise and professionalism to the changing class of intellectual disability. In

this section I introduce the complexity of public discourse in relation to the *disabled* family.

In the years after the Second World War, discourses idealizing home and hearth

encouraged women who had participated in the war effort to leave public roles and return

to the privacy of the home. Discourses of the perfect nuclear family promoted separate

roles and spaces for women and men; women would occupy the private space of home,

care, and the emotions, whereas men occupied the public space of the markets and reason.

Children were at the core of this domestic ideal as "a source of pride and satisfaction "

(Jones, 2004, p. 324), and the goal of childrearing was to produce the self-sufficient liberal

citizen (Brockley, 2004). The birth of a disabled child was considered a family tragedy, as

"nowhere in this picture of familial bliss was there space for a child who...was not 'perfect'"

(Jones, 2004, p. 325). Disability was a particular affront to middle-classed families who

hoped to "transfer their lifestyle and status" to the next generation. Literature of the 1950s

referring to families with a disabled child told sad tales of marriage run to ruin and siblings

"driven into delinquency and social isolation by the burden and stigma" (Brockley, 2004, p.

146). Professionals, increasingly interested in the psychological health of families, often

saw the disabled child as a threat to the marriage, to the family, and in particular to the

mother (Castles, 2004).

Mothers and professionals. Ideas about motherhood that gave mothers moral

authority over child rearing were increasingly supplanted in the twentieth century by

scientific theories about mothering (Brockley, 2004). This is not to say that women were

relieved of the responsibility to provide care, only that they could no longer be trusted to

do it right. While *all* mothers were the focus of surveillance, advice, and professional opinion, the mothers of children with disabilities were particularly targeted for professional expertise (Brockley, 2004). Professional literature warned that these "mothers were not properly training their children and would instead overprotect and spoil them or reject them and push them beyond their abilities" (Brockley, 2004, p. 139). If she cared, she cared too much, and if she did not care, then there was something wrong with her. Paradoxically, as mothers were constructed as less and less capable through discourses of professional expertise, families were increasingly dependent on doctors and other professionals for help.

Families could only access the help sanctioned by the state and the medical profession, and the institutionalization of disabled children was touted as the antidote for much that ailed families. By institutionalizing the disabled child, the mother could return to her duties as wife and mother to her other children, and bring some stability to a situation that had become untidy (Brockley, 2004). Families who chose to keep their disabled child at home against medical advice were on their own. Some families who tried to care for their child at home might eventually "relinquish their claims to provide care only when they were no longer able to manage, and institutional care took over" (Fine, 2005, p. 248). Those who accepted the advice of experts to institutionalize their child at birth often lost all contact and claim to the child. Families who wanted to continue to be meaningfully involved in the life and care of their institutionalized child "were considered…interfering and their involvement typically discouraged" (Fine, 2007, p. 199). Either a mother looked after her child, to the peril of herself and the rest of the family, or she surrendered him to institutional staff (Brockley, 2004; Fine, 2005).

Class and Intellectual Disability. The 1950s marks a complex and at times antagonistic alliance between professionals and the parents of a disabled child. On the one hand the scientific story about parenting a child with an intellectual disability levelled an attack on mothers whose instincts and motives were not to be trusted. On the other hand scientific discourse helped to socially reposition intellectual disability, moving it from the social and moral "depravity" of the lower class (Brockley, 2004). With the advent of scientific discourse (which still tapped ideas about heredity) disability moved out of the purview of morality and into biology, and intellectual disability became an *illness* that could afflict any family, regardless of social status (Metzel, 2004). This had an important effect on the middle-classed family with a disabled child; while genetically suspect, they were nonetheless able to preserve their middle-class status.

A second factor that helped to move intellectual disability away from its connection to the lower classes to something that can even happen in "good" families, was in the 1950s and 1960s, when upper class families embodied by well-known public persons such as Pearl Buck, Roy Rogers, and the Kennedys, "came out" as families with disabled children. Wielding a great deal of social influence, for example, through the use of confessional literature such as Pearl Buck's *The Child Who Never Grew* (1950), these famous families sanctioned institutionalization as the best option for families (Trent, 1994). It was in institutions, they insisted, that these children could receive the specialized education and training that they needed, although in fact institutions of this time provided little more than basic care (Metzel, 2004). In addition to promoting the institution for children and their families, these testimonies were also instrumental in spreading the powerful story of disability as a tragedy, and the family its victim. This was an important discourse in

eliciting popular and political support for the relief of disabled families (Brockley, 2004).

Unlike the lower classed parents of children with disabilities in previous decades, the

middle classed parents of the 1950s and 1960s could be *heard* by the state, and the call for

charity soon blossomed into a call for rights.

    Parent Activism. The changing social class of intellectual disability challenged the

post-war definition of the *normal* family, as middle class families with disabled children

pressured the state to meet the needs of *all* families (Jones, 2004). These initiatives, largely

led by mothers, became the parent activism movement, a movement that was touted as a

"testimony of the power of middle classed family values" (p. 340). The mothers who led

the advocacy movement were not looking to substantially challenge social structures, but

to forge a place for their child to be able to participate within existing structures as fully as

any other child (Panitch, 2008). With integration as its goal, parent activism gained

momentum from the 1950s to the 1970s and focused on residential institutions and

schools (Metzel, 2004). Connected to the notion of education as a middle class value,

parent and advocates asserted that disabled children had the capacity to learn and were

entitled to the same public education as all other children. At first this education was

conceptualized as segregated, but soon parents advocated for integration or *mainstreaming*

(Trent, 1994; Jones, 2004).

    Activism pertaining to residential institutions also shifted from segregation to

integration. During the 1950s and 1960s, admissions to institutions soared and the

demand for more beds continued to outpace the capacity for admissions (Metzel, 2004).

Parents lobbied for more beds to be made available, and for improvements to the care that

was provided to their children in institutions. But the popularity of institutions would be

their downfall as overcrowding and underfunding stretched the capacity of the state, administrators, and staff, to provide anything above minimum care and even then often in deplorable conditions (Metzel, 2004, Trent, 1994). By the 1970s, with the mounting public critique of institutions and a broader disability rights movement underway, parents turned adamantly away from institutions (Metzel, 2004). But parents did not advocate for the closure of institutions with the idea that their children would move back home. They argued that their adult children had a right to a normal life in the community, not a life of eternal childhood lived out under the care of their mother (Woodlands Parents Group, 1983b).

Using a distinctly rights-based approach, they reasoned that if the state accepted the premise that people with disabilities had a right to state resources within the institution, this provision should be available in the community (Feindel, 2008; Panitch, 2008). In terms of rewriting social scripts this achievement is significant. These parents (mostly mothers) were able to redefine "normal" in the public and political imagination. Where "normal" had been that people with disabilities lived in institutions, or were looked after by their mothers at home, this new script asserted that a "normal" life for a person with a disability was living as independently as possible in the community. Parent activism played a central role in the community living movement in British Columbia through educating politicians, bureaucrats, professionals, and service providers about disability rights. While parents adamantly lobbied the state to commit to institutional closures and the development of community residences (Feindel, 2008; Panitch, 2008), they acknowledged "the obstacles the Government will encounter in pursuing deinstitutionalization" (Woodlands Parents Group, 1983a, p. 5). Presumably these

obstacles were economic restraint and public acceptance of the plan. Parents spoke to the issue of fiscal responsibility in a statement directed to the provincial government, affirming that they "recognize[d] that the Government's initiatives for economic restraint must be respected…[and] have kept in mind the resources that can be drawn upon both inside and outside Government, to provide the highest quality of life with the least disruption of presently available services" (Woodlands Parents Group, 1983a, p. 5).

In the move to the community the antagonism between parents and professionals was apparent. Parents challenged the notion of specialized needs and as much as possible tried to minimize the professionalized services and supports that had been part of the institutional package (Feindel, 2008). Even though professionals would continue to be powerful in the lives of people with disabilities and their families, the role of the community support worker would be designed as a de-professionalized role (Mission Association for Community Living, 1988a). Shut out of their child's life by professional staff who minded the doors at the institution, where parents had to make appointments to visit their own child based on institutional schedules, parents were ready for an "open door" into their child's life (Feindel, 2008; Panitch, 2008; Trent, 1994; McCallum, 2001). For this to happen, parents made it clear from the outset that the homes in the community belonged to the individuals who lived in them, not the agencies that administrated the homes, or the staff who worked there (Feindel, 2008).

Normalization Theory. Normalization theory originated in Denmark in the 1950s with Niels Erik Bank-Mikklesen, a leading administrator of social services for people with intellectual disabilities. The statement that best describes Bank-Mikklesen's normalization is " letting the mentally retarded obtain an existence as close to normal as possible" (Bank-

Mikklesen, 1969, quoted in Wolfensberger, 1972, p. 27). Normalization was adopted by the executive director of the Swedish Association of Retarded Children, Bente Nirje, who described it as "making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of mainstream society" (Nirje, 1969, quoted in Wolfensberger, 1972, p. 27). Psychologist Wolf Wolfensberger brought normalization theory to North America in the 1960s, and is credited with its successful promulgation in Canada and the United States. In his popular book *The Principle of Normalization in Human Services,* Wolfensberger (1972) defined normalization as the "utilization of a means which are as culturally normative as possible, in order to establish and/or maintain personal behaviours and characteristics which are as culturally normative as possible" (p. 28). With Wolfensberger, the focus of normalization shifted from addressing the social environment that was available to the person with a disability to supporting the person with a disability to adopt normal behaviours. It became a theory more attentive to helping the individual fit into society rather than changing or challenging the social environment to meet varying needs or abilities, although this was not entirely set aside.

Wolfenberger's (1972) ideas appealed to parents looking for a better life for their child, to educators looking for direction in training caregivers how to prioritize goals of support, and to newly commissioned community-based service providers looking for a framework for the design and evaluation of their services. In terms of support services, Wolfensberger (1972) was concerned with the way that "deviant or potentially deviant" (p. 31) individuals present or behave, and he was concerned with how deviant or potentially deviant individuals are "interpreted to others" (p. 32) through symbolic representations

such as labels, stereotypes, and role perceptions. To address these concerns, he suggested

three levels of action: the first was at the level of the human manager (support worker), the

second was at the level of intimate social systems such as family and friends, and the third

was at the level of society. The *human manager*, or support worker, would ensure that

people with disabilities did not present as *deviant* or in any other way reflect devalued

stereotypes. For example, an adult should not exhibit child-like behaviour, such as carrying

a doll in public. Wolfensberger stressed the importance of normative presentation, such as

walking with a typical gait so as not to draw attention to oneself. He questioned the merit

of wearing a hearing aid, which he suggested was more stigmatizing than being hard of

hearing. He talked about the importance of appropriate clothing, "grooming and hairstyle

that we might confer upon such a person" (Wolfensberger, 1972, p. 34) in order for them to

conform to cultural norms. According to Wolfensberger, any quality or attribute that

contributed to symbolic devaluating or diminished role expectancy was cause for

intervention on the part of the support worker.

As in other regions, when large institutions were closing in British Columbia,

normalization theory provided a compelling theoretical framework for services in the

community (Burnell & Trip, 2010). Parents lobbying for community-based residential

options used normalization theory to support their argument when speaking to

government officials. Normalization theory even entered the lexicon of the state, for

example, when Grace McCarthy, Minister of Human Resources, stood in the British

Columbia Legislature and declared that the state's commitment to close large institutions

was "consistent with the principles of normalization which have been prevalent throughout

North America since 1969" (Hansard, 1983a, p. 2913). Having the attention of parents and

policy-makers alike, this theory had a central role in determining the goals of support, and how these goals would be realized through support workers.

The Social Model of Disability. The social model of disability is a social theory that makes three claims: disabled people are an oppressed group; there is a politically meaningful distinction between impairment and disability; and disability is a form of social oppression, not an embodied impairment (Shakespeare & Watson, 2002). The social model of disability, in direct contrast to the medical model of disability, makes a politically salient distinction between impairment, as "lacking all or part of a limb, or having a defective limb organism or part of the body" (UPIAS, 1976, quoted in Goodley, 2001) and disability, which is the "disadvantage or restriction of an activity based on contemporary social organization" (UPIAS, 1976, quoted in Goodley, 2001). Using this distinction, activists with disabilities (and their advocates) have been able to re-route public and political response to their needs from a tragedy-charity model to one of rights and entitlements. The rise of the social model of disability shifted the goals of policy from individual rehabilitation to focus on removing social barriers and discriminatory laws and practices. It emboldened individuals, many of whom had lived with shame about their disability, to relocate this disability outside of themselves and into a society that was failing to recognize their needs and entitlements (Shakespeare & Watson, 2002).

The disability rights movement. The disability rights movement gained momentum alongside other identity-based social movements of the 1970s, such as the women's movement and the gay rights movement. Disability activists lobbied for social and material access to the redistributive rights that are enshrined in citizenship discourse (Charlton, 1998). In Canada, the disability movement demonstrated its political strength through

successfully negotiating the inclusion of disability as a protected category in section 15 of the Canadian Charter of Rights and Freedoms (Panitch, 2008). Canadian activism changed public perception and public policy in ways that increased access to employment, education, health services, and community inclusion for disabled people (Wheelchair, 2014). During the 1980s the voices of disabled people were heard and legislation, such as the Blind Persons Act and the Employment Equity Act, was passed in response to the difficulties that disabled people reported (Wheelchair, 2014).

Activists were steadfast about the centrality of independence and self-determination for people with disabilities (Morris, 1991; Shakespeare, 2000, Kittay, 2001). They "insisted that the independence and productivity that are essential to be considered equal citizens in a liberal society are no less attainable for the disabled than for the non-disabled" (Kittay, 2001, p. 558). In the data I analyze in the next chapter this assertion is echoed by parents advocating for services to support their children to live independently in the community (Woodlands Parents Group, 1983b). Dependency was often seen as a condition of helplessness and those who embodied it "a burden," while independence was considered an "unproblematic and universally desired goal" (Fine & Glendining, 2005. p. 602). However, the failure to account for impairments that compromised reasoning, decision-making, and executive functions limited the usefulness of the call for independence for people with intellectual disabilities who depended on others to help with decision-making. Thus, "the severely mentally retarded have least benefited from the inclusion fought for by the disability community" (Ferguson, 1994 as cited in Kittay 2001).

The unique challenge of intellectual disability. Given the privileged status of "independence and productivity" (Kittay, 2001, p. 558) within a liberal paradigm, Kittay

suggests that the inclusion of people with intellectual disabilities may be "liberalism's limit

case" (p. 559). She explains that political participation and inclusion within liberalism is

predicated on the rational, universal subject coming to voice. However, in the case of

people with intellectual disabilities who do not have

> a claim to cognitive parity, even those who can speak are not recognized as
> authors or agents in their own right. Those who cannot speak must depend
> on others to speak for them. Those who can speak find that their voice is
> given no authority. Perhaps there is no more disabling disablement. (Kittay,
> 2001, p. 559)

It is important not to conflate dependency and disability, however being dependent on

advocates in order to participate in a society that is constructed on the assumption of an

"association of equals" (Kittay, 2001, p. 559) complicates the political and social

participation of some people with intellectual disabilities.

Dependency for voice has profound implications for day-to-day supports (Kittay,

2001). While people with physical disabilities were able to lobby for and manage self-

directed funding and services, people with intellectual disabilities were subject to more

paternalistic approaches to service, and more strictly governed choices (for example, group

homes rather than independent living arrangements). Despite the rhetoric of self-

determination inherent to the social model of disability, people with *intellectual* disabilities

generally have advocates or family to administrate self-directed benefits, such as

individualized funding. This layer of administration, whether it is the state or the family,

has an impact on the lives of people with disabilities as someone is often governing or

mediating their choices, or range of choices (Kittay, 2001).

In his book entitled *Help*, disability scholar Tom Shakespeare (2000) problematizes care, suggesting that it can be a form of colonial rule, under which people surrender access to their homes and bodies in exchange for the help they need (Shakespeare, 2000). While he insists on the autonomy of people with disabilities to define, direct, and administrate personal support, he acknowledges that this degree of self-determination is often unavailable to people with intellectual disabilities. Often dependent on family or support workers for decisions about their care and daily lives, people with intellectual disabilities can be subject to a form of paternalism that threatens their dignity and self-efficacy.

Paternalism can be defined as acting on behalf of another individual, usually on the basis of care or protection, but without their explicit consent (Reid, Floyd, & Bryan, 2010). While paternalism is appropriately realized in the relationship between parents and young children, when carried over into other stages of life, and other relationships, it manifests as an undesirable response to need. This suggests the importance of making a distinction between "justified and unjustified paternalism" (p. 4). Unjustified paternalism strips people of self-determination, undermines the care relationship, and often limits access to the normal risks of life that are enriching.

The question of how much (if any) paternalism is justified in the helping relationship between an adult person with an intellectual disability and their family or support staff has haunted support services since the inception of the community living movement (Race, Boxall, & Carson, 2005). Part of this difficulty has been navigating socially produced impairment (for example, being illiterate in a society that is structured around literacy) and the corresponding socially produced dependency (Goodley, 2001). Support workers are asked to enact the paternalism inherent to normalization, a

paternalism directed at mitigating the material and symbolic effects of impairments, while

at the same time denying (or downplaying) embodied impairment through focusing on the

ways in which society disables access to a normal life (Race, Boxall, & Carson, 2005).

Within the framework of paid support, it is the presence of the worker's mind and body

that makes it possible to negate the disabling effects of impairment, however it is theorized.

In this section I looked at how changes in the way that people thought about

disability changed how services and supports were designed. The critique of institutions

motivated a shift away from a large-scale and segregated institutional model to

community-based supports designed to give people with disabilities access to

opportunities by right of citizenship. In the next section I look at the social and political

environment that surrounded services in British Columbia in the 1980s, I consider issues

pertaining to care labour, and then take a brief look at the community as a social space.

Part Two: Politics, Care, and Space

Popular narratives of deinstitutionalization focus on the rights of people with

intellectual disabilities, on the power of grassroots political action, and on a progressive

society that treats its most vulnerable citizens with dignity. While the community living

movement of the 1980s advocated for the rights of people with disabilities to live normal

lives in the community, deinstitutionalization in British Columbia can also be viewed as a

policy that was congruent with the values of privatization, reduced statutory responsibility

for social care, and "flexible" labour conditions. Added to this, during these same years

more women joined the paid work force, which gave rise to a larger care industry for

dependents. While caregiving is a gendered, classed, and raced practice and this, no doubt,

influences *who* provides community support services, for the purpose of this thesis I focus on care as a feminized and devalued *practice* that takes place in the gendered space of the home.

In this section I provide a snapshot of British Columbia in 1983. This was the year when the provincial government introduced restraint legislation accompanied by twenty-six bills that, in one way or another, decreased social protections. This change marked the introduction of neoliberal political and economic rationales to the province, thus beginning an enduring program of privatization and deregulation, and the promotion of an increasingly atomized and responsibilized citizenry. Moving away from provincial politics, I look at some of the contexts for care labour, touching on care as a feminized practice and noting that the spaces where care typically takes place are gendered spaces. Feminized work environments and care practices produce and discipline the community support worker through discourses that tap maternal commitments, homes as private spaces rather than work places, and care as a self-less offering. I also consider "community" as an unexamined partner in the community living project. The social space of the community is one of the contexts for the work of support, and the needs of the community constituted a worker who could span the private world of the group home and the public space of the community.

Politics in BC circa the Community Living Movement. While having the reputation for a politics of the Wild West, the political scene in British Columbia by the 1980s was in one sense quite stable, given that the Social Credit party had governed almost continuously since 1952. The Social Credit (Socred) was a free-enterprise political party developed in the late 1940s, largely in response to the threat of the socialist Co-operative

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Commonwealth Federation. The first Social Credit premier, W.A.C. Bennett (1952-1972),

was followed by his son Bill Bennett, who won his first mandate in 1975. In 1986, Bill

Vander Zalm was elected for what would be end of the Social Credit reign in BC (Blake,

Carty, & Erickson, 1989). The success of the Socreds in BC coincided with the post-war

boom time, a time in North America that marked an alliance between Fordist[6] industry and

the social provision of the Keynsian[7] welfare state. While not entirely comprehensive[8], this

settlement did account for a strengthened working class and labour stability and led to a

modest sharing of the spoils during these years (Carroll & Ratner, 2007). But by the late

1970s the heydays of Fordism had reached a crawl, the welfare state settlement was

cracking and British Columbia, particularly vulnerable due to dependency on the export of

natural resources, was faced with reduced demands for products and increased demands

for social services (Carroll & Ratner, 2007; Hak, 2013).

In 1983, Social Credit premier Bill Bennett responded to this situation with austerity

legislation.[9] "Austerity" and "balanced budgets" could be explained as a governance

strategy typical of the Socreds since their inception, but the vehemence with which the

"new economic reality" (Marchak, 1984, p. 23) was wrought on the people of British

Columbia was unprecedented (Ruff, 1984; Rankin, 1984). The government pushed through

austerity measures to meet the competitive advance of global supply and demand, citing

high wages, comprehensive benefits, and labour standards negotiated through collective

bargaining as "fetters upon supply" (Carroll & Ratner, 2007, p. 42). Changes to collective

agreements included wage freezes, a reduction of the civil service by twenty-five percent

over 3 years, a clause for dismissal based on undefined "reasonable cause" (Rankin, 1984,

p.173), and changes to collective agreements based on the employer's "ability to pay" (Ruff,

1984, p. 158). The Social Credit restraint legislation of 1983 was not just more "Wild West" politics from British Columbia, but part of a larger initiative connected to global changes. These changes, emblematic of neoliberalism, insinuated themselves into the fabric of the social life of the community, shifting social expectations, identity, and responsibility from the state to the individual (Larner, 2000; Brown, 2005).

Neoliberalism is a political and economic rationality premised on the "conviction that markets, not government, hold the key to prosperity and freedom" (Sandel, 2012, p. 6). It is a rationality that structures the relationship between the market, citizens, and the state in ways that foster market competition at the expense of social protections. Privatizing services, deregulating trade, accentuating individual responsibility, and weakening worker protections are all trademarks of neoliberalism (Larner, 2000). These initiatives were exemplified in the 1983 restraint legislation, which paved the way for privatized health services under the auspices of contracting out[10] (Malcolmson, 1984). Within this paradigm social responsibilities and "risks that were once collectively managed, can become individualized" (Scourfield, 2007, p. 112) while being touted as choice and control. The transfer of care from state institutions to service agencies in British Columbia transferred the risk and responsibility for care and services from the state to individuals or private sector service agencies that were often run by parent and advocacy groups.

In British Columbia, the language of choice and individualism that accompanied neoliberal economic policy (Hall, 2011) hit a chord with community living advocates. However, in order for community living to be successful, *both* the staff and the residents had to move from the institutional "mass-management programmes" (Fine, 2012, p. 8) to more nuanced person-centered care and individualized planning (Fine, 2012). *In principle*,

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community living provided people with disabilities the opportunity to live independently, with service plans that were focused around individual goals and preferences. These changes in the structure and management of services necessitated a "flexible" worker who would work in the group homes, her hours of work governed by the goal of providing a "family-like living arrangement" (Hansard, 1983a, p. 2913). Thus, while the closure of institutions in favour of homes in the community was a triumph for people with disabilities, for workers the shifting geography of care often meant "lost security and recognition, their conditions of work increasingly casualised and often de-professionalised" (Fine, 2012, p. 11).

A Social Context for Care. The need for caregivers, or "dependency workers" (Kittay, 1999, p. 30), to help people unable to care for themselves is a persisting fact of life. Therefore, before I discuss care labour I would like to take a moment to talk about dependency, as it is theorized by Eva Feder Kittay, a disability scholar and parent of a woman with a disability. Kittay (1999) explores notions of dependency and independence by looking at the theoretical frameworks available to understand need and provision in relation to disability. Carefully navigating the danger of medical discourses that devalue some lives in relation to others, she asserts that people with severe intellectual disabilities are profoundly dependent, and, as others have noted (see Goodley, 2001), the social model of disability does not adequately address this vulnerability. To explore this dilemma she looks to the work of social contractarian John Rawls (1971), a leading proponent of liberal notions of justice that shape contemporary liberalism. She submits his treatise *Theory of Justice* to a "dependency critique" (Kittay, 1999, p. 76) that takes into account both anticipated and unanticipated dependency, and the care required to tend to it. She notes

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that Rawls' *Theory of Justice*, which argues that principles of justice are contingent upon an implicit social contract, "fails to attend to the fact of human dependency and the consequences of this dependency on social organization" (p. 76).

Kittay (1999) counters Rawls with the suggestion that any theory of justice purporting to be inclusively egalitarian must begin with a consideration of dependency. She asserts that to privilege independence is to see dependency itself as reduced personhood, and that failing to account for the ordinary and extra-ordinary circumstances of dependency renders people who are dependent and those who provide care politically and socially unequal. Kittay (1999, 2011) articulates an ethic of care founded on the reality that all people experience periods of dependence in their lives, and suggests that if dependency is accepted as a normal condition of our humanity and not an aberration, both providing and receiving care are elevated. She posits that *independence* is a socially constructed ideal (Kittay, 2011), and that no one lives without the help of others. Further, Kittay asserts that the failure to accept dependence, for ourselves or for others, profoundly interferes with our ability to address care needs, which in turn places demands on caregivers.

Caregiving is considered the "unskilled" work of the lower classes, and these "workers are more subject to exploitation than most" (Kittay, 2001, p. 561). As a gendered practice often provided in private spaces, the caregiver is a worker who sits outside the purview of public concern (Boris & Klein, 2012). It is work that is "farmed in" from around the globe through temporary worker programs; it is work that continues to bring low wages, minimal benefits, and unstable employment to caregivers (Boris & Klein, 2012). Cancian and Oliker (2000) stress the importance of considering care and gender together,

as caregiving is often assumed to be the extension of a woman's biology and personality. Accompanying these "natural" explanations linking women to care, there are also social explanations that look at the ways that society is structured institutionally and culturally to produce rationales for caregiving as a feminized practice (Boris & Klein, 2012). The combination of biological and social discourse that structures caregiving as a private activity that is naturally taken up by women, and ideally provided in *private* spaces (Cancian & Oliker, 2000) depends on separate, gendered, spheres for women and men.

Qualities attributed to the feminized *private sphere* are vulnerability, dependency, domesticity, shelter, safety, caring, nurturing, relational, and hidden; whereas discourses of the *public sphere*, the purview of men, denote the "rough and tumble" competition of the market, and the qualities needed to survive and prosper "out there" include autonomy, independence, masculinity, power, and force (Weedon, 1987). Ideological distinctions between the private and public spheres have been useful in deskilling caregiving by linking it to the private sphere where it is recognized as virtuous practice with intrinsic, rather than market, value (Weedon, 1987).

The terms "private" and "public" are also used to make economic distinctions to describe the different responsibilities and functions of the state and the individual within a political economy. The public sector is understood to be *collective* governance for services that the state administrates in accordance with public will. This includes services such as health care, social services, legal and judiciary systems, education, and public works. Conversely, the private sector, often referred to as the "business sector," foregrounds *individual* freedom and responsibility, and personal economic advancement. Just as discourses of the public and private sphere have a material effect on who provides paid and

unpaid care, discourses of the public and private sectors complicate who is responsible to pay for care.

With the advent of community living, care moved from public institutions into the private spaces of group *homes*, although services continued to be publically funded and managed through private (usually not-for-profit) companies that exercised competitive business model practices of the market sector. Deinstitutionalization is discursively linked to the privatization of care through asserting the right of people with disabilities to independent and private lives in the community where care belongs to "citizen's private rather than public concerns"(Kittay, 1999, p. 26). Private care in a private space would supposedly provide the best opportunity for people with disabilities to lives unfettered by regulations, schedules, and shop stewards. But the use of these ambivalent spaces, (not public and not private) rendered this care relatively invisible in the public arena, where it would be more apt to be recognized as "work."

In their studies on home care workers, Neysmith and Aronson (1999), and Boris and Klein (2012) explore some of the complexities of care work that takes place in private spaces. Home care workers are hired through formal employment processes and are contracted through their job descriptions to provide a range of services. But the work itself, like work in group homes, is performed in informal and isolated settings, and what is required on any given day varies, despite the job descriptions. The complexity of the work these women do in the home is largely unseen and the services they provide are considered an extension of their biology (Boris & Klein, 2012). This is central to caregiving being classified as unskilled, devalued, and de-professionalized, which is an important factor in "justifying low wages for caregivers" (Cancian & Oliker, 2000, p. 87). Boris and Klein

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(2012) note that workers themselves are sometimes reluctant to identify as workers, resisting discourses of "market rationality (that) turned such work into mere labor" (p. 8). But whether it is for love or money, it is work that is seen as "unskilled work that allegedly any woman could perform" (p. 8). A paradox emerges: as an extension of a women's biology, care is not "real work" and, in the popular imagination, it is only "real care" if it is freely given (Boris & Klein, 2012). Care cannot be both care *and* work.

While gender is perhaps the most important ordering principle in the provision of care, I do not want to lose sight of the importance of class and race. Care work has long been racialized and classed in the form of slavery and servitude (Tronto, 1993). In the United States, the labour of racialized women (in particular) contributes significantly to the care provided in the community in the wake of large-scale institutional closures (Boris & Klein, 2012). In Canada, changing immigration schemes continue to allow the exploitation of racialized immigrants in informal care environments (Zaman, 2006). Regarding the preponderance of male caregivers, historically in institutions, men and women were segregated and male attendants were assigned to men, and women to women (Trent, 1994; Carlson, 2010). In the back wards that Jones (1975) studied, one third of the attendants were men. Today, in the agency where I work, approximately thirty five percent of the direct service workers are men. The fact of male caregivers does not shift care from being a feminized practice, it only serves to lower the status of men who do care work.

Based on biological discourse that links care to motherhood it is important to recognize the place of the mothers of the community living movement. The success of community living can be recognized, in part, as the achievement of middle classed mothers who became "accidental activists" (Panitch, 2008, p. 1) in order to fight for care for their

children to live outside of institutions, *and* outside of the family home. According to

researchers, their activism was inspired by a sense of gendered responsibility to care for

their child and thus was an extension of their mothering (Feindel, 2008; Panitch, 2008).

While their work to challenge social structures that disadvantaged their children might

have put them in alliance with many of the goals of the women's movement, this "alliance

was of little interest to the women…who did not see themselves as feminists" Panitch,

2008, p. 26). Importantly, this fight for the rights of people with disabilities was, in large

part, a fight for their right to be free of abuse by paid staff. I imagine that the mothers

advocating for their children were unlikely to have much concern for the rights of workers

of any gender (Feindel, 2008; McCallum, 2001). Nonetheless, mothers and workers were in

relationship with one another, and parents advised workers to

> …respect families for the journey that they have travelled. When they come
> to realize that you want the best quality of life for their sons and daughters,
> they will be a valuable resource for you. It is only with a team effort that we
> will be able to build supportive relationships around the handicapped
> person. (Western Family-to-Family, n.d.1, p. 4)

In group homes there would be women and men who provided the care, and the mothers

who would help to inform the standards for this care.

In addition to the complex dynamic between mothers and workers, which might

easily be a study of its own, the community living movement reveals the challenge of

recruiting *private, unskilled,* and *cheap* labour. Crocker and Cran (2010) suggest that from

the outset of the community living project,

> …human resources issues such as low wages, high turnover and poor
> qualifications [emerged, and the] crisis of finding qualified staff caused the
> phrase, 'two feet and heartbeat,' to become coined by community service

providers; frustrated that they may have to take anyone 'standing and breathing' off the street to work in the field. (p. 61)

The ideal worker would be standing and breathing, she would work for cheap, stay for as long as she was needed, and she would be qualified.

Enter the Community. Community is a political space where contests for inclusion, exclusion, citizenship, and belonging are waged (Staeheli, 2008). It is also a space where these contests are masked, and as such it is a physical and social space "full of, and…constituted by, contradictions" (Staeheli, 2008, p. 7). At the time that institutions were closing in British Columbia, "community" was being evoked as a benevolent, interested, and welcoming place by most of the parties involved, despite the fact that the state had trepidations about how welcoming the community would be (Hansard, 1985), and parents had experienced prejudice and discrimination from neighbours (Feindel, 2008). Bauman (2001) notes that while community is generally considered unequivocally "good," often it "stands for the kind of world which is not, regrettably, available to us – but that we would dearly wish to inhabit and which we hope to repossess" (p. 3). This notion of a community that we can return to, a "paradise lost" (p. 3), is central to the narrative of the community living movement. Having been segregated from community, now people would *return*, to live as full citizens with a full sense of belonging and social entitlement. The imagined community (Anderson, 1983) played an important role in the plans and goals of parents, service agencies, and the state.

Ideas about community, belonging, and citizenship rights bind together in complex ways. For some scholars, community inclusion is the precursor to citizenship. It is through our membership in the community that we make claims and participate as citizens. Other

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scholars invert this, suggesting that citizenship entitles us to recognition and redistribution

rights in the community, including rights to participate in the civic and political life of the

community (Staeheli, 2008). It is this second proposition that informed the community

living movement. Based on a legal framework, which begins with an assertion of

personhood, community living activists claimed community inclusion as an entitlement of

people moving from institutions to the community. This focus on how *individuals* claim

citizenship and achieve belonging had an impact on the purpose and goals of support.

Within the context of neoliberalism, discourses of citizenship and community

inclusion were increasingly measured along the axis of fulfilling social responsibilities

rather than exercising social rights. It is a shift that registers participation as a measure of

belonging. In 1989, with the reworking of normalization theory, Wolf Wolfensberger

seemed to channel this idea in his theory of valued social roles. Under the banner of *social

role valourization*, Wolfensberger (Wolfensberger & Thomas, 1999) promoted the

importance of having personal *resources* or *assets* (talents, abilities, willingness) in order to

establish one's *value.* He suggested that we belong, or are socially valuable, when we

perform or embody a valued social role. The acquisition of social capital, or a valued social

role, was essential to the project of community inclusion. However, within this paradigm,

> Society is perceived as fundamentally just and stable, so that learning
> disability services simply need to locate a menu of vacant slots and help the
> person to decide what they would like to do, learn the correct behaviour and
> then engage in the opportunity of their choice. (Bates & Davies, 2010, p. 202)

But society is neither just, nor stable, and Wolfensberger's theory of valued social roles

does little to address structural inequality or discrimination that would limit the access to

community for those unable to generate social capital, or achieve a valued social role (Chenoweh & Stehlik, 2004).

Another way we might trouble the imagined community of state and advocacy discourse is to look at how the concept of community can be used for social control in the project of shifting statutory responsibilities to the community (Staeheli, 2003). This is made possible, in part, through the blurring of "public" and "private" under the auspices of "community." Through this blurring, community becomes a gendered (feminized) space (Staeheli, 2003), a space of benevolent, relational encounter, apparently free of and untarnished by the competition of the market. Community is depoliticized through assigning it a quasi-domestic status. Community becomes " a 'space of in-betweeness' linking public and private in ways that reflect political ideologies about responsibility for social welfare" (Staeheli, 2003, p. 818) which shift the responsibility for provision and outcomes toward informal provision by the community.

In 1983, when large institutions in British Columbia were slated to close, the intention of the Social Credit government to distance itself from direct service provision was evident in the privatization of services. But it was not simply the private sector for-profit and not-for-profit service providers who would be involved, the voluntary sector, or "community", was also expected to participate. The following excerpt, from question period at the BC legislature, is between Grace McCarthy, Minister of Human Resources, and opposition party (New Democrats) MLA Emery Barnes, after the announcement that Tranquille, a large institution in the interior of British Columbia, would close immanently. Mrs. McCarthy has apparently suggested that voluntary community resources will help to

meet the needs of people moving to the community, and in this debate Mr. Barnes seeks

clarification:

> **MR. BARNES:** …What specific churches, service clubs and other facilities in the community will be available as volunteers? Have you been in touch with any specific ones? Would you please table that information, if you have it available?

> **HON. MRS. McCARTHY:** Mr. Speaker, my response to the question, both yesterday and within the media in the last couple of days, was that I am quite confident that there are service clubs, that there are different institutions who will. I don't plan, as the Minister of Human Resources, to organize those. Those will come from the community as they have traditionally. They have been inspired by people who want to do good works in the community, have done good works in the community and will continue to do so.

> **MR. BARNES:** I can appreciate the tradition of cooperation by volunteers in the community, but is the minister suggesting to the House that the government is now expecting people through the volunteers and through some kind of charity program, by whatever means, to pick up the statutory responsibilities that it has?

> **HON. MRS. McCARTHY:** The short answer is no. The extended answer is the fact that we have many services in place within the ministry, and we'll continue to do that good job we've always done, with a very professional and good staff.

> **MR. BARNES:** Just one final question on this. Could the minister indicate specifically the churches and the service clubs that she herself has been in touch with, and would she table that information? In other words, what consultation has she had with respect to the plan she has?

> **HON. MRS. McCARTHY**: No.

> (Hansard, 1983b, pp. 533-534)

The community as a space of good will, produced in this dialogue by *both* parties, is

unquestioned. What is at issue is ideological, in terms of statutory versus community

responsibilities for social care. This conversation illustrates the sense, at least on the part

of the state, that deinstitutionalization included the informal participation of community volunteers and organizations to welcome people with disabilities back into the community.

Through this brief discussion of community, we see that "community" functioned as an unexamined repository where good things would happen for people with disabilities. Their right to belong was claimed through citizenship, and this belonging would be secured through assuming valued social roles. For workers, building networks in the community and fostering community inclusion was a significant challenge, given that "[p]aid dependency workers are frequently drawn from classes or groups who are themselves relatively powerless within society at large, and who occupy a social status lower than their charge" (Kittay, 2001, p. 561). Added to this, it was work that would be done within an imagined community, a community that did not exist, as such.

Conclusion

In this chapter we get a sense of how the identity of the community support worker was bound to that of the institutional worker of the past, and how important it was to distinguish the services in the community from the institution. As institutions came under scrutiny from the academy, the media, parents, the state, and the public, the need to change how society cared for people with disabilities surfaced. Social and medical rationales for segregation were no longer acceptable and ideas about rights became a new ordering principle for designing services with and for people with disabilities.

The parent advocacy movement, which emerged through the confluence of the medicalization and changing class of disability, lobbied the state for services that would help their families and children live according to middle classed norms. The last thing that

parents wanted was to experience the pain of institutionalizing their children, again.

Parents would play a much larger roll in community living services than they were ever

able to within the system of large institutions, and normalization theory provided a

theoretical framework for these parents as they advocated for lives as normal as possible

for their children. The disability rights movement of these years challenged services to

disabled people that used a charity rationale. Using a social model of disability, activists

pressured the state to remove barriers, laws, and policies that disadvantaged people with

impairments. Inspired by the social model of disability to move the disability out of the

person and expose a disabling society, parents eagerly looked forward to reclaiming a

vision for their child unencumbered by a disabling diagnosis. Added to this, the

longstanding antagonism between parents and professionals resonated in the community

as a call for workers whose credentials were personal rather than professional. While the

language of the community living movement was distinctly rights-based, these rights

focused on securing social and political rights for people with disabilities within the status

quo. The community was assumed to be a benevolent and welcoming place; it was just a

matter of helping people with disabilities find their place in the social order. The purpose

and goals of providing support to people with disabilities shifted from providing care based

on need, to facilitating participation in the community as a right of citizenship.

Turning to the political landscape in British Columbia, the restraint legislation of

1983 was a watershed in provincial politics, as economic priorities have since that time

increasingly structured social life and concerns. Neoliberalism, the political and economic

ideology that informed these priorities, works at the level of policy, ideology, and

governmentality to reshape social expectations and social identities (Larner, 2000). In the

context of neoliberalism care services were increasingly privatized and worker protections

in the form of job security, benefits, and employment standards eroded. The interests of

the state for a privatized non-unionized social service delivery system conveniently

dovetailed with the interests of community living proponents who were looking for

individualized and flexible supports. At the same time that these responsibilities for care

were being redistributed, the demands for social care were increasing, due, in part, to the

increasing numbers of women joining the workforce. Ironically, care work, already

devalued through discourses that naturalized it as "women's work," was further devalued

when middle classed women could opt not to do it (Kittay, 1999). The status of caregiving

as a traditionally devalued practice served to complicate matters within group homes, as

caregiving responsibilities disappeared in importance beneath the social justice goals of

the community living movement.

These social changes contribute to a range of possibilities for how the community

support worker of the 1980s would be imagined, and what policy makers, parents, and

agencies would strive to avoid. The institutional worker evokes images of cruelty and

neglect, perhaps even a monster. The worker implied through the medical model of

disability suggests a detached, instrumental, knowledgeable, professional. For those

designing services, creating distance between this institutional/medical worker and the

community support worker was paramount. From Wolfensberger's (1972) normalization

theory we are offered the "human manager," a worker concerned with managing the

presentation and representation of the disabled person in an attempt to ensure that the

supported individual is valued in his or her community. Within the social model of

disability, the worker is a potentially threatening and colonizing presence; necessary but

unwelcome. These contingent interests represent the conditions of possibility that

informed the desires of parents, service providers, the state, and the community as they

imagined the community support worker. In the next chapter I analyze the data in order to

explore how these conditions were transmuted into the necessity for a particular worker.

Chapter 4: The Worker as She was Imagined

A worker told me the story of being trapped in the bathroom at a group home where she worked while a resident, who frequently had violent episodes, railed around the house breaking things and screaming. While she was afraid of him, she was also afraid for him, his housemates, and the other staff. She wanted to take him for a psychiatric assessment, but his mother refused to allow this for fear that he would be re-diagnosed and re-institutionalized.

How was the community support worker produced as a particular subject at the time when large institutions were closing in British Columbia? In order to explore this question and to get a clearer sense of what the original mandate of the community support worker was at the time the role was designed, and further how this might speak to the concerns of contemporary workers, I have taken up a Foucauldian genealogy "to critically show the way in which certain practices, beliefs, and conceptions have become problematic" (Koopman, 2010, p. 95). The beliefs, practices, and conceptions that produced the community support worker are found at two levels in this research. The first is at the level of the conditions of possibility, which I discussed in the previous chapter, and the second is at the level of the archive, which I explore here.

In this chapter, using a Foucauldian discourse analysis I engage the archival data. My observations are guided by the epistemological commitments of this study as outlined in the methodology chapter; these commitments attend to language, tone, discourse, assumptions about care, and focus on how subjectivity is formed and deformed in texts (Carabine, 2001). For example, based on my analysis I can see how "memories" of the institutional worker inform, by contrast, the vision of the ideal community support worker, how interplay between the medical model of disability and the social model of disability

complicate ideas about what makes "good" support, and how discourses that produce a support worker *who really cares* depend on discourses that define caregiving as a feminized practice (Cancian & Oliker, 2000). The tone and language used to deploy these discourses are present in the documents from parents and agencies that direct workers to attend to the people they support through appeals that conflate independence with dignity. Paradoxically, the context for these discourses is the community living movement, which is perhaps most clearly understood as a response to dependency and disability (Burnell & Trip, 2010; Kittay, 2011). The data, which I briefly reintroduce here, comprises texts that respond to a variety of needs, including those for support.

Data from parents includes a collection of mini-newsletters written by the Woodlands Parents Group. These newsletters were used by this grassroots group to educate and communicate with policy makers and with parents who might be anxious about deinstitutionalization. They are documents that encouraged parents to "dream again," while at the same time reassuring them that these dreams will be supported by sound policy, monitoring, and good quality care. Documents from other parent groups include instructions from parents to workers. From the British Columbia Government Employees Union I use a 1984 policy statement that addresses deinstitutionalization and outlines the Union's conditions for what care in the community *should* look like. The Union promotes publicly funded support that will be realized through unionized government workers as an expression of "a continuing commitment by government to provide adequate funding, monitoring and maintenance of high standards of care" (British Columbia Government Employees Union, 1984, p. iii). The Union is unencumbered by a

concern about institutions or institutional practices, asserting confidently that institutional care is good care, no matter where it is offered.

From the Province of British Columbia, I analyze two publicly distributed pamphlets from the Ministry of Social Services and Housing - *Services for the Mentally Retarded* and *Community Living*. These pamphlets outline the state's public position on community living services, attempt to speak to any concerns the public may have, and provide a broad overview of the state's commitment to helping families with disabled children. Like the Union, although less overtly, the Ministry is in favour of institutional practices that govern health and safety, although these documents also include language that suggests an understanding of the principles of normalization. In these texts the Ministry provides an implicit look at staff in the delivery of direct services to people with disabilities, however staff are more pointedly referred to as a resource for the public. The largest collection of documents comes from three service agencies. These documents include job descriptions, agency mandates, vision statements, an organizational resume, and training materials. These materials are a rich source of data, describing in detail what the worker will do, and the qualities that she will embody. Taken together, these four sources of data constitute a series of narratives and counter-narratives that tell many different stories about the community support worker.

In this analysis I place these documents in a conversation with one another in order to complicate the findings. By juxtaposing the different sources of data I am able to see how the worker is created to meet a complex plethora of needs and desires not limited to serving people with disabilities. In order to manage the breadth of findings, I structure my analysis across three themes: *support, worker*, and *community*. My observations are

captured by the following questions: What kind of *support* is required in the community and how is it distinguished, or not, from support offered in the institution? Based on the descriptions of support, what kind of *worker* did citizens with disabilities need, and what kind of worker did parents, agencies, the state, and society need? How do the ways that the *community* is talked about constitute a particular worker? What kind of worker did the community need? My exploration of the data along the themes of *support, worker*, and *community* yields the community support worker, *as she was imagined.*

The findings paint a picture of a truly amazing worker. Community living is imagined as *a system* of care and while the person of the worker is at times subsumed into this system, she is nonetheless a moral, caring, responsive component of this system. While meeting all the custodial needs of the people she cares for she also promotes a meaningful life in the community, social integration, employment and educational opportunities, and teaches independence. Additionally, she does home maintenance, cooks, cleans, and does the laundry and shopping. Further to this, the worker takes up the role of mother, housekeeper, homemaker, often described in terms reminiscent of the perfect and enduring mother and ideal wife of the 1950s. In relation to the community, the worker functions as a bridge, spanning the distance between acceptance and acceptability, dependence and independence, and the privacy of home and the world at large. It is a complex portrait.

Support: What kind of *support* was required?

> Your new job will involve so much more than just basic custodial care. You will be helping handicapped people to secure their rightful place in the community. Total acceptance of handicapped people in our society, is just a

dream for today, but for tomorrow, it will become a reality. (Western Family-to-Family, n.d. 1, p. 4)

Ideas about *support* for people with intellectual disabilities cannot be abstracted from the historical conditions from which they emerge. As the institutions close, those involved in this initiative are eager to define how support in the community will be different than what had been offered in the institution. For families, advocates, and policy makers, rethinking support centers on redefining needs. As the advocates of people with disabilities promote a "rightful place in the community" (Western Family to Family, n.d.1, p. 4) for people with disabilities, the focus of support shifts from meeting custodial needs to fulfilling social rights. However, the needs of people with disabilities are not the only needs that workers attend to. When community living begins on a large scale, agencies administrating support in the community need to comply with regulations, the provincial government needs to be accountable to the public, and parents have high expectations for a new life for their family member. All of these needs are in some respects the concern of workers.

Despite changes in rhetoric around needs, in many ways the job of providing support in the community is similar to that of providing support in the institution, in particular, meeting needs for basic personal care, meals, and therapeutic needs remains much the same. However, in the move from the institution to the community the job of support changed in a radical way. In the institution health care and activity workers worked directly with the residents but a large team of staff, such as janitors, cooks, laundry services, groundskeepers, administrators, practical nurses, and rehabilitation therapists also worked on site. In the community these roles are amalgamated and the community

support worker becomes the staff of the institution rolled into one worker. In this section I

first discuss how the purpose of support in the community is conceived through a

redefinition of need. I then explore some of the familiar and unfamiliar tasks that the

community support worker takes up in order to provide this support. This dynamic

between new and old needs, and familiar and unfamiliar tasks, helps to shape the newly

minted community support worker.

From Custodial Needs to Social Rights. Redefining the needs of people with

intellectual disabilities is an important characteristic of the community living movement.

Proponents of community living assume that custodial needs will continue to be met,

however with the advent of Wolfensberger's normalization theory, the social model of

disability, and in a context of rising individualism of the 1970s and 1980s, the community

living movement ushers in discourse on other important needs and rights. Social needs

and rights, such as the need for friendship and belonging, and the right to self-

determination, autonomy, independence, and self-expression move to the forefront in

conversations about support. This change in focus is articulated in the *Organizational

Resume* of one agency:

> In our vision of people we see two sets of needs which people bring. We
> distinguish between the needs of people which relate to identified
> handicaps:--these we meet through careful planning and provision of direct
> service; and the needs of people which relate to everyone, regardless of
> perceived handicaps:- - these are the needs which we meet by bringing
> people home to their community, their family, their friends and to
> themselves everyday through deliberate honoring, valuing and caring.
> (Mission Association for Community Living, 1989a, p. 2)

Parents provide important and admirable leadership in redefining the needs of their children, insisting that their children have the same social needs and rights as anyone else. In contemporary terms it is an obvious statement to make, but it was a revolutionary statement at the time when these parents were helping create community living services. In a public statement from 1983, parents outline a vision for services:

> The ideal goal that we envision is a system of integrated supports and services in the community promoting the on-going development of each person with a handicap living in the community, regardless of his or her age or severity of disability. We view our sons and daughters as having worth, and we believe they are entitled to opportunities enabling them to participate as full members of society; that is, to live with dignity, respect, and self-determination to the fullest extent possible, thereby achieving independence and self-sufficiency. (Woodlands Parents Group, 1983a, p. 8)

Loosely tapping discourses of the social model of disability which claim that people are disabled by social and physical structures rather than by embodied physical or mental impairments, parents articulate the effects of a disabling diagnosis:

> [The] diagnosis may mean that they are cut off from family, friendships, and most of the other supports that enable the rhythm of life to work in a natural way. In short, our sons and daughters, and we as parents, have been prevented from having a vision for their lives. (Woodlands Parents Group, 1983b, p. 3)

Parents propose to "negate the original diagnosis and reclaim our vision" (p. 3). Reclaiming the vision works to shift the epicenter of need significantly; services that had been focused on helping people to bathe, eat, move, or communicate are supplanted by a priority to support people to participate in the community, to love and be loved, to become self-responsible, self-actualized, and independent (Woodlands Parents Group, 1983b).

According to parents, having a vision for people with intellectual disabilities is a way of "looking at our children from the position of their strengths so that they can fully explore and develop their inborn capabilities" (Woodlands Parents Group, 1983b, p. 3). A vision provides "an appreciation of who the person is and can be, given the appropriate supports" (Community Living Society, n.d., p. 19). Parents encourage workers to identify with the people they support, to hold a vision for that person, and to recognize that

> ...behind the shell which (perhaps) cannot walk, or talk, is a person who has needs for friends; who wants to achieve degrees of independence; who wants to be in control of his own life; who wants to be valued as a person; who wants what each of us wants for ourselves! (Woodlands Parents Group, 1984a, p. 3)

Workers are advised that, "when carried out in practice, the vision will enable the person you support to expand her inner sense of freedom over the dead weight of negative inner experiences. It will help animate her in a positive way" (Community Living Society, n.d., p. 19). While the notion of support being guided by a vision is a unique contribution that parents make to services for people with intellectual disabilities, it is not a contribution without complexity. This way of approaching services leaves people with disabilities vulnerable to having the values and desires of others projected on their lives (Dunn, Clare, & Holland, 2010; Drinkwater, 2005). Nonetheless, it is an important act of leadership and resistance on the part of parents in their bid to reclaim a normal life for themselves and their children in the context of limiting and pathologising medical discourse.

Supporting access to a life of independence is one of the main themes that permeates all of the documents. According to the Ministry of Social Services and Housing (1987b) community-based programs exist for the purpose of providing

> ...training and support for mentally retarded adults to develop their personal and social skills so that they can become more independent. Individual services may include training in personal hygiene, use of public transportation, budgeting, communication and health and safety. (p. 5)

Independence for people with intellectual disabilities is a central rationale for deinstitutionalization, it is the promise the state made to the community, and it is an important part of the vision held by parents (Ministry of Social Services and Housing, 1987a; Woodlands Parents Group, 1983a). The documents written by agencies, clearly influenced by parents, focus on social needs rather than needs that come from having impairments. The support worker's job description outlines three goals of support: "to provide, for people with a handicap, support in their own home which is integrated into society; to assist individuals in their personal awareness and growth; and to foster relationships in the community" (Community Living Society, 1985, p. 22-23). It is at the level of "specific responsibilities" (p. 24) that providing personal care, meals, housekeeping, and administrative duties are listed. Shifting the focus of need significantly changes the goals of support, and for the worker this means that meeting the custodial needs of the person she supports becomes the foundation on which she does her "real" work, which is to promote dignity through independence.

However, the community support worker's role exceeds her duty to provide direct supports to individuals. Her reach includes meeting the needs of the community living project itself. This comes in the form of supporting the needs of the state to reassure the

community that community living is responsible policy, and in helping service agencies to be accountable for contractual obligations. The needs of the state are evidenced in one of the publicly distributed pamphlets written as a series of answers to mock frequently-asked-questions (Ministry of Social Services and Housing, 1987a). Answering these questions in a measured and reasonable tone, the state cues the community to the *right* response to the appearance of a group home in the neighbourhood. The state encourages the community to be sympathetic and supportive of the community living project and to see this project in the context of human dignity rather than contracting out. The presence of on-site staff makes it possible for the state to reassure the public that community living will fulfill all of the attributes of the institution (i.e. keeping society safe from people with disabilities, keeping people with disabilities safe from society, and relieving the burden on families) and allow the state to pursue the program of privatizing human services.

The needs of service agencies are stated in the form of needing to meet regulatory standards for care and reporting. Despite the shift in focus toward meeting social needs and rights (such as *independence*), custodial needs are still a foremost concern. Parents and the public are reassured by the State that agency-run community group homes will be governed by

> standards and expectations (that) are defined as part of the contract for services. Health and safety standards are specified for licensed facilities (i.e. three or more residents) under the Community Care Facility Act and are monitored by the Provincial Licensing Board (Ministry of Health). (Ministry of Social Services and Housing, 1987a, p. 5)

The worker plays an important role in ensuring an agency's compliance with the service contract through fulfilling a host of administrative duties in addition to meeting health and

safety guidelines. These institutional practices undermine descriptions of the community living narrative of "normal lives in the community," and create tensions for workers who are supporting independence while simultaneously defining its limits, documenting its progress, and at times, blatantly manufacturing it (Burnell & Trip, 2010; Hawkins, Redley, & Holland, 2011).

Changing ideas about people with disabilities, from bodies that need to be taken care of to people with hopes, desires, and agency, radically challenges ideas about support and all that it entails. The social needs for independence, self-determination, and self-responsibility are "added on top" of custodial needs, which are still considered necessary but of a lower order. Discourses of need and necessity structure the policies, practices, and goals of support that produce and govern workers charged with meeting the needs of people living in group homes. I now look at the tasks that relate to meeting these needs. What would workers actually *do*? The data clearly articulates that despite the stated priority to support the social needs and rights of people with disabilities, the workers' tasks are largely tied to meeting custodial needs and meeting the needs of the state and service agencies.

Familiar and Unfamiliar Tasks. Guidelines for the tasks that the community support worker takes up are primarily found in agency job descriptions, although both the state and parent groups make contributions to how the needs of people with disabilities living in the community are met. Meeting these needs involves performing tasks that relate directly to serving individuals, and it also includes tasks that support the infrastructure of the community living project. Tasks attending to this direct and indirect service blend together in ways that at times put the needs of the supported individual in conflict with the

needs of the agency, parents, the state, or community. For example, people with disabilities

have the right to eat whatever they want, as long as it follows the "nutritional standards

based on the Canada Food Guide (Community Living Society, 1985, p. 28). While parents,

advocates, and agencies insist that people with disabilities have the right to self-

determination, the way this self-determination manifests needs to comply with "acceptable

standards" (p. 28).

As noted previously, agency documents demonstrate that service agencies prioritize

social needs over custodial needs. Goals relating to community integration and

relationship building are prominent in the job descriptions but the tasks attached to these

goals are vague, or do not seem to correlate to the goal. For example, the worker:

> ...ensures each resident is fully involved in his or her community. This
> includes assisting each resident with planning for and purchasing their
> clothing and other personal needs. (Mission Association for Community
> Living, 1988a, p. 1)
>
> ...fosters and promotes personal relationships and involvement in
> community groups, i.e. church groups, special interest groups, service
> associations, sports groups etc. (Mission Association for Community Living,
> 1988a, p. 1)
>
> ...plays an active role in developing supportive relationships with
> neighbours, local merchants, and other people who live and/or work in the
> area. (Community Living Society, 1985, p. 25)

Perhaps best described by one agency as "community development" (Community Living

Society, 1985, p. 25), these responsibilities point to a worker who is socially confident, has

social connections that she can tap into, can intuit so-called norms and presentation, and is

familiar with customs and resources in the community.

All of the documents refer to the importance of teaching and training in the home as a focus for the community support worker. Teaching tasks are mentioned largely in connection with supporting self-sufficiency and independence. For example, the worker, "as an integral part of home life, conducts a continuous learning program inclusive of all areas of personal growth and directed towards the individual becoming as self sufficient as possible in his or her home setting" (Mission Association of Community Living, 1988a, p. 1). She "assist[s] in ensuring that each resident attains his or her maximal level of language-communication proficiency and develops necessary interpersonal communication skills" (Community Living Society, 1985, p. 35). The Mission Association for Community Living (1989b) states that "our programs focus on support and training...staff help, show and teach each person in all aspects of the following..." (p. 4). The list that follows comprises twenty-three items, from personal care to transportation to safety and security. It is a list that, for all intents and purposes, replicates the responsibilities of the worker. While the worker is responsible for the completion of all her tasks to an acceptable standard, she is not simply to perform this work; she is to teach the people she supports to do it. If she asserts her role as the worker responsible for housekeeping tasks by tending to the tasks herself, or claiming to, then she undermines her role as the worker responsible for teaching and thus violates the narrative of independence she is there to support and maintain. This dilemma invites the question: Why not *actually* teach people to be independent?

The story about disability and community living asserts that in the community independence is an attainable goal for people with disabilities, although sometimes this is qualified as "as independently as possible." Persisting dependence is not part of the community living imaginary. Agencies and parents insisting on independence as the goal

nonetheless recognize the challenge that this might entail in some circumstances. In the event that people with disabilities are not achieving independent life skills, workers are told "to accept the challenge and responsibility for any lack of progress rather than blame the person we are supposed to help by labeling him/her incompetent" (Mission Association for Community Living, n.d.2, p. 1). Another training document states emphatically, "if a person is not learning the trainer has failed to teach appropriately" (Spectrum Society for Community Living, 1989e, p. 1). Workers are told to "be diligent in your attempts to support the individual, and find ways to overcome your own feelings of apathy or discouragement" (Community Living Society, n.d., p. 17). Any lack of progress on the road to independence is borne by the worker, who "while anticipating and striving for his future growth, [should] also be tolerant towards, accepting of, and content with him as he is at present" (p. 17).

Apart from supporting the social needs of people with disabilities, the imperative of meeting custodial needs remains. The community living project, despite using the language of the social model of disability and disability rights activism, is tied inextricably to the medical model of disability (Burnell & Trip, 2010). This is demonstrated in the data most profoundly by the need for agencies to comply with licensing regulations and the Community Care Act. These policies and regulations govern individualized pathology, they shape assessment practices, treatments, and care plans; the community support worker plays a central role in providing the care outlined in these plans. This is evidenced in one job description as "30 hours contact care" (Mission Association of Community Living, 1988c, p. 2). Tasks relating to meeting custodial needs are listed last in the job descriptions. These tasks include:

...feeding those unable to feed themselves and to support the development of these self-care skills; responsible for assisting residents in toileting, bathing, dressing and transfers; responsible for regular physiotherapy routines and daily health care techniques. (Mission Association for Community Living, 1988a, p. 1-2)

...assists in arranging for acquisition, storage and distribution of medications or teaches self-administration of medications to residents. (Community Living Society, 1985, p. 35)

...ensures that the transportation needs are met. This includes, where necessary, to and from work, medical appointments and all shopping and leisure time trips. (Mission Association for Community Living, 1988a, p. 2)

And there are other tasks that are less to do with caring or supporting individuals

directly, and more to do with making sure the agency meets its contractual obligations:

... monitoring on medications, weight, ailments, nails, BMs, etc; assessing program needs through the Individual Program Plan format; ensuring that all programs, data, charts, etc. are carried out. (Mission Association for Community Living, n.d.1, p. 1)

...responsible for attending meetings, writing reports and recordkeeping as deemed necessary by the Supervisor; is responsible for proper financial recordkeeping and accounting for petty cash, receipts from charge accounts, submitting these receipts on a regular basis to the Supervisor; is responsible for daily maintenance upkeep on the home and light housekeeping duties. (Mission Association for Community Living, 1988a, p. 2)

[A worker in a supervisory role is] responsible for overall planning; prepares and monitors budgets; prepares and forwards billings to funding ministries; ensures government and resident monies and benefits are being disbursed and utilized in accordance with the residents' needs and the Association's regulation, selection, training, supervision, support, coordination and dismissal of residential staff. (Mission Association for Community Living, 1988b, p. 1)

These tasks suggest a multi-skilled, organized, and flexible worker able to keep the needs and interests of the person she supports at the forefront of her concern, while in the background supporting the infrastructure for the care she provides. This spatial analogy serves to underline the complexities that come when one person is doing a job that used to be done by many. The tasks that had been performed in the institution by a large group of differentiated workers such as cooks, janitors, supply procurement officers, record keepers, drivers, and groundskeepers still need to be done; theses tasks now come under the auspices of the community support worker.

In summary then, contradictions in the texts about supporting social rights and needs and custodial needs highlight the challenges for the community support worker. Needs are rewritten in such a way that the need for personal care, meals, laundry, and other aspects of custodial care for people with disabilities disappears behind a narrative that privileges meeting social needs for independence, self-determination and full lives in the community. This means that tasks attached to meeting custodial care, already traditionally devalued, are further diminished in importance and recognition. This is not to say that policy makers and parents did not insist that custodial care should be done well, only that it was work that is done as a matter of course in the context of the more important work of facilitating community integration, personal growth, and life skills.

Worker: What kind of *worker* did society need?

Finding a *particular* worker in the texts is challenging. In the data workers are spoken about in professional and familial terms, and then obliquely as systems that surround, support, or serve people with disabilities. At times seemingly separate from her

humanity the worker is a component of policy and possibility, a prosthetic that helps people with disabilities live "as full and normal a life as possible in the community" (Community Living Society, 1985, p. 13). However, the notion of an inhuman support is not sustained, and the humanity of the worker is navigated through discourses of qualifications and qualities. The other image of the worker articulated in the data resembled an archetype of the ideal mother and wife, circa 1950. The use of the family metaphor in services to people with intellectual disabilities is pervasive, and it serves to produce the worker as a mother, homemaker, and housekeeper.

The expanse between the worker as the soul of the machine, the worker as a system that cares, and the worker as a mother pointed to a plethora of assumptions connected to what makes a worker a *good* worker. Within this complex expanse it is difficult to reconcile a coherent statement about the identity of the community support worker. However, whether system or human, the data indicates that the worker of the community living movement must be distinguished from her institutional counterpart.

The worker is part of a well-run system. In statements suggesting a well-organized system, the Ministry of Social Services and Housing (1987a), reassures the public that people with disabilities are moving from institutions to the community "with the supports needed to develop the normal lifestyles of the neighbourhood" (p. 1). According to the British Columbia Government Employees Union (1984), institutions should be replaced by "a system of community care, such as group homes, that facilitates the goals of normalization" (p. 3), noting further that "[a] system of care utilizing smaller facilities such as group homes tends to be more flexible in their ability to respond to the individual needs of the handicapped" (p. 3). The Community Living Society (1985), a service agency,

promotes a "supportive system that responds to the needs of the individual, enhances the opportunity for growth and development, and maintains a responsible focus on the individual" (p. 4). The texts point to a system that can be "flexible," "responsive," "facilitate" goals, and "enhance" opportunities; the worker is subsumed as an instrumental component of this system.

That said, the worker within the system is not completely dehumanized; she is the part of the system that cares.

> Parents now believe that all individuals regardless of the degree of handicap – can live meaningful lives in the community, if there is a system in place that surrounds that person with a network of supports which focus on his or her strengths. (Woodlands Parents Group, 1983b, p. 11, underline in original)

Parents, through their "mutual concerns to help their sons and daughters living a meaningful life...[have the] realization that *a system had to be found which embraced the beliefs and values of parents*" (Woodlands Parents Group, 1983b, p. 3, emphasis added). One of the service agencies speaks of "*systems that have a moral base*, a values base" (p. 3, emphasis added). Instructions to mirror the values of parents, to believe what parents believe, to have a moral base, go far beyond a description of duties and tasks, and reach into *who* the worker within the system has to *be* over and above what she is to do. Disciplining the worker "is no longer simply an art of distributing bodies, of extracting time from them and accumulating it, but of composing forces in order to obtain an efficient machine" (Foucault, 1975, p. 164). The forces to govern the *system that cares* come in the form of texts that articulate the worker as moral, flexible, and responsive.

While these qualities make the worker in the system a *good system*, what makes a community support worker a *good worker*? The data points to a worker with qualifications

that reassure parents and the public that workers in the community are governed by the same formal standards as the worker in the institution. However, agencies (in particular) make a pointed distinction between the community support worker and the institutional worker; training for workers is important, and this is certainly tied to the notion of qualifications, however intrinsic qualities of "goodness" have more traction. For example, while some agencies suggest "Good staff members require good training and orientation. There must be continuous training for all staff members" (Mission Association for Community Living, n.d.2, p. 1), other agencies advise that, "money is better spent on hiring good people than on developing detailed systems and mechanism to ensure program quality. The mechanisms will only work if good people are carrying them out" (Spectrum Society for Community Living, 1989b, p. 3).

Agencies, the union, and the state, all refer to qualifications in their communications with parents and the public. The worker, as part of a regulated system of care, is tied to policies or regulations that demand qualifications. However, despite numerous references to these qualifications throughout the data, there is only one document that lists what these qualifications are:

- o Previous work experience with multiply handicapped people in community settings and/or
- o Post secondary education in a related field;
- o Ability to communicate effectively;
- o Demonstrated ability to work as a member of a team;
- o Good mental and physical health;
- o Warm personal nature;
- o Basic first aid certificate;

      o   Valid class 5 drivers license;

      o   A tuberculosis skin test is a pre-employment requirement.

<div align="right">(Mission Association for Community Living, 1988a, p. 3)</div>

This list of minimal qualifications suggests that formal qualifications, while required through licensing and regulations, are not the focus of what qualifies a worker.

Devaluing credentials makes sense in the context of the anti-professionalism of the disability rights movement (Shakespeare, 2000) and the legacy of parent activism that challenged the often-controlling authority of professionals in the lives of children and families with a disability (Brockley, 2004). The data evidences an alternative way of qualifying workers in lieu of formal qualifications. This evaluation takes stock of the personal qualities and attitudes of workers and asks: Are they a "fit" for the work? These qualities and attitudes fall outside the purview of training and qualifications; a person is or is not a good worker. So while the worker of the community living movement has the minimal qualifications required by licensing, more importantly she embodies the right qualities. The intersection of this regulatory and anti-professional discourse meets in the person of the worker; the *service delivery system* meets *the compassionate worker*. This combination of "manager-mother" foreshadows the next finding in which I explore the constitutive use of the family-link metaphor in the production of the community support worker as a surrogate mother.

      The worker is a mother, homemaker, and housekeeper. The fact that the places where people with disabilities live are called group *homes* means that the family metaphor is evoked from the outset of the community living movement. Through discourses that state "individuals are best served in his or her home community in

<div align="right">101</div>

circumstances that most resemble family-like arrangements" (Community Living Society, 1985, p. 6) workers are encouraged to take up family-like roles in the lives of the people that they support. The Ministry of Social Services and Housing (1987a) describes the "community residence [as] a home, occupied by a small group of people who are not, biologically, a family but who live together in much the same way that a family does" (p. 5). While the British Columbia Government Employees Union does not use the same type of language as parent and service agencies, it is possible to hear references to a family-like dynamic in the Union policy statement; workers were "familiar with individual needs and desires" (British Columbia Government Employees Union, 1984, p. 4) and "care givers act as role models for the handicapped" (p. 4). By way of distinguishing support in the community from the institution, the Ministry of Social Services and Housing uses the family metaphor in the following statement (1987a):

> the focus of community living is to enhance an individual's independent functioning through the teaching of life skills and patterns of socialization...These caregivers look after all the administrative details, as well as the health and training of the people in the home. They are responsible for the physical, social and emotional health of those in their care and for ensuring that they participate in work, leisure and training activities and contacts out side the home, *much as a parent would.* (p. 5-6, emphasis added)

While the worker is not considered an actual member of this family, many of the qualities and responsibilities ascribed to her are recognizable as the province of motherhood. She is called to attend to the growth and development of the people who live in the home, and she is responsible for their social education, an education to help them join the larger community as a participating member. These excerpts from a 1985 job

description outline duties of workers that are reminiscent of those typically taken up by mothers:

- o to assist each person to discover and grow in his/her interests and abilities.

- o to assist each individual to learn how to identify different emotions in themselves and others and to explain ways in which these emotions affect the behavior of self and others.

- o to assist each individual to learn how to behave in an acceptable manner in public places.

- o to assist each individual to learn to identify and express their own basic physical, psychological and spiritual needs.

- o to assist each individual to develop some goal directed behaviour and to strive toward self-actualization. (Community Living Society, 1985, p. 22-23)

Added to this, the ideal attitude of the worker reflects a *maternal* commitment:

> Caregiving has to emerge out of unconditional love, and the change has to start with daily interactions...We have to show it in our every action – generous when we are denied, helping when we are refused, and warm when we are rejected. (Spectrum Society for Community Living, 1989a, p. 8)

The worker is encouraged to "exhibit enthusiasm and cheerfulness in the presence of the person you support, thereby communicating to him that you find it more a pleasure than a chore or just a 'job' to be with him and to address his needs" (Community Living Society, n.d., p. 16, quotations in original). She is to "ensure the individual's sense of inner security develops to, and remains at, a normal level" (Community Living Society, 1985, p. 13). The intimacy of the relationship between a mother and child resonates through these instructions. The role of the community support worker goes beyond a fiduciary duty to care, it extends into the realm of love.

Discourses that signify "mother" reach deep into long held cultural narratives of women as caregivers. Qualities ascribed to women as selfless nurturers are highly represented in the data. For example, support workers are told to:

> Cultivate an attitude of loyalty to the person you support, and demonstrate a readiness to make sacrifices for his benefit.

> Do not anxiously expect an unbroken chain of quick successes or spectacular breakthroughs in your efforts to support him, as this attitude would indicate a lack of sensitivity, and would shift your focus to the fulfillment of your own career ambitions and away from addressing his needs. (Community Living Society, n.d., p. 16 -17)

In addition to these discourses of selfless service, the data contains more general references to feminized behaviours and attitudes as ideal attributes of a support worker:

> Be genuine and frank, but temper these virtues with simple kindness.

> Be neat, attractively groomed and reasonably orderly, as you would in the presence of any person you genuinely respect.

> Exercise the same prudence and discretion in your speech and manners as you would in the presence of any person you genuinely respect. (Community Living Society, n.d., p. 16-17)

The family metaphor also accommodates other feminized roles the worker assumes, such as those of homemaker and housekeeper. As a homemaker, the worker

> ...assists each resident in developing an awareness of the security and comforts typically found in a home in the community. This includes providing for a comfortable social setting, providing opportunities for privacy and encouraging visits by guests, parents and guardians. (Mission Association for Community Living, 1988a, p. 1)

She is expected to "foster a spirit of welcome for all who come to the home" (Community

Living Society, 1985, p. 33) and is reminded that "making visitors feel welcome in the home

is a great gift to the individuals living there" (Western Family to Family, n.d.1, p. 2).

Keep in mind that it is not just any home that is being made. The demand for

normalcy, largely articulated through documents written by parents and influenced by

normalization theory, means that middle class values are written on the home and hearth

of community residences. These values are evident in statements that prioritize middle

class social norms. For example, the worker will "ensure that each member [of the

household] has and wears adequate clothing which is appropriate for his/her age and is

stylish and seasonally correct" (p. 27). She will "provide a residential environment of

moral and practical support for each resident in terms of their educational, vocational and

extraordinary recreational/leisure needs and programs" (p. 34), and "ensur[e] that

birthdays and days of special importance to residents are celebrated" and "that holidays

are structured to meet individual needs and that holiday plans of individual residents are

carried out" (p. 33). As homemakers, workers uphold these values on behalf of individuals

and their families.

Housekeeping tasks are listed in all of the job descriptions; the worker "ensure[s]

that housekeeping and house and yard maintenance consist of a permanent acceptable

standard" (Community Living Society, 1985, p. 28), and, "where applicable, (she) helps

assume responsibilities for vehicle maintenance: servicing, gasing (sic), cleaning"

(Community Living Society, 1985, p. 36). One job description contains a detailed cleaning

list for the night shift that includes janitorial tasks that seem quite institutional:

"clean/disinfect floors and fixtures nightly, clean walls each Thursday paying particular

attention to tile grouting...ironing and mending as needed; mark unlabeled clothing...clean all flat surfaces (Mission Association for Community Living, n.d.1, p. 2). And even though other sections of the job description instruct the worker to support residents to independently maintain their own home, much of the cleaning is done during the night shift while the residents are sleeping.

The use of the family metaphor serves to produce the worker as a parent-like figure, most recognizably a mother. This effectively shifts the work of support from a job to a calling; support is not only deskilled, but it is moved out of the realm of employment. Unlike her institutional counterpart, whose single role responsibilities preserved her status as a particular type of employee with specific duties, the broadness of the community support role, the wide range of duties, and the private space in which she works blur the line between her role as a paid caregiver and that of a devoted mother, dedicated homemaker, and maid.

In summary, the data reveals a *worker* who is trained, competent, organized, and she is loving. To talk about her as a "human resource" is to miss the resounding complexity of her tasks. She is human *and* resource, a system with a human face. It is difficult for these ideas to be held simultaneously and the identity of the worker toggles back and forth between human - resource, mother - manager, devoted - system. The presence of the institutional worker stands in the shadows of this dynamic as a cautionary tale. While the community living project is rife with institutional practices, preserving the status and identity of the worker as "not institutional" through discourses of love, devotion, and generosity is an important part of the project. If the worker is not an institutional worker, then the home is not an institution. Further, it is in the worker's own interest to hide the

institutional content of her work and role in order to distance herself from the workers of the institution and preserve her identity as one of the "good" workers.

Community: What kind of worker did the *community* need?

The community produced in and by the data forms the social and geographic context for the worker and her work. Anderson (1983) suggests, "communities are distinguished, not by their falsity/genuiness, but the style in which they are imagined" (p. 6). In the documents, the word "community" often seems to stand as shorthand for a wide range of values, such as inclusiveness, togetherness, and belonging. This community is actively (perhaps *forcefully*) imagined as an ideal place where people live meaningful lives shaped by participation and social integration. Yet parent groups, the state, agencies, and the union are aware that the community is also exclusive, and has historically been unfriendly and even hostile to people with disabilities. Some parents believe that people with disabilities will never be accepted, noting, "many people do still prefer to walk on the other side of the street" (Western Family to Family, n.d.1, p. 4). Reassurance for people reticent to accept community living as a possibility comes in the form of "a wide range of services…available to help integrate mentally retarded citizens into the community" (Ministry of Social Services and Housing, 1987b, p. 1). The community support worker is an important component of these services.

Community integration is a persistent theme of the community living movement. However, the way that integration is spoken about in the data makes it clear that integration is not simply a play on Sandra Harding's adage "add [people with disabilities] and stir." Integration emerges as a complex and conditional endeavour, with the obligation

to conform to social norms placed on people with disabilities and their staff. A more limited demand of "increased awareness" is made of the community, which is imagined as fair and welcoming, but perhaps ignorant. These findings suggest that the presence of a worker alongside the person being supported is meant to dissipate some of the concern and anxiety the public or parents had about institutional closures (Ministry of Social Services and Housing, 1987a). The worker helps the person she supports "fit in" (p. 9) to the neighbourhood where they live, and she helps the community get to know their new neighbours. A further finding explicates how the community is produced as distinct from the institution, yet host to institutional practices. The community is adamantly positioned as the counterpoint to the institution in ways that seem to deny or hide the institutional structures and practices that govern how support is provided in group homes. Within the community "that is not an institution," the support worker surreptitiously navigates her identity, and the purpose of her presence next to the person that she is paid to support.

The community support worker is a bridge. A central theme that distinguishes support in institutions from support outside of institutions is the concept of integration: "Services should support the integration of mentally retarded people into the mainstream of community living whenever possible" (Ministry of Social Services and Housing, 1987b, p. 1). But in the documents it is evident that integration is conditional. First, it is assumed that the person with a disability needs to learn socially acceptable behaviours. To this end the worker is advised to "assist each individual manifest a dignified self-image and personal behaviours at home and in public places" (Community Living Society, 1985, p. 9). Second, the community is seen to need increased awareness and education in order to foster the acceptance (or integration) of people with disabilities in the community. The

Ministry of Social Services and Housing (1987a) prompts the community: "We hope we can count on you to help make their [people with disabilities] return as smooth as possible" (Ministry of Social Services and Housing, 1987a, p. 2). The worker addresses these issues; she helps people with disabilities fit in, and she helps the community become more aware and welcoming. In pursuit of these objectives the worker is spoken about in ways that evoke images of a "bridge."

The worker spans the distance between the person she supports and the community. Community members with concerns "about small children being bothered by people from the home are invited to go and talk to the staff who know each of the residents" (Ministry of Social Services and Housing, 1987a, p. 9). The workers ensure that the homes themselves are indistinguishable from other homes in the neighbourhood. This is evidenced in one of the pamphlets from the Ministry of Social Services and Housing in which the community is told *twice* that "there are no signs identifying them as a community residence and, as you look down a street, you would not be able to tell that one of the houses was being used for a group of people with handicaps…" (p. 7). The state reassures the community that the group home "will not disrupt the neighbourhood anymore than a *normal* family – maybe less because staff are very much aware of the need to 'fit in'" (p. 9, quotations in original, emphasis added). Staff provide upkeep to the property so group homes do not interfere with neighbourhood values, such as property values: "A number of studies have been undertaken…they have all shown that community residences do not affect the value of properties around them" (Ministry of Social Services and Housing, 1987a, p. 9). And as a final example of the bridging role the worker plays, the state encourages the community to "take the initiative in getting to know your new neighbours"

(p. 9) and advises that if people "do not know how to talk to people with mental handicaps ask the staff for suggestions" (p. 9).

In helping people with disabilities access the community, workers take up guidelines from Wolfensberger's normalization theory that recommend staff "provide opportunities for the community to interact with, and meet, and learn to accept and value their citizens with mental handicaps" (Spectrum Society for Community Living, 1989c, p. 2) while at the same time, supporting "individuals with disabilities to access a lifestyle which matches the norms, patterns, and variety within the mainstream society" (p. 2). The worker will "support individuals with disabilities in recognizing the impact of personal appearance on the perception of others" (p. 2). On the bridge to integration, people with disabilities are supported to extend a self that is recognizable and acceptable to the community.

Discourses of sameness and "fitting in" as conditions of integration complicate the role and identity of the worker. Integration means that people with disabilities would

> ...have day to day routines the same as other people and join in many of the same activities. They swim at the local pools, choose a local doctor and dentist, pick up a burger at the local fast food outlet, shop at the supermarket and choose clothing and Christmas gifts at the mall. (Ministry of Social Services and Housing, 1987a, p. 9)

While this passage describes the freestanding individual, in all likelihood a worker provides support to the individual in order for them to engage in most of these activities. I am not suggesting that this passage *should* mention the worker, but I am noting that to include the presence of a worker would not simply be strange, it would undermine the community living narrative of dignity that accompanies independence and self-sufficiency.

In part, integration means making disability invisible. By extension, this makes the ongoing

presence of support workers difficult to explain, at least from a policy perspective.

The community is configured as the mainstream, a wide-open space in contrast to

the closed-in carceral vision of the institution. The metaphor of the worker as a bridge

between these two apparently distinct spaces is more complex than simply facilitating

networks or building community awareness. The worker as a bridge might also function as

the accommodation between the imagined community and the experienced community.

The presence of the worker makes it possible for people to participate *as if* the community

were welcoming. Further, the community also contains closed spaces, it contains "home-

like" spaces where people with disabilities live and learn what they need to know to

participate in the mainstream. To this end, we might also see the worker as a bridge

between the private world of home, dependence, and difference, and the public world of

the independent individual who is homogenized within the community. The worker does

not live in the group home, and her status in the community is difficult to place. She is

imagined as the armature for a destination, working in an undefined space between the

public and private, difference and sameness, and dependence and independence.

The community support worker is an institutional worker. The community of

the community living movement cannot be separated from the institution that is positioned

as its opposite. While the institution is a place of isolation and abuse, the community is the

"spirited, accepting community in which we live" (Mission Association for Community

Living, 1989b, p. 2). As supposedly separate spaces, they hold mutually exclusive

possibilities for people with disabilities. But the line between these spaces is not so easily

drawn, and despite discourse that suggests the community is a place where people with

disabilities "have the opportunity to live as a full member of society" (Community Living Society, 1985, p.15), the structures that make community living possible, including the presence of community support workers, are governed by many of the same practices and assumptions that informed and produced the institution.

The analysis I conducted on the texts suggests that social spaces have agency: the community *provides* meaningful lives, homes *provide* safety, and living arrangements *enable*. For example, the stated goals of one agency are "to facilitate the individual's dignity by providing the individual with living arrangements and other opportunities which enable him/her to pursue as full, dignified and normal a life as possible in the community" (Community Living Society, 1985, p. 9). The state suggests that "*Homes* get people with mental handicaps back into normal living environments where they can go about the business of living and learning at their own pace" (Ministry of Social Services and Housing, 1987a, p. 8, emphasis added). These statements, superficially congruent with the social model of disability, imply that it is primarily the environment that limits people with intellectual disabilities and that a change in venue will free them to participate as full citizens. However, describing the community as a space of freedom and possibility ignores the limitations of embodied impairment and the institutional mechanisms put in place to make opening group homes possible.

Although the narrative of the community living movement hails "homes" in the community, it is always with the awareness that these places are in fact "home-like settings in the community" (Ministry of Social Services and Housing, 1987b, p. 1). Group homes are referred to as "facilities" by the state, the union, agencies, and parents. The language used to describe these homes is the language of policy makers. The union advocates "adequate

community-based residential facilities and support services," and agencies develop guidelines "as a means of ensuring that the physical facility promotes…a normal lifestyle for its handicapped occupants, that the occupant's safety needs are met, and that the community accepts the occupants and facility" (Community Living Society, 1985, p. 19). Group homes are governed by regulations and legislation, and have strict rules for safety and monitoring: "The agency responsible for people with handicaps living in a residence should ensure that provision is made for having a strong external monitoring component involved in, and fully accessible to, the residence" (Community Living Society, 1985, p. 20). Medications are locked up, an inventory of the resident's personal belongings is done semi-annually, and financial records are submitted for auditing (Mission Association for Community Living, 1988a; 1988c). The dichotomy of community versus institution also establishes the dichotomy of home versus workplace. For example, workers are advised by parents: "We like this to look and feel like a home, not a resource…the obvious posting of schedules or ~~union~~ papers announce this as a workplace rather than a home" (Western Family to Family, n.d.2, p.1, text struck out in original). The community of the community living movement is the space where individual actors are purported to pursue their own interests, but in the context of a highly structured service delivery system.

Institutional practices did not stay within the walls of the abandoned edifice, but followed people with disabilities into the community. While the community is spoken about as the antithesis of the institution, the data confirms that community living contains practices and ways of thinking about support for people with disabilities that perpetuate the institution. The community support worker navigates the waters between minding the official narrative of community living and enacting the institutional practices that

accompanied people with disabilities from the institution to the community. The worker's identity is tied to the space in which she works. If group homes are institutions, then her identity moves closer to that of the workers in the institution. If, however group homes are ordinary homes in the community, then the state is able to claim a social justice agenda, parents are able to steer clear of the idea that they are still in some way institutionalizing their children, and the worker, as distinct from the institutional worker, is able to preserve her own innocence.

In summary, the community of the community living movement focuses on the recuperation of people with disabilities from the margins, but it is also constitutive of the workers who accompany them on this journey. The worker functions as a bridge between the community and people with intellectual disabilities, standing between the people she supports and their neighbours in such a way that neighbours can control how much direct contact that they have with people with disabilities. As a bridge, the worker helps negotiate the demands of belonging that span the distance between dependence and independence, and ability and disability.

Importantly, "the community" of the community living movement is spoken of as a space that is the resounding opposite of the institution. The exodus to the community is as much a journey away from the institution and its signifiers, as it is a journey towards an imagined community and its promises. However, much of what produces an institution, as such, comes in the form of institutional practices and policies, and these artefacts of the institution exist and thrive in any environment where they are used, including the community. In order to preserve the narrative of community living as distinct from living in an institution, workers are imagined in such a way that they embody the institutional

practices while actively hiding the signifiers, which at times includes masking their identity as workers.

Conclusion

In pursuit of the question: <u>How was the community support worker produced as a particular subject at the time when large institutions were closing in British Columbia?</u> my analysis of the data yielded six findings. The first finding shows that while continuing to attend to the custodial needs of supported individuals, the community support worker is idealized as a worker who advances social needs and rights. However, the next finding suggests that despite this shift in focus, the days and nights of workers are taken up by attending to the custodial needs of supported individuals, as well as meeting the needs of agencies for accountability, and the needs of the community for mediation between group home residents and neighbours. The third and fourth findings point to a worker that is at once a maternal figure and a component of a well-run system. She is a complex blend of efficiency and affection who performs tasks that work in tandem to keep the group home running as a system, while attending to the developmental and socialization needs of the residents. Findings in relation to the community suggest that the worker is, in the end, an institutional worker, one who functions very much as the walls of the institution once did in terms of keeping people with disabilities safe, providing reassurance for the community, and supporting families. She is a bridge between the community and the home, a form of gatekeeper within an ableist paradigm who mitigates disability in the context of a world of imposed "normalcy."

These findings demonstrate how the worker is produced through discourses of self-less service and competence, through the influence of the spaces where she works, and through the tasks that she performs. Taken together they suggest a domestic worker who is flexible and ephemeral, at times human and at other times simply a resource. This worker continues to be reminiscent of her institutional counterpart through institutional practices that structure support along the rationales of the medical model of disability. The support she provides largely attends to the custodial and disability-related needs of the people she supports. This is in direct contradiction to discourses of growth, development, and the attainment of independence, which comprise the defining goals of the community living movement. With independence as the goal of service, the continued presence of the worker is hard to account for. From the time she is first imagined, the divide between her persisting presence as a caregiver and her presence as a teacher, model, or bridge, which is idealized as a temporary measure, forms a central tension in the community support worker role and identity.

Chapter 5: A Failure of the Imagination

I used to work in a group home where we supported a woman named Marilyn, who could be aggressive at times. As a result, we tried to keep our distance, but because she needed help with all of her personal care we had to get close to her. Most of how she was touched was to do with us performing one 'care' act or another, as quickly as possible. One day while Marilyn was having her afternoon rest, Sharon (my co-worker) and I were getting the housework done. It was my turn to make dinner and at a certain point I realized I couldn't hear Sharon moving around. I found her in Marilyn's room, curled up alongside Marilyn on the bed. Marilyn had pulled Sharon's hand up, and held it close to her cheek. They were sleeping peacefully as the afternoon sun caught the end of the bed, keeping their toes warm.

What do *I* know about being a community support worker based on my experience of the role? As I consider the data and the findings, I have been reflecting on what *I think* I know, calling up experiences, remembering encounters with parents, with my supervisors, and with the people I support. In relation to these memories and reflections I ask, again, what is the story the data alludes to? What do the findings say about the worker who is desired, as she was imagined? What do they "truly" want from the community support worker? If they could just say it, directly, without rationalization, persuasion, or indignation: What do they want (from us)? There are several themes that emerged in the findings that will help to flesh this out.

In 1964, Anne Bancroft won an Academy Award for her portrayal of Anne Sullivan, Helen Keller's teacher, in *The Miracle Worker*. Sullivan is a partially blind, poor, young Irish woman who, through commitment, passion, and a *firm but kind* approach, delivers young Helen from animality to civility (Hughes, 2012). It is a powerful story that tugs on the hearts of parents with disabled children: With the right medicine, therapy, schedule,

program, teacher, worker, so much could be possible. It might also be a powerful story in the minds of policy makers looking to cut costs: With access to a labour force of poor, young, partially blind, Irish women (or the contemporary equivalent), so much could be possible. I can attest that it is a powerful story in the mind of a community support worker: If I am dedicated and creative, if I never give up, if I never leave, so much could be possible. The Miracle Worker.

And there is another worker who stands nearby who also has a relationship with the desires expressed in the data. The institutional worker is a constant absent-presence; she is in all of the findings. However, she is an institutional worker who is a composite of *three* institutions; the large institution of the past, where she stands as a cautionary tale, the institution of the group home, recognizable as licensing, care plans, and the audit culture; and the institution of the family, evoked in the family linked metaphor that features so prevalently in the data. This three-fold institutional worker takes care of everything, she embodies the entire staff roll from the institution, from cook to groundskeeper, she embodies all the goodness of mother, housekeeper, and homemaker, and she does whatever she can keep her distance from the institutional worker of the past. She is the worker, as imagined.

In this chapter, by way of completing the circle of the genealogy from present to past and back again, I revisit the conditions of possibility, touching on the way that these conditions informed the desires and produced the needs outlined in the findings. Then, pulling the findings together, I tried to get a sense of how this imagined worker might meet the contemporary worker. It is also important to note that workers have agency, and I reflect on how workers might find a "margin of freedom" (O'Farrell, 2005, p. 109) within

the constraints of discourses that shape them according to the historical times and social spaces in which they work. Finally, I bring the findings to the present and hold them up against current conditions of possibility, which suggest a move away from a reliance on paid supports to a "blended" approach that includes family, friends, and neighbours. It is important to recognize this as a proposition, just one offer or possibility from which a new order might emerge.

Revisiting the Conditions of Possibility

> *Pinel replied calmly: 'Citizen, I am convinced that these madmen are so intractable only because they have been deprived of air and liberty.*
>
> (Foucault, 1965, p. 242)

The moment Pinel, the 19th century alienist, loosed the chains on the inmates of the Bicêtre, did not mark the end of madness; it simply changed the approach to the problem of madness (Foucault, 1965). In the same way, when large institutions closed in favour of community group homes, this did not mark the end of disability and dependency, it simply marked a change in social response. It is a new order that is, in many ways, similar to the one it replaced.   However, this idea is not congruent with the narrative of the community living movement. As a social justice grassroots movement, the advent of community living is touted as a new beginning for people with intellectual disabilities. Having been deprived of "air and liberty" they would now be free to return to the communities into which they had been born and take their place as citizens in this welcoming community. This is how the story was told at the time the institutions closed; this is how it *could* be told, and how it continues to be told.

Conditions of possibility are contingencies that are present at a particular moment in history, they circumscribe the limits of what can be said or thought at that time, they are the *espiteme*. In this section I discuss my findings in relation to the conditions of possibility outlined in Chapter Three. In setting out on this research I was aware that the beginning of community living movement was an important moment in time, it was a moment that continues to be idealized in the various training and strategic planning sessions that I have attended. As noted earlier, the story is that there were the golden years when due to the political savvy and sheer passion of parents and advocates, large institutions were closed and people with disabilities moved into the community. There is also the accompanying narrative that society had simply grown more civil: We don't lock up human beings and call it "care" anymore. There is also the story of an advancing political rationale that favoured the privatization of social services. There are also the enduring, unspoken stories of caregiving as the devalued work of the underclass, of dependency as a burden, and disability as a problem. By looking at what *could* be said, thought, and desired within the conditions of possibility and holding this up to the findings, we get a sense of how the desires for a particular life for people with disabilities, coupled with historically situated economic rationalities, manufactures the necessity for a particular worker.

The critique of the institution and institutional worker is a defining reference point for when services in the community were developed. While the institutional worker is held responsible for much of what went wrong in the institution, institutional practices themselves survived the restructuring of services and are the foundation for services in the community. Regulatory practices take the form of persistent surveillance (even when bathing or using the toilet), coaching for daily decision-making, prompts for hygiene

practices, the regulation of diet, and the enforcement of bedtimes. In concert with government regulations designed to address risk or negative publicity for the project of deinstitutionalization, "centralized institutional surveillance has been replaced by a 'carceral archipelago' of 'community-based' services which appear 'open and small-sized,' yet could be 'restrictive and regimented internally'" (Kumari-Campbell, 2003, p. 202). Importantly, while the worker finds herself working in an institution, she cannot resemble the institutional worker.

Normalization theory makes certain demands on how the worker is imagined; she is someone who controls the signs and signifiers of disability. Normalization theory is a recuperative theory holding that people with disabilities can be rescued from institutions where they were kept out of sight and out of mind to take their place in society as valued citizens. However, as noted in the findings, normalization theory itself lays down conditions for integration into the community. The promise of normalization theory is not only normal lives in the context of normal communities, but also the refashioning of people with disabilities as more normal. This ableist stance underlines the fact that "community living [is], in part, pivoted on the notion of 'sameness' rather than 'difference' between people with an intellectual disability and the rest of society, 'difference' having been coded negatively" (Burrell & Trip, 2011, p. 179). The imagined worker uses normalization theory to help minimize the presentation of disability, and ideally make it disappear.

The social model of disability, as noted earlier, is a social theory that makes claims for rights, justice, fairness, and the opportunity to participate fully in the areas of education, employment, and the social life of the community. The cornerstone of the social model of disability is the call for society to recognize how its social institutions and physical

environments disable people who have impairments. Evidence of the social model of disability is seen in the parent newsletters, particularly in passages that frame their claims for resources in the language of citizenship and rights. As noted in Chapter Three, while the social model of disability is useful in providing a theory of disability that advances the rights and opportunities of some people with disabilities, it is taken up more problematically in the area of intellectual disability. This is evidenced in the data by the assertion of parents to "negate the original diagnosis" (Woodlands Parents Group, 1983b, p. 3). Laudable from a political perspective, it does not address the issue of embodied impairment. Connected to this, the social model of disability and disability rights activism focus on independence, largely connected to the independent living movement. While group homes are markedly different from large institutions, they cannot rightly be considered independent living. Nonetheless, in all of the data independence remains a persisting goal for people with intellectual disabilities. The imagined worker teaches the skills necessary for people to live as independently as possible.

For parents, symbolically and actually distancing group homes and workers from the institution is of paramount importance. Having been through the trauma of institutionalizing their children, followed by the arduous process of closing the institution, the data indicates that parents are very clear about what they hope this new living arrangement and staff will deliver. They want opportunities for their children to reclaim the life that the diagnosis and the institution had taken from them. Shut out by institutional staff, and by professionals who told them to walk away (Panitch, 2008), parents want back in; they want to be involved in the life of their children. Families imagine workers who welcome the presence of family, who honour family, and who accept and embody "the

beliefs and values of families" (Woodlands Parents Group, 1983b, p. 3). The presence of the

imagined worker allows families to live out a normal family narrative; children grow up,

they live in their own home, they celebrate family events, but they have their own lives.

In Chapter Three I discussed Jones' (1975) study of the hospital back wards, in

which she explores the family-link metaphor. It is interesting to see this metaphor surface

again in the data, particularly given that there is some similarity to the way Jones notes its

use. Jones (1975) suggests that on the ward the family metaphor is useful in comparison

with some of the other more negative metaphors that are used, but that ultimately it fails to

mitigate negative staff attitudes, in part because when the "children" on the ward did not

"mature," the staff reacted disrespectfully. In group homes, this metaphor is evoked

through the space of the home, in the tasks the workers take up, and in the attitude they are

to have toward the people they support. The worker in the group home is imagined as

someone who teaches the people who live in the home to become more independent "much

as a parent would" (Ministry of Social Services and Housing, 1987a, p. 6). While the family

metaphor seems to play out differently in the hospital than it does in group homes, I

suggest that they point to the same issue of ongoing dependency. Kittay (2001) articulates

that within liberal society there is little accommodation of *ordinary* dependency, never

mind the exceptional dependency of someone who may need care for their whole life.

Dependency, it seems, can only be thought of as the ordinary dependence of children; this

is how the metaphor fails in the case of support for adults with intellectual disabilities,

whether it is in a hospital or a group home.

Added to this mix of ideas, dreams, and desires, the BC government embarks on a

new order that we now recognize as neoliberalism. At the inception of this new order the

state introduces legislation to limit the bargaining power of the British Columbia Government Employees Union. While the union is involved in the conversations about deinstitutionalization, it is interesting to note in the findings how little influence the union has. As the funder, the state arbitrates the debate over deinstitutionalization, and the ideas put forth by the union are overshadowed by the voices of parents. While parents speak the language of normal lives in the community, the union continues to overtly promote institutional services and workers. The state is able to adopt the language of the parents, while structuring the services very much as the union recommended, but without the unionized labour. This maneuverer is standard neoliberal fare. Stuart Hall (2011) suggests, "neo-liberalism performs a massive work of trans-coding while remaining in sight of the lexicon on which it draws. It can do its dis-articulating and re-articulating work because these ideas have long been inscribed in social practices and institutions and sedimented into the 'habitus' of everyday life, common sense and popular consciousness" (p. 711).

    While generally accepted as nefarious, neoliberalism has one appreciable quality; neoliberalism is labile. Neo-liberalism is "not one thing. It combines with other models, modifying them. It borrows, evolves and diversifies. It is constantly 'in process'" (Hall, 2011, p. 708). Neoliberalism can make a meal out of anything; it is a shopper in the market place of the conditions of possibility. One of the things that neoliberalism is particularly adept at making a meal of is desire (Hall, 2011). When parents challenged the state to provide flexible, home-like supports in the community for their children, building their case strongly against the unionized institutional worker, the neoliberal state, amidst head

to head conflict with union leaders, advances their cause. Grassroots parent activism is, obviously, not the only contingency in play:

> … the independent living movement gained momentum at the same time that the government began denying funding to unionized positions in nursing homes and other institutions while trumpeting the cost-effectiveness of using flexible labourers as personal attendants…This deregulation of the workplace brought significant changes to care providers' safety and rights while governments and businesses promoted public-private partnerships in mental health, rehabilitative services, and various forms of outpatient community services. As a result of these measures, government responsibilities have been downloaded onto municipalities, non-governmental organizations, grassroots organizations and charities, or individual families. (Fritsch, 2014)

In recognizing how necessity is socially produced, we can see how claims for a new order emerge contingently. For example, the necessity for a "flexible" worker is produced through blending the desires of parents and the desires of a neo-conservative state; it is remarkable how well the employment conditions for non-unionized workers dovetails with the need to provide a "home-like environment." These workers are hired for their "warm personal nature" (Mission Association for Community Living, 1988a, p. 3) and require minimal formal qualifications. There are very few barriers to becoming a community support worker, which makes it an easy job to obtain for immigrants whose credentials are not recognized, for people without formal education, for mothers looking to pick up a few shifts, and for students.

The conditions of possibility delimit what *can* and *cannot* be said at a particular moment in time. What _cannot be said_, as evidenced in the data, is that the community support worker of the 1980s is needed to provide support as cost effectively as possible to people who are dependent. What _is said_ is a more uplifting narrative; the community

support worker is needed to foster community integration and teach life skills, so that people who have been living in institutions can live independently in the community. In the next section I revisit the findings to look at the imagined worker of the 1980s in the context of this vision.

A Failure of the Imagination

In thinking about how to focus my findings I look at what they point to. What is the desired or imagined purpose behind the various ways a worker can show up? What does the worker have to be, or do, to realize this desire or purpose? I have two propositions. I suggest that the community support worker of the 1980s is imagined as an *invisible* worker, one known only by her effects, and second, that she is *temporary*. In her invisibility (as a worker) she helps deny the reality of the group home as an institution, which preserves the narrative of "homes" in the community and the vision of independent, culturally normative lives. The workers of the community living movement, by all accounts in the data, are a temporary measure, put in place to provide training and support to help people become more independent, and to help build personal networks in the community to fulfill the social needs of the people they support.

The worker is made invisible, as a worker, in several ways. She is recruited for her personality, rather than her credentials. She keeps house; the worker's days and nights are still largely taken up meeting needs for personal care, cleaning, laundry, cooking, shopping, and documentation. Given the devalued work of caregiving, homemaking, and the private (feminized) spaces where these activities happen, this work is inherently invisible, and the worker along with it. Another discursive strategy that renders the worker invisible, *as a*

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worker, is the evocation of the family metaphor; group homes are homes and workers are surrogate family. As a mother, housekeeper and homemaker, all roles where the labour is not contracted or compensated, the worker disappears *as a worker.*

The worker of the community living movement is imagined as a temporary worker. The findings show that her "real" work is to promote the independence of people with disabilities. Documents from the state, from parents, and from agencies go to great lengths to stress independence as the goal of service. The family metaphor, again, serves to underline the temporary nature of the arrangement; children grow up. The notion of the mother who socializes children, prepares them for independence, and teaches the life skills they need to be on their own contributes to the community living narrative as an independent living movement, and workers as a temporary measure.

Promoting independence is social justice work. Everything the worker does alongside the person she supports means something in excess of the task. However, in order for the fullness of the task to be realized (not just learning to mow the lawn, but doing it independently) the worker must disappear, or at least seem to. There is a teaching technique often used in the field of intellectual disability called "hand over hand." The teacher places her hand over the hand of the individual to guide them through the task being learned. As the student becomes more familiar with the movements, the teacher slowly withdraws her hand, and eventually leaves altogether. The findings indicate that the worker is to do this with almost every aspect of her job. Tied to the idea that the subjectivity of the worker is inextricably bound to the identity of the person she supports, the imagined worker, as invisible and temporary, produces the person she supports as

independent and able. To *show up* and to *stay* is a betrayal of the person she supports as it renders them disabled and dependent.

Why are we (still) here?

Clearly the community support worker of the 1980s has been a failure of the imagination and a resounding disappointment. So, why *are* we still standing here, unwanted, apparently unwarranted, and not sufficiently unseen? The most basic answer is to point out that we are not standing here by ourselves; we are standing next to people who need our help. Based on the findings, grappling with the emergent discourse of "full lives in the community" was a central concern for policy makers, agencies, and parents who were trying to imagine how these lives would be supported, and what kind of worker was needed. However, supporting *lives* is different than supporting *people*, and ultimately the community support worker of the 1980s was needed for the same purpose that all workers and caregivers have ever been needed.

The community living movement cannot be separated from its purpose as a solution for "the problem" of dependency, disability, and ongoing need. While in "advanced liberal democracies acknowledgement of the reality of dependency is denied through the promotion of an ideal of individual autonomy" (Fine & Glendinning, 2005, p. 613), the fact remains that some people with intellectual disabilities need to be cared for, sometimes for their whole lives, and sometimes in highly complex ways. Neither I, nor the workers who have come before me, have been able to change this, despite the negation of the diagnosis. Nor have we been able to change the community in any significant way. While people with disabilities continue to be cared for *in* communities, they are not, to any large degree cared

for *by* the community, except through the proxy of paid staff (Bayley, 1973). The idea of negating the diagnosis was an important discursive move, but it created almost as many problems as it solved. Yes, it was an important challenge to pathologising medical discourse but it did not account for the ongoing embodied needs that could not be jettisoned through evoking counter-discourse. Perhaps a more useful approach, if we are speaking in the realm of contingencies, would be to negate *dependency as a problem*. This entails acknowledging, at a social and political level, that dependency is a normal expression of our humanity (Kittay, 2011). It is a reality that we all experience times of dependency. However, this is not something that I imagine policy makers or the lean state wants to hear.

Given the focus of this research to look at how the worker was produced, I would like to speak about how she might resist discourses that ask her to be invisible, to deny the "work" of what she does, and to limit the expression of her singularity. Stuart Hall (2011) suggests that within the constraints of a neoliberal order "excluded social forces, whose consent has not been won, whose interests have not been taken into account, form the basis of counter movements, resistance, alternative strategies and visions…and the struggle over a hegemonic system starts anew" (p. 727-728). While laying claim to a new hegemony seems a tall order, there is a sense of hope in the idea that changes in the public realm are begun within the privacy of our relationships, including our relationship with our sense of self.

To this end, Foucault is concerned with ethics in the most intimate way, at the level of the subject. For Foucault our ethics are based on a relationship that we have with ourselves, one that centres on "how we constitute ourselves as moral subjects" (O'Farrell,

2005, p. 109). Moral subjects, according to Foucault, recognize their responsibility to "reflect upon and choose how to exist in the historically and culturally specific situation they find themselves in" (p. 117). It is the strategic actions of the individual, acting out their morality moment by moment in response to these imperfect conditions that creates the opportunity for an ethico-political intervention. Foucault insists that there is always a margin of freedom to act, "there is always something that can be done, even if it is not easy" (O'Farrell, 2005, p. 117).

Turning back to the community support worker, here is another metaphor. It has to do with seeing the worker at the outset of the community living movement conceptualized as a kind of toxin that was a product of the institution. However, workers were still needed in the community, and so in the community this worker becomes a (discursively) controlled substance. What I think is *more* true is that the worker was not the toxin or the poison, but rather a portion of the antidote. I suggest that it is the relational nature of care, the bond between the worker and the person she helps that remedies, or at least mitigates the harm to both parties that can be caused by the institutional practices and rationalities that inform community living services. I am gratefully reminded that, "life and love are always 'in excess' of the institutions and forces that produce and constrain them" (V. House, personal communication, February 8, 2014). I have witnessed love and life in the relationships between people receiving and giving care; I can attest to the unique quality of these relationships.

> *When I arrived for work Patty greeted me at the door saying, "Happy Mothers' Day!" She gave me a hug, and then handed me a silk flower with a paper doily wrapped around its plastic stem, "You are like a mother to us here….sort of."*

Apart from enjoying and valuing the relationships we have with the people we support, perhaps there are conversations that workers might have amongst themselves, and with anyone who is listening. It is important to deny narratives that suggest our presence as workers next to the people we support is in some way corrupt. It is not a wage that corrupts the care relationship; care is corrupted through the dehumanization or exploitation of the person who is being supported and/or the person paid to provide the support. It is also important to reject the notion that if we show up as workers it betrays the independence or dignity of the people we support. Dependency is a fact, it need not be a problem, and it is certainly not the exception. Being dependent and meeting the dependency needs of others is an exceedingly normal expression of our humanity.

Current Conditions: Is it really just about the money?

Despite concerns about funding constraints and the rising costs of care (CLBC, 2013), it is *never* just about the money. There is *always* a story to go with it…undeserving – deserving, independent – dependent, natural – unnatural, able – disabled. There is also the discrepancy between the original narrative of community living and the current state of affairs to contend with. According to a report evaluating services for British Columbians with disabilities (Queenswood Consulting, 2011) people with disabilities have an overrepresentation of people paid to be in their lives and these paid services have supplanted the supports of family. This report contains a number of recommendations to make services to people with disabilities more viable:

> CLBC is also promoting a conceptual shift towards meeting disability related needs by ensuring that family, community, and other "natural" supports remain in place and are not supplanted by funded services. This is consistent

with its foundational goal of ensuring that community and generic supports
are inherently part of planning to meet the disability-related needs of
individuals with developmental disabilities. It expands this approach, though,
to make families and support systems a more considered, active, and
identified part of supports and services. The hope is that this will foster a
greater shared understanding that, within current financial restraints,
government alone cannot be responsible for serving people with disabilities.
(p. 27, emphasis added)

This statement includes a reference to the "foundational goals" of the funder to

ensure "community and generic supports are inherently part of planning." Based on this

research I can attest that community and generic supports were indeed connected to

foundational goals for the community living movement. As indicated in the data and other

materials, from the outset of the community living movement there were concerns about

the overrepresentation of paid people in the lives of people with disabilities. The ongoing

presence of the community support worker, ephemeral, ideally invisible and temporary, is

implicated in the failure of these foundational goals to be realized.

It is the community support worker, not the imagined community and not the state,

who is the receptacle for disappointment. It would be fatuous to suggest that *all*

community support workers rise to the fullness of what the role of supporting someone

can be, however we might ask how current discourse of the worker as a disappointment

might be one of the conditions of possibility for what happens next. The rising cost of care

coupled with "disappointing results" lays the foundation for a *seemingly* inevitable solution;

dispense with a model that requires workers, or at least workers whose employment is

structured as it is now. This solution is reflected in current policy initiatives from

Community Living British Columbia (CLBC, 2013) that aim to prioritize the natural

supports of family and friends, and in the absence of these supports, awarding contracts for home sharing (the family metaphor, again) and life companions, both options very similar to foster care. It is a move toward *workerless* supports. Support workers as a shadow of themselves will become even more casualised as respite workers. While the worker of the 1980s disappeared discursively, subsumed into a system, re-formed as a mother, and encouraged to hide, it seems that current policy initiatives aim to disappear her, actually. A new order begins to take shape.

Chapter 6: Afterword

Debbie: You're the staff here.
Bev: If I am the staff, then who are you?
Debbie: I'm 'trouble.'

The questions guiding this thesis ask: At the time when the community support role was first created in the 1980s, what *was* the worker supposed to do, and who *did she need to be* to be successful in this role? How was she produced as a particular subject at the time she was first needed? These questions emerge out of my sense that there is something unclear about my role; I have the persisting feeling that just being at the side of the person I support is somehow not right. This research began as problematization of my experience as a worker, a problematization that led me on a journey to look at how the worker of the 1980s is produced as a particular subject in archival documents.

I found this worker produced as a confluence of desire, utility and contradiction, and most pointedly, despite the social justice goals that infuse her mandate, this worker meets basic needs. The question is whose needs? While her overt mandate is to provide support to people with disabilities, ultimately the worker is attending to a wider social need to meet the ongoing dependency of some citizens. The synchronous emergence of a neoliberal rationale that increasingly seeks to diffuse statutory responsibilities for care and shift them to an imagined community is central to this story. The worker, as a bridge to this community is caught between a visionary goal of inclusion, a community that has not materialized as imagined, and a state that is taking its hands off the steering wheel.

So, are workers implicated in the fact that people with disabilities do not live out the lives promised in the community living narrative of the 1980s? It is not my intention to evade this question, but to trouble it. In bringing the findings from this research to bear on this question I can see that it generates other questions. Foucault's promise is that having looked at the past, at the confluence of events, ideas, and desires, I can "make the past no longer present" (O'Farrell, 2005, p. 72). In light of this, a reorientation with the past might invite the following alternative questions: How is it that dependency cannot be accounted for in a society that puts so much stock in accounting? Or, how is it that dependency is so persistently conceptualized within the family metaphor? What does the use of this metaphor allow in terms of social organization? *If* we allow that dependency *is* a problem, then whose problem is it? These alternative questions are my proposition for beginning a new conversation about support for people with disabilities and how we can collectively care for those who provide this support.

I can be disciplined

While the process of unpacking all of the details relating to the identity of the support worker has been, frankly, transformative, what is more interesting was just how hard it has been for me to do this. Chambon (1999) notes, "Foucault took the stance that transformative knowledge is disturbing by nature. It disturbs commonly acceptable ways of doing it and disturbs the person implementing it" (p. 53). In the course of writing the thesis I continued to work at my job, go to meetings of support workers and administrative staff, and chat with my colleagues. These experiences happened on one level, while the archives circled around in the back of my mind, disturbingly.

More disturbing, however, was how often while writing I had the thought, "I can't say that," or I would feel afraid that one of the parents, one of my supervisors, or my co-workers would read the thesis and I would be called to account for violating central narratives of the community living movement by speaking opening about dependency, or simply by making workers visible. I was recently at a meeting and a *new* staff person spoke, not disrespectfully, about the limitation of someone he supported; he was corrected. It is easy to see this in the context of "the violence of representation" but perhaps Kittay (2011) says it best when she asserts, "dependence unacknowledged is still not independence" (p. 570). When walking in the world as a community support worker there is a way of believing and way of thinking that is quite dense, and over the months as I wrote, I felt myself pressed up against this denseness on a daily basis. The awareness of this weight has awoken a strong sense of solidarity with my co-workers; I feel more appreciative of them and what they bring to their work. I know what they are up against. I have shared some of what I am learning in the hope of impressing on them just how important it is to show up.

I am still curious

What follows is less a recommendation for future research than it is a curiosity wish list. Given the possibility of group homes being phased out in favour of home share arrangements or family care, workers will likely be required for respite services. This new arrangement implies that families or home share contractors will be hiring and supervising workers who will be piecing their livelihood together across many homes and under the supervision of many different families. Connected to this, the issue of class surfaced periodically in this research and seemed to point to something important about the

interplay between neoliberalism and care services in relation to class. This seems like an important thing to keep an eye on.

In an earlier version of the thesis I included a section that looked at L'Arche, a faith-based organization that has provided companionship and support to people with disabilities since the 1960s. While this section did not make the final draft of the thesis, reading about L'Arche awakened many questions for me about what a faith practice brings to thinking about care. Connected to this, research that looks at the ethics of various faith communities, as a foundation for providing support for people with intellectual disabilities would be interesting, particularly given the multi-faith composition of most staff teams.

Finally, having burrowed around in the past and met my vocational predecessor, I am now interested in research that interviews contemporary support workers and invites them to reflect on and theorize their work, identity, and the relationships they have with the people they support.

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Appendix: Inventory of Data

Parent and Advocacy Groups

Source: Woodlands Parents Group
Title: Mini-Newsletters, Issues 1 - 5
Date: 1983 - 1984
Location: Community Living Society Library
Description: These newsletters were self-published by the Woodlands Parents Group, a grassroots advocacy group of parents with children in Woodlands. These newsletters were intended as parent-to-parent communication, but they were also used to educate state policy makers and advocates.

Source: Western Family-to-Family
Title: When Parents were the caregivers the shift was never over/ Snit List/ Survey
Date: no dates (estimate: circa 1988)
Location: Inclusion BC Archives
Description: Four-page document written in a conversational style from a mother to an imaginary worker

The Province of British Columbia

Source: Ministry of Social Services and Housing, Province of British Columbia
Title: Community Living /Services for the Mentally Retarded
Date: 1987
Description: The first of these two pamphlets was used by the state to educate the community about community living group homes that may open in their neighbourhood, and the second pamphlet is an introduction to services offered by the state to families with a disability.
Location: British Columbia Legislative Library

The British Columbia Government Employees Union

Source: British Columbia Government Employees Union
Title: Revised Policy Statement on De-institutionalization adopted by the Provincial Executive of the B.C. Government Employees Union
Date: 1984

Description: 14- page document that outlines the Union's position on deinstitutionalization.
Location: BCGEU Archives, Burnaby BC

Service Agencies

Source: Mission Association of Community Living
Title: Job Descriptions, Agency Mandate, Organizational Resume
Date: 1987 – 1989
Description: These document are a package of agency materials that outline services the organization offers. It is a package that may have been used in an application for funding, as it includes information about the organizational structure, as well as detailed job descriptions.
Location: Inclusion BC Archives

Source: Spectrum Society for Community Living
Title: Training Materials, various workshops
Date: 1989
Description: These documents are a collection of training notes from workshops, they are in note/point form and cover a wide variety of topics common to training sessions of the day (normalization, gentle teaching).
Location: Spectrum Society for Community Living Archives

Source: The Community Living Society
Title: Explorations
Date: 1985
Description: 35-page document that includes statements on monitoring, communication with the government, job descriptions, and agency policies. Internal publication for agency use.
Location: Community Living Society Library

Source: The Community Living Society
Title: Values Manual
Date: no date (estimate: circa 1985)
Description: partial archive, pages 16 - 25, internal publication for staff values training.
Location: Community Living Society Library

Endnotes

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[1] This phrase is the mission statement for the Community Living Society, the company that I currently work for. See http://www.communitylivingsociety.ca/

[2] Michael Kendrick, quoted from training session Burnaby BC, September 2010.

[3] The term *care* is contested amongst disability scholars and advocacy groups and, according to scholar Tom Shakespeare (2000), is problematic on several counts. Shakespeare notes that care has the connotation of sickness, frailty or infantalization. As it is an activity given to those who are dependent, Shakespeare prefers the terms *help* or *assistance,* which might be offered without the connotation of dependence. While I register Shakespeare's concern, based on my experience of *help* being a highly complex activity that runs the gamut between *care, help, advocacy, teaching* and *support,* in this proposal I use a variety of terms to describe the act of helping people with intellectual disabilities.

[4] According to researcher Cameron Crawford (2008) housing options for people with intellectual disabilities (ID), the prevalence of people with ID in various studies fluctuates from 1-3% of the general population. Using the median of 2% of the population of BC from the 1986 census this gives a figure of approximately 4955 people with ID in the province in the mid 1980s. Figures for community and institutional care reflect that 2877 people were served in publically funded residences (Ministry of Human Resources, 1988), leaving 2078 people, presumably cared for by family, with little or no state support.

[5] In his book *Mental Handicap and Community Care* (1973), Michael Bayley makes an important distinction between care in and care by the community. He suggests in the case of care in the community, like care out of the community (segregated institutions) "need not concern itself with the community from which the client is being removed" (p. 10) whereas care by the community "demands that some consideration should be given to what is meant when we use the word community" (p. 10). For the most part, care in British Columbia can be understood as care *in* the community, rather than care *by* the community.

[6] Fordist – referring to American industrialist Henry Ford. "Fordist" stands for an economic imperative of unrestricted mass production – mass consumption.

[7] The "Keysian welfare state" is short hand for an economic theory that asserts that the state bears some responsibility for the welfare of its citizens. In response to economic recession, British economist John Maynard Keynes (1883-1946) proposed that government subsidies and incentives were more productive than austerity. In this way citizens could continue to participate in the market, both as workers and consumers, and keep capital in motion. This was achieved in the 1970s through the issuing of credit in the form of credit cards, rather than subsidies to business or improvements to social programs.

[8] According to Esping-Anderson's (1989) analysis of the welfare state, the Canadian regime, a liberal welfare state, with its means-tested, minimal payment, stigmatized offerings does little to de-commodify labour, and reflects the Poor Law's of the 19th century forcing people into the market with no regard for social need.

[9] Bill 3: Public Sector Restraint Act introduced in the legislature in 1983 (British Columbia Civil Liberties Association, 1983).

[10] Contracting out is defined as "a form of privatization whereby the government maintains some form of control over service (generally through funding) but the day-to-day operation, policy-making and planning are carried out by a private agency" (British Columbia Government Employees Union, 1985, p. 40).