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LIVING IN THIS BODY: HEARING THE VOICES OF WOMEN WITH DISABILITIES

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LIVING IN THIS BODY: HEARING THE VOICES OF WOMEN WITH DISABILITIES

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by

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Abstract

This research explored factors associated with self-determination among university-educated women with physical disabilities. Autoethnography and case study methods were employed. Participants were the researcher and five other women. Semi-structured interviews were conducted and the researcher also responded to the interview questions. Interviews were transcribed verbatim and transcripts were analyzed using a content analysis procedure. Journal entries by the researcher were analyzed as part of the autoethnographic data. Themes from the researcher data were compared to themes from the participant data at four levels: identical themes, similar themes, overlapping themes and unique theme. Themes were also compared to available literature concerning the experiences of people with disabilities. Implications for educators and counsellors were presented.

Keywords: Disabilities, Women, Post-Secondary Education, Self-Determination, Identity

Dedication

For my sister, Reba, whose voice has been the loudest of all those who have cheered me on this journey.

Acknowledgements

To my parents: Thank you for disbelieving the naysayers. Thank you for allowing and encouraging me to believe that success was possible. Thank you for trusting me enough to let me go about it my way.

To my sisters: Reba, thank you for being the backbone of my support network. Katie, thank you for being my inspiration. Sarah, thank you for your patience with me.

To my friends: Thank you to each and every one of you who have supported me in ways too numerous to name here.

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To my Advisor, Dr. Jason Brown. Thank you for your confidence in me. Thank you for encouraging me to take an idea that was a little out of the ordinary and run with it. This has been such an enriching and intriguing process. I thank you for your endless patience, your keen editor's eye and for maintaining your sense of humour the whole way along.

To my interview participants: Thank you to each of you for lending your voices to this project. I feel privileged that you have shared your experiences with me.

To Donna Reimer: Thank you for giving me the push I needed. You helped me believe I could do this.

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Chapter 1 – Introduction

The term "disability" usually implies a reduced capability to do or accomplish something relative to the standards of a particular group. Two major perspectives for defining disability are medical and social (MacKenzie, Hurst & Crompton, 2009). The medical perspective focuses on physical impairments caused by illness or injury and the social perspective focuses on social inclusion or exclusion that occurs as a consequence of the impairments. Socially, a person is said to have a disability when his or her body fails to meet societal standards for optimally functioning bodies (Wendell, 1996). Because both societal expectations and physical environments are based on presumed physical capabilities, people with disabilities encounter social and physical barriers as they move through everyday life. Attempts to negotiate these barriers are a significant part of the lived experiences of people with disabilities.

To enhance social awareness and promote change regarding how disabilities and people who experience them are understood and accommodated it is essential to define disability socially. Disabilities are "...a key aspect of human experience" that have implications for the lives of those who have them and those who do not (Society for Disability Studies, 2010). Political and cultural dimensions of disability studies also add important insights about the lived experience of disability in both historical and current contexts. Such an understanding is crucial if inclusivity is to be achieved.

In the present study, the experiences of university-educated women with physical disabilities are explored in depth to illuminate the ways in which the continual negotiation of physical and social barriers shapes their sense of self-determination. Self-determination is the ability to make life decisions independently, and to act toward seeing those decisions realized. Understanding the factors that influence self-determination for women with disabilities is essential to enhance their experiences of social participation.

The researcher is a participant in the study that combines autoethnographic and case study methods to describe commonalities in experience using an ecological framework which is employed by others in the field of disability research (Sobsey, 1994). An ecological framework focuses on the interactions between individuals and their social environments (Bronfenbrenner, 1977), and in the present study it is used to describe how personal experiences at different levels of environmental influence affect one's sense of self-determination. As a woman with a disability, the researcher has personally encountered physical and social barriers and facilitators that have affected self-determination. It is therefore anticipated that others may have similar or shared experiences. The common experiences across case studies of other women will supply that point of reference. Similarities between the researcher's personal experiences, those of the other participants and the issues identified in the literature will be compared.

Benefits of this Research

In order for counsellors, educators and other professionals to provide effective services to women with disabilities they should have an awareness of the realities and implications of the daily challenges these women face. Results of the study will be useful to service providers by highlighting particular experiences that women with disabilities may have in the classroom, the workplace, as well as other settings that influence their sense of who they are as self-determined people. For example, issues related to the influence of disability on identity and self-concept are often relevant in counselling and clients may undertake in-depth explorations of these experiences in therapy. This research will identify some of the issues that may emerge during those explorations.

Structure of this Thesis

Chapter Two is a review of the literature relevant to the topic under study. Factors from the psychological literature that are associated with self-determination for people with physical disabilities are presented from within an ecological framework. In Chapter Three the methodology of the study is described. Chapter Four includes findings of the analyses of case study and autoethnographic data. In Chapter Five the two sets of data are compared and commonalities between the two are identified. The commonalities between the data sets are then compared to the literature.

Chapter 2 – Literature Review

National data indicate that many Canadians experience a health problem or condition that limits their activity. According to the 2006 Participation and Activity Limitation Survey (PALS), pain, mobility and agility were causes of activity limitation for over 10% of Canadian adults (over the age of 15). Nearly three-quarters of those who endorsed activity limitation associated with one source also reported limitations associated with the other two. Women were more highly represented in limitations associated with pain or mobility than men across age groups (Statistics Canada, 2006a). Other causes of limited activity included hearing (5%), seeing (3%), learning (3%), biological (2%), memory (2%) and speech (2%) (Statistics Canada, 2006a).

Those who reported activity limitations also reported lower education, employment and income levels than those without activity limitations. Just over 10% of individuals who reported an activity limitation held a university degree compared to 20% of those who did not (Statistics Canada, 2006b; Statistics Canada 2006c). Over 40% of individuals who reported an activity limitation were employed, compared to 70% of those who did not (Statistics Canada, 2006d; Statistics Canada 2006e). Those who reported an activity limitation were slightly more likely to have no income in the year leading up to the census and twice as likely as those who did not report an activity limitation to have an annual gross income of less than $20,000 (Statistics Canada 2006f; Statistics Canada 2006g).

It is apparent that physical conditions are associated with limited participation for many Canadians and that those limitations are associated with reduced educational, occupational and economic opportunities. However, relatively little is known about what it is like for individuals with disabilities to interact with the physical and social world on a daily basis. Working definitions are presented in this chapter and followed by a review of the literature on the experience of individuals with physical disabilities associated with self-determination. The review is organized through the levels of an ecological framework and contextualized through the developmental lens of young adulthood.

Defining "Disability"

Newman (2009) suggests that definitions are not static, but rather, describe entities as they are situated in various temporal, cultural and circumstantial contexts. Definitions "...reflect how words are understood by those who use them" (Newman, 2009, p 2). Aristotle's definition of disability as "political exclusion" in the 4th century BCE began the association of the term with notions of deficiency and exclusion. These two factors remain apparent within contemporary definitions of disability, corresponding to the medical and social models respectively.

Medical models of disability focus on "... the individual in terms of their deficiencies, ailments or inabilities" (MacKenzie, Hurst, & Crompton, 2009, p. 55). The medical model locates the problem of disability in a "damaged" body. In contrast, social models of disability focus on factors outside of the individual. Proponents of social models argue that disabilities "...are not caused by [individuals'] impairments, but by an environment that does not take account of their impairments" (MacKenzie, Hurst, & Crompton, 2009, p 55). It has been argued (Leonardi, Bickenbach, Bediran, Kostanjsek, & Chatterji, 2006), that definitions of disability should attend to both the physical and social realities of each individual.

According to Wendell (1996), a person can be said to have a physical disability when his or her body falls outside accepted societal norms for "...strength, energy, movement, function and proper control [which] are unnoticed assumptions for most people who can meet them[.]" (p 87). Wendell's definition is social, locating the problem of disability within the environment. She suggests that societal structures (social and physical) are based on assumed norms of functioning which disadvantage people with physical impairments. However, Wendell's reference to the body also invites direct exploration of the physical capabilities and limitations of the body in which an individual lives. Bodily realities and environmental influences taken together yield a rich description of an individual's experience with disability (Wendell, 1996).

Self-Determination

When examining the experiences of people with disabilities, researchers should attend to factors that affect the development of beliefs about the self. It has been suggested that one's core concept of dynamic self (the self that acts in the world) is affected by "contextual influences [such as social support, impact of disability on daily living and influence of family], which flow into the core, interact with it in mutual impact and flow out again as actions and consequences" (Noonan et al., 2004, p71). The contextual influences have an impact on experience of both interdependence and self-determination.

From birth, survival requires dependency, but with maturity, separateness develops. Independence is characterized by acting without the aid or influence of others while interdependence involves a mutually beneficial connection between the acting individual and others in his or her environment (Raeff, 2006). It is the exercise of choice in balancing dependence, independence and interdependence to meet needs that is important. The exercise of self-determination is the choice of when to act independently and when to act together with others in order to achieve or accomplish something.

Self-determination may be defined as the ability to make and carry out one's own decisions. It is a "person-centered and person-directed" process by which an individual seeks and accepts ultimate responsibility for authorship of his or her own life experiences (Petersen, 2009). A self-determined individual has the freedom and authority to make choices about what happens and the capacity to exert influence to bring those choices to fruition (Petersen, 2009; Smith & Routel, 2010). The development of self-determination can be understood as a function of interactions between self and environment.

The environment offers both limitations and opportunities that hinder or facilitate an individual's attempt to exercise freedom and agency (Petersen, 2009). The process is authored by each individual in light of personal goals and in the context of family and culture (Smith & Routel, 2010). However, people with physical disabilities interacting with physical structures and social conventions based on an able-bodied norm experience challenges that are not encountered by those who are able-bodied. These challenges can frustrate efforts for self-determination. Supports and accommodations that meet physical and social needs of people with disabilities do assist. However, a key facet of self-determination is not whether an individual acts independently, but whether she or he exerts control over where, when and in what manner the desired effects will be achieved (Wehmeyer, Abery, Mithaug, & Stancliffe, 2003).

Ecological Framework

Ecological frameworks are based on analyses of human-environment interactions in social contexts of varying proximity to the individual (Bronfenbrenner, 1977). Sobsey's (1994) application focused on factors contributing to vulnerability to abuse among people with disabilities. For the purpose of the present study his application is adapted to explore factors associated with self-determination.

Levels of an ecological framework include the microsystem, macrosystem and exosystem. The microsystem refers to an individual's immediate social circle, including family and close friends. The macrosystem includes the individual's surrounding community, including social, educational and employment settings (Sobsey, 1994). Interactions within the individual and between elements of the microsystem and macrosystem are situated within the exosystem, which is the societal context. The exosystem includes "shared ways of seeing, thinking and doing. It relates to the *commonalities* – values and patterns of thought and behaviour, an assumed *consensus* about what is right and what is normal; it produces *conformity* to social norms," (Thompson, 2006, p. 27 italics in original).

By definition, the levels of an ecological framework interact. For example, experiences in the family affect feelings and cognitions about the self. The revised self-references alter the way in which a person conducts him or herself in interpersonal interactions. The levels also blend, making distinctions regarding exact the location of relevant experiences challenging. However, the framework does provide a structure to organize psychological research evidence. The following review is based on recent studies that speak to experiences of people with physical disabilities and identify factors associated with self-determination according to characteristics within the individual, as well as microsystem and macrosystem levels.

Individual level. Research on factors associated with self-determination among individuals with physical disabilities has focused on self-worth and its relationship to perceived motor competence. These factors are prominent in the research on participation of youth in physical activities and associated with evidence about what it can be like to feel "normal" when one has a physical disability.

Self-worth is the perception of the self as worthy and competent. There are two dimensions including a global sense of self-worth, which is an overall positive perception about the self, and a specific sense of self-worth, which is associated with perceived competence in particular domains of functioning encountered in everyday life (Harter, 1988). Research with elementary school children who had physical disabilities found they displayed similar appraisals of global self-worth as their able-bodied peers (Schuengel et al., 2006). However, adolescents with physical disabilities perceived themselves as less competent than their able-bodied peers in relation to physical self-worth (Skinner & Piek, 2001). In both studies however, and consistent with additional research (Antle, 2004), the effects of disability on both general and specific self-worth are mitigated by perceived social support from peers and parents.

For individuals with physical disabilities, the domain of physical competence is especially salient. Physical competence refers to the ability to accomplish tasks that are necessary for the moment-to-moment experiences of daily living (Harter, 1988). Researchers have focused on motor competence, which is the ability to perform significant gross motor activities necessary in everyday life (Schuengel et al., 2006). The integration of children and youth with physical disabilities in the same physical activities as their able-bodied peers has provided researchers with useful insights about differential effects. When experiences are positive, they foster a sense of belonging and social participation among youth with physical disabilities. However, others have experienced a reduced sense of athletic competence (Schuengel et al., 2006). Negative experiences of integrated physical activities have led to decreased sense of competence, increased social isolation and diminished participation in physical activity (Goodwin & Watkinson, 2000).

In order to facilitate positive experiences physical activities should be adapted in such a way as not to highlight the limitations of some participants (Gaskin, Andersen & Morris, 2009). Physical realities of all participants should be taken into account and appropriately accommodated for without reference to deficiency. Positive appraisals of physical competence were reported among groups of adolescent boys and girls who were involved in individual sports such as Karate and team sports for individuals with and without disabilities, such as wheelchair basketball (Bedini & Anderson, 2005; Taub, Blinde, & Greer, 1999). When given opportunity for physical activity on a more level playing field with peers, individuals develop confidence, improved health and sense of belonging (Taub, Blinde & Greer, 1999).

The evidence on self-worth and motor competence suggests that self-determination is reinforced when the playing field is equitable, and sport can offer, the opportunity to view activities a personal 'proving ground' where one can showcase abilities (Taub, Blinde & Greer, 1999). The concept of normalcy is a thread implicitly or explicitly woven through a great deal of the literature concerning persons with physical disabilities (e.g. Bedini & Anderson, 2005). There is a clear desire on the part of people with disabilities to participate without being segregated, limited, judged or differently treated on the basis of their abilities.

Microsystem level. Though individuals with disabilities may not perceive themselves to be different from others, family dynamics sometimes highlight the differences noticed by parents and have an impact on self-determination. Research suggests that people with disabilities are parented differently than those who do not have disabilities on several dimensions including protectiveness, overprotectiveness and autonomy-fostering behaviour.

Parental protectiveness has been characterized as an adaptive parenting behaviour and an attempt to shield children form physical, emotional or social harm. Researchers have identified three types of maternal protectiveness: protectiveness around the use of objects or activities inside or outside the house, protectiveness from possibly upsetting information and protectiveness from undesirable images and messages in the media (Power & Hill, 2008). Research suggests that parents of young adults with disabilities most disproportionately and frequently use protective strategies regarding objects and activities. In addition, mothers of adolescents with disabilities are more likely to express a need to protect their children from future disappointments by helping them gain a new outlook on life goals they see as unrealistic (Hogansen, Powers, Greenan, Gil-Kashiwabara & Powers, 2008).

Overprotectiveness is behaviour clearly excessive in proportion to the risk present in a challenging situation (Holmbeck et al., 2002). Parents of children with disabilities endorse more overprotective beliefs on surveys and display more overprotective behaviour during observed interactions with their children than do parents of able-bodied children. They cite concern for their children's safety as a reason for being overprotective. Common and persistent fears are that children might hurt themselves, get into a situation they are not able to handle by themselves or require help and not be able to obtain it (Holmbeck et al., 2002; Powers, Hogansen, Greenan, Powers & Gil-Kashiwabara, 2008; Galambos, Darrah & Magill-Evans, 2007).

Parental overprotectiveness is negatively correlated with autonomy-fostering behaviour (Holmbeck et al., 2002). Autonomy is fostered by the confidence parents have in their children to make sound, well-informed and independent decisions about their lives. Parents who show high levels of overprotectiveness of adolescents with disabilities tend to possess lower levels of autonomy-fostering beliefs (Holmbeck et al., 2002). Mothers are more likely than fathers to endorse or exhibit overprotective behaviour (Hogansen, Powers, Greenan, Gil-Kashiwabara & Powers, 2008; Holmbeck et al., 2002), and fathers are more autonomy fostering with their adolescents who do not have disabilities compared to those parenting a youth with a disability (Galambos, Darrah & Magill-Evans, 2007).

Autonomy fostering is associated with psychosocial maturity. Fostering of autonomy by fathers is associated with psychosocial maturity among adolescents who have disabilities (Galambos, Magill-Evans & Darrah, 2008). One interpretation of this finding is that adolescent independence and self-sufficiency lead to increased willingness by fathers to encourage autonomy. Another possible interpretation is that paternal encouragement of autonomy encourages adolescents to see themselves as more competent and to achieve a greater degree of self-sufficiency that reflects greater psychosocial maturity. In addition, psychosocial maturity is also associated with high levels of perceived social support (Antle, Montgomery & Stapleford, 2009).

Parents of children and adolescents with disabilities experience tension between their desire to foster independent functioning and their felt duty to ensure that their children do not come to harm (Holmbeck et al., 2002). Evidence suggests that parents more often err on the side of protection and this does not go unnoticed by their young adults. Adolescents without disabilities are more likely to say their parents treat them as the age they are or slightly older, while adolescents with disabilities are more likely to say their parents treat them as though they were the same age or younger than they are (Galambos, Darrah & Magill-Evans, 2007).

Despite perceived overprotection adolescents with disabilities rate parents as their greatest sources of support, providing practical assistance with tasks of daily living as well as encouragement in reaching life goals (Power & Hill, 2008). Parents provide support by giving information and emotional support as well as fostering a family environment characterized by belonging and mutuality (Antle, Montgomery & Stapleford, 2009).

Parents of individuals with disabilities may struggle to balance the fostering of autonomy with the wish to protect their children from harm. At the same time, individuals with disabilities may experience conflict between the desire for independence and the need to look to others for help with some tasks in daily life.

Macrosystem level. Factors within the community have a significant effect on the self-determination experiences of individuals with disabilities. Accessibility of physical spaces and activities, transportation, access to higher education and employment as well as attitudes of others play a part in forming each person's experience of the community in which they live.

Physically inaccessible spaces are markers of difference that, by their structural reality, exclude people with disabilities from full participation in their communities (Imrie & Kumar, 1998). Not only do inaccessible spaces exclude people with disabilities, they also carry an implicit message about the lack of priority given the needs of individuals with disabilities. Physically inaccessible spaces are indicators that the community is not meeting the needs of all of its members.

Just as community spaces can be inaccessible due to physical barriers, community events can be inaccessible due to their physical demands. People with disabilities miss opportunities to interact with others in their communities because of activities tailored to the needs of able-bodied participants. This is especially true in organized sport, which may offer many opportunities for participants able to walk and run, but few for athletes who cannot (Bedini & Anderson, 2005). Non-athletic community events can present similar barriers when they necessitate certain levels of stamina or freedom of movement. Community spaces that are only partially accessible present a further concern as they restrict people with disabilities to a particular area in which an event is taking place. For example, a multi-level facility may only have one accessible level, which does not facilitate full participation for those unable to negotiate stairs (Taub, McLory & Bartnick, 2008).

Transportation within the community can become a problem for people with disabilities as they attempt to attend work, school or social events, or as they attempt to run every day errands such as purchasing groceries. When compared to adults without disabilities, a much smaller percentage of adults with disabilities drive automobiles. Those who do not drive themselves often rely on public or parallel accessible transit services. Accessible transit can often be unpredictable or unreliable and may require patrons to plan and book trips days in advance (Darrah, Magill-Evans & Galambos, 2009). Consequently people with disabilities have less freedom to respond to spontaneous social invitations or unexpected practical needs.

Access to higher education is an area of urgent concern for many individuals with disabilities. Individuals who have been placed in specialized education programs may find that these programs are not expected to lead to post-secondary education and therefore opportunities for such endeavours are curtailed (Darrah, Magill-Evans & Galambos, 2010). In these cases parental support and advocacy are extremely important. Involvement of students with disabilities in the completion and evaluation of their Individual Education Plan is also instrumental in ensuring a smooth transition to post-secondary opportunities (Morningstar et al., 2010).

As they look to enter the work force, recruitment, early retention and advancement opportunities are especially key for adolescents with disabilities. Adolescents and their parents rated the securing of meaningful employment as an important task in the transition to adulthood (Darrah, Magill-Evans & Galambos, 2010). Parents and adolescents also reported that those who aspired to obtain meaningful employment had few opportunities to achieve it. This problem was attributed to a low degree of support for young adults with physical disabilities to enter the work force (Powers, Hogansen, Greenan, Powers & Gil-Kashiwabara, 2008).

In order to make meaningful employment more accessible for people with disabilities, recruitment strategies of employers must be altered and provision of appropriate accommodations within the workplace must be offered within a disability-sensitive corporate culture (Hernandez, 2009). Policies that provide support for persons with disabilities who use assistive devices need to promote workforce participation. For example, a problem faced by many who receive financial support for assistive devices is that they lose that support upon employment (Darrah, Magill-Evans & Galambos, 2010).

The employment concerns of people with disabilities illustrate the fact that not all barriers encountered by people with disabilities are physical. As they move through the social world people with physical disabilities must often confront the mistaken or stigmatizing attitudes of others (Gilson, Tulson & Gill, 1997). Sometimes well-meaning and sometimes malicious, attitudes of others are powerful influences on the self-concept of people with disabilities.

The reactions of others can imply that the life experiences of people with disabilities must be incomplete, unhappy or fraught with constant hardship (Taub, Blinde & Greer, 1999; Gilson, Tulson & Gill, 1997). While visible physical disabilities more readily invoke reactions, invisible disabilities present different social challenges. Those with invisible disabilities may struggle to find a way to make their needs known without seeming to intrude, make excuses or invite pity (Gilson, Tulson & Gill, 1997). An invisible disability creates problems around disclosure of needs while a visible, more severe disability may lead to others' fear of saying the wrong thing (Green, Davis, Karshmer, Marsh & Straight, 2005). Sentiments expressed by others to the person with a disability may be well intentioned and meant to communicate empathy, but when received as sympathetic or patronizing they seriously undermine the sense of self as a complete and functioning person. To avoid the potential for embarrassment, many ignore the disability and sometimes even the *person* with the disability. It has been found that others are most comfortable approaching and offering assistance to individuals whose disabilities are visible and mild (Green, Davis, Karshmer, Marsh & Straight, 2005).

The experience of self-determination among people with disabilities in their communities is affected by physical barriers encountered in social spaces or activities, by logistical concerns about availability of programming and support, transportation and mobility, education and employment as well as by attitudes displayed by others towards them. Messages about the rights of people with disabilities to participate in their communities are embedded throughout the macrosystem.

Summary of Ecological Factors

Research on the experiences of individuals with physical disabilities regarding self-determination can be organized according to levels within the ecological framework including individual, microsystem and macrosystem. Within each level psychological research identifies relevant factors. The individual level includes experiences such as cognitions, beliefs and feelings about self as well as lived bodily experiences of the disability. A review of the literature on individual factors includes self-worth, physical competence and normalcy. In the microsystem, the immediate environment, relationships with family are particularly well-studied. Factors such as parental protectiveness and overprotectiveness, autonomy-fostering behaviours and social support are apparent. The macrosystem includes the local community affecting pursuits of education, leisure and employment. Factors from existing research include accessibility of physical spaces and activities, transportation, education and employment as well as attitudes of other people encountered in day-to-day life.

Developmental Context

There is a dearth of research on the development of self-determination among emerging adults with physical disabilities. In this section, the developmental stage of emerging adulthood is described and followed by a review of literature regarding the potential challenges faced by individuals with disabilities as they navigate this transitional period.

Emerging adulthood. During the time individuals move through their 20's, significant role changes may take place. Emerging adulthood is a time of "...serious choice and relatively permanent commitment" (Lerner, Brown & Kier, 2005, p 234.) as individuals negotiate decisions such as moving away from the parental home, deciding whether to pursue post-secondary education and choosing a career path along with personal life decisions around relationships. Emerging adulthood is an important period of development because choices made during this time can have a significant effect on later life satisfaction. Although the decisions made are highly personal there is a component of societal pressure. Social norms can become family and personal expectations about changes to be made. These changes may include moving from role of student to employee or moving away from the parental home. For those continuing on in post-secondary education emerging adulthood may extend into mid- or late 20's (Lerner, Brown & Kier, 2005).

Emerging adulthood among people with disabilities. People with disabilities face additional challenges during the period of emerging adulthood. Individuals with disabilities must balance societal expectations with their own and others' ideas about what they can or cannot, should or should not do (Petersen, 2009). Expectations for emerging adults often come into conflict with expectations about the capabilities and ideal life paths.

Providers of transition programming for people with disabilities may see emerging adulthood as a particularly challenging time. A one size fits all service mandate designed to accommodate individuals so they can be productive and make a contribution to society is often espoused (Petersen, 2009). However it is absolutely crucial that what is offered fits with the self-determined individual's experience and helps that individual reach a life goal which she or he has defined for self (Smith & Routel, 2010).

Employment and education are two areas where support is absent or not optimal (Petersen, 2009; Smith & Routel, 2010). People with disabilities may be directed toward programs that aim to place them in jobs thought to be commensurate with their skills immediately upon the completion of high school. In these programs individuals may be given little or no opportunity to choose what kind of work they will do, or indeed, whether they wish to forgo post-secondary education and enter the workplace. Many individuals are judged to be unable to succeed in post-secondary education and therefore, supports for achieving this goal are not provided (Petersen, 2009). Despite the increased challenges of the emerging adulthood for people with physical disabilities some individuals successfully undertake post-secondary education. However, little is known about their personal experiences.

Summary and Rationale for the Study

According to the national census, many Canadians have a disability. While medical or deficiency-related approaches have been emphasized by some, the social construction and personal experience of disability have become a focus for counsellors looking at ways to promote optimum experiences in interpersonal and developmental contexts. Self-determination has been identified as an important experience among all people, and in particular, people with disabilities.

Using an ecological framework, the literature identifies several factors operating between the individual and her or his immediate environment as well as broader community context that affect the self-determination experiences of those with a physical disability. There has been very little attention in the research literature regarding the experiences of individuals during emerging adulthood who have achieved success in post-secondary education. In the present study, experiences associated with self-determination among university-educated women living with physical disabilities are explored.

Chapter 3 – Methodology

The purpose of the study was to explore factors associated with self-determination among university-educated women with physical disabilities. A qualitative method was selected because it provided the greatest flexibility to include both the researchers' personal experiences and those of another group of women in similar circumstances. The qualitative method also encouraged a rich exploration and yielded a deep description of experiences. In this chapter a description of the research design is followed by detailed description of the methods employed for data collection and analysis of the researcher's own experiences on the topic as well as the experiences of other participants.

A particular strength of qualitative methods is the respect for voices of the participants and the opportunity for their free expression about the unique aspects of day-to-day experiences. According to Max Van Manen, the aim of research in the social sciences is "...to meet human beings- men, women, children- *there,* where they are naturally engaged in their worlds." (Van Manen, 1997, p. 18). This research aims to study life as it is lived, intervening only so far as to encourage description and clarification (Chang, 2008). In addition, qualitative researchers recognize their subjective experience and are encouraged to use it as data, making a concerted effort to tease out and articulate sources of subjectivity and their effect on the question(s) at hand (Morrow, 2005). The approach selected specifically included both case study and autoethnographic methods to explore experiences of self-determination among university-educated women with physical disabilities.

The rationale for including both methods was to provide a formal structure for the collection and analysis of written data about the researcher's personal experience through autoethnography and to provide breadth to the study by collecting data from other individuals through case study methodology. The comparison between three data sources including the case study, autoethnography and previous research, via literature review, provided an opportunity to locate commonalities.

Case Study

A case study is a detailed exploration of experiences during a particular timeframe and context (Yin, 2003). Although case studies often utilize multiple data sources, that requirement is also met by comparing data for convergence across participants (Stake, 1995). Behaviours, cognitions and emotions do not occur in isolation, but interact and give rise to meaning within the contexts in which they occur (Creswell, 2003). The case study is a method by which to "...turn distinctive human experience and behaviour into data, making it possible to study the richness of such phenomena as friendship, play, and imagination" (Stiles, 2009, p18). Case studies are exploratory; their aim is to understand experiences from the perspective of the participant, not the researcher. The researcher must impose enough structure to ensure methodological rigour, but not so much as to narrow the exploration of the participants' experiences (Yin, 2003).

The steps for conducting collective case study research as outlined by Creswell (2004) were followed. These included: 1) identification of the purpose of the research and design that will produce the intended results, 2) procedure to gain access and consent of participants, 3) data collection, 4) data analysis and 5) reporting of results.

Purpose and design. The purpose of the study was to explore factors associated with self-determination among university-educated women with physical disabilities. Consistent with the use of case study research as an expression of shared meaning regarding a phenomenon across individuals, the researcher recruited potential participants from whom interview data were collected.

Access and consent. The researcher posted advertisements (see Appendix A) about the study in various locations in large university campuses. The advertisements were also shared electronically through the disability organizations in the universities to their contacts. All recipients of the posters were asked to pass along the information about the study to other potential participants. Interested individuals were invited to contact the researcher directly to obtain additional information about the study and what participation would involve. Arrangements were made to meet for the purposes of an interview in a mutually agreeable location. At the time of meeting potential participants were presented with a letter of information and consent form (see Appendix B) and a signature was obtained prior to the interview.

Participants. Participants were five women in their 20's, all of whom had, at the time of writing, completed at least one university degree. All five self-identified as having a physical disability. All were Caucasian and identified their socio-economic status as middle or upper-middle class. Academic interests among the participants were varied including psychology, sociology, women's studies, geography and food/health sciences. Identity as a student/scholar was an important part of these participants' experiences, as were their attempts to negotiate the transition from the completion of one phase of their education to the next educational or professional employment goal. All but one used a mobility aid of some kind.

Data collection. Data were collected via semi-structured interviews. The questions focused on physical realities of the disability, messages received from others about it and words that captured the personal experience of disability. Additional questions included the meaning of self-determination as well as what promoted and detracted from it. Finally, questions about personal experience of independence, physical obstacles faced, community support as well as educational and employment experiences were asked. The questions are attached in Appendix C.

The researcher conducted one interview with each participant. Each interview lasted between 1 and 1.5 hours. The interviews were conducted face to face, and with the permission of each participant, her interview was audiotaped and transcribed verbatim. Each participant was asked to review a copy of her own transcript and make additions or changes to ensure that experiences were properly represented. Some participants indicated parts of their interviews that they did not want used in the published results. These areas were noted by the researcher and were not included in the published analysis.

Data analysis. Following editing and approval by participants of their transcripts, the analysis was performed according to the steps outlined by Creswell (2003) for qualitative content analysis. The researcher began by reading all transcripts to obtain an overall understanding of the content. Second, each transcript was reviewed in detail and significant phrases or ideas were noted. In step three, the meaning units identified in the previous step were coded with a one or two-word label that represented the content. A list of meaning units by code is attached in Appendix D. In step four, the codes were listed and grouped together conceptually. In step five, the groups of codes were organized into themes. A list of themes and codes within each are attached in Appendix E.

Autoethnography

Autoethnography is the study of the self in a cultural context (Chang, 2008). The experiences of a particular phenomenon as lived by the researcher were examined from the researcher's cultural perspective. That is to say, the researcher's experiences were analysed in light of her membership in her social context with its norms about communication, behaviour and interpretation of the world (Chang, 2008). There are many variations of autoethnography (Creswell, 2004). While it is becoming increasingly popular as performance-based research (Denzin, 2001), autoethnography is most commonly expressed as a personal narrative (Holman-Jones, 2005). However, researchers may use it to express the meaning of their struggles through a thematic analysis of personal experience (Bochner & Ellis, 2006).

The steps for conducting autoethnographic research as outlined by Creswell (2004) were followed. These included: 1) identification of the purpose of the study and design that would yield the intended results, 2) specification of the nature and collection of data, 3) analysis of data consistent with the design and 4) reporting of results.

Purpose and design. The purpose of the autoethnography was to explore the researcher's personal experiences as a university-educated adult woman with a physical disability that shaped her sense of self-determination. Consistent with the use of autoethnography as an expression of meaning through thematic analysis of experience, the researcher embarked on a process of personal data collection.

Data collection. All data were recorded by the researcher through personal audio recordings or written in her journal. All audio recordings were transcribed verbatim. The data included recollections of past experiences, personal observations and reflections throughout the research process. The researcher considered and responded to the same research questions she asked other participants. The questions used are included in Appendix C.

The researcher responded to these questions before conducting her first case study interview. After each interview, she revisited the questions and recorded any thoughts or self-observations stimulated by each conversation with a participant. The researcher continually re-examined her experiences to notice how those interactions served to illuminate aspects of her own experience that had not previously been explored. Chang (2008) referred to this exercise as "border crossing". After encountering the experiences of others she was presented with a challenge to a personal belief about a particular experience or culture. Specifically, the researcher reflected on the following questions after each interview: 1) what aspects of this participant's experiences with disability are similar to mine? 2) what aspects are different? and 3) what do these similarities and differences mean regarding the experiences of self-determination?

Participant. The researcher was 27 years old at the time of writing. She was a woman of colour who had a physical disability. She was completing a master's degree. She identified socioeconomic status as middle class and her academic interests in areas of psychology, women's studies and theology.

Data analysis. Data from the journal, research questions and border crossing were combined and analyzed using a qualitative content analysis procedure outlined by Creswell (2003). First, the researcher read through all data to get an overall idea of content. Second, she extracted words or phrases conveying an important idea from the texts. Third, the extracted meaning units were labelled with one or two word code to represent the main content of each. Meaning units are listed by code in Appendix F.

Fourth, the codes were listed and reviewed to identify conceptual connections between them. Fifth, codes sharing conceptual similarity with each other were grouped together into themes (Creswell, 2003). A list of themes by code can be found in Appendix G. The themes were reviewed to ensure that they accurately represented the researcher's experiences.

Similarities Across Data Sets

The final step in the analysis was to compare the themes that emerged from analysis of case study data with the autoethnographic data and factors identified in the literature review. It was expected that some themes would be present in participant data and the literature review. These themes would be considered the most strongly supported. Similarities within and between the researcher's personal experience and the experiences of the other participants would speak to commonalities that were not yet reflected in the research literature.

Trustworthiness

Trustworthiness refers to the extent that one can place confidence in the results of research (Van Manen, 1997). A study can be said to have high trustworthiness when the findings closely reflect the experiences of participants and the meanings they attach to those experiences (Leitz, Langer, & Furman, 2006*)*. Several strategies were employed to promote trustworthiness in the study. First, saturation was sought when determining the appropriate number of participants in the case study (Morrow, 2005). After three interviews with novel information in each, a fourth and fifth were deemed necessary to obtain more evidence of similarity across participants experiences. Second, member checks were used with case study participants who had the opportunity to review and edit their data. Third, data were collected from several individuals, compared to the researcher's own experiences and those commonalities were compared to the literature on the same topic. This strategy added support to the main findings (Chang, 2008).

Summary of Methodology

The study employed qualitative methodology consisting of case study and autoethnographic procedures. A common set of questions was used to explore the experience of self-determination among university-educated women with physical disabilities. The researcher recorded her own responses to the research questions and reflected on her responses after each interview with a case study participant. Data for the case study and autoethnography sets were analyzed separately using the same content analysis procedure. Results are presented in Chapter 4, and a comparison of the results of data from participants to the available literature is presented in Chapter 5.

Chapter 4 – Results

In this chapter the results of data analysis from the case study and autoethnography are presented separately. As the case study data were analyzed before the autoethnography data, case study results are presented first.

Case Study

Case study is a detailed exploration of experiences during a particular timeframe and context. Five university-educated women with physical disabilities recruited from the same geographic area and of similar age participated in individual interviews on the topic of self-determination. Analysis of the transcribed interviews was performed using a qualitative content analysis procedure. Five themes emerged from the analysis, including: Experienced Self, Reflected Self, Self in Community, Self as Learner and Professional and Self in Family. In this section a detailed description of each theme is presented. Quotations are used to illustrate the various ways participants made meaning of experiences of self-determination.

Experienced self. The Experienced Self concerned participants' personal experience of disability. Participants described their disability as a medical condition, but the labels and biological markers did not reflect their day-to-day mixed experience of frustration over their difficulties and gratitude for the personal and external resources that helped them do what others took for granted. University experiences provided external validation that disability should not be reduced to a condition and that it could be what one defined it to be. For participants, disability was not characterized in the negative. It was simply one aspect of identity and did not overshadow qualities of strength and determination that gave them energy and confidence to do what they wanted to do.

Participants named their disability using medical terminology.

> *...I have spastic cerebral palsy that affects all four of my limbs...*

However, these labels and terminology communicated little about the challenges they felt. Participants expressed frustration at being in a world that assumed standards of functionality, which were very different from their realities.

> *...Well, because my disability is mainly affected on one side of my body, being my left, a lot of my frustrations come from the fact that...I used to get frustrated, especially when I was younger, about not being able to do things that two handed people would take for granted...*

Participants' day-to-day experiences were very different from those who did not share their physical challenges.

> *...I always know that when, for example, getting up to go to class in the morning, it's always going to take me, like...what could take somebody, say if they have a class at 8:30, they can get up at quarter after eight and go get breakfast and jump in their pair of clothes and be out the door in time to go to class. But if I had that same class at right-thirty, chances are, I'm going to be up by like six-o'clock...*

Mobility aids such as wheelchairs, scooters or walkers affected their movement and how they got around.

> *...I have tight hamstrings, so when I do stand, my knees are always bent and it sort of makes my gait a little bit closed like a goalie. But for the most part I use a wheelchair so, I can't walk...*

> *...My right side has always been stronger than my left side but...and that I can't walk without the walker . I basically have no balance otherwise. I always say that if I don't have something supporting me, chances are I'm going to fall down on my butt...*

Comparing themselves to able-bodied others created negative feelings. Over time, the realities of their disabilities became easier to accept.

> *...I definitely, when I was younger, went through kind of a "why me" angst, I don't want to say rage but just frustrated stage, but then you know it grew into acceptance. It's a long hard road, no one straightforward*

> *path, but I think it kind of goes with the idea yeah, I'm a person and everybody's different, so somebody else is a person who speaks six languages. It's, you know, people can call themselves what they want, but I think it's kind of important to accept yourself before taking on a label but not being happy with it...*
>
> *..I can't deny that I secretly wish when I see people jumping in and out of the shower or going for a run or something first thing in the morning that I wish I could do that....I do . But I'm also at a point where I know what I can and can't do and I'll try to adapt things so that I can try to do as much of it as I can...*

Participants relied on the personal strengths and resources such as faith, self-confidence, determination and stubbornness that made them capable people.

> *...Well...I grew up in a really, really strong faith-based household and a pretty strong faith community. So I not only had access to the technology to make myself successful, but the mindset of, you know, God has a plan for you and...um....if you want to do something, set your mind to it and you will accomplish it...*

Asserting independence by refusing unnecessary assistance was an important component in the maintenance of self-efficacy.

> *..unless I know that I can't do something after ten, twelve tries, then and only then will I be willing to admit that OK, I need help, Can you help me grab this, do this, whatever . But I've always been...I see myself as the person first so I want to prove to myself that I can do something so it's believing in yourself enough to realize that yes, even if you have problems and there are difficulties, that you still have the strength in you to keep going...*

Participants found value in locating the problem of disability in the attitudes of others and the restrictions placed on their participation in the world around them because of the assumptions of able-bodied norms.

> *...I am more able to look at it like this is not my problem, it's society's problem. And like, that makes me feel a lot better about myself...*

Independence did not necessitate working alone to accomplish something, but rather, having autonomy in life decisions.

> *...[I]t becomes a question of how do you define independence. Is independence dong everything completely on your own without anybody's help? Because nobody does that....[I]s independence doing something for yourself, or knowing how to get it done?*

This view did not preclude obtaining assistance from an individual or organization. Rather, independence rested in the ability to make independent decisions. Self-determination meant making one's own choices, setting one's own goals and deciding how these aims were to be achieved.

> *...Well I think that self-determination means sort of like, setting goals, like your ability to set goals and achieve them, and also your ability to make your own decisions on top of that. To set goals and make your own decisions...*
>
> *...I would define self-determination as being able to make your own...like your own, quote...sorry, I've been reading a lot of Foucault, so your own [air quotes] choices, and being able to sort of like direct your own life and your own destiny, do what you want, self-determination I think goes hand in hand with concepts of individuality and being able to recognize your own purpose and autonomy...*
>
> *...For me, you know, it's setting goals for myself, thinking of what do I want to accomplish, what makes me happy, what makes me fulfilled, what makes me feel productive and I am the type, I am the person who does set in two years from now, in five years from now, in ten years from now, these are some landmarks...*

Goal setting was readily achievable with little or no help from others, but carrying out tasks associated with meeting the goal sometimes required their assistance.

> *...So like I was saying before, I feel as though the first half of self-regulation is readily achievable. Um, but in terms of actually reaching a goal, there are several interplaying factors which may or may not be a direct result of my disability, that can impede my ability to actually fulfill what is involved with self-regulation...*

Technological aids were extremely important in addressing non-mobility-related aspects. Participants expressed gratitude for technological advances that enhanced the scope of assistance that technology provided to make tasks of daily living more accessible.

> *...to use a computer, typing is not practical because I use my four fingers mainly, so I can use voice recognition software instead. Similarly, instead of reading a textbook in print, I have my University textbooks given to me in PDF files and get screen readers to read them, which avoids of visual impairment because there is voice feedback for me...auditory feedback...*

Non-physical aspects of the disability experience were also described. Participants spoke about the small but constant adjustments that were necessary to negotiate this reduced capability to locate oneself in space.

> *...it might be characterized as like a learning disability but technically it's due to the brain damage caused by cerebral palsy, I have really intense issues with like spatial recognition and it manifests itself almost as like dyslexia, but it wouldn't be medically understood as dyslexia because it is a manifestation of brain damage...[s]o for example, when I drive to work, I go a really specific way, and then I know that when I get to the playground, the driveway right after it is going to be the one that I turn into. But sometimes if I come from the other way, so that it goes driveway, playground, every time I miss the driveway because I turn after the playground...*

Participants noted that their disability had become an integrated part of their identity. Experiences during post-secondary study had contributed to the positioning of disability as an identity category.

> *...When I went to grad school and learned about the social and cultural models of disability, it was far easier for me to be like, "Yeah, that makes sense. That's in line with what I do and who I am." You know, so disability is on a parallel with gender, race and class, and it really made sense for me...*

The fact that disability was taken up as something interesting and worth of analysis instead of as a devalued status was an "enriching and empowering" experience.

> *...One of the things that I really valued that experience and the program is that it made disability something interesting to stop and think about. In the same way we would stop and think about race as something...the*

> *experience of being racialized as something of interest of the experience of gender being something interesting. It was a space where disability was interesting in the same analytical ways. And I just wanted to live there forever...*

The place of disability within personal identity was an important consideration for deciding what language to use for self-reference. There was something to be said for person-first language but participants also questioned its necessity, given that disability had been integrated into their identity.

> *...I'm not the kid with, I'm not "that CP kid" kind of thing. I am a person with a disability, I am a person with CP. So the person comes first, the CP comes second, kind of thing...*

> *...I wouldn't say that I have an aversion to person-first language, but I think that from a theoretical perspective it's really interesting because I work really hard to acknowledge my disability as an intersection of my identities, so I really question why there is a need to separate the disability from the person if we're going to think about it as an identity...like an identity category. So in the same way that I would never be like, "I am experiencing femaleness" or "I happen to be Irish." (like from a million years ago, potato famine sort of thing.) I question why I would identify as "person with a disability"...*

The perspective of disability-as-identity increased participants' comfort levels with different modes of self-reference regarding disability.

> *...I consider myself completely adjusted to my disability. It's been the way it is forever. It's all I've known and I'm totally cool with that. When I think of myself, I think of myself as being in a wheelchair. But, for people who, you know, don't identify as having a disability, language can be a major, major issue...*

> *...If I were to identify myself I would say "disabled person" but I feel that both terms have merit and it's a really fluid sort of space for me right now intellectually...*

In the Experienced Self theme, physical realities, differences from norms, and the place of disability in identity were described. The personal meaning of independence and self-determination served to highlight the internal and external resources that helped them achieve their goals.

The reflected self. The Reflected Self concerned feedback participants received about themselves through social interactions. Reflections of themselves from others, particularly during elementary and secondary school, failed to acknowledge important parts of who they were as well as important pieces of the disability that were not visible. The invisible aspects were open to misinterpretation by others and fueled covert erroneous judgments about capacity, while the visible aspects led to more open, but not necessarily more open-minded, discussion. Language that others used in reference to disability was sometimes inconsistent with how participants defined themselves as individuals. They felt limited by the judgment of others about their potential. Participants felt they were not recognized as capable adults with real human needs for praise that validated their accomplishments and aspirations as adult women. Participants felt both normal and different at the same time, but to counteract stereotypes they put extra pressure on themselves to be accomplished.

Ironically, while some people in their lives addressed disability by placing limitations, others tried to erase or ignore its presence altogether.

> *...I think the elementary and high school way of adapting to a disability is "Let's teach them to be as normal as possible." Because they assume that that's the best definition of functionality...*

Participants explained that the focus of some teachers and educational assistants was to teach students with disabilities to accomplish the same tasks as their peers in a way that was as close to their peers' method as possible.

> *...looking back on what my educational experiences were prior to university, I would have liked various special educators and whatnot to focus more on making me functional as opposed to making me typical.*

Each described the relative visibility or invisibility of certain aspects of her disability. In some ways, invisible aspects were more difficult to negotiate because they lead to assumptions of capabilities a person did not have.

> *...People...and I mean I guess rightly so, always assume that everyone can write and everyone can read so quite often when I have to be like, "I can't write, can you fill that out for me?" People most times, people are pretty good about doing it, but they still look at me like I have three heads...*

Participants reflected on the uncomfortable moments that arose when they disclosed a disability in order to obtain necessary assistance or consideration.

> *...for example, holding a door open, it's almost automatic for someone in a wheelchair for society to do that. But if I only have one good hand and I am carrying a heavy bag of groceries or whatever, people might not give me the same consideration...*

Participants explained that, in situations where invisible aspects of disability were problematic, others took up their genuine limitations as incompetence. This was especially true with non-physical aspects of disability, such as spatial difficulties.

> *...it's not something that a lot of people notice and then because my other, the rest of my life, I guess I appear pretty competent with my skills, so people often don't acknowledge it as something that's embodied, they acknowledge it as me being, like...silly...*

In contrast, when reflecting on the more visible aspects of disability, participants noted that they did create opportunities for educating others.

> *...I try to be as open about it as possible. Like I've never been the type that if they ask me what happened, I'm going to bite their head off because they're asking . I think it's better that they're asking than they don't ask at all and just stand there and gawk at me for 20 minutes! But I try to be as inclusive and as informative as I can do a degree that they can understand and I'm not going to go into the psychobabble of it all...*

Additionally, participants experienced intrusive curiosity from others who, for various reasons, may not have realized their questions were offensive.

> *...Sometimes people are very nosy and will ask you anything. Like I've had people ask me...once they find out I do have a physical disability, can you drive, can you have sex, you know, would you ask anyone on the street...People want to know, but sometimes people don't know how best to approach situations, and sometimes by overthinking situations, they make it worse. So I think that's where a lot of the impulsiveness comes, of can you have sex, can you have kids, what have you...*

When disability was visible, the language used by others to refer to it became significant. Participants talked about finding a balance between refusing to tolerate derogatory language and understanding when a slight may have been unintentional.

> *...I've come to a point in my life where...I mean, intentional demeaning is not honourable by any means, but political correctness is such a variable idea, and it changes so frequently, and in my experience, people who use the wrong words aren't doing so to be malicious, and the minute that I am dismayed over such things is the minute that I'm angry over something that wasn't intentionally negative, and something they didn't know and completely overlooked. So therefore, for me to be angry about those things serves no purpose...*

They expected and appreciated sensitivity, but did not see a need for others to be overly cautious about language use.

> *...I don't even know what it means to be differently abled. I mean, I don't have a special "sixth sense" because I have CP. Like...and I think that just...even though you're, quote, unquote "being nice" about disability, you're still bringing attention to it by special terms...*

Each participant shared experiences of being infantilized or patronized. Others seemed to equate disability with less capability to handle adult responsibilities independently.

> *This is another sort of issue I get asked a lot is like why are you by yourself, like, why are you doing this...um, like, yeah, why are you doing this, why are you by yourself and why do you have to do this? And these aren't things like why do you have to walk down the 401, they're things*

> *like, why did you go to the emergency room by yourself? Why do you feel the need to get groceries? Do you really have to go in this restaurant? And these are things that people who aren't disabled usually like...I don't know. When's the last time you... or, well, one of your able-bodied friends got asked, "So, why are you getting groceries? Why do you have to do this? It would be easier if you just didn't. Isn't there somebody to help you?"*

Receiving what seemed like positive attention for certain basic tasks also undermined attempts to be taken seriously as a functioning adult.

> *...I may surprise some people, but I'm not five. And so, when you're overly impressed by things that you take for granted, such as putting on a shirt for example, that is just....uh, it's completely irrelevant to me. I don't need people to be proud of me for putting on my own shirt. I need people to be proud of me for things that are on the same playing field as they are...*

Participants also noted the pressure of gendered adult role expectations, which intersected with disability in their own and others' evaluations of their success as functioning adult members of a societal group.

> *...society in general, able-bodied or disabled, especially for women, if you don't have a career, you're nothing. And if you don't have a man, like...you're also nothing... [A]nd like, that's what grown-up women have*

Negative attitudes toward disability may make these social expectations harder to achieve

> *So many people think that "You are single because no one loves you because you're in a wheelchair and that'll just never happen. You are poor because that's the way the cookie crumbles and you are unemployed because, again you're in a wheelchair. No one hires you."*

Participants noted this catch-22 of pressure and stereotype especially in relation to romantic relationships.

> *There are a lot of people I know and I've had frank conversations with and they just find that they would never even consider dating someone with a disability because it is too much for them to handle.*

Participants shared a number of experiences where limitations were placed on them based on what others thought they were able to achieve. The limitations did not match what the participants' felt capable of. This occurred especially in educational contexts.

> *... in terms of school, like in high school, the special ed department and a lot of the teachers were like, "Well this[going to University] is just not done." Like one of my favourite stories ever is the special ed teacher... [h]e was like, "So what are you going to do after high school?" And I was like, "I'm going to go to University sir." And he was like, well, he laughed and was like, "You need to apply, eh?" And I was like, "I did. I got into [school name] last week." 'Cause I did. And then he was like, "Really? How did you do that?" and I was like, "I applied and they let me in." And like, I had to* go home *and bring him back the letter that said I was accepted.*

Participants spoke of addressing stereotype, and of the need to make compensatory efforts to prove their abilities in realms other than the physical.

> *...the way that I mitigate that is by being really dressed up and using a really highbrow vocabulary as a way of illustrating to even the person who holds the most denigrated understanding of people who are disabled that I am in fact quite competent and worthy of their respect...*

Hyper-performance in other areas of competence was a way of proving competence and securing a valued place within the social order.

> *I spend an exorbitant amount on clothes, shoes and make-up, and while that can be taken up as "Ha ha, you're a shopaholic, you love shoes and make up!" and while that is kind of true, it's also done as like, purchasing a uniform and purchasing things and I feel ob...I would, I guess maybe not...obligated's not the word, but I feel like I have access to a certain social power if I am able to super hyper-perform my gender or hyper-perform my intelligence. Like I really think that part of why I am in grad school and striving to get a PhD is both...like I think that what I am studying is interesting and I'm a relatively cerebral person, but I'm not...I also like the concept of like, it puts me in a space where disability is intersected with something that really confounds the common sense understanding of disability.*

There was also recognition of the potential advantages of certain identity categories within which participants were able to situate themselves.

> *...I would say that a huge part of my success and my ability to conceptualize myself as being a capable being is that I'm white, I'm from a middle class family and my parents were married for sixteen years, and I went to school in a Catholic system...*

These identity statuses, not achieved but ascribed, were described during the interview process as "social capital" which was used to gain access to certain spaces of privilege. However, it was also acknowledged that those advantages came at a price.

> *...I still think it's problematic because normalizing or buying into a hegemonic ideal of who gets resources and who gets space is so screwed up and I think it's violent to the individual and really does a disservices to the collective energy of society...really...personally I have a tension with that because I think that if I were to give advice to disabled children, I would never want to be like, "Just try to look real normal." Because I think that's awful, but I think that essentially...and normal is a problematic word, I acknowledge that. But like, I think that enacting and making use of cultural capital is useful in negotiating an already flawed system. But I would really like to empower...I would really like to think about ways we can disturb social organization instead. So it's a reluctant strategy.*

In the Reflected Self theme, participants discussed the reactions of other people to their disabilities. Participants encountered assumptions about their capability and potential, as well as intelligence and maturity based on the presence of a visible or invisible disability. Participants strove to challenge the devalued status of disability by excelling in other domains.

Self in community. Self in Community focused on participants' experiences in the broader physical and social spaces in which they resided. They noted that neighborhoods were not set up to meet the needs of people with physical disabilities and because of that they encountered daily hassles including obtaining transportation and getting groceries. Social connections with others eased those problems, because when the physical environment was not responsive people who understood and were helpful would compensate for it. Participants noted the irony of inaccessibility in the physical environment and the structural inaccessibility of services for people with disabilities. Participants felt that the narrow scope of accessible spaces and services carried a negative message about the right of people with disabilities to participate fully in their communities, and highlighted the need to advocate for others who faced these problems.

Transportation has always been my little pet peeve because I don't drive.

Participants also found that alternatives to automobile transportation were not always convenient or accessible. For example, public transit could not always be counted on for accessibility.

> *...a good example is, quite often the TTC accessible features are broken. And quite often I am met with, "Well, you should have called the lift line." Which is a line that says which elevators are not working today And I mean, in theory, it's a good thing, but my thing is, when able-bodied people have to start calling to see if the stairs are running, then I will call to see if the elevators are running. And then, the other thing is, quite often when this happens, like, it doesn't matter that the elevator is out. Like even if I had've known, that's still how I have to get home, so like that's...it's not going to help...*

Other services such as parallel transit, while guaranteed to be physically accessible, had very little flexibility and limited participants' ability to decide where they wanted to go and when.

> *...you have to pre-book all of your transportation and you have to know where you want to go and how long you want to be there and when you want to come back, days in advance... and if I want to just go to the mall and hang around for a few hours, I can't do that because I have to specify "OK, well I want to go to the mall at nine and come back at three...*

Closely linked to the absence of reliable, independent transportation was the ability to accomplish daily tasks. One such concern was groceries.

> *...the hassle it takes to actually physically go get groceries is kind of ridonculous...*

Participants noted the difficulties of getting to the store, obtaining needed items and transporting them home while negotiating mobility devices and/or semi-accessible transit.

> *...I really like this area and my community because it's relatively safe and it's...because I don't drive I can access a lot of things, and one of the things I really like is I like having access to a lot of stuff all by myself, because it doesn't remind me quite...like then I am able to do a lot of things people would do with a car without one. And it doesn't make me feel as bad that I can't drive... and also, I can do stuff by myself, which is great...*

Participants expressed that being surrounded by people who understood their needs and were willing to help when necessary contributed to their sense of being able to accomplish both daily life tasks and larger goals.

> In [*this community]* *if it's the middle of winter and I drop my cell phone in the middle of the town square, well, luckily I can just go around the corner and grab my hairdresser who's cut my hair for ten years and say, "Yo, can you come? My cell phone is in the middle of the square and I need to pick it up."*

In addition to the microcosmic considerations of day-to-day interaction with individuals in community, participants reflected on larger social structures within those communities. Participants expressed interest in participating in opportunities such as community athletics.

> *I always found it difficult to engage in team sports because I'm not in a wheelchair so, for example, wheelchair rugby, wheelchair basketball, etc., they don't...they actually would hinder me if I were to participate rather than play on my strengths. But at the same time, there's not a demand or supply enough to create a you know...a disability...a disabled league with*

> *no...like with people who don't need that much adaptation they just need that much...equal playing partners...[and] as a result I've always been engaged in more solitary or individual sports, which, you know, great, but it would be great to have a team experience once in a while.*

Regarding community services for people with disabilities, participants noted several concerns, beginning with awareness of a continually changing web of resources for which the means of access was not always clear.

> *The services in this day and age change so frequently and improve so frequently that, you know, I was aware of Ontario disability support programs from three years ago that I assumed are the same today. I call and find out that the whole system has been overhauled, which is probably for the better, but I was never informed of said changes.*

Participants explained that services co-ordinated and delivered together for children were separated and differentiated for adults, making them harder to access.

> *...I find that it's hard to access disability services- if you're an adult- that are good [and] that don't require you to do lots of paperwork and be under these specific weird categories. So that is frustrating, but I find there's really no services past eighteen...*

The compartmentalized nature of services meant that resources that may have been beneficial were accessed with difficulty or not at all. One particularly concerning difficulty participants' mentioned was obtaining repairs for mobility devices.

> *Getting an approval for a wheelchair repair [through ODSP] can take months. And so then you have people that...their legs are essentially broken because you won't help them... and I think that comes back to...people don't seem to understand that wheelchairs are a lot of money so it's not uncommon for somebody to only have one wheelchair. Like people don't have spare wheelchairs in their houses.*

Participants expressed frustration with measures that appeared to make a space or service more accessible, but in fact, did not. In some cases, these were blatant, almost comical oversights in the layout of the built environment.

> *...I went to the gym the other day and I really had to go to the bathroom, so I ran into the...or I wanted to run into the bathroom and once I got in, I noticed that there was an accessible bathroom stall, however, to get into that stall, you had to go through two doors, both of which were pull open and there was no button, so I found it kind of ironic that they would have an accessible stall, but not an accessible way to get into the accessible stall...*

Other instances were subtler, giving the appearance of accessibility without actually being accessible.

> *Starbucks is now required to have one accessible table. Which is fine, but now, because they have that one table, it doesn't, like, they're considered accessible and it doesn't matter if all of the other tables are up three thousand flights of stairs, they're still technically accessible because they have that one table that can support one wheelchair. Because as we know, all people go out for coffee by themselves.*

Instances of accessibility in appearance only were particularly frustrating. First, they presented a situation in which a person with a disability had less access to a space or service than would an able-bodied person. Second, such inaccessible accessibility prompted some to locate the problem not in the fact of inaccessibility, but in the failure of a person with a disability to negotiate a space, which *appeared* accessible but was not.

> *... it's even more aggravating than doing nothing. Because at least if you did nothing that would be quite obvious, you know? Going into an accessible bathroom that literally is four inches wider than a non-accessible bathroom? Like, they're both not accessible, and now I just look difficult because I can't fit into the slightly, minimally bigger bathroom.*

Participants spoke at length about the messages society gave people with a disability about their right to participate. If certain services and spaces were not accessible, it would seem to indicate that societal participation of persons with disabilities was given less importance than participation by those who conformed to an able-bodied norm.

> *...I think that the real focus on access within policy is in making consumer spaces accessible, and I think that really changes the way you negotiate life when you use a wheelchair, and it also only makes room for a very specific kind of disabled person because....like, for example, I know the mall is always accessible and I know that government buildings are always accessible. So what does that do to my experience that like...I can be a consumer and I can produce civic experiences...*

Too often, selective accessibility was met with an attitude of unconcern, indicating that persons with disabilities should not expect to participate fully in their social worlds.

> *...quite often, rather than being met with like, "We're so sorry this happened and let us assist you and how can we help you?" it's, "You should have known better than to leave your house."*

This restricted participation was keenly felt as a personally devaluing experience and a comment on one's right to participate in the community. Also related to the devaluation of social participation of persons with disabilities was the idea that people with disabilities should be happy with any accommodation, even if it did not place the person on equal footing with able-bodied others in the community. Again, the example of accessible transit services:

> *...You know, they think nothing of being an hour late or leaving 20 minutes early or leaving someone on the bus for two hours when it's really only a 15 minute direct route, I think these are like societal facades that are just degrading and it's...you can't fight something that looks good to the rest of society . So the rest of society looks at these parallel transit buses and says, "Oh, isn't that great that we have door to door service for disabled people . They must be so happy, happy, happy."*

The pervasive acceptance of the limited participation of people with disabilities had an alarmingly negative effect on self-perception. When observing others with disabilities who seemed willing to accept a limited degree of participation, interview participants felt called upon to advocate for their rights to access services and participate in the community.

> *...sometimes me and my sister will talk about colleagues or friends we know in wheelchairs and we'll say that they very much have an attitude of, "It's very nice that the able-bodied people let us live in their world." And me and my sister's attitude is like, "Why wouldn't I be here?" And I think that that's something my parents, as crazy as they are, helped instil in us is, "You have every right to be here just like everybody else...*
>
> *...even some people with disabilities who consider themselves a burden to society and don't leave room for the fact that they deserve the same privileges as anyone else contribute to this whole, um...docile movement of, well, you know, we're disabled so we should just be thankful for what we have or what we get or whatever. Those are the kinds of things that make me upset...*

In the Self in Community theme, participants discussed the physical and social barriers they encountered as they attempted to participate in their communities. They faced challenges getting transportation and finding activities such as athletics to participate in. They noted the frequently changing landscape of disability services, and difficulties locating and benefitting from those services. While they found social support in their community, participants frequently encountered inaccessibility and were aware of the negative messages it sent about their value and role.

Self as learner and professional. The Self as Learner and Professional described participants' accounts of their experiences in educational and employment settings. As primary and secondary students, participants had been told directly what they would and would not be able to do and their educational pathways were already determined for them. While researching universities they similarly found policies that paid little attention to individual needs. Participants did have success in settings that offered individualized supports and collaborative planning. Participants voiced practical concerns about employment such as finding a good fit for short-term employment to help with income, getting the accommodations they needed from a prospective employer as well as how to transition from government sponsorship for mobility devices and technology when they become ineligible. Negotiating the politics of disability in the workplace was also an important concern, as was finding employment that was commensurate with participants' skills and training.

Participants spoke of the necessity to contradict stereotyped assumptions of their ability to undertake post-secondary studies. Often, those voicing such assumptions were doing so based on what they felt to be a "realistic picture" of what a person with a disability would be able to accomplish.

> *The person they hired to be my assistant didn't understand me whatsoever, was very belittling and just not, in general, supportive of my dreams. And she would say things to me like, you know, "You'll never make it to University" and these kinds of things that were by no means assisting me, even if it was to give me a realistic picture.*

Participants recounted such experiences with educational assistants at the elementary school level and with guidance departments at their secondary schools.

> *They sent me and my sister home with a letter that said "Please sign this so your kids can't take advanced courses because they're disabled and they can't do it." And there was no intellectual tests or discussion. It was like, "Your children are disabled. They will not be doing this." And even when we were in OAC, every time we had trouble, his solution was why don't you just quit?*

It is ironic that, in an educational setting, students with disabilities were often hindered and discouraged rather than supported and encouraged in their wish to undertake post-secondary studies. In some cases, educators went so far as to attempt to preclude the possibility of post-secondary study by placing a student in non-university-level high school courses.

Once it had been established that post-secondary studies were going to be perused, the accessibility of post-secondary institutions became an important consideration.

> *...I think a large part of how I chose was based on the Center for Students with Disabilities, in terms of what they did offer, because I knew I would need help and I knew that was going to be a large part so if it didn't work out, that was automatically going to be nixed in terms of a potential opportunity...*

In order to ensure the success of a post-secondary opportunity, participants undertook personal research into the accessibility provisions each potential institution was able to offer. Sometimes, participants would be met with a systematic approach that was not a good fit with individual needs.

> *...they would say to me, you know, "How do you do things?" And I would explain about the auditory textbooks and the one on one assistance and the reader/scribes, and they would sit there and say, "Oh, well we don't do reader/scribe accommodations anymore." And I thought, OK, so you've made a systemic change without regard for individual needs whatsoever...*

Participants found that approaches favouring greater individual attention and collaborative planning were a more effective way to meet accessibility needs. With such individual and collaborative attention, all were able to experience success at the university level.

Participants discussed the types of employment that seemed available to them. The described the unavailability of service-industry work to address specific and time limited financial goals, such as using the summer to work and save for post-secondary education. While not fulfilling long-term professional aspirations, participants acknowledged that greater availability of service industry jobs, as options for short-term employment, would have been appreciated.

> *Well retail is pretty much out because it.... the fact that the walker is pretty wide and a lot of department stores are smaller and I can't be on my feet a large part of the day or I get tired.*

Participants speculated about the effects of the visibility of their disability and suggested that disability did not matter so much at the application stage.

> *I don't write across my resume in red crayon, "gimp" [both laugh], so like when they initially see my resume, they have no idea who I am or what I do. So I feel that it's almost foolish to be like, "They're discriminating against me 'cause I'm in a wheelchair!" Because how many places that have seen my resume know that I'm disabled? Because nobody knows who I am on paper*

But participants also pointed out that, in face-to-face interviews, disability became an issue when a circumstance in the interview forced disclosure.

> *...filling out job applications or being asked at job interviews, I think I have almost shot myself in the foot because I have had to identify that I can't fill this out. And I think that throws people off or scares them a bit....I find it interesting, being in human resource management ,,cause everybody's like, "Oh you don't have to tell." But inevitably, sometimes it does come out in the initial stages of the interview and I think that in some situations that has led to me getting screened out for the position...*

Once a position was obtained, persons with disabilities confronted the issue of asking for specific accommodations. Issues to be considered were timing of request, which specific accommodations to ask for, and how the disclosure of disability and request for accommodation would be received by supervisors and co-workers.

> *I could ask for supports such as, it's easier for me to type on a laptop because I type with one hand as opposed to a full sized keyboard, but I still can, and I still do very well typing on a full sized keyboard. So you know, do I really want to go through the process of saying I have a disability and I need this vs. over time, you know, telling employers or co-workers what my strengths or weaknesses are.*

Participants expressed concerns about the attitudes of potential employers toward their disability-related limitations. For example, an employee's disability-related needs may be different from what an employer would expect.

> *It's interesting because quite often people think that a barrier to employment is something like, there's no ramp, and that's really not my issue. The job developer I'm seeing is all about, "People don't want to hire you because of wheelchair" and really, all wheelchair needs is a ramp and it's good. Wheelchair is good. But to function as an adult, I need about a thousand dollars of adaptive software.*

Participants also spoke of the catch-22 of obtaining professional employment, given their use of government support programs to cover some disability-related costs.

> *I'm also discouraged by the fact that, you know, ODSP covers exorbitant wheelchair repair costs and medical costs and whatnot. If I no longer receive ODSP, I will be expected to pay for these things myself. Except that, even if I make a well-to-do, well-off salary, the costs incurred with wheelchair repair alone would be exorbitant for anyone.*

In the Self as Learner and Professional theme, participants described the limitations others assumed about their educational potential that they overcame with parental encouragement and advocacy. Individualized supports were an important component of post-secondary success. Participants found that employment was a complex issue. They negotiated availability of employment, suitability of employment for their interests and level of training, as well as the additional issues of securing accommodation, negotiating attitudes toward disability in the workplace and negotiating the effect of employment on necessary social supports.

Self in family. In Self in Family, participants spoke at length about how their experiences were shaped by family influences. They described positive experiences wherein family members acknowledged participants' disabilities but did not characterize disability as limitation. This section focuses on the influence of parents. Analysis of sibling influence was omitted due to the risk of identifying some participants by the unique character of their stories.

The efforts of parents went beyond the home and into the school and community where parents were advocates for the full participation of their children. Participants perceived their parents efforts to protect them, and sometimes felt that these efforts were excessive.

It seemed that much of the work that parents did in helping participants negotiate disability was to remove the idea of disability-as-limitation from dialogue about the present and future.

> *My parents were always very much like, "You are going to grow up and you are going to be normal and it's going to be fine."*

While participants expressed appreciation for this encouragement, it was sometimes hard for their parents to understand the complex realities of their disabilities.

> *...they're frustrated by I don't know, my personal frustration with... winter, for example. They don't really understand that it can be such a..not only a physical drain, but an emotional and mental drain. SO I think my parents...the best way I can probably say it is that my parents have been great at physical adaptations but mentally they might not understand the emotional or sociological or cultural complexities which physical barriers can interfere with...*

Participants explained that, in some cases their parents were not sure what her disability would mean for their day to day lives, so they chose to suspend expectation and let them discover their own life courses. The open attitudes adopted by their parents were instrumental in allowing them to choose experiences that may not have been considered typical. Parental support for the ability to undertake "normal" social experiences was a significant factor in their level of social participation.

Parental advocacy was an important contributor to participants' success. When others imposed disability-related limitations based on assumptions, it was often parents who stepped in to ensure that participants were included in a way that reflected their abilities.

> *So my Mom sort of went to the school and worked with the special ed department that I would be taking all advanced classes given the reflection of my marks and who I am and what I do and while she believed in me, there was a sense within the school and with the teacher of, "We're going to do this because your Mom is ridiculous."*

Tenacity on the part of parents was a factor in the success of their academic achievements in high school. The advocacy role, when undertaken by a mother, formed part of a larger picture of socially advantageous statuses that could be used to access resources and assistance.

> *I think that my Mom's ability to do that is highly...not motivated, but highly propelled by the intersections of class, race and....class race and gender too, because by doing this, she was taking up the "Good Mom" role and so becoming a girl guide leader and managing the basketball team and driving us everywhere, that was something that was understood as highly socially appropriate, and things that good moms do. And so, when you have a good Mom and kids from a white middle class family who are understood as good kids from a good family with a good Mom, it becomes this thing of, "Why wouldn't the community accept them, because at the end of the day, they're good kids with a good Mom and they just can't walk."*

While parents were supportive, moments of parental overprotectiveness were not altogether unheard of.

> *Definitely there are still times where, you know, I'll, my parents will be like, "Oh, you can't do that." Or "You shouldn't do that." And I'll be like, "Why not?*
>
> *This past summer, my Mom went away for a week, out west for a wedding, leaving me at the house by myself for a week, and you would have thought that by her leaving, my world according to them would have crumbled to an end because my grandma and my uncle and my Mom's boyfriend kept*

> *calling me and my next door neighbour kept calling me on a daily basis to make sure that everything was fine and I didn't need any help.*

Participants expressed gratitude for their parents' concern, but also a feeling of not being trusted to act independently and seek help when necessary. However, participants also noted that some of their parents' protective efforts did help them to see certain situations more realistically.

> *...she's always been the type to encourage me to go for what I think, but she's also been the type to still look at the reality of the scenario too .For example. When I [wanted to be a Marine Biologist] And she's like, "[name], you can't be in water that's less than 86 degrees and you can't get on and off boats." So it's like...she's always kept me in that same line but she's always willing enough to say, "You can go for whatever you think, just be realistic about it at the same time...*

In light of the fact that all participants had successfully completed at least one post-secondary degree, the balance between parental protection and parental encouragement of autonomy seemed an important consideration. Participants identified excessive parental protection as a potentially limiting factor among their classmates who also had physical disabilities.

> *...classmates of mine, some of the 13 who graduated with me who still live at home ten years later with their parents, haven't had a job...I don't know how much their parents push them or how much they're overprotecting them but you know...why did my parents push me so far in one way and other parents pushed the other way...*

In the Self in Family theme, parents were seen as an important source of support. Parents did not characterize disability as limitation, but they helped participants to develop a realistic picture of what they could accomplish. Parents played an advocacy role in participants' lives. While their parents were protective, they sometimes found this protection to be excessive. Participants characterized parents as important to their success.

Autoethnography

Autoethnography is the study of self in a cultural context. I shared the contexts of age, geographic location and physical disability with case study participants. I answered the same questions that I posed to them and reflected on my responses after each case study interview. From the qualitative content analysis of data from my transcribed notes and recordings, seven themes emerged. The themes included: Physical Self, Perceiving the Self, the Self Perceived, Seeking "Normality", Self in Family, Self as Learner and Professional and the Reflexive Self. In this section a detailed description of each theme is presented. Quotations are used to illustrate the ways I made meaning of personal experiences of self-determination.

In the first six themes, quotes that appeared in my journal or interview transcripts are presented in the past tense, but the meanings contained within are analyzed in the present tense. They reflect my lived experiences as they continue to be experienced in day-to-day life. The seventh theme (Reflexive Self) is presented in the past tense as it concerned thoughts and realizations that occurred at specific points throughout the research.

The physical self. The Physical Self concerns my direct physical experience of having cerebral palsy. I prefer to speak about my disability in experiential terms that describe what cerebral palsy is like for me. I experience differences in movement such as limping and limited dexterity, along with some pain and spatial orientation issues. Developing an understanding of my disability has helped me to make adjustments and adaptations, but I still notice an internal tension with the physical realities of disability as I strive for "normalcy."

When asked about my disability, I prefer to give an account of the way I personally experience cerebral palsy, rather than a medical narrative of what cerebral palsy is or what causes it. I believe that this is more useful in helping people understand how my disability affects me.

> *I have spastic cerebral palsy, which basically means that all my muscles are tighter than they should be. Because of this, I have a little trouble controlling some parts of my body....I walk with a limp, my hands don't always work as well as I would like them do, that sort of thing. It also means that I have pain a lot of the time. Just imagine if certain muscles were permanently tensed.*

When explaining cerebral palsy in this way, I am trying to give a picture of the way I experience cerebral palsy, rather than an explanation of what cerebral palsy "is" because I know there are so many different ways it can manifest in a person. In the past, others have refused to believe that I have CP because I can walk or talk or perform some other functions or tasks that the person thought individuals with cerebral palsy could not do. Naming my disability in this circumstance affords the chance to dispel a myth related to cerebral palsy.

Another aspect of my experience that becomes important for me to explain is the spatial difficulty that results from damage in certain parts of my brain.

> *I'm always trying to explain to people that I have no abstract spatial sense....like, none . I can't form a picture of a spatial relationship between two places or objects unless I am looking at them. The example I use is like, right now, sitting in my house, I couldn't give you directions to get from here to the University. It's somewhere I go every day. I obviously know how to get there, but I can't tell you how unless I'm looking . If I need to give someone directions, I'll look at a map and memorize the fact that you turn left at this street and right at that one, but it's a set of declarative facts, not a spatial representation, and I can't recall it if I forget it. I also...because I can't really locate distinct points in space in relation to other points or objects, I get disoriented a lot. This becomes really embarrassing when it's something like...I go out for dinner and get*

> *up to use the washroom, and then I get turned around and confused on my way back to the table. It's awful*

For much of my life, I did not understand that this spatial difficulty was a manifestation of the effects of my CP. I recall the immense relief in finding out that my difficulties had an explanation.

> *I remember when I first had that conversation with a friend and she told me that the spatial issues I was describing were common for someone with CP. I was so absolutely relieved, you have no idea. I think I said, "You mean I'm not stupid?"*

Before I knew that there was a reason for my spatial difficulties, that lack of directional or spatial sense existed as a frustrating incompetence. Once I realized that there was an explanation for it, it was at once easier to accept it and realize that it was not a marker of my intelligence. I also learned to anticipate my spatial difficulty and make small adjustments for it.

> *If I' m in the library stacks and I need to go leave to get a step-stool, I stick a post-it note to the floor to remind myself what shelf I'm at. In Church, I put a hymnbook on the pew when I go up for communion so I know which seat is mine.*

Recognizing and predicting this particular feature of my experience allows me to make adjustments to my environment so that the lack of spatial sense causes less of a problem than it might previously have.

Because of my cerebral palsy, I walk with a slight limp. This has become so much part of my experience that it is usually unproblematic and nearly overlooked.

> *Sure I limp, but it never really becomes a problem. It certainly doesn't slow me down. I walk fairly quickly, usually, and I'm fond of saying, "Imagine if I didn't limp. I'd walk so fast there'd be fire coming out of the back of my shoes!"*

More commonly problematic in terms of walking are issues such as balance.

> *Because of my balance, I have trouble negotiating narrow spaces. I'm always afraid I will lose my balance and fall and hurt or embarrass myself. When I have to traverse a narrow space, there is a moment of fear that I don't think most people appreciate. Like, for example people are supposed to leave their backpacks on the floor of the bus, but when someone leaves one in my path to the door, now I'm worried I'm going to trip over it.*

Part of the problem with balance is simply the feeling of unsteadiness or uncertainty. The lack of balance means that I move through the world less freely and with more worry than I might if I were steadier on my feet.

I always think of my balance as paralleled with the trouble I sometimes have with finger and hand dexterity. There is (albeit to a lesser degree) the same feeling of unsteadiness or clumsiness.

> *I have trouble with my hands. I never really understood how I was different until I was trying to do food service in the summer of 2005, and I would be slinging food and always half a step slower than everyone, and I started to notice it then, the lack of dexterity, because you're constantly working with your hands . And suddenly it all made sense, the fact that sewing on a button can literally take me hours, or that I chop vegetables more slowly than anyone I have ever met. 'Cause my hands just can't move around object and manipulate them as fast of as well. You may not notice unless you were looking for it, but the difference is there.*

This was another instance where lack of understanding of my own experience caused me to question my own competence, this time in the physical realm.

> *Before I realized this problem with my hands, again, I used to fault myself for my "clumsiness" Now that I have become aware of the way that my hands function, I'm better able to accept it and adjust for it. It does mean that I have a harder time independently addressing what, for most people, are minor problems like a shirt losing a button. Now the question becomes whether to struggle to fix it or have someone do it for me. It's a choice I sometimes wish I didn't have to make.*

My lived bodily experience of CP does involve some amount of pain. Because muscles are tighter than they should be, a certain amount of pain is a normal part of everyday experience.

> *Pain has become so normal now that it is almost a non-event. Something always hurts, usually my hip. The muscles are always tight, like a marionette string being wrenched upwards.*
>
> *The experience of pain is not overly problematic now, as the pain is usually mild or moderate. My worry is what pain now means for functionality in the future.*
>
> *Every time something hurts, I get anxious. I ask myself if it is connected to the CP, and it always makes me wonder how things are going to be 10, 20, 30 years from now. How much pain? How many thing I will not be able to do anymore? How much help will I need?*
>
> *I find it difficult to make meaning of pain in a way that does not cause a degree of worry for my future capabilities to live and function independently. Because of this, I feel as though I worry about the future more than someone my age may otherwise.*

The Physical Self described my embodied experience of cerebral palsy with reference to control, spatial difficulty, pain and the accompanying worry. Body shape and the role of physical activity were briefly discussed.

Perceiving the self. Perceiving the Self refers to my feelings and observations about my experiences with disability. In the way that I perceive myself and my experiences of living in the body I inhabit, there is a pervasive dialogue of normalizing or minimizing the effects of disability. I prefer language that allows me to make meaning of my experiences without positioning disability as a primary status. Through my interactions with the environment and with others I repeatedly become aware of myself as a person with a disability.

I am more aware of the presence of my disability than I used to be, but I think that a lot of my internal tendencies toward normalization of experience happen almost automatically, without concerted effort.

> *It's funny, because I have always know that I have CP, and I understand that CP is a disability, but it's almost like, over the years, I have been slowly waking up to the idea of myself as a person with a disability. It's much more present now than it ever was, and even with that idea in mind it's like....living in this body is all I have ever known. I have no basis for comparison.*

Even though I understand the physical realties of my body, it is as though I sometimes make meaning of them in a way that separates me from the idea of disability. I know that my physical experiences are different from most people's, and that these differences usually reside in the fact that I experience less physical functionality than is considered the norm. And yet, I have often experienced a feeling of being divorced from the idea of disability.

> *When I was little, 7 or 8, my Dad and I want to a hockey game. We'd have had to stand in the top deck, but my Dad told someone that I had a disability and we ended up seated right behind the boards. At the time, even though I was wearing my AFO, [ankle-foot orthotic] it felt wrong. I didn't think of myself as having a "disability" then. In hindsight, I know there's no way I could have spent an entire hockey game on my feet, so the sought accommodation was obviously valid.*

Retrospection on this event shows me that difference was present and necessitated an accommodation to allow me to participate in that experience. However, when I am comforted by difference in the moment, I sometimes fail to recognize its meaning.

> *When I was a preteen, someone spoke to me about getting involved in athletics for people with CP. It sounded like a good idea at the time, but nothing ever came of it. I've sometimes wondered why. I wonder if part of it had to do with not identifying myself as a person with a disability. I wanted to think of myself as just like other kids.*

There is a sense here of pushing back against the idea of disability; not wanting to do anything that would see me singled out or marked as different. I see the same tendency in my own comments about language use, recorded before the first interview in this study.

> *I don't like the term, "disabled." I mean, I really don't. It feels to me like defining the person you're speaking of by their physical limitation. It feels like saying, right from the get-go that this person can't be understood apart from the fact that their capabilities in some realm or another fall below what is considered the norm. I prefer the term "person with a disability" as a self-reference. I feel like it gives me a little more of a say in defining the ways that disability affects my life. It gives me some more control. But then, "differently abled" is almost too PC and patronizing, I am a woman with a disability. That's my reality and there's no point in...softening it, I guess is a good word*

The strong reaction to the first term is, I think, a rejection of the idea that my worth or importance is defined by what I am able or not able to do. By preferring "person with a disability" I am asserting my right to be respected in my personhood before any attention is given to lack or limitation. On the other hand, the rejection of "differently abled" shows me a wish to say something concrete and understandable about the fact that my physical experience is atypical, in a way that can prove disadvantageous in certain contexts and environments.

Despite this acknowledgement of difference, one may wonder if my efforts at normalization have, in a way, worked too well. Sometimes, I seem to forget my bodily realities until I am directly confronted by them.

> *Sometimes I'll even forget that I limp. Someone once said to me, "Hey. Are you limping?" And I went, "NO!" like it was the most ridiculous thing, and then I thought about it and said, "Well, yeah, but I always do." When I really notice the limp is if I walk by a mirror, and I have this moment where I think, That girl can't be me. She looks so broken and clumsy and ungraceful...lumbering around like that. And I mean, that's*

> *shocking. I would never say that about anyone else with a limp, but that's what I think when I see my own walk in the mirror.*

The shock, and almost sense of disdain that I feel when I see my limp in a mirror may again arise from the fact that I spend so much energy trying to convince myself that I am "normal" that a physical representation of my own difference is shocking. The negative reaction also tells me something about my attitudes toward bodies, which don't function "normally." There is a tension there. When my gaze is directed toward others, I readily realize and acknowledge that bodies need not be "normal" to be valued, and yet if, "normal" is the standard to which I hold my own body, it will always fall short.

There is a sense of something to prove here; needing to show myself as capable. Sometimes, efforts to assert my capability can be taken to somewhat of an extreme.

> *I am so stubborn and fiercely independent that I think I sometimes shoot myself in the foot while trying to prove I can do things on my own. I probably refuse help that even able-bodied people would accept. Like, I once arrived to visit an out of town friend and she told me off for not calling her from the train station. It was like, she would have picked me up, not because the CP prevents me from getting around, so much as because it was pouring rain and I was dragging a huge suitcase.*

Dialling this fierce independence back to a productive and sensible level, I realize that what I may be asserting here is simply my capability to be a self-determining individual. Reflecting on self-determination before the start of the interviews, I said:

> *I would see it as the ability to be independent and to make my own decisions...to make independent decisions in my life, to decide if and when I need help, how much I need and how much I would like someone to help me. Self-determination means being able to set goals. I decide what I want and act independently to get those things when I want to act by myself. But self-determination also means that when I do need help I can get it without having to jump through a bunch of hoops.*

Having defined what self-determination meant for me, I turned to the question of how that sense of ability to self-determine had developed. I answered myself thus:

> *I think a lot of making my own sense of self-determination easier is the way that I see myself as an independent person, who is capable, for the most part, of doing most things that everyone else would do…I guess the ability to have those typical experiences…even if I have to do them differently.*

And there again is the idea of being able to do "the same things as everyone else." I began to ask myself where that idea came from, and how it may have been influenced by my social experiences.

Perceiving the Self explored my self-perception in light of my physical realities. It described attempts to deny physical difference as well as the repeated experience of becoming aware of that difference. Self-referring language was explored. This theme also illustrated my attempts to prove myself to be capable and independent.

The self perceived. The Self Perceived refers to reflections of myself as a person with disability that I encounter from others with whom I interact. Others in my social world often react to my disability in ways that are troubling to me. I have been pitied, treated as though I am delicate, completely ignored and openly mocked. Well-meaning others sometimes ask intrusive questions or make patronizing statements. As I move through the world, I take opportunities to address stereotypes and misguided assumptions about people with disabilities.

Reflecting on how others in my social world seem to perceive me helps illuminate my need to act as though I am just like everyone else.

> *Seeing how certain people treat me when they know I have CP, the fawning, the acting as though I am delicate, I understand that my own perception of what I am capable of would be very different if I allowed this attitude to influence my experience too much…*

Here, it seems as though I am working against an attitude that I perceive from others in my social world that suggests persons with disabilities are less capable than those without, and are in need of protection. Ironically, this attitude does not seem explicitly tied to the idea of physical difference alone.

> *People's reactions to me and assumptions about me change when they realize that I limp because I have CP and not because of an injury. Things are all normal when someone thinks that like... I have a knee injury or something, but as soon as I set the record straight, I start getting that patronizing, pitying crap.*

It is as though someone with an injury was "normal" once and will be "normal" again so there is no need to worry. The person with a disability, on the other hand, is viewed as permanently abnormal or deficient. The two ideas elicit entirely different reactions. When the abnormality is disability related, sometimes it is cause for more attention. This attention is not always positive.

> *One of the first days I lived here, some guy made fun of me on the street. He was standing talking to someone, and when I went to walk around him, I lost my balance and teetered a little. He then blocked my path and imitated my walk with a leering smile. I was so shocked and sad and angry, and I already missed home so much that all I could think was, "I fucking hate this stupid city." Because I was convinced that this never would have happened at home.*

For this man, (and others I have encountered) the visible presence of disability is an invitation to blatantly devalue me in a way that one would not if one considered me an equal. For some in the social world then, disability is taken up as a completely denigrated, undesirable status that warrants derision. Although I encounter such blatant discrimination seldom, I am always on the watch for it, and sometimes wonder, in hindsight, if I have encountered it.

> *I think back on that experience where I got brushed off at the medical clinic after I hurt my foot, and I wonder if it was some combination of things about my appearance that made me seem like a person who deserved to be ignored. I know I was limping badly and I remember I was wearing my big grey coat, flapping open because a button was missing. Part of me wondered if the doctor looked at me and decided, "Poor, black, disabled woman, not really worthy of my attention."*

The unfortunate thing about situations like this is that I will never know if that is what actually happened, and so I may miss opportunities to call discrimination what it is and to take a stand against it. Here is an example of the constant watchfulness that can be occasioned by one's awareness of their intersecting identity categories. Here too is shown my awareness of inhabiting a number of "difference" categories at the same time.

> *I was having this conversation with a guy in my philosophy class about the fact that people give me weird looks when I tell them my Irish last name, then I was telling him that I'm adopted and the rest of my family is white. So then, the professor overheard me, and when I went to her office hours later, the first thing she says to me is, "You're limping. Did you hurt yourself?" And I said "No, I have cerebral palsy." and she goes, "You have cerebral palsy too? And you grew up in [hometown]? How much fun was* that?." *And we laughed about it, you know. But then later, when I went to tell my Mom this conversation, like ha ha, funny story, and her reaction was like... she thought I was saying that being adopted or black or having CP was a bad thing. I had to try to explain to her, no, there's nothing *wrong* with it, but in a place like [hometown], it does make you a bit of a marked woman, and you do notice. And so, fortunately or unfortunately, do other people.*

Ironically, my racial difference is something of which I am almost constantly aware, and yet, it seems that I am always re-settling into the awareness of my physical difference and what it means for my moment-to-moment experience.

When confronted with a marker of difference, some people express their curiosities in ways that are awkward or even offensive.

> *I once had a man with whom I was just beginning a relationship question my sexual functioning. I mean, he asked in the most delicate way possible, but the point of his question was, am I physically able to have sex . And on*

> *the one hand, that is eventually going to be a legit question to have of someone you're in a relationship with. But on the other hand, you just wouldn't *ask* an able-bodied person that question.*

In situations like this one, disability seems to become an anomaly or a spectacle and I become a specimen for observation. It is dismaying to me that difference is sometimes so jarring as to preclude basic mutual respect in social interactions.

Reflecting on persons who do not know an offensive question, even as they are asking it, brought me to mind of others who don't know a patronizing assumption even as they are voicing it.

> *I had a conversation recently with someone where it was that old thing of them going, "Oh you have done so well for yourself," and me being like, "No, really it is just my life." And it kept being pressed, like, "No it is really surprising because of your disability" and I was just not in the mood to educate, so I got kind of pissed off. I didn't let him know I was, but in my head I was just like, OK, go ahead, keep patting me on the head and patronizing me. Make my day."*

I cannot entirely fault the speaker of statements like this. From his or her perspective, what is said here may appear as a compliment. However, the implicit assumption is that disability is an impairment, which should render expectations for success low or non-existent. I prefer to see my accomplishments as successes in their own right.

> *I tend to locate the value of my accomplishments in the accomplishments themselves, not in the fact that I accomplished this or that and I have a disability...Like, the fact that I almost have a Master's degree is awesome because it's a Master's degree, not because I have a disability.*

At first glance, this statement seemed to contradict one that I had made on another occasion.

> *Sometimes I think about the fact that I am here in graduate school, and then I think of those people who told my parents that, basically, the CP would prevent me from accomplishing very much in the academic or*

> *professional sphere, and I just want to laugh and laugh to think what they would have to say now.*

But the difference here is that, in the second case, someone's prior assumptions are challenged by a later-occurring success. That is somehow different from clinging to a stereotyped assumption in the midst of a conversation with someone who proves it wrong

The Self Perceived described my experiences of others' reactions to my disability. I recalled experiences of being mocked, ignored, patronized or asked intrusive questions. My efforts to challenge stereotypes and assumptions and to reframe the value of my successes were explored.

Seeking "normality". Seeking "normality" refers to my efforts to be and act in social spaces in the same way a person without a disability might. As I become more aware of myself as a person with disability, I am able to discuss disability issues in more depth and question the meanings of disability for others and myself. As I interrogate my own experience, I become aware of gaps in my knowledge about disability-related resources. In seeking "normalized" experience, the inability to drive is a significant barrier to social and practical interaction with my environment.

As I move through the social world, there is a strong sense of desire to participate in that world in a way that would be considered "normal." That is to say, I want the same opportunities and considerations as anyone else. Because of the tension, which sometimes exists between what I know I am able to do and what others might assume that I am able to do, this wish for "normal" participation carries with it an imperative of proving my ability to participate normally. Intentionally or not, this can sometimes lead to erasure of my disability.

> *Sometimes I lose the line between "playing the disability card" and simply speaking from my experience. The second is good obviously, but I don't want to do the first and it is hard to find the line.*

In not wanting to arouse pity or give any reason for people to treat me differently, I wonder if I sometimes miss opportunities to educate others about my disability-related experiences and what they might mean.

> *I would say it's only recently, like maybe in the last four years or so, that I've really recognized how important disability is as a site for discourse and analysis. As I moved through the University environment, I got very used to questioning experiences and meanings around race and gender, but it took a little while for me to start doing that with disability. It's like, I spent so long trying to convince myself and everyone else how "normal" I was that I missed a chance to really engage with disability as a concept.*

In fact, I reflected later, I feel like parts of my experience as a person with a disability are missing, swept up and erased in that effort to convince myself and everyone else that disability didn't make me "different." Conceptualizing the self as "the same" as everyone else is useful for certain types of social participation, but I am continually realizing the disadvantages of this strategy as well.

> *The truth is, I just don't know what supports are out there for me in terms of programs like ODSP. It's almost like, I spend so much time trying to convince myself and others that I am "normal" that I never concerned myself with the resources that were out there and how they might help me . I don't want something I don't need or deserve, but if there are resources out there that I could be using, I would like to use them.*

When I was a child, certain physical differences were addressed and assistance provided through physiotherapy and the use of ankle-foot orthotics. But because I never involved myself in disability-related discourse or exploration, there is a large gap in my awareness of the services available to me.

Because the physical realities of my disability are only mildly limiting in a physical sense, the strategy of claiming normality in social participation has worked for the most part. The notable exception is found in my inability to drive a car, and resulting reliance on public transit. This is very easily the most limiting aspect of my cerebral palsy.

> *It really is a big deal in terms of not being able to go where I want when I want. I mean, there is transit, sure, but transit authorities don't seem to take into account that the people most likely to use transit are the people who may have other mobility issues and are going to be hampered by the fact that bus stops are really far apart, or on main roads only. Then there are certain places in the city that buses don't go, so those parts of the city are not accessible without a car.*

My sense of my ability to move freely within the city in which I live is severely curtailed by the realities and limitations of the transit system. Also, even where the transit system operates in an optimally convenient manner there are certain activities that are difficult if not impossible to accomplish without a car.

> *Getting groceries is probably my least favourite task because it just involves so much walking and hauling heavy stuff around. And part of the problem is that the bus stops are not conveniently located, but even if they were more so, transporting groceries on public transit is just a nightmare. And there is certain stuff you just can't do. Like you can't bring certain large household items home on the bus, so you pay for a cab or you do without.*

Some tasks almost certainly do require a car in order to accomplish them, and ironically, these are often tasks that are necessary for daily living. Other tasks are possible, but not always convenient. This reality can curtail certain types of social participation.

> *Often I'll get invited to a party or something, and it's in an out of the way location, and I think, do I really want to get on the bus in the dark and then walk two blocks to get to the place, and then how am I going to get home? I'll have to call a cab and that costs money. I could call someone and ask for a ride, but I don't want to be that person all the time, it's annoying.. So sometimes I will run all that through my head and just decide to stay home*

It seems that my choices here are social exclusion or the dependence I try so hard to avoid. This highlights the degree to which driving is tied to independence, so that an adult, functioning independently in a social context, is expected to be able to access and drive a vehicle.

> *I've often said that being able to drive is one of those things that everyone just expects a functioning adult to be able to do. After a certain age, everyone just assumes that everyone else drives, and when I have to speak up and say I don't, people just, like, look at me as if I have three heads, and it's like, what do you mean you can't* drive?!" *Like it's the most unimaginable thing on the planet. And then people start acting like I should just get up off my butt and go get my licence already, because clearly my life would be so much easier and I am just being ridiculous. And it's like, no, there's a little more to it than that.*

Lack of ability to drive can sometimes seriously undermine my efforts to be a self-determining individual. First, there is the practical reality of the mobility restrictions imposed by not driving. Furthermore, I frequently encounter attitudes which situate driving as a non-negotiable part of the life experiences of a functioning adult. Ability to drive is such an entrenched assumption that its absence can significantly affect an individual's experiences of social participation and acceptance.

Seeking "Normality" explored my desire to participate in the world in a way that appears "normal." The strategy of erasing disability has advantages and disadvantages. Inability to drive is a significant detriment to "normal" participation in community. Not driving can cause frustrations around accessibility, practical concerns and social contact. I also feel pressure from the expectation that every functional adult has the ability to drive.

Self in family. Self in Family concerns the influence of my immediate family. As I was growing up, my family did not treat my disability as a problem. Disability-related needs were met in a matter of fact fashion, and the physical realities of disability were not characterized as limitations. My parents also discouraged others from problematizing disability and imposing limitations. Normalization was an oft-used strategy for addressing disability.

My writings and observations on the topic of family seem to bear out one overall message about the way my disability was handled in the family: it was mostly a non-issue. Disability related necessities were met.

> *I remember I used to have to go to physiotherapy and occupational therapy, and between the two of those, my parents would take me twice or three times a week. I went to the chiropractor a lot too, when I was a kid*

But other than those necessary attentions, the cerebral palsy was not made much of.

> *I very seldom remember either of my parents saying that I couldn't do x, y or z because of the CP. It was just taken as a matter of course. Like, when I was a kid, Mom would say, "Please go crawl up the stairs and get me this or do that." . And now I realize she had me crawl because my balance was bad and I probably would have fallen down the stairs at age 4 or however old I was, if I had tried to walk. But it was never, "Oh, you have CP, you can't do this."*

My parents and other family members were careful not to link the idea of cerebral palsy with a narrative of limitation. They also stepped in to mitigate situations in which others may impose a narrative of limitation.

> *I played softball one year, so of course we told my coach that I had CP. And she was all ready to make a huge fuss about it and my Dad was like, "No, really, she's fine. I mean, she's not going to be the best player on the team, but there's no need to make a big deal here."*

The decision to attend to disability-related issues without assuming or playing up limitation was a decision my parents made early in my life. In a journal entry reflecting on my adoption, I wrote:

> *Mom mentions sometimes how there were people who tried to tell she and Dad that I was going to have all of these physical and intellectual problems because of the CP...never walk, never function in a regular classroom, could only ever hope to hold a menial part time job, etc. I guess my parents just sort of heard all this and decided to wait and see. And I walked late, but I did walk. And I did just fine in a regular classroom. Nobody made a big deal about it and I think that was good in some ways....allowed me to just get on with things.*

Reflecting on this, I realize with gratitude that my parents took somewhat of a chance, not knowing how much disability-related assistance I would need, nor how that would affect their experience of parenting me. However, as I grew and achieved milestones, I was never given the idea that they were improbable or that I should expect at some point to "hit this ceiling" of my capabilities. This lack of assumed limitation may have allowed more success than would have been possible if I had been given an expectation of "maxing out" my abilities.

Reflecting on my upbringing, I would say that I was encouraged without being given a sense of something to overcome. I was never given any reason to see why the things I set out to achieve would not be possible, disability notwithstanding. Regarding the degree of independence afforded by my parents, I cannot say if it was any more or any less than would have been afforded had I not had cerebral palsy. My older siblings were far enough apart from me in age for me not to have observed the amount of independence they were encouraged to have. Reflecting on my teenage years, I wrote,

> *Again, I never had a sense that the CP had much to do with what I was or was not allowed to do. The only exception, in hindsight, was driving, and at the time, I had no idea that CP was the reason that my parents were so reluctant for me to take driver's ed. I would say, certainly there were times when I would have liked to be given more independence, but I think it was normal teenager stuff, not necessarily related to the CP.*

It seems then, that my experiences as a teenager were pretty typical in terms of the move toward greater independence. For the most part, greater degrees of independence were supported as I grew up. Disability was never given as a reason for me not to undertake a particular activity. Struggles around the degree of independence allowed were, I think, within the realm of normal parent-teenager interactions.

Reflecting on my parents' approach to my disability, I see a recurring theme of normalization, almost erasure. Although certain features of my physical experience were uncommon (for example, wearing an Ankle-Foot Orthotic) there was little dialogue around a concept of disability.

> *And when I was growing up..., like, sure I understood that I had cerebral palsy, but it was never a big "difference" thing. It was like, he has brown eyes and she has black hair and I have CP. Like, not a big deal. And that's good in some ways, because I know some people with disabilities who get to adulthood and are still always saying, "I can't, I can't I cant." Whereas with me it's more like, "Well sure I can. Why wouldn't I?"*
>
> *The problem is, when you don't really understand yourself as having a disability, you can't really make meaning of it, so when you come up against something you actually can't do or an opportunity that's not available to you because of your disability, you don't even know what to do with yourself.*

Although grateful for the fact that disability was not taken up as a limitation or a mark of incompetence during my upbringing, I have, in recent years, become aware that there is somewhat of a disconnect between my experiences in the world and my identity as a person. On an abstract level, I still seem to want to embrace the idea that I am "just like everyone else," but on an experiential level I am acutely aware that this is untrue, at least as concerns my embodied experience.

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In Self in Family I reflected that my family treated disability in a matter-of-fact way. Needs were attended to and adaptations made without reference to disability-related limitation. The negative assumptions of others were not entertained. Throughout my childhood, normalization was a strategy used to de-problematize disability. This strategy allowed for freedom from limitation, but has necessitated a re-examination of the role of disability in my life.

Self as learner and professional. The Self as Learner and Professional theme speaks to my experiences in the world of school and work. In my education, my parents played an early advocacy role which paved the way for a supportive experience in elementary and high school. Along the way, I encountered challenges I did not recognize as disability-related. In the world of work, I was confronted by my physical limitations. This experience has led to different strategies such as openness or attempts to "pass" as an able-bodied person, depending on context.

Through elementary and high school, I succeeded well in academic endeavours. I credit this possibility in part to a decision my parents made before I started school.

> *Mom tells me she had gone to talk to the principal about physical considerations such as, could I be assigned to a ground floor classroom so I didn't have to climb the stairs every day. She explained my disability and apparently the principal said, "Well lady, there are* schools *for children like that." So of course my parents refused to send me to that school, which may have saved me from an academic life of teachers who expected me not to accomplish much.*

In that first interaction, my mother encountered someone who did not seem interested in helping to provide me with an accessible education. Seeing this, my parents moved me to another school, where it was hoped the learning environment would be more conducive to success.

In elementary school, I was treated like any other of the students. I excelled at most subjects and this was taken in stride. This attitude of normalization worked well in the classroom, but for a few notable exceptions.

> *I remember when I was in first grade, I used to have fits with those printing exercises. I'd be the last to finish and I used to get all stressed out. Then in third grade, learning to write cursive was awful, awful, awful. I remember actually crying one night over a practice worksheet of the small cursive letter f. And then again, in 6th grade, I could not make head or tail of how to measure an angle with a protractor. Looking at it now, it's obvious that the writing issues had to do with dexterity and function of my hands, and the thing about the angles was a spatial issue. I wish I'd known that at the time, because I was a keener, and not being good at things really freaked me out.*

These are a few instances in which bringing the issue of disability to the forefront would have been helpful for me in understanding what was happening. As it was, these tasks were approached as challenges to be overcome, without much mention of disability.

As I continued through elementary and high school, disability continued to exist only in the background. The idea that I would eventually attend University was treated simply as a matter of course.

> *As far as my parents and teachers went, it was like, "Well of course you're going to University, look at your marks." It was never a big thing in any way, it was just the next step. I mean, my parents said I didn't have to go if I didn't want to, but I did want to and no one tried to stop me*

University level study was highly encouraged as a reflection of my marks and my interests. Here, the absence of a disability narrative to this point in my education may have turned out to be beneficial, as there was no concept of limitation to be overcome.

> *Because disability had been mostly absent from my educational narrative up to that point, I did not seek any accommodations from the centre for students with disabilities. In fact, disability didn't really enter my University experience until a second year philosophy class in which I became conscious of disability as a point of discursive interest*

My awareness of disability as an identity category and as a point of analysis was slower in coming than one might expect. Perhaps this is because I did not enter the educational space of University with an idea of disability as a significant contributor to my experience.

Disability may have been slow to emerge as significant in the academic space, but the sphere of employment provided a very specific disability-related experience in 2005. Reflecting before an interview, I described it as follows:

> *That job in food service was pretty tough on me because it was the first time I really had to admit, yeah, I'm different from everyone else. It was the first time I'd had to say, "No, I can't do that as well as everyone else." And I mean, all it was was slinging fries and pizza around, but I was abysmal at it, and I'm used to being good at things, so it was pretty awful. Also, you can't sit your co-worker down in the middle of a rainy Saturday afternoon and explain your CP. All they know is that they needed that pizza five minutes ago, and now you've gone and sliced it wrong.*

I recall that summer as one of significant unhappiness because I was continually met with an inability to be competent in the workplace. I had not really understood that it was going to be a problem when I started, and then once I did start, I felt like I had to see it through. My next step after that job was interesting as well.

> *I'm not sure if I still didn't understand or I was trying to prove something, but I went back into a very similar job, and when I was there, I kept getting these subtle messages of not being good enough. Somehow I would always find myself doing the grunt work like prepping potatoes or lining trays instead of cooking and serving food or working cash*

With the situation in perspective, it almost appears that I had adopted my old strategy of trying to prove competence by erasing the disability. In this instance, that undertaking was not successful.

> *In the interest of full disclosure, I'd told my boss a bit about my CP in the interview, and we talked about it at work sometimes, so it was very "out there." But then I suppose it put her in an awkward position because she*

> *wanted to fire me on account of being too slow, but she couldn't because it was the CP that was making me slow. So then when I missed that shift that time, it gave her the excuse she needed and I was out just like that. Not that I'd miss the job, but I needed the money.*

Getting fired from that job showed me the writing on the wall, and gave me to understand that, to be successful in the world of work, I would need to pursue only jobs that matched my skills and avoided my weaknesses. At my first professional full-time job, however, I was pleasantly surprised to find such an accepting environment as regarded my disability.

> *A few times a year, around exams, we would have hundreds of files flying around the office and we at the front would spend all day filing. Well, one day, my boss saw me wince as I got up from a file drawer close to the ground. She thought I was having CP related pain, and I was, but no more than I might have on a normal day anyway. So she insisted on finishing my files, and I insisted that I could do it, and we had a little friendly stand-off and a laugh about it. I don't remember who did the files in the end, but I did remember thinking that the pain was nowhere near enough for me to say "I can't" to an aspect of my job.*

Interestingly, even with such an open, accepting work environment, my instinctive reaction was to subtract my disability completely from that environment. Reflecting on my career choice, I realize that it is less likely than it might be in other fields for disability to become an obstacle in the hiring process once I have progressed tp the interview stage.

> *I know that an employer is not really allowed to ask me about my limp, so they're either going to assume I've hurt myself or they're going to remain in the dark about the exact nature of my disability. And the other thing is, with the field I have chosen, once I'm in the door, my CP doesn't matter in the sense that it doesn't necessitate any accommodations in order for me to do my job.*

In a recent journal entry about researching my professional employment options, however, I wrote the following about perceived availability of jobs in my field.

> *The one thing I have noticed with the human services field is that a lot of jobs are case-worker types, and they require you to have a licence and access to a vehicle. I mean, it's fine in terms of the fact that that's not really what I want to find myself doing, but it also means that, if I don't find my "ideal job" right away, I will have a harder time going into an entry level position in my field and working my way up from there.*

What I am facing in the realm of professional jobs is a narrowed set of options for positions to which I am qualified to apply. Once I establish qualification for a job, however, my disability becomes, at worst, a non-issue, and at best, an asset.

> *Depending on the agency and the population served, it may be an advantage for me to have a lived experience of disability. I'll have to be careful...it might be opening a can of worms to bring it up in an interview, but the kind of agency I would like to work for would by the type to encourage discussion around disability in the same way as race, sex/ gender, class, etc. as a valid component of engaging with client experience.*

Reflecting on Self as Learner and Professional, I realize that it will not be prudent of me to continue erasing, ignoring or downplaying disability. It forms part of my ongoing experience, and it is therefore important that I make ongoing efforts to understand how it may inform my professional practice.

The reflexive self. The Reflexive Self contains self-observations, which have arisen from my work on this project.Completing this study encouraged me to take a close look at my own relationship with disability. I questioned my own view of others with disabilities and wondered if I might be perpetuating stereotype or discrimination. My relationship to disability as an identity category was explored through language and through the strategies I use when thinking about myself and when appearing in the social world. I concluded that erasure of disability has been an often used strategy for me. In undertaking qualitative research, I felt both freed to question my role in the study and constrained by the limits of what can realistically be included in the final product.

> *So I'll do these interviews and I sit and think later, about how I complain that I had to walk here or there and it was far or it was winter and the sidewalk wasn't plowed, and then I realize that if I used a mobility device, I couldn't go some of the places I go or do some of the things I do. Or I'll think of how my hands kind of don't work, but for the most part, they do. And when I think about those things I feel...lucky is the word that's coming to me but I don't want to say lucky because then I think, "Am I doing that gross pitying thing that people do? I see it in their facial expressions, I hear it in their voices when my limp is bad or something and I can just hear them thinking how lucky they are that their bodies are whole and functioning. And I hate it. So I hope I'm not turning around and doing it to my participants."*

In thinking about myself and about my disability in relationship to the disabilities experienced by my participants, there was a sense of gratefulness for the things that I *am* able to do even though I have cerebral palsy. That gratefulness caused uneasiness because it was born of comparison between myself and another person with a disability, I did not want to see in myself the attitude of pity I have seen in able-bodied others when they compare themselves to me.

> *You know, for all I think that I am conscious of disability issues...after all, I am a person with a disability too, right?- I do and think some pretty ableist things sometimes. Like the other day, I was at the library and I went to lock my bike to the railing of the accessible ramp, and I thought to myself, "Oh, it's fine, people can get around it." And then I thought, "How is that any different from able-bodied people who put stuff in your path and think nothing of it, and then you're rooted to the spot because you're afraid to trip and fall and make a scene?" So I moved my bike, of course. And now, like I wonder how many times I've done stupid stuff like that in the past and not even realized it*

Participating in the study has made me more aware of how I inhabit physical space and how my assumptions about others physical capabilities can make me an unwilling contributor to the physical barriers that others with disabilities may encounter in public spaces. The accessibility of public spaces in general also became more noticeable during the completion of this work.

> *I'll notice stuff about so called accessible spaces that I never noticed before too; like how is this bathroom supposed to be accessible if the stall is not much bigger than the non- accessible stall, and like, that's stuff my participants have said. Or, like, I'll go places and walk up the stairs like I usually would, but I'll take more notice of whether or not there is a visible, accessible way to get into the place.*

During completion of the project, I became more conscious of accessibility concerns in the built environment, even if they did not directly affect me or anyone I was with that the time. I also became more conscious of spaces, which may appear accessible but are not.

In discussions with participants about the language they preferred as self-reference, I became conscious that my reaction to language was much different from theirs.

> *My participants seem so much more comfortable with the word "disabled" that I am. And as vehement as I was in my dislike of it not so very long ago, I now wonder what's up with that. I mean, we all dislike certain words that are from like, back in the day, and now it's like, "Really, are we still using that word?" But there's something about the word "disabled" and what it means for identity that my participants are much more comfortable about than me.*

As a result of my work with study participants, I began to question my language uses and preferences and what they meant for my relationship with disability.

> *I think it's this whole thing about disability and identity. We all talk about how we are used to our physical realities and it's that thing of, "What's the matter, it's just my life." but somehow they seem to be more comfortable about it than me.*

As I proceeded through data collection, I struggled to articulate how my relationship to disability was different from that of my participants.

> *I figured it out after this one interview, and all of a sudden it was this lightbulb moment of, "I relate to disability by doing my best to erase it." And the thing is, it's problematizing the study in a way. Without even realizing it, I've positioned disability in this study a problem and as*

> *something to be overcome. If you'd asked me personally, I probably wouldn't have said that. I'd have been like, "It's [disability] not a problem, per se, it's just my reality." And I was saying that and my participants were saying that but we weren't speaking the same language*

By comparing my experiences with the experiences of my participants, I began to realize that, although we were similar in viewing our disabilities as part of the reality of our life and identity our strategies for addressing the lived reality of disability differed. My relationship to disability influenced the way that the study was constructed.

> *I began to realize that what I keep doing is to try to get as close to a "normal" (read, non-able bodied) experience as possible It's like I'm trying to pass for able-bodied, where my participants are more like, "No, I have a disability and that makes my experiences different from people who don't have a disability."*

I began to notice that, while my participants' experiential narratives gave clear voice to the position of disability within their identity, my own narrative was full of the ways in which I was trying to prove myself to be just like everyone else. Participants may have been trying to prove that disability could be present in a person's experience and not preclude personal success. By contrast, it seemed that I was trying to prove that I could remove disability from my experience enough to allow success. There was an element of erasure in my narrative that was not present in the narratives of my participants.

> *This thing about erasing the disability, I think it's a strategy I adopted from my parents, and I don't begrudge it at all, I mean, I was already black and adopted, so maybe the thinking was, in this place and in this time, it will be good for her if she is physically as much like other kids as possible. And the strategy seemed to work inasmuch as I did well going through school and adjusting socially and all of that. And it's not like anyone tried to pretend I didn't limp or wear a brace or whatever, it was like, "You can be successful even though you have a disability. Just look at all the normal stuff you can do." Where, with my participants, it was more like, "You have a disability **and** you can be successful from within that experience." I'm not saying that one is more right, but like...I feel like I'm finally starting to embrace the reality of disability after keeping it at arm's length for years.*

My relationship to my own disability was brought into focus and changed by the experience of interviewing my participants. I identified the position of disability in my life in a way that I had not before and it provided food for thought.

> *I listen to my participants talk about access to services and resources, and yeah, sometimes they're talking about the fact that access to these things is absolutely abysmal, but the point is, they know about all of these systems and agencies that I have never had to navigate because I have never approached them, because to approach them you first have to acknowledge yourself as a person with a disability, and I never did so with as much intention as it would take to access services.*

Through conversations with my participants, I realized my lack of awareness around what community resources are in place to assist people with disabilities. I came to an awareness that the way in which I have positioned myself as a person with a disability throughout my life experiences may have an effect on how I position myself as a counsellor with a disability both now and in the future.

> *Here's the thing. It's one thing if I'm not really aware of the practical resources that are out there for people with disabilities, I mean, I can find out about that so that I have that information available for clients who want it. But if I am appearing professionally as "counsellor with a disability" that's going to mean a certain thing to clients, especially if they, too have disabilities. And sure, I have all those practical experiences of navigating this or that tangible barrier, but when counselling is so much about self-knowledge, what do I, as a practitioner do with the fact that I've spent my life making this one part of my identity as unnoticeable as possible?*

As a result of my work on this project, I was lead to question the effect that disability has on my identity as a professional counsellor. The gaps in my practical knowledge seemed fairly easy to address, but I questioned whether the strategy of disability erasure had created a space in which I would not be able to be genuine about this aspect of my identity within a therapeutic relationship with a client for whom disability is also significant.

The nature of the research undertaken here facilitated a unique research experience.

> *When I realized that I had been framing the study in a problematic way, all of a sudden I was just...grateful again for the design of this study. If this was quantitative research, these would be the types of things that kept me up at night worrying about accuracy of results. Now, I can just acknowledge the shift and move on.*

The nature of qualitative research gave me room to describe participant experience and to examine my own role in and influence on the way that ideas would be presented. However, since qualitative research gives voice to many details and nuances, it can create conflicts for the researcher.

> *There is so much here, and some of it will just have to be left on the cutting room floor, so to speak. What my participants have given me is so rich that I almost feel like I'm cheating them by leaving so much out. But you know, the thesis has gotta get finished so I have to get brutal sometimes. And it's a weird conflict in a study which is about hearing people's voices, that in the end, I do have to silence some in the service of a manuscript that just has to get finished*

The rich yield of qualitative research created conflict for me as a researcher. I felt torn between presenting a manageable volume of data and giving voice to the entirety of participant experience. The necessity to remain faithful to one methodological framework caused similar conflicts.

> *The way I'm conducting this research, I need to focus on similarities across interviews and I don't get to bring to light those unique points and perspectives offered by each individual participant. It makes me sad 'cause again, it's just like there's so much missing.*

The requirement for consistency in method across the study felt limiting in that it prevented me from exploring some of the individual nuances of experience shared with me by my participants.

In evaluating the advantages and disadvantages of conducting research in this manner, I viewed the experience as largely a positive one. This methodological framework allowed me to hear the stories of others who had similar experiences to myself. The interviews and resulting analysis provided a rich experience of learning about the lives of my participants, and about my own life and experiences. I was able to make meaning of my own experiences in ways that have strengthened my self-awareness in personal and professional realms.

The Reflexive Self Theme illustrated my reflections on the ways in which my self-perception and my relationship to the concept of disability were influenced by interactions with my participants. The structure of the study itself was also examined. In examining the past in light of participant interviews, I noted some instances of hypocrisy on my part, but I also noted an increased awareness of disability issues and ways of relating to disability. Assumptions underlying the study as well as methodological advantages and disadvantages were explored.

Chapter Summary

Results were presented in two parts. The five themes from the case study were presented and followed by a presentation of the seven themes from the autoethnography. The case study themes described participants' personal experiences of their disabilities, the reactions of others, participation in their communities, the role of their families and experiences in educational and employment settings. The autoethnography themes described the researcher's physical experience of her disability, her self-perception, the reactions of others, her quest for "normalized" experience, experiences in the family, experiences of education and work and reflections on the study itself.

Chapter 5 – Discussion

This research explored factors associated with self-determination among university-educated women with physical disabilities. Five university-educated women recruited from the same geographic area and of similar age participated in individual interviews. The researcher also answered the interview questions and reflected on responses after each participant interview. Content analyses were performed separately on the case study data first and then the autoethnographic data.

Summary

Case study. Five themes emerged from the case study analysis, including: Experienced Self, Reflected Self, Self in Community, Self as Learner and Professional and Self in Family. The Experienced Self encompassed lived bodily experiences, personal attitudes toward disability and discussion of how disability influenced personal identity development. This theme also contained an exploration of the participants' ideas about independence, interdependence and self-determination. The Reflected Self explored attitudes toward disability that the participants had experienced through interactions with non-family individuals in their social worlds. This theme illuminated participants' experiences of the assumptions and stereotypes attributed to them by others on the basis of visible or disclosed disability.

Self in Community described participants' experiences of inclusion or exclusion from community settings on the basis of their disabilities. Perceptions of access to public spaces, availability of supportive resources and the demonstrated right to participate in society were explored. Self as Learner and Professional described the perceptions of others and themselves regarding participants' potential for success and achievement in academic and employment efforts. Participants described the receptiveness of others in the workplace and educational setting to disabilities in general, and to accommodation and social support. Self in Family focused on participants' disability-related experiences in their immediate families. The theme included explorations of parental support and advocacy as well as parental protectiveness.

Autoethnography. Seven themes emerged from the anutoethnograhy analysis, including: Physical Self, Perceiving the Self, the Self Perceived, Seeking "Normality", Self in Family, Self as Learner and Professional and the Reflexive Self. The Physical Self concerned the researcher's embodied experience of her physical disability. This theme illustrated experiences with upper and lower bodily mobility and control, spatial sense and pain. Perceiving the Self explored the researcher's perception of herself as a person with a disability. This theme explored the extent to which the researcher was aware of her physical disability as she moved through daily life. It explored the researcher's use of self-referring language as well as the place of "person with a disability" in her continuing formation of self-identity. This theme also explored the researcher's ideas about independence and self-determination.

The Self Perceived presented the disability-related experiences encountered by the researcher as she moved through the social world. Explored here were others' perceptions of the researcher and how these perceptions were affected by others' knowledge of her disability. Experiences with stereotype, discrimination and other-assumed limitations were explored in this theme.

Seeking "Normality" described the extent to which the researcher attempted to move through her social world in a way that was "just like everyone else", that is to say, a way that mirrored the experiences of able-bodied others. The concepts of disability as a site for discourse, normalization and a social participation strategy were explored along with the areas in which in which normalization was rendered impossible.

Self in Family illustrated the researcher's experiences as a person with a disability in her immediate family. Parental support, advocacy, encouragement of independence and degree of protectiveness were explored in this theme. Finally, Self as Learner and Professional explored the researcher's experiences in school and work settings. Areas touched on included early educational experiences, encouragement of post-secondary study and experiences in university, as well as early employment experiences, transition to the world of professional work and relative visibility of the disability.

Organization of the Discussion

This chapter presents a comparison of themes from the case study to themes from the autoethnography. The literature is revisited to consider consistency between themes and the ecological framework as well as factors within that framework. Finally, implications for professional practice are explored.

Comparison of Themes

Case study results were compared with the autoethnographic results to identify similarities between the two data sets. The autoethnographic data yielded seven themes and the case study interview data yielded five. Although some of the particulars were framed in a slightly different manner between the data sets, major themes and areas of exploration were similar bearing out closely related experiences of the factors associated with self-determination among university-educated women with physical disabilities.

Correspondence was described in four levels including identical themes, combined similar themes, overlapping themes as well as unique themes.

Identical themes. Two of the themes from the case study data were repeated in the autoethnographic data. These themes were Self in Family and Self as Learner and Professional. Parents encouraged participants to view themselves as competent and capable and not to treat disability as a limitation. Parents acted as advocates to mitigate more inclusive social experiences for their children. There was mention of parental overprotection, but the overall parental attitude was one of support and encouragement for independence and autonomy. Participants recounted parental advocacy as an important factor in their educational experience and made a positive contribution to self-determination.

In discussing employment experiences, the same concerns about accessibility of non-professional or para-professional short-term work were identified. Visibility and disclosure of disability in the workplace as well as workplace attitudes toward disability were noted. There was consistent support for idea that an attitude of receptiveness to disability was important in establishing comfort and fostering open discussion as well as readiness to accommodate disability related needs. Participants consistently expressed their desire to be employed in a setting that fostered their self-determination through flexibility, accommodation of individual needs and continuing reflexivity to concepts surrounding disability including opportunities for professional advancement.

Combined similar themes. Two of case study themes combined, including Experienced Self and The Reflected Self, covered content similar to three of the autoethnography themes combined, including The Physical Self, Perceiving the Self and

The Self Perceived. These two sets of themes were similar across three dimensions, including experiences of the physical body, relating to the self as a person with a disability and others' perceptions of disability.

The physical body. In terms of the physical body, spatial difficulties were apparent. Participants noted that difficulty arose from the invisibility of the spatial component of the disability, which was seen as incompetence by others. This undermined their sense of self-efficacy. It was also noted that certain aspects of their physical limitations (e.g. limited dexterity) were also less visible to others and lead to less assistance or understanding.

Relating to the self. Disability was discussed as an identity category. For the researcher, disability was often an ignored, erased or hidden while for case study participants the tendency was to either "forget" or attempt to compensate for differences. When intentional, this strategy was an attempt to bolster a sense of self-efficacy or prove competence and value to others. Disability was embraced as an identity category and deliberate attempts were made to intersect it with identities of privilege in order to make it visible and undermine the stigma attached to it.

All participants in the study mentioned the use of language for self-reference and expressed a degree of comfort with person-first language. When asked about terms considered more "politically correct" such as "differently abled", participants indicated that the term seemed needlessly euphemistic and therefore, not useful. These sentiments were consistent with the researcher's thoughts.

Describing factors that contributed to their success all referred to self-determination as well as independence, stubbornness and a refusal to take 'no' for an answer. It was agreed that self-determination did not require a person to act completely independently to accomplish a goal, but rather to exercise autonomous decision making over what was to be accomplished and how. These traits were all useful when dealing with others who viewed disability as a limitation or a hindrance.

Perceptions of others. Reflecting on the ways in which efforts to self-determine might be inhibited by the perceptions of others, it was consistently reported that perceived limitations based on disability, patronizing attitudes and surprise at participants' ability to succeed were experienced. In addition, patronizing and infantilizing attitudes that repeatedly undermined their perception of self as autonomous, capable people were noted. All had experience with incidents of intrusive questioning and were left with the feeling that such questions would probably not be asked of an able-bodied person.

Overlapping themes. The theme Self in Community from the case study and Seeking "Normality" from the autoethnography shared some consistent content despite differing in the areas of experience. The most significant overlap concerned driving a car. Participants shared that not driving made necessary daily tasks extremely difficult, and limited social participation as well as participation in the community in general. It also made the non-driver feel less competent and less adult or "grown up".

While access to social supports as an adult was consistent, the perspectives were different. For the researcher the challenge was about knowing where to begin exploring options for support without having a context of prior access. For case study participants the concern was decentralization of resources after passing one's eighteenth birthday.

Unique theme. The Reflexive Self theme contained the researcher's observations about herself and about the study as it was conducted. The researcher discussed her changing awareness of herself as a person with a disability. The meaning of disability as an identity category was explored and the researcher looked closely at the strategies she had been using to situate disability within her identity. In this theme, insights about the study structure were also articulated.

Comparison to Literature

An ecological framework adapted from Bronfenbrenner (1977) and Sobsey (1994) was used to organize the literature on factors associated with self-determination among individuals with physical disabilities. The framework included nested spheres of influence of increasing proximity to the individual. Data from the themes in case study and autoethnography referring to bodily experience as well as self-perception fit most closely at the individual level, while themes referring to family fit most clearly at the microsystem level. Education and employment, as well as sense of inclusion in the community appeared to fit within the macrosystem.

The apparent usefulness of the ecological framework to identify issues associated with self-determination among individuals with a physical disability was consistent with results of a similar study by Noonan and colleagues (2004). In that study, it was found that the core concept of the dynamic self (self acting in the world) was influenced by three main factors: influence of disability on daily living tasks, influence of the family and availability of social support. The findings from both the present study and Noonan et al (2004) suggest that the ecological framework and factors at the individual, micro and macro levels are useful for exploring the topic of personal experiences of disability.

Similarities at the individual level. Individual-level ecological factors highlighted by participants and apparent in the literature included visibility and disclosure as well as independence and interdependence.

Participants spoke about the awkwardness involved in disclosing and/or seeking assistance on the basis of an invisible aspect of their disability (Green, et al, 2005). They were sometimes met with misunderstanding or the suggestion that they were exaggerating or making excuses. Gilson and colleagues (1997) found that disclosure of disability-related difficulties lead to feelings of incompetence when the disability was not visible enough to others to account for the apparent struggle. Data from the present study mirrored this finding particularly regarding experiences with spatial difficulties and the reactions of others to those difficulties.

Green and colleagues (2005) suggested that the most advantageous level of visibility was somewhere in the middle. Individuals with invisible disabilities often went unaided even when help was necessary while individuals with highly visible disabilities found themselves being stared at or ignored by people who were not sure how to approach them. Participants shared similar experiences of being ignored or being gawked at by strangers who seemed afraid to answer a question or offer assistance.

Similarities between the literature and the current data were also noted across concepts of competence and self-worth (Bedini & Anderson, 2005; Goodwin & Watkinson, 2000) as well as interdependence and self-determination. Among participants interdependence was described similarly to Raeffe's (2006) definition insofar as experiences did not necessitate acting alone and that working with others was necessary at times to achieve a self-defined goal. Regarding self-determination the ideas of goal setting and autonomous decision-making presented in the literature by Noonan et al. (2004) were repeated in the present study.

Similarities at the microsystem level. At the microsystem level parental influence was a significant defining factor in experiences of self-determination. Participants repeated ideas of parental overprotection but also endorsed themes of parental support and autonomy fostering which were present in the literature (Galambos, Magill-Evans & Darrah, 2008; Holmbeck et al., 2002). Participants' successful educational attainment and their embrace of adult roles bore out the connection between autonomy fostering and psychosocial maturity (Antle, Montgomery & Stapleford, 2009; Galambos, Darrah & Magill-Evans, 2007).

Parents were important sources of support for people with disabilities as they made the transition to adulthood (Power & Hill, 2008). Participants credited their parents for practical assistance as well as continued encouragement toward goals. According to participants the efforts of their parents were extremely important to their continued motivation and success.

Participants noted a degree of parental protection that was excessive at times. The described overzealous efforts to ensure that they had access to the physical and practical assistance they might need. However, they spoke with appreciation about parental assistance in checking the realism of stated goals against physical reality, which was also noted by Hogansen and colleagues (2008).

The literature bore out a connection between parental fostering of autonomy and increased psychosocial maturity among adolescents with disabilities. It was not clear whether parents fostered autonomy because they believed the adolescents to be mature, or whether encouragement of autonomy contributed to greater maturity. In either case, participants in both data sets highlighted a similar connection. Participants recalled that their parents had provided support and encouragement for their pursuits of independence, and that it helped them a great deal with their educational pursuits.

Similarities at the macrosystem level. Participants experienced frustration with physical and structural inaccessibility within the community as well as attempts to limit educational attainment on the basis of disability. These concerns were also present in the literature. Accessibility to employment was also a significant concern in the literature and among participants.

Inaccessibility of physical spaces restricted the community participation of people with disabilities and conveyed messages about whose participation was valid (Imrie & Kumar, 1998). Participants in this study echoed these concerns, indicating that their participation in the community was limited to certain types of experiences and was given less importance than participation of the able-bodied majority. Participants also commented on their lack of opportunity to engage in athletic/sporting pursuits in a team environment, an observation that was also noted by researchers (Bedini & Anderson, 2005; Taub, McLory & Bartnick, 2008).

It was noted that power structures within a community tended to be arranged in ways that catered to the needs of able-bodied individuals (Gill, 1999). Due to assumptions about what was normal, the social and structural organization of many communities failed to account for basic needs of non able-bodied members. The consequences of such structures were noted and expressed by all participants, illustrated with everyday concerns such as buying groceries or securing transportation from one place to another within the cities where they live. Data in the present study also referred to implicit messages conveyed by these structures about their rights as persons with disabilities to participate in their communities and was consistent with existing research (Thompson, 2006).

In the literature on employment, access to meaningful work was highlighted as a major concern for persons with disabilities as well as for their parents on their behalf (Darrah, Magill-Evans & Galambos, 2010). There was a clear and strong desire to obtain employment that matched their interests, skills and training. Additionally, each expressed concerns about the availability of such employment opportunities given their unique accessibility needs. They knew there were many jobs for which they would be intellectually capable, but for which they would need significant accommodations to physically accomplish. Uncertainty abounded over the willingness of potential employers to provide such accommodation.

Differences across levels. There were several differences between the existing literature and themes based on participants' experiences. These differences suggest possible areas for further study.

The literature addressing individuals' personal experiences of disability focused heavily on perceived limitations to daily activities. While there was some attention on concepts such as self-concept or perception of self-efficacy, the psychological literature leaned more toward deficiency or pathology than participants in the study had experienced.

Another important difference highlighted by study participants was the role that disability played in one's personal concept of identity. The literature characterized disability as an obstacle to be overcome by an individual. The participants in this study offered a different perspective. Their view embraced disability as a part of identity and constantly reflected on personal, interpersonal and societal levels. From this perspective, obstacles were seen as evidence of a need for changes to social structures rather than indicators of personal shortcomings.

An overarching theme in the literature on parental influence was the limited willingness of parents to foster autonomy and encourage independence. Previous studies acknowledged parents as sources of support, but evidence of their overprotective efforts seemed to be given greater weight. In the present study, the opposite pattern was observed. While participants acknowledged that their parents could sometimes be overprotective, they were more significantly sources of encouragement and actively fostered autonomy.

The literature on education and employment for people with disabilities did not often concern post-secondary education. The emphasis was on placement in life skills training or other community based supports. In much of the literature, it seemed a forgone conclusion that post-secondary study was not an option available to persons with disabilities. Although study participants encountered this attitude from some educational professionals, self-advocacy as well as support and advocacy from parents and other individuals were instrumental in helping them achieve post-secondary success.

The literature on community resources seemed to address only the structured social services that were available in each community. The social implications of the services that were or were not available did not get addressed. Participants spoke at length about availability of community resources as an indicator of the perceived right of persons with disabilities to participate in their communities. Study participants in both data sets took up the social meaning of lack of access to adequate resources and daily necessities.

Differences between available literature and the experiences of study participants suggested important directions for future research. Participants spoke at length about their direct physical experiences of disability, an area that had received relatively little attention in psychological scholarship. Participants also challenged the idea repeatedly presented by the literature that disability should be taken up as deficit. Participants' reflections on family experiences focused more on support and autonomy fostering, and participants experienced a greater degree of success at the post-secondary level than the literature might have led one to expect.

Implications for Parents

This study has important implications for parents of children, adolescents and young adults with disabilities. All participants in this study identified their parents as significant sources of support in their achievement of success. Participants identified parental interventions such as advocacy in educational settings. They also identified parental attitudes such as affirmation of aspirations and allowance of risk-taking that fostered independence. The experiences of participants in this study illustrate that it is important for parents to be prepared to act in an advocacy role when others would impose limitations on their children because of disability. This preparedness to intervene when necessary must be balanced with parental willingness to treat their children with disabilities as strong, competent and capable, rather than delicate or fragile. Parents must be willing to let children with disabilities make their own decisions and even their own mistakes in an age-appropriate fashion as they mature. If such fostering of autonomy begins in childhood, it can help to foster a stable sense of the self as a worthy, competent person who is capable of success.

Implications for Professional Practice

In the literature on disability, considerable attention is placed on the factors that prevent persons with disabilities from achieving post-secondary education or satisfying employment. Statistics illustrate the education and income gap between persons with disabilities and persons without. Awareness of such discrepancies is important, as it would seem to signal that the opportunities afforded to persons with disabilities are not equal to those offered to those without. This is an important indicator of the need for social change, and it must be attended to. However, participants in this study have succeeded at the postsecondary level, as do many other individuals with disabilities.. Attending more closely to the experiences of these individuals could be instructive in determining which avenues of support should be enhanced in order to facilitate greater educational and professional attainment among people with disabilities.

Implications for educators. The experiences of participants as well as the relative silence in the literature about pot-secondary attainment should be alarming to educational professionals working with students who have physical disabilities. The presence of a physical disability must never be taken as proof, in itself, of an individual's inability to succeed at the post-secondary level. Rather, capabilities and potentials should be evaluated on an individual basis with an eye to ways in which the provision of support could facilitate greater opportunity for success. Individual students' preferences and aspirations should be taken into account and supported.

For those who work in the university environment, this study illustrates the importance of providing comprehensive support services to enhance the success of students with disabilities. Making students aware of these services is an important recruitment consideration and the continued provision of support through the university career can enhance opportunities for success.

Implications for counsellors. This study has important implications for providing counselling to individuals with disabilities. Disability-related experiences are crucial and have a significant impact on the life experiences of people with disabilities. It is therefore imperative for counselling professionals to make explicit their willingness to engage in exploration of disability-related experiences with clients for whom it is relevant. There are many factors to consider and questions to answer.

Counsellors must take care not to reduce a client's issues to the common denominator of disability. As the counselling process begins and the client tells his or her story, counsellor and client should work together to draw an important distinction. Has the client come into counselling for an issue that is specifically related to the disability experience (e.g. discrimination, lack of support), or for another issue that may be affected in a more peripheral way by disability-related experiences? Finally, on this point, counsellors should allow the client to take the lead in discussing disability-related issues. If the discussion has been opened but disability experiences have not been identified as relevant by the client, it should be shifted aside to be returned to at the discretion of the client.

Counsellors should attend closely to the ways in which clients characterize both the disability itself and personal experiences of it. What role has having a physical disability played in the client's identity formation? Has the categorization or status of person with a disability been primarily embraced, integrated into identity, ignored, downplayed or, to the degree possible, erased by the client? What might be some of the reasons for a client's particular orientation to the lived realities of disabilities and how has this orientation been either a positive or negative contributor to the client's experiences in the world? Has the client's orientation to disability changed over time? What have been the contributing factors to this change?

If disability is to be discussed, counsellors should follow the client's lead regarding language. What language does the client use to refer to him or herself in relation to the disability? Should the counsellor use the same or different language? Are there any terms or phrases that should be avoided? Person-first language seems to be the current convention in the counselling literature, but counsellors should always check for individual client preferences.

Counsellors need to be aware of the ways in which their previous experiences position them in the counselling room, in their own perception and in the perception of the client. An able-bodied counsellor paired with a client who has a disability should be aware that he or she, the counsellor occupies a position (able-bodied person) which has traditionally been taken up by society as privileged over the client's position (person with a disability). Because the balance of power in the counselling room is already weighted in favour of the counsellor, issues of power and privilege as they relate to physical ability should be attended to. If the power imbalance becomes explicit during sessions (either the client expresses discomfort or the counsellor voices an assumption that is rooted in able-bodied privilege) the counsellor should own that privilege and communicate his or her willingness to explore with the client how this power imbalance may be negotiated.

For counsellors who have disabilities working with clients who also have disabilities there is a slightly different set of concerns. The power imbalance may still be present if the counsellor and client differ significantly in physical ability levels. In addition to this negotiation, the counsellor must make a decision about the use of self during the sessions. To what extent will the counsellor's experiences as a person with a disability be useful as a point of reference for understanding the client? If this is done, how much of that process will be made explicit? That is to say, how much will the counsellor disclose to the client about his or her own disability? As with any issue, counsellors employing the use of self to understand clients with disabilities must be extremely careful not to impose personal views and conceptualizations of disability experience on to the experiences of the client. When employing use of self, counsellors need to check with the client constantly in order to ensure that they are responding empathetically and accurately to the client's experience and not simply reacting to their own.

For counsellors who have a disability working with clients who do not, how do the multiple power imbalances affect the counsellor-client relationship? How do counsellor and client negotiate the different spaces of privilege each of them occupy? Does the counsellor have a responsibility during sessions to challenge stereotypes and promote education about people with disabilities? If this is done, how can it proceed in a way that respects the client's freedom to express him or herself in sessions?

Before engaging in therapy with a client who has a disability, counsellors with and without disabilities would do well to examine their views about disability itself and about people with disabilities. What does the counsellor view as the place of disability within the self-concept? Is it an intersection of identity? Is it a marker of difference? Is it positive, negative or neutral? Should disability status be embraced, ignored or erased? Should people with disabilities attempt to normalize their experiences to match as closely as possible the experiences of able-bodied others in their social world or should they seek resources that would allow them to function in ways that are *different* from able-bodied others? Counsellors should enter the therapeutic relationship with some idea of their perspectives on disability issues but also with awareness that those perspectives may be shifted through interactions with the client.

Implications for counsellors based on themes from the study. A closer look at the themes presented in the study can alert counsellors to some disability-related issues that may emerge in the therapeutic context. As with any client concern, exploration of disability related issues should take place on a client-led basis only.

Clients may wish to explore the role of disability in their self-concept, especially if that role is changing. This issue may be especially salient for clients who are approaching or moving through a period of transition, whether or not the transition is directly disability-related.

If the client wishes it, direct discussion of the embodied realities of the disability and the ways in which it affects the client as s/he moves through the world may be useful in enhancing the counsellor's understanding of the client. For example, a counsellor who had never experienced the kind of spatial difficulties described in this study may not understand their significant implications for the client's experience.

Degree of independence desired by the client and afforded to the client by others may be a significant concern, especially if the two do not match. The client may be dealing with limitations imposed on her/him by others, based on those others' assumptions about people with disabilities. These assumed limitations may cross the line into prejudice and discrimination. The therapy room can be a safe place to explore these experiences and their meaning for the client, and if desired to develop strategies and scripts for addressing common incidents around stereotype.

The role of family in the disability experience may be an important concern for some clients. To what degree have they felt supported and understood by their family members on disability-related issues? Has there been conflict around the degree of independence desired by the client vs. the degree allowed for by caregivers? Are there people in the family who have played roles of support and advocacy?

Within their communities, what sense have people with disabilities gotten about their right to participate fully in the community experience? The therapy room may be a place where some clients choose to explore the implicit messages about people with disabilities that are contained in society's assumption of an able-bodied norm. Some clients may have been able to "other" the problem from themselves, viewing their decreased participation as the sign of a societal lack while others may have internalized the idea of their decreased right to participate as a consequence of their disability. Counsellors must decide how to approach clients who subscribe to this second view of their place in the community. From a human rights perspective, it would seem prudent to challenge this perspective. However, counsellors must also ask themselves whether reframing large parts of the client's experiences as injustices would be of harm or benefit to the client given his or her current circumstances and ability to change them.

Finally, clients may wish to explore the formal or informal sauces of support that are provided through their community. It is important for counsellors to have a working knowledge of disability-related services in the communities in which they work in order that they may provide appropriate referrals to clients when indicated.

In sum, counsellors are responsible for educating themselves. While exploring some of the ideas presented in this section, counsellors must take care not to situate their clients in the constant role of educators. Counsellors will look to clients to be experts in their own experiences but should also undertake independent efforts to educate themselves about some of the experiences and concerns that are frequently experienced and expressed by people with disabilities. Entering the session with an open-minded and flexible knowledge of these issues will allow counsellors to integrate ideas from research and professional development with the lived knowledge held by the client who sits before them. In this way, counsellors will be better equipped to provide an open, validating therapeutic environment to clients with disabilities.

Conclusion

This study presented some issues for consideration by professionals who work with people with disabilities. Care must be taken to refrain from disability-related assumptions of capability. Professionals, especially counsellors, should display a willingness to explore disability-related issues if clients indicate a wish or need to do so. Exploration of disability-related issues should be non-reductive and client-led, allowing the client to define the role of disability in his or her experience. Counsellors must take care to attend to issues surrounding disability and power.

Some potential issues for exploration in a therapeutic context include the role of disability in identity, the influence of family on disability-related experiences and the challenges and facilitators to full participation of the individual in community.

Limitations

The sampling methods used for this study may have imposed a limitation on the diversity of experiences which were captured. Posters were distributed to Disability Service organizations on the campuses of several universities in Southern Ontario. Snowball sampling was also used. These sampling methods may have produced a very homogeneous sample of participants.

The data for this study were extremely rich. Although the methodology allowed a thorough overview of the major themes in the data sets and the literature, it did not capture the full scope of the experiences illustrated in the literature. Using a broad, comparative method allowed for the clear illustration of similarities and differences in experience, but it did not make use of the full depth of experiences contained in each interview. Using a research method that allowed for detailed analysis of each individual interview and then a comparison between all interviews would yield a much clearer picture of each participant's unique experiences. Although such detailed analysis was not the focus of this project, the entire, unabridged set of meaning units is presented in the Appendices.

Finally, although the interviews yielded a rich description of the experiences of six women, it is impossible to say that all aspects of disability experience have been represented here. The lived experience of physical disability is unique to each person depending on individual factors as well as the social context in which a person lives. This study provides suggestions for starting points from which educational professionals and others may begin to engage with and seek understanding of the experiences of people with disabilities.

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Appendix A: Poster Advertisement

DISABILITIES AND SELF-DETERMINATION

Female students, 20-30 years of age, born with a disability and completed 3 or more years of university may be eligible to participate in an interview study.

Contact Wendy Walsh

XXXXXX@XXX.XX

Appendix B: Letter of Information and Consent Form

Living In This Body: Hearing the voices of women with disabilities

LETTER OF INFORMATION

Introduction

My name is Wendy Walsh and I am a Master's Student at the Faculty of Education at The University of Western Ontario. I am currently conducting research into the everyday experiences of women with physical disabilities and I would like to invite you to participate in this study.

Purpose of the study

The aim of this study is to explore the factors which help or hinder women with disabilities as they try to achieve self-determination. (a sense of their ability to make decisions about their lives.)

If you agree to participate

The study requires that you have sufficient command of the English language to be able to describe your past experiences and your feelings about those experiences in some detail.

If you agree to participate in this study you will be asked to participate in an interview of 1.5-2 hours in length. If you give permission, the interview will be recorded using an audio device. I will come to you home if you wish, or we can arrange another mutually convenient location to meet. After the interview, I will transcribe our session verbatim and send you a copy of the transcript, asking you to make any additions and changes you would like to make. I will remain in contact with you for the duration of the project (approximately one year) and I will ask for your feedback on occasion.

Confidentiality

The information collected will be used for research purposes only, and neither your name nor information which could identify you will be used in any publication or presentation of the study results. All identifying information collected during the study will be kept confidential. Audio recordings and any hard copies of interview transcripts will be kept in locked storage. Soft copies of interview transcripts and recordings will be password protected on the researcher's computer. All transcripts and audio recordings will be destroyed after five years.

Risks & Benefits

There is a possibility that participation in this study may cause you some distress if during your interview you speak about or recall a particularly difficult aspect of your experiences with disability. The researcher will discuss with you some organizations from which you may seek assistance if you experience distress after participating in this study

Voluntary Participation
Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time

Questions
If you have any questions about the conduct of this study or your rights as a research participant you may contact the Manager, Office of Research Ethics, The University of Western Ontario at 519-661-3036 or ethics@uwo.ca. If you have any questions about this study, please contact Wendy Walsh at XXXXXX, or Dr Jason Brown at XXXXXXX

This letter is yours to keep for future reference.

[Signature]

Living In This Body: Hearing the voices of women with disabilities
Wendy Walsh, University of Western Ontario
Dr. Jason Brown, University of Western Ontario
CONSENT FORM

I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

Name (please print):

Signature: Date:

Appendix C: Interview Questions

1) Can you speak a little bit about the physical realities of your disability? Are there things that you are not able to do, or that you must do differently from others because of your physical challenges?
2) This project uses language such as "an individual with a disability" "women with disabilities" "people with disabilities", etc.. Are you comfortable with this use of language to refer to and describe your own experiences? If not, what language do you prefer to use?
3) What does the concept of self-determination mean to you? If you were a self-determined individual, what would that look like in your day to day life?
4) Are there things about yourself (things that you do, think, or feel, or that you believe about yourself) that make it easier for you to achieve self-determination? Are there things you do, think, feel or believe that make self-determination harder for you?
5) Are there things that people in your family do or say (or have done/said in the past) to facilitate self-determination for you? Are there things they do or say (have done or have said) that make self-determination more difficult for you?
6) Have your family members allowed/encouraged you to have a certain degree of independence as you moved into adulthood? Was that more or less independence than you felt you should be able to have?
7) What messages (spoken or otherwise) have you gotten from your family members about your disability?

8) What messages (spoken or otherwise) have you gotten from others in your social world about your disability? Do these messages help or hurt your efforts to achieve self-determination?

9) Can you speak about any physical obstacles you tend to encounter as you are going about your life?

10) Do you feel that your needs as a person with a disability are supported within your community? If they are, what community supports are you using? If they are not, what needs to happen in your community in order for your needs to be met? Do you feel that your opportunities for participation in your community are/have been the same as or different from people without disabilities? In what ways?

11) You have undertaken post-secondary study . Can you speak about the ways in which you were supported in that undertaking? Can you speak about the ways in which you were discouraged during those efforts? Do you feel that your access to post-secondary educational opportunities is/has been the same as or different from people without disabilities? In what ways?

12) Can you comment on your feelings about the degree to which satisfying, meaningful employment is accessible to you? Do you feel that your access to meaningful employment opportunities is/has been the same as or different from people without disabilities? In what ways?

13) Are there any other thoughts, feelings, experiences, anecdotes, etc. that you would like to share about self-determination and your experiences with disability?

Appendix D: Meaning Units by Code (Case Study)

Acceptance vs. Erasure

I think the elementary and high school way of adapting to a disability is "Let's teach them to be as normal as possible." Because they assume that that's the best definition of functionality

when you get to University, it's a lot more along the lines of, "Well, we already know you're intelligent so let's just go with what you can do and deal with how that affects your University experience.
A major focus is... not deleting the disability, but I don't know of another word to...maybe absolving the disability and focusing on making you independent

looking back on what my educational experiences were prior to University, I would have liked various special educators and whatnot to focus more on making me functional as opposed to making me typical

Accepting Disability Identity

I have incorporated my disability into my self-concept. By the same token, the fact that it's integrated means that I don't recognize it, and so I assume that, you know, I can be just like anyone else, be just as versatile, travel wherever they do, accomplish whatever they do on their timelines, and then a variety of circumstances has taught me that I can't do those kinds of things just like anyone else might.

I also think it helped that fifty percent of my family, like there's four of us, is disabled, so it became, it was very much taken up on a cultural space. Like there were often kids we would play with who could walk and we would all play hide and seek on our knees, because it's not fun if there's four of you playing and you catch the same two people all the time.

I definitely, when I was younger, went through kind of a "why me" angst, I don't want to say rage but just frustrated stage, but then you know it grew into acceptance. It's a long hard road, no one straightforward path, but I think it kind of goes with the idea yeah, I'm a person and everybody's different, so somebody else is a person who speaks six languages. It's, you know, people can call themselves what they want, but I think it's kind of important to accept yourself before taking on a label but not being happy with it.

I can't deny that I secretly wish when I see people jumping in and out of the shower or going for a run or something first thing in the morning that I wish I could do that....I do. But I'm also at a point where I know what I can and can't do and I'll try to adapt things so that I can try to do as much of it as I can *having a disability does have its advantages, because like, when I went to Disney world as a kid, they always let me get to the front of the line and we had primo parking with the parking pass. So I mean, as well as I know there are disadvantages because I can't get around quickly, there are disadvantages too. I wouldn't have met the people that I have in my life without having it and I don't begrudge that at all.*

I'm actually happy that little kids are willing to do that and their parents will sometimes have me explain it because they don't know how to, just because...and I think they feel like if...that they're hurting my feelings if it's brought out in the open, but I know I have a disability, it's part of who I am. It's not all of who I am but I am...I have CP

At one point I taught life skills and it was awful, awful, awful, because I don't subscribe to the concepts that people with disabilities need to be rehabilitated or normalized. I understand passing or performance of quote, unquote, "normal" as being a subversive act to gain resources, so you don't really want a life skills teacher who feels that what they're doing is just really crappy practice.

...a lot of my friends have even said that they don't see the walker, they just see me. It's just...according to my one friend, a cage that's wrapped around my ass 24/7 in terms of the walker. [researcher laughs] but they don't see that. Or...for example one time, I went out with a friend and we were going to go out to a bar downtown and we started walking and she...and we got to the front of the bar, and I said, "Um...[name]?" And she looked, and as she started to walk up the stairs I'm like, "Um, stairs, me walker." And she's like, "Oh! Sorry! I didn't even...I hang around with you so often that I don't even remember that you have the walker."

...people have had to kick me in the butt sometimes and bring me back to reality because I like to tend to believe that I am too much like a regular person every once in a while, to the point where I, like I said, I'm stubborn to realize that there are things that I can't do.

Accessibility of Employment

Oh....this is my biggest worry right now. I have come to terms with the fact that, like I have mentioned to you many times, I rely on people profusely, and my own productivity, outside of my own head, in physical terms is...I don't know....I don't even know if it's worth the hourly wages that I would be expected to accrue if I was going to support myself.

Even if they do see past my disability and say yeah, we can hire you based on your qualifications, then I'm faced with, OK, technically I have the intelligence to do this job, but how am I physically going to accomplish it?

Quite often people will give you things to read and I can read a little bit, but I would prefer to read large bodies of text on the computer. So that's hard. And it's interesting because quite often people think that a barrier to employment is something like, there's no ramp, and that's really not my issue. The job developer I'm seeing is all about, "People don't want to hire you because of wheelchair" and really, all wheelchair needs is a ramp and it's good. Wheelchair is good. But to function as an adult, I need about a thousand dollars of adaptive software.

I try not to think about it but I think that maybe if I didn't have a disability I would have a few more options, and I don't mean in terms of professional jobs, I mean that...I could just go...I mean, quite often people will be like [mocking voice] "They're hiring at Dairy Queen. You should go work at Dairy Queen. You are lazy because you won't work at Dairy Queen." And like, I don't work at Dairy Queen because I physically can't get back there. Like, I physically can't do a service job because I physically can't get in it. So I think that if I could walk, in terms of temporary jobs I would not be unemployed, but I would still have the same trouble getting a professional job.

it's probably going to be a little bit harder for me to find a job because I do require accommodations to work, but I am not sure if that's the whole entire reason I don't have a job, because there's a lot of factors that I can't control.

I think it's really interesting that the space where I have had the most success has been in finding jobs that are focused around service or advocacy for people with disabilities and I'm happy because that's become my passion but I think about how much that was shaped by the fact that I didn't have access to other employment spaces. Like, I'm quite sure if I could have been a barista at Starbucks, I just would have worked in Starbucks or the Daily Grind, which was a coffee shop at my University and lived in[city] because it was a pretty awesome town and that's really what everyone did during the summer.

I found myself doing things like, saying things like, in applying for jobs with different organizations, saying things like, "I think I really want to help disabled people, I have a passion for helping, I like to help." And just over and over again that rhetoric of disability equals deficit and then what would happen is...and this is closer to my experience of employment, so like...in between the life skills job and the job I have now, interview after interview would....I found that unless I lied, I wouldn't get a callback. And then when I did get hired, there was often a huge discrepancy between the paradigm of the organization and my personal values and ideology

> *So I think about, what does that say about the correlation between disability and job security, if number one, it was really difficult for me to get a job and then it's an accident that I have a job that is both awesome and accommodating to my disability,*
>
> *I feel like, systemically, I have less access to private sector jobs or sector jobs that might be more stable and I think that has to do with systemically, how we take up employment for disabled people and I could possibly grandstand for hours about that. But it's an interesting discourse.*
>
> *Well retail is pretty much out because it....well not only the fact that I'm short but the fact that the walker is pretty wide and a lot of department stores are smaller and I can't be on my feet a large part of the day or I get tired*
>
> *I always get annoyed by the fact that I have to...that I'm set up with the government handouts and that I can't get a job because people won't hire me and all that, they see the walker and things as like gigantic liability, like there's a light over my walker that says, "Do not hire. Will break things." Or something.*
>
> *And like, it does annoy me sometimes that most kids, by the age of 16 have a job in some area of some sort like waiting tables or working retail in some store where they like the things, and I can't do that so I have to do those sorts of things,*
>
> *"Oh, she's disabled. Let's give her a desk job." Because she can't walk with her walker that far, so therefore, if we give her a job behind a desk, it's a good idea." OK, yes. I will grant you that a job behind a desk is good because it's a job, but I don't want it to be....I hate the whole stereotype of, "This is the only thing she can do."*

Accessibility of Post-Secondary Education

> *I will say that the...accommodations and the accessibility features offered at the University I chose were major selling features of my secondary educational....er, post-secondary educational ideals. I know for other students in other universities who have substantial physical impairments, it's a major struggle for them and they are perhaps not functioning at full capacity because of the obstacles they face, and that, of course, leads to...less success and perhaps, potentially less professional opportunities.*
>
> *When I was visiting other post-secondary institutions about grad school, they would say to me, you know, "How do you do things?" And I would explain about the auditory textbooks and the one on one assistance and the reader/scribes, and they would sit there and say, "Oh, well we don't do reader/scribe accommodations anymore." And I thought, OK, so*

you've made a systemic change without regard for individual needs whatsoever

, I think a large part of how I chose was based on the center for students with disabilities, in terms of what they did offer, because I knew I would need help and I knew that was going to be a large part so if it didn't work out, that was automatically going to be nixed in terms of a potential opportunity

I find that it's a little harder because they're not willing to come to a different campus after the class is done. Like some profs are willing to but some profs say no, they aren't willing to do that. So in that instance, it does annoy me, because it's not my fault that I need those...like I know that I write slower so I need the extra time, I know I'm signed up to get the extra time, but at the same time, just because I can't write with the class doesn't mean that I should be able to not have the opportunity to ask profs for clarifications on something just because I'm not in the room.

Access to Supportive Services

But a large part of that too is societal infrastructure, right? Some cities are richer than others. Naturally, those cities will have better parallel transit systems and whatnot, And so, how much of this is human belligerence on the part of people who design systems without considering the plight of disabled people and how much of it is that we just don't have the means to make our systems more effective?

I know a lot about my disability and about my own body and I'm OK directing my own life, but directing my own medical needs and things like wheelchair referrals and whatnot is an extremely complex...life issue. And I don't have the expertise to know how to combine all of these services. And the fact that, you know, there's a different specialist for that and a different specialist for this and a different thing for this is very overwhelming, you know?

I'm not suggesting that people who don't need certain things should be entitled to them because they want them, but systemic rules never work. People are individuals and success is based on individual adaptation. Therefore, general stipulations are very rarely a good answer to a huge question.

I'm also discouraged by the fact that, you know, ODSP covers exorbitant wheelchair repair costs and medical costs and whatnot. If I no longer receive ODSP, I will be expected to pay for these things myself. Except that, even if I make a well-to-do, well-off salary, the costs incurred with wheelchair repair alone would be exorbitant for anyone.

Well one of the other things that's really interesting that's really interesting about being disabled is that you can do anything you want and you can do lots of fantastic things that most able-bodied people would never ever get to do. But everything costs a million and twelve dollars, and I'm not even exaggerating. My wheelchair alone is six thousand dollars. So like, you can water-ski, you can do a triathlon, you can...pretty much do anything you want, but everything is upwards of ten thousand dollars and driving is no exception. Like I needed to get an assessment to see if I could drive and then the driving lessons are even more expensive

one of the things that is really interesting about being disabled and getting all that power is that you can do a lot of stuff, but you usually have to have a lot of money. It's usually the...and my sister wrote a different paper that kind of changed my tune but usually, the happiest disabled people are the ones with the most money, which is kind of the same with stand-up people, is like, or, non-disabled people. The happiest people are usually the people with money. And I know money doesn't buy happiness but I'm talking about like...their basic needs are met.

Ok. I find that it's hard to access disability services if you're an adult, that are good. That don't require you to do lots of paperwork and be under these specific weird categories. So that is frustrating, but I find there's really no services past eighteen. And it's unfortunate because people in wheelchairs still need services past eighteen.

Addressing Stereotype

I don't want to fall into these stereotypes, which is again, like I mentioned before when we were talking, I have a really hard time...I'm currently technically unemployed right now, and I have a really hard time admitting I'm poor and unemployed because those are stereotypical disabled-person things and I am not a stereotypical disabled person, and I'm also, like I'm poor and unemployed, but it has really nothing to do with me being disabled but so many people think that "You are single because no one loves you because you're in a wheelchair and that'll just never happen. You are poor because that's the way the cookie crumbles and you are unemployed because, again you're in a wheelchair. No one hires you."

that's why I said there's little grains of truth. It might be harder...well, it probably is...it probably is harder for me to get a job, it maybe is harder to find a man who will accept me with a disability, but it's not impossible. And I mean I think that that's one of the things you need to realize is that it's not worth sort of dwelling, and I know that it's not productive to dwell on those facts, but it is hard.

And I think that's why it's also so important for me to have these things, because, not that I'm ashamed of being disabled, but these are the things *the separate you from having...being a stereotypical disabled person. And I've had lots of conversations with my sister about this, and I know, again, having the three things doesn't make you a better person or even a better disabled person, but in society"s, I guess, eyes, it does.*

with strangers, sometimes you can do subversive things, or sometimes you can produce an awkward tension that causes people to think about what they do., but it all depends on the concept and the situation

Access to Daily Necessities

the hassle it takes to actually physically go get groceries is kind of ridonculous.

public transit is really hard because it's kind of quasi-accessible in [this city] and they don't have very good...I guess, alternatives if it's broken. And then generally, most of the transitemployees are pretty intolerant of disability of any kind. And the citydoesn't really see that as an issue. We're not really sure why the citydoesn't see that as an issue, but they don't.

getting an approval for a wheelchair repair can take months. And so then you have people that...their legs are essentially broken because you won't help them.
D: Yeah, and I think that comes back to...people don't seem to understand that wheelchairs are a lot of money so it's not uncommon for somebody to only have one wheelchair. Like people don't have spare wheelchairs in their houses.

Yeah and just in general, I just find that it's rather insulting to give somebody $1000 a month and then be like, "Your rent should only be $400." Like...it's[not possible in this city]

and to get on a subsidized housing list is a two year wait. And even...the houses aren't nice. Which...I understand they're subsidized, but still.

in general, I really like this area and my community because it's relatively safe and it's...because I don't drive I can access a lot of things, and one of the things I really like is I like having access to a lot of stuff all by myself, because it doesn't remind me quite...like then I am able to do a lot of things people would do with a car without one. And it doesn't make me feel as bad that I can't drive.

W: Because it doesn't become an issue as often.
D: Yeah, and also, I can do stuff by myself, which is great, because quite often when I lived in St. Catharines, I would have to ask somebody to help

me on the bus or help me get groceries, and it's just nice to be like, "I am out of milk. Here I go!"

weather elements are huge, and I think it's something that isn't taken up as a viable access concern because often spaces are accessible but maybe their snow removal isn't as diligent

snow screws up bearings and causes things to seize and salt is bad for everything, so I think about how that affect my life, trying to negotiate snow and weather elements, but also, the amount of time and money and effort I spend on maintaining my wheelchair in an adverse climate is probably something that is idiosyncratic to riding around on a wheelchair all the time. When I try to conceptualize it to other people I say, "Think about if you were really eccentric and insisted that you would only ride your bike all the time, no walking ever."

transportation has always been my little pet peeve because I don't drive.

you have to pre-book all of your transportation and you have to know where you want to go and how long you want to be there and when you want to come back, days in advance. Half of the time I never know what I'm doing a couple of hours from now, never mind a couple of days from now, and if I want to just go to the mall and hang around for a few hours, I can't do that because I have to specify "OK, well I want to go to the mall at nine and come back at three."

Assistive Services

I use attendant care services to get up in the morning, for bathing, housekeeping, and to have meal preparation in the afternoon, and washroom, and then again in the evening to go to bed.

I do know that I have access to the best attendant care program in all of Canada. It's called [program name] and in enables me to hire whom I want to, to work when I need them to, to do what I need to have dome for a specified number of hours per month, And this has enabled me so much freedom because other attendant care programs, people are often left with a sense of....like I said before, self-regulation is huge, and without that piece of being able to control your own, um...life, we'll say, it can be really hard to be self-determining. For example, if you rely on another type of attendant care agency where they hire who is qualified and send them to your doorstep and you simply have to make friends when they get there, can be quite unnerving. There's also a lack of accountability, because the person who's helping you doesn't work for you directly so, you know, being late or not coming at all is not of significant consequence to that person who's supposedly helping you. Thirdly, they define where and when they service you. And so, if they're only available at nine PM to *come to your house, then you can't come to someone's party and stay until ten or eleven because you won't get to bed that night*

And to not have a say over that I think leads to lack of initiative, and maybe even a lack of motivation for some people, because they can't control it anyway, so what's the point?
And other people directing you which, there's no need to be self-determined if other people are going to direct you regardless?

And so, the ability to make my own schedules and live my own life has contributed to freedom within the city. Furthermore, the fact that I can take my attendants to other places in Ontario and have them accompany me gives me the freedom to not necessarily act independently but to do what I want to do without restrictions on my own actions because they will help me accomplish whatever needs to be done. So, it's a big piece of self-efficacy.

Assistive Technology

To use a computer, typing is not practical because I use my four fingers mainly, so I can use voice recognition software instead. Similarly, instead of reading a textbook in print, I have my University textbooks given to me in PDF files and get screen readers to read them, which avoids of visual impairment because there is voice feedback for me...auditory feedback.

I've actually been totally surprised by my...uh, my University experience because I've been introduced to more technology and devices that make things possible in the University environment than I was back home in elementary and high school.

I use adaptive technology to communicate in the written word.. U, so like voice activated software and word projection stuff.

Athletic Participation

It was always frustrating to try to join a lot of team sports in that sense, even though I really wanted to because I am an athletic individual.

I always found it difficult to engage in team sports because I'm not in a wheelchair so, for example, wheelchair rugby, wheelchair basketball, etc., they don't...they actually would hinder me if I were to participate rather than play on my strengths. But at the same time, there's not a demand or supply enough to create a you know...a disability...a disabled league with no...like with people who don't need that much adaptation they just need that much...equal playing partners. But if I were to, say, join an intermural or just recreational league, not professional, you still have that spectrum of people who are just doing it for fun and exercise and the people who want to win. Whereas I would probably fall more...a little bit competitive, *but I would just like to play a soccer game, but how do I reconcile that with being the weakest member of the team physically, running around, kicking a ball, when I have limited ankle-food flection.*

as a result I've always been engaged in more solitary or individual sports, which, you know, great, but it would be great to have a team experience once in a while.

Autonomy Fostering

And I think that's why, even though I am having such trouble finding a job, I haven't resorted to giving up because my parents have instilled in me, "You can get a job." And also "You need to be a grown-up and grown-ups don't get money from the government." Like there's nothing wrong with people who collect social assistance, but they have been very adamant that, "You will grow up and you will be a grown-up and grown-ups have jobs."

They don't really worry a lot as parents and I kind of think, also throughout my childhood, and me and my sister actually discussed this last night, like I wasn't able to take small risks, so they often let us take big risks. And that's things like, I wasn't allowed...I couldn't ride...like, I didn't ride the bus by myself until I was nineteen because the bus was not accessible when I was little. So instead, like...my Mom let my sister go to basketball camp in the States by herself...all by herself, when she was 12. And I think that was my Mom saying, "This is you learning how to do things." And kind of going above and beyond the call to get independence, just because she couldn't start out easy with things. But she's always really encouraged us to be independent. Because I think she knows she's not always going to be there

I think in a way it was freeing for me to not have many expectations placed on me by my parents. So it allowed me to kind of go on my own, off the beaten path. 'Cause you know, otherwise, I probably would not have gone to almost every continent or lived overseas for extended periods of time.

my parents, they didn't...you know, they asked about some of my adaptations, whether I signed up for the centre for students with disabilities, but they weren't overprotective in trying to find out the answers for themselves

Compensating

I feel like I've kind of intentionally created this persona of someone who is all over the place and highly animated and always into new things and having different adventures, and I feel like within that sort of identity or persona, there...I've created a lot of space for failure to be an innocuous *experience because best case scenario I succeed and worst case scenario I have a hilarious story later.*

I think it originally started as a coping mechanism to externally try to negotiate spaces where I was understood as deviant or not fitting in, and then it's sort of evolved into this tool to like...draw people closer to me. Telling stories and entertaining people really is my first step to making someone my friend.

But if I were to think about how disability has changed my experience of, or my understanding of success and failure, I would say that it's probably....actually, OK, this isn't contrary to my beliefs. Interesting. I'd say it's really created a very fluid experience between the two because moving through the world as being disabled and especially going to, like, moving through spaces like school and education, in the beginning, or sometimes later on, there was always this experience of like, "Ok, you're going to do this. It's not going to go well."

there's something that becomes less scary when you're always sort of in a space of, "This is probably going to be unpleasant." And then, nine times out of ten, even if it's not awesome, it's not nearly as bad as everybody else projected onto you and that's...I think in some ways I'm really lucky because I have had a lot of moments of, "This is going to be awful" and then it hasn't really been that bad.

Again, I way that I mitigate that is by being really dressed up and using a really highbrow vocabulary as a way of illustrating to even the person who holds the most denigrated understanding of people who are disabled that I am in fact quite competent and worthy of their respect

Derogatory Language

And I don't think that sitting back and saying Oh yeah, it's OK to use stupid words that went...that went out with the dark ages is OK, because then those languages can take on a life or their own and perpetuate negative stereotypes, etc.

I also hate the word "crippled" It makes me cringe every time I hear it. I'm either physically disabled or handicapped. I'm not crippled. But I also understand that that's the language they were brought up on. But I also am one of those people..like you have to advance your knowledge with the times, and we're now in 2010 people. Like, come on.

Diagnostic

I have spastic cerebral palsy that affects all four of my limbs

I also have visual and fine motor issues as well, related to cerebral palsy.

> *And it was so enriching and empowering to think about that and it's so interesting. One of the things that I really valued that experience and the program is that it made disability something interesting to stop and think about. In the same way we would stop and think about race as something...the experience of being racialized as something of interest of the experience of gender being something interesting. It was a space where disability was interesting in the same analytical ways. And I just wanted to live there forever.*

Educating Others

> *sometimes you just don't want to verbalize it. Even though I'm pretty good at standing up for myself. Just sometimes, it's just, it's too tiring to have to explain it.*

> *People will notice there is something different about me but not understand. So I've had people ask me if I have been in a car accident, injured myself doing 'x' activity based on the context I am in, or why are you limping.*

> *Sometimes people are very nosy and will ask you anything. Like I've had people ask me...once they find out I do have a physical disability, can you drive, can you have sex, you know, would you ask anyone on the street*

> *People want to know, but sometimes people don't know how best to approach situations, and sometimes by overthinking situations, they make it worse. So I think that's where a lot of the impulsiveness comes, of can you have sex, can you have kids, what have you. So sometimes I inwardly roll my eyes and go, OK, here we go, another teachable moment, I get to be a role model, an ambassador, whatever people want...mentor. But sometimes I don't want to be!*

> *I've had to do that a lot with little kids who, when they see me at the mall or something, they point at the walker and they're like, "What's that?" or "What happened to you?" And I just try to explain that when I was born, I didn't breathe right away when I was first born, so as a result, the part of my brain that controls my legs doesn't work as well as yours and as a result I need the walker to help me move, kind of thing, and I don't move as fast.*

> *I try to be as open about it as possible. Like I've never been the type that if they ask me what happened, I'm going to bite their head off because they're asking. I think it's better that they're asking than they don't ask at all and just stand there and gawk at me for 20 minutes! But I try to be as inclusive and as informative as I can do a degree that they can understand and I'm not going to go into the psychobabble of it all.*

Encouraging Independence

I think that the idea behind making kids as independent as they can be is not entirely faulty because you need to push kids in general to see what they're capable of. And so, whether or not you have a disability, kids surprise themselves daily with the skills they acquire. And so, with a disability, that's even more pronounced.

However, there comes a point when you recognize, and for me this was in late secondary or University, that there are various things that you're not capable of, and to focus on those things is in some ways futile when your energy can be better spent doing other things. For example, if I can take an hour to put on a shirt, that's great. Yay for me, I'm independent. But at the same time, if I can take five minutes to instruct another person on how I like my shirt to be on, that's just as functional and frees me up for a lot more productivity

think the problem with regard to the educational system for people with disabilities is that there's a fine line between focusing on skill development for physical skills and skill development for functional skills. And they're two totally different skills. If I'm focusing on how to tell you how to make my bed, that's a lot different from focusing on actually making it.

Embodied Difference

Well, I can't walk, and that's a big part of normal society, is walking.

I do have issues with my disability specifically related to the fact that I consider myself less mobile than a lot of people with my disability. For example, most people who sit in a power wheelchair, you know, have no problem leaning forward and pushing a push-button door. I can't lean forward. And I...commonly think, you know, if I could do these things, the world would be more accessible to me. I could reach more push buttons."

I can't physically write, so that's always been hard for me.

I use screen readers and get people to read things to me and things like that. So that's very different than the average person because the average person, it's assumed, can sit down with a pen and write something. And it's also assumed that the average person can read without any trouble. So yeah, I do do a lot of stuff different.

I have tight hamstrings, so when I do stand, my knees are always bent and it sort of makes my gait a little bit closed like a goalie. But for the most part I use a wheelchair so, I can't walk and I write slower and a little bit bigger than everybody else

It might be characterized as like a learning disability but technically it's due to the brain damage caused by cerebral palsy, I have really intense issues with like spatial recognition and it manifests itself almost as like dyslexia, but it wouldn't be medically understood as dyslexia because it is a manifestation of brain damage.

So for example, when I drive to work, I go a really specific way, and then I know that when I get to the playground, the driveway right after it is going to be the one that I turn into. But sometimes if I come from the other way, so that it goes driveway, playground, every time I miss the driveway because I turn after the playground.

Well, because my disability is mainly affected on one side of my body, being my left, a lot of my frustrations come from the fact that...I used to get frustrated, especially when I was younger, about not being able to do things that two handed people would take for granted.

...I actually say that my body is a bit lopsided in the sense that one side is stronger than the other.

...in gym class for example, being picked...I was always picked last for sports in primary school because I couldn't run fastest because one of my legs is affected.

It actually really seen as an adaptation to anybody else but to me. I recently joined a gym and along with having a gym membership, I decided to work with a personal trainer. And that personal trainer just so happened to have worked...or have interacted and worked with stroke patients in the past. So I didn't really seek her out as someone who has information or ideas about how to adapt gym equipment to a person with my needs, but it's an added bonus in my case.

, I always know that when, for example, getting up to go to class in the morning, it's always going to take me, like...what could take somebody, say if they have a class at 8:30, they can get up at quarter after eight and go get breakfast and jump in their pair of clothes and be out the door in time to go to class. But if I had that same class at right-thirty, chances are, I'm going to be up by like six-o'clock because I know it takes me 20 minutes to get dressed because I have to scan across the room, grab the right clothes...it's always going to take me longer, but it's not something that I begrudge or anything, I just know that that's part of how my life has always been, so I just know that it always takes me longer.

Inaccessible Accessibility

when there are services such as parallel transit who say they exist to make people with disabilities more mobile and more integrated into the *community and yet, you know, they think nothing of being an hour late or leaving 20 minutes early or leaving someone on the bus for two hours when it's really only a 15 minute direct route, I think these are like societal facades that are just degrading and it's...you can't fight something that looks good to the rest of society.*

And the thing is, as you put it, doing something so that we don't have to do something else, I think it's a common response and it's even more aggravating than doing nothing. Because at least if you did nothing that would be quite obvious, you know? Going into an accessible bathroom that literally is four inches wider than a non-accessible bathroom? Like, they're both not accessible, and now I just look difficult because I can't fit into the slightly, minimally bigger bathroom.

I wanted to go to the bank, and the bank was not accessible at this particular bank. And it seemed very odd to me that the bank would not be accessible, because after the two steps, they had like an electric door for a person in a wheelchair so I was like, there's gotta be some way in which you can get inside the bank.

For example, Starbucks is now required to have one accessible table. Which is fine, but now, because they have that one table, it doesn't, like, they're considered accessible and it doesn't matter if all of the other tables are up three thousand flights of stairs, they're still technically accessible because they have that one table that can support one wheelchair. Because as we know, all people go out for coffee by themselves. [smiles]

I went to the gym the other day and I really had to go to the bathroom, so I ran into the...or I wanted to run into the bathroom and once I got in, I noticed that there was an accessible bathroom stall, however, to get into that stall, you had to go through two doors, both of which were pull open and there was no button, so I found it kind of ironic that they would have an accessible stall, but not an accessible way to get into the accessible stall.

Independence vs. Interdependence

I like how you said absolute independence, because it becomes a question of how do you define independence. Is independence dong everything completely on your own without anybody's help? Because nobody does that.

is independence doing something for yourself, or knowing how to get it done?

I would say that's almost the definition of my independence, because, just because I can't physically accomplish something doesn't mean that I can't determine what is going to be accomplished, how and when it's going to be accomplished. I feel that, in a lot of circumstances, my definition of how and when is unfortunately secondary to myself, as in I...I am quick to rely on others and focus on their skills as opposed to looking at the task in front of me and assuming that I can find a way to accomplish all or most of it. Usually, I'm of the mindset that, "Well, I know that I can't do this and this and this, so I might as well go ahead and find someone else to do it for me." As opposed to thinking, "Well, OK, I need to find a way to adapt and deal with this." Because my way of adapting is simply to ask people with other skills.

I mean, I've acknowledged that it's a problem, which in itself is troublesome, but the fact that it's gotten me this far makes it like...well, it's not really that bad because I'm completely satisfied with the things that I consider my accomplishments. So, it's only troublesome I guess in the psychological sense, meaning that...to verbalize that to you it kind of troublesome, but in my daily life, I don't think about the fact that, oh I just asked somebody instead of trying to find a way to adapt to it.

I'm independent in a good way that I'm independent to the point where...unless I know that I really can't do something, I want to try it on my own first.

Infantalizing

But there is such a thing as being told that so much that it becomes demeaning. You know, I may be...I may surprise some people, but I'm not five. And so, when you're overly impressed by things that you take for granted, such as putting on a shirt for example, that is just....uh, it's completely irrelevant to me. I don't need people to be proud of me for putting on my own shirt. I need people to be proud of me for things that are on the same playing field as they are.

again I feel like it's one of those things like you should have known better than to go get coffee, or why do you need to go get coffee by yourself? Why isn't someone bringing you coffee? Which is another sort of issue I get asked a lot is like why are you by yourself, like, why are you doing this...um, like, yeah, why are you doing this, why are you by yourself and why do you have to do this? And these aren't things like why do you have to walk down the 401, they're things like, why did you go to the emergency room by yourself? Why do you feel the need to get groceries? Do you really have to go in this restaurant? And these are things that people who aren't disabled usually like...I don't know. When's the last time you or one of your able-bodied friends got asked, "So, why are you getting groceries? Why do you have to do this? It would be easier if you just didn't. Isn't *there somebody to help you?" And I think that's what pisses me off the most...oh, I'm sorry, I shouldn't have said that. [researcher indicates with her hands that it's OK] is that there's this perception that someone should be taking care of me, and it's almost irritating when I am doing things myself because there actually isn't anybody to take care of me. And that is also an obstacle that I run into a lot, is like, on top of the physical things, people's attitudes that somebody should be doing this for you.*

get groceries, go to the Emergency room, go out for coffee, go on airplanes. Things that...these are not...like I'm not trying to go over Niagara falls in a barrel, I'm trying to go...like....do normal things. Like these are what grownups do. Grownups go get groceries, pay their bills, grownups live in apartments by themselves. When grownups get sick they go to the doctor by themselves....because they are grownups.

quite often I will get asked "Where's your mother?" or, "Who puts you to bed at night?" or...you know, stuff like that.

I was at a wedding a couple of weeks ago and... I was standing...I was sitting in the receiving line, and this man turns around to me and, super well-meaning and says, "You're all dressed up!" in a condescending see-saw voice.
And I said, "Yes I am" in a grown-up voice.
And he said "Good for you!!!"
And I said, "Thank you, it took a long time?" and then he asked if I...if the bride had been my helper and that's why I was here and I said no, I went to University with the bride and he said, "Oh, OK" and again, "Good for you!!!" And I just thought...that was such a demoralizing experience...I found it really violent to have to survive that...that sort of negative attitude.

Informal (Social) Community Support

I've made a lot of contacts, and most people in [this community] know of me and have seen me around and I didn't realize how much this contributes to my wellbeing. Last summer I went on an exchange for two months and I was so excited to be in another part of Canada and independently explore and blah blah blah, and I was flabbergasted by my incapacity to do things that I would normally take for granted back home. For example, travelling down the street to the local stores and stuff posted scads of problems because I can't read road signs and I don't know the layout very well, so if I leave, I won't recognize the way back because I haven't done the route sixty million times.

And things like, in [this community] if it's the middle of winter and I drop my cell phone in the middle of the town square, well, luckily I can just go around the corner and grab my hairdresser who's cut my hair for ten *years and say, "Yo, can you come? My cell phone is in the middle of the square and I need to pick it up." Whereas in a foreign situation where I know no one and I can't expect people to understand where I'm coming from, it's a lot harder to come up to a random stranger and say, "Uh, excuse me, I know I don't know you, but could you just, you know, walk down a block with me and pick up my cell phone and set me up just perfectly?" I mean, those kinds of things don't work. And so, as independent as I am and as proud of myself as I am for that and as far as I have come, I realize the value of community in making that possible*

in order for me to become independent and to develop to my full capacity, it is important that the community around me understands me as well as possible.

it's almost like Maslow's hierarchy of needs. It's like, if you are settled in one place for long enough, you can eventually find the adaptations or support or strive to get the ball rolling. But a lot of times it takes a committed person...individual or group

Internal Resources

Well...I grew up in a really, really strong faith-based household and a pretty strong faith community. So I not only had access to the technology to make myself successful, but the mindset of, you know, God has a plan for you and...um....if you want to do something, set your mind to it and you will accomplish it.

I mean, I'm not stupid. I can see that my disability will cause obstacles, but I didn't...or rather,...[intelligible] I should say that I wasn't ignorant to the fact that my disability will cause issues, I just felt as though they wouldn't be complete barriers, that I would always find a way around it.

Basically, I just don't take no for an answer. So if someone says, "Well, you know, it's not really possible for us to get your power chair into the car and take you places." I say, "Well, OK, I'm going to get myself a folding power wheelchair..." and then, you know, technically it's still not possible to bring a typical power wheelchair into someone's car, but the wheelchair that I then accumulated was one that would meet my needs.

There have been moments in my life when I face unexpected obstacles and it brings me down, but I find most of those things are temporary because, again, it's just another challenge that I find gratification in overcoming, you know? The fact that I can have an honours degree with severe dyslexia-like symptoms, I'm kind of proud of the fact that I got through University and still can't read a page. Because I find...for example, there's a number of people who will go, "Yeah, I'm not stupid. I can read. I'm in

University." Well, I'm not stupid either, but I can't read, and I'm still in University. Like that's pretty cool, you know?

I make a point of not hanging out with people who are discouraging to me. Um...and I think that\s self-preservation at its best.

I know I have a disability but it's not the first thing that I notice. So unless I know that I can't do something after ten, twelve tries, then and only then will I be willing to admit that OK, I need help, Can you help me grab this, do this, whatever. But I've always been...I see myself as the person first so I want to prove to myself that I can do something so it's believing in yourself enough to realize that yes, even if you have problems and there are difficulties, that you still have the strength in you to keep going,

Language and Education

I will gladly say, "You know, instead of calling me crippled, it would be more up to date if you said disabled or differently abled"

Language and Identity

On the other hand, I consider myself completely adjusted to my disability. It's been the way it is forever. It's all I've known and I'm totally cool with that. When I think of myself, I think of myself as being in a wheelchair. But, for people who, you know, don't identify as having a disability, language can be a major, major issue.

Actually, I feel your language is pretty good and I don't know whether it's because I know you are also disabled..you walk different. That's how I know. So I think that sometimes as a disabled person, if a person is disabled I don't really look at what they're saying as much, as critically when they're talking about disability, but then just in terms of looking at your study if you were a stand-up person....that didn't limp, I would probably be like, yeah, it's cool, it's fine. DW

I wouldn't say that I have an aversion to person-first language, but I think that from a theoretical perspective it's really interesting because I work really hard to acknowledge my disability as an intersection of my identities, so I really question why there is a need to separate the disability from the person if we're going to think about it as an identity...like an identity category. So in the same way that I would never be like, "I am experiencing femaleness" or "I happen to be Irish." (like from a million years ago, potato famine sort of thing.) I question why I would identify as "person with a disability."

If I were to identify myself I would say "disabled person" but I feel that both terms have merit and it's a really fluid sort of space for me right now intellectually.

I refer to myself as a person with a disability and I know people have said that's sort of cheesy because you're putting the person first and then the disability second to kind of emphasize how I feel about myself EA

I'm not the kid with, I'm not "that CP kid" kind of thing. I am a person with a disability, I am a person with CP. So the person comes first, the CP comes second, kind of thing

Language and Intention

I've come to a point in my life where...I mean, intentional demeaning is not honourable by any means, but political correctness is such a variable idea, and it changes so frequently, and in my experience, people who use the wrong words aren't doing so to be malicious, and the minute that I am dismayed over such things is the minute that I'm angry over something that wasn't intentionally negative, and something they didn't know and completely overlooked. So therefore, for me to be angry about those things serves no purpose

I would much rather they ask me questions than just stare and gawk, or ask me what type of language that I would prefer used, like, is it OK if I use this term, and that type of thing. But, I think it just all boils down to the fact that they need to use language as opposed to not saying anything. So I think that any language at this point is better than none at all,

Other-Assumed Limitations

Educational assistants who would act as my scribes and my physical help throughout the school day were...were commonly not of my same mindset, and you know, a couple of them thought that they would be doing me a real favour if they gave me a more realistic notion of what I was capable of, and would say things like, "Well you know, considering that you only have one good hand, maybe shop class isn't for you

when somebody else tells you flat out that you are not capable of something that you have no control over, that's...I don't know how to describe that form of discouragement other than, it's completely damaging and not worthwhile.

Things like, "Oh, you know, you shouldn't participate in language learning because reading is so difficult for you. Because my visual skills are a problem, my auditory sense is that much more developed. Therefore, I discovered on my own that languages come very very naturally to me. Sure I can't read them, and I'm not going to, you know, read a novel in Spanish or French and write a dissertation on it. But I can very well carry on a social conversation with someone from another country or another *language. And that, to me is a skill that, if it were fostered more, could have been, could have led to several more opportunities.*

I had done pretty well in grade nine, but there was still this understanding that I would be put in basic or general classes because I was disabled.

The person they hired to be my assistant didn't understand me whatsoever, was very belittling and just not, in general, supportive of my dreams. And she would say things to me like, you know, "You " ll never make it to University" and these kinds of things that were by no means assisting me, even if it was to give me a realistic picture.

in terms of school, like in high school, the special ed department and a lot of the teachers were like, "Well this is just not done."

He was like, "So what are you going to do after high school?" And I was like, "I'm going to go to University sir." And he was like, well, he laughed and was like, "You need to apply, eh?" And I was like, "I did. I got into [school name] last week." „Cause I did. And then he was like, "Really? How did you do that?" and I was like, "I applied and they let me in." And like, I had to go home and bring him back the letter that said I was accepted, and it just...that was again like all through OAC and even in grade nine. They sent me and my sister home with a letter that said "Please sign this so your kids can't take advanced courses because they're disabled and they can't do it." And there was no intellectual tests or discussion. It was like, "Your children are disabled. They will not be doing this." And even when we were in OAC, every time we had trouble, his solution was why don't you just quit?

one of the things I really liked was that your questions didn't seem to be leading. I'm trying to think of...you've probably had these experiences where you're in a situation where the questions people are asking, like they want to hear that you stay at home and cry. And, like, until they get that negative, crappy answer, you're not leaving. So they don't want to hear that your life is fine and sometimes you go out for pizza with your friends on Fridays and generally like it. Like they want to hear, "I really wish I was dead instead of being disabled."

Actually, I remember my sister, over lunch one day when she was visiting me, she said that she was surprised that I finished University...or that I managed to get through the first semester or first year, because they didn't know. They...I think parents or other family members view of others is often much different than the person feels for themselves, *They, automatically some of them assume when they see the walker than I can't go out and dance, or I can't...I don;t know, that I can't go on a treadmill. They're amazed when I even mention that type of thing.*

Some are even amazed that I'm at school and doing what I can do, because I don't think they understand...they think that disability equals not being able to go to school at all because you have a walker, oh my God, and a lot of places aren't accessible

Other-ing the Problem

I am more able to look at it like this is not my problem, it's society "s problem. And like, that makes me feel a lot better about myself.

And often the people who were excluding me were conceptualized within my inner circle...so I'm thinking like parents and family and friends, as being the one with the problem.

Parental Advocacy

When I was having trouble in school, my Mom advocated for me to get the proper accommodations, and then in OAC at one point we were having trouble so she came in to talk to the special ed teacher and the special ed teacher "s only total solution was, "A lot of people with disabilities have trouble with OAC courses, maybe they just shouldn't be doing this." And my Mom "s answer was, "What "s your point? Let's solve this."

So my Mom sort of went to the school and worked with the special ed department that I would be taking all advanced classes given the reflection of my marks and who I am and what I do and while she believed in me, there was a sense within the school and with the teacher of, "We're going to do this because your Mom is ridiculous.

she did a lot of what Dorothy Smith calls "shadow work" to make sure that we were included. So if we went on a field trip., she went with us because she knew that the school wouldn't let us go unless she was there

Overprotectiveness

Definitely there are still times where, you know, I'll, my parents will be like, "Oh, you can't do that." Or "You shouldn't do that." And I'll be like, "Why not?

But I've also had problems with them, like for example, this past summer, my Mom went away for a week, out west for a wedding, leaving me at the house by myself for a week, and you would have thought that by her leaving, my world according to them would have crumbled to an end because my grandma and my uncle and my Mom's boyfriend kept calling *me and my next door neighbour kept calling me on a daily basis to make sure that everything was fine and I didn't need any help.*

I understand that they're asking me if I need help and whatnot, but when it's to the point where they ask so much, it gets a little insulting. Like, if I need your help, I'll ask. Until that point, wait for it

I know classmates of mine, some of the 13 that graduated with me who still live at home 10 years later...I don't know how much their parents push them or how much they are overprotecting them but you know...why did my parents push me so far in one way and other parents pushed the other way?

Parental Support

my family's been pretty supportive in terms of self-determination, even though...I would say I don't get along with my parents, but they've always been pretty good in self-determination

My family has always been super supportive in terms of schooling and things like that, and believing that I am the person first, the disability second.

she's always been the type to encourage me to go for what I think, but she's also been the type to still look at the reality of the scenario too. For example. When I [wanted to be a Marine Biologist] And she's like, "[name], you can't be in water that's less than 86 degrees and you can't get on and off boats." So it's like...she's always kept me in that same line but she's always willing enough to say, "You can go for whatever you think, just be realistic about it at the same time."

Patronizing

Society kind of has either a "That's amazing that you can do it." Attitude or...which is a bit patronizing at times, because, yeah, of course I can walk down stairs without any problems... Why shouldn't I? What were you expecting?

Physical Aids

I use a power wheelchair and, I am virtually independent in my power wheelchair I can't walk, so I use a manual wheelchair.

Political Correctness

I mean, I don't even know what it means to be differently abled. I mean, I don't have a special "sixth sense" because I have CP. Like...and I think that just...even though you're, quote, unquote "being nice" about disability, you're still bringing attention to it by special terms

kind of in the past ten years where it's disabilities in lower case and Abilities in upper case.
W: Right, so like small d-i-s, capital A
L: Yeah, which I kind of, I have mixed feelings about that one.

Right To Participate

And even some people with disabilities who consider themselves a burden to society and don't leave room for the fact that they deserve the same privileges as anyone else contribute to this whole, um...docile movement of, well, you know, we're disabled so we should just be thankful for what we have or what we get or whatever. Those are the kinds of things that make me upset.

I was telling my friends and my sister this story and I said, "I guess it was pretty silly of me to try to go to the inaccessible bank." And generally, everybody's statements were not that it was silly that you wanted to go to the bank, but it was more silly that the bank was not accessible.

everybody I talked to just said that the bottom line is that the bank should be accessible, not that you should have known better than to go to the inaccessible bank.

from my perspective it was like "What person in a wheelchair tries to go to the inaccessible bank? Like I should have known better." And that's usually what I'm met with when I am trying to do something that's not accessible, is, you should know better than to do this.

a good example is, quite often the TTC accessible features are broken. And quite often I am met with, "Well, you should have called the lift line." Which is a line that says which elevators are not working today. And I mean, in theory, it's a good thing, but my thing is, when able-bodied people have to start calling to see if the stairs are running, then I will call to see if the elevators are running

quite often, rather than being met with like, "We're so sorry this happened and let us assist you and how can we help you?" it's, "You should have known better than to leave your house."

Yeah. Like I really like grocery shopping at night because no one stares at me, no one asks what I'm doing. There's not that many people in the store, so I'm not going to bump into anyone. And it's just really nice cause it's like, something I can do, and I can just go get groceries. But I shouldn't have to become nocturnal...

I know, like, you shouldn't blame society for all your problems, but it's society "s problem, not mine. Like it shouldn't cost eleven thousand, *million, kabillion dollars for me to learn how to drive. It shouldn't be a big deal that I want to come home at 1AM on the TTC.*

sometimes me and my sister will talk about colleagues or friend s we know in wheelchairs and we'll say that they very much have an attitude of, "It's very nice that the able-bodied people let us live in their world." And me and my sister " s attitude is like, "Why wouldn't I be here?" And I think that that's something my parents, as crazy as they are, helped instil in us is, "You have every right to be here just like everybody else.

I think that the real focus on access within policy is in making consumer spaces accessible, and I think that really changes the way you negotiate life when you use a wheelchair, and it also only makes room for a very specific kind of disabled person because.... like, for example, I know the mall is always accessible and I know that government buildings are always accessible. So what does that do to my experience that like...I can be a consumer and I can produce civic experiences.

if there was one thing I could change about being disabled, it's that sort of space of what do you do when somebody doesn't acknowledge that you have value, or when your society doesn't...only makes space for you when they need you, so when they need your money, or when they need your body to count, so like I am thinking about civically.

Role Expectations

society in general, able-bodied or disabled, especially for women, if you don't have a career, you're nothing. And if you don't have a man, like...you're also nothing.

D: Yeah, and like, that's what grown-up women have. They have jobs, they have boyfriends or partners and they drive. And those are three things I currently don't have. And I mean, so...I know that doesn't make me any less of a person and you can still be a wonderful, fantastic person without these three things, but at the end of the day, I still feel like shit because I don't have any of these three things. But I'm working towards...most of them.

Role Modelling

I think my parents, because they didn't know what to expect from me, because just when I was born, a lot of societal views of disability and integration were changing, so there were no benchmarks or role models or things which they could really say what my life was going to be like.

my parents brought me up as, "You might not have had a role model, but you can be a role model to other people." Which I kind of like, I kind of don't like.

it would be great to see...it would have been great to know role models or have people which I could understand, or not understand but associate with that have been through some of my challenges.

Self Determination

Well, my psychology background says that self-determination is the ability to define a goal and act willingly towards it. In many circumstances, I feel like my ability to define goals is completely fine, unaffected by a disability. However, my ability to accomplish them is somewhat impaired in many circumstances and so, self-regulation becomes this weird, "OK, well I know where I need to be, but there's several obstacles to get there."

So like I was saying before, I feel as though the first half of self-regulation is readily achievable. Um, but in terms of actually reaching a goal, there are several interplaying factors which may or may not be a direct result of my disability, that can impede my ability to actually fulfill what is involved with self-regulation.

Well I think that self-determination means sort of like, setting goals, like your ability to set goals and achieve them, and also your ability to make your own decisions on top of that. To set goals and make your own decisions

Like everyone has self-determination within them, but you need to develop self-determination, and that's why parents give kids choices, so that when you're an adult you can determine things and have the autonomy for yourself to achieve the different goals you want.

I would define self-determination as being able to make your own...like your own, quote...sorry, I've been reading a lot of Foucault, so your own [air quotes] choices, and being able to sort of like direct your own life and your own destiny, do what you want, self-determination I think goes hand in hand with concepts of individuality and being able to recognize your own purpose and autonomy.

Self-determination kind of...it's a bit about self-worth, how much you want to push yourself, how you, what you think your starting point is vs. where you see other people starting from. And sometimes those two don't always reconcile, so it can be frustrating. But it can be frustrating for anybody. Self-determination is what you want to do, what you want to get out of life or your outlook or ambitions or interest

For me, you know, it's setting goals for myself, thinking of what do I want to accomplish, what makes me happy, what makes me fulfilled, what makes me feel productive and I am the type, I am the person who does set *in two years from now, in five years from now, in ten years from now, these are some landmarks*

So, I guess if you're friends and you know them very well it can be very good for your self-determination and then if they don't know you at all they assume that you can't do anything and then it kind of puts you in a bad mood and then you have no self-determination whatsoever because then you can, on occasion, go into the mood where you're like, "Is this how everybody is going to perceive me?" kind of thing.

Service to Majority Needs

I'm in a wheelchair. So that requires me to do a lot of things...like I can do a lot of things just like normal people, but I have to do them...almost everything differently. Because it's from a sitting perspective. And I mean, most of that is not because I physically have to do them differently, but just because society isn't usually set up for people with...who use mobility aids to do things differently.

Starbucks is so big that they really don't care if they...like they don't really care if you're happy, because you know what? If you, person in wheelchair do not wish to get your coffee from Starbucks because you feel personally that their accessibility is not good enough, when you leave, five more people will come in that think the coffee shop is just fabulous, so either way, they're making money,

And I find that that's a lot of the issue with accessibility is either you're told that, you know, no one uses this, there's one of you and nineteen of them, kind of like more of a numbers game, and that is kind of frustrating.

a lot of people aren't willing to spend the extra dollars to retrofit their bathroom with all the things that they think we might need, but it's like, "All I really need is a grab bar and we're good to go." So I'm hoping that, at some point, it's going to be more of a forward thinking thing to just automatically make things accessible for those who need it.

Sibling Influence

being the younger sibling and having an able-bodied older sibling who was very popular, she modeled, she was a very good athlete, she was a popular person. I know a lot of siblings, no matter what always feel like they have to live up to the standards of their siblings or match or better them

Social Capital

I would say that a huge part of my success and my ability to conceptualize myself as being a capable being is that I'm white, I'm from a middle class *family and my parents were married for sixteen years, and I went to school in a Catholic system.*

Like...my Mom quit her job when I was two because it was too hard to work and also make sure that Desiree and I were like....to take us to doctor's appointments and make sure that we had the best care. And my Dad maintained his job. And I think about what was really interesting about that...I wrote a paper on this...is, so my Mom quit her job as...she was a bookkeeper and then she was a legal assistant as well, so those were her two main fields, but my Mom had access to power suits and lawyers, and understood human rights rhetoric and jargon, and is a ridiculously, I'm sure later on I will say bad things about my Mom...but is a ridiculously strong-willed woman, and so she had the luxury of...like she was a girl guide leader, she researched sports opportunities, she took us to like...and this becomes kind of problematic, but for the first six years of our lives, every possible rehab doctor surgeon, healer that could possibly be available

I think about the fact that my Mom essentially mitigated an entirely inclusive education experience, and then put extreme effort into making sure that I had typical social experiences outside of school is probably huge and I think that my Mom's ability to do that is highly...not motivated, but highly propelled by the intersections of class, race and....class race and gender too, because by doing this, she was taking up the "Good Mom" role and so becoming a girl guide leader and managing the basketball team and driving us everywhere, that was something that was understood as highly socially appropriate, and things that good moms do. And so, when you have a good Mom and kids from a white middle class family who are understood as good kids from a good family with a good Mom, it becomes this thing of, "Why wouldn't the community accept them, because at the end of the day, they're good kids with a good Mom and they just can't walk."

Often the reason, or the sense making device of why we were included was because we "just" couldn't walk. So there was huge pressure to continue to perform competency and intelligence and in that space I got kind of stressed out about failing because not achieving that competency or demonstrating that intelligence would potentially not allow me to have that sort of access to an inclusive space.

I've had the opportunity to speak with someone who does my job in the city where I grew up, and he often talks about my old high school as being really hard to talk about inclusion and inclusive education and I keep saying, "Oh, I had a great experience." And I keep thinking about how much my privilege and the way I was able to sort of brandish that social and cultural capital affected that.

> *my experience is not necessarily grounded in an overcoming narrative of like, "You can do anything, you just have to do it a little bit differently." I think that a lot of my success has been mitigated by other spaces of privilege.*
>
> *I spend an exorbitant amount on clothes, shoes and make-up, and while that can be taken up as "Ha ha, you're a shopaholic, you love shoes and make up!" and while that is kind of true, it's also done as like, purchasing a uniform and purchasing things and I feel ob...I would, I guess maybe not...obligated's not the word, but I feel like I have access to a certain social power if I am able to super hyper-perform my gender or hyper-perform my intelligence. Like I really think that part of why I am in grad school and striving to get a PhD is both...like I think that what I am studying is interesting and I'm a relatively cerebral person, but I'm not...I also like the concept of like, it puts me in a space where disability is intersected with something that really confounds the common sense understanding of disability.*
>
> *I still think it's problematic because normalizing or buying into a hegemonic ideal of who gets resources and who gets space is so screwed up and I think it's violent to the individual and really does a disservices to the collective energy of society...really...personally I have a tension with that because I think that if I were to give advice to disabled children, I would never want to be like, "Just try to look real normal." Because I think that's awful, but I think that essentially...and normal is a problematic word, I acknowledge that. But like, I think that enacting and making use of cultural capital is useful in negotiating an already flawed system. But I would really like to empower...I would really like to think about ways we can disturb social organization instead. So it's a reluctant strategy.*
>
> *I understand being able to play up identities of privilege and power as a way of negotiating systemic and individual ignorance that I encounter within society, and I think it's both cool that I found that strategy but also probably really really bad because I...and that sounds reductive, but I find that it has caused me to not really live in the moment because I am constantly thinking about what's next and what am I going to do next. So I'm going to get my PhD and then where am I going to work, what am I going to do, who am I going to publish with. So it's always that next step. And I question like....if I didn't feel such an obligation to find new and interesting ways to intersect disability with power, would I spend more time in the moment?*

Social Participation

there are certain spaces where I don't...depending on who I'm with, I don't really like going to un-accessible bars unless I know the people and the community at the bar really well, because often there is tension with the fact that I don't really fit into the space and then people are drinking and not everyone is really reflexive to difference when they're intoxicated, and then there becomes that space of...that may cause anxiety

And what I have noticed has happened is like, I am the go-out-for-dinner queen. I go out for dinner with all of my friends all of the time, and often it's a way of quietly negotiating inaccessible houses

while I do go out at night and do stuff, a lot of bars and clubs aren't accessible, and when they are it's often through very awkward things, and I wonder, how does that affect me meeting people? What does that do to who I date and what comes up?

Social/Relational Desirability

So I spend a lot of time either avoiding people who are going to bring me...like put those statements front and centre in my mind or like pushing those little tiny statements out of your head. And these are things like, "No one will ever love you because you're in a wheelchair. You will never get married and have a baby because you're in a wheelchair.

I can't spend time thinking and believing that nobody will love me because I'm in a wheelchair.

an ignorant comment on the street is somewhat more easy to...or, yeah, easier to dismiss than being rejected by a potential suitor on the basis that I am disabled

there are a lot of people I know and I've had frank conversations with and they just find that thy would never even consider dating someone with a disability because it is too much for them to handle.

I have had questions myself when I was younger like why do I not fit the societal definition of what is beautiful, what is desirable, I'll never get a boyfriend, I'll never date, etc. It's an issue in the dating world but...um, I haven't really had any partners that have made it an issue if that makes sense.

in terms of the personal aspect of looking at myself, like for example, a goal of finding a boyfriend or something like that. I, a lot of the time, automatically assume that some guys will look and they might see the walker first and me second. So they might think, "Oh, that's a lot of...that's a lot to handle and a lot of baggage, I don't want to go there yet

Standards of Physical Beauty

> *I can only think of one model that is internationally known that has a physical disability, and she's an amputee, so it doesn't really match my disability.*
>
> *I'll watch people that will go out for jogs, and then they're all the fit, trim little size zero. And I know that I'm not super-skinny but I'm not fat either, but because of my body shape and the fact that I have scoliosis and I'm short, and I have a back curve and things, my bum sticks out and my stomach sticks out*
>
> *I have many times where I automatically think because my stomach sticks out a bit because my spine is curved, my butt sticks out because my spine is curved, that I'm fat. It may be true, it may not be true. I don't know what my actual weight is because of these things.*

Visibility and Disclosure

> *People...and I mean I guess rightly so, always assume that everyone can write and everyone can read so quite often when I have to be like, "I can't write, can you fill that out for me?" People most times, people are pretty good about doing it, but they still look at me like I have three heads.*
>
> *visibly, my hands don't look like there's anything wrong, so it's hard for people to comprehend, „cause people always think that people with "crunchy hands" can't write, but that's not true. Most people with crunchy hands actually can write. But I can't*
>
> *it's not something that a lot of people notice and then because my other, the rest of my life, I guess I appear pretty competent with my skills, so people often don't acknowledge it as something that's embodied, they acknowledge it as me being, like...silly.*
>
> *because people with disabilities in many cases are seen as either being completely dependent on others or in a wheelchair but not having a so-called invisible disability, and even though I do have a physical, visible disability, it gets unnoticed by many people unless I specifically tell them.*
>
> *, holding a door open, it's almost automatic for someone in a wheelchair for society to do that. But if I only have one good hand and I am carrying a heavy bag of groceries or whatever, people might not give me the same consideration.*
>
> *even when I have been vocal and said, "I have a physical disability, I'm sorry, could you please help me?" I remember there have been...not all the time. But there have been times when people have not known how to*

react because there was no visible indication of what I may need assistance with.

because no one likes to be singled out in a negative light, but at the same time, I don't want to have to disclose my disability to every person that I meet.

I used to say a lot that I fell through the cracks in terms of being a person with a disability because I walk with a limp but I'm not in a wheelchair. So people just don't understand that it's a spectrum. It's not one or the other.

just as an example, legally, I am allowed to sit in the physical disability section of a public transit bus. I have that right. And people are supposed to, you know, give up their seat for me. Do I want to identify myself? Well how do I...they might just see me as a lazy 20-something who just wants a seat closer to the door. I've had old ladies be like, "Why should I give you...why should I give up my seat for you."

Sometimes the best way to break the ice in situations when disclosing a disability is to be self-deprecating. But that might just be my mannerisms and humour.

Workplace Disclosure

filling out job applications or being asked at job interviews, I think I have almost shot myself in the foot because I have had to identify that I can't fill this out. And I think that throws people off or scares them a bit.

I find it interesting, being in human resource management „cause everybody's like, "Oh you don't have to tell." But inevitably, sometimes it does come out in the initial stages of the interview and I think that in some situations that has led to me getting screened out for the position.

And I don't write across my resume in red crayon, "gimp" [researcher bursts out laughing. Both laugh], so like when they initially see my resume, they have no idea who I am or what I do.
D: so I feel that it's almost foolish to be like, "They're discriminating against me „cause I'm in a wheelchair!" Because how many places that have seen my resume know that I'm disabled? Because nobody knows who I am on paper

"I could ask for supports such as, it's easier for me to type on a laptop because I type with one hand as opposed to a full sized keyboard, but I still can, and I still do very well typing on a full sized keyboard. So you know, do I really want to go through the process of saying I have a

disability and I need this vs. over time, you know, telling employers or co-workers what my strengths or weaknesses are.

Disability in the workplace is a bit of a touchy subject no matter if you're asking for accommodations or if you're not...I think that employers themselves...they may have HR but not all companies have an HR person who knows the rights and legalities of what can be accommodated for.

First impressions count so it's going to...being a grad student, I am going to be looking for a job soon, and yeah, that's crossed my mind. What do people think of me when they see me? How can I change that to make it less visible or do I want to bring a cane to make it more visible?

Appendix E: Codes by Theme (Case Study)

Theme 1: The Experienced Self

Embodied Difference, Other-ing the problem, diagnostic, physical aids, assistive services, assistive technology, accepting disability identity, encouraging independence, independence vs. interdependence, internal resources

Theme 2: The Reflected Self

Acceptance vs. Erasure, Language and Intention, Language and Identity, Derogatory Language, Political Correctness, Other-Assumed Limitations, Infantilizing, Compensating, Role Modelling, Patronizing, Standards of Physical Beauty

Theme 3: Self as Community Participant

Social Participation, Right to Participate, Inaccessible Accessibility, Access to Supportive Services, Informal (Social) Community Support, Service to Majority Needs, Access to Daily Necessities

Theme 4: Self in Family

Parental Support, Parental Advocacy, Autonomy Fostering, Overprotectiveness

Theme 5: Self as Learner/Professional

Accessibility of Post-Secondary Education, Workplace Disclosure, Accessibility of Employment, Visibility and Disclosure

Appendix F: Meaning Units by Code (Autothnography)

Accepting Limitations

I get so tired of having to explain to people, even to those closest to me, that certain everyday tasks that they take for granted are actually physically not possible, or if they are possible, they are much more trouble than they are worth. They'll tell me not to place limits on myself or that I should just try the task another way, and it's like, trust me, it's not that I like being unable to do these things. I would rather be able, and I have tired, so when I say that I can't it's because I actually can't.

Accessibility of Transportation

It really is a big deal in terms of not being able to go where I want when I want. I mean, there is transit, sure, but transit authorities don't seem to take into account that the people most likely to use transit are the people who may have other mobility issues and are going to be hampered by the fact that bus stops are really far apart, or on main roads only. Then there are certain places in the city that buses don't go, so those parts of the city are not accessible without a car.

Addressing Needs

I remember I used to have to go to physiotherapy and occupational therapy, and between the two of those, my parents would take me twice or three times a week. I went to the chiropractor a lot too, when I was a kid

Adult Expectations

With driving, it's not the physical barrier... or I guess not just the physical barrier. I mean...not driving is a pain in the butt, that's for sure. But part of the problem is the social stigma attached to it, because there is this idea that a functioning adult should be able to drive, and if you can't drive, then you must not be a functioning adult.

I've often said that being able to drive is one of those things that everyone just expects a functioning adult to be able to do. After a certain age, everyone just assumes that everyone else drives, and when I have to speak up and say I don't, people just, like, look at me as if I have three heads, and it's like, what do you mean you can't drive?!" Like it's the most unimaginable thing on the planet. And then people start acting like I should just get up off my butt and go get my licence already, because clearly my life would be so much easier and I am just being ridiculous. And it's like, no, there's a little more to it than that.

Advantages of Method

When I realized that I had been framing the study in a problematic way, all of a sudden I was just...grateful again for the design of this study. If this was quantitative research, these would be the types of things that kept *me up at night worrying about accuracy of results. Now, I can just acknowledge the shift and move on.*

Being Ignored

I think back on that experience where I got brushed off at the medical clinic after I hurt my foot, and I wonder if it was some combination of things about my appearance that made me seem like a person who deserved to be ignored. I know I was limping badly and I remember I was wearing my big grey coat, flapping open because a button was missing. Part of me wondered if the doctor looked at me and decided, "Poor, black, disabled woman, not really worthy of my attention."

Being Mocked

One of the first days I lived here, some guy made fun of me on the street. He was standing talking to someone, and when I went to walk around him, I lost my balance and teetered a little. He then blocked my path and imitated my walk with a leering smile. I was so shocked and sad and angry, and I already missed home so much that all I could think was, I fucking hate this stupid city." Because I was convinced that this never would have happened at home."

Body Shape

She used to admonish me, "Tuck your bum in" and would put one hand on my stomach and the other on my butt to correct my posture. Even when I was really young, that was embarrassing, as much the physical correction as having attention called to the way I carry myself. And to a certain extent, I can't really help it. My tight hip muscles rock my entire pelvis forward, so my butt just sticks out anyway, no matter how straight up I stand.

For the longest time, I didn't even understand that the muscular tightness around my hips had literally rocked everything forward. A physiotherapist pointed it out one time, and now I am constantly aware of it, especially when I think about how it makes me look in certain clothes. At least now I understand why I have such a hard time buying pants.

Challenging Stereotype

Sometimes I think about the fact that I am here in Graduate school, and then I think of those people who told my parents that, basically, the CP would prevent me from accomplishing very much in the academic of professional sphere, and I just want to laugh and laugh to think what they would have to say now.

Control

Sure I limp, but it never really becomes a problem. It certainly doesn't slow me down. I walk fairly quickly, usually, and I'm fond of saying, *"Imagine if I didn't limp. I'd walk so fast there'd be fire coming out of the back of my shoes!*

Because of my balance, I have trouble negotiating narrow spaces. I'm always afraid I will lose my balance and fall and hurt or embarrass myself. When I have to traverse a narrow space, there is a moment of fear that I don't think most people appreciate. Like, for example people are supposed to leave their backpacks on the floor of the bus, but when someone leaves one in my path to the door, now I'm worried I'm going to trip over it.

I have trouble with my hands. I never really understood how I was different until I was trying to do food service in the summer of 2005, and I would be slinging food and always half a step slower than everyone, and I started to notice it then, the lack of dexterity, because you're constantly working with your hands . And suddenly it all made sense, the fact that sewing on a button can literally take me hours, or that I chop vegetables more slowly than anyone I have ever met. 'Cause my hands just can't move around object and manipulate them as fast of as well. You may not notice unless you were looking for it, but the difference is there.

Before I realized this problem with my hands, again, I used to fault myself for my "clumsiness" Now that I have become aware of the way that my hands function, I'm better able to accept it and adjust for it. It does mean that I have a harder time independently addressing what, for most people, are minor problems like a shirt losing a button. Now the question becomes whether to struggle to fix it or have someone do it for me. It's a choice I sometimes wish I didn't have to make.

My balance is way less than perfect, my gait is jerky and sometimes I have a hard time making my arms or legs do what I want them to do. There was actually this one incident in a restaurant where I was having trouble negotiating the table and bench legs to get into a booth, and one girl we were with gave me this look and was like. "I don't see why it's so hard for you to get into that seat." And I thought, "Well no, of course you wouldn't. Your balance is normal and your legs do what you want them to do."

Defining Cerebral Palsy

I have spastic cerebral palsy, which basically means that all my muscles are tighter than they should be. Because of this, I have a little trouble controlling some parts of my body....I walk with a limp, my hands don't always work as well as I would like them do, that sort of thing. It also means that I have pain a lot of the time. Just imagine if certain muscles were permanently tensed.

Denying Difference

When I was a preteen, someone spoke to me about getting involved in athletics for people with CP. It sounded like a good idea at the time, but nothing ever came of it. I've sometimes wondered why. I wonder if part of it had to do with not identifying myself as a person with a disability. I wanted to think of myself as just like other kids.

Developing a Disability Consciousness

I would say it's only recently, like maybe in the last four years or so, that I've really recognized how important disability is as a site for discourse and analysis. As I moved through the University environment, I got very used to questioning experiences and meanings around race and gender, but it took a little while for me to start doing that with disability. It's like, I spent so long trying to convince myself and everyone else how "normal" I was that I missed a chance to really engage with disability as a concept.

Because disability had been mostly absent from my educational narrative up to that point, I did not seek any accommodations from the centre for students with disabilities. In fact, disability didn't really enter my University experience until a second year philosophy class in which I became conscious of disability as a point of discursive interest

Differing Strategies

I began to realize that what I keep doing is to try to get as close to a "normal" (read, non-able bodied) experience as possible It's like I'm trying to pass for able-bodied, where my participants are more like, "No, I have a disability and that makes my experiences different from people who don't have a disability."

This thing about erasing the disability, I think it's a strategy I adopted from my parents, and I don't begrudge it at all, I mean, I was already black and adopted, so maybe the thinking was, in this place and in this time, it will be good for her if she is physically as much like other kids as possible. And the strategy seemed to work inasmuch as I did well going through school and adjusting socially and all of that. And it's not like anyone tried to pretend I didn't limp or wear a brace or whatever, it was like, "You can be successful even though you have a disability. Just look at all the normal stuff you can do." Where, with my participants, it was more like, "You have a disability and you can be successful from within that experience." I'm not saying that one is more right, but like...I feel like I'm finally starting to embrace the reality of disability after keeping it at arm's length for years.

Disadvantages of Method

There is so much here, and some of it will just have to be left on the cutting room floor, so to speak. What my participants have given me is so *rich that I almost feel like I'm cheating them by leaving so much out. But you know, the thesis has gotta get finished so I have to get brutal sometimes. And it's a weird conflict in a study which is about hearing people's voices, that in the end, I do have to silence some in the service of a manuscript that just has to get finished*

The way I'm conducting this research, I need to focus on similarities across interviews and I don't get to bring to light those unique points and perspectives offered by each individual participant. It makes me sad 'cause again, it's just like there's so much missing.

Encountering Limitation

That job in food service was pretty tough on me because it was the first time I really had to admit, yeah, I'm different from everyone else. It was the first time I'd had to say, "No, I can't do that as well as everyone else." And I mean, all it was was slinging fries and pizza around, but I was abysmal at it, and I'm used to being good at things, so it was pretty awful. Also, you can't sit your co-worker down in the middle of a rainy Saturday afternoon and explain your CP . All they know is that they needed that pizza five minutes ago, and now you've gone and sliced it wrong.

I'm not sure if I still didn't understand or I was trying to prove something, but I went back into a very similar job, and when I was there, I kept getting these subtle messages of not being good enough. Somehow I would always find myself doing the grunt work like prepping potatoes or lining trays instead of cooking and serving food or working cash

Encountering Physical Self

Every once in a while, when I see myself in a picture or happen to notice how I am holding my body, I "catch myself: doing this thing where my hand is turned in at the wrist and flexed, fingers bunched up, almost claw like, and I always think, "Woah, why does it look like there is something wrong with my hand?" and I now that this is just the way hands appear sometimes when one has CP, but it doesn't seem to me like my hand should look like that.

Sometimes I'll even forget that I limp. Someone once said to me, "Hey. Are you limping?" And I went, "NO!" like it was the most ridiculous thing, and then I thought about it and said, "Well, yeah, but I always do." When I really notice the limp is if I walk by a mirror, and I have this moment where I think, That girl can't be me. She looks so broken and clumsy and ungraceful...lumbering around like that. And I mean, that's shocking. I would never say that about anyone else with a limp, but that's what I think when I see my own walk in the mirror.

Encouraging Success

> *When I see the way that some people treat me because of my CP, I realize that my ideas and expectations of what I am able to do would be much different if I had been raised with some of the limitations that others impose on me. This is where I realize that the way my parents went about things was important for what I have been able to accomplish*

Faith

> *Every once in a while, someone will suggest that I might wonder why God made me like this, but I never really do. Having a disability doesn't give me a sense of being less good or less whole before God or anything like that.*
>
> *There is an attempt to turn even pain into a positive. It is very Catholic of me, of course, but "offering it up" helps me to feel that even physical pain is not necessarily a negative thing, even though of course I don't enjoy being in pain.*

Feeling Limited

> *In the pool the other night, I wanted so badly to feel free to play and splash, but between poor eyesight, poor balance, the fact that I can't really swim and the fact that my leg kept threatening to go into spasm at any moment, I was completely uncomfortable and on edge.*
>
> *It's funny that I often have this idea or perception of myself who is relatively graceful from the waist up, or, I don't know, from my navel up, but this graceful top half is rooted in a really clumsy, klutzy trunk.*

Healthy Minimization

> *I very seldom remember either of my parents saying that I couldn't do x, y or z because of the CP. It was just taken as a matter of course. Like, when I was a kid, Mom would say, "Please go crawl up the stairs and get me this or do that" . And now I realize she had me crawl because my balance was bad and I probably would have fallen down the stairs at age 4 or however old I was, if I had tried to walk. But it was never, "Oh, you have CP, you can't do this."*
>
> *I played softball one year, so of course we told my coach that I had CP. And she was all ready to make a huge fuss about it and my Dad was like, "No, really, she's fine. I mean, she's not going to be the best player on the team, but there's no need to make a big deal here."*
>
> *And when I was growing up..., like, sure I understood that I had cerebral palsy, but it was never a big "difference" thing. It was like, he has brown eyes and she has black hair and I have CP. Like, not a big deal. And that's good in some ways, because I know some people with disabilities who get*

to adulthood and are still always saying, "I can't, I can't I cant." Whereas with me it's more like, "Well sure I can. Why wouldn't I?"

Hypocrisy

I feel snobbish and...ableist when I say this next, but if half an hour of physical activity tires you out, for the rest of the day, you can't keep up with me. Unfortunately, I am not a very patient person, and that's really ironic when I know what it's like to have to beg the patience of someone because my body doesn't work just quite like theirs.
So I'll do these interviews and I sit and think later, about how I complain that I had to walk here or there and it was far or it was winter and the sidewalk wasn't plowed, and then I realize that if I used a mobility device, I couldn't go some of the places I go or do some of the thing I do. Or I'll think of how my hands kind of don't work, but for the most part, they do. And when I think about those things I feel...lucky is the word that's coming to me but I don't want to say lucky because then I think, "Am I doing that gross pitying thing that people do? I see it in their facial expressions, I hear it in their voices when my limp is bad or something and I can just hear them thinking how lucky they are that their bodies are whole and functioning. And I hate it. So I hope I'm not turning around and doing it to my participants."

You know, for all I think that I am conscious of disability issues...after all, I am a person with a disability too, right?- I do and think some pretty ableist things sometimes. Like the other day, I was at the library and I went to lock my bike to the railing of the accessible ramp, and I thought to myself, "Oh, it's fine, people can get around it." And then I thought, "How is that any different from able-bodied people who put stuff in your path and think nothing of it, and then you're rooted to the spot because you're afraid to trip and fall and make a scene?" So I moved my bike, of course. And now, like I wonder how many times I've done stupid stuff like that in the past and not even realized it

Identity and Acceptance

My participants seem more willing than I am to acknowledge themselves as people with disabilities and to be visible as people with disabilities and I wonder if part of that is that I spend a lot of time...denying, I guess, that I am a person with a disability. I spend a lot of time trying to be just like everyone else, where I wonder if my participants have sort of integrated into their self-concept that "I'm not like everyone else...and that's not really a problem."

My participants seem so much more comfortable with the word "disabled" that I am. And as vehement as I was in my dislike of it not so very long ago, I now wonder what's up with that. I mean, we all dislike certain words that are from like, back in the day, and now it's like, *"Really, are we still using that word?" But there's something about the word "disabled" and what it means for identity that my participants are much more comfortable about than me.*

I think it's this whole thing about disability and identity. We all talk about how we are used to our physical realities and it's that thing of, "What's the matter, it's just my life." but somehow they seem to be more comfortable about it than me.

Increasing Awareness

Sometimes, especially lately, I have a moment of hesitation about using a space or a service if I recognized that it is inaccessible to someone else who might need or want to use it. It's like, even though the inaccessibility doesn't affect me directly, I still find it problematic.

I'll notice stuff about so called accessible spaces that I never noticed before too; like how is this bathroom supposed to be accessible if the stall is not much bigger than the non- accessible stall, and like, that's stuff my participants have said. Or, like, I'll go places and walk up the stairs like I usually would, but I'll take more notice of whether or not there is a visible, accessible way to get into the place.

Independence

Again, I never had a sense that the CP had much to do with what I was or was not allowed to do. The only exception, in hindsight, was driving, and at the time, I had no idea that CP was the reason that my parents were so reluctant for me to take driver's ed. I would say, certainly there were times when I would have liked to be given more independence, but I think it was normal teenager stuff, not necessarily related to the CP.

Intrusive Questions

*I once had a man with whom I was just beginning a relationship question my sexual functioning. I mean, he asked in the most delicate way possible, but the point of his question was, am I physically able to have sex . And on the one hand, that is eventually going to be a legit question to have of someone you're in a relationship with. But on the other hand, you just wouldn't *ask* an able-bodied person that question.*

Invisibility

*There are times where I am so tired, or my feet are hurting or something, and I want to sit down, but these are situations where it would seem inappropriate because I look physically healthy. Like, I don't *look* like I belong in the accessible seating section on the bus, but at the end of a long day, if I am exhausted and in pain, so that my balance is more off than usual, the reality might be that I have every right to sit there, and maybe even to ask someone else to move so that I can.*

Invisible Barriers

I remember when I was in first grade, I used to have fits with those printing exercises. I'd be the last to finish and I used to get all stressed out. Then in third grade, learning to write cursive was awful, awful, awful. I remember actually crying one night over a practice worksheet of the small cursive letter f. And then again, in 6th grade, I could not make head or tail of how to measure an angle with a protractor. Looking at it now, it's obvious that the writing issues had to do with dexterity and function of my hands, and the thing about the angles was a spatial issue. I wish I'd known that at the time, because I was a keener, and not being good at things really freaked me

Language

I don't like the term, "disabled." I mean, I really don't. It feels to me like defining the person you're speaking of by their physical limitation. It feels like saying, right from the get-go that this person can't be understood apart from the fact that their capabilities in some realm or another fall below what is considered the norm. I prefer the term "person with a disability" as a self-reference. I feel like it gives me a little more of a say in defining the ways that disability affects my life. It gives me some more control. But then, "differently abled" is almost too PC and patronizing, I am a woman with a disability. That's my reality and there's no point in...softening it, I guess is a good word

Limited Awareness

The truth is, I just don't know what supports are out there for me in terms of programs like ODSP. It's almost like, I spend so much time trying to convince myself and others that I am "normal" that I never concerned myself with the resources that were out there and how they might help me. I don't want something I don't need or deserve, but if there are resources out there that I could be using, I would like to use them.

Multiple Differences

*I was having this conversation with a guy in my philosophy class about the fact that people give me weird looks when I tell them my Irish last name, then I was telling him that I'm adopted and the rest of my family is white. So then, the professor overheard me, and when I went to her office hours later, the first thing she says to me is, "You're limping. Did you hurt yourself?" And I said "No, I have cerebral palsy." and she goes, "You have cerebral palsy too? And you grew up in Peterborough? How much fun was that?." And we laughed about it, you know. But then later, when I went to tell my Mom this conversation, like ha ha, funny story, and her reaction was like... she thought I was saying that being adopted or black or having CP was a bad thing. I had to try to explain to her, no, there's nothing *wrong* with it, but in a place like Peterborough, it does make* *you a bit of a marked woman, and you do notice. And so, fortunately or unfortunately, do other people.*

Narrowed Options

The one thing I have noticed with the human services field is that a lot of jobs are case-worker types, and they require you to have a licence and access to a vehicle. I mean, it's fine in terms of the fact that that's not really what I want to find myself doing, but it also means that, if I don't find my "ideal job" right away, I will have a harder time going into an entry level position in my field and working my way up from there.

Negative Assumptions

He said, "Cool! I didn't know you could ride a bike!" and for some reason, that pissed me off and I said, "Of course I can ride an effing bike. Why shouldn't I be able to?"

Back when I was considering becoming a nun, I had several communities turn me away from even inquiring because of disability reasons. Some of it was the driving thing, but one vocation director told me (never having met me) that she had doubts about my ability to keep up with the life of those Sisters, who were teachers. And I thought that was hilarious, because really, I would like to see some of them keep up with me the way my life was at that point. I was surprised when my days didn't last 18 hours back then!

Seeing how certain people treat me when they know I have CP, the fawning, the acting as though I am delicate, I understand that my own perception of what I am capable of would be very different if I allowed this attitude to influence my experience too much

People's reactions to me and assumptions about me change when they realize that I limp because I have CP and not because of an injury. Things are all normal when someone thinks that like... I have a knee injury or something, but as soon as I set the record straight, I start getting that patronizing, pitying crap.

Pain

...it was one of those times where my excess muscle tone was so acute that all the muscles from my left calf to my foot were in acute spasm, and my leg was so badly cramped that it had me gasping, groaning and barely able to move except in this weird, badly limping, jerky kind of way. And when it gets bad like that, I have to take an over the counter muscle relaxer, which I don't like doing because it leaves me fuzzy and more uncoordinated than usual

Pain has become so normal now that it is almost a non-event. Something always hurts, usually my hip. The muscles are always tight, like a marionette string being wrenched upwards.

Once when I was a kid, my physio sent us home with this muscle stimulation machine, which works by causing your muscles to contract and relax. Apparently it wasn't supposed to hurt but I remember hating it and screaming in pain. I mean, it really hurt. My parents quit making me use it before too long.

Parental Advocacy

Mom tells me she had gone to talk to the principal about physical considerations such as, could I be assigned to a ground floor classroom so I didn't have to climb the stairs every day. She explained my disability and apparently the principal said, "Well lady, there are schools for children like that. So of course my parents refused to send me to that school, which may have saved me from an academic life of teachers who expected me not to accomplish much.

Patronizing

I had a conversation recently with someone where it was that old thing of them going, "Oh you have done so well for yourself," and me being like, "No, really it is just my life." And it kept being pressed, like, no it is really surprising because of your disability" and I was just not in the mood to educate, so I got kind of pissed off. I didn't let him know I was, but in my head I was just like, OK, go ahead, keep patting me on the head and patronizing me. Make my day."

Physical Activity

I try to keep as active as I can. I walk everywhere (not that I have a choice!) and I go to the gym regularly. There is a sense of pride, or maybe reassurance in being physically active.

"Playing the Card"

Before I left to interview for this program, a friend asked me if I thought that being black or having a disability would change my likelihood of getting in. I told her that I hoped not. I want the same chance as everyone else and nothing more. I never want to think that I am getting an unfair advantage because of my CP or my skin colour. I told her that I would never "play the card" but if my experiences helped me in some way, I would be OK with that.

Sometimes I lose the line between "playing the disability card" and simply speaking from my experience. The second is good obviously, but I don't want to do the first and it is hard to find the line.

Practical Concerns

Getting groceries is probably my least favourite task because it just involves so much walking and hauling heavy stuff around. And part of the problem is that the bus stops are not conveniently located, but even if they were more so, transporting groceries on public transit is just a nightmare. And there is certain stuff you just can't do. Like you can't bring certain large household items home on the bus, so you pay for a cab or you do without.

Problematic Minimization

The problem is, when you don't really understand yourself as having a disability, you can't really make meaning of it, so when you come up against something you actually can't do or an opportunity that's not available to you because of your disability, you don't even know what to do with yourself.

Professional Implications

Here's the thing. It's one thing if I'm not really aware of the practical resources that are out there for people with disabilities, I mean, I can find out about that so that I have that information available for clients who want it. But if I am appearing professionally as "counsellor with a disability" that's going to mean a certain thing to clients, especially if they, too have disabilities. And sure, I have all those practical experiences of navigating this or that tangible barrier, but when counselling is so much about self-knowledge, what do I, as a practitioner do with the fact that I've spent my life making this one part of my identity as unnoticeable as possible.

Proving Capability

Maybe it's that I don't want attention focused on my difference because I feel as though that attention to difference always ends up focused on what I cannot do because of it.

Proving Independence

It becomes stupid sometimes, how much I hesitate in asking for help. I avoid it in certain situations where probably any able-bodied person would ask for help.

I am so stubborn and fiercely independent that I think I sometimes shoot myself in the foot while trying to prove I can do things on my own. I probably refuse help that even able-bodied people would accept. Like, I once arrived to visit an out of town friend and she told me off for not calling her from the train station. It was like, she would have picked me up, not because the CP prevents me from getting around, so much as because it was pouring rain and I was dragging a huge suitcase.

Proving Normalcy

I don't want to be that person on the trip, that person who is always slowing the group down or always saying, "I can't." Somehow, this trip has become one of those occasions where I have to prove that I am normal, but let's be honest here, that pressure comes from myself more than any of my friends.

J told me today that she advised our tour guide that we may have to stop or slow down sometimes because of a person with a disability...me. She said she hoped I was not offended and I'm not, but my first instinct was to brush off the provision and say that I don't need any special treatment. The honest truth, though, is that I may need it, especially if we are going to be walking as much as it looks like we will.

Self-Determination

I would see it as the ability to be independent and to make my own decisions...to make independent decisions in my life, to decide if and when I need help, how much I need and how much I would like someone to help me. Self-determination means being able to set goals. I decide what I want and act independently to get those things when I want to act by myself. But self-determination also means that when I do need help I can get it without having to jump through a bunch of hoops.

I think a lot of making my own sense of self-determination easier is the way that I see myself as an independent person, who is capable, for the most part, of doing most things that everyone else would do...I guess the ability to have those typical experiences...even if I have to do them differently.

Self-Made Adaptations

I think that, as far as school goes, I knew which classes to avoid. For example, I knew that anything that required me to do geometry would be trouble.

Shifting Meanings

I figured it out after this one interview, and all of a sudden it was this lightbulb moment of, "I relate to disability by doing my best to erase it." And the thing is, it's problematizing the study in a way. Without even realizing it, I've positioned disability in this study a problem and as something to be overcome. If you'd asked me personally, I probably wouldn't have said that. I'd have been like, "It's [disability] not a problem, per se, it's just my reality." And I was saying that and my participants were saying that but we weren't speaking the same language

Social Involvement

> *Often I'll get invited to a party or something, and it's in an out of the way location, and I think, do I really want to get on the bus in the dark and then walk two blocks to get to the place, and then how am I going to get home? I'll have to call a cab and that costs money. I could call someone and ask for a ride, but I don't want to be that person all the time, it's annoying. So sometimes I will run all that through my head and just decide to stay home.*

Spatial Difficulties

> *Susan offered me a ride home the other day and I said no because I couldn't remember how to get home from where we were. Now I know, going North on Richmond Street, you turn left to go West and then Right to go north again and then it's a left after that, and I didn't have to think about that last left because I know that the pattern is ABA. But I only know any of this because I looked at a map after I got home and pieced it together.*
>
> *Someone drove me home one of the first nights I was here, and I was embarrassed beyond belief at not being able to give directions. And then she pulled out a map and I couldn't read it, not because I can't read maps, but because it was too dark for me to see it. And the whole thing just made me feel so stupid.*
>
> *I'm always trying to explain to people that I have no abstract spatial sense....like, none. I can't form a picture of a spatial relationship between two places or objects unless I am looking at them. The example I use is like, right now, sitting in my house, I couldn't give you directions to get from here to the University. It's somewhere I go every day. I obviously know how to get there, but I can't tell you how unless I'm looking. If I need to give someone directions, I'll look at a map and memorize the fact that you turn left at this street and right at that one, but it's a set of declarative facts, not a spatial representation, and I can't recall it if I forget it. I also...because I can't really locate distinct points in space in relation to other points or objects, I get disoriented a lot. This becomes really embarrassing when it's something like...I go out for dinner and get up to use the washroom, and then I get turned around and confused on my way back to the table. It's awful*
>
> *I remember when I first had that conversation with Sam and she told me that the spatial issues I was describing were common for someone with CP. I was so absolutely relieved, you have no idea. I think I said, "You mean I'm not stupid?"*
>
> *If I' m in the library stacks and I need to go leave to get a step-stool, I stick a post-it note to the floor to remind myself what shelf I'm at. In*

Church, I put a hymnbook on the pew when I go up for communion so I know which seat is mine.

Support for Aspirations

As far as my parents and teachers went, it was like, "Well of course you're going to University, look at your marks." It was never a big thing in any way, it was just the next step. I mean, my parents said I didn't have to go if I didn't want to, but I did want to and no one tried to stop me

Use of Self

Depending on the agency and the population served, it may be an advantage for me to have a lived experience of disability. I'll have to be careful...it might be opening a can of worms to bring it up in an interview, but the kind of agency I would like to work for would by the type to encourage discussion around disability in the same way as race, sex/ gender, class, etc. as a valid component of engaging with client experience.

Valuing Success

I tend to locate the value of my accomplishments in the accomplishments themselves, not in the fact that I accomplished this or that and I have a disability...Like, the fact that I almost have a master's degree is awesome because it's a Master's degree, not because I have a disability.

Visibility

In the interest of full disclosure, I'd told my boss a bit about my CP in the interview, and we talked about it at work sometimes, so it was very "out there." But then I suppose it put her in an awkward position because she wanted to fire me on account of being too slow, but she couldn't because it was the CP that was making me slow. So then when I missed that shift that time, it gave her the excuse she needed and I was out just like that. Not that I'd miss the job, but I needed the money.

. I know that an employer is not really allowed to ask me about my limp, so they're either going to assume I've hurt myself or they're going to remain in the dark about the exact nature of my disability. And the other thing is, with the field I have chosen, once I'm in the door, my CP doesn't matter in the sense that it doesn't necessitate any accommodations in order for me to do my job.

A few times a year, around exams, we would have hundreds of files flying around the office and we at the front would spend all day filing. Well, one day, my boss saw me wince as I got up from a file drawer close to the ground. She thought I was having CP related pain, and I was, but no more than I might have on a normal day anyway. So she insisted on finishing my files, and I insisted that I could do it, and we had a little friendly stand-off *and a laugh about it. I don't remember who did the files in the end, but I did remember thinking that the pain was nowhere near enough for me to say "I can't" to an aspect of my job.*

Waking up

It's funny, because I have always know that I have CP, and I understand that CP is a disability, but it's almost like, over the years, I have been slowly waking up to the idea of myself as a person with a disability. It's much more present now than it ever was, and even with that idea in mind it's like....living in this body is all I have ever known. I have no basis for comparison.

When I was little, 7 or 8. My Dad and I want to a hockey game. We'd have had to stand in the top deck, but my Dad told someone that I had a disability and we ended up seated right behind the boards. At the time, even though I was wearing my AFO, it felt wrong. I didn't think of myself as having a "disability" then. In hindsight, I know there's no way I could have spent an entire hockey game on my feet, so the sought accommodation was obviously valid.

Worry

Having this foot injury freaks me out more than the CP ever did. It's unpredictable and I don't want to hurt it worse because I already have the CP, and I kind of figure, if I damage my "good foot", where will I be?

My hands are a mess right now. It hurts to grasp a fork or hold a pen. It is freaking me out. It could be a muscle thing from all the time I am spending in front of the computer doing work, or it could be a CP thing. If it is a CP thing, will it always be like this? How has will it get worse? If it feels like this at 27, how bad is it going to be twenty or thirty years down the road. I kind of hate that I have to worry about this at my age.

The experience of pain is not overly problematic now, as the pain is usually mild or moderate. My worry is what pain now means for functionality in the future.

Every time something hurts, I get anxious. I ask myself if it is connected to the CP, and it always makes me wonder how things are going to be 10, 20, 30 years from now. How much pain? How many thing I will not be able to do anymore? How much help will I need?

I find it difficult to make meaning of pain in a way that does not cause a degree of worry for my future capabilities to live and function independently. Because of this, I feel as though I worry about the future more than someone my age may otherwise.

Appendix G: Codes by Theme (Autoethnography)

Theme 1: The Physical Self

Defining Cerebral Palsy, Spatial Difficulties, Control, Pain, Worry, Feeling Limited, Body Shape, Physical Activity

Theme 2: Perceiving the Self

Waking Up, Denying Difference, Language, Self-Determination, Encountering Physical Self, Proving Independence, Proving Capability, Faith

Theme 3: The Self Perceived

Negative Assumptions, Being Mocked, Being Ignored, Multiple Differences, Intrusive Questions, Patronizing, Valuing Success, Challenging Stereotypes, Invisibility

Theme 4: Seeking "Normalized" Experience

"Playing the Card", Acknowledging Difference, Limited Awareness, Accessibility of Transportation, Practical Concerns, Social Involvement, Adult Expectations, Parental Advocacy, Proving Normalcy

Theme 5: Self in Family

Addressing Needs, Healthy Minimization, Problematic Minimization, Encouraging Success, Independence

Theme Six: Self as Learner/Professional

Parental Advocacy, Invisible Barriers, Encouraging Success, Developing Disability Consciousness, Encountering Limitation, Visibility, Self-Made Adaptation, Passing, Narrowed Options, Use of Self

Theme Seven: Reflexive Self

Hypocrisy, Increasing Awareness, Identity and Acceptance, Shifting Meanings, Differing Strategies, Professional Implications, Advantages of Method, Disadvantages of Method