Bringing the Body Back:
Adults with Developmental Disabilities, Resistance, and Independence

by

Kathleen Yvonne Herzog

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Department of Sociology

University of Alberta

ABSTRACT:

In this thesis, I engage with the following research problem: how the body can practically, theoretically, and comprehensively be brought back into conversations of disability, while simultaneously acknowledging the agency (vis-à-vis independence) of individuals with disabilities as well as social factors associated with disability. To address this research problem, I interviewed Edmontonian adults with developmental disabilities who are part of the Persons with Developmental Disabilities Program (PDD), and gathered well-rounded accounts of their lives. These accounts include information about their identities, physical and social experiences within the broad context of the PDD program, as well as the meanings that independence and autonomy had for them, whether they felt this way, and why. In particular, while participants were unfamiliar with "autonomy," they were at ease with the term independence, which had unique meanings for them based on personal experiences and relationships. Additionally, I use Deleuze and Guattari's theory of the body-without-organs (BwO), or body-self, to interpret participants' accounts and ascertain one of the major insights of this thesis. Specifically, that although use of the medical model of disability (by PDD and others) seeks to pathologize and medicalize (territorialize) this study's participants, as passive and dependent on the services offered to them, participants attempted to resist this territorialization in their everyday lives through their relations with assistive designs and devices, medical procedures, family, and support staff.

KEYWORDS:

Developmental disabilities; Persons with Developmental Disabilities Program (PDD); medical model of disability; Deleuze and Guattari; body-without-organs (BwO); body-self; territorialization; agency; resistance; independence; and autonomy

PREFACE:

This thesis is an original work by Kathleen Yvonne Herzog. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name "Adults with Developmental Disabilities, Autonomy and Health Care Services", No. Pro00036963, May 6, 2013. No part of this thesis has been previously published.

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Chapter One: Introduction

The goal of this first chapter is to provide the reader with a clear sense of what to expect from this thesis. As such, I begin by introducing and positioning myself in relation to my research, which I then provide background on. Next, I pose the research problem and the central questions that need to be asked to elicit potential solutions. Of course, this explication only matters if the research in question is significant, which I assure you it is. Hence, I direct attention towards multiple reasons for why this research is important and, lastly, I offer a brief outline of the following chapters.

The researcher

To begin, it bears emphasizing that both quantitative and qualitative research is inherently and unavoidably subjective. While researchers take pains to ensure their research is completed in as rigorous a manner as possible, at the end of the day, their experiences, beliefs, values, interests, practices, and perspectives still inevitably influence their research, from the design stage to the final product. However, that researchers influence their research is not necessarily bad, especially if they are aware they do so. Indeed, there is more cause for concern when researchers believe their projects occur within a vacuum and are immune from the influence of variables beyond those explicitly specified; these researchers fail to recognize the intricate and broad web of factors that shapes their research and its outcomes.

Rather, being aware of one's presence in research – being reflexive – encourages one to take a step back, examine his or herself, and really think about how he or she has unknowingly and purposefully shaped the research. By no means though does this self-reflection need to be left until after the research is complete; ideally, it will occur throughout the research process. For instance, Maxwell uses the concept of "experiential knowledge" to refer to the components of the researcher's identity and background that he or she brings to the research (2013, p. 44), which he or she will likely be unaware of without engaging in self-reflection. While experiential knowledge has traditionally and negatively been equated with bias, especially in quantitative research, its recognition here is seen as a valuable element of research (Maxwell, 2013, p. 44). Indeed, attempts to bracket one's life from one's research have the effect of dismissing "a major source of insights, hypotheses, and validity checks" (Maxwell, 2013, p. 45).

Therefore, I endeavor to be as transparent as possible regarding my own experiences, beliefs, values, interests, practices, and perspectives that have shaped this research. In the appropriate chapters, I discuss how these factors specifically relate to the research process; however; I begin by providing background on myself.

Looking back to the fall of 2006, it was then that I began my post-secondary studies in my hometown at the University of Lethbridge (U of L) as a math major. I had enjoyed this subject in high school and it also helped that one of my friends was entering the program. However, as my first year of university came to a close, it was more than apparent that this was a very challenging major. Despite having been A+ students, the lives of my friend and I were consumed with math homework that reaped little reward, while students in other programs appeared to be enjoying one pub crawl after another while still pulling good grades. My determination to succeed in math did not waver however until I took my first course in sociology. Yes, Dr. Tom Perks was to blame – for his energy, enthusiasm, and love of the field were utterly contagious. In the fall of 2007, I became a sociology major hoping this would be a valuable and exciting way to learn skills that would allow me to truly make a difference in people's lives.

A year later, I decided to take a semester off to travel to Europe, where I was able to further broaden my social and cultural awareness and cement what will likely be a lifelong need to travel. Before leaving for this trip, I temporarily resigned from my job at the L.A. Gallery (a local custom framing and art studio), where I had worked since I was 15. Despite enjoying and being very successful during my years there, upon returning from Europe with an entrenched love of sociology, the time had come to pursue a position in the field of social welfare. I began to search for such a job, of which the opportunities for given the size and conservative nature of Lethbridge were few and far between. Nonetheless, I was hired as a rehabilitation[1] worker at an agency that provides community access services for individuals with disabilities.[2] Perhaps this was a natural fit as my mother worked with individuals with disabilities for over 20 years. And yet, as this was the first time I worked directly with members of this group, it was certainly a new experience.

In January 2009, I returned to the University, where I finished my studies two years later. Throughout this time and now, passion and determination were crucial to maintaining a high grade point average while volunteering and working. During these two years, I had the sincere privilege of working with one man in particular, whom I will refer to as Ralph and who came to be like a grandfather to me. Ralph and I spent time together a couple afternoons a week and on alternating weekends. He was exceptionally independent and my role in his life was primarily one of friendship, as he otherwise only required transportation to and from his usual haunts and, like many of us, motivation to clean his apartment. Ralph was a gifted storyteller and prolific smoker; he was the type of man who would advise me not to come into work if there was too much snow, for doing so might risk my safety.

If this is starting to sound like a eulogy, that is because, in some ways, it is. Having battled many hardships – child abuse, drug addictions, his son's suicide,

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[1] While rehabilitation is a seemingly neutral term, it becomes value laden when used alongside disability (see Rioux and Daly, 2006).

[2] I use the terminology "individuals with disabilities" throughout this thesis. Although there is lack of consensus on the most appropriate language, this expression has traditionally been invoked to respect the personhood of these individuals and reinforce that they are people first (Zola in Strohschein and Weitz, 2014, p. 183).

separation from his family, and incomprehensible pain – Ralph ultimately took his own life. This thesis is perhaps the one good thing to come of this, for it is inspired in many ways by Ralph and his enduring strength of character.

Prior to his passing, and after graduating, I was promoted to the position of program coordinator within the same agency, which involved supervising a community access program for adults with developmental disabilities. Whereas before I had worked directly with one individual, Ralph, I was now responsible for overseeing the services received by upwards of 20 individuals and the staff who provided these services. This opportunity offered me a greater understanding of the lived experiences of individuals with disabilities, and allowed me to expand skills, such as critical thinking and problem solving, which I knew would assist me in a master's program.

I continued to work in this position until July 2012, by which time I had accepted an offer of admission to the master's program at the University of Alberta in the Department of Sociology. At the suggestion of another beloved U of L professor (Dr. William Ramp), in my research prospectus, I had consciously merged for the first time my recent work experience with what had been, up until that point, my most significant research interests: the spatial, theoretical, and social aspects of consumerism and consumption. Although doing so had merely seemed like a way to strengthen my application, it gradually contributed to the preeminence of disability studies among my research interests, while consumption and consumerism took a back seat, for the time being.

My time at the University of Alberta began with a year of coursework and employment as a research assistant at the City-Region Studies Centre, where I continue to be involved in a project titled Nanotechnology and the Community. While nanotechnology is not one of my primary interests, implementing this research allowed me to work closely with one of my supervisors (Dr. Rob Shields), and extend my skills in several areas: developing partnerships and engagement activities and materials, coordinating events, and collecting and analyzing qualitative research data. For instance, it was here that I learned to use NVivo software which, in reading “Chapter Three: Methodology,” you will see was an instrumental if not somewhat misguided part of the data analysis for this project. In January 2014, I became a teaching assistant for an undergraduate sociology of health and illness course, which was taught by my other supervisor (Dr. Lisa Strohschein) and more closely matched my own research interests. Indeed, I had taken Dr. Strohschein’s graduate course with the same name in the fall of 2012.

Lastly, whether researchers are or are not part of the groups they study has been referred to as insider or outsider status, respectively. Because I am not considered part of a group of individuals with disabilities (at least conventionally), I am an outsider, and do not have first-hand experience with many of the situations individuals with disabilities encounter.

It is with this context in mind that the reader should proceed, although I take care to elucidate further connections between myself and my research where pertinent.

Research background

As I have alluded, this research involves individuals with disabilities. In choosing to study this group, I propose that the experiences of its members are unique from those of their non-disabled counterparts and that, in their own right, they are of interest and worthy of scholarly attention. Indeed, as I demonstrate, many academics have been actively engaged in this area. However, that individuals with disabilities are “research subjects” does not necessarily mean scholars are or should be voyeurs uncovering certain universal truths about these individuals, if such truths even exist. Rather, this research is guided by the belief that one must learn as much as possible about a topic directly from its source. Although we may never know exactly how it feels to walk in another’s shoes, we can attempt to understand by asking about and listening to others’ stories of their experiences.

Thus, my initial interest and intent in conducting this research was to hear and write about how individuals with disabilities experienced autonomy, when accessing and receiving health care services. However, like the majority of research, my project has evolved since its inception over a year ago, and there are two main reasons for this: first, upon interviewing individuals with disabilities, it quickly became apparent they were not familiar with the concept of autonomy, despite the existence of literature on its relevance for these individuals.[3] When this lack of familiarity became known within the interviews, participants were offered the definition of autonomy put forward by Wehmeyer,[4] who is arguably the chief proponent of the importance of this concept for individuals with disabilities. However, despite the provision of this definition, participants seemed either complacent or confused about the role of this concept in their lives. Admittedly, some of this misunderstanding may have been my fault; I could have had examples of autonomous behaviour on hand to offer participants or further encouraged these conversations. Nonetheless, participants were familiar with a component of this definition – independence.

This awareness was not entirely surprising to me given my work experience, where many individuals were mindful of the importance of independence. Indeed, in this agency's mission statement alone, the term independence was used twice alongside synonyms such as "choice" and "control." An additional but related goal was to ensure the individuals we serviced were seen as productive and contributing members of society – as "normal." Thus, individuals were

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[3] Indeed, many authors address the significance of autonomy for individuals with disabilities, including, but not limited to, Calkins et al., 2011; Childress, 1982; Childress, 1990; Childress et al., 2002; Ells, 2001; Field et al., 1998; Lachapelle et al., 2005; Leece and Leece, 2011; Leece and Peace, 2010; Manning and Gaul, 1997; Nonnemacher and Bambara, 2011; Palmer and Wehmeyer, 1998; Reindal, 1999; Shogren and Broussard, 2011; Sims and Gulyurtl, 2013; Wehmeyer, 1998; Wehmeyer, 1999; Wehmeyer, 2004; Wehmeyer, 2005; Wehmeyer, Bersani, and Gagne, 2000; Wehmeyer and Bolding, 1999; Wehmeyer and Metzler, 1995; Wehmeyer and Mithaug, 2006; Wehmeyer and Palmer, 2003; Wehmeyer and Schwartz, 1997; Wehmeyer and Schwartz, 1998; Wehmeyer, Kelchner, and Richards, 1996; and Wullink et al., 2009.

[4] For Wehmeyer, autonomy is defined as occurring when the actions of an individual correspond with "his or her own preferences, interests, and/or abilities" and are independent – "free from undue external influence or interference" (1996, p. 25; Wehmeyer, Kelchner, and Richards, 1996, p. 632).

encouraged to do as much for themselves as possible, and attempts were made to either maintain or increase their independence. While I consider myself fortunate enough to have worked at an agency that strived to value each individual's interests and goals, the ultimate goals of independence, rehabilitation, and normalization were questioned rarely, if ever. It was unthinkable that being an individual with a disability and the experiences that entails might be life-affirming pursuits in themselves.

This failure to question and desire to maintain the status quo is not agency specific and results in part from dictates made by the Alberta Government. Indeed, in this province, conversations about adults with developmental disabilities are incomplete without knowledge of their main government funding body: the Persons with Developmental Disabilities Program, also known as PDD. For the majority of adults with developmental disabilities, access to this funding is crucial as it allows them to receive otherwise expensive services from community disability agencies free of charge. More specifically, unless receiving PDD funded Family Managed Services, PDD provides disability agencies with the necessary monies to offer services to approved individuals with developmental disabilities, so that these individuals do not have to pay for this assistance themselves. In this sense, the disability agencies act as intermediaries between PDD and adults with developmental disabilities. Should an individual not be approved, it is likely his or her only recourse will be to privately pay for services.

Further shaping this experience is that both adults with developmental disabilities and disability agencies must meet certain criteria to be approved for funding. In this way, PDD defines what a suitable developmental disability is for the province to support. Specifically, PDD uses the following measures to determine whether adults are eligible for funding:

1. The individual must have a ‘significant limitation in intellectual capacity.’ This means an IQ score of 70 or below.
2. The individual must have a ‘significant limitation in adaptive skills.’ This means the individual needs help with daily living activities like making food. PDD measures this by checking whether the person needs help with six or more out of 24 typical skills.
3. The individual must have had both of these two limitations before he or she turned 18 (Alberta Human Services a, 2014).

While individuals themselves must meet these criteria, as mentioned, PDD also has measures for the disability agencies that service these individuals and which, thereby, are the ultimate recipients of funding. For our purposes, most important among these measures is that disability agencies, as subsidiaries of PDD, must comply with the following mission statement: “[t]he PDD program works with others to support adults with developmental disabilities to be included in community life and to be as *independent* as possible” (Alberta Human Services b, 2014; emphasis added). While the focus here is on developmental disabilities, those with other disabilities and the agencies that service them are also subject to these types of regulations.

Additionally, the funding of many social service providers has become tied to evidence or outcomes based practices. That is, social service providers may lose funding if they cannot generate specific evidence or outcomes that support the efficacy of their practices. While these conditions make an agency more accountable, which has pros and cons, in the case of PDD, these conditions have the added effect of ensuring agencies encourage the ideal of independence among adults with developmental disabilities. That is, because disability service providers must demonstrate implementation of PDD’s mission statement to prove they are effective, they must be seen as endorsing independence.[5] However, it is problematic to assume that what independence means to one person, or government funding body, is the same as what independence means to another, such as a disability agency or an individual with a disability. Thus, this is a complicated issue to which I return and which leads me to suggest, throughout this thesis, that there is a need to examine the notions and experiences of independence belonging to individuals with disabilities themselves.

Returning to how this project has evolved, I alluded to this research focusing on experiences within health care services, and, although this is still the case, some of the ways in which it does so are more subtle than I initially envisioned. Indeed, this thesis became more sophisticated when, largely due to encouragement from one of my supervisors (Dr. Lisa Strohschein), I broadened my focus to account for a long-standing argument across disability studies, the sociology of health and illness, the sociology of the body, and the lesser known but emerging sociology of disability. That is, across these fields, there appears to be agreement about the need to "bring the body back in" to conversations of disability, but lack of consensus about what exactly this means and how it should be done. However, among other things, consideration of this well-established argument allows us to see how the medical establishment is rhetorically and otherwise present in individuals' everyday experiences (for example, through the criteria PDD uses to define developmental disabilities).

Those unfamiliar with disability scholarship may be inclined to suppose the body would be a necessary starting point for engagement with this subject. Indeed, we often judge whether others have or do not have disabilities solely on the appearance of their bodies, and the general public continues to think of disability largely in terms of what bodies can and cannot do (i.e. their functional limitations). However, while historical, lay, and medical understandings of

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[5] Conversely, "because agencies receive funding based on how many clients they serve, agencies sometimes unintentionally encourage individuals to remain dependent on their services" (Strohschein and Weitz, 2014, p. 191).

disability have drawn on the body, over the past few decades within disability studies, a social model of disability was actively used to supplant these biological views, by shifting focus away from the body to the social roots of disability. This shift in understanding has been widely embraced and highly successful in facilitating many political gains for individuals with disabilities, but, like preceding views, unfortunately has also had negative consequences (although it is unlikely these have been as grave, considering that biological views gave rise to institutionalization and eugenics) (see Harris-Zsovan, 2010 for a history of eugenics within Alberta). Thus, to provide background for the current research, here, I briefly examine the biological or medical model of the "disabled body," its replacement by the social model of disability, and contemporary calls for the re-integration of the body within accounts of disability.

To begin, as per the medical model, disability exists within the affected individual's body. Ostensibly, once identified, disability can be managed on a case by case basis through biomedical treatments and rehabilitation – techniques that respectively form the basis of the two primary approaches within the medical model. Therefore, much like disease, disability is treated as pathology and becomes the terrain of doctors and other professionals (Rioux and Daly, 2006, p. 306). Subsequently, the medical model is both *individualizing* and *depoliticizing*. That is, this model focuses exclusively on the affected individual's body without consideration of macro-level, social factors. While the medical model supports an outdated view of disability, its use continues to have important real-life consequences.

The social model of disability, then, needs to be understood as a reaction by individuals with disabilities and disability rights activists to the limitations and critiques of the medical model (Barnes and Mercer, 2010, p. 29), which include, but are not limited to, biological determinism[6] and the medicalization of disability. Therefore, in contrast to the medical model, explanations of disability within the social model are not medicalized, and instead locate disability within social contexts, particularly of an environmental or human rights nature. According to this model, while some individuals with disabilities experience illness, neither this nor other biological factors constitute disability – structural factors do (Rioux and Daly, 2006, p. 306). Therefore, unlike the determinism found in the medical model, proponents of the social model do not believe disability is caused by factors within individuals' bodies but by societal conditions (Hughes and Paterson, 1997, p. 328; Rioux and Daly, 2006, p. 308). However, this belief ironically reflects another form of determinism, albeit one social in nature.

One way the social model succeeded in distancing itself from the medical model is by distinguishing between "impairment" and "disability," where the former refers to individual bodies and their specific physical conditions and the latter to social situations resulting from those conditions.[7] Whereas the medical model can then be seen as focusing exclusively on impairment, the social model wholly favors disability and is thereby *de-individualizing* but *politicizing*. Indeed, this model has brought issues of citizenship and politics to the forefront of disability debates (Albrecht, 1992; Hughes and Paterson, 1997, p. 325), with interventions focusing on ending discrimination and segregation as well as increasing autonomy and positive views of disability (Shakespeare, 1993, p. 249). I elaborate on this important distinction between impairment and disability shortly.

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[6] When biological determinism occurs, bodies and their actions are merely chalked up to physical structures (Fox, 2012, p. 25). As a result, the ability of bodies to change in response to circumstances is ignored, as is how social factors affect experiences (Fox, 2012, p. 25 and 27).

[7] More specifically, impairment has traditionally been defined "as lacking part or all of a limb, or having a defective limb, organism or mechanism of the body," whereas disability has been defined as "the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities" (UPIAS in Oliver, 1996, p. 22).

For now, however, despite the achievements and virtues of the social model, it contains several shortcomings that need to be addressed. Scholars began to direct attention towards these limitations in the 1990s, by arguing that progress for disability rights was neither consistent nor keeping pace with the needs and ambitions of individuals with disabilities (Strohschein and Weitz, 2014, p. 180). This model's first limitation then is that a focus on human rights at the macro-level ignores the variances that exist among individuals with disabilities, in favour of a generalizing and essentialist view. While individuals with disabilities likely want the same basic rights, after this, the objectives and experiences of these individuals differ widely. Furthermore, although it is safe to say that most individuals with disabilities confront the same basic barriers, such as discrimination and exclusion, additional barriers are encountered based on individual circumstances. Indeed, as was seen among feminists, strong differences exist based on class, ethnicity, age, and, in the case of individuals with disabilities, gender and disability type (Thomas and Corker, 2002, p. 24). Thus, the social model provides a "big picture" account that is unable to explain variations in experiences of disability – that is, that not all individuals experience disability in the same way.

Secondly, because the notion of impairment is absent (in contradistinction with the medical model), the social model fails to acknowledge the importance of individuals' bodies in relation to the social elements of disability (Thomas and Corker, 2002; Strohschein and Weitz, 2014, p. 181). More precisely, the social model does not allow for the interdependence of physical and social factors due to the distinction between impairment and disability, which "replicates a division between the biological and social domains" (Barnes and Mercer, 2010, p. 30). Consequently, for Oliver, who is arguably the founder of the social model, "'disablement has *nothing* to do with the body;'" accordingly, use of the "'social model is not an attempt to deal with the personal restrictions of impairment but the social barriers of disability'" (in Barnes and Mercer, 2010, p. 30; emphasis added). Thus, although the tenets of the social model encourage individuals with disabilities to address social barriers, they are simultaneously prevented from voicing their bodily experiences, thereby causing an awkward tension (Strohschein and Weitz, 2014, p. 181). While it is now increasingly recognized that the body is the stage on which the experience of disability plays out, the social model in part abandoned the body for fear that discussion of biology, pain, and other deeply individual experiences would be used to recast disability as nothing more than physical limitations (Shakespeare in Hughes and Paterson, 1997, p. 328). Nonetheless, because the social model is unable to reconcile individual experiences with social factors, it has limited use for understanding experiences of disability, particularly as these relate to the body.

Thus, within previous sociological accounts of disability, bodily difficulties have been understated (Kelly and Field, 1996, p. 247). By failing to consider impairment, proponents of the social model have let it remain within the medical sphere, and thereby rely on medical discourse to understand the body (Hughes and Paterson, 1997, p. 326). Therefore, the "disabled body" is merely viewed as a faulty machine to be serviced by doctors and therapists and is utterly lacking in agency (Hughes and Paterson, 1997). Moreover, individuals with disabilities become dependent, disembodied subjects whose bodies do not have histories, feelings, or meanings (Hughes and Paterson, 1997).

However, since the 1980s, the general significance of the body has been underscored for a variety of reasons (Malacrida and Low, 2008, p. 9; Shilling, 2012, p. 32). In particular, the body has received attention due to "the rise of 'second wave' feminism, demographic changes that have focused attention on the needs of the elderly in Western societies," and the "'crisis' in our certainty about what bodies are" (Malacrida and Low, 2008, p. 9). The rise of the body can also be attributed to the emergence of alternative lifestyles and environmental concerns in the 1960s, increases in consumer consumption around the same time, and Western responses "to physical manifestations of Muslim identities such as the wearing of the hijab" (Shilling, 2012, p. 37-43). In relation to disability, scholars working within the sociology of the body have examined, among other things, bodily experiences of the eugenics movement and institutionalization (Malacrida, 2008), the reproductive rights of individuals with disabilities (Kent, 2008), and how gender influences the disadvantages associated with disability (Gerschick and Miller, 2008; Zitzelsberger, 2008). Thus, the physicality of the body and impairment are rightfully re-emerging as subjects for debate within the disability movement (Hughes and Paterson, 1997, p. 325-6), generating a need to construct a proper sociology of disability that addresses these topics.

While I return to this subject in the literature review, for now, suffice it to say that those studying disability from an academic standpoint increasingly recognize the necessity of creating a distinct sociology of disability, with a unified, core body of knowledge from which to draw and which addresses the physicality of the body and impairment alongside social factors. Certainly, the imperative to engage in such an endeavor has become clear to me throughout the course of this thesis. Although there are scholars making similar arguments about disability across disability studies, the sociology of health and illness, and the sociology of the body, there are also marked ontological and epistemological differences across and within these fields. These differences have resulted in entrenched debates about the nature of disability, as well as lack of consensus around many everyday disability issues, making it difficult to envision ways to move forward both academically and practically. However, developing a sociology of disability involves attempts to overcome these stalemates, and there seems to be some agreement that central to this effort is a need to bring the body back in (namely, impairment) while maintaining a focus on social context.

Research problem

Thus, my focus on disability, independence, and the body speaks to a central problem that is the subject of this research:

How the body can practically, theoretically, and comprehensively be brought
back into conversations of disability, while simultaneously acknowledging
the agency (vis-à-vis independence) of individuals with disabilities
as well as social factors associated with disability.

In the context of this study, such a focus on agency and independence involves efforts to understand how adults with developmental disabilities themselves view independence. This understanding is important because, as illuminated by my brief review of disability services, the public rhetoric of independence is entrenched and pervasive. Consequently, disability service providers may assume that all individuals inherently want or need to be independent, and that this notion means the same thing for everyone. Moreover, this term is used so often that its value and even what it means are not questioned – it becomes, in effect, an empty buzzword that sounds good in a mission statement. However, the situation becomes worse when its value for and meaning in someone else’s life are assumed.

To address this research problem, I gathered well-rounded, first-hand accounts of the lives of Edmontonian adults with developmental disabilities. These accounts include information about their identities, physical and social experiences within the broad context of the PDD program, as well as the meanings that independence and autonomy had for them, whether they felt this way, and why. The participants in this study were adults with developmental disabilities, as defined by PDD, who were their own guardians. Being one’s own guardian implies one is “high functioning,” for lack of better words, able to engage in conversation, and reflect on his or her experiences and independence, as well as meanings of the latter. While I discuss these considerations further in the methodology chapter, that participants’ were their own guardians also alleviates some ethical concerns associated with conducting research with individuals with disabilities, who are typically deemed a vulnerable population (Irvine, 2010, p. 24).

Research questions

In this study, I employ several research questions to determine how the body can practically, theoretically, and comprehensively be brought back into conversations of disability, while simultaneously acknowledging the agency (vis-à-vis independence) of individuals with disabilities as well as social factors associated with disability. As previously mentioned, in the context of this study, such a focus on agency and independence involves efforts to understand how adults with developmental disabilities themselves view independence. Thus, the research questions include the following:

1) How do Edmontonian adults in the PDD program describe and interpret a variety of their life experiences?

2) What do autonomy and independence mean to Edmontonian adults in the PDD program? Do they feel they meet their own definitions of these constructs, and why do they feel this way?

3) How do Edmontonian adults in the PDD program react when they perceive their experiences as limiting?

Significance of study

Additionally, while we can ask interesting questions about any phenomenon in the world, these questions and their answers vary in significance. However, this research contributes to a variety of positive outcomes, which I have listed in no particular order:

1) This thesis and the interviews provide(d) a forum for adults with developmental disabilities to share their experiences, stories, opinions, and suggestions, which does not happen nearly enough. By valuing these perspectives, this study seeks to challenge the perception that because individuals with disabilities are marginalized, their knowledge of

disability is "'defective,' not usually worthy, credible or useful" (Michalko in Hansen and Janz, 2009, p. 31);

2) The findings contribute to a sociology of disability and supplement this vital yet understudied area. In addition to striving to provide a basis for such a sociology (by bringing the body back in), this research speaks to the experiences of individuals with developmental disabilities, who figure much less frequently in research than individuals with physical disabilities (Ward, Nichols, and Freedman, 2010, p. 280);

3) The findings have practical implications for a variety of groups including, but not limited to, individuals with disabilities and their guardians, families, support staff, and friends; disability service providers; government funding bodies; advocates of the Disability Rights Movement, and health care professionals;

4) By examining a variety of life experiences, this study seeks to situate disability within a broad context and treat it holistically, rather than simply as a medical condition;

5) And, last but not least, this thesis provides a template for future projects that seek to give voice to those who are traditionally silenced – especially individuals with disabilities.

Thesis outline

By now, the reader should have a basic understanding of the nature of this study. In the next chapter, the literature review, I seek to expand this understanding by presenting arguments for the creation of a sociology of disability, as well as models of the body that could provide the basis for such a sociology. Specifically, I assess what are arguably the most common models of the body – those within phenomenology and social constructionism, which, for the purposes of our review, includes symbolic interactionism, post-structuralism, and post-modernism – as well as Shilling's corporeal realist model and Deleuze and Guattari's body-without-organs (BwO) or body-self,[8] as explicated by Fox.

In Chapter Three, I discuss the exploratory project in which the first interview was conducted, as well as the methodology that informs this qualitative research. Woven throughout this chapter are the ethical considerations and practices employed to establish trust and ensure rigor, among other things, and many of which are specific to individuals with disabilities. While this research does not particularly conform to any one of the main five qualitative research strategies, approaches, or frameworks, it more importantly builds on the theoretical perspective developed in the second chapter – namely, that of Deleuze and Guattari. Specifically, the coding and analysis of my research data reflects the guidelines of Fox and Ward, who are cognizant of respecting "the fundamental ontology of Deleuze and Guattari's approach" (2008, p. 1012). While Fox and Ward use their framework to "empirically gather and analyse health identity data" (2008, p. 1012), I use it to make meaning and extend the value of coding I had already done. Accordingly, the concepts of "body-self" and "territorialization"[9] emerged during analysis as powerful ways of making sense of the interviews and the life experiences that participants spoke of.

Located in Chapter Four are participants' accounts of how they experienced aspects of their lives within the context of the PDD program and, in particular, the ways they felt they were presented with both opportunities and obstacles. After introducing the participants by providing brief biographies on them, I examine

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[8] Although described in detail in the following chapter, the body-self can briefly be defined as embodied subjectivity or the "body-without-organs (BwO)" (Fox, 2002, p. 347). The BwO is distinct from biomedical or natural views of the body that give rise to the "body-*with*-organs," which is also known as the "organism" (Deleuze and Guattari in Fox, 2012, p. 66; emphasis added).

[9] Although described in detail in the following chapter, the BwO can be viewed as a dynamic space in which varying levels of power are exerted – influencing the body to varying degrees and bringing into being and affecting the nature of this space as a configured and mappable territory; this process of configuration is territorialization.

how they interpreted their physical experiences, with assistive designs and devices and medical procedures, as providing opportunities and constraints. I then consider participants' accounts of their social experiences with family and support staff, and the possibilities and limitations they felt these provided. Lastly, I consider the meanings that independence and autonomy had for participants, whether they felt this way, and why.

Lastly, in Chapter Five, I use a sociology of the body approach to further render participants' accounts meaningful, in relation to each other and the literature. Specifically, I address the issue of whether and how participants' accounts reflect territorialization of the body-self and allow possibilities for them to resist (de-territorialization and alternative territorializations). Throughout this discussion, I emphasize the importance of taking the body seriously – explaining how the need to do so becomes further apparent when interviewing people with developmental disabilities – and situate the current study within existing research, including that on independence and autonomy. Accordingly, I then consider this study's limitations and areas for further research.

I sincerely hope that the reader will gain insight from this recap of my evolving quest over the past year to better understand how the body can practically, theoretically, and comprehensively be brought back into conversations of disability, while simultaneously acknowledging the agency and independence of individuals with disabilities, as well as social factors.

Chapter Two: Literature Review

Taking up the argument begun in the last chapter, there appears to be agreement among scholars working across the diverse fields of disability studies, the sociology of health and illness, and the sociology of the body that physicality needs to be reintroduced to conversations of disability. For too long, use of the social model of disability has relegated body matters to the back burner. And yet, partly because there are marked ontological and epistemological differences across and within these fields, questions remain about just how the body should theoretically be brought back in, without neglecting the agency and independence of individuals with disabilities or social factors associated with disability. Indeed, the differences across and within these fields have resulted in entrenched debates about the nature of disability, as well as lack of consensus around many everyday disability issues, making it difficult to envision ways to move forward both academically and practically.

Consequently, those studying disability from an academic standpoint increasingly recognize the need to create a distinct sociology of disability, with a unified, core body of knowledge that transcends these stalemates. Although the purpose of this thesis is not to advance a comprehensive sociology of disability, I do seek to contribute to the progress made by other scholars, such as Thomas, in this endeavor. Certainly, the creation of a sociology of disability must respond to calls to reintroduce physicality – the accomplishment of which, I contend, depends on viewing the body in a particular way; that is, on moving towards a dynamic model of the body. It is no longer a question of *if* the body should be brought back in, but of *how*; indeed, for Williams, as responsible, biologically-vulnerable human beings, we are all implicated in this exercise – the stakes of which are high and are neglected at our peril (2006, p. 23-4). Therefore, throughout this thesis, I attempt to illustrate how the body can be brought back in by providing a model of the body that is capable of exercising agency and independence, and which can illuminate the accounts of a small group of Edmontonian adults with developmental disabilities. It is my hope this model of the body will provide a useful basis for the advancement of a sociology of disability.

Thus, this chapter begins with a brief overview of arguments for developing a sociology of disability, which is followed by a thorough engagement with existing models of the body. Such engagement entails critically examining these models for their ability to provide insight into agency, independence, and the physical aspects of disability, without neglecting social context. Given the breadth of work across disability studies, the sociology of health and illness, and the sociology of the body, many models of the body exist that speak more or less successfully to disability, including Deleuze and Guattari's "body-without-organs" as explicated by Fox (2012). Because this model of the body accommodates impairment and disability, agency and independence, and social factors, I conclude this is the model best poised to facilitate a well-rounded understanding of a body capable of exercising agency and independence, especially when later applied to participants' accounts.

Arguments for a sociology of disability

To begin, because the role of impairment is entirely missing from the social model, its use fails to acknowledge the importance of physicality in constituting disability, as well as how disability impacts back upon the body. Due to this oversight, and although termed a "sociology of impairment," the need for a sociology of disability was debatably first articulated by Hughes and Paterson already nearly twenty years ago (1997), and their arguments have become well established if not entirely taken up. Hughes and Paterson problematize the social model's division of impairment (body) and disability (culture), which is founded on the Cartesian separation of body and mind (1997, p. 329). They advocate that physiology and anatomy alone do not create impairment but that "it emerges only at the intersection of bodies, minds and cultures" (Hughes and Paterson, 1997, p. 329). Likewise, the same could be said of disability, in that it is not comprised of social factors alone but also of that which is biological. Hence, central to their case is that the concepts of disability and impairment need to be realigned to further the identity politics of the disability movement (1997, p. 325).

Just five years later, by dialogically engaging with each other's theoretical position, the feminists Thomas and Corker made similar arguments to those of Hughes and Paterson. Despite coming from the different backgrounds of Marxism and post-structuralism, respectively, Thomas and Corker agree that the social model both fails and needs to take impairment and the body into account when theorizing disability (2002). Thus, they seek to locate the physicality of impairment within broader conceptions of disability, and the rationale for this pursuit contains three key arguments (2002).

First, impairment and disability vary and are culturally and historically contingent social phenomena; moreover, impairment and the body are active entities intertwined with the social (i.e. disability) (Thomas and Corker, 2002, p. 19 and 23). Indeed, disability can be seen as partly socially determined because conceptions of it are fluid and have changed over time. For example, many languages still reflect the view that left-handedness was once traditionally and cross-culturally considered a disability (Brym, Roberts, Strohschein, and Lie, 2015). However, left-handedness is certainly not construed as a disability anymore, at least in North America. Numerous other examples of the changing nature of "disability" can be found upon reviewing the different editions of the American Psychiatric Association's *Diagnostic and Statistical Manual* (DSM).

Thomas and Corker's second argument for bringing the body back in is that disability theorists "*have* to engage with impairment in order to get on with the main task – theorizing and exposing disability, and thus clarifying the political terrain for challenging disablism" (2002, p. 24). In particular, Thomas suggests disability theorists should strive to acknowledge and understand how impairment and its effects are personally experienced, by exploring impairment "as a biosocial phenomenon" and analyzing how each type of impairment is uniquely experienced (in Thomas and Corker, 2002, p. 24). Analysis of the experience of each type of impairment is especially relevant because no two impairments are experienced the same way - even the same impairment is experienced differently by different people. Indeed, though the participants in my research are all classified as having developmental disabilities, their individual experiences are unique.

Lastly, Thomas and Corker argue that in order for physicality to be reintroduced to conversations of disability, we must first do away with the Cartesian dualisms "of mind/body, individual/society and structure/culture" (Thomas and Corker, 2002, p. 29).[10] While there is concern that applying certain theoretical strands, such as social constructionism, to disability issues will foster incomprehensible academic conversations (Corker and Shakespeare, 2002, p. 14; Strohschein and Weitz, 2014, p. 182-3), research guided by theoretical frameworks is necessary for the development of emancipatory projects and, consequently, inclusive societies (Strohschein and Weitz, 2014, p. 183). Until there is engagement with and general consensus on how to incorporate impairment and the body into disability theory, we will continue to be bogged down in the same debates we have been since the 1990s, meanwhile detracting effort from the amount of positive, practical change that could be affected in the lives of people with disabilities.

Echoing these arguments, Thomas recently re-articulated the desire to create a sociology of disability within mainstream sociology (2012a, p. 210). She envisions this new sub-discipline as "a variant of *equality and diversity studies*," with the academic treatment of disability being similar to that of "gender, 'race', sexuality, age and social class" (Thomas, 2012a, p. 210). Additionally, Thomas would like to see a primary focus on disablism and a secondary engagement with "impairment effects:"

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[10] See page 26-7 for why these dualisms are theoretically and methodologically problematic.

> the *direct and unavoidable* impacts that ‘impairments’ (physical, sensory, intellectual, emotional) have on individuals’ embodied functioning in the social world. Impairments and impairment effects are always bio-social and culturally constructed in character, and may occur at any stage in the life course (2012a, p. 209 and 211).

While these concepts are familiar to those working within disability studies, they are not yet part of the sociological canon (Thomas, 2012a, p. 211). Thus, it is Thomas’ hope that when disability is no longer just a small part of the domain of the sociology of health and illness, it will come to be viewed as a primary factor in global social differences and injustice (2012a, p. 209).

While there is a “far away, down the road” quality to Thomas’ writing, calls such as hers for a sociology of disability can find opportune footing where the sociology of health and illness, disability studies, and the sociology of the body intersect. Indeed, these fields all take a stance on impairment in some way or another. Additionally, interdisciplinary engagement already occurs, for instance, around the new norm of dying slowly rather than quickly, at least in the Western world, which results in part from increased longevity alongside the presence of degenerative and chronic diseases (Scambler and Scambler, 2010, p. 1) and is considered the outcome of the “epidemiological transition” (Strohschein and Weitz, 2014, p. 21). Moreover, as I have argued, for impairment to be part of the sociology of disability, scholars need to be able to draw from a model of the body that takes account of agency, independence, and social factors. Because the sociology of the body has engaged with physicality for quite some time, it makes sense to consider whether this field contains an adequate model of the body that could be used as a starting point for a sociology of disability.

Thus, to further the arguments I have outlined for a sociology of disability based on a working model of the body, I now turn to the sociology of the body in hopes of finding such a model that accommodates impairment, disability, agency, independence, and social factors.

Choosing among models of the body

If the sociology of disability is to be comprehensive – a worthwhile aim – it follows that the model of the body from which its proponents draw should also be all-inclusive and able to capture diversity. That is, for reasons already detailed, it is crucial that use of this model allows physicality (especially impairment), disability, agency, and independence to be taken into account alongside social factors. However, in the quest to find such a model, one encounters many possibilities even within the sociology of the body, including, but not limited to, those found within social constructionism, which, for the purposes of our review, includes symbolic interactionism, post-structuralism, and post-modernism. Additionally, many models of the body exist within phenomenology or the sociology of embodiment, theories of structuration, actor-network theory, feminism, and critical realism.

Yet, as we will see, critical examination of the body models within these areas reveals that while each contains useful components for understanding aspects of the body, each is also limited in that it is not able to facilitate a comprehensive understanding of the body. Shilling also recognizes this limitation, contending that each model offers important insights but regarding divergent aspects of embodiment (2012, p. 248). For instance, and just to point out a few of these insights, while those using social constructionist models view the body as a structural-transmission site, proponents of structuration theories maintain the body is an active environmental architect (Shilling, 2012, p. 248), and those working within science and technology studies may simultaneously view it as a "surface, vehicle, and circuit" (Crawford, 2013, p. 434). Thus, due to the sheer volume and variety of body models, one may be left wondering about possible courses of action, especially when seeking to make use of a theory in conjunction with research data; indeed, I was confronted with this uncertainty, asking myself whether I needed to pick one model or could draw on the characteristics of several.

Thankfully, Shilling echoes these challenges and offers four ways to navigate this terrain of body models (2012, p. 248). However, because I choose to focus on the two ways to move forward I find most viable (Shilling's first and fourth options), here, I just briefly mention the two other ways. Shilling's second route involves generating an entirely new model of the body, having discarded previous attempts, while the third option entails recognizing that the elusive nature of the body is best met with a variety of models that highlight its different aspects (2012, p. 248-9). Although hypothetically feasible, travelling down either of these routes could undermine existing advances and the established character of body studies, as well as perpetuate the potential unruliness of this field of knowledge (2012, p. 249-50).

Option one: choose the best model

The first way to move forward that I seriously consider is choosing one model of the body, deeming it to be the ideal approach and rejecting the others (Shilling, 2012, p. 248). Thus, in this subsection, I respectively assess what are arguably the most common models of the body – those within phenomenology and social constructionism (the latter of which, as previously mentioned, here includes symbolic interactionist, post-structuralist, and post-modernist approaches).

Phenomenology is based on the investigation of consciousness and experience. Therefore, phenomenologists attempt to understand phenomenon in their totality, instead of within the narrow confines of Cartesian dualisms (Iwakuma, 2002, p. 76). Writing in the '60s and using the notion of embodiment, which highlights connectivity and nuance, the esteemed phenomenologist Merleau-Ponty demonstrated that dualistic, "either-or" standpoints cannot suitably illuminate the nature of human existence (Iwakuma, 2002, p. 77-8). Indeed, for Merleau-Ponty, the body was more complex and comprised of a group of meanings through which one lived; instead of *having* bodies, we *are* our bodies (in Iwakuma, 2002, p. 78 and 85). More recently in the '80s, post-modernists expanded this argument to critique all Cartesian dualisms, such "as nature/culture, subject/object, substance/extended substance and body/soul" (Iwakuma, 2002, p. 76). As we will see, whereas use of social constructionist models tends to result in a view of the body as an object (due to their concern with what it means to *have* a body), use of phenomenological models entails viewing the body as a subject (i.e. one *is* a body) (Hughes and Paterson, 1997, p. 335; Fox, 2012, p. 49).

Hence, theories of impairment within phenomenology begin with the supposition that the body is a subject open to experience, capable of exercising agency, and "a site of meaning and source of knowledge about the world" (Hughes and Paterson, 1997, p. 334). The world is not merely experienced *through* the impaired body; the impaired body is *the basis* for all worldly experiences, including disability (Hughes and Paterson, 1997, p. 335). Additionally, the social experience of impairment and disability is part of a complex system involving affliction and oppression – a system to which the body is inextricably tied (Hughes and Paterson, 1997, p. 334-5). Thus, because phenomenology does not separate social and bodily experience, its use can facilitate an embodied analysis of exclusion and oppression (Hughes and Paterson, 1997, p. 335), as well as disability.

Several contemporary scholars writing within the sociology of the body use such an embodied approach. Indeed, Williams variously charts the fluctuations of the mind-body dualism as chronic illness plays out (1996), as well as reflects on the instability of the "embodied self in conditions of late modernity" – a period of prolonged reflexivity giving rise to the treatment of the body and self as problem and/or pathology (2000, p. 40). Additionally, Papadimitriou draws in part on the phenomenological work of Merleau-Ponty and of Hughes and Paterson to understand the body as biological, socio-cultural, and capable of exercising agency, particularly when it comes to adults with spinal cord injuries who are learning to use wheelchairs and engaged in a "creative process of re-embodiment"

(2008, p. 691-2). Also, in seeking to understand the experience of visual impairment, Anvik explores the everyday situations and life story of a woman who is blind (2009). And lastly, Peuravaara uses a phenomenological model of the lived body to examine how young women with intellectual impairments experience issues associated with disability, identity, gender, and normality (2013).

Thus, while we now know what adopting a phenomenological view of the body illuminates – that the body is a subject capable of exercising agency and that impairment and disability can be reunited – what does its exclusive use leave in the dark? For one, it lacks the capabilities of the other models; it is not as well positioned as social constructionist models, for instance, to demonstrate how the body is a structural-transmission site, which is those models' specialty. Additionally, for Foucault, phenomenology is unable to address language and the unconscious (in Rabinow and Rose, 2003, p. 83). It has also been accused of being apolitical, individualistic (Hughes and Paterson, 1997, p. 338), and essentialist (Fox, 2002, p. 347) due to its micro-level approach and focus on personal experiences. Indeed, while not directly critiquing phenomenology, Finkelstein maintains that individuals with disabilities should devote their energy to affecting social change, rather than fixating on experiential aspects of disability or impairment (in Thomas, 2004, p. 572). Furthermore, phenomenology is critiqued for being apolitical due to the absence of a clear engagement with politics or a call to action.

However, perhaps these limitations merely result from phenomenology, rather than the use of just one model of the body. Indeed, while use of phenomenological models yields insights about how the body and impairment are experienced, the application of social constructionist models generates understandings of how the body and impairment are socially *constituted*. Thus, these models also warrant investigation. Due to the limited scope of this thesis and following Shilling's lead (2012), here, I briefly examine social constructionist models of the body across symbolic interactionism, post-structuralism, and post-modernism, even though these are each well established and vastly different traditions in their own right.

As its name suggests, those drawing on symbolic interactionism from within the sociology of the body view the body as constituted in and through interaction. Many of these theorists draw on Goffman's pioneering work on the topics of deviance, stigma, everyday interactions, narrative, self-management, emotional labor, the front and back stages, negotiation, and identity. More precisely, Goffman was interested in how the body acted in social contexts, and while he deemed the body the focal point of people's lives, he maintained that external structures ultimately determined its significance (in Shilling, 2012, p. 75). Thus, although Shilling contends that Goffman did not explicitly develop a theory or model of the body (Shilling, 2012, p. 90), the body can be seen in Goffman's work as action and/or as "a 'sign vehicle' through which social information about ourselves is both intentionally and unintentionally conveyed to others" (in Malacrida and Low, 2008, p. x).

Nonetheless, contemporary scholars working within the symbolic interactionist stream have successfully applied Goffman's ideas to the analysis of the body and disability. For instance, Kelly and Field draw on the interconnected notions of identity, self, and everyday experience in their attempt to integrate the body into a sociological account of how chronic illness and, to a lesser extent, disability are experienced (1996, p. 241). They argue that there is a need to address embodied aspects of chronic illness and disability because they affect social and physical activities (1996, p. 241). On the other hand, Coleman-Fountain and McLaughlin contend that use of Goffman's work, and that on social interaction more generally, aids in understanding how disability produces inequalities (2013, p. 138). Specifically, this understanding is facilitated by examining

> (i) the importance of […] the materiality of the body in interaction and exploring under what conditions that materiality is produced as impaired; and (ii) how norms of interaction are further secured via the accounts produced by cultural narratives and institutional processes, which sustain the inequalities embedded in how performances are judged and carried out (Coleman-Fountain and McLaughlin, 2013, p. 138).

In the same vein, and arguably even more influential than Kelly and Field's writing is that of Frank, who similarly focuses on illness and whose work is vastly applicable. Having previously written about his experience of cancer (2002), Frank sets his sights on compiling and analyzing the stories of others in similar situations to better understand his own (2013). According to Frank, we need the stories of others to tell our own narrative, for we are all "wounded storytellers" (2013, p. xi). Furthermore, the ability to reconstruct one's narrative following illness is important not only to the storyteller but also for eliciting empathy (Frank in Strohschein and Weitz, 2012, p. 188). Indeed, drawing on this work, Smith and Sparkes examine the "tellability" of a young man's narrative of his acquired physical disability and the differing forms of embodiment entailed in his journey (2008, p. 217). For Smith and Sparkes, tellability, "narrative repair," and embodiment, although not fixed, result in part from impairment effects, and there is space to challenge the conditions that make some stories untellable (2008, p. 217).

As previously mentioned, much work within symbolic interactionism draws on that of Goffman, and the same tendency is present within post-structuralism when it comes to Foucault's work (Williams, 2006, p. 7). Invoked alongside or in place of Foucault, other influential proponents of post-structuralism within the sociology of the body include Douglas, Turner (Nettleton, 2012, p. 48-51; Shilling, 2012), and Elias (Nettleton, 2012, p. 50-1). Zeroing in on Turner, who has perhaps engaged most with Foucault's work within the sociology of the body, in seeking to develop "a sociology of the 'embodied self,'" he argues that the self has been construed as disembodied for too long (in Elliott, 2009, p. 74). Instead, within postmodern, urban culture, the body should be seen as a connector of "self-identity, physical self-regulation and sexuality" (Turner in Elliott, 2009, p. 74). Indeed, for Turner, the embodied self is embedded in a political struggle in which it is increasingly becoming a subject/object of "institutional management, regulation and surveillance" (in Elliott, 2009, p. 75). While the preceding sentences merely offer a glimpse into the wealth of Turner's work, they give us a taste of what to expect from post-structuralist views of the body.

Hence, when conceptualizing impairment through the lens of post-structuralism, impairment and its physical sensations are viewed as power-embedded discursive constructs (Hughes and Paterson, 1997, p. 329 and 332). Thus, within post-structuralism, both impairment and the body are socially constructed (Foucault in Hughes and Paterson, 1997, p. 332). Because language is used to understand impairment and its associated physical sensations, impairment is not just expressed but filtered and legitimated through language that can be subjected to discursive analysis (Hughes and Paterson, 1997, p. 329 and 332). Moreover, it is primarily medical language that is used to describe impairment in an authoritative manner, and, thus, that constructs and ordinates impaired bodies (Hughes and Paterson, 1997, p. 333). The diagnostic labels medicine applies to the body are part and parcel of systems of meaning and therefore their assignment to the body also assigns meaning (Hughes and Paterson, 1997, p. 333).

As a result, a particular type of body is produced with specific "signs, symptoms, behavior and normative expectations" (Hughes and Paterson, 1997, p. 333). Particular impairments thus warrant specific treatment of the body concerned, and this treatment entails social interactions, relations, and technology. However, despite this determinism, and drawing from disability studies and post-structuralism, Shakespeare contends that individuals with disabilities can reconstruct their identities through actively fashioning the discourses that comprise their life stories (in Williams, 1999, p. 804). These transformations could occur either alongside the medical discourse, by giving it additional meanings, or by resisting it directly.

Turning to post-modernism, the body is similarly seen as a social construct, but further conceptualizations are contested. Indeed, while those post-modernists who claim Foucault as their own adopt his view of the body as a discursively-dependent fabrication (in Nettleton, 2010, p. 50), others maintain that the social and cultural context beyond language affects aspects of bodies, such as "mannerisms, gait, [and] shape" (Nettleton, 2010, p. 48). Ironically, attempts to clarify just what the body actually is have created an academic landscape littered with bodies (Williams, 1999, p. 799), in which the body is simultaneously "everywhere and nowhere" (Williams, 2006, p. 6).

Correspondingly, an overall theme across post-modern theories of the body is that because we are no longer sure what the body is (Nettleton, 2010, p. 48), it has increasingly become a source of uncertainty in determining "who we really are." Associated with the concept of uncertainty is that of risk, which is usefully taken up in Burns, Watson, and Paterson's study of the body and disability in the outdoors (2013). For instance, these authors find, among other things, that individuals with disabilities identify three types of risk associated with the outdoors (2013, p. 1066). "Bodily risk" due to one's impairment is the type cited most often, alongside descriptions of the imperative to be aware of bodily needs and limitations (Burns, Watson, and Paterson, 2013, p. 1066). Additionally, other scholars who have contributed to post-modern theories of the body include Giddens, Frank, Martin, Waldby, and Shilling himself (Nettleton, 2010, p. 51-5).

Due to limitations of length, with this cursory idea of how proponents of social constructionism conceptualize the body – as physically affected by its social and cultural milieu (symbolic interactionism), as a fabrication dependent on its discursive context (post-structuralism), and as a source of uncertainty and risk (post-modernism) – I want to *briefly* consider some limitations of these models.

For instance, beginning with symbolic interactionist models of the body, those that draw on Goffman's work run the risk of associating impairment and other physical "abnormalities" with social deviance. Indeed, Strohschein and Weitz's appraisal and consequent revision of Goffman's definition of stigma provides evidence that connections between impairment and deviance are considered outdated and problematic (2014, p. 197). Turning to post-structuralism and post-modernism, Hutchinson accuses these models of being deterministic and reductionist (2006, p. 9), while Williams finds an "'epistemic fallacy'" at play that results in the problematic conflation of epistemological and ontological domains (1999, p. 805). In particular, the charges of determinism and reductionism are levied due to the dismissal, in part or outright, of the body's "underlying 'natural' or 'bio-physical' reality;" consequently, the body becomes nothing more than a product of discourse (Williams, 2006, p. 7) or another social construct, and effectively disappears. Lastly, an oft-cited concern with the use of post-structuralism is that it affords little if any agency to individuals (Fox, 2002, p. 348), despite its critique of structuralism.

Although I chose to focus on what are arguably the most common models of the body (phenomenological and social constructionist) to illustrate the pros and cons of using one approach, I could just have easily zeroed in on models of the body within *theories of structuration* (see Bryant and Jary, 1991; Shilling, 1991; Edwards and Imrie, 2003; Wacquant, 2004; and Shilling, 2012), *actor-network theory* (see Bloomfield, Latham, and Vurdubakis, 2010; Schillmeier, 2010; Thomas, 2012b; Shilling, 2012; and Crawford, 2013), *feminism* (see Garland-Thomson, 2011, and Shilling, 2012), and *critical realism* (see Williams, 1999, and Hutchinson, 2006), which have also been subjected to critique.[11] Thankfully, however, having realized these flaws himself, Shilling (2012) offers another way forward that we can now consider.

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[11] Certainly, no theory is perfect and critiques of both phenomenological and social constructionist approaches are not without their defenses. Nonetheless, in addition to the comprehensiveness and insights lost by neglecting other theories, recognizing the existence of these critiques ultimately aids in choosing a model of the body.

Option two: choose the best parts of all the models

The second way of moving forward in choosing a model of the body actually involves less choosing and more creating – that is, of a comprehensive framework based on the most useful aspects of each model (Shilling, 2012, p. 248-9). Developing such a framework avoids the pitfalls inherent in the individual models, and is consequently the way forward both Shilling and I prefer (2012, p. 249-50). However, caution must be used to ensure the bodily aspects drawn on are compatible (Shilling, 2012, p. 249) but not conflated; rather, the body's unique capacities should be seen as interacting with one another (Archer in Shilling, 2012, p. 249). Shilling (2012) and Fox (2012) separately offer two such frameworks, the latter of which I contend builds on the theoretical basis of the former.

At the centre of Shilling's framework is a socio-natural body shaped by social factors and with "emergent properties and capacities" that also give rise to society over time (2012, p. 249-50). While such a body sounds simple enough, as envisioned by Shilling through the lens of "corporeal realism," it is also all-encompassing (2012, p. 250). That is, the body is

> a multi-dimensional medium for the constitution of society: a location for the attempted transmission of socially approved techniques, habits and norms; possessed of emergent properties and capacities (evolutionarily given and irreducible to presently existing social relationships and technologies) that also make it a lived vehicle for the varied experience and mediation of these societal phenomenon; and an active recreator/re-creator of society (Shilling, 2012, p. 250).

But what of the faults contained in each of these components (which were previously treated as models in their own right)? For Shilling, the use of corporeal realism allows one to draw on the insights of these models without accepting them in their totality (2012, p. 250). This selection process is possible because a realist perspective does not conflate or assume a determining relationship between body subjects and their embodiment of social factors, and recognizes the "*distinctive ontological properties*" of each of the processes that constitute the body – hence the label "realism" (Shilling, 2012, p. 250). That is, by adopting a realist perspective, we are encouraged to consider the unique nature of each body-constituting process and refrain from assuming that lived experiences or societal transmissions necessarily result in bodily changes (Shilling, 2012, p. 251). For instance, not all embodied subjects have internalized the societal norm of efficiency, as evidenced by individuals who prefer to indulge and engage in excess (Hadfield in Shilling, 2012, p. 251), or who elevate religious considerations above those of efficiency (Mellor and Shilling in Shilling, 2012, p. 251).

In drawing together the diverse models of the body within constructionist, phenomenological, and structuration theories, Shilling's development of a corporeal realist model (2012) is certainly to be applauded. However, he stops short of providing the methods needed to practically apply this model, whereas Fox (2012) *shows how* comprehensive studies of the body can draw on elements of the models previously discussed, to varying degrees.

A beginner's guide to the body-without-organs

Fox demonstrates how Deleuze and Guattari's comprehensive model of the body can be applied to illuminate the body's nature within health and social care contexts (2012). Although abstractly described as "a body without organs (BwO), reconfigured in terms of intensities and flows, fragments and multiplicities, involving an endless process of becoming (other)" (Deleuze and Guattari in Williams, 1999, p. 800), in the hands of Fox and in this thesis, this model of the body not only becomes much clearer, but something more. Nonetheless, a few caveats are needed before we proceed. Indeed, that the work of Deleuze, who is no stranger to jargon, is dense, complex, and highly abstract is well known and cannot be overstated. Thus, within this section, mention of his (and Guattari's) crucial concepts are followed by footnotes that provide more information. However, these footnotes are by no means thorough and I recommend interested readers engage in further research, which is beyond the scope of this MA thesis – hence, the title of this subsection.

To begin, that I have devoted little space in this chapter to addressing so-called "natural," medical, or biological models of the "disabled body," which proponents of the social model of disability rally against, does not mean they are unimportant. Indeed, that there is an overwhelming desire and need to bring impairment back into conversations of disability, alongside social factors, illustrates the necessity of incorporating aspects of both biological and social models into a comprehensive framework. However, although researchers working with one or other of these models seem to possess a never-ending capacity for generating increasingly detailed descriptions and explanations of the body, the fact remains that they are rarely engaging with both models (Fox, 2012, p. 56). Even when social scientists do acknowledge physicality, it is usually only as a starting point for society's subsequent fashioning of the body – although biologists are certainly not exempt from similar charges of neglect (Fox, 2012, p. 56). Nonetheless, because the physical reality of disability impacts relationships, independence, and other social aspects of individuals' lives, there is a need "to develop a coherent and holistic understanding of embodiment" (Fox, 2012, p. 56-7). In addition to the analytic insights offered by such an understanding, this appreciation would have practical implications for those involved in body work and for experiences of disability and care (Fox, 2012, p. 57).

Relations

The creation of a coherent and holistic model begins with realizing the body does not have to be either a biological *or* social entity – it can be both – and that its presence in the world involves interaction with other humans, non-human actors, and inanimate objects (Fox, 2012, p. 56-8). According to Fox,

> If we accept that the human body is both biological (an organism that is constituted from the physical constituents of atoms, molecules and cells), *and* social (an agent that engages with human culture and shapes that culture); if we take this as given, then it follows that the body has relations (to other things or people) in both these realms (2012, p. 58).

Thus, the body is part of a network that includes, but it not limited to, its biological or physical, psychological, emotional, social, cultural, and political connections or relations (Fox, 2012, p. 58-60). Furthermore, the body has myriad relations within each of these areas; that is, it has numerous physical relations, as well as a multitude of social relations and so on (Fox, 2012, p. 59-61). All these relations work both ways (influencing the body and being influenced by it), and combine to create the body's "ecology," or its position within its social and physical environment (Fox, 2012, p. 58).

Therefore, we can illuminate the body's ecology by describing its relations; for instance, the body has countless relations of a physical nature which connect it to its material environment (Fox, 2012, p. 59). At a basic level, the body's relations with air, water, food, shelter, and clothing form the components of survival. Certainly, the body "breathes in air and, as part of its respiratory and metabolic processes, uses oxygen to generate energy, in the process creating carbon dioxide, which is then expired" (Fox, 2012, p. 59). Additionally, the body has relations with water and the "plants, animals and other essential minerals" it consumes and ultimately releases back to the environment through the workings of its digestive system (Fox, 2012, p. 59). Because this environment is not always an easy place to live in, the body has developed relations with clothing and shelter, among other mediating tools, to keep it safe from the elements, chemicals, and other agents causing injury and infection (Fox, 2012, p. 59). However, while these relations mitigate the body's connection to time allowing it to survive longer, the body still degenerates (Fox, 2012, p. 59). Throughout the body's life, it physically affects other bodies and the environment: "directly or through the use of tools, in creative or destructive actions; through sexual contact and child-rearing; or in the many other daily interactions a body can have with what is around it" (Fox, 2012, p. 59).

Beyond the physical relations bodies have, they also have countless relations of a socio-cultural and philosophical nature. Indeed, according to Fox,

> Bodies relate to other humans, animals, even inanimate objects in ways that are more than simply physical: they love, or hate, or admire, or they care for these others; they engage and interact to build relationships that are intellectual and emotional, economic and political (2012, p. 60).

Moreover, bodies both generate and are deeply rooted in culture – culture which is based on the body's dual capacity to assign meanings to itself and the world around it, and to communicate these understandings (Fox, 2012, p. 60-1). Thus, from these humble beginnings, bodies ultimately give rise to the "social and cultural groups," "political and economic systems," and social institutions that comprise culture (Fox, 2012, p. 61). In turn, culture itself "may create religious or philosophical relations with ideas and ideals; philosophical or political creeds; divinities that define good and bad; and rules about how one 'should' behave, and what should happen if these rules are transgressed" (Fox, 2012, p. 61). Nonetheless, once built, these socio-cultural constructs are not impermeable; through the daily relations our bodies have with others, as well as with institutions and ideas, these constructs are weakened, strengthened, or merely sustained (Fox, 2012, p. 61).

Although each of us have bodies that develop philosophical, cultural, social, emotional, psychological, physical, and other relations, the exact nature of these varies depending on the individual (Fox, 2012, p. 61-2). For example, while it is likely that a member of parliament will have many political relations, she will perhaps not have as many cultural relations as someone who is a street performer;

moreover, just as two individuals with the same impairment will not have the same experience, nor will two members of parliament have the same political relations. However, because equal weight is given to all the body's relations within this approach, its use does not force us to prioritize the physical aspects of the body over the social, or vice versa (Fox, 2012, p. 62). Such an approach does not focus so much on what the body is (its ontology), allowing us instead to illuminate "what it *does*" by considering its relations (Fox, 2012, p. 62).

To further develop this perspective on the body, it is useful to examine the work of Deleuze and Guattari, whose method consists of documenting a body's attachments and relations (Fox, 2012, p. 63), which constitute "the limit of a person's embodied subjectivity" (Fox, 2002, p. 347). Thus, zeroing in on these relations is akin to focusing on a body's capabilities (Buchanan in Fox, 2012, p. 63), not in a functional sense but as per the following line of inquiry: "'what is a body *capable* of doing?', or 'what *else* can a body do?' Another helpful question to ask is 'what are the *limits* to what a body can do?'" (Fox, 2012, p. 63). Seeking answers to these questions, Deleuze and Guattari apply their method to individuals with mental health issues, noting they are indeed limited in what they can do (in Fox, 2012, p. 63). However, it is unusual for these individuals' interactions and physical behaviours to actually result from physical limits;[12] rather, these interactions and behaviours manifest from limits of a social, psychological, or emotional nature, which themselves arise from the body's relations over time (Deleuze and Guattari in Fox, 2012, p. 63).

And yet, because Deleuze and Guattari maintain that all individuals have a "positive, creative potential"[13] or force they can channel, perhaps with the

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[12] Deleuze and Guattari may have underemphasized the role of biological relations in mental health issues due to the popularity of the anti-psychiatry movement when they were writing (Fox, 2012, p. 63-4). Nonetheless, because their method does not value certain types of relations over others, a greater focus on the physical aspects of mental health could be achieved easily (Fox, 2012, p. 64).

[13] In the hands of Deleuze, the concept of potential merits examination in its own right. However, due to the scope of this thesis, suffice it to say it offers a reminder that while power affects the way things currently are, "potential forces for change are just as real" (Hroch, 2012, p. 143).

assistance of others, it is possible for people to escape and transcend their current limiting relations and conditions (in Fox, 2012, p. 63 and 65). Therefore, because embodiment is seen as "active and motivated" and the current state of a body (what it is) is deemed less important than what it can "become,"[14] use of this model can lead to emancipation from the body's limits, particularly those that biomedical approaches impose (Fox, 2012, p. 64). Thus, the body's two-way social and physical relations interact dynamically with a second element to provide rationale for the body's actions and limits (Deleuze and Guattari in Fox, 2012, p. 64-5).

This second element is the body's "active, experimenting, engaged, and engaging" nature – characterized by impactful complexity, unpredictability, and choice-making – that exists alongside its capacity and desire to create new relations (Deleuze and Guattari in Fox, 2012, p. 65-7). The multiplicity of potentials constitutes the "virtuality" of bodies as opposed to their actual materiality (Shields, 2003). In general, bodies with a greater amount of relations are capable of doing more, and interaction between a body's relations and agency gives rise to its actions and limits (Fox, 2012, p. 66-7). This body, which is itself a limit, can be referred to as the body-without-organs (BwO): embodied subjectivity or the "body-self"[15] (Fox, 2002, p. 347). The BwO is therefore distinct from biomedical or natural views of the body that give rise to the "body-*with*-organs," or the "organism" (Deleuze and Guattari in Fox, 2012, p. 66; emphasis added). Much of Deleuze and Guattari's work is a critique of the reductionism that is entailed in reducing the body-self to a static object of rational knowledge without the potentiality for the body-self to transform itself and its relations again and again.

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[14] Among other things, "becoming" reflects the notion that reality itself is an ongoing process of "repetitions of difference" (Tiessen, 2012, p. 34), where difference is a crucial concept that can itself be unpacked.

[15] Like the process of becoming described in the previous footnote, the term BwO is ripe with meaning which, again, escapes articulation here. Indeed, among other things, the BwO can never be actualized – "it is always out of reach. It is an image without likeness; it resists organization. It is the anarchist body, denaturalized" (Wallin, 2012, p. 39).

Assemblages

Turning to Deleuze and Guattari's concept of "assemblage," which results from "the interaction between all of a body's relations" (in Fox, 2012, p. 67), its beauty is that it is able to diagram (Deleuze, 1988) the body's relations without diminishing the uniqueness found within each one. [16] Additionally, assemblages are unpredictable and describe dynamic, embodied processes; they are about doing (Deleuze and Guattari in Fox, 2012, p. 67) and often occur in conjunction with verbs (for example, there are fasting and relaxing assemblages). Moreover, assemblages are the foundation of every action and experience, and link the body with its relations and natural and social context (Fox, 2012, p. 67 and 69). That each individual has unique experiences and actions speaks to the equally distinct character of his or her assemblages and the affordances within them that, like the interacting relations that comprise them, are themselves shaped by "experience, beliefs and attitudes, or from bodily dispositions" (Deleuze and Guattari in Fox, 2012, p. 67). Thus, embodiment varies from person to person because of differences in individuals' assemblages (Fox, 2012, p. 69). For instance, the peculiarities of an individual's health care assemblage may illuminate reasons for lack of access to timely advice, as well as reasons for compliance with professional suggestions rather than those of other supporters.

Returning to the BwO, it can be seen in part as the amalgamation of its building blocks; the sum of the body's interacting relations result in assemblages which, when taken together, in turn give rise to the BwO (Fox, 2012, p. 69). That is, because assemblages are comprised of interacting relations that shape the BwO, assemblages themselves also shape the BwO, configuring it along with the limits of embodiment or the body's capacities (Fox, 2012, p. 69). Put succinctly, use of this model generates an understanding of bodies as

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[16] Although an intricate process, in practical terms, the conceptual openness of "assemblage" makes it a superb "tool for sociological theorizing and analysis. The assemblage can formulate a collective from what otherwise appears to be disparate elements and thus forges connections from diverse and numerous orders" (Kruger, 2012, p. 29).

> neither fixed nor given, but as particular historical configurations of the material and immaterial, captured and articulated through various assemblages which to some extent determine them as particular bodies, but never manage entirely to exclude the movement of differing and the possibility of becoming otherwise (Currier in Fox, 2012, p. 70).

Given the many types of relations – physical, psychological, emotional, social, cultural, political, philosophical, and so on – that give rise to assemblages, it is perhaps not surprising that our bodies consequently create and are implicated in networks far beyond their physical limits (Fox, 2012, p. 70).

Territorialization

While use of Deleuze and Guattari's model of the BwO involves considering all types of relations, power differentials occur because each relation differs in its capacity to influence the body or be influenced by it (Fox, 2012, p. 70). Furthermore, a relation interacts unpredictably with others in ways that determine its significance within an assemblage as well as the ways it shapes the BwO (Fox, 2012, p. 70). Therefore, the BwO can be viewed as a dynamic space in which assembled relations exert various levels of power, influencing and being influenced by the body to varying degrees; hence, the influence wielded by the body's assembled relations brings into being and affects the nature of this space as a configured and mappable territory or the BwO (Fox, 2012, p. 70-1). To better understand this process, we can think of "territory" in a very literal sense, and think of the relation between a territory of land and one of its many rulers. For sake of argument, each ruler (i.e. relation) in this territory will possess a different amount of power, and will consequently influence the territory and be influenced by it to varying degrees. Now, perhaps all the rulers come together to form a ruling council (i.e. assemblage). Based on each ruler's power, he or she will have more or less significance in this ruling assemblage with effects on the territory (i.e. BwO).

This process of configuration is referred to as the "territorialization" of the BwO, and can result in a re-definition or "change in character" (Deleuze and Guattari in Fox, 2012, p. 71). For example, with the addition of other relations, a relation between an individual and a health care professional is likely to give rise to a biomedical assemblage that "territorializes" the individual as a patient, "her/his symptoms into a disease" (Deleuze and Guattari in Fox, 2012, p. 71), and the health care professional into an expert. Indeed, this territorialization is familiar to individuals with disabilities engaged in health care encounters. In countries with social or welfare programs, the medical profession regulates access to rehabilitation, assistive equipment (e.g. wheelchairs), training, education, and economic supports for individuals with disabilities (Albrecht, 1992, p. 67; Stone in Rioux and Daly, 2006, p. 307; Hansen and Janz, 2009, p. 31; and McColl, Jarzynowska, and Shortt, 2010). As we will see, this regulation is enacted through the medical profession's scientific assessment and determination of whether the nature of an individual's disability warrants access to any of the above benefits (Rioux and Daly, 2006, p. 307).

Territorialization occurs in much of human interaction and often revolves around social constructs and their meanings (Deleuze and Guattari in Fox, 2012, p. 71). However, because the potential exists to partly or totally resist all forces (Fox, 2012, p. 71), there is nothing final about this process. Indeed, a territorialized BwO can continuously be de-territorialized and subsequently re-territorialized by forces at play within the assemblages (Fox, 2012, p. 72). Thus, the BwO is the scene in which both territorialization and resistance play out (Fox, 2012, p. 72). To illustrate this latter point, consider again the individual in the health care encounter; he or she could in fact attempt to embody the role of health care consumer rather than that of passive patient (Fox and Ward in Fox, 2012, p. 72); he or she has *agency*. Additionally, his or her relations with family, friends, and/or support staff, as well as a personal desire for independence, might provide the support and strength needed for such an assertion (Fox, 2012, p. 72). Thus, through applying the concept of territorialization, we can explain how individuals are both variously influenced by and resist relations of a social, physical, or psychological nature, reflecting the "capacity of the body to re-shape its assemblages and 'become-other'" (Fox, 2012, p. 72-3).

Biomedical territorialization and alternate outcomes

As previously mentioned, the territorialization that occurs within health care encounters, and in biomedicine more generally, of bodies into biomedical bodies – what Deleuze and Guattari critically refer to as "organisms" or "bodies *with* organs" – is of especial importance to individuals with disabilities. According to Fox, such territorializations are the outcome "of powerful forces emanating from biomedicine, inherent in the medicalizing processes of health care that turn bodies into patients, and their experiences of their sick bodies into case histories of disease" (2012, p. 73). Similarly, experiences of disability within health care encounters are classified as impairment – a label with widespread ramifications. Thus, as previously mentioned, within biomedicine, disability exists within the affected individual's body and, ostensibly, once identified, can be managed on a case by case basis through biomedical treatments and rehabilitation. Therefore, much like disease, disability is treated as pathology and becomes the terrain of doctors and other professionals (Rioux and Daly, 2006, p. 306).

However, as the title of this subsection suggests, it is possible to move beyond the body-with-organs and the territorialization of biomedicine, which, although powerful, is only one of many potential configurations or territorializations of the body (Fox, 2012, p. 73). Indeed, as evidenced by our earlier review of differing body models, there are many ways to interpret or territorialize the body; that is, these models are competing territorializations (Fox, 2012, p. 73). Thus, although it may be difficult to conceive of an alternative to the body-with-organs when it comes to individuals who are sick or have disabilities and may depend on health care professionals, we can better understand "patients" and "impaired individuals" as subjects of biomedicine's territorialization, whose BwOs have been territorialized ("organ"-ized) into bodies *with* organs and are thereby limited in what they can do (Fox, 2012, p. 74). Due to the dominant role biomedicine plays in our culture, resisting its territorialization and physical, psychological, and social impacts is exceedingly difficult (Fox, 2012, p. 73).

Nonetheless, resistance is possible and one may find “a *line of flight* from that territorialization to a new state of embodiment” in which the “body can do more (or different things)” (Fox, 2012, p. 74-5). The potential role of others in this process of “re-territorialization,” as well as its significance, should not be underestimated (Fox, 2012, p. 74-5). Indeed, through engaging in a line of flight from biomedicine’s territorialization of the body, one may be able to realize a dream and re-invent his or herself by taking on a new position or identity, so to speak (Buchanan in Fox, 2012, p. 75). In addition to relations with family and friends and the support and strength they provide, relations with support staff and health care professionals may either hinder individuals (by medicalizing them, among other things) or empower individuals by assisting them “to move beyond the current limits of their embodiment” (Fox in Fox, 2012, p. 75).

Consequently, Fox endeavors to encourage a dual understanding of care, in which it can either limit the body and its opportunities (what the body can do), or support the body to transcend limitations (providing a line of flight) (2012, p. 177). As the field of professional care grows, the dual nature of care becomes clearer, along with its ability to significantly influence individuals’ experiences, for better or for worse (Fox, 2012, p. 177). Indeed, although one of the main roles of support staff is, arguably, to provide care, the importance of this seemingly common-sense role can be easily forgotten, overlooked, and obscured amidst the increasing bureaucratization and rationalization of care, within the field of disability services and social services more broadly.

Thus, Fox distinguishes between “the vigil of care” and “the gift of care” (2012). Under the former model, regulatory frameworks are imposed upon care recipients, who are routinely scrutinized (Fox, 2012, p. 178), medicalized, and territorialized.

Needless to say, this type of care experience can result in a downward spiral, in which care recipients become increasingly dependent on care providers (Biggs in Fox, 2012, p. 178). However, when care is seen as a gift, the opposite trend occurs – recipients are neither medicalized nor unduly monitored, and are provided with opportunities and possibilities. Within this type of care experience, recipients can experience a line of flight to increased independency (Fox, 2012, p. 178).

Use of this model begs the question "*what can a body do*?" (Fox, 2002, p. 355) and, in this manner, "what can a body become?" Such a focus involves recognizing that although physical constraints partly determine what bodies are capable of, we can still envision, desire, and attempt to actualize a body-without-organs beyond these limits (Buchanan in Fox, 2002, p. 355), as well as a body-with-organs that is other than its current configuration. The body is not merely a passive surface on which the structures and forces of society are inscribed; it is "active, experimenting, engaged and engaging" – it can do things (Fox, 2002, p. 356). Furthermore, this approach can be defined by what it is not: it is neither concerned with the substance or essential nature of the body, nor does it give rise to a functionalist model of the body concerned with cause and effect (Deleuze and Guattari in Fox, 2002, p. 355). Rather, its use entails enumerating a body's relations (Deleuze and Guattari in Fox, 2002, p. 356), whether these are physical and biological or socio-cultural and philosophical in nature (Fox, 2002, p. 356).

In summary, this approach to the body breaks down walls between the physical and social, which both constitute embodiment (Fox, 2012, p. 78-9). That these worlds can be incorporated is made clearer through the BwO, which emerges from the diversity of all the body's relations and their roles within its assemblages (Fox, 2012, p. 79). Thus, embodiment is the culmination of all a body's relations (Fox, 2012, p. 80). Moreover, these relations do not inscribe themselves on the body, resulting in a passive form of embodiment; rather, "embodiment is a dynamic, reflexive 'reading' of the social by an active, experimenting, motivated life-force” and conjures “the multiplying, becoming-other body that is always capable of a new interpretation, another nuance” (Fox, 2012, p. 80).

Thus, for Deleuze and Guattari, disability is a configuration seen as part of relations. Indeed, relations determine the capabilities and capacities of the body in specific situations, and relations themselves are limited from infinite to finite in any given context, moment, or situation. When relations are limiting, they are disempowering; when relations open up opportunities and possibilities, they are empowering and enabling. Similarly, conceptions of temporary able-bodiedness (see McRuer, 2006) illustrate the contingency of disability, assist in dissolving the able-bodied/disabled dichotomy, and serve as a reminder that all bodies experience disability to varying degrees.

Conclusion

To conclude, this chapter began with the contention that there is a need to create a distinct sociology of disability, with a unified, core body of knowledge that transcends the stalemates occurring across the diverse yet interrelated fields of disability studies, the sociology of health and illness, and the sociology of the body. Certainly, the creation of a sociology of disability must respond to calls to reintroduce physicality – the accomplishment of which, I argue, depends on viewing the body in a particular way; that is, on having a model of the body. Therefore, throughout this thesis, I attempt to illustrate how the body can be brought back in by providing a dynamic model of the body that is capable of exercising agency and independence, and that illuminates the accounts of a small group of Edmontonian adults with developmental disabilities. Given the breadth of work across disability studies, the sociology of health and illness, and the sociology of the body, many body models exist that speak more or less successfully to disability, including Deleuze and Guattari’s body-without-organs (BwO), or body-self, as explicated by Fox. However, because this model accommodates impairment and disability, agency and independence, and social factors, I conclude it is the model best poised to facilitate a well-rounded understanding of a body capable of exercising agency and independence, especially when later applied to participants' accounts. It is a model that is inclusive, comprehensive, broadly applicable, and highly relevant.

Building on the theoretical perspective developed here, in the next chapter, I discuss the exploratory project in which this study's first interview was conducted, as well as the methodology that informs my qualitative research. Woven throughout this chapter are the ethical considerations and practices employed to establish trust and ensure rigor, among other things, and many of which are specific to individuals with disabilities.

Chapter Three: Methodology

Having established the need to bring the body back into conversations of disability, in the last chapter, I argued that doing so relies on having a model of the body that is capable of exercising agency and independence. While many models exist that speak more or less successfully to disability, I concluded that Deleuze and Guattari's body-without-organs (BwO), as explicated by Fox, is best poised to facilitate a well-rounded understanding of the body-self. Indeed, this model accommodates impairment and disability, agency and independence, and social factors; it is inclusive, comprehensive, broadly applicable, and highly relevant. Furthermore, I proposed that this model could be used to interpret the accounts of a small group of Edmontonian adults with developmental disabilities. However, although we now have a model of the body at our disposal, we do not yet know how we are going to use it to understand the accounts of these individuals or really even who these individuals are. Thus, before presenting their accounts (in the next chapter), I provide background on *how* this inductive research[17] was conducted, including the steps taken to gather and analyze this study's data and the rationale behind them.

Specifically, in this chapter, I discuss the exploratory project in which I conducted the first interview. I then address the methodology behind this research, including the ethical considerations and practices I employed to establish trust and ensure rigor, among other things. Many of these considerations are specific to individuals with disabilities.[18] Additionally, this research does not particularly conform to any one of the main five qualitative research strategies, approaches, or frameworks – namely, grounded theory, ethnography, case study, phenomenology, or narrative

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[17] Inductive research differs from deductive research in that, among other things, the researcher does not follow a strict sequence of steps based on initial decisions (Maxwell, 2013, p. 2). Rather, as was the case in this study, "[t]he activities of collecting and analyzing data, developing and modifying theory, elaborating or refocusing the research questions, and identifying and addressing validity threats are usually all going on more or less simultaneously, each influencing all of the others" (Maxwell, 2013, p. 2).

[18] This study was approved by the University of Alberta and adhered to its ethical guidelines.

research (Denzin and Lincoln in Merriam et al., 2002, p. 6; Creswell, 2013). Instead, it more importantly builds on the theoretical perspective advanced in the last chapter by ultimately drawing on methodology developed by Fox and Ward, who are cognizant of respecting “the fundamental ontology of Deleuze and Guattari’s approach” (2008, p. 1012). While Fox and Ward use their framework to “empirically gather and analyse health identity data” (2008, p. 1012), I use it to make meaning and extend the value of the coding I had already done. Accordingly, the concepts of “body-self” and “territorialization” emerged during analysis as powerful ways of making sense of the interviews and the life experiences that participants spoke of.

Exploratory project

To begin, my overview of how this research was conducted begins in the winter semester of 2013, before this study was officially underway. At the time, I was taking a qualitative research methods course and involved in a related Community Service-Learning (CSL) project. As its name suggests, this program facilitates mutually beneficial relationships between community organizations and the University, by allowing students to engage with these organizations as part of their education. In particular, I worked with a community disability agency dealing with the following dilemma: while many individuals with disabilities are actively involved in their communities, their contributions frequently go unnoticed by the non-disabled public. Moreover, the invisibility of this assistance does little to counteract and may even increase the negative attitudes many non-disabled people still have regarding disability.

In response, through their ongoing project, the agency I worked with aims to bring engaged individuals with disabilities into the spotlight by showcasing the positive impacts they have on their communities. Furthermore, this project focuses on building relationships between individuals with disabilities and those who are non-disabled, and assisting individuals with disabilities to be proud of who they are, explore their interests, and consider related, creative possibilities for employment. In addition to attending and engaging in participant observation at a couple of workshops based on these activities, my role in this project was to separately interview two individuals with disabilities also involved in this project. These interviews focused on their dreams for the future and experiences of having a “good life,” sense of belonging, and community connections; engaging civically and in community development; making the world a better place; being a leader; and/or fulfilling valued roles.

Not only did this project relate to my research interests, but participating in it assisted me to develop positive connections and relationships with individuals with disabilities in Edmonton, as well as with individuals working within disability services, such as the project’s leaders. Consequently, in co-designing the interview guide I would use with the aforementioned individuals, the project’s leaders were more than willing to let me incorporate questions in line with my specific research interests. At the time, these interests involved how individuals with disabilities experienced autonomy, when accessing and receiving health care services. Moreover, when I asked if I could use the interview data in my thesis, they said they were hoping I would and offered to arrange further interviews. Later, following the acceptance of my ethics and thesis proposals, I would take them up on this offer and, thus, theirs became the agency from which I would ultimately draw all my participants. Accordingly, I refer to this exploratory project periodically in the following sections, and the reader now has the background to contextualize these references.

Thus, without further ado, let us examine the nitty-gritty of this study’s methodology.

Methodology

Indeed, having identified a theoretical framework, research questions, and a research problem – how the body can practically, theoretically, and comprehensively be brought back into conversations of disability, while simultaneously acknowledging the agency (vis-à-vis independence) of individuals with disabilities as well as social factors associated with disability – it is time to consider why the methodology used was best suited for this research. As previously mentioned, I gathered well-rounded, first-hand accounts of the lives of Edmontonian adults with developmental disabilities. These accounts include information about their identities, physical and social experiences within the broad context of the PDD program, as well as the meanings that independence and autonomy had for them, whether they felt this way, and why.

But how and why did I decide it would be best to conduct interviews rather than participant observation, some other qualitative research method, or even quantitative research for that matter? And how and why did I choose to conduct these interviews with Edmontonian adults with developmental disabilities rather than members of some other group? These questions and others related to the methodology of this research are certainly worthy of exploration and are thus taken up in this section, which is divided based on 1) design, 2) sample, 3) participant recruitment, 4) instruments and data collection procedures, 5) formal reflection, 6) transcription, 7) coding, and 8) analysis.

Design

To begin, qualitative methods were deemed best suited to address this study's research problem and questions after learning about, discussing, and considering what use of these methods illuminates in contrast to those of a quantitative nature, which, as their name suggests, are generally associated with the ability to capture a wide breadth of information. Indeed, I initially considered using quantitative methods due to this benefit, my initial comfort with them, and because, when I was still working within a community disability agency in 2011, Persons with Developmental Disabilities (PDD) had just begun conducting the "My Life Survey" (Alberta Human Services c, 2014). At a preliminary level, the purpose of this ongoing survey is to assess quality of life as self-reported by recipients of PDD funding (Alberta Human Services c, 2014). While certainly not without its faults, an interesting feature of this survey is that individuals who receive PDD funding themselves are trained as surveyors; that is, they are the ones who ask the questions (Alberta Human Services c, 2014). Nonetheless, despite my initial interest in such an approach – particularly that individuals with disabilities were the ones asking questions of their peers – I had an increasing desire to elicit answers of a depth that could not be attained through the nominal or ordinal measures of the My Life Survey, and which are common to quantitative methods more generally (see Babbie and Benaquisto, 2010, p. 133-4).

Moreover, while individuals with developmental disabilities have certainly been involved in quantitative research, qualitative research with members of this population is lacking, despite the benefits of its methods (Irvine, 2010, p. 21-2). For instance, unlike quantitative data, that collected in qualitative research can speak for itself when text is adorned with quotes from individuals with disabilities (Kitchin in Irvine, 2010, p. 22). Indeed, in the next chapter, I strive to present such an approach, which seeks to include "the 'voice' of persons with disabilities directly and result in unambiguous research that has clear connections between theory and the lives of people with disabilities" (Irvine, 2010, p. 22). Additionally, while hopes that any of my participants would one day read this thesis may be wishful thinking, by virtue of it entailing qualitative research, it is likely more accessible than quantitative analysis (Irvine, 2010, p. 22).

Many decisions regarding this study's methodology were also influenced by the content and instructors of two related courses: qualitative research methods, as previously mentioned, taught by Dr. Sara Dorow; and research design, taught by Dr. Herb Northcott. For instance, that I was already conducting interviews within the qualitative research methods course that I could use in my thesis was added incentive to continue with this method, and I would be remiss not to acknowledge this impetus and convenience. Furthermore, because these interviews were with members of the population I sought to research and included questions based on my specific research interests at the time, I had a chance to gain "a feel" for how my later interviews would play out, as I gradually became more comfortable and learned what worked and what did not. Thus, in combination with the aforementioned workshops, these interviews served as a form of "observational research," helping to focus my interview guide (Fox and Ward, 2008, p. 1013) (see Appendix). Last but not least, interviews can be empowering. In this case, adults with developmental disabilities were provided with a way to share their experiences, stories, opinions, and suggestions, which does not happen nearly enough.

Thus, for these reasons and based on discussions with my supervisors and other professors within the departments of sociology, rehabilitation medicine, and physical education, consensus was reached that use of qualitative methods, and interviews in particular, would be best suited to this research. Having reviewed why interviews were the method employed to collect this study's data, let us consider the specifics of who I interviewed (i.e. the sample). As the reader will see, many of these details were determined by ethical considerations, especially since individuals with disabilities are typically deemed a vulnerable population within research protocols (Irvine, 2010, p. 24).

Sample

To be involved in this study, participants had to meet five criteria, which were each important for various reasons and which I discuss in no particular order. Needless to say, the first criterion was that they needed to have a developmental disability. As mentioned in the introductory chapter, in addition to my personal reasons for being interested in these individuals' lives, I suggest their experiences are unique from those of their non-disabled counterparts and that, in their own right, they are of interest and worthy of scholarly attention.

By valuing these perspectives, this study seeks to challenge the perception that because individuals with disabilities are marginalized, their knowledge of disability is "'defective,' not usually worthy, credible or useful" (Michalko in

Hansen and Janz, 2009, p. 31). Thus, this research is guided by the belief that one must learn as much as possible about a topic directly from its source. Although we may never know exactly how it feels to walk in another's shoes, we can attempt to understand by asking about and listening to others' stories of their experiences. This is an opinion to which I held fast despite a warning about the potential difficulty entailed in gaining ethical approval to speak directly with individuals with disabilities, rather than, say, non-disabled service providers. While I cannot say for certain whether I experienced increased difficulty in having my ethics application approved, in the following subsection, I speak to some unique ethical considerations associated with working with members of this population.

How were developmental disabilities conceptualized and how did I determine who "made the cut?" Although being part of the PDD program ultimately became a broad focus of this study, and would have been one way to determine whether potential participants had developmental disabilities, this focus was unintentional and not present at the time of recruitment. Nonetheless, all participants were recruited from the same agency, where all adults with disabilities receive PDD funding. Therefore, by virtue of receiving this funding and consequently services from this agency, each participant had already been classified as having a developmental disability by PDD which, the reader will recall, uses the following measures:

1. The individual must have a 'significant limitation in intellectual capacity.' This means an IQ score of 70 or below.
2. The individual must have a 'significant limitation in adaptive skills.' This means the individual needs help with daily living activities like making food. PDD measures this by checking whether the person needs help with six or more out of 24 typical skills.
3. The individual must have had both of these two limitations before he or she turned 18 (Alberta Human Services a, 2014).

At the time of recruitment, my rationale for deeming PDD-approved individuals as sufficiently having developmental disabilities was threefold. First, adhering to the specificity of PDD's measures allowed for a more homogenous sample, which could not be achieved as easily with use of a less precise, more academic definition of disability. In studies such as this one, where the researcher seeks to understand similar experiences from various viewpoints, it is important to minimize diversity across participants to ensure that they do in fact have similar experiences. Secondly, PDD approval is not easily attained; that is, in demonstrating they meet these criteria, individuals are put through the wringer, usually much more so than individuals demonstrating eligibility to participate in a research study. If individuals meet PDD's stringent measures for developmental disabilities, they likely meet the criteria of most other definitions of developmental disabilities.

Lastly, although PDD conceptualizes developmental disabilities largely in terms of functional limitations – resulting in an incomplete picture of disability which I here risk propagating – in the everyday lives of individuals with developmental disabilities, PDD's measures likely have more meaning and impact than any other definition of developmental disabilities. As previously mentioned, access to this funding is crucial for the majority of adults with developmental disabilities, as it allows them to receive services from community disability agencies, and, indeed, the PDD program and its roles in participants' lives would ultimately become a broad focus of this study. Nonetheless, the goal was always to move beyond PDD's definition to contextualize disability, examine a variety of life experiences, and produce a "balanced and nuanced account" (Shakespeare, 2012, p. 131). Thus, my initial use of PDD's definition was also meant to mirror the example set by Hélène Ouellette-Kuntz, who contends such a move "is not meant to be dismissive of the environmental factors that, in interaction with body function impairments and activity limitations, contribute to disability (World Health Organization 2001) but rather reflects the language used by the research, clinical and policy community" (2005, p. 114).

The second criterion individuals had to meet to participate in this study was being an adult, defined as age 18 and over. The purpose of this criterion was largely ethical in nature. Indeed, as previously mentioned, ethical considerations played a role, if not determined, many methodological details, especially since individuals with disabilities are typically deemed a vulnerable population within research protocols. Recognizing this concern, I knew if I added “minors” (another vulnerable designation) to the list of participants’ characteristics, my ethics application would almost certainly be flagged as problematic. While there is definitely precedence for ethics considerations such as these, in some ways, they have unfortunate or unintended consequences, such as when they deter researchers from completing valuable work in areas worthy of study. Indeed, Kipnis echoes this concern in contending that vulnerability should not be conceived “as a flashing red light ordering researchers to stop, but rather as a cautionary signal, calling for proper safeguards” (2006). Nonetheless, in this study, that participants were approved for funding by PDD meant they were already age 18 and over.

Thirdly, to participate in this study, participants needed to be their own guardians. Although one might be tempted to think this would already be the case given that participants were adults, many adults with developmental disabilities are not their own guardians (Irvine, 2010, p. 25); that is, there is a guardianship order in place usually assigning this role to family or the province (as in the Office of the Public Guardian (OPG)) (see Alberta Human Services d, 2014). When these orders are in place, guardians make many decisions on behalf of, but hopefully in consultation with, adults with developmental disabilities, including whether they should participate in research studies such as mine. Moreover, based on my experience in a disability agency and in working with the gatekeeper of this study, there seems to be some consensus that those working for OPG (public guardians) are increasingly becoming more reluctant to offer consent on behalf of adults with developmental disabilities for anything not strictly necessary, such as participating in a research study. This is not to say that public guardians are depriving these adults of opportunities per say; rather, that they appear more hesitant to provide consent for anything outside the box, whether due to liability or other issues.

Additionally, as previously mentioned, being one's own guardian implies one is "high functioning" (for lack of better words), able to engage in conversation, and reflect on his or her experiences and independence, as well as meanings of the latter. And, last but not least, there are logistical concerns associated with having to go through an intermediary (guardian) and, much like adding "minor" to the list of participants' characteristics, ethical concerns related to interviewing adults who both have developmental disabilities and are not their own guardians.

This brings us to our fourth and fifth criteria for participation in this study, which are also logistical – participants needed to live in the Edmonton area[19] (which was already the case if they received services from the aforementioned community disability agency) and, due to this study's in-depth nature and because I am not bilingual, participants needed to be able to speak English. Had the study not been as in-depth, it may have been possible to use assistive communication devices, such as images. Indeed, in the previously mentioned My Life Survey, participants were able to respond to questions by pointing to pictures of happy, sad, or neutral faces. Nonetheless, to participate in this study, participants needed to be adults (age 18 and over) with developmental disabilities (as defined by PDD) living in Edmonton who were their own guardians and could speak English.

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[19] I initially considered interviewing adults with developmental disabilities at the agency where I worked in Lethbridge. Indeed, I had connections there but realized these individuals may have experienced difficulty in distinguishing between my roles as researcher and as former support staff. Therefore, they could have felt obligated to comply with the research or thought I was capable of changing things in their lives I could no longer influence. Similarly, Irvine discusses concerns about role conflict during a project involving individuals with developmental disabilities (2010, p. 25). Like myself, here, "researchers had to be conscious not to fall into a role of support personnel (a role they had previously worked in) while interviewing the participants" (Irvine, 2010, p. 25).

Because it was anticipated the interviews would be long (approximately an hour to two hours each), I was advised by my supervisors to recruit a total of five participants. However, because I had already conducted one interview during my exploratory project with an individual who met the participation criteria (the other interview was with an individual who had a public guardian), and she and the University's Research Ethics Office granted my request to reuse this data, it was only necessary to recruit four more participants. I was willing to interview up to ten individuals in attempts to achieve saturation (i.e. no new topics emerge after coding the transcripts), however, this was not necessary. Thus, the purposive sample[20] used for this research was comprised of five participants who met the aforementioned criteria, and was therefore non-representative of any specific population. Furthermore, the findings of this study are not generalizable to any specific population; however; qualitative researchers have repeatedly emphasized that generalizability, at least in the traditional quantitative sense, is not the purpose of qualitative studies (for instance, see Sandelowski, 1996). Rather, such studies seek to develop "an adequate description, interpretation, and explanation" of a particular case (Maxwell, 2013, p. 79), and may contain "idiographic generalizations" (as opposed to those of a nomothetic nature and typical of quantitative research) (Sandelowski, 1996, p. 527).

Participant recruitment

Due to the strict inclusion criteria for participants, the use of an intermediary in participant recruitment was appropriate and necessary for this study. As previously mentioned, during the course of my exploratory project at a community disability agency, a senior manager volunteered to recruit participants, and I chose to accept this offer. He or she had extensive knowledge, experiences, and connections related to developmental disabilities, and was consequently more than qualified to fill this role. Thus, this individual became this study's gatekeeper, and I continue to enjoy a good working relationship with him or her. I

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[20] Researchers who engage in purposive sampling select those participants they think will be most useful to the study (Babbie and Benaquisto, 2010, p. 182).

am fortunate in this regard, for the success of such relationships is not a guarantee and requires ongoing negotiation (Maxwell, 2013, p. 90).

The gatekeeper freely provided informed consent to be involved in this study. The confidentiality and consent form he or she signed stipulates, among other things, that his or her identity (including workplace) will remain confidential (i.e. only the participants and I know who he or she is), that the gatekeeper must maintain the confidentiality of participants' identities (i.e. only he or she and I know who participants are), and that the gatekeeper had the right to discontinue his or her role in recruiting participants at any time without consequence (see Appendix).

Thus, the gatekeeper and I worked together to form a group of four participants who met the previously mentioned criteria and who ideally expressed, directly or indirectly, to the gatekeeper that they had a wide range of experiences with health care services (purposive sampling), as I thought the inclusion of various experiences would assist in achieving saturation. Although it is possible that the gatekeeper's biases influenced participant selection, this is not of concern as the sample is not meant to be representative. After identifying potential participants, the gatekeeper individually approached them about the study and, if they were interested, provided them with my contact information and a letter (see Appendix) and/or DVD about the research. The latter was produced following the gatekeeper's advice that film can be a more accessible medium for individuals with disabilities than the written word, and that providing such a visual aid can facilitate informed consent. Indeed, non-print materials can be a key resource in communication with individuals with disabilities (Hansen and Janz, 2009, p. 31).

However, recruiting participants was easier said than done. Indeed, given the small sample size and large clientele of the community disability agency (approximately 300 individuals), at the outset, it seemed highly unlikely that participants would need to be recruited by other means. While such a situation thankfully never transpired, at one point, I thought it would be necessary for me to locate another disability service-provider in Edmonton that was willing and qualified to act as a gatekeeper, with the responsibilities discussed previously. In hindsight, I believe difficulty in recruiting participants likely arose because I overestimated how many individuals were their own guardians; the gatekeeper often mentioned how much easier participant recruitment would be without this criterion. Consequently, if I were to do it all over again, with the assistance of the gatekeeper, I would ensure the existence of many potential participants at an earlier stage in the research process, and, if their availability could not be confirmed, I would be prepared to make connections with another disability service-provider.

Instruments and data collection procedures

Despite these setbacks in recruiting participants, I conducted five interviews by mid-September 2013; although there were only four new participants, I interviewed the first participant (from the exploratory project) a second time to ensure I asked her the same questions I asked other participants.

As previously demonstrated, many decisions regarding this study's methodology were determined by ethical considerations, and the details of its data collection procedures are no exception. For instance, because participants were their own guardians, they had the capacity to give free and informed consent. However, I expected participants might still experience difficulty in reading and/or comprehending the consent form. To remedy this difficulty and ensure informed consent was obtained, the consent form was written in an accessible manner (see Appendix). Additionally, I read aloud and thoroughly explained to participants the details of the consent form and information letter; I emphasized the purpose of the interview, the voluntary nature of their participation, that they could refrain from answering questions, and that they could end the interview at any time without consequence, noting that withdrawal of responses would not be possible after September 30, 2013. Furthermore, I answered any questions participants had and explained their identities would remain confidential rather than anonymous, due to the use of a gatekeeper in this study; that is, the gatekeeper is unable to link participants to specific responses unless he or she has knowledge pertaining to these responses due to his or her ongoing associations with the participants.

Secondly, knowing that some individuals with developmental disabilities are unable to write their names (Molyneux et al. in Irvine, 2010, p. 26), and therefore sign consent forms, I made a provision in my ethics application that, if this was the case, providing audio-recorded, verbal consent would be an option; however, this was not necessary as all participants were able to write their names, albeit sometimes with difficulty. In this regard, I found it useful to carry a clipboard as a writing surface for individuals who were unable to reach a flat surface (for instance, because of a table not being the right height for their wheelchair). Indeed, these steps reflect the need for researchers to be prepared to use alternative means to document the consent of individuals with developmental disabilities (Molyneux et al. in Irvine, 2010, p. 26). For Irvine, it is here that "[v]erbal communication between the researcher and the participants becomes extremely important" (2010, p. 26).

In conducting these approximately hour and a half long interviews, I made use of an interview guide. This guide was designed with the feedback of others in mind to have face validity;[21] be comprehensive, straight-forward, and open-ended; and elicit participants' first-hand accounts. Therefore, in sharing their experiences, participants were prompted to include information about their identities, physical and social experiences within the broad context of the PDD program, as well as the meanings that independence and autonomy had for them, whether they felt this way, and why. Furthermore, this guide was tested in the exploratory project and subsequently refined.[22]

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[21] An interview guide can be seen as having face validity if its measures seem reasonable (Babbie and Benaquisto, 2010, p. 142).

[22] In particular, the interview guide was refined to include specific questions about autonomy and to address its relevance for individuals with disabilities, as per Calkins et al., 2011; Childress, 1982; Childress, 1990; Childress et al., 2002; Ells, 2001; Field et al., 1998; Lachapelle et al., 2005; Leece and Leece, 2011; Leece and Peace, 2010; Manning and Gaul, 1997; Nonnemacher and

During the interviews, I strived to be an active listener. It was important to me that participants be able to tell their stories in an unhampered manner, and direct the conversation as they saw fit. Moreover, doing so may empower participants and assist in rectifying the power imbalance between them and the researcher (Irvine, 2010, p. 24). My approach was beneficial when, for instance, towards the end of the fourth interview, the participant (Richard) explained he had been hit by a car as a child. Although I cannot say for certain that Richard would not have shared this story had the interview been more structured, this situation does demonstrate that important information can come out of what was otherwise seemingly irrelevant conversation. Nonetheless, there were limitations to these interviews, which were audio-recorded with participants' permission, and which I discuss in the analysis subsection.

Regarding compensation, each participant received a $25 gift card, from a range of choices, in thanks after his or her interview concluded. I decided to give gift cards in lieu of cash and without notice to avoid coercion, as adults with developmental disabilities tend to have low levels of income and could be persuaded to participate in a study by the prospect of a reward. After being interviewed, participants also received copies of the information letter and consent form. Additionally, the gatekeeper was provided with a $50 gift card in thanks after the last interview, which was in September 2013, and he or she did not know about this gift card beforehand.

Formal reflection

Switching gears a bit, as a qualitative researcher, I recognize I am the main research instrument (Maxwell, 2013, p. 91). Therefore, I have endeavored to be reflexive throughout the research process and in writing this thesis, making my

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Bambara, 2011; Palmer and Wehmeyer, 1998; Reindal, 1999; Shogren and Broussard, 2011; Sims and Gulyurtl, 2013; Wehmeyer, 1998; Wehmeyer, 1999; Wehmeyer, 2004; Wehmeyer, 2005; Wehmeyer, Bersani, and Gagne, 2000; Wehmeyer and Bolding, 1999; Wehmeyer and Metzler, 1995; Wehmeyer and Mithaug, 2006; Wehmeyer and Palmer, 2003; Wehmeyer and Schwartz, 1997; Wehmeyer and Schwartz, 1998; Wehmeyer, Kelchner, and Richards, 1996; and Wullink et al., 2009.

background, opinions, interests, decisions, and actions transparent, as they undoubtedly influence the outcomes.

Thus, in this subsection, I briefly discuss one of the more formal ways I strived to be reflexive. That is, as soon as possible after each interview finished, I formally reflected on the interview. In all cases, these reflections began within an hour and a half of the interview’s conclusion. Reflections included pertinent information that was not caught by the audio recorder, such as my impressions of the tone and quality of the interview, rapport with the participant, remaining questions, behavioral and other visual observations, and interactions with staff. These reflections were recorded in various ways, whether by handwriting, typing, or audio recording, and some of them inform the participant biographies found in the next chapter. Reflections were directly entered, scanned, or transcribed into an electronic research portfolio, which I began keeping prior to the commencement of this research and which I maintained throughout the research process. These reflections shed light on the interview process – encouraging me to make slight modifications (for example, attempting to schedule the interviews in the mornings to avoid researcher fatigue, and rethinking follow-up questions) – as well as ultimately facilitate a deeper understanding of the interview data, and, as Fox and Ward tentatively suggest, increase reflexivity (2008, p. 1013).

Transcription

Shortly after I completed each interview and formally reflected on it, I began transcribing the corresponding audio recording. In some cases, I was able to take this step on the same day as the interview or on the following day. While this turnaround was ideal as the interview remained fresh in my mind, it was not always possible due to the closeness of the next interview (for example, I interviewed two participants within the same week), or due to my other commitments. The maximum amount of time that passed between completing an interview and commencing transcription of that interview was three weeks, which was the case for my second interview as I was out of the province for that time.

Additionally, I did not transcribe more than one interview at a time; that is, I completed the transcript I was working on before beginning to transcribe the next interview. Working through and focusing on one interview at a time assisted me in gaining an intimate understanding of each participant which, for Sandelowski, is one of the quintessential purposes of qualitative research (1996, p. 525).

To facilitate the transcription process, I used Express Scribe v 5.55 NCH Software that was recommended by a colleague. Using this program involved transferring the audio files from the recorder to the software. I could then play the audio files at a slower or faster pace, and easily rewind, pause, or fast forward them while typing. These features assisted me to ensure the audio files were transcribed verbatim as accurately as possible, and were particularly useful when a participant was soft spoken or his speech was slurred (Sean and Richard, respectively).

Within each transcript, I noted background noises, interruptions (whether self- or other-imposed), and both my and the participant's tone of voice, memorable body language, short versus long pauses in speech, and vocal expressions such as laughter or words that were not fully formed. Later, when I coded or reviewed the transcripts, these notations assisted me to recall the context in which statements were made. I also made several attempts to understand any speech that was initially unclear, however, if an accurate understanding could not be achieved, I simply designated the speech as "[unclear]." While transcribing, I also took handwritten notes of any additional observations or insights, which were helpful in the analysis, construction, and interpretation of participants' accounts.

Coding

After all the audio files were transcribed, I loaded the completed interview transcripts into NVivo 10 – coding software I became familiar with during my role as a graduate research assistant at the City-Region Studies Centre (Faculty of Extension, University of Alberta). However, as part of my exploratory project, I had previously hand coded the first transcript using the processes of open and axial coding, which arise from the strategy of grounded theory. The purpose of open coding, as its name suggests, is to widely open inquiry (Berg, 2009, p. 353) while labeling categories (Babbie and Benaquisto, 2010, p. 326). These categories were descriptive in nature and identified, among other things, "the contexts, conditions, and consequences in which patients' [sic] accessed health care" (Charmaz in Ward, Nichols, and Freedman, 2010, p. 283). I had then engaged in axial coding – "intensive coding around one category" (Berg, 2009, p. 356) – by examining categories in depth, refining these categories, and identifying their properties (Babbie and Benaquisto, 2010, p. 326). Furthermore, I noted potential outliers, relationships, and subject changes, and considered why participants spoke about seemingly different issues simultaneously.

Thus, based on this preliminary coding and my familiarity with the transcripts, I was already aware of several codes that spoke to the data when I started using NVivo. Consequently, after loading the transcripts, I began by creating the codes – or 'nodes' in NVivo terminology – of 'advocacy,' 'autonomy,' 'birth place,' 'community involvement,' 'disability type and diagnosis,' 'education and school,' 'ETS and DATS,' 'independence,' 'self-description,' and 'shyness.' As was the case when transcribing the interviews, I coded the transcripts in chronological order. Here, returning to the beginning encouraged me to recall and focus on concepts from the first interviews rather than simply those that came out of the more recent interviews.

While the first ten codes I created in NVivo remained useful, it quickly became apparent that more codes would be required to accurately represent the data. Thus, as I worked through the transcripts, I created codes as needed. Furthermore, as new codes were developed, I reviewed the previously coded transcripts for instances where new codes might better represent the data, and recoded that data if this were the case. 'Romantic relationships' was the last code created and no new codes emerged after coding the fourth transcript, indicating that saturation had been reached. Additionally, due to the amount of codes, I frequently revisited my list of them to refresh my memory. By the time all six transcripts were coded, I had created 48 independent codes, or 'parent nodes' according to NVivo terminology – each with many subcodes.

Analysis

But what is a researcher, especially a novice one, to do with so many codes? Indeed, this is where things started to unravel and my use of NVivo became, well, useless. Despite or perhaps because of spending over a month meticulously coding my transcripts, line by line, the end result was rather disappointing. While this engagement facilitated familiarity with the transcripts, in addition to using too many codes, the codes I created were too general and had little if any explanatory power. For instance, while seemingly specific, even a subcode like 'AISH' (Assured Income for the Severely Handicapped) provided no sense of whether that participant received this financial assistance, was trying to secure it, or merely invoked it in some other way. Certainly, Fox and Ward, whose approach I turn to shortly, avoid this pitfall by using codes that reflect participants' engagement with topics (2008, p. 1013). Additionally, I became caught up in the technological capabilities of NVivo, concerning myself with the "analytical relevance" of the frequency and coverage of the codes, as well as the correlations between them – none of which bodes well for data analysis, especially of qualitative research.

During this time, one of my supervisors (Dr. Lisa Strohschein) and I reviewed the transcripts, in attempts to ensure all relevant information was identified; however; after doing so, we realized the interviews were limited in several ways. Recognizing that interviewing is a skill that takes time to develop, and that some challenges arose because participants were reticent (Abigail) or experienced difficulty communicating (Richard), a number of these shortcomings fell to me. For instance, the interviews were quite conversational and covered a wide range of topics, but sometimes failed to get to the heart of the matter; they suffered from lack of pointed questions and did not always achieve the level of depth required to ascertain how participants truly felt about the various topics discussed. There were times when I simply agreed with participants, rather than asking why they voiced a particular opinion, or, conversely, when I unintentionally led the conversation. The latter of these situations involves a delicate balance: although all interviewers direct the conversation to some extent, their questions need to be worded in such a way that they do not unduly influence the respondent's answers (i.e. ideally, the participant should respond based on how he or she truly feels about a particular topic). However, I was able to overcome some of these limitations in interviewing the first participant for a second time, which suggests this research may have benefitted from second or even third interviews with each participant.

Thankfully, Fox and Ward offer a way out of this lacuna through methodology they developed and applied to data concerning health identities (2008, p. 1012), but which I contend can be used just as fruitfully to understand disability.

Recalling the theoretical framework developed in the last chapter, Fox and Ward suggest that qualitative methods, especially interviews, "offer two ways into the Deleuzian ontology of the BwO and identity" (2008, p. 1012). First, they encourage participants to engage in reflection, which can result in de-territorialization (Fox and Ward, 2008, p. 1013); such reflection may result in an "'Aha!' moment" that enables participants to move from one type of territorialization to another more preferable type. Secondly, interviews are a tool for researchers such as myself to collect data about participants' relations (Fox and Ward, 2008, p. 1012-3). While I did not conduct interviews with this purpose in mind, all the topics and factors my participants discussed and with which they have connections – all the codes – are nonetheless relations. Therefore, it was easy for me to rearrange my codes to reflect participants' physical and social relations. Mirroring my own experience, Fox and Ward note the impossibility of ascertaining or explicating all a participant's relations, due to the incomprehensible amount of connections each of us has (2008, p. 1013).

Nonetheless, they maintain that interviews at least cover participants' main relations when they focus on particular areas, such as health identity (2008, p. 1013) or, as I contend, disability.

After coding, Fox and Ward recommend engaging with the transcripts, either manually or through software like NVivo, to identify key codes (relations) (2008, p. 1013-4). Such a process, I discovered, is thoroughly time consuming and misleading if one looks to the frequency, coverage, and/or correlations of codes for significance. Instead, one needs to consider the research questions and the codes that best correspond with them and, as per Fox and Ward, appear most salient in structuring participants' reflections on themselves and their lives (2008, p. 1014). For instance, in analyzing the data from an interview about "masculine health identities among young UK males," Fox and Ward identify 11 key codes (2008, p. 1013-4).

Similarly, having largely reorganized my codes into the two overriding sections of physical and social relations, I was able to identify four key codes (relations) within these sections that all participants appeared to associate with their experiences of disability. Specifically, all participants discussed how their relations with assistive designs and devices, medical procedures (physical relations), family, and disability support staff (social relations) were connected to their experiences of disability, as well as the meanings that independence and autonomy had for them, whether they felt this way, and why. As previously mentioned, in beginning to think about participants' relations, it is useful to remember that all bodies have an infinite amount of relations of a physical and social nature, as well as relations beyond these realms (for example, individuals also have political relations). Thus, while a complete account of the body-self, or BwO, would need to be based on *all* a participant's relations, because the focus here is on understanding experiences associated with disability, I chose to focus on those relations participants most clearly connected to their experiences of disability. For example, while all participants discussed the activities they participate in, these were not included unless participants clearly related them to disability, as they experience it.

Furthermore, while it is important to recognize that physical and social relations both constitute the body-self, it is helpful not to get too hung up on which realm any given relation belongs to. Indeed, these realms are not mutually exclusive and while the nature of a body's relations with, say, medical procedures is largely physical, the body also has social relations with these. For instance, and just to name a couple, individuals have social relations with medical procedures in that the necessity of these is usually determined through interactions with health care professionals working within the field of biomedicine (Fox, 2012, p. 96). Additionally, the degree to which an individual must pay for medical procedures is mediated by his or her health insurance plan, or lack thereof.

Thus, all these relations and the further relations they give rise to weave a web that is difficult to unravel, but that is okay. Remember, physical and social relations are equally valid and, ultimately, the realm relations come from is of little significance. However, in endeavoring to show that both types of relations do indeed give rise to the body-self, in the next chapter, I present participants' relations within the realm I think best captures their nature, as discussed by participants. Nonetheless, in attempting to create an account of participants' relations that is both as thorough and readable as possible, I also allow the other realm to creep in. Such an allowance occurs when, for example, I include the impacts of Marcia's past physiotherapy and current lack thereof (physical relations) within the social relations subsection.

Lastly, I would like to briefly explain some of the difficulties and considerations surrounding how to best present participants' accounts, which are located in the next chapter. While writing-up these accounts, I fluctuated between using a third-person perspective and using block quotations from the transcripts (the more traditional approach). Although I began by using block quotations, due to the conversational nature of the interviews, which the transcripts reflect, I felt that writing from a third-person perspective facilitated greater information sharing, as I was able to be more concise and highlight as much relevant information as possible. In doing so, my paragraphs were largely composed of participants' own words and direct quotations, although I "cleaned up" the latter in terms of grammar and repetition. Moreover, as much as possible, I tried to maintain the meaning, context, and order of their statements, while creating a chapter that was thorough and readable. Additionally, throughout this chapter, I had also incorporated my interpretation of participants' accounts, based on the theoretical framework of this thesis.

However, after presenting participants' accounts in this way, and showing them to my supervisors, it became apparent that participants' own voices had become lost. Although creating this invisibility around participants was certainly not my intention, it was nonetheless obvious and contradicted my initial aims in conducting this research. Thus, with the assistance of my supervisors and using block quotations, I reworked participants' accounts into their present form, which is more true to the participants, interviews, and spirit of this thesis. Moreover, aside from ensuring confidentiality, that I did not clean up these block quotations allows the reader to see for themselves some of the ways the body intruded during the interviews (for example, through communication difficulties), which I address further in the discussion chapter. Additionally, it became apparent that, in attempting to offer an interpretation alongside participants' accounts, I had inserted my own opinions and used language peppered with jargon. To overcome these limitations, I simply refer to participants' relations as experiences and refrain from discussing territorialization until I reach the discussion chapter. Thus, it is there that I interpret and demonstrate how participants' accounts fit within the guiding theoretical framework; that is, how territorialization occurs and how participants resist or accept this process.

Conclusion

In the previous chapter, I claimed that Deleuze and Guattari’s body-without-organs (BwO), as explicated by Fox, is best poised to facilitate a well-rounded understanding of a body capable of exercising agency and independence, especially when later applied to participants’ accounts. However, before presenting these accounts (in the next chapter), it was necessary to provide background on how this inductive research was conducted, including the rationale behind the steps taken to ethically gather and analyze these accounts. Specifically, in this chapter, I have discussed the exploratory project in which the first interview was conducted, before turning to the methodology behind this research. I strived to demonstrate that although this research is not particularly informed by any one of the main five qualitative research strategies, it more importantly builds on the theoretical perspective developed in the last chapter by being grounded in methodology developed by Fox and Ward, which is rooted in Deleuze and Guattari’s ontology (2008, p. 1012). Thus, this chapter bridges the theoretical perspective developed in the previous chapter with the presentation and interpretation of participants’ accounts in the remaining two chapters.

Chapter Four: Participants' Accounts

Having reviewed the theoretical background and steps taken to gather and analyze this study's data, perhaps you, the reader, have been anticipating the arrival of this chapter. It is now time to describe how participants experience aspects of their lives within the context of the Persons with Developmental Disabilities Program (PDD) and, in particular, to explore the ways in which their engagement in this program presents them both with opportunities and obstacles. I leave it to the final chapter to evaluate how participants' accounts can be interpreted in terms of the guiding theoretical framework of this thesis, by addressing at that point the issue of whether and how participants' accounts reflect territorialization of the body-self and allow possibilities for them to resist or be more independent. Regardless, it must be recognized that the presentation in this chapter is my telling; there is no neutral story given that the narratives gathered must be arranged in a meaningful way, with specific areas of interest reflected in the coding used and in the framing of excerpts.

Here, I introduce the participants by providing brief biographies on them, based on my impressions and information they revealed during the interviews. Having provided a glimpse of who these individuals are, I turn toward the research questions of this thesis. I first examine how participants interpret their physical experiences, with assistive designs and devices and medical procedures, as providing opportunities and constraints. Secondly, I consider participants' accounts of their social experiences with family and support staff, and the possibilities and limitations they feel these provide. All of these experiences take place within the broad context of the PDD program, and participants discuss their specific disabilities throughout their accounts. Lastly, given the extent of debates amongst practitioners and disability researchers, I consider the meanings that independence and autonomy have for participants, whether they feel this way, and why.

Participant biographies

The reader will recall that five participants were involved in this study, each of whom is his or her own guardian, resides in Edmonton, speaks English, is 18 or older, and classified as having a developmental disability, allowing them to apply for and, in these cases, receive funding from PDD. Many details about participants' lives are unveiled throughout this chapter, however, it is helpful to have some basics upfront, including their ages, type of residence, status as an employee or volunteer, and how they describe their disabilities. Regarding the latter, participants used biomedical terms such as cerebral palsy, epilepsy, and anaplastic astrocytoma throughout their accounts. Although discussed in the next chapter, that participants frequently described themselves with these terms, which appeared to be part of their everyday vocabularies, reflects the social function and explanatory power of these terms but also participants' medicalization or territorialization by biomedicine. Additionally, in these biographies, I have included my initial impressions of participants, which are recalled from the formal reflections I completed promptly after the interviews. Lastly, each participant was assigned a pseudonym and any identifying information has been removed from these biographies and their accounts.

To begin, the first participant I interviewed was Marcia, in February 2013. As discussed in the previous chapter, at the time, I was taking a qualitative research methods course and involved in a related exploratory project at the agency from which I would eventually draw all my participants. Certainly, my interaction with Marcia was an impetus for maintaining this connection; she was likable, easy to talk with, and despite her saying she tends to be shy, we had plenty to talk about. We also laughed a lot, which was therapeutic for me given that it was my first interview and I was a bit stressed about everything being in place.

Once the audio recorder was on, Marcia introduced herself as someone between 30 and 40 years old who was born in northern Alberta two months early with cerebral palsy. Marcia uses a wheelchair and, in her introduction, described herself as very outgoing and witty, but very shy when uncomfortable with something. I would interview Marcia for a second time in September 2013 to ensure I covered the same ground with her as I did with the other participants. At this time, Marcia had successfully moved from the “group home” she shared with three roommates to her own apartment, which she had been looking forward to for some time.

In the meantime, the second interview I conducted was with Abigail, who is between 40 and 50 years old, likes to bake and cook, volunteers, and describes her disability as having epilepsy. This interview was not conducted until five months after the first interview with Marcia, following the completion of my exploratory project and the approval of my thesis proposal. When I initially phoned Abigail to arrange this interview, our conversation was quite brief as Abigail provided short, clipped responses despite my mentioning I had met her before (at a workshop). However, based on our previous encounter during which Abigail was vibrant, likable, always smiling, and overall much less guarded, I was hopeful I could get her talking during our interview. I was able to re-establish this rapport to some extent; on the one hand, Abigail independently brought up several topics that she seemed comfortable talking about but, on the other hand, she sometimes appeared distracted and merely provided one word responses.

Less than a month later, I interviewed Lori, who is very outgoing, has a sharp sense of humor, and describes her disability as being hard of hearing. Even when setting up our interview and considering the need for privacy and lack of noise, Lori joked about everywhere seeming quiet to her. Lori is between 20 and 30 years old and was diagnosed with an anaplastic astrocytoma (brain tumor) when she was between 10 and 20 years old and living in British Columbia. Lori now lives in Edmonton and resides exclusively with her mom, as her parents have since divorced. She was the only participant who did not live in her own apartment without roommates, aside from the time prior to Marcia’s move.

Additionally, Lori has volunteered in the past but is not regularly engaged in this activity.

Later that month, I interviewed my first male participant, Richard, who is between 50 and 60 years old and retired after holding several paid positions. Richard was born just outside Edmonton and describes his disability as having a hard time walking. Nonetheless, Richard likes to walk and uses his walker to do so, in front of the building where he lives or at the farmers' market, where he goes every Saturday. On Sundays, Richard sees his mom, whom he helps and takes out for supper. Certainly, I found Richard to be very sweet and endearing. Unfortunately, it was often difficult for me to discern what he was saying and clarity was sometimes not reached, if it was at all, until after I returned home and listened to audio passages multiple times. However, as time passed during the interview, it did become easier for me to understand Richard and, as previously mentioned, through the quotations, it should be possible to see some of the ways the body intruded, although I address this topic further in the discussion chapter.

The last new participant, Sean, was interviewed five days after Richard, which was admittedly a tight turnaround. Sean resides in the same building as Richard[23] and is similar in age – between 50 and 60 years old. He was born in Edmonton and describes his disabilities as being unable to read or write very well, being unable to lift anything heavy, and having a bad shoulder. In his introduction, Sean described himself as "a really quiet person" and as "really hard to get to know with anybody," offering that it is hard for him to talk to women like me! Sean added that it is also hard for him to express his feelings and that he has always been shy. I found Sean to be exceptionally considerate and, like Lori, to have a keen sense of humor. Additionally, throughout his life, Sean worked as a paid employee at a variety of jobs and is now a volunteer.

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[23] Although Sean's apartment is in the same building as Richard's, they live in separate wings based on their individual needs.

While that brings us to the end of the participants, their characteristics are summarized in the following table for easy reference:

Table 1: Participants' Characteristics

Participant's Name	**Participant's Age in Years**	**Participant's Description of his or her Disability**	**Participant's Type of Residence**	**Participant's Status as an Employee or Volunteer**
Marcia	30 - 40	Cerebral Palsy	Group home with three roommates, followed by move to her own apartment	Previously a volunteer
Abigail	40 - 50	Epilepsy	Her own apartment	Volunteer
Lori	20 - 30	Hard of hearing	Family home with her mother	Previously a volunteer
Richard	50 - 60	Hard time walking	His own apartment	Retired; previously an employee
Sean	50 - 60	Can't read and write very good, can't lift anything heavy, bad shoulder	His own apartment	Volunteer and previously an employee

Limits, opportunities, and physical experiences

Now that we know a bit about the participants, let us consider how they interpreted their physical experiences, with assistive designs and devices and medical procedures, as providing opportunities and constraints.

Experiences with assistive designs and devices

All participants discussed their physical experiences with assistive designs and devices, and their perceptions of the limitations and opportunities these engender. Here, I present Marcia's, Richard's, and Abigail's accounts of these experiences.

To begin, Marcia discusses how her use of a wheelchair both constrains and enables opportunities. Regarding the former outcome, in returning to a conversation about how she has “always wanted to be like, a social worker,” Marcia expresses her feeling that her use of a wheelchair led to her being stigmatized when she was investigating employment opportunities:

> <u>Interviewer:</u> “I remember, you said, you would like to be a social worker.”
> <u>Marcia:</u> “Uh huh. Uh huh.”
> <u>Interviewer:</u> “Have you still been thinking about that at all?”
> <u>Marcia:</u> “Yeah I went for some, testing and stuff. ‘Cause you know, ah, because, I’m in a wheelchair and they like to put like stigma on you. ‘You only have to go for testing,’ and see, if you’re smart enough pretty much. And s-, pretty much told me, I wasn’t. So [laughs] umm, I’m just thinking like, not to totally give up but to, what other avenues I can go through right now. ‘Cause they also told me [clears throat] I would need to take some upgrading because, like I said [laughs] because I wasn’t that smart. So they told me that I needed upgrading and, yeah all that fun stuff. So umm, I am working on a couple of goals, to go back to school and to go on a holiday [says proudly] by the end of 2014.”

Nonetheless, Marcia also shares how her use of a wheelchair enables her to do many things. Not only does she use it to be more mobile, which is a feat in itself, but she also uses it to her advantage in uniquely personal ways. For instance, Marcia uses her wheelchair to participate in yoga (her “new favorite” activity), during which she relaxes, notices all her muscles, and can get out of her chair with assistance. Use of her wheelchair also allows her to physically and socially connect with the bodies of others, as in when her caregiver’s child jumps up for a ride on her lap:

> <u>Marcia:</u> “Umm. I know you’re supposed to like, umm, well, they always want me not to not carry her but I do carry her like I, umm, I carry her on

> my lap like if we go to the mall together. And she, always jumps up on me. And, yeah, calls me Auntie Marcia."

Another example Marcia offers of using her wheelchair in ways that exceed and transgress its original purpose is her humorous recollection of her and her sister horsing around, with her sister pushing her in her manual chair and having it up on two wheels. Therefore, while Marcia feels she is sometimes stigmatized, she also shares how she is able to explore many opportunities by making her wheelchair her own and using it to participate in her own way.

Turning to assistive designs, Marcia spoke of her experiences with these in reference to her new apartment, which she acquired between our first and second interviews. Marcia's apartment and several other suites in her building are meant to be wheelchair accessible; however; Marcia finds that her apartment does not meet all of her needs. Although her individual apartment is stair-free and the doorways are larger, "the thing that sucks is that the cupboards are like, so high," making it next to impossible for her to open, let alone retrieve items from, these cupboards. Moreover, Marcia points out that her apartment contains carpet which she believes should not be there because her wheelchair tracks in mud and snow:

> <u>Marcia:</u> "Even they put carpet in the, in the apartment. Like for a wheelchair accessible apartment there shouldn't be carpet. Yeah 'cause the m-mud right? Yeah. And, the snow in the winter and, yeah. But, I guess they'll learn. When they go to build the next building."

Accordingly, Marcia suggests that, prior to building these apartments, an individual in a wheelchair should have been solicited to design his or her own suite and offer advice that would be taken seriously:

> <u>Marcia:</u> "They almost should have had someone, like in a wheelchair, design their own apartment. You know what I mean like?"

> Interviewer: “Yeah. That’s a great idea.”
> Marcia: “As they were building the building you know.”
> Interviewer: “Yeah. I’d be curious to know if they asked anyone’s advice. Hmm.”
> Marcia: “Probably not. I mean they probably did but they probably, didn’t listen to anyone.”

While it is clear that the apartment has been designed in ways that overlook the needs of those with physical disabilities, Marcia herself is quick to say that she loves living in her new apartment. The thing she likes most about it is having “the independence to do whatever” she wants, such as being on the computer for however long and being able to go out when she wants with nobody telling her what time she has to be back. Referring to when she lived with roommates, Marcia feels she has more freedom now and in her words, “I could pretty much do whatever I wanted but like, outside of the house right?”

For another participant, Richard, his experiences with his walker are similar to Marcia’s experiences with her wheelchair. That is, Richard’s walker is not a barrier but facilitates possibilities, letting him access the outdoors or community in his own way. Indeed, he enjoys using his walker in front of his building or at the farmers’ market on Saturdays:

> Richard: “I like to walk around. I use my walker to walk around in the front or in the, the farmers’ market and a place that I like.”
> Interviewer: “Mmm. Do you go down to the farmers’ market pretty often?”
> Richard: “Yeah. Every Saturday.”

Moreover, it is important to Richard that his walker be the right height for him, and he likes being able to carry it on the bus or sit down and rest his legs on it:

> <u>Richard:</u> “They give me one of those grey ones [the one he currently has]. We had a low walker. That not low.”
> <u>Interviewer:</u> “And, and this one’s better right?”
> <u>Richard:</u> “Yeah. My height for me.”
> <u>Interviewer:</u> “Yeah that looks like a nice walker.”
> <u>Richard:</u> “It is. I like the basket [unclear]. Stay on it real easy. Carry it on the bus or on the, sit down, put my legs on it.”

In short, while the walker represents to others that he has a disability, Richard himself is proud and emotionally attached to his walker.

Like Marcia’s wheelchair, Richard’s walker has also enabled him to connect with others. Although he has a different walker now, for a time, Richard was connected to a good buddy via a walker he had used and then given Richard to help him balance:

> <u>Interviewer</u>: “So do you wanna tell me a little bit about your disability [Richard]?”
> <u>Richard:</u> “Ah yeah I have a hard time walking. Use my walker. And my good buddy who passed away gave one of those to me to help me balance.”
> <u>Interviewer:</u> “Oh I see. Have you always had a bit of trouble with balance?”
> <u>Richard:</u> “Mmm hmm.”

Through this walker, Richard also developed experiences to other bodies when both his doctor and “some old guy” at his mom’s nursing home respectively repaired a wheel and twice fixed its brakes:

> <u>Interviewer:</u> “Do you have to take the walker in for repairs once in a while?”

> <u>Richard:</u> "Ah not this one ah yet. That other one's still half new. The red one got the wheel changed once in the [doctor's] office. He. Not really good job on the screw. Came off. And we got to trouble the brakes. One of my mom's old building."
> <u>Interviewer:</u> "So where did you go when you had to get the repairs?"
> <u>Richard:</u> "Ah went to Dr. ah try and make it to [my doctor's] ah clinic and ah behind the, ah, Superstore. We made it. They still had the wheel. He put a screw in there really not really tight."
> <u>Interviewer:</u> "Oh. So [your doctor] fixed it?"
> <u>Richard:</u> "Yeah the wheel, and ah, the brakes, my mom's old ah nursin' home. Some old guy got the, from that ah, ten-speed brakes put on the ah the red one. To fix twice."
> <u>Interviewer:</u> [laughs] "Well that's nice that those people could help fix it."
> <u>Richard:</u> "Oh yeah."

Thus, in describing his experiences with assistive devices, Richard also shares how they have allowed him to navigate the community, as well as connect with and receive assistance from others.

On the other hand, Abigail's experiences with assistive devices involve her wearing an identification tag that labels her as epileptic, and is meant to relay this information to others should she experience a seizure and be unable to communicate her need for assistance. However, in practice, Abigail became scared when she had a seizure on public transit and no one helped her, even though she was wearing her identification tag:

> <u>Abigail:</u> "One time I had a seizure on the bus. ETS bus once."
> <u>Interviewer:</u> "Mmm. What was that like?"
> <u>Abigail:</u> "It's scary."
> <u>Interviewer:</u> "Yeah. Were some people able to help you?"
> <u>Abigail:</u> [shakes her head]

> Interviewer: “No.”
>
> Abigail: “Like one time I, was off one of my meds they don’t know what to do because, I had one right beside the driver they didn’t even call. And next time if I go on the bus they should be, be aware that I’m wearing this [points to chain].”
>
> Interviewer: “Yeah. Were you wearing that at the time?”
>
> Abigail: “Yeah.”
>
> Interviewer: “Yeah. They should have done something hey? Yeah that’s not good.”
>
> Abigail: “Because they should be calling 911 if I had a seizure. But no…”

Thus, Abigail felt she did her part in making others aware that she might need assistance, and that these individuals should have met her halfway by responding appropriately. Although it has been 13 years since Abigail had a seizure, and presumably this experience on the bus, she continues to wear her chain and emphasized to me the importance of others knowing first aid, as we will see in the experiences with support staff subsection.

Experiences with medical procedures

All participants discussed their physical experiences with a variety of medical procedures, and their perceptions of the limitations and opportunities these engender. Here, I present Sean’s, Lori’s, and Marcia’s accounts of these experiences, in which, much like participants’ descriptions of their disabilities, the reader will note their use of medical terminology.

To begin, Sean has experiences with a battery of medical procedures, which he feels have enabled and limited him. Regarding the former outcome, he feels these procedures have allowed him to overcome injuries and greatly reduced the pain these caused. For example, when Sean was doing renovations, he noticed a “lump” forming on his body, but waited quite a while before seeking medical attention for what would be diagnosed as a hernia. Ultimately, Sean had three operations on two hernias, which were on each side of his body, as, after the first operation, Sean somehow ruptured the area that was healing. Although it was really painful, the area where this hernia was is better and has not hurt him ever since. Prior to being operated on, the hernia on the other side of his body was not as severe and now, similarly, this area is better than it used to be but hurts just a little bit. However, as a consequence of these medical procedures, Sean cannot lift anything heavy, and he attributes his receipt of AISH (Assured Income for the Severely Handicapped) payments to this:

> Sean: "Then I finally, finally got it fixed. What they did is umm she's move in and they put wire [unclear] put a wire mesh on it. They have to remove umm, some guts out of it that was rotten. Wasn't cancerous but they had to remove 'em. He missed them, so he removed them and then he put a, put a strong mesh on it. So it hasn't hurt me ever since. But the other one it hurt just a little bit. I got it operated on. Wasn't as bad as the other one. This one was really painful."
> Interviewer: "And is the other one better now?"
> Sean: "Ah that one is better and the other one isn't as bad. That's the reason why I'm on AISH. I can't lift anything heavy anymore. And I can't lift anything heavy 'cause of the surgery [unclear]."

At the time of our interview, Sean was anticipating another surgery, however, he expressed his uncertainties about what this procedure would entail, as well as his sister's worries regarding its efficacy. According to Sean, he has a bad shoulder that sags, with a rotator cuff in "such bad shape" it needs to be replaced – everything needs to be realigned, though he does not know if the surgeon will raise his shoulder up or "put pins in it:"

> Sean: "But [the specialist] said ah this shoulder notice it sags?"
> Interviewer: "Okay."

> Sean: “That’s [unclear]. I dunno if they’ll they’ll raise it up. My doctor says rotation cuff’s in such bad shape, that it’s gotta be replaced. Realigned everything and then set things up. I dunno if he’s gonna put any pins in it or not though. I’m not too sure.”
>
> Sean: “Yeah my sister isn’t too sure if it’s a good idea. Sometimes they don’t work out.”
> Interviewer: “Well, umm have you talked to your doctor about it?”
> Sean: “I tried I’ve gotta phone him. He said he will be back sometime next weekend.”

Thus, Sean was going to call his doctor in attempts to alleviate these uncertainties, and try to soak his shoulder in a hot tub in the meantime.

Similarly, Lori’s experiences with medical procedures are complex, and she feels these have been limiting and enabling. When Lori was finally diagnosed with an anaplastic astrocytoma (brain tumor), the suggested treatment was surgery, chemotherapy, and radiation. However, before the doctors would operate, they asked Lori, who was between 10 and 15 years old at the time, to sign her own consent form for this procedure. In addition to some of the complications she experienced, Lori describes this situation and how she felt about it (that it was peculiar, confusing, and led her to feel pressured):

> Lori: “So umm I had surgery the next day. ‘Cause I was really, really quite sick, and, umm the funny thing is is, at the hospital, they made me, a [10 – 15] year old sign for my own surgery.”
> Interviewer: “That is interesting.”
> Lori: “In BC they consider if the child they think is mature enough. They can be responsible for making their own decisions. So my mom she actually signed too because she didn’t want me to feel bad if something went bad, like the surgery... Well I did have umm, major complications. I

> had to learn to walk again, talk again, and think again. I didn't know my name for, probably about, four years. I was [the same] age until I was probably about 20 [laughs], which was interesting. Every ev- it was [the same age] for everything 'cause it was just what was kind of stuck in my brain. Umm so my long-term memory is, somewhat good. I still get foggy but umm short-term memory's shot."
>
> Interviewer: "Just going back to when you said they had you sign the release form for your own surgery. Do you remember what you thought about that at the time?"
> Lori: "I was somewhat confused, well I I was, well basically. I'll answer the question and hopefully remember the rest of it later [laughs]. But umm basically I was confused big time because, all I knew was they took a picture of my brain. And like they, explained a little bit about things but they compl- the doctors still like I was [10 – 15 years old] and even probably if I was 20 the way they explained it to me, I wouldn't understand it. 'Cause they use their technical, big words and stuff like that."
>
> Lori: "Umm, I *really* didn't wanna do it but they kinda make you feel like you're important and you have to do it kind of thing. And my mom didn't want me to do it 'cause she didn't think it was right. And, the thing is umm BC law. I don't know if they changed it now but it was really fuzzy like it was just if the medical profession thought that the child was mature enough they would let the child decide things."

In addition to those complications previously described (being unable to walk, talk, think, recall her name or age, and easily access long- or short-term memories), in expressing her belief that she and her mom were misinformed, Lori explains the impacts of her whole head receiving radiation:

> <u>Lori:</u> “We were led to understand that the little laser targets would just target certain areas but, it was actually like you know when a bullet explodes? So even though they had the little laser lined up the whole head was kind of done.”
> <u>Interviewer:</u> “Oh. So maybe like a spray action?”
> <u>Lori:</u> “Yeah like a spray bottle like a [unclear] wide spray. So that caused a lot of damage as for the short-term memory loss and some other issues are going on.”

Moreover, Lori feels that while her doctors told her certain side effects were possible or more likely, they did not mention her hearing could be affected. Now, she is severely hard of hearing but does not yet need a cochlear implant, which she sees as a good thing although her hearing is becoming worse. Consequently, Lori experiences difficulty navigating various environments and feels she needs to insulate herself:

> <u>Lori:</u> “Umm, so, that was part of things and then the chemotherapy they said, there’s certain side effects that were possible or more likely to happen. One they didn’t mention period was hearing. And now I’m severely h-hard of hearing and it just seems to keep going downhill. So I’m too good for a cochlear implant, which is a good thing but I’m, not really that good in the outer world so I need to be bubble girl [laughs].”

However, while Lori’s experiences with medical procedures have clearly resulted in limitations and reinforced her dependence on others, Lori herself recognizes they also reduced the impacts of disease and ensured her survival. Indeed, even though the doctors were ultimately unable to guarantee they had removed and destroyed all the cancerous tissue, Lori thinks she would probably not be alive had she not been subject to these procedures. For Lori, there was a need to compromise and be decisive:

> Lori: "They wanted to make sure that they supposedly killed everything. But even after ph- all that phooey stuff, they can't really guarantee they killed everything so, it's kind of experimentation. I'm a guinea pig which is, okay 'cause if I probably wasn't experimented on I wouldn't be around anymore so, you have to give and take with things and split moment decisions, 'Sure! Let's just chop my brain up.'"

Alongside these hands-on medical procedures, participants had experiences with medical procedures for accessibility and safety, or lack thereof. In this vein, recognizing that hospitals have to be accessible for wheelchairs and other assistive devices and the sheer volume of people who are hard of hearing, Lori and her mom inquired about what Lori's hospital has for hard of hearing people. According to Lori, they were simply told the hospital does not have any sort of protocol. Furthermore, while staff in some wards may have decided to implement things themselves, this is not consistent throughout the hospital.

Thus, in addition to being familiar with the terror-inducing hospital experiences of other people with hearing problems, Lori's conviction that medical procedures for accessibility and safety are non-existent or inconsistent reflects her own negative experiences (feeling dependent or abandoned, discriminated against, afraid, unsafe, and overwhelmed):

> Lori: "So, basically, you need to have somebody like a family member with you which isn't always possible or else you're just left there. So umm there's a couple of [people] that have gone in like whether it's, for cochlear implants or for other things but umm, they have some hair raising experiences, going into the hospital and hearing problems."

> Lori: "It's truly discrimination 'cause they don't have supports for other people which are hard of hearing and it's not like they would have to revamp the whole hospital to put them in. Well like I can under- like even

> if they had like even on each ward they had one room that was setup for people that were hard of hearing, which could also be setup for patients that are other issues too. But like umm, if there's emergencies they won't hear the alarms going to get out. And there's no flashing lights or anything like that and. I've yeah it's a nightmare being hard of hearing 'cause you don't hear noises coming behin- well I don't hear them behind me. I don't hear car alarms or ah sirens umm the fire trucks, buses. I've nearly been hit by cars and mind you if you're in the hospital there's not usually cars in the hospital [laughs] but yeah there's... So it's, not safe whether you're in a supposed safe environment or w-whether you're out in the open in public. So it's mind boggling."

However, in spite of these limitations, in these excerpts, Lori recognizes the possibility for things to be otherwise – for her and others' experiences with medical procedures to be different, better, and enable accessibility, safety, and, ultimately, independence. Indeed, Lori suggests the hospital needs flashing lights and could have just one room in each ward set up for people who are hard of hearing or have other needs. Additionally, she and her mom told the hospital staff about the supports implemented elsewhere:

> <u>Lori:</u> "They need to *think outside the box*. And it's just little things that they could do but, they don't want to do it and when we approached the hospital, to do the, we actually told them what was in those packages in [another province], and what they were doing and like there's like signages saying like umm, 'Give hearing aids before you speak to me,' or, 'Speak clearly and loudly,' 'Face me,' kind of thing, instruction signs."

According to Lori, she and her mom were told that the staff at Lori's hospital do not have enough time to engage in these practices. Nonetheless, Lori encourages people to recognize that although they may not be hard of hearing yet, sooner or later these issues will affect them. Therefore, they should consider that if supports are not in place at this point in time, when their hearing or the hearing of somebody they care about starts "going downhill," the supports will not be in place for them either:

> Lori: "People don't think. Like, 'Oh I'm not really hard of hearing so it doesn't affect me' but sooner or later they will be 'cause usually as you age your hearing doesn't usually improve and, they should think about that kind of thing and if it's not in place at this point in time when it comes t- their's time or somebody they care about's time that their hearing starts going downhill it won't be in place for them."

Lastly, in addition to experiences with hands-on medical procedures and those associated with accessibility and safety, participants had experiences with medical procedures of an interactional nature, which could be limiting or enabling. Indeed, when it comes to doctors working with individuals with disabilities, Marcia thinks doctors should not direct all their questions to attending caregivers because individuals might know how to speak up for themselves. Although Marcia concedes it would be difficult to question a person who is non-verbal, she maintains that questions should be directed to individuals who can speak clearly and well for themselves, as they may know themselves better than do their caregivers:

> Interviewer: "In general is there anything special you think doctors should know about people with disabilities?"
> Marcia: "Don't always ask the caregiver. 'Cause the person, might know how to speak up for themselves. I can understand if, the person is non-verbal, but if the person can speak, clearly and well for themselves then, ask the person, because the person, that you're talking about, knows themselves better than, sometimes the caregiver would."

Indeed, recalling when she was younger as well as times in Edmonton, Marcia feels her doctor only spoke with her caregiver, although Marcia admits she was "very, very shy" at this latter time. Now, she quickly speaks up for herself:

> Interviewer: "Has that happened to you sometimes, where, the doctor just talks to the caregiver?"
> Marcia: "Umm [laughs] yeah. Happened a lot when I was younger. And then, umm, well a lot here too when I, when I was very, very shy. That's why, but now I. I just like, quickly speak up for myself. And cut the doctor off sometimes before she can say, 'So what's wrong with her today?' You know?"

Similarly, Lori does not feel like doctors talk to her when her mom attends her appointments, although Lori thinks her hearing might play a role:

> Interviewer: "When you're at your appointments and your mom comes with you, do you feel like the doctors still talk to you? Or do you find they..."
> Lori: "No."
> Interviewer: "...address their comments more to your mom? Or?"
> Lori: "They address them more to my mom. Which might be hearing related."

Limits, opportunities, and social experiences

In the previous sections, we learned about how participants interpret their physical experiences, with assistive designs and devices and medical procedures, as providing opportunities and constraints. And yet, if we solely look to participants' physical experiences, we are left with an incomplete view of how they perceive their lives, limits, and opportunities. For instance, while we know some information about Marcia based on her physical experiences, these tell us little about the social elements of her life. We do not know, for example, that she became less mobile after she and her family moved to a reservation. To understand this situation and others, we also need to consider participants' accounts of their social experiences, and it is to these that I now turn. Specifically, this section contains participants' accounts of their experiences with family and support staff, and the possibilities and limitations they feel these provide. These experiences are not mutually exclusive; that they overlap is indicated by Marcia's consideration of some support staff as family members or fictive kin, and by the role Abigail's dad plays in her experiences with support staff, among other things.

Experiences with family

All participants discussed their social experiences with family, and their perceptions of the limitations and opportunities these engender. Here, I present Marcia's, Lori's, and Richard's accounts of these experiences.

To begin, Marcia describes how her interactions with family are both enabling and limiting. During our first interview, a conversation about alternative medicine led Marcia to describe how her aunt, who is a medicine woman, said she could use her skills to help Marcia learn to walk again; although a doctor was unable to envision Marcia as ambulatory, Marcia's aunt challenged this view and was able to picture Marcia as an accomplished walker, achieved through the practice and application of traditional medicine. Because Marcia and her aunt were grieving the loss of Marcia's father at the time, Marcia told her they would discuss this proposition later. When asked if she believed her aunt or was interested in walking again, Marcia said she knows she could walk again if she really wanted, but it would require extensive physiotherapy. Moreover, Marcia explains how, before moving to the reserve, she participated in a special program that involved school in the mornings and physiotherapy in the form of swimming in the afternoons. However, when she no longer had access to the necessary resources, she was unable to continue her physiotherapy and became sad and depressed:

> Marcia: "Uh, my auntie on my father's side is a medicine woman. So she told me, just after my dad passed away, she's like, "You know, another

doctor's told you that you can't like walk," but that there is umm a way that she can help me, learn how to walk again, because, umm, she like a medicine woman right? I told her um, umm, at the time because she was grieving, and she was grieving the loss of my father, and I said, umm, I'll talk to you when you're, umm, a lot more healthy minded 'cause neither am I like I'm not healthy right now I'm not, umm, like I don't have a healthy mind because I just lost my dad and, umm, we'll talk about it but I haven't like seen her for, a long time. [Laughs] Which is actually kind of funny, umm, 'cause my mom just went to see her the other day and she says she's doing good."

<u>Interviewer:</u> "Oh that's good. So when [your aunt] told you that about, being able to walk again, did you, believe her or is that something you were interested in er?"

<u>Marcia:</u> "Umm, I know, I know I could walk again if I really wanted to umm, but it would take a lot of, physiotherapy. Like a lot of physiotherapy. And I would have been able to keep up my, umm, physiotherapy it's just that umm, when we moved from, [northern Alberta] when I was younger, 'cause I went to school in [northern Alberta], umm, they had like a special program, where I would go to school in the mornings, and then have my, like physio done in the afternoon. And, yeah, like, even on Wednesdays I would go, to the school in the mornings and swimming."

<u>Interviewer:</u> "Oh okay, and that was the physio. Swimming?"

<u>Marcia:</u> "Yeah. And, I was, pretty good little fish, and, I was actually pretty fit back then, and umm. But because we moved back to the reservation, it didn't have what I needed to keep up with my, physio. Like it didn't have the proper features [unclear], it didn't have the pool, didn't have, umm, [unclear], and then, uh, it didn't have that like it didn't, um uh, umm, that's why I, didn't like it and that's why I, umm, I guess in a lot of ways that's why I developed depression and sadness, umm, because I couldn't keep up my regimen of, physiotherapy I guess. Umm, but, now

> that I'm here in the city I'm always too active to, go swimming and, you know. But maybe once I move, I'll get somebody that really loves to go swimming and then, maybe they'll take me swimming too [laughs]."

Thus, for Marcia, moving to the reserve with her family triggered events (being unable to continue her physiotherapy and being unable to improve or maintain her mobility) that ultimately caused her to feel sad and depressed and which have contributed to her reluctance to try to walk again, despite remembrance of a body lived differently and the offer of assistance from her aunt.

However, Marcia also relays how, after moving to the reserve, she had the dream to be independent and on her own, which her parents supported and which has led to her living in her own apartment:

> <u>Marcia:</u> "So, yeah. 'Cause umm, I'll tell you umm, ever since I've was 13 I've always thought like, umm, maybe 12 or 13, I've always umm, had the dream to be umm, independent and on my own. Like, umm, like my parent always told me, they weren't like umm, 'Oh you can't do this because you're in a wheelchair.' They were always like umm, 'You can do it. You can do it. You can do it.' Umm, 'You just have to put your mind to it. And you have to focus,' like, 'You have to focus on, what you want,' 'cause they always said to us, 'We're we're not gonna always be here,' and stuff so umm, 'You, like you guys need to umm, focus on what you guys want,' and ah. Yeah when I first moved here it took me ten years to finally get on my own but it's umm, it happened."

Therefore, while moving to the reserve with her family was clearly a negative experience for Marcia, she feels these relationships have also contributed to her living on her own which, the reader will recall, she loves.

Similarly, Lori describes the difficulties associated with moving to a new province, and how her relationships and interactions with family have shaped her experiences in various ways. Here, Lori discusses how this move, her recent diagnosis, and lack of supports combined with her dad's job loss to create financial stress for her family:

> <u>Lori:</u> "And s- umm so it was we moved out to BC 'cause my dad got a job transfer. And umm within moving there, like w-within a month I got I was diagnosed basically. Umm but everything got a hundred times worse health wise. And with no supports, family or friends or knowing anyone or knowing even where the medical places are, it makes it tough. And then my dad got l- umm laid-off probably, I don't know not even a month after I got diagnosed so then there was no money, and lots of the medicine I was on wasn't covered. So when you're taking, four to six anti-nausea pills that cost 20 dollars each a *day*, it gets really, really costly [audibly inhales]. And then..."
> <u>Interviewer:</u> "That adds up fast."
> <u>Lori:</u> "...worst is if you're throwing them up then you're [laughs]. It's not getting any better so, it was quite, hard money wise too."

However, throughout our interview, Lori characterizes her mom as a force to be reckoned with – often laughing and referring to her as "militant mother" – and here explains the role her mom played in ensuring Lori received proper care during this time, and even in ensuring Lori's survival:

> <u>Lori:</u> "When I used to go for chemotherapy like after surgery and everything umm, you'd get to the chemo appointment and they'd sit you in the waiting room and it would be basically ten minutes to ten and all the nurses were putting their jackets on to go home. And we're still waiting there for chemo and they're like, 'Oh, you weren't seen? Well you can come tomorrow' kind of thing and it's..."

> <u>Interviewer:</u> “Oh no.”
>
> <u>Lori:</u> “...it’s like life and death if you don’t have the chemo at the right time it won’t react right. So my mom used to go berserk at them which, I’m sorry they deserved but umm like I know they have hectic lives [unclear]. But umm, then there was other days that we’d go in for the chemo and they’d have to order my chemo specially in ‘cause it was a different type. And they’d say, ‘Oh it didn’t arrive. [pause] Come back next week.’ M-my mom, ‘No you get that thing here right now!’ [laughing]. But umm if my mom wasn’t around I’d probably not be around too ‘cause she’s a little go getter [laughs].”
>
> <u>Interviewer:</u> “She sounds like it.”
>
> <u>Lori:</u> “She is. It’s that’s her job.”

Nonetheless, with no support from community services and her dad’s job loss, Lori speaks to the stress she feels she and others experienced while she was sick, and how her family structure changed. Indeed, her mom and dad began to have relationship issues, prompting her dad to attempt and ultimately succeed in leaving Lori and her mom to live on their own, which, for Lori, reinforced the importance of her mom in her life:

> <u>Lori:</u> “So it was really tough with no support and then mom we actually went to see a social worker once and basically she sat a-across the table from my parents and said, ‘Well what would you like to know?’ But like how could we know what was out in the world if they didn’t say, ‘Well if you’re having, [sighs] transportation issues or you need like homecare help or anything,’ ‘cause I never had, any sort of rehab or homecare or, anything. And, when you’re parents, well one of them’s working so, doing whatever, and then, he--- , then the family structure like my mom and dad started having, relationship issues. And then at one poin- because it was mainly probably ‘cause of the illness and the stress and stuff and then at one point my dad actually had his bag packed and was leaving, but umm,

> that's really stressful for everyone but, then my mom being the militant one said, 'You leave when I'll tell you to leave,' [laughs] kind of thing. So he didn't quite make it out the door that day [said jovially]. But it did happen eventually when we came back to Alberta but, you just kinda, learn who the important people in life are. Like militant mother [laughs]. Yeah so it being sick is really, stressful for *everyone*. Even the dog was stressed out."

Thus, while Lori is still in contact with her dad, she experiences this relationship as limiting and characterizes him as detached and unreliable:

> Lori: "He lives in Edmonton but he's kind of in name only so he's not a support in any way. He says that if I needed help he would but, I phone him, I leave him messages, I don't hear from him for a month kind of thing so. If there's an emergency he's not my number one call."

Lori and her dad further depart ways on the issue of her future, where Lori's opinions more closely mirror those of her mom and account for the restrictions bodies can impose:

> Lori: "So umm, like my mom she's more realistic than a lot of parents of children with issues umm but like my dad is unrealistic like he wants me to go to college and get a degree and get a full time job and I'd love to do that but my body has other plans."[24]

Therefore, for all these reasons, and while Lori's dad supports the possibility of her succeeding at post-secondary schooling and working fulltime, Lori continues to draw more strength from her relationship with her mom who, as we will see, encourages Lori's independence in her own way.

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[24] This statement reflects one of the few instances when participants directly distanced themselves from their bodies, maintaining the body/self dichotomy that Deleuze and Guattari's approach seeks to transcend.

Similar to Lori’s experiences with her mom, Richard describes how his relationship with his mom facilitated his recovery after a vivid childhood accident, in which he was twice hit by a taxi after exiting his school bus:

> Richard: “Right after [under ten] years old I got hit. Cab hit me. Comin’ outta the school bus. He didn’t he never stopped. And then he saw 12, 13, 14 police cars in front of him and he backed up and hit me again.”
> Interviewer: “No.”
> Richard: “Second time yeah. Wearin’ a body cast from here, all the way down my toes. With a bolt screw inside my ah keepin’ everything together.”
>
> Interviewer: “So did you stop going to school after that?”
> Richard: “No we had the teachers and my momma, she ah give me all the paperwork and...”
> Interviewer: “Oh good.”
> Richard: “...gave me all the, in an envelope. I watched that cab. Bus’s got the lights going and all the…”
> Interviewer: “So, you must have been in the hospital for a while.”
> Richard: “Uh huh wearin’ a body cast for a long time and then we finally get home and try walkin’ on the body cast went, went down, broke my cast, brought me another one. Mom take me down there, givin’ ah myself another cast. And then we w- start walk again after that. Then ah, next we could taken ah go to the [slightly unclear - Alberta?] get that cast off. I still had crutches.”

Thus, with the assistance of his mom, Richard was able to continue his schooling and walk again after this accident. Moreover, Richard relays how he now cares for his mom, by paying for supper, hanging up her clothes, assisting her with her wheelchair, and taking her to the store:

> Richard: “And I see Momma after Sunday. Help her out. Pay for supper. She lives in a nurses ah nur- ah, a-t the, at a place where all the nurses looks after her. Doctors.”
>
> Richard: “Goin’ to see Momma on S- and help her out a little bit. She’s in the wheelchair. The nursin’ home. A lot of nurses over there [unclear] her that. I [unclear] her. She got somethin’ hangin’ up me hangin’ up with t- one of those hangers and hang your clothes up for her.”
> Interviewer: “You do that for your mom?”
> Richard: “Uh huh.”
> Interviewer: “Oh that’s very...”
> Richard: “And I...”
> Interviewer: “...nice.”
> Richard: “...help her push her wheelchair in suppertime. Sometimes she wants go to the, grocery. Get little bottles of, ah fruit water. Or the big one. Do that for her and. Like a drugstore in front of the building [unclear].”

Experiences with support staff

In addition to participants’ social experiences with family, they also have experiences of this nature with support staff, which they variously perceive as limiting or enabling. Here, I present Abigail’s and Sean’s accounts of these experiences.

To begin, Abigail has social experiences with support staff that she experiences as limiting. For instance, Abigail explains why she feels her support staff are an obstacle to her gaining paid employment, and how she may have to speak with her dad and the “head boss” for her support staff to listen to her:

> Interviewer: “Do you work anywhere where you do get paid?”
> Abigail: “No! I’m trying to but.”

> <u>Interviewer:</u> “It’s taking a while to...”
>
> <u>Abigail:</u> “It’s umm. If I go- if I get a job paying that means I have to. Umm. I have to get up and quit complaining about my migraines. It’s hard. ‘Cause it runs in the family. I can’t, someone’s one of my staff says, ‘You’re playing games.’ I’m not! ‘Cause I get migraines because of my menstrual cycle or the weather [unclear].”
>
> <u>Interviewer:</u> “Yeah. Have you ever talked to a doctor about them?”
>
> <u>Abigail:</u> [sounding frustrated] “Yeah she said, ‘Take Advil.’”
>
> <u>Interviewer:</u> “Yeah. Does that help?”
>
> <u>Abigail:</u> “Sometimes. Depends on, [unclear]. Sometimes, depends on, sometimes. And sometimes it doesn’t. My team leader she says I’m playing games. I said, ‘No!’ And I said if she has any questions she can call my dad.”
>
> <u>Interviewer:</u> “Yeah. Do you see your dad pretty often?”
>
> <u>Abigail:</u> “Mmm hmm. I probably will give him a call later. And tell him, ‘One of the staff doesn’t believe me that I get mi- get mi- I do get migraines but she said I’m playing games. If I play games, she won’t let me get a like a paid job. With money. ‘Cause it’s not my fault.’”
>
> <u>Interviewer:</u> “No that sounds like a frustrating situation.”
>
> <u>Abigail:</u> “Yeah. And if she doesn’t listen to me I’ll go to the, go to the head off- head boss here.”
>
> <u>Interviewer:</u> “Yeah. Have you ever had to do that before? Go to the head boss?”
>
> <u>Abigail:</u> “Mmm hmm.”
>
> <u>Interviewer:</u> “Yeah. Were they able to help you out?”
>
> <u>Abigail:</u> “Yeah.”

In addition to her staff’s involvement in determining whether she is employable, Abigail’s staff play a role in her seizure protocol. However, Abigail feels this involvement is necessary, and explains how it provides her with some semblance of safety and security, although there is still room for improvement:

> Abigail: “If I go for a shower I have to phone down and tell them that I’m going to shower. ‘Cause if I go in the bath tub and I don’t tell them, I could easy drown. And some people say, ‘Why won’t you go into a bath tub?’ I say, ‘I can’t because if I have a ep-epilepsy seizure, who is gonna come and rescue me? No one.’”
>
> Abigail: “And some staff don’t know that I’m epileptic and I can, I can drown. And I said to(o), ‘They should take first aid on epilepsy.’ ‘Cause all staff should.”

Thus, Abigail feels her staff’s involvement in her life is justified to varying degrees (sometimes more than others).

On the other hand, Sean’s support staff are less involved in his daily life than are Abigail’s support staff. Thus, in discussing these experiences, Sean explained how he “was included for a learn how to read and write program,” which involved him meeting a tutor at the library. Although Sean feels this experience had limitations (as we will see in the next section), he expresses his genuine surprise and pride in having had his participation unexpectedly recognized:

> Sean: “Then one day I was sitting there and, here comes the [newspaper] [laughs]. Decided to take a picture of me and the tutor. I have a I have a picture in the [paper] of her and me.”
> Interviewer: “Well that’s that’s very nice.”
> Sean: “I’d never been on the paper before.”
> Interviewer: “Oh that’s exciting.”
> Sean: “Yeah.”
>
> Sean: “[My agency] had it in the front office some years.”
> Interviewer: “Oh nice. Yeah I’ll have to umm try and see that sometime.”

> Sean: "Yeah she made a whole bunch of copies and then she gave me a whole bunch of copies. Then I gave one to my worker. Yeah she was in the paper quite a few times. And they came over and decided to talk to me for a little while and they talked to her for a little while."
> Interviewer: "Yeah, that's really nice."
> Sean: "And then they took pictures."
> Interviewer: "Yeah that's a pretty special honor to be in the paper."
> Sean: "Yeah."

During our interview, Sean was eager to show me one of these copies but could not find it.

Meanings of independence and autonomy

To recap, in the previous sections, we examined how participants interpret their physical experiences, with assistive designs and devices and medical procedures, as providing opportunities and constraints. Additionally, we considered participants' accounts of their social experiences with family and support staff, and the possibilities and limitations they feel these provide. Although the notion of independence is invoked in some of these accounts, it is now time to more closely consider the meanings that independence and autonomy have for participants, whether they feel this way, and why. Certainly, as per the introductory chapter, independence in experiences and relationships is a preoccupation of disability services, and an important element in discussions of disability generally. However, assuming that independence means the same thing for everyone is problematic. Thus, understanding just what the construct of independence means to participants is an essential task; this would also be the case for autonomy, however, as mentioned previously, participants were unfamiliar with and therefore did not assign meaning to this construct.[25] Nonetheless, they were at ease with the term independence.

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[25] During the interviews, participants were asked if they had heard of autonomy. Despite indications that autonomy is a difficult notion for anyone to define, it was important for me to

For Sean, independence means "being alone and by yourself." When asked if he feels independent, he replies, "Umm, not as much as I would like to be." He would like to spell and read better, and although he was working on these skills with his tutor, as previously mentioned, here, he also speaks to how he felt limited in this program:

> <u>Interviewer:</u> "Have you heard of independence?"
> <u>Sean:</u> "Yeah."
> <u>Interviewer:</u> "Yeah, and, can you tell me what that means to you?"
> <u>Sean:</u> "That means ah being alone and by yourself."
>
> <u>Interviewer:</u> "Umm, do you feel though like you're pretty independent?"
> <u>Sean:</u> "Umm, not as much as I would like to be."
> <u>Interviewer:</u> "Oh okay. So are there certain things you'd like to be able to do that you can't?"
> <u>Sean:</u> "Yeah. I would like to spell better and read better. Like I was doin' that before. I have a real big binder full of that stuff I used to do. In my closet. All things I was doing over, the years with my tutor. I have in the binder. For a record."
> <u>Interviewer:</u> "So you did that for quite a while?"
> <u>Sean:</u> "Yeah."
> <u>Interviewer:</u> "Yeah. But then you, took a break?"
> <u>Sean:</u> "Yeah. I did a lot of reading for her. She would ah, she would read aloud, for a little while, in front of me, and then I would read out loud in front of... And then she would give me homework. Oh about ten pages, and I would have to fill them out."
> <u>Interviewer:</u> "Okay. And did you find that helped?"
> <u>Sean:</u> "Ah it helped a little bit."

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offer participants the opportunity to do so. However, despite its use in the literature and supposed relevance for individuals with disabilities, none of the participants were familiar with autonomy. Indeed, Sean was the only one who even guessed what this concept might refer to: "It means history kinda?"

> <u>Interviewer:</u> "I noticed that you have a sheet [on the table]. Is that for practicing your letters?"
> <u>Sean:</u> [picks up sheet] "Yeah I'm trying to do it."
>
> <u>Interviewer:</u> "Oh sure. So why did you decide to take a break?"
> <u>Sean:</u> "Ah I just figured that, figured that she was just telling me the same thing again and again and I didn't like that too much... Then she asked me if I wanna quit and I. I sort of said, 'Can you tell?'"
> <u>Interviewer:</u> "So when you start up again do you think you'll try to do it with a different person?"
> <u>Sean:</u> "I like the other person."
> <u>Interviewer:</u> "Yeah. Yeah. So is that something [your agency] might help you line up or?"
> <u>Sean:</u> "Yeah. We went to the office already. They're gonna try and find someone."

Thus, although Sean felt he had some success in improving his spelling and reading, which he associates with independence, he felt limited in this endeavor through his interactions with his tutor. However, this experience has not deterred his overall desire to spell and read better and, at the time of our interview, Sean had already requested another tutor.

Building on Sean's conception of independence as being alone and by yourself, Marcia explains how, having moved to her own apartment, she feels she has more independence than when she lived with roommates. However, Marcia adds her own twist in that, for her, independence also means choosing what she wants to do, rather than having someone else decide, and is a good way of learning life lessons, such as being less shy:

> <u>Interviewer:</u> "So, you said already that you feel like you have more independence living here?"

> <u>Marcia:</u> "Yes."
>
> <u>Interviewer:</u> "Yeah. So what does independence mean to you?"
>
> <u>Marcia:</u> "Independence means, umm. Choosing what I want to do and having no one like decide what I'm gonna do, for me. Umm. Independence is like, a good way of learning, life lessons. Umm. Ah [laughs]. I dunno [laughs lightly]."
>
> <u>Interviewer:</u> "That sounds really good. That sounds perfect. Umm, so do you think, like you said learning life lessons, so maybe umm, when you get to do things on your own, you learn things?"
>
> <u>Marcia:</u> "Yes. I learn not to be as shy [laughs lightly]."
>
> <u>Interviewer:</u> "Do you find you have to interact with more people? Or?"
>
> <u>Marcia:</u> "Umm."
>
> <u>Interviewer:</u> "Or different people maybe?"
>
> <u>Marcia:</u> "Yeah like different people every day. It's not always the same people. Like, umm when I'm out in the community by myself 'cause I do do that more often, umm. I'm having to, umm, talk more [laughs]. Umm and not be as shy and yeah. It's good but, I'm still l-like I struggle with it, but, it's part of learning right?"

Turning to Abigail, while she does not discuss independence at length, like Marcia, she associates this notion with living on her own, which she prefers to living with roommates:

> <u>Interviewer:</u> "You live on your own right now though right?"
>
> <u>Abigail:</u> "Yeah."
>
> <u>Interviewer:</u> "No roommates?"
>
> <u>Abigail:</u> "Nope."
>
> <u>Interviewer:</u> "Do you like that better er?"
>
> <u>Abigail:</u> "Yes. And I don't have no one to bug."
>
> <u>Interviewer:</u> "And no one to bug you [laughs]."

> <u>Abigail:</u> "Nope. I'm more independent that way. When I used to live with, with roommates it *is hard*. You have to have, s-. It's hard to figure out what they eat and what they like."
> <u>Interviewer:</u> "Mmm. 'Cause did you do the cooking?"
> <u>Abigail:</u> "Mmm hmm."

Similarly, Lori's understanding of independence is also associated with her experiences with others. However, Lori highlights the role her mother plays in attempting to foster her independence, and explains how her hearing and memory interfere with these attempts, causing things to become increasingly problematic and upsetting:

> <u>Lori:</u> "So umm my mom she would just like me to be able to cope with life and what it throws me which, I do in some ways but I'm not quite, there yet. I would say I'm 50 percent [laughs]. So umm she'd like it if I could go to the doctors and do that kind of stuff by mys- like self just going to into the appointment but we're still at the a t-time like she'll let me out of the car from the parking lot then I will, probably, 60 percent of the time make it to the right doctor's office [laughs]. There's been I was lost in the hospital for three hours trying to get to an appointment once [laughing]."
> <u>Interviewer:</u> "That's a long time."
> <u>Lori:</u> "'Cause- it is and 'cause, and then if you go to the front desk and you don't hear that well you say, 'Well I have to go to this doctor, and, [unclear] an eye appointment.' Then 'What's the doctor's name?' I'm like, 'I don't remember...' then that leads to further problems and then you can't really hear what they're saying and then you're getting upset and so then I just took off and started taking elevator rides everywhere and running around floors and [laughs] yeah so in the meantime I'm going up in the elevator my mom's going down... Yeah so that's when [my agency]

> realized I have a big issue. So umm, I think kind of my mom wants me to be independent but it might not be on the level as everybody else is."

While Lori is unsure whether she will be able to achieve her mom's "independence thing," she accepts it and tries – noting she feels her mom is more realistic than others. Indeed, she feels others' suggestions can lead to further problems:

> Interviewer: "So do you think umm maybe your mom has one definition of independence and you have another? Uh..."
> Lori: "Umm."
> Interviewer: " ...would that be a good way to put it or?"
> Lori: "It's sometimes yeah but I think she's a lot more realistic than a lot of other people. So I can accept her independence thing whether, it's gonna happen is another story but, I can I try things and, like I find umm a lot of people will suggest, 'Do this,' or suggest, 'Do that,' but then, this one crutch will give me five other problems in some other area."

Thus, for Lori, her hearing, memory, and others all play a key role in what independence means and how she pursues it.

And, last but not least, for Richard, independence involves looking good and trying to look after himself, which is something he wants to do:

> Interviewer: "So can I ask you [Richard] what does independence mean to you?"
> Richard: "Oh ah. Look good."
> Interviewer: "Look good? [laughs]"
> Richard: "Yeah. Look good. [Pause] I wanna try it myself. [Unclear] there you want is try [unclear] looks after myself. I'm gonna try to looks after

> myself. Years ago my mom one ah the, looks after the with kids. Now she in a nursing home. My brother, his wife, workin' [in another province]."

Thus, for Richard, it appears that independence (taking care of himself) is also associated with his mom being in a nursing home and no longer looking after him and his siblings – some of whom no longer live in Alberta. Richard feels he is able to be pretty independent; where he lives now, he has no trouble at all, the support staff assist with meal provision, and Richard also cooks his own food:

> <u>Interviewer:</u> "Do you feel like you're able to be pretty independent here?"
> <u>Richard:</u> "Oh yeah. No trouble at all. They keep food in that little room in there. In supper, breakfast, supper, and lunch area."
> <u>Interviewer:</u> "Mmm. So you go down there for your meals?"
> <u>Richard:</u> "Yeah. And I cook in here. Once in a while we buy myself popcorn chicken or the, Big Mac and chips and then we eat right here."

Therefore, while participants were unfamiliar with "autonomy," they were at ease with the term independence and expressed what this meant to them, whether they felt this way, and why. As we have seen, while there are some similarities, independence has unique meanings based on personal experiences and relationships. Aside from Abigail, who, as previously mentioned, only spoke briefly about independence, all participants expressed a desire to increase their independence, as they understood it – whether this involved learning how to spell and read better, learning to be less shy, navigating the medical system, or looking after oneself. Additionally, both Marcia and Abigail felt they experienced increased independence upon moving into their own apartments.

Conclusion

To summarize, the purpose of this chapter was to describe how participants experienced aspects of their lives, within the broad context of the PDD program. Specifically, we considered how participants felt they were presented with both opportunities and obstacles in their physical and social experiences, with assistive designs and devices, medical procedures, family, and support staff. Lastly, regarding independence and autonomy, we examined the meanings (or, with regard to the latter, lack thereof) that these notions had for participants, whether they felt this way, and why.

However, while we have learned a great deal from participants about their life experiences within the PDD program, and know from the introductory chapter the eligibility criteria they must meet to secure PDD funding, we do not yet know how this application process is experienced. Thus, looking towards the next chapter, in which I evaluate how participants' accounts can be interpreted via the guiding theoretical framework of this thesis (as well as situate the current study within existing research and consider this study's limitations and areas for further research), I would like to leave the reader with one last example. Although Lori was the only participant who spoke about applying for PDD funding, here, I present her account as a starting point (to set the mood, if you will) for the discussions that follow.

> <u>Lori:</u> "I've started I finally got funding through PDD. And that was a huge challenge 'cause like I just finished high school, which was a curse and a blessing but, umm we went we did a walk-in kind of thing to appoint- like we didn't have an appointment just we wanted to fill the forms out and see what PDD was about. Umm, we went there and, a lady came out and she gave us the form and she started talking to us and she she said, 'Here's the form,' and gave me a pen and said, 'Fill it out.' So I wrote my name down or something like that and she said, 'Oh no that won't do,' and she took the piece of paper, ripped it up, threw it in garbage, and said, 'So you don't qualify.' 'Cause I could write my name, and I was articulate. Supposedly articulate. [Audibly inhales] Yeah so umm..."
> <u>Interviewer:</u> "That's not right."

Lori: “...that wasn’t right protocol period but, they do that type of thing apparently a lot because they only have a certain budget and apparently if they’re under budget they get bonuses kind of type thing...”

Lori: “‘Cause umm, I was ripped up torn paper in front of us and then we just kind of left dep- sad and depressed kind of thing ‘cause like what are we gonna do now? And my mom’s stressing out. She was actually crying too because she because there’s no support, there’s no family.”

Lori: “But we’ve heard a lot of people being denied and they’re like really high risk type people that need, s- that type of help […]. But anyways umm, w- she my mom decided we’re gonna try this again. ‘Cause umm, apparently once you apply to PDD, if you get rejected which is usual umm you can reapply but you have to basically appeal and I think once you appeal once I don’t think you’re allowed to appeal ever again. So it was like a final decision. So, my mom with the help a l- of social worker, [my agency], and the umm, what’s the other one? Social worker and neuropsychologist umm decided that I should try to reapply but the problem is is, umm like I had the injury [before I was 18] but because I graduated high school and supposedly could write my name type thing that was points against me big time. And like when I graduated high school I had a full-time teacher’s assistant.”

Lori: “I had to go for a neuropsychology test […]. So, they said, ‘Why don’t you come and see our neuropsychologist and he’ll do the testing.’ I’m not naming any names. This is bad but umm, basically I went into the office and, he seemed okay and nice and, I always say yeah I’m gonna be friendly and nice with everyone until something happens [laughs]. And so anyways umm I knew that I needed this testing done to get what I needed, but umm, so the testing was done on the computer screen and I have umm multisensory, issues like ah, basically I get hand tremors and stuff like that and hand-eye coordination, I see double vision, and many other things I missed. Anyways umm, basically he wanted me I don't I think he showed you and of course memory things too so they showed you [unclear] how many words and then they take it away after 30 seconds and then they certain words kind of pop up. And you had to click something when you saw the word that was you remember. And of course, me i-it's mainly the memory stuff. I'm clicking the ones that I remember. Maybe I might remember them from 20 years ago [laughs]. And the short term memory I don't remember much period. So umm, then he accused me of cheating because I was getting them wrong. And I just turned to him and said, 'I'm getting them wrong because I thought I was getting them right?!' But anyways umm so he was actually yelling at me and I started crying and he was accusing me of cheating, and not even trying, and that just stressed me even further. And I'm sitting in this chair in this closed room like with no light like the lights are low and everything 'cause l-looking at the computer screen, and I was just cry-crying my eyes out and 'cause, like to me cheating is like one of the worst things in the world. I've always been taught that and it's I never do it and umm, I was balling my eyes out and I'm like, umm I actually felt like getting out of the chair and throwing it over and storming out of the room but, then of course I wouldn't get any funding 'cause I didn't finish the testing. So umm, so e-eventually he apologized. But for a professional, and actually the first thing that came to mind like kind of he said he was sorry and umm I said kind of, 'Okay,' but when I left my mom knew I was really upset. So once we left the building I told her what happened. So she's like, 'You're going to see the [agency] social worker or neuropsychologist,' […] so, umm, I left a message and the social worker called me back and she said, 'That's not very good, what happened.' She was really actually kind of upset and it when the first thing after I left the building I'm like, how many other people does he treat like this, so that they freak out..."

<u>Interviewer:</u> "No kidding."

Lori: "...and panic and do other stuff. 'Cause of course with the money issue but we're not going there [laughs]. Umm so anyways umm, basically my social worker called him [laughs] and […] he phoned the house after sh- he'd finished talking with her to apologize to my mother. I didn't want to speak to him [laughs] but mysteriously he said that I was approved. So I don't know whether the extra phone call from my social worker helped [laughs] or what…"

Lori: "So I'm glad I got my, PDD funding [said with relief] even if it did involve some stress and me wanting to throw the chair over and storm out but. I knew it..."
Interviewer: "I'm I'm glad you got it too, especially after all that."
Lori: "It was stressful but, I don't think if the phone call didn't happen it woulda happened, like they'd just probably said, 'Oh see ya' [laughs]."

Chapter Five: Discussion

In the previous chapter, we gained an understanding of how participants experienced aspects of their lives within the broad context of the Persons with Developmental Disabilities Program (PDD), including the ways they were presented with both opportunities and obstacles. Additionally, we learned that independence had unique meanings for participants based on personal experiences and relationships. In this chapter, I use a sociology of the body approach to interpret participants' accounts. Specifically, I address the issue of whether and how participants' accounts reflect territorialization of the body-self and allow possibilities for them to resist. Throughout this discussion, I emphasize the importance of taking the body seriously – explaining how the need to do so becomes further apparent when interviewing people with developmental disabilities – and situate the current study within existing research, including that on independence and autonomy. Accordingly, I then consider this study's limitations and areas for future research.

A sociology of the body approach to participants' accounts

Throughout this thesis, I have argued that there is a need to create a distinct sociology of disability, with a unified, core body of knowledge that transcends the stalemates occurring across the diverse yet interrelated fields of disability studies, the sociology of health and illness, and the sociology of the body. Moreover, I contend that the creation of a sociology of disability must respond to calls to reintroduce physicality, to understand impairment outside of the medical domain, among other things (Hughes and Paterson, 1997, p. 326). I maintain this endeavor depends on viewing the body in a particular way; that is, on having a model of the body. Given the breadth of work across disability studies, the sociology of health and illness, and the sociology of the body, we saw in the literature review that many body models exist. Additionally, we saw how others have used these models to speak more or less successfully to disability.

Thus, having examined the accounts of this study's participants in the last chapter, here, I use a sociology of the body approach to interpret these accounts. Throughout this interpretation, I indicate how the current study parallels with and departs from previous work and theory on the body, disability, independence, and autonomy, as well as emphasize the importance of taking the body seriously – theoretically and practically. Ultimately, this discussion reinforces my contention that Deleuze and Guattari's theory of the body-without-organs (BwO), or body-self, is the model best poised to facilitate a well-rounded understanding of a body capable of exercising agency and independence.

Cultivating a sociology of the body approach and considering participants' accounts in this light begins with the recognition that while accepting a disability diagnosis may allow participants to receive formal support through PDD, doing so simultaneously pathologizes and medicalizes them. In particular, in exchange for the services they received, the participants in this study were obliged to accept the biomedical label of "developmental disability." Indeed, as per the introductory chapter, for PDD, this label is comprised of the following measures:

1. The individual must have a 'significant limitation in intellectual capacity.' This means an IQ score of 70 or below.
2. The individual must have a 'significant limitation in adaptive skills.' This means the individual needs help with daily living activities like making food. PDD measures this by checking whether the person needs help with six or more out of 24 typical skills.
3. The individual must have had both of these two limitations before he or she turned 18 (Alberta Human Services a, 2014).

Because these criteria solely focus on limitations that are physical and functional in nature, they directly reflect a biological or medical model of disability. That is, PDD's funding approach relies on a medical model of disability, in which disability is a pathology that exists within the affected individual's body (Rioux and Daly, 2006). Ostensibly, once identified, disability can be managed on a case by case basis through biomedical treatments and rehabilitation (Rioux and Daly, 2006). Indeed, where rehabilitation is here secured through PDD funding and supplied by the majority of community disability agencies, the former is invoked through PDD's use of medical assessments to determine whether adults have significant limitations. For instance, in determining an individual's intellectual capacity, "[t]he I.Q. test must be administered by a registered psychologist under the Health Professions Act who adheres to the College of Alberta Psychologists Standards of Practice (2005)" (Alberta Human Services e, 2014).

Thus, that PDD adopts a medical model of disability, wherein disability is the terrain of doctors and other professionals (Rioux and Daly, 2006), is evidenced by its use of psychologists to assess individuals applying for funding, among other things, and showcases the power that "experts" have in maintaining discourses of disability, which have important real-life consequences. Certainly, while not necessarily representative of other participants' experiences, we saw at the end of the last chapter how Lori described the PDD application process – as a huge challenge, depressing, saddening, stressful, and really upsetting. Additionally, by using medical assessments to evaluate disability, PDD reinforces the medical establishment's role as a gatekeeper to disability benefits. As in other countries with social or welfare programs, here, access to economic supports and rehabilitation is regulated, as is assistive equipment, training, and education for individuals with disabilities (Albrecht, 1992, p. 67; Stone in Rioux and Daly, 2006, p. 307; Hansen and Janz, 2009, p. 31; and McColl, Jarzynowska, and Shortt, 2010). In sum, because use of the medical model involves focusing exclusively on the affected individual's body and neglecting macro-level, social factors, its application is both individualizing and depoliticizing. Therefore, disability comes to be viewed as a social burden but a private responsibility; that is, the onus is on the individual to do whatever it takes to not become a social burden.

Here, use of post-structuralist models of the body offer illumination. The reader will recall that, when viewed through this lens, impairment and its physical sensations are seen as power-embedded discursive constructs (Hughes and Paterson, 1997, p. 329 and 332). Thus, within post-structuralism, both impairment and the body are socially constructed (Foucault in Hughes and Paterson, 1997, p. 332). Because language is used to understand impairment and its associated physical sensations, impairment is seen as a product of language that can be subjected to discursive analysis (Hughes and Paterson, 1997, p. 329 and 332). Moreover, it is primarily medical language that is used to describe impairment and, thus, construct impaired bodies (Hughes and Paterson, 1997, p. 333). The diagnostic labels medicine applies to the body are embedded with meaning and therefore their assignment to the body also assigns meaning (Hughes and Paterson, 1997, p. 333). As a result, a particular type of body is produced with specific “signs, symptoms, behavior and normative expectations” (Hughes and Paterson, 1997, p. 333).

Thus, according to this perspective, because PDD determines eligibility for funding through medical assessments and diagnoses, and these are imbued with and assign meaning, they give rise to a particular type of body – namely, one that is pathologized and medicalized. While I would argue that this is the case – that PDD’s use of the medical model of disability does pathologize and medicalize individuals – we also learned in the literature review that there are limitations to post-structuralist models of the body. Of most concern here is that these models are deterministic and reductionist (Hutchinson, 2006, p. 9) because they dismiss, in part or outright, the body’s “underlying ‘natural’ or ‘bio-physical’ reality;” consequently, the body becomes nothing more than a product of discourse (Williams, 2006, p. 7) or another social construct, and effectively disappears. Indeed, using post-structuralist models, we are unable to fully account for instances in which the body plays a very real role, such as how Lori felt her experience of applying for PDD funding was affected by all sorts of body matters – her ability to physically write her name and speak articulately, as well as multisensory issues, hand tremors, hand-eye coordination, double vision, memory, and emotional responses. Similarly, an oft-cited concern with the use of post-structuralism is that if affords little if any agency to individuals (Fox, 2002, p. 348). Thus, application of these models fails to illuminate, among other things, Lori's response to PDD's assessment of her funding-eligibility.

The theoretical need to take the body seriously is also reinforced by practical considerations. Indeed, the body played a very real role in this study's methodology, particularly concerning communication. I was able to anticipate and accommodate some of these bodily interferences. For instance, because film can be a more accessible medium for individuals with disabilities than the written word, and thereby facilitate informed consent, the reader will recall that potential participants were offered a DVD about the research. That is, with the gatekeeper's advice, I was able to anticipate how the body might impact the research process with regard to reading abilities, and attempted to reduce this possibility. Indeed, Hansen and Janz suggest that non-print materials can be a key resource in communication with individuals with disabilities (2009, p. 31). Moreover, I anticipated the body might impact the research process in that many individuals with disabilities speak languages other than English, including sign language, and/or use assistive communication devices, such as pictures. However, because I am not bilingual and due to the in-depth nature of this study, it was necessary that participants be able to speak English. Thus, many of the considerations in the methodology chapter have just as much to do with the body as they do with ethics or logistics.

Nonetheless, there were ways the body interfered that I had little control over. In particular, I experienced several difficulties in conducting the interviews due to the body's tangible roles in these interactions. As previously mentioned, I attempted to show the reader where and how these intrusions occurred by not cleaning up quotations (beyond the need to ensure confidentiality). In particular, there were times when participants were soft spoken, mumbled, or slurred their speech. Although I often asked participants to clarify what they meant in these instances, sometimes the conversation changed and returning to the previous thread would have detracted from the current topic. Additionally, even though I experienced the most difficulty understanding Richard, it simply seemed inconsiderate to continuously ask him to clarify what he meant, especially when I felt I had a general idea. Afterwards, in transcribing the audio recordings of the interviews, I made several attempts to understand any speech that was initially unclear, however, if an accurate understanding could not be achieved, I simply designated the speech as “[unclear].” This practice is especially apparent in the transcript of my interview with Richard, in which “[unclear]” is written where many of his words should be.

My body has also played a role in the telling of participants’ stories. For instance, there were times during the interviews when I stumbled on my words and participants needed to ask me to clarify what I meant. Furthermore, during the first part of my interview with Sean, I could hear inconsistent yet loud construction noises coming from outside, which partially interfered with my ability to hear him. Additionally, my body played a role in transcribing, when I had to listen to and record what I heard from the audio recordings.

Thus, it is not only through speech that the body played a role in these interactions, but also through hearing, as well as body language, emotional expression, and in countless other ways – some of which are apparent within the quotations in the last chapter. To a certain extent, this focus on communication, telling stories, and the body in interaction reflects that of work being done within the symbolic interactionist strains of the sociology of the body. Here, the reader will recall that many of these scholars draw on Goffman’s pioneering work and apply his ideas to the analysis of the body and disability. For instance, Kelly and Field draw on the interconnected notions of identity, self, and everyday experience in their attempt to integrate the body into a sociological account of how chronic illness and, to a lesser extent, disability are experienced (1996, p.

241).

In considering Marcia and Richard’s experiences with their assistive devices, we can see parallels with those studied by Papadimitriou, who also understands the body as biological, socio-cultural, and capable of exercising agency (2008, p. 692). Specifically, she observes and interviews adults with spinal cord injuries who are learning to use wheelchairs and engaging in a “creative process of re-embodiment” (2008, p. 691-2). In doing so, she emphasizes how one’s use of a wheelchair can enable possibilities – for instance, through the performance of a “wheelie” (2008, p. 696-7). However, whereas Papadimitriou examines these possibilities alongside learning to use a wheelchair (2008), in the next section, I apply the model of the body-self to illuminate different aspects of the use of assistive devices – specifically, how Marcia and Richard use these devices in uniquely personal ways and thereby resist territorializing medical claims.

Additionally, in considering Lori’s relations with medical procedures for accessibility and safety, or lack thereof, the reader will recall that these caused her to feel dependent or abandoned, discriminated against, afraid, unsafe, and overwhelmed; in other words, she felt her relations with these procedures presented risks. In the literature review, we saw how Burns, Watson, and Paterson use the concept of risk to study the body and disability in the outdoors (2013). Doing so, these authors find, among other things, that individuals with disabilities identify three types of risk associated with the outdoors (2013, p. 1066). “Bodily risk” due to one’s impairment is the type cited most often, alongside descriptions of the imperative to be aware of bodily needs and limitations (Burns, Watson, and Paterson, 2013, p. 1066). In describing how her hearing influences her relations with medical procedures for accessibility and safety, Lori’s account mirrors these findings.

A view of participants' accounts through the lens of the body-self

Nonetheless, as previously argued, Deleuze and Guattari's theory of the body-without-organs (BwO), or body-self, accommodates useful concepts from a wide range of theories, as well as impairment and disability, agency and independence, and social factors. Thus, it is the model best poised to facilitate a well-rounded understanding of a body capable of exercising agency and independence, especially when applied to participants' accounts. In particular, using the model of the body-self, we are able to accommodate agency alongside external forces and ascertain one of the major insights of this thesis:

Although use of the medical model seeks to pathologize and medicalize (territorialize) this study's participants, as passive and dependent on the services offered to them, participants attempt to resist this territorialization in their everyday lives through their relations with assistive designs and devices, medical procedures, family, and support staff.

For example, in Marcia's account of her relations with family, we can see how a medical model of disability has been present in her life, and territorialized her to some degree as dependent on the services offered to her – namely, biomedical treatments and rehabilitation. The reader will recall that this is an individualizing and depoliticizing model, in which disability comes to be viewed as a social burden but a private responsibility; that is, the onus is on the individual to do whatever it takes to not become a social burden. Indeed, Marcia explained how, at an early age, she was diagnosed with cerebral palsy and enrolled in a physiotherapy program. Moreover, Marcia described how, although her parents acknowledged she used a wheelchair, they encouraged her to just put her mind to and focus on the things she wanted, because they were not always going to be around. Thus, Marcia was taught that she must accept responsibility for her condition and ensure she was not dependent on her parents, and that this could be achieved through physiotherapy and her own willpower. It is perhaps not surprising then that Marcia became sad and depressed upon moving to a reserve where she was unable to continue her physiotherapy, which she felt her mobility depended on. Indeed, Marcia felt she could walk again with extensive physiotherapy, and was reluctant when her aunt offered the same outcome with alternative medicine.

However, although participants might have been territorialized in part as passive and dependent on the services offered to them, there were ways they attempted to mitigate or resist this process – perhaps through relations they experienced as enabling (i.e. presenting opportunities). Indeed, although Marcia was reluctant to walk again, we saw how both she and Richard used their assistive devices – a wheelchair and walker, respectively – to participate on their own terms, whether outdoors or at yoga or the farmers' market. Moreover, both Marcia and Richard used these assistive devices to physically and socially connect with the bodies of others. Thus, by exceeding and transgressing the original purpose of their assistive devices, Marcia and Richard resisted the territorializing medical claim that assistive devices should chiefly be used for rehabilitation and to approximate the mobility of those who are non-disabled. Certainly, Marcia and Richard's use of their assistive devices was not governed by this medical ideal. Additionally, that Sean was so knowledgeable about the medical procedures he had undergone, and was actively seeking information about his proposed shoulder surgery, indicates his attempts to be a knowledgeable health care consumer, who does not merely accept the options offered to him but questions whether these are the best courses of action.

More generally, participants also attempted to mitigate or resist being territorialized (as passive and dependent on the services offered to them) by altering relations they experienced as limiting or constraining opportunities. For example, in response to the limiting role Abigail felt her support staff were playing in determining her employment opportunities, or lack thereof, she was considering speaking with her dad and the "head boss" to encourage her staff to listen to her. Additionally, we saw how Lori attempted to alter her relations with medical procedures for accessibility and safety, which she experienced as limiting, when she and her mom encouraged the staff at Lori's hospital to adopt the supports implemented elsewhere for those who are hard of hearing. Thus, participants actively attempted to change relations associated with rehabilitation and biomedical treatments that they experienced as limiting, and thereby resisted being territorialized as passive and dependent on these services. Moreover, Abigail and Lori drew on their relations with family – with Abigail's dad and Lori's mom, respectively – to engage in this resistance.

Therefore, while use of the medical model supports an outdated view of disability, it continues to have important real-life consequences. In particular, to receive PDD funding – the main form of financial support available to individuals with developmental disabilities – individuals must to some extent accept PDD's use of the medical model which seeks to territorialize them as passive and dependent on the services offered to them. In the preceding paragraphs, I demonstrated how this process is evident in participants' accounts, but also how they resist being territorialized as passive and dependent in various ways.

That participants can and do engage in these actions in their everyday lives provides evidence in contrast to both medical and social models of disability. Indeed, as we have seen, the medical model is unable to account for resistance – for individuals' agency and opposition to being pathologized, medicalized, and territorialized. Furthermore, while the social model locates disability and emancipation within social contexts, particularly of an environmental or human rights nature, we have seen that, for these participants, resistance is not occurring in courtrooms or mass political demonstrations; rather, it is occurring through participants' daily engagements, interactions, and relations with assistive designs and devices, medical procedures, family, and support staff. Therefore, resistance is neither absent nor confined to macro, political economic, structural, or human rights levels. It can and does occur through the body-self and its relations within the micro and mezzo levels of daily life.

By offering evidence to the contrary of both medical and social models of disability, these findings provide a call and reinforce the need to move beyond these oft-criticized frameworks. Moreover, I have briefly demonstrated how use of Deleuze and Guattari's theory of the body-without-organs (BwO), as explicated by Fox, could provide a viable alternative (a third way if you will) to conventional understandings of disability. Indeed, as we have seen, this model can be applied to usefully illuminate real-life situations. Instead of simply seeing disability as a product of either the biological body or structural factors, here, disability is seen as part of one's physical *and* social relations.

Furthermore, coming full circle, acknowledging that physical relations do play a role in disability (alongside social relations) allows us to bring the body back into conversations of disability. Here, we return to the underlying argument of this thesis: that the creation of a sociology of disability must respond to calls to reintroduce physicality – the accomplishment of which depends on viewing the body in a particular way; that is, on having a model of the body. Because Deleuze and Guattari's theory of the body-without-organs (BwO) is inclusive, comprehensive, and broadly applicable, among other things, I rest in my contention that their model is best poised to facilitate a well-rounded understanding of a body capable of exercising agency and independence.

Meanings of independence and autonomy

Regarding independence and autonomy, in the introductory chapter, I suggested that because disability service providers have an imperative to endorse independence, there is a need to examine the notions and experiences of independence belonging to individuals with disabilities themselves. Accordingly, we saw in the last chapter that, when asked what independence meant to them, participants responded in unique ways based on personal experiences and relationships. Aside from Abigail, who, as previously mentioned, only spoke briefly about independence, all participants expressed a desire to increase their independence, as they understood it – whether this involved learning how to spell and read better, learning to be less shy, navigating the medical system, or looking after oneself. Additionally, both Marcia and Abigail felt they experienced increased independence upon moving into their own apartments.

Thus, what it means to be independent varies by individual, and I suggest that attempts to facilitate independence should take these divergences into account. Respecting individual meanings of independence may be especially important within disability agencies that engage in rehabilitation. Indeed, this practice often relies on what guardians, agencies, and doctors want for a certain individual, rather than on what that individual wants for him or herself. Strohschein and Weitz refer to this structure as “a hierarchical pattern of care,” which operates under “the premise that social service providers understand clients’ needs, desires, problems, and strengths better than the clients themselves do and that social service providers are thus better equipped than clients to make decisions regarding clients’ lives” (2014, p. 191). Certainly, we saw how this was the case for Abigail, who felt her support staff did not understand the nature of her migraines, or even believed she experienced these. As a result, Abigail felt her staff unfairly restricted her employment opportunities. However, Abigail felt she could rally support from her dad and the “head boss,” which suggests it is possible for others to play positive roles in assisting individuals to achieve their goals.

Turning to autonomy, while I have not written about this notion at length, it is notable in its absence from the vocabularies of this study’s participants. Here, it is useful to compare this finding to those of Shogren and Broussard (2011), whose study draws on Wehmeyer’s work and initially provided a stepping-off point for my own research. Indeed, like me, they contend that the views of individuals with intellectual disabilities have not been systematically explored by researchers, and they seek to correct this discrepancy by conducting interviews with these individuals (2011, p. 86). Specifically, the purpose of these interviews is to ascertain the meanings and relevance of self-determination for members of this group (Shogren and Broussard, 2011, p. 86-7). Whereas autonomy and independence are both typically conceptualized as part of self-determination (Wehmeyer, 1996; Wehmeyer, Kelchner, and Richards, 1996), here, Shogren and Broussard do not specifically address autonomy. Nonetheless, of the 17 individuals they interviewed, 12 were at ease with the term self-determination, and "[t]hree said that they had heard of self-determination but were not exactly sure what it meant" (Shogren and Broussard, 2011, p. 90).

Similarly, in interviewing ten adults with developmental disabilities, Nonnemacher and Bambara examine how these adults feel that their staffs' actions impede or facilitate their self-determination (2011). Additionally, they ask their participants about what self-determination means to them, and represent these meanings with two themes: "speaking out and being in charge" (Nonnemacher and Bambara, 2011, p. 331). These findings are similar to those of Shogren and Broussard, who cite "choice and control, setting and working towards goals, and advocacy" as the key themes within their participants' meanings of self-determination (2011, p. 90). Interestingly, like Shogren and Broussard (2011), Nonnemacher and Bambara do not appear to use the term autonomy with their participants (2011). Moreover, they draw attention to the limited role of adults with developmental disabilities in Wehmeyer's measurements of self-determination, and instead seek "to understand the influences of self-determination from a personal perspective" (Nonnemacher and Bambara, 2011, p. 328).

Indeed, returning to the current study, it quickly became apparent during the interviews that participants were unfamiliar with the concept of autonomy, despite the existence of literature on its relevance for individuals with disabilities. Although participants were offered the definition of autonomy put forward by Wehmeyer (see 1996, p. 25; Wehmeyer, Kelchner, and Richards, 1996, p. 632; or page 6 of the introductory chapter), who is arguably the chief proponent of the importance of this concept for individuals with disabilities, participants seemed either complacent or confused about the role of "autonomy" in their lives. Admittedly, some of this misunderstanding may have been my fault; I could have had examples of autonomous behaviour on hand to offer participants or further encouraged these conversations.

Nonetheless, lack of familiarity with even the word autonomy and/or its meaning among this study's participants suggests there may be a disconnect between academia and people's lived experiences, which needs to be resolved if "autonomy" is to be meaningful to individuals with disabilities. Indeed, "autonomy" does not seem to be an organizing factor or ideal for participants, judging by its absence and the confusion around the term in the interviews. Additionally, that this study's participants were at ease with the term independence, and that individuals in other studies were comfortable with "self-determination," suggests these may be more accessible terms than autonomy.

Research limitations and reflections

However, like the notion of autonomy and all academic research, this study contains limitations and is not exempt from some charges. The reader will recall this study's sample was comprised of five adults (age 18 and over) with developmental disabilities, who were participants in the PDD program living in Edmonton, and who were their own guardians and could speak English. Thus, this is a very specific group; in particular, that they all received PDD funded services and were their own guardians is exceptional. Indeed, as previously mentioned, many adults with developmental disabilities are not their own guardians (Irvine, 2010, p. 25), and many individuals with disabilities fall through the cracks and do not receive support services.

While none of these characteristics are exactly limitations in the context of qualitative research, their consideration is still important. Despite the problems inherent in PDD funding, because they were able to access services, perhaps participants still had more support, opportunities, and possibilities to engage in resistance and be independent, among other things, than an individual needing but not receiving funding. We do not know. Moreover, we cannot assume that any individual meeting this study's criteria necessarily has limiting or enabling relations with assistive designs and devices, medical procedures, family, or support staff. Furthermore, relations themselves fluctuate, so that even though an individual might currently experience a particular relation as enabling, he or she may later come to see that same relation as limiting, or vice versa. Thus, the findings of this study are not generalizable to any specific population (please see the methodology chapter for further discussion of the notion of generalizability within qualitative research). However, use of Deleuze and Guattari's theory of the body-without-organs (BwO) is still applicable to studies of other populations and is encouraged.

Regarding limitations, although I have tried to mention them throughout this thesis, here, I highlight what I consider the main limitations of this study. To begin, these limitations arise from me conducting interviews without an understanding of the body-self, which became a crucial concept within this research. Although my focus at the time on experiences of autonomy within health care services did not necessarily call for knowledge of the body-self, such an understanding would have been beneficial when it became a pervasive, underlying topic across these conversations, especially in light of autonomy's absence. Therefore, there were instances when the body-self was brought up during interviews but dismissed or not explored as fully as possible. I neither knew to look for it, nor that "autonomy" would repeatedly be such a non-starter.

Consequently, had I known the idea of the body-self would form the basis of this thesis, and to generate a more comprehensive account, I would have familiarized myself with the sociology of the body literature earlier and altered my interview questions. For instance, I might have begun by asking, "Are you familiar with the criteria PDD uses to determine whether individuals are eligible for funding? If so, how do you feel about these measures?" Nonetheless, it is still interesting that the concepts of body-self and territorialization emerged during analysis as powerful ways of making sense of the interviews and the life experiences that participants spoke of.

I owe my ultimate embracement of Deleuze and Guattari's work to my supervisors, Dr. Lisa Strohschein and Dr. Rob Shields, who recognized the value of a more theoretical engagement, particularly with the body-self and its constraints and opportunities within the broader context of biomedicine, including the PDD program. As previously mentioned, this broader focus allowed me, on a small-scale, to bring the body back into conversations of disability. Nonetheless, that I chose to rely heavily on Fox's interpretation of Deleuze and Guattari's work warrants mentioning here. Indeed, his is only one of many readings of their work, but it is oft-cited, accessible (i.e. the text is user-friendly, whereas other interpretations and Deleuze and Guattari's original work can be highly abstract), and demonstrates how their theory can be applied to real-life scenarios within health and social care contexts.

Additionally, while recognizing that interviewing is a skill that takes time to develop, and that some challenges arose because participants were reticent or experienced difficulty communicating, I am responsible for several limitations concerning the interviews. For instance, the interviews were quite conversational and covered a wide range of topics, but sometimes failed to get to the heart of the matter; they suffered from lack of pointed questions and did not achieve the level of depth required to always ascertain how participants felt about the various topics discussed. There were times when I simply agreed with participants, rather than asking why they voiced a particular opinion, or, conversely, when I unintentionally led the conversation. The latter of these situations involves a delicate balance: although all interviewers direct the conversation to some extent, their questions need to be worded in such a way that they do not unduly influence the respondent's answers (i.e. ideally, the participant should respond based on how he or she truly feels about a particular topic). However, I was able to overcome some of these limitations in interviewing the first participant for a second time, which suggests this research may have benefitted from second or even third interviews with each participant.

Indeed, while time consuming, I recommend other researchers new to interviewing consider engaging in this activity a couple times with each of their participants. Doing so should facilitate greater levels of comfort and confidence, both for the researcher and interviewee, which will in turn lead to deeper, more meaningful conversation. Interviewing the same person across several sessions would also likely be beneficial when researchers wish to interview individuals with disabilities but have little experience with members of this population, or when participants themselves do not have prior experience with interviews. As always, practice makes perfect.

Areas for future research

In addition to those ways this research could be improved upon, there are areas that could be explored for new studies such as, in my case, a PhD dissertation. For example, one could further probe what the absence of "autonomy" implies. While the findings of qualitative research do not particularly lend themselves to comparisons with other data, it would nonetheless be valuable and interesting to conduct a similar study with members of a different population and see the differences that emerge. For instance, one could explore relations, limitations, opportunities, territorialization, and resistance among adults with developmental and/or other disabilities who do not receive PDD funding, are not their own guardians, and/or do not speak English (there are endless variations of these characteristics). Indeed, it seems likely the relations of individuals with developmental disabilities who do not receive PDD funding would differ from those found here, especially as they might not have access to assistive designs and devices and/or disability support staff.

Furthermore, it would be worthwhile to examine territorialization among individuals considered to have other disabilities, such as brain injuries or physical disabilities, and who receive funding from other organizations. In such a study, one could examine how individuals are deemed eligible for funding from that organization and the implications this has for territorialization. Here, research questions might include "do all organizations that provide funding for disability services use biomedical criteria to determine who receives funding? If not, how do these varying criteria impact and territorialize the body-self? Are there consequences for individuals' feelings of independence and value?"

Additionally, further research could provide additional launch pads into the work of Deleuze and Guattari. Certainly, the complexity and breadth of Deleuze and Guattari's work offers much terrain for further fruitful engagement with the body, disability, and independence, among other things. In particular, rather than examining the interplay of physical and social relations, territorialization, and independence, one could examine how the body-self might have *affective* relations to independence (i.e. how it might be possible for individuals to have psychological and/or emotional connections to this notion, whether they feel it is present in their lives or it is something they are striving to acquire or cultivate).

Last but certainly not least, and while beyond the scope of this thesis, further studies in this vein would do well to incorporate individuals with disabilities in each step of the research process – from its design to its dissemination.

Conclusion

To summarize, in this chapter, I used a sociology of the body approach to interpret participants' accounts. Specifically, I applied Deleuze and Guattari's theory of the body-without-organs (BwO), or body-self, to ascertain one of the major insights of this thesis: that although use of the medical model of disability (by PDD and others) seeks to pathologize and medicalize (territorialize) this study's participants, as passive and dependent on the services offered to them, participants attempt to resist this territorialization in their everyday lives through their relations with assistive designs and devices, medical procedures, family, and support staff. Throughout this discussion, I emphasized the importance of taking the body seriously – explaining how the need to do so becomes further apparent when interviewing people with developmental disabilities – and situated the current study within existing research, including that on independence and autonomy. In particular, while this study's participants were unfamiliar with "autonomy," they were at ease with the term independence, which had unique meanings for them based on personal experiences and relationships. Aside from one participant, who only spoke briefly about independence, all participants expressed a desire to increase their independence, as they understood it – whether this involved learning how to spell and read better, learning to be less shy, navigating the medical system, or looking after oneself. Lastly, I considered this study's limitations and areas for future research.

Returning to the beginning, at the outset of this thesis, I claimed this research would contribute to a number of practical outcomes, which I believe it has. To recap, in no particular order, these include the following:

1) The findings have practical implications for a variety of groups including, but not limited to, individuals with disabilities and their guardians, families, and friends; disability service providers; government funding bodies; and advocates of the Disability Rights Movement. Indeed, by examining a variety of factors and life experiences, this study seeks to situate disability within a broad context and view it holistically, rather than simply as a medical condition;

2) Individuals classified as having developmental disabilities figure much less frequently in research than those classified as having physical disabilities (Ward, Nichols, and Freedman, 2010, p. 280). Therefore, this thesis and the interviews provide(d) a forum for adults with developmental

disabilities to share their experiences, stories, opinions, and suggestions, which does not happen nearly enough. By valuing these perspectives, this study seeks to challenge the perception that because individuals with disabilities are marginalized, their knowledge of disability is "'defective,' not usually worthy, credible or useful" (Michalko in Hansen and Janz, 2009, p. 31). Thus, while it has been assumed that individuals with disabilities are poor informants, this study's participants had valuable insights on their own experiences;

3) And, last but not least, this thesis provides a template for future projects that seek to give voice to those who are traditionally silenced – especially individuals with disabilities.

In conclusion, to ensure these outcomes are fully realized, and as both a scholar and disability rights advocate, it is now my duty and privilege to ensure this research is disseminated through appropriate conferences and publications. It is my hope this study's holistic focus on physical and social relations will be well-received and taken up by others. For those in a position to either conduct or participate in research, this study demonstrates some of the possibilities for individuals with disabilities in this enterprise – especially adults with developmental disabilities. As stated in the introductory chapter, I sincerely hope you, the reader, have gained insight from this recap of my evolving quest to better understand how the body can be brought back into conversations of disability, while simultaneously acknowledging the agency and independence of individuals with disabilities, as well as social factors.

WORKS CITED:

Alberta Human Services a. *Quick Guide to PDD*. Accessed 31 July 2014. Available from http://humanservices.alberta.ca/disability-services/pdd-guide.html.

Alberta Human Services b. *Program Purpose*. Accessed 27 February 2014. Available from http://humanservices.alberta.ca/pdd-online/program-purpose.aspx.

Alberta Human Services c. *My Life Survey: the Personal Outcomes Index*. Accessed 2 August 2014. Available from http://www.humanservices.alberta.ca/disability-services/pdd-poi.html.

Alberta Human Services d. *Office of the Public Guardian (OPG)*. Accessed 6 August 2014. Available from http://humanservices.alberta.ca/guardianship-trusteeship/office-public-guardian.html.

Alberta Human Services e. *Developmental Disabilities Guidelines*. Accessed 18 October 2014. Available from http://humanservices.alberta.ca/disability-services/pdd-developmental-disabilities-guidelines.html.

Albrecht, Gary L. *The Disability Business: Rehabilitation in America*. Newbury Park, CA: Sage, 1992.

Anvik, Cecilie Høj. "Embodied Spaces in the Making: Visually Impaired People, Bodies and Surroundings." *Scandinavian Journal of Disability Research* 11, no. 2 (2009): 145-57.

Babbie, Earl, and Lucia Benaquisto. *Fundamentals of Social Research*. 2nd ed. Toronto: Nelson Education Ltd., 2010.

Berg, Bruce L. *Qualitative Research Methods for the Social Sciences*. 7th ed. Boston: Allyn & Bacon, 2009.

Bloomfield, Brian P., Yvonne Latham, and Theo Vurdubakis. "Bodies, Technologies and Action Possibilities: When is an Affordance?" *Sociology* 44, no. 3 (2010): 415-33.

Bryant, Christopher G.A. and David Jary, eds., *Gidden's Theory of Structuration: A Critical Appreciation*. London: Routledge, 1991.

Brym, Robert, Lance Roberts, Lisa Strohschein, and John Lie. *Sociology: Your Compass for a New World*. 5th ed. Toronto: Nelson, 2015.

Burns, Nicola, Nick Watson, and Kevin Paterson. "Risky Bodies in Risky Spaces: Disabled People's Pursuit of Outdoor Leisure." *Disability & Society* 28, no. 8 (2013): 1059-73.

Calkins, Carl et al. "Introduction to the Special Issue on Scaling Up Efforts to Promote the Self-Determination of People with Developmental Disabilities." *Exceptionality* 19, no. 1 (2011): 2-5.

Childress, James F. *Who Should Decide? Paternalism in Health Care*. New York: Oxford University Press, 1982.

Childress, James F. "The Place of Autonomy in Bioethics." *The Hastings Center Report* 20, no. 1 (1990): 12-7.

Childress, James F., et al. “Public Health Ethics: Mapping the Terrain.” *Journal of Law, Medicine & Ethics* 30, no. 2 (2002): 170-8.

Coleman-Fountain, Edmund, and Janice McLaughlin. “The Interactions of Disability and Impairment.” *Social Theory & Health* 11, no. 2 (2013): 133-50.

Corker, Marian, and Tom Shakespeare. “Mapping the Terrain.” Pp. 1-17 in *Disability/Postmodernity: Embodying Disability Theory*, edited by M. Corker and T. Shakespeare. New York: Continuum, 2002.

Crawford, Cassandra S. “‘You Don’t Need a Body to Feel a Body’: Phantom Limb Syndrome and Corporeal Transgression.” *Sociology of Health & Illness* 35, no. 3 (2013): 434-48.

Creswell, John W. *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. Los Angeles: SAGE, 2013.

Deleuze, Gilles. *Foucault*. Minneapolis: University of Minnesota Press, 1988.

Edwards, Claire, and Rob Imrie. “Disability and Bodies as Bearers of Value.” *Sociology* 37, no. 2 (2003): 239-56.

Elliott, Anthony. *Contemporary Social Theory: An Introduction*. London: Routledge, 2009.

Ells, C. “Lessons about Autonomy from the Experience of Disability.” *Social Theory & Practice* 27, no. 4 (2001): 599-615.

Field, Sharon et al. “Self-Determination for Persons with Disabilities: A Position Statement of the Division on Career Development and Transition.” *Career Development for Exceptional Individuals* 21, no. 2 (1998): 113-28.

Fox, Nick J. “Refracting ‘Health’: Deleuze, Guattari and Body-Self.” *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine* 6, no. 3 (2002): 347-63.

Fox, Nick J. *The Body: Key Themes in Health and Social Care*. Cambridge: Polity Press, 2012.

Fox, Nick J., and Katie J. Ward. “What are Health Identities and How May we Study them?” *Sociology of Health and Illness* 30, no. 7 (2008): 1007-21.

Frank, Arthur W. *At the Will of the Body: Reflections on Illness*. 2nd ed. New York: Houghton Mifflin, 2002.

Frank, Arthur W. *The Wounded Storyteller: Body, Illness, and Ethics*. 2nd ed. Chicago: The University of Chicago Press, 2013.

Garland-Thomson, Rosemarie. “Misfits: A Feminist Materialist Disability Concept.” *Hypatia* 26, no. 3 (2011): 591-609.

Gerschick, Thomas J., and Adam S. Miller. “Coming to Terms: Masculinity and Physical Disability.” Pp. 246-51 in *Sociology of the Body: A Reader*, edited by C. Malacrida and J. Low. Toronto: Oxford University Press, 2008.

Hansen, Nancy E., and Heidi L. Janz. “The Ethics of Making Space for Non-Conformist Minds and Bodies in Healthcare.” *Developmental Disabilities Bulletin* 37, no. 1/2 (2009): 29-43.

Harris-Zsovan, Jane. *Eugenics and the Firewall: Canada's Nasty Little Secret.* Winnipeg: J. Gordon Shillingford Publishing Inc., 2010.

Hroch, Petra. "Potential." Pp. 141-3 in *Demystifying Deleuze: An Introductory Assemblage of Crucial Concepts*, edited by R. Shields and M. Vallee. Ottawa: Red Quill Books, 2012.

Hughes, Bill, and Kevin Paterson. "The Social Model of Disability and the Disappearing Body: Towards a Sociology of Impairment." *Disability and Society* 12, no. 3 (1997): 325-40.

Hutchison, Nichola. "Disabling Beliefs? Impaired Embodiment in the Religious Tradition of the West." *Body & Society* 12, no. 4 (2006): 1-24.

Irvine, Angela. "Conducting Qualitative Research with Individuals with Developmental Disabilities: Methodological and Ethical Considerations." *Developmental Disabilities Bulletin* 38, no. 1 and 2 (2010): 21-34.

Iwakuma, Miho. "The Body as Embodiment: An Investigation of the Body by Merleau-Ponty." Pp. 88-100 in *Disability/Postmodernity: Embodying Disability Theory*, edited by M. Corker and T. Shakespeare. New York: Continuum, 2002.

Kelly, Michael, and David Field. "Medical Sociology, Chronic Illness and the Body." *Sociology of Health and Illness* 18, no. 2 (1996): 241-57.

Kent, Deborah. "Somewhere a Mockingbird." Pp. 242-5 in *Sociology of the Body: A Reader*, edited by C. Malacrida and J. Low. Toronto: Oxford University Press, 2008.

Kipnis, Kenneth. *Vulnerability in Research Subjects: A Bioethical Taxonomy*

(Research Involving Human Participants V2) [article online]. 2006. Online Ethics Centre. Accessed 9 August 2014. Available from http://www.onlineethics.org/Topics/RespResearch/ResResources/nbacindex/nbachindex/hkipnis.aspx.

Kruger, Erin. “Assemblage.” Pp. 29-31 in *Demystifying Deleuze: An Introductory Assemblage of Crucial Concepts*, edited by R. Shields and M. Vallee. Ottawa: Red Quill Books, 2012.

Lachapelle, Yves et al. “The Relationship between Quality of Life and Self-Determination: An International Study.” *Journal of Intellectual Disability Research* 49, no. 10 (2005): 740-4.

Leece, J., and D. Leece. “Personalisation: Perceptions of the Role of Social Work in a World of Brokers and Budgets.” *British Journal of Social Work* 41, no. 2 (2011): 204-23.

Leece, J., and S. Peace. “Developing New Understandings of Independence and Autonomy in the Personalised Relationship.” *British Journal of Social Work* 40, no. 6 (2010): 1847-65.

Malacrida, Claudia. “Discipline and Dehumanization in a Total Institution: Institutional Survivors’ Descriptions of Time-out Rooms.” Pp. 76-83 in *Sociology of the Body: A Reader*, edited by C. Malacrida and J. Low. Toronto: Oxford University Press, 2008.

Malacrida, Claudia, and Jacqueline Low. “Introduction.” Pp. ix-xv in *Sociology of the Body: A Reader*, edited by C. Malacrida and J. Low. Toronto: Oxford University Press, 2008.

Manning, S., and C.E. Gaul. “The Ethics of Informed Consent: A Critical Variable in the Self-Determination of Health and Mental Health Clients.” *Social Work in Health Care* 25, no. 3 (1997): 103-17.

Maxwell, Joseph A. *Qualitative Research Design: An Interactive Approach*. 3rd ed. Thousand Oaks, CA: SAGE Publications, Inc., 2013.

McColl, Mary Ann, Anna Jarzynowska, and S.E.D. Shortt. “Unmet Health Care Needs of People with Disabilities: Population Level Evidence.” *Disability & Society* 25, no. 2 (2010): 205-18.

McRuer, Robert. *Crip Theory: Cultural Signs of Queerness and Disability*. New York: New York University Press, 2006.

Merriam, Sharan B., et al. *Qualitative Research in Practice.* San Francisco: Jossey-Bass, 2002.

Nettleton, Sarah. “The Sociology of the Body.” Pp. 47-68 in *The New Blackwell Companion to Medical Sociology*, edited by W.C. Cockerham. Malden, MA: Wiley-Blackwell, 2010.

Nonnemacher, Stacy L., and Linda M. Bambara. “‘I’m Supposed to Be In Charge’: Self-Advocates’ Perspectives on Their Self-Determination Support Needs.” *Intellectual and Developmental Disabilities* 49, no. 5 (2011): 327-40.

Oliver, Michael. *Understanding Disability: From Theory to Practice*. New York: St. Martin’s Press, 1996.

Ouellette-Kuntz, Hélène. “Understanding Health Disparities and Inequities Faced by Individuals with Intellectual Disabilities.” *Journal of Applied Research in Intellectual Disabilities* 18, no. 2 (2005): 113-21.

Palmer, Susan B., and Michael L. Wehmeyer. “Students’ Expectations of the Future: Hopelessness as a Barrier to Self-Determination.” *Mental Retardation* 36, no. 2 (1998): 128-36.

Papadimitriou, Christina. “Becoming En-Wheeled: The Situated Accomplishment of Re-Embodiment as a Wheelchair User After Spinal Cord Injury." *Disability & Society* 23, no. 7 (2008): 691-704.

Peuravaara, Kamila. “Theorizing the Body: Conceptions of Disability, Gender and Normality.” *Disability & Society* 28, no. 3 (2013): 408-17.

Rabinow, Paul, and Nikolas Rose, eds., *The Essential Foucault: Selections from the Essential Works of Foucault 1954-1984*. New York: The New Press, 2003.

Reindal, S.M. “Independence, Dependence, Interdependence: Some Reflections on the Subject and Personal Autonomy.” *Disability & Society* 14, no. 3 (1999): 353-67.

Rioux, Marcia, and Tamara Daly. “Constructing Disability and Illness.” Pp. 305-24 in *Staying Alive: Critical Perspectives on Health, Illness, and Health Care*, edited by D. Raphael, T. Bryant, and M. Rioux. Toronto: Canadian Scholars’ Press Inc., 2006.

Sandelowski, Margarete. “Focus on Qualitative Methods: One is the Liveliest Number: The Case Orientation of Qualitative Research.” *Research in Nursing and Health*. 19 (1996): 525-9.

Scambler, Graham, and Sasha Scambler, eds., *New Directions in the Sociology of Chronic and Disabling Conditions: Assaults on the Lifeworld*. Hampshire, England: Palgrave Macmillan, 2010.

Schillmeier, Michael W. J. *Rethinking Disability: Bodies, Senses, and Things*. New York: Routledge, 2010.

Shakespeare, Tom. “Disabled People’s Self-Organisation: A New Social Movement?” *Disability, Handicap and Society* 8, no. 3 (1993): 249-64.

Shakespeare, Tom. “Still a Health Issue.” *Disability and Health Journal* 5 (2012): 129-31.

Shields, Rob. *The Virtual.* London: Routledge, 2002.

Shilling, Chris. “Educating the Body: Physical Capital and the Production of Social Inequalities.” *Sociology* 25, no. 4 (1991): 653-72.

Shilling, Chris. *The Body and Social Theory*. 3rd ed. London: SAGE Publications Ltd., 2012.

Shogren Karrie A., and Ricky Broussard. “Exploring the Perceptions of Self-Determination of Individuals with Intellectual Disability.” *Intellectual and Developmental Disabilities* 49, no. 2 (2011): 86-102.

Sims, David, and Sandra S. Cabrita Gulyurtlu. “A Scoping Review of Personalisation in the UK: Approaches to Social Work and People with Learning Disabilities. *Health & Social Care in the Community* 22, no. 1 (2014): 13-21.

Smith, Brett, and Andrew C. Sparkes. “Changing Bodies, Changing Narratives and the Consequences of Tellability: A Case Study of Becoming Disabled Through Sport.” *Sociology of Health & Illness* 30, no. 2 (2008): 217-36.

Strohschein, Lisa, and Rose Weitz, *The Sociology of Health, Illness and Health Care in Canada: A Critical Approach*. Toronto: Nelson Education Ltd., 2014.

Tiessen, Matthew. “Becoming.” Pp. 33-5 in *Demystifying Deleuze: An Introductory Assemblage of Crucial Concepts*, edited by R. Shields and M. Vallee. Ottawa: Red Quill Books, 2012.

Thomas, Carol, and Marian Corker. “A Journey around the Social Model.” Pp. 18-31 in *Disability/Postmodernity: Embodying Disability Theory*, edited by M. Corker and T. Shakespeare. New York: Continuum, 2002.

Thomas, Carol. “How is Disability Understood? An Examination of Sociological Approaches.” *Disability and Society* 19, no. 6 (2004): 569-583.

Thomas, Carol. “Theorising Disability and Chronic Illness: Where Next for Perspectives in Medical Sociology?” *Social Theory & Health* 10, no. 3 (2012a): 209-28.

Thomas, Gareth. “Rethinking Disability: Bodies, Senses, and Things - By Michael Schillmeier.” *The Sociological Review*, no. 3 (2012b): 575.

Wacquant, Loic. *Body and Soul*: *Notebooks of an Apprentice Boxer*. New York: Oxford University Press, 2004.

Wallin, Jason. "Body without Organs (BwO)." Pp. 37-40 in *Demystifying Deleuze: An Introductory Assemblage of Crucial Concepts*, edited by R. Shields and M. Vallee. Ottawa: Red Quill Books, 2012.

Ward, Rolanda L., Amanda D. Nichols, and Ruth I. Freedman. "Uncovering Health Care Inequalities Among Adults with Intellectual and Developmental Disabilities." *Health & Social Work* 35, no. 4 (2010): 280-90.

Wehmeyer, Michael L. "Self-Determination as an Educational Outcome: Why is it Important to Children, Youth, and Adults with Disabilities?" Pp. 17-36 in *Self-Determination Across the Life Span*, edited by D. J. Sands and M.L. Wehmeyer. Baltimore: Paul H. Brookes Publishing Co., 1996.

Wehmeyer, Michael L. "Self-Determination and Individuals with Significant Disabilities: Examining Meanings and Misinterpretations." *Research and Practice for Persons with Severe Disabilities* 23, no. 1 (1998): 5-16.

Wehmeyer, Michael L. "A Functional Model of Self-Determination: Describing Development and Implementing Instruction." *Focus On Autism & Other Developmental Disabilities* 14, no. 1 (1999): 53-61.

Wehmeyer, Michael L. "Self-Determination and the Empowerment of People with Disabilities." *American Rehabilitation* 28, no. 1 (2004): 22-9.

Wehmeyer, Michael L. "Self-Determination and Individuals with Severe Disabilities: Re-Examining Meanings and Misinterpretations." *Research & Practice for Persons with Severe Disabilities* 30, no. 3 (2005): 113-20.

Wehmeyer, Michael L., Hank Bersani, Jr., and Ray Gagne. “Riding the Third Wave.” *Focus On Autism & Other Developmental Disabilities* 15, no. 2 (2000): 106-15.

Wehmeyer, Michael L., and Nancy Bolding. “Self-Determination across Living and Working Environments: A Matched-Samples Study of Adults with Mental Retardation.” *Mental Retardation* 37, no. 5 (1999): 353-63.

Wehmeyer, Michael L., Kathy Kelchner, and Sandy Richards. “Essential Characteristics of Self-Determined Behavior of Individuals with Mental Retardation.” *American Journal on Mental Retardation*. 100 (1996): 632-42.

Wehmeyer, Michael L., and Christina A. Metzler. “How Self-Determined are People with Mental Retardation? The National Consumer Survey.” *Mental Retardation* 33, no. 2 (1995): 111-9.

Wehmeyer, Michael L., and Dennis E. Mithaug. “Self-Determination, Causal Agency, and Mental Retardation.” *International Review of Research in Mental Retardation*. 31 (2006): 31-71.

Wehmeyer, Michael L., and Susan B. Palmer. “Adult Outcomes for Students with Cognitive Disabilities Three-Years after High School: The Impact of Self-Determination.” *Education & Training in Developmental Disabilities* 38, no. 2 (2003): 131-44.

Wehmeyer, Michael, and Michelle Schwartz. “Self-Determination and Positive Adult Outcomes: A Follow-Up Study of Youth with Mental Retardation.” *Exceptional Children* 63, no. 2 (1997): 245-55.

Wehmeyer, Michael L., and Michelle Schwartz. "The Relationship between Self-Determination and Quality of Life for Adults with Mental Retardation." *Education & Training in Mental Retardation & Developmental Disabilities* 33, no. 1 (1998): 3-12.

Williams, Simon J. "The Vicissitudes of Embodiment Across the Chronic Illness Trajectory." *Body and Society* 2, no. 2 (1996): 23-47.

Williams, Simon J. "Is Anybody There? Critical Realism, Chronic Illness and the Disability Debate." *Sociology of Health & Illness* 21, no. 6 (1999): 797-819.

Williams, Simon J. "Chronic Illness as Biographical Disruption or Biographical Disruption as Chronic Illness? Reflections on a Core Concept." *Sociology of Health & Illness* 22, no. 1 (2000): 40-67.

Williams, Simon J. "Medical Sociology and the Biological Body: Where are We Now and Where Do We Go from Here?" *Health* 10, no. 1 (2006): 5-30.

Wullink, M. et al. "Autonomy in Relation to Health among People with Intellectual Disability: A Literature Review." *Journal of Intellectual Disability Research* 53, part 9 (2009): 816-26.

Zitzelsberger, Hilde. "(In)visibility: Accounts of Embodiment of Woman with Physical Disabilities and Differences." Pp. 252-6 in *Sociology of the Body: A Reader*, edited by C. Malacrida and J. Low. Toronto: Oxford University Press, 2008.

APPENDICES:

*Please note that the questions that compose the interview guide were not asked verbatim; this guide was simply a resource for the interviewer.

CONFIDENTIALITY AGREEMENT AND CONSENT FOR GATEKEEPER

Researcher: Kathleen Herzog, Graduate Student, University of Alberta
Email: […] Ph: […]

Supervisor: Dr. Lisa Strohschein, Associate Professor of Sociology, University of Alberta
Email: […] Ph: […]

You are being invited to assist a master's student (Kathleen Herzog) from the University of Alberta in conducting research for her master's thesis. Kathleen would like to work with you to recruit participants for interviews about health care services and autonomy. The interviews will inform Kathleen's research, which has the following aims:

- To explore how a variety of health care services are approached and experienced, both positively and negatively, by adults with developmental disabilities who live in Edmonton;

- To understand how and to what degree Edmontonian adults with developmental disabilities feel that they exert autonomy over health care decisions;

- To comprehend how the life experiences of adults with developmental disabilities inform their perceived levels of autonomy with respect to health care services;

- And, ultimately, to ascertain whether there is a gap between formalized rights and how Edmontonian adults with developmental disabilities perceive their rights due to, among other things, limited options presented by the social and physical structures of their surroundings, not being given opportunities to make their own decisions, and/or not having full access to assistance and information.

Your identity and the name of your workplace will remain confidential; Kathleen will not use your name or the name of your workplace in her master's thesis or other publications.

Additionally, it is imperative that you maintain the confidentiality of participants' identities; this means that you cannot discuss the participants' identities with anyone other than Kathleen. You will not have access to any of the interview data.

You have the right to withdraw from this project at any time without consequence.

Please check mark the following boxes if you agree with the corresponding statement:

☐ I understand the above information.

☐ Any questions that I had about the above information were answered for me.

☐ I understand that my identity and the name of my workplace will remain confidential.

☐ I agree not to discuss participants' identities with anyone other than Kathleen.

☐ I understand that I can withdraw from the project at any time without consequence.

☐ I understand that if I have any general questions or concerns after my assistance with the project is finished, I can contact Dr. Lisa Strohschein or Kathleen.

☐ Kathleen may contact me in the future if she has questions for me about this research.

______________________________	______________________________
Signature of Gatekeeper	Name of Gatekeeper

Date: ______________________________

I agree, as a researcher, to uphold the terms and conditions outlined above.

______________________________	______________________________
Signature of Researcher	Name of Researcher

Date: ______________________________

INFORMATION LETTER

Adults with Developmental Disabilities and their Experiences of Autonomy When Accessing and Receiving Health Care Services

Research Investigator:	**Supervisor:**
Kathleen Herzog, Master's Student […]	Professor Lisa Strohschein […]

Background
As an adult with a developmental disability, you are being invited to take part in a research project with myself (a master's student from the University of Alberta). I would like to interview you about health care services and independence. The information from the interview would be presented in my master's thesis and in appropriate publications, as well as at scholarly conferences.

Purpose
Your experiences and opinions on health care services and independence would help me achieve the following goals of my research:

- To look at positive and negative parts of health care as they are experienced by adults with developmental disabilities;
- To understand how adults with developmental disabilities rate their doctors and health care providers (i.e. are your needs being met?);
- To understand if adults with developmental disabilities are independent when making health care decisions; and
- To understand how adults with developmental disabilities view their rights.

Study Procedures
The interview will be conducted at […], will probably take about one hour, and will be conducted in a conversational style. If you become tired, we can take breaks and/or finish the interview at another time.

With your permission, I will audio record the interview. This will help me to remember and write about the interview as accurately as possible. I will be the only one who will listen to any recorded material. If you are not comfortable with being audio recorded during the interview, I will take notes instead.

Benefits
Participating in an interview will benefit you by giving you the chance to share your experiences, stories, opinions, and suggestions. I believe that you will also gain a sense of empowerment and value from participating in an interview. Information from this study will lead to a better understanding of developmental disabilities, health care services, and independence. I also hope that this study will provide an outline for future projects that seek to give voice

INFORMATION LETTER CONTINUED

Adults with Developmental Disabilities and their Experiences of Autonomy When Accessing and Receiving Health Care Services

to those who are traditionally silenced – especially individuals with disabilities. If you provide general recommendations for improving experiences with health care services and/or independence, I will include these recommendations in my master's thesis.

Risk
The interview is designed to protect your dignity and preserve your well-being. Due to the topics being discussed (health care services and independence) and because you will be asked to recall your experiences, it is possible that you might feel stressed, embarrassed, worried, anxious, scared, or distressed. However, I will not be directly asking about negative experiences and you can choose to share as much or as little as you want. Also, because we will be having an in-depth, approximately hour-long conversation, it is possible that you might become tired. You will be able to take breaks though whenever you wish, participate in the interview across multiple sessions and, of course, end the interview at any time.

Voluntary Participation
You are under no obligation to participate in this study. Participation is completely voluntary. You have the right to not answer particular questions, to end the interview at any time, and to withdraw from the project without consequence. If you decline to continue or you wish to withdraw from the study, your information will be removed from the study upon your request. To do this, you must contact me by **September 30, 2013**; I will then destroy that information.

Confidentiality
I will not use your real name or any identifying information in my master's thesis, other publications, or presentations. Data for all uses will be handled in compliance with the University of Alberta Standards. Data will be kept confidential and I will be the only one who has access to it. All information that I keep (audio recordings, notes, transcripts) will be stored in a locked, secure location and will be destroyed after ten years in a way that ensures privacy and confidentiality.

Further Information
If you have any general questions or concerns after the interview, you may contact me or Professor Lisa Strohschein via the contact information provided on the first page. If you have any concerns about this study, you may contact the University of Alberta's Research Ethics Office at 780-492-2615. This office has no direct involvement with this project.

CONSENT FORM

Adults with Developmental Disabilities and their Experiences of Autonomy When Accessing and Receiving Health Care Services

Principal Investigator: Kathleen Herzog, Graduate Student, University of Alberta, Ph: […]

Supervisor: Professor Lisa Strohschein, Associate Professor of Sociology, University of Alberta, Ph: […]

Do you understand that you have been asked to be in a research study?	Yes	No
Have you read and received a copy of the attached Information Sheet?	Yes	No
Do you understand the benefits and risks involved in taking part in this research study?	Yes	No
Have you had an opportunity to ask questions and discuss this study?	Yes	No
Do you understand that you are free to refuse to participate, or to withdraw from the study at any time, without consequence, and that your information will be withdrawn at your request?	Yes	No
Has the issue of confidentiality been explained to you? Do you understand who will have access to your information?	Yes	No
Can Kathleen contact you in the future if she has questions about this interview?		

This study was explained to me by: ______________________________

I have read and understood the attached information letter and agree to take part in this study:

______________________ ______________________

Signature of Research Participant Date

____

Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

______________________ ______________________

Signature of Investigator or Designee Date

INTERVIEW GUIDE

**Please note that the questions that compose the interview guide were not asked verbatim; this guide was simply a resource for the interviewer.

Introduction: My name is Katie and I'm a student at the University of Alberta. I just moved to Edmonton in August and before that I used to live in Lethbridge. The reason why I moved to Edmonton though was to go to school here, and I'm really enjoying that. Since I started school I've been studying disabilities and health care. I'm interested in studying the experiences that individuals with disabilities have with health care, and how independent individuals with disabilities are when making decisions about health care. This is a really broad area but it includes experiences and decisions related to health information, health care services, doctors and practitioners, and medications and supplements. I've been looking forward to talking with you today and can't wait to get started.

1) Can you tell me a little bit about yourself?
    a. What kind of things do you enjoy doing?
    b. Do you have any plans for the summer?

2) Can you tell me a little bit about your disability? How does it impact your life?

3) What disability services do you receive?

4) How have health care services been a part of your life?

5) What types of health care professionals do you see?

6) Do you choose how often you have appointments? Do you wish that you had more or less appointments?

7) Do you make your own appointments? Is this what you prefer?

8) Do you do anything to prepare for your appointments (ex: accessing resources for health information)? Why or why not?

9) Do you go to your appointments alone or with someone else? Is this what you prefer? If both, does the dynamic change?

10) Do you feel like you have enough time to talk? Do you feel like you're listened to?

11) Do you feel like you can ask questions? Are you satisfied with the answers that you get?

12) Do you feel like you get to make decisions when this is possible? Do you feel like you can say "no" if there is something that you don't agree with?

13) Overall, how do you feel about the amount of input you have in your appointments?

14) Overall, how do you feel about your relationships with health care professionals? Is there anything that would help you to have better relationships with them?

15) Is there anything special that you think health care professionals should know about individuals with disabilities? Or do when working with them?

16) Overall, how do you feel about your experiences with health care services?

17) What words would you use to describe yourself when you're a patient?

18) Do you participate in any disability rights or self-advocacy activities? Why or why not? If so, what have you learned from these activities?

19) Are you familiar with the word autonomy?
    a. If not, offer Wehmeyer's definition. For example, when it comes to birth control or the flu shot (unless agency mandated).
    b. If so, what does it mean to you? How did you learn about autonomy?

20) When it comes to health care services, do you feel that you act according to your own preferences, interests and/or abilities? Why or why not? How do you feel about this?

21) When it comes to health care services, do you feel that you act independently, free from undue external influence or interference? Why or why not? How do you feel about this?

22) Are there other areas of your life that you feel you are autonomous in? Why or why not? How do you feel about this?

23) Do you think there is a connection between how autonomous you are in other areas of your life and how autonomous you are with health care services?

24) Have you ever had any types of alternative medicine (for example, massage, acupuncture, etc.)? Why or why not?
    a. If so, proceed with the following prompts.
        i. Was it your idea to do this treatment? If not, how did you find out about this treatment?
        ii. Was this treatment a positive experience for you? Why or why not?
        iii. Is this treatment something that you would do again? Why or why not?

    iv. Are there other types of alternative medicine that you would like to try? Why or why not?

25) Is there anything else that you would like to add about your life experiences or your experiences with health care services?

26) Would you be interested in meeting again one on one or with the other interview participants to discuss the findings of this study?