TIMING IS EVERYTHING?

THE IMPACT OF GENDER AND DISABILITY ON THE LIFE COURSE

by

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Abstract

Living with a physical disability is a personal and social process. Increasingly, research has shown that the presence of disability affects family formation, education and employment trajectories and outcomes. This raises questions about why life trajectories and outcomes of disabled people are variable and how individual agency and social processes affect life outcomes. In this qualitative study these issues are explored using interview findings of ten women and ten men with early and adult onset disabilities. Findings indicate that those with early onset often experience disrupted education trajectories and unpaid work histories. Those with adult onset disabilities have disrupted work trajectories, with women reporting greater rates of divorce or delayed childbearing as a result of disability. The value of this research comes from recognizing that age of disability onset and gender have distinct consequences on life course experiences and outcomes.

Keywords: disability; gender; life course; age of onset; life histories

Subject Terms: people with disabilities – life histories;
people with disabilities – life course perspective;
people with disabilities – personal narratives;
people with disabilities – work and education trajectories;
people with disabilities – family formation, marriage;
people with disabilities – Canada

Dedication

This thesis is dedicated to the memory of my mother

Suzanna Rudwaleit
(1943-1990)

A single parent of extraordinary determination and vision,
and a good feminist to boot.

And to the memory of

Mark Gordon Fisher
(1953-1996)

Giesela Piorun
(1920-1997)

Dr. Ellen Margaret Thomas Gee
(1950-2002)

Leona Koslowski
(1910-2003)

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To Joan Meister, founder and former president of the DisAbled Women's Network (DAWN), thank you for your humour, support, guidance and love of Buddhist vegetarian food. I want to thank my very wonderful family and friends. I particularly want to thank my former spouse, Randy, who endured many years of my absence and supported me in the ways he thought best. Last but not least, I want to thank my son, Miikka, for just being who he is.

Table of Contents

List of Tables

A Note to the Reader

I have written this thesis with the view to provide a forum of ideas and experiences for people who live with a physical disability. I have excluded persons with other disabilities, such as people whose primary disability may be mental or intellectual, people who are blind or have low vision, people who are deaf or hard of hearing, and others whose disabilities are not yet fully understood or acknowledged by the existing epistemology of medicine or science. This exclusion is the result of attempting to finish a graduate degree that is manageable for me and my need to work full-time to support myself while conducting this project. I also had to respect what was within my area of interest. After completing twenty in-depth, in-person interviews, I feel that almost everything I was told needs to be included within this thesis. However, this is a work of partialness and fragments, even though I am a reluctant editor.

The experiences that you will read about are the reflections and consequences of a society which is still attempting to grasp the concept of disability. These experiences resonate with the vibrations of a greater social system. As a sociologist, I am concerned that the reader understands that we conduct our lives within particular social constructs, economic systems, and familial, gender based, cultural expectations about appropriate behaviour based on body types, age, ethnicity, sex, sexual orientation, and race. For persons with disabilities the norm is conformity to *able-bodiedness*. For those who fall short of the socially constructed norm, society still operates as though it is appropriate to segregate, marginalize, sterilize, devalue, delegitimize, ostracize and blame them. Stereotypes of people with disabilities legitimize how they are treated because their experiences are outside of the non-disabled, taken-for-granted view of the world. This view is the cultural imperialism of the non-disabled. A dominant ideology persists predicated on the belief that physical normalcy is not only desirable and attainable, but is something we can control. Fatigue and pain are the symptoms of malingerers. The fundamental belief that a disability resides solely in the individual helps to maintain the dominant, non-disabled ideology that society is not responsible for the exclusion of persons with disabilities from mainstream culture and day-to-day life. This notion is key to understanding the treatment of disabled people, socially, economically and politically.

It is my hope that this thesis might be useful to persons with and without a disability. For persons with a disability the thesis may provide insight into or relay experiences that validate the experiences of living with a disability. For those who are (temporarily) non-disabled, this thesis is intended to provide an understanding of what life is like for some people with a physical disability. Of course I also hope that I have contributed to the academic literature on persons with a disability. Most of all, I hope that the women and men who all contributed to this project will be pleased with it.

CHAPTER 1 — EXPLORING DISABILITY: INTRODUCTION

1.0 Introduction

When I first began research in the area of disability it was evident that the medical and vocational professionals were the most prolific contributors to this field and significantly more was written about the prevention of disability and about types of rehabilitation, rather than the lives of persons living with a physical disability. Typically, disability was defined as an individual pathology to be remedied by cure, rehabilitation or some form of medical intervention. Research on and conceptualizations about persons with disabilities were often drawn from male populations (e.g., war veterans) and/or provided by non-disabled men (Morris, 1993). Through this lens, the phenomena of disability was androgynous and homogeneous. Rarely was disability conceptualized as socially constructed or as the consequence of a disabling environment, which could admit to variation by class, culture or race. Similarly, very little literature was directed toward the subjective experiences of women and men with a physical disability, and the variations or similarities of these experiences. Also, there was little consideration of the position of persons within the context of the larger social structure. By focusing on disability as a disease, and separate from the person, issues of gender, age, race, family status, ethnicity, class, occupation and socio-economic status were not addressed, and the lives of people with a disability were decontextualized and depoliticized.

Since the mid 1980's, however, research and theory on persons with disabilities has been authored by those with disabilities and those outside the medical community. This has resulted in a shift from biomedical interpretations of disability to the recognition that disability is socially constructed. The literature and theory (Begum, 1992; Finkelstein, 1993;

Morris, 1993; Oliver, 1990) in the social sciences began to examine disability in the context of disabling environments, segregation in education systems, exclusion from the work force, institutionalisation of people with disabilities, discriminatory social policies and poverty. Parallels were drawn between the oppression and segregation of minority groups and people with disabilities. It was clear that people with disabilities were systemically oppressed by policies, social organizations, inaccessible environments and a social world organized by and around the needs of the non-disabled (Morris, 1991). *Disability* was the consequence of social and institutional processes, and attitudinal and environmental barriers, while *impairment* was biological fact.

By the mid 1980's, women with disabilities and feminist scholars were writing experiential and cultural accounts of living with a disability and articulating disability as a gendered experience. Like gender, disability was theorized as socially constructed (Hillyer 1993; Morris, 1991, 1992; Thomas, 2001; Traustadottir & Kristiansen, 2004; Wendell 1989). Women and men's experiences of living with a disability had very different implications and outcomes on the basis of social and cultural constructions of what it meant to be a woman or a man. Feminist theory in disability studies also emphasized the importance of studying the personal experience of disability as a route to theorizing the wider social position of women (and men) (Morris, 1992, 1993a, 1993b; Thomas, 2001; Wendell, 1996). Several women's anthologies and books have provided personal and political insights into the issues facing women with disabilities, with many of the contributors being disabled (Begum, 1992; Browne, Connors & Stern, 1985; Driedger & Gray, 1992; Matthews, 1983; Morris, 1996; Saxton & Howe 1987; Thomas, 1997; Wendell, 1996;). A key contribution of these works is their focus on the diversity of women with disabilities. They have also raised salient issues regarding ableism, sexism, dependence and independence, institutionalized discrimination inherent in policies, and access to medical care, housing, day care, work and school.

Comparatively little has been written by men with disabilities (Shakespeare, 2006). One of the few accounts which provides a personal, male perspective on disability is Robert Murphy's *The Body Silent*. Murphy (1990) asserts that economic dependency affects "the social standing of men more deeply than women" since men are traditionally perceived to be the "bread winners" and since most motor-disabled people are not employed and/or are dependent on social assistance or their families (p. 204). Murphy's assertion raises issues regarding the experiences of disability in the lives of women and men, and how disability can affect women and men differently – especially within the context of socially constructed age and gender roles.

A tendency in the research literature on people with disabilities is the assumption that people with disabilities are adults or seniors, as opposed to people with congenital or childhood onset disabilities (Priestley, 2001, 2003). The onset of a disability occurs at all ages of the human life span. Yet very little disability-related research appears to acknowledge this fact, or make distinctions in research findings by age of disability onset. Disabled people's access to resources, support and mainstream society vary substantially over the life course and this has long term economic, political and personal implications for how they live their lives (Albrecht & Levy, 1991; Helmius, 2004). Despite recent developments of a life course perspective conceptualizing the social implications of living with a disability, research on age of disability onset is unexplored and under-theorized.

According to the 2001[1] Participation and Activity Limitation Survey (PALS), about

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[1] Results from the 2006 Census were not available at the date of this research.

3,601,000 Canadians report that they had a disability, and about 1,968,500 are aged 15 to 64. To put these numbers in perspective, about 12.4 percent of the Canadian population under age 65 has a disability, and about 10 percent aged 15 to 64 have a disability (Cocette & Duclos, 2002). Quantitative research findings consistently indicate that disabled Canadians are less educated, have higher poverty rates, higher unemployment rates and are more likely to live alone when compared to non-disabled Canadians (Fawcett, 1996; Roeher Institute, 2004). Similarly, people with disabilities are more likely to live below the poverty line and more likely to be single parents (Fawcett, 2000). For women with disabilities, the disparities are more acute. Despite the number of working age Canadians with a disability, little sociological research exists about the lives of women and men with physical disabilities and how this may vary by age of disability onset. For example, the Roeher Institute (2004) reports that people living with a disability from their early years will likely have a different educational and employment trajectory than those who become disabled after years of involvement in the paid labour force. Unlike most non-disabled people, people with disabilities will, in many cases, require some support for employment, education or training that are specific to their disability, that are generally not well understood by the general population, and for many people are not sufficiently available, accessible or affordable. Given that disability onset can and does occur at all ages over the life course, formal and informal support available may also vary (Albrecht & Levy, 1991; Priestley, 2003). Yet, little research appears to exist which compares the education, employment and family formation experiences or outcomes of people with disabilities in terms age of disability onset and gender.

This research attempts to delineate some of the subjective and objective experiences of disability on the life course by examining how the age at onset of disability may affect personal, educational, employment or family plans and how this may vary by gender. A key concern is to understand how age of disability onset and gender affect life course trajectories, transitions and subsequent outcomes. When a person becomes disabled may have significant implications for how her/his life progresses. The onset of a disability may have very different implications for a young, working mother than for a semi-retired father. I base this on the idea that women and men have differential access to resources and support systems (e.g., vocational counseling, special education programs, family and friends, disability-related income programs, attendant care) throughout their lives, and that access to these resources (e.g., perceived need) varies by age and sex. This research will provide insights into which people have the least or most resources and support systems available to them, and why.

1.1 Research Questions

1. The research asks the question: how do age of disability onset and gender affect the life course experiences of women and men with physical disabilities in regard to education, work and family formation?
    a. Are there variations in the life course trajectories, transitions and outcomes regarding education, work, marriage and childbirth in terms of gender and age of disability onset?
    b. How do formal and informal supports and policy provisions affect participant life course trajectories and transitions?

1.2 Definition of Terms

PHYSICAL DISABILITY : refers to persons with physical impairments and chronic illnesses which affect stamina and strength. It refers to people who have reduced motor skills and mobility functions such as difficulty with standing, walking, sitting, reaching, holding, bending, kneeling, stair climbing and other activities associated with daily living.

DISABILITY : a physical impairment or health problem expected to last 6 months or longer which limits a person in the kind or amount of activity they can do at home, at school, at work, or in other activities such as sports or leisure. In this research, *disability* refers to physical impairments, and *disability* may also be the result of disabling structural, social and cultural environment in which a person conducts her/his day-to-day living.

AGE OF DISABILITY ONSET when a disability first begins to affect a person's ability to perform day-to-day activities at home, at work, at school or in travel, leisure or sports. In cases where the onset of the disability is gradual, the onset is when a person first perceives some limitation in her/his day-to-day activities. The onset of a disability may also coincide with the naming or awareness of the condition – such as a medical diagnosis.

The organization of this study is as follows: chapter 2 provides the theoretical orientations used in this study. Chapter 3 provides a review of the related literature addressing disability and the life course, education, employment, marriage and parenting and a discussion regarding severity of disability. Chapter 4 discusses the research design and methodology of the study. Chapter 5 presents an analysis and discussion of the interview data and findings. Chapter 6 contains the study's conclusion and implications for future research. The study concludes with appendices and references.

CHAPTER 2 — THEORETICAL FRAMEWORKS: CONCEPTUALIZING DISABILITY OVER THE LIFE COURSE

2.1 Social Model of Disability

Within the scope of this thesis I draw from the social model of disability as a theoretical starting point. The social model of disability defines disability as socially imposed and constructed by non-disabled society (Finkelstein, 1993; Oliver, 1990). Disability is not interpreted as simply an individual, biomedical condition but as a set of socially created experiences of social restrictions (Leicester and Lovell, 1997), and exists as a form of social exclusion from mainstream life and therefore as systemic oppression (Finkelstein, 1993; Oliver, 1990). Central to the social model of disability is the assertion that social and cultural processes greatly influence the lives and opportunities of people with disabilities (Traustadottir & Kristiansen, 2004) and any study of persons with disabilities needs to analyze the social, economic and political contexts in which they conduct their lives (Corker, 2001; Drake, 1996; Oliver, 1990; Shakespeare, Gillespie-Sells & Davies, 1996).

The conceptual distinction between *impairment* and *disability* is central to the social model of disability and articulates the difference between the individual experience of having an impairment and the social restrictions imposed by a culturally dominant, non-disabled society. Conceptualized within a social model of disability, *impairment* is defined as the lack of part or all of a limb, or having a defective limb, organ or mechanism of the body. In contrast, *disability* is the loss or limitation of opportunities that prevents people who have impairments from taking part in the normal life of the community on an equal level with others due to physical and social barriers (Finkelstein & French, 1993). Within this framework diseases and impairments are organically based. In contrast, disability is the consequence of social factors which create barriers, perpetuate segregation and deny opportunities. These factors include prejudicial attitudes, institutional discrimination, (Morris, 1996), stereotypes, lack of access to rehabilitation, housing, schooling, as well as occupational barriers and meagre financial resources. In this context, *disability* is more limiting than the physical *impairment* itself. This concept places the focus of analysis on the social, economic and political environment and away from the individuals who have impairments (Albrecht, 1992). By conceptualizing disability as the consequence of an *ableist* society and environment, the social model of disability suggests that rearranging the social and physical environments, and accounting for disabled people's needs would eliminate or minimize their disability (Finkelstein 1993; Oliver, 1990).

2.2 Feminist Takes on Disability

While the social model of disability is immensely useful to conceptualize and define ways of thinking about disability as socially constructed, several disabled feminist scholars (French, 1993; Morris, 1991, 1993a, 1993b; Thomas, 2004; Wendell, 1996) raise concerns regarding a theoretical and methodological approach that emphasizes that many physical impairments can be solved through social manipulation (French, 1993) or by changing the environment, at the risk of ignoring many types of disabilities which result in real physical limitations. As noted by Wendell (1996):

> I believe that in thinking about the social construction of disability we need to strike a balance between, on the one hand, thinking of a body's abilities and limitations as given by nature and/or accident, as immutable and uncontrollable, and, on the other hand, thinking of them as so constructed by society and culture as to be controllable by human thought, will, and action. We need to acknowledge that social justice and cultural change can eliminate a great deal of disability while recognizing there may be much suffering and limitation that they cannot fix. (p. 45)

Disabilities which result in physical pain, fatigue or nausea, cannot be mitigated by the social environment, and these experiences must also be acknowledged and recognized as valid parts of having a disability (Morris, 1992, 1993a, 1993b; Thomas, 2004). Denying the physical and sensory experiences in people's bodies only serves to further isolate and marginalize them, and impoverishes all people's understanding of the physiological limitations they deal with each day. From a feminist perspective, it is important to recognize that the experience of living with a disability (i.e. impairment) is affected by material resources, social policies, institutional discrimination and prejudicial attitudes, *and* to recognize the personal, day-to-day experiences of living with a disability and the physiological limitations associated with a disability.

As a method of theory building and enquiry, feminists (French and Corker, 1993; Monks, 1995; Morris, 1991; Thomas 2004; Traustadottir & Kristiansen, 2004) argue that experiential accounts of living with a disability break down the public/political and personal/private dichotomy inherent in the social model of disability. The division between *impairment* as personal, private and individual experiences and *disability* as social, political and systemic, obscures power relations and make invisible the experiences of the private and personal (Begum, 1992; Morris, 1993a, 1993b; Thomas, 2001; Traustadottir & Kristiansen, 2004). In feminism, the personal is political. Thomas (2001) argues that as a result of the separation of the private and public "whole areas of disability experience, and thus disablism, are eclipsed because they are located in the so-called private domain of life" (p.55). Within a feminist framework, the concepts of *disability* and *impairment* are intertwined (Morris, 1991, 1992, 1993a, 1993b; Thomas, 2001).

The social model of disability also fails to acknowledge variations of experience among women and men with disabilities, or to explore the *gendered* experience of disability (French and Corker, 1993; Monks, 1995; Morris, 1991; Thomas 2004; Traustadottir &

Kristiansen, 2004). Using a *gender approach* in disability research means focusing on the social construction of difference between men and women with disabilities and analyzing what these differences mean with regard to power, influence, social status and access to economic resources (Shakespeare, 1996; Traustadottir & Kristiansen, 2004). Morris (1991) argues that because the cultural ideals of female beauty, nurturing and care giving, are so tied up with women's roles and identities as wives, mothers, care takers and lovers, women's experience of disability will be very different from men's Even Shakespeare (1996), a disabled male scholar, notes that very few experiential accounts of men with disabilities exist to offer any comparison. Women and men occupy different economic and social positions in society, and this has a direct influence on how they are conceptualized and treated (Fine & Asch, 1988), regardless of the presence of a physical disability.

2.3 Life Course Perspective

The sociology of the life course is the study of progression through a series of socially defined, age-related social roles, transitions, events and stages resulting in unfolding trajectories and social careers from cradle to grave (Carr, Ryff, Singer & Magee, 1996). Elder (1991) defines the life course as "pathways through the age differentiated life span to social patterns in the timing duration, spacing and order of events" (p.63). Life course research is the study of individual lives and social processes extending over the individual life span, with a traditional focus on the family life course (marriage, child rearing, divorce), education histories, and employment and occupational careers (Mayer & Tuma, 1990).

The life course perspective operates at the intersection of biographical, social and historical time, and conceptualizes individual (biographical) time as a socially created pathway, with socially marked and personally significant guideposts (Hagestad, 1991). For example, when (and of course why or why not) we marry, divorce, begin and complete school, enter or exit the labour market, or form families and care for them, are transitional events that occur within specific ideological, social, economic and historical settings. Thus, the meaning, occurrence and timing of transitions are socially constructed, and will vary over time by generation.

The metaphor of a pathway constructed of socially and culturally significant turning points and life events is based on two core concepts in life course research – trajectories and transitions (Elder, 1985). The concept of a trajectory refers to a pathway over the life span which can be charted by linking social roles across successive years (Elder, 1985) and documenting influential events (Elder, 1991). Each trajectory is marked by a sequence of transitions which mark changes in social roles that are anticipated or unexpected, gradual or abrupt (Elder, 1985). Transitions are rites of passage, turning points and life events that entail a change in roles which are socially marked, created and shared (Hagestad, 1991) or personally significant.

Trajectories and transitions structure the life course through the timing, occurrence and arrangement of events, and the management of resources, goals and demands in the individual's life (Elder, 1985). The study of trajectories and transitions is premised on the idea that individuals do not progress through a series of fixed or predetermined stages as they age, but engage in a process of choice, negotiation and struggle as they move across the life course, relinquishing and entering roles (Albrecht & Levy, 1991; Fincher, 1993; Murphy, 1987; Priestley, 2003). Typically, individuals re-evaluate their lives and expectations over time, pursue their life goals, and attempt to come to terms with the circumstances and events they experience within greater social and structural constraints and cultural dictates of the society in which they live (Hareven, 1982).

In this way, the life course perspective examines the relationship between the social (macro) and the subjective (micro) construction of the life course (Heinz, 1991). It emphasizes that micro-level phenomena should be interpreted in terms of macro-level contextual features and that conversely, macro-level phenomena should be viewed in light of their significance for and impact on micro-level phenomena (Marshall, 1987). In other words, social forces not only "trickle down" to individual lives but also "percolate up" from individual action and thereby modify existing social processes and institutions (Mayer & Tuma, 1990).

The idea that individual lives and experiences are embedded in and play out temporally within changing social, economic, political and historical contexts (Priestley, 2003) implies that people of the different ages and generations will have varying life course experiences. Thus the study individual time, generational time and historical time are central to the life course perspective (Mitchell, 2006). Individual time refers to chronological age (Mitchell, 2006) and associated roles and statuses as people age (Priestley, 2003). Generational time refers to age groups or cohorts in which people are groups based on their age, while historical time refers to societal or macro-level changes and events and how these affect individual lives (Mitchell, 2006). When individuals are born at the same time with distinct years of birth that have a shared historical experience, they are referred to as a cohort (Mitchell, 2006). A generation can consist of several cohorts, who have encountered different historical periods (Mitchell, 2006). When a historical event differentially affects people of different cohorts this is a cohort effect. In the alternative, when the event has the same affect on different cohorts, then it is a period effect. Thus, an understanding of the location of people's lives in their respective historical contexts may identify or explain circumstances that have differentially or similarly affected people's lives (Mitchell, 2006).

According to Elder (1991), the challenge for any life course study is to keep both individual and environmental variations in the picture, and to investigate the process by which the two are linked. Environmental variations refer to institutional processes or history. One conceptual mechanism linking interaction between changing lives and institutional processes is the life stage principle. The life stage principle posits that the influence of a transition on the life course depends on the stage at which individuals experience the event. When a person becomes disabled is indicative of the roles, relationships, support and resources they have at that point in the life course, and how society will treat them (Albrecht & Levy, 1991; Priestley, 2003). Many transitions are anticipated through social institutions, laws or policies, or cultural expectations (e.g., going to school, entering the labour force, becoming a legal adult), and opportunities exist for anticipation and preparation for entry into and exit from social roles. Yet, when a transition is unexpected or unanticipated, existing social institutions and processes are absent to provide the support for negotiating the new role. Similarly, institutional processes or arrangements may stratify (privilege or disadvantage) generations of people by allocating differential opportunities and resources (O'Rand, 1996) influencing subsequent life course trajectories, transitions and outcomes. Research has shown that children with disabilities are exhibiting higher rates of secondary school completion and improved academic performance as a result of increased education initiatives in the U.S. in the 1990's (Wagner, Newman, Cameto & Levine, 2005b). However, less is known about the long-term life course trajectories of people with disabilities, or how the experience of living with a physical disability (at varying ages) affects movement through, or sequencing of, subsequent life course roles and transitions (Zarb, 1993).

This thesis builds upon the idea that disabled people's lives are influenced by social structures, institutional processes, and historical circumstances, which determine and regulate their access to the education system, the labour market, sources of income, job opportunities, marriage and child birth. Using the concepts of transitions and trajectories, this research examines how age of disability onset may alter the occurrence or timing of subsequent transitions, and alter or redirect life course trajectories of women and men with physical disabilities. It also builds on the idea that people with disabilities have agency; that they can defy, work around, influence and change the existing social structures and institutional processes. The study of the everyday lives of women and men with disabilities reflects greater social systems at work (Abu-Lughod, 1993). Disability is a social and personal process, and the experience and consequences of living with a physical disability will vary by gender and age of disability onset. *When* women and men become disabled influences the outcome of their lives because formal and informal support is allocated on the basis of gender and is variable over the life course.

CHAPTER 3 — LITERATURE REVIEW

3.0 Introduction

This research explores how age of disability onset and gender impact the life course of women and men with physical disabilities. This chapter provides a review of the research literature concerning disability and/or gender and life course research (section 3.1); severity of disability (section 3.2); disability and education (section 3.3); disability and work (section 3.4); disability research on marriage and family formation (sections 3.5 and 3.6), and a summary of the research literature (section 3.7).

3.1 Disability and the Life Course Perspective

The literature linking the life course perspective to the experiences of living with a disability is diverse methodologically and theoretically. Early research (Albrecht & Levy, 1991) first theorized how disability at one stage in the life course could affect subsequent life transitions and trajectories. Building on the idea of role sequencing (the relative positioning of a life event or transition relative to the normative ordering of other life course events and transitions), the earlier the age of onset, the more potential the presence of a disability has to "redefine social roles, processes and relationships, and alter and redirect people'ss lives" (Albrecht & Levy, 1991, p. 6). Likewise, the onset of a disability may prevent the transition to subsequent roles, such as worker or parent, and thereby compromise individuals' trajectories and expectations. The drawback of this early work, however, is the absence of experiential accounts to test and support these concepts.

Despite the potential for a disability to affect and alter the life course, little literature has explored this relationship. Some literature has used the life course perspective to document life histories through the use of personal narratives (Frank, 1990; Monks, 1995).

For example, the life course of a woman, born without limbs, reports that major life course transitions were dating, moving out on her own, marriage, divorce and re-marriage (Frank, 1990). The use of narrative analysis underscores the importance of how the woman who is the subject of the study views her own life.

More recently, however, research on disability and the life course points to the instrumental influence of social institutions and policies to regulate transitions and roles (Priestley, 2003; Stone, 1991). Priestley (2003) argues that *special* education fails to invest in the human capital of children with disabilities, and is geared toward normalizing children and maintaining continued dependency into adulthood (Priestley, 2003). Thus people with early onset disabilities are less likely to establish work careers and more likely to experience long-term systemic dependency. Paid employment, living independently or parenting are transitions signifying adulthood (Priestley, 2003), yet people with disabilities are systemically denied access to those roles, or scrutinized when they choose them.

The impact of generation on the life course of people with disabilities is also underexplored, yet has important implications for understanding normative shifts over time and the social roles open to men and women. Helmius' (2004) research on the sexual experiences of three generations of women with early onset disabilities, shows that women born after 1960 are more sexually active and more likely to assume traditional female roles (wife and mother) compared to women born prior to 1960. Comparatively, older women, born from 1923 to 1959, were often exempt from traditional female roles (wife) and resulted in women pursuing non-traditional female roles (i.e., pursuing higher levels of education and entering the paid labor force).

There is literature to suggest that concepts of adjustment, happiness and satisfaction are related to age of disability onset. The value of this literature directs attention to an important starting point: how living with (adjusting to) a disability may vary by age of onset. A common theme is that people who acquire a disability, especially young adults, are less likely to adjust to the disability compared to those with a congenital disability (Fine & Asch, 1990) and people with congenital disabilities are more well-adjusted and accept their disability as "normal" for them. Shakespeare et al (1996) report that those with acquired disabilities can be so devastated that, in some cases, they are unable to resume or reconstruct their lives, despite having the so-called advantages of mainstream socialization, education and work histories. While those with congenital disabilities may be more well-adjusted, they are also perceived to be disadvantaged because they do not have the "mainstream" experiences previously enjoyed by some of those with an acquired disability, or the opportunity to socialize and develop skills associated with being non-disabled (Shakespeare et al, 1996). Studies measuring the happiness (Uppal, 2006) and satisfaction (Zarb, 1993) of people with a range of disabilities over the life course also find that happiness, or satisfaction, is more likely in people with congenital disabilities, and less likely to be observed in people whose onset occurred within the last five years. Happiness is not constant, however, and decreases for those with a congenital disability by young adulthood, and increases again later in the life course (Uppal, 2006; Zarb,1993). Among those with acquired disabilities, quality of life, satisfaction and happiness are greater ten to fifteen years after the onset (Creek, Moore, Oliver, Salisbury, Silver & Zarb, 1987; Uppal, 2006; Zarb, 1993), suggesting a period of adjustment and acceptance.

Morris (1991, 1992), Oliver (1990), and Finkelstein and French (1993) argue that a crucial factor affecting well being and quality of life for people with disabilities is the availability of financial resources, access to paid employment, social inclusion, access to education and health care, and familial, community and formal support. This is supported by Uppal'ss (2006) findings, which indicate that those who are employed are more happy. Creek et al (1987) also report that perceptions of quality of life are positively correlated with the presence of material resources and support, such as adequate income, employment, adequate attendant and health care, accessible housing and environments, and social interaction in the community. Thus, resources and support may help to mitigate the effects of the devastation of adult onset disability.

However, access to formal and informal support may not be available to all people who have a disability and is contingent upon a medical diagnosis (Blaxter, 1980). Stone (1991) documents the role of *gatekeepers*, especially doctors and rehabilitation specialists, who influence the lives of persons with disabilities. Those deemed *legitimate* in terms of being disabled have measurable, observable symptoms, receive medical care, disability-related services, income benefits, home care, rehabilitation, or accommodations at school or work (Brown, 1987; Stone, 1991). Similarly, informal support, provided by family or friends, may also be contingent on obtaining a medical diagnosis (Wendell, 1996). While the onset of a disability is a major personal transition (Morris, 1991; Oliver, Zarb, Silvert, Moore & Salisbury, 1988; Wendell, 1996; Zarb, 1993), the diagnosis marks a social transition that legitimates the new status. If formal support is specifically directed towards certain disabilities, or contingent upon a diagnosis, then the life course of those who fail to meet the criteria of *disabled* will be substantially disadvantaged.

Some literature indicates that informal support will vary over the life course of a person with a disability, and that there are gender differences in the provision of these supports. McGarth and Garnat (1993) show that the age of a disabled person is significant in determining the availability of support networks. For example, young people with disabilities have larger familial support networks (e.g., parent(s), grandparents, aunts, uncles, close family friends), while persons who are older rely on smaller family networks (sisters, surviving parent(s) or relatives) which are often augmented by professional care givers. For those who are married at the time of onset, spouses may commonly take on the role of care giving, however, it is more common for men to anticipate this than women (Fine & Asch, 1988; Thompson, 1981; Zarb, 1993), and more likely for wives to provide personal care to husbands (Morris, 1991; Parker, 1993). Among older couples, spousal care is more likely regardless of the gender of the care giver (Blaxter, 1980; Parker, 1993). While literature exists to support the prevalence of spousal care, especially for men, Morgan, Patrick and Charlton (1984) indicate that many married people lack support from their spouses and caution against assuming that spousal support during and after the onset is a given component of marriage.

The idea that formal support is differentially allocated over the life course is the focus of a study by Burkhauser and Duncan (1989). They conclude that the U.S. Social Security programs are unable to mitigate the effects of income loss associated with the presence of a disability among younger women and men. This income loss is especially acute for those in the career building years, aged 20 to 34. While the study does not explicitly focus on economic losses resulting from disability, it does highlight the lack of institutional resources and consequent economic vulnerability of young adults who become disabled and leave the paid labour force. Other research (Blaxter, 1980; Russo & Jansen, 1988) links the receipt of disability-related income programs directly to women and men's labour force status at the time on the onset, and concludes that men fare better than women in the long term as a result of men's attachment to the workforce.

Some literature remarks on the paucity of research exploring life experience as it relates to physical disability and the need to research individual lives within a larger social and economic framework (Strauss, 1987; Turner-Henson & Holaday, 1995) and on the basis of gender and race (Kronenfeld, 2006). Other literature addresses the need for people with disabilities, and their families, to secure formal support (Corbin, 1991; Fagerhaugh, Suczek & Wiener, 1991; Rolland, 1987). This research, however, fails to address how formal support (financial resources, counseling, respite or attendant care) affects the ability of individuals and families to cope with a disability, or to articulate that resources are often differentially accessed and allocated on the basis of gender, age, work status or socioeconomic background.

While most life course literature does not directly incorporate disability into its research, there are some general themes which complement this research. One area of inquiry focuses on how people cope with discontinuities in the life course and with "frictions between institutionalized patterns and their biographical project," and deal with restrictions in choice or agency (Heinz, 1991c, 1991d). Instutionalized patterns are entries and exits from social roles or states (student, worker, parent, spouse, grandparent) which are common to persons of the same age or generation, and are regulated through age requirements, social institutions (schools), policies and law, or social ideas about appropriate timing or behaviour. While none of the contributors in Heinz's collection (1991a, 1991b) addresses disability as a discontinuity in the life course, there is literature to support the idea that the onset of disability creates some tension between the life and goals as previously envisioned and the renegotiation of different ones. Most people engage in the process of reflexively assessing, negotiating and constructing their lives within larger social, economic and political systems, yet little research is available to suggest how people with disabilities negotiate and construct their lives.

Works by Gee and Kimball (1987), Rossi (1980, 1985), Cohen (1987), Allatt, Keil, Bryman, and Bytheway (1987), and Katz and Monk (1993) focus on gender and life course. In particular, these authors underscore how women's links to the familial life course dominate life course research and suggest that this research bias stems from sex-role stereotypes regarding the primacy of women's relation to the family, and the institutions and policies which assume women are mothers, wives or homemakers. While life course literature and research has focused on men's work lives and women's domestic lives (Heinz, 1991c, 1991d), the lives of those with a disability are still peripheral. If life course research focuses on women's domestic roles, then women with disabilities are excluded by default if they are perceived as unable to occupy the roles of mother, wife, lover and mate. Similarly, the work lives of persons with disabilities are largely undocumented: by definition, a person cannot be disabled and engaged in paid employment, or, in the alternative, they are "rehabilitated" or "recover" and are no longer "disabled" if they return to paid employment. *Working with a disability* confounds non-disabled conceptions and stereotypes of disability, and work disincentives associated with the receipt of disability income benefits relegates those who can work to the ranks of the underemployed. As a result much life course research ignores the diversity of disabled women and men's unique roles and experiences over the life course and fails to conceptualize differences by age of onset (Priestley, 2003) and over time.

3.2 Severity of Disability

Overall, discussion of the severity of a disability as a factor affecting daily life and life outcomes is not a common feature in the literature as the focus is not on people's disabilities *per se* but on the limitations imposed on them as a result of social, political and economic exclusion, inaccessible environments, lack of material resources, prejudicial attitudes and work disincentives. Severity of disability is defined as the *level* of functioning and ability (or inability) to perform day-to-day activities of living. A mild disability implies fewer limitations in performing daily tasks, and a severe disability implies marked limitations. More and more, however, the literature recognizes that many disabilities can be mitigated through the use of technical aids (such as voice activated software and computers), accessible environments, attendant support in the home, work place and school, and general ideological and social acceptance of disability as another physical characteristic. In several studies, the severity of a disability is found not to be a factor affecting quality of life, a return to work, educational attainment or other daily activities (Blaxter, 1980; Canadian Abilities Foundation, 2004; Creek et al, 1987; Morris, 1991; Zarb, 1993). This is not to suggest that technical aids and environmental adaptations and accommodations can remedy all experiences associated with a disability, but to recognize that the experience of living with a disability is heterogeneously influenced by personal, social, economic and historical circumstances. Another problem with the concept of severity is that it is defined or measured quite differently by type of disability, and from study to study.

The tension between conceptualizing disability as an impairment, which implies a concept of severity (ranging from mild to severe), and disability as a consequence of structural and systemic inequalities and barriers, continues to be a fundamental area of debate in disability studies (Thomas, 2004). This thesis does not offer the answer to this. However, I believe that severity of disability can be understood as ongoing or temporary limitations imposed by the environment and by personal experiences of disability, such as pain or fatigue. I would suggest that the requirement for increasing levels of assistance, accommodation and environmental adaptation may be correlated with increasing levels of severity. While there is some literature which indicates that requiring a wheelchair, relying on machines to perform activities (respirators, communication devices) or assistance with everyday activities (attendant care) are indicative of severe disabilities (Blaxter, 1980) and increased deviation from so-called normal function (Chappel, 1991; Finkelstein & French, 1993), my review of the literature would suggest there is limited consensus about how to define *severity* (Morris, 1996). However, whatever the historical, social, material or biological base, disability, and gender, must be understood as socially constructed, mediated categories of experience (Harris & Wideman, 1988; Stanley & Wise, 1993).

3.3 Disability and Education

There appears to be very little research literature which compares variations in educational attainment or outcomes by age of disability onset and gender. The most recent Canadian studies, based on surveys conducted by Statistics Canada, examine the literacy gap and use of special education programs among children with disabilities (Uppal et al, 2007), and the number who attend special education classes and require assistance (Kohen, 2006). However, there is no information regarding long term educational outcomes among children with physical disabilities. Recent American studies, based on the National Longitundinal Transition Study, Waves 1 and 2, indicate that youth with disabilities are half as likely to attend college, 25 percent as likely to attend university, and generally obtain lower standard scores in school compared to the general population (Wagner et al, 2005a, 2005b, 2006). A major drawback to these findings, however, is that they are based on youth with a broad range of disabilities (i.e., learning and emotional disabilities, brain injury, autism, intellectual disabilities, orthopedic disabilities, or speech, hearing or visual impairments).

In addition to the kind of disability, age of onset and gender are critical to understanding educational experiences and outcomes since public education systems (elementary and secondary) may be inaccessible, lack sufficient levels of staffing or services (Kohen, 2006), and lack the availability of special education programs (Uppal et al, 2007) to effectively teach or include students with disabilities. Similarly, vocational rehabilitation for adults may be influenced by poor vocational counseling, inadequate financing and poor understandings of employer expectations. The literature, however, on the presence of a physical disability and educational outcomes and needs, is not unanimous. Some studies are dated, or, in the alternative, do not address differences on the basis of gender, or age of onset. There is consensus, however, that informal and formal support and financial resources contribute to the success of educational outcomes and experiences of those with early or adult onset disabilities.

There is some evidence to show that women with congenital disabilities have lower levels of educational attainment compared to those who acquire a disability later in life. A study conducted by the DisAbled Women's Network (DAWN) (Ridington, 1989) presents findings from a nation-wide survey of 248 Canadian women with disabilities. The findings most relevant to this research are educational differences between women whose disability was present at birth or in early childhood, and those whose disability was acquired. Over one third (35 percent) of the women with a disability present at birth or in early childhood had educational attainments of grade eleven or less, in comparison to only 9 percent whose onset was within the last 10 years or more. However, about 25 percent of the women had either undergraduate or graduate degrees regardless of age of onset. According to the study, women with disabilities from birth or early childhood report that they are provided with therapy instead of an academic education, and were often expected to rely on social assistance as opposed to working. Matthews' (1993) qualitative study of 45 women (from the Maritime Provinces), indicates that those who were hospitalized as children were not provided with tutoring or schooling, and this ultimately precluded them from returning to school and completing their education. Others could not attend school as a result of inaccessible schools and/or inadequate school transportation, consequently many women dropped out of school, completing secondary school equivalency programs or similar university prerequisites, and then entering college or university.

Numerous experiential accounts also indicate that periods of hospitalization (Saxton, 1987a), recovery from surgery (Cepko, 1987; Saxton, 1987a; Walker, 1987), ongoing medical appointments and therapy (Mason, 1987), and daily rehabilitation result in exclusion from school and the important socialization processes which occur at school (Turner-Hensen & Holaday, 1995). A Canadian study (Barrera, Shaw, Speechley, Maunsel & Pogany, 2005) of 800 childhood cancer survivors and a control group (non-disabled children) reports similar outcomes. Compared to the control group, the children who had cancer were two to three times more likely to fail a grade, attend learning disabled or special education programs, twice as likely to report academic or other school problems, and two to three times more likely to report lower grades in English, math, social studies and science. However, gender is not related to the children's educational difficulties. The study notes that repeated absences from school, as a result of treatment, contribute to poor social integration and the children report having less friends than the control group. The competing needs of schooling, recovery and health care regimes, appear to affect school attendance, academic success and completion (Matthews, 1983) among those with a disability onset prior to the completion of secondary school.

Fine and Asch (1988) report that many children with a disability still spend far more time in special classes than they do alongside non-disabled students, yet little is known about how gender influences the education of children or youth with disabilities. Segregation as a result of special schools or institutionalization is a common experience for children with a disability (French, 1996; Morris, 1997; Saxton, 1987b). Growing up in an institution may result in estrangement from family members (Morris, 1997; Saxton, 1987b), limited formal education (French, 1996), or social unfamiliarity with non-disabled children (Leicester & Lovell, 1997; Raymond & Davis, 1987). Morris (1997) reports that many people raised in institutions are provided with no options for independent living once they reach adulthood other than moving into adult institutions. Other literature suggests that children with disabilities are not taught the same life skills as non-disabled children (French, 1993; Saxton & Howe, 1987).

Despite these findings, other literature indicates that women with a congenital or childhood-onset disability have higher educational attainments in comparison to women who acquired a disability after adolescence (Rousso, 1988). It is suggested that parents put the strategies and resources in place early on once they know about the disability and its effects are anticipated. Parental support, advocacy and socioeconomic status are reported to be the most important factors affecting the educational outcomes, self-esteem and "social success" of people with congenital or childhood-onset disabilities (Barrera et al, 2005; Browne et al, 1985; Rousso, 1998; Saxton and Howe, 1987). Fine and Asch (1988) document the lives of two women with cerebral palsy. One woman attended university and became an economist. Her middle-class parents insisted on a mainstream education and could afford modifications to their home and the necessary equipment to provide for her day-to-day care. The other woman was institutionalized from infancy, has never worked and only completed elementary school. Her mother, a single parent receiving Social Security, was encouraged to institutionalize her daughter and did not have the personal or economic resources to advocate for her.

Rousso's (1988) study indicates that parental advocacy has a positive influence on scholastic achievement and integration into paid employment. Other experiential accounts indicate that parents have the same, or higher, expectations of their disabled and non-disabled children (Saxton & Howe, 1987). Some women, who were integrated into mainstream schools, were expected to attend college and university, to marry, to have children and to lead full, personally meaningful lives (Browne et al, 1985; Saxton & Howe, 1987). As Brown (1987) writes:

> It has not been easy for me to find my place in society... It took hard work, self-discipline and positive thinking. I had to demand the training that was needed in each situation. On the other hand, I was born with many advantages. My family was warm and supportive. They paid for my college education. It was always clear to me that blue-collar work was temporary. (p. 40)

Other studies indicate the educational needs of people with early onset disabilities are met inconsistently. A research report prepared by the Canadian Abilities Foundation (2004) presents findings on the employment experiences of over 1,200 Canadians aged 15 to 64 with physical disabilities. The study indicates that of those whose disability occurred when they were students[2], almost half reported that they required more formal education to improve their qualifications and job prospects, but for those whose disability was present from birth or infancy or alternately acquired as adults, a lower proportion (37 and 39 percent respectively) indicated they required more education. The question then becomes, why does such a large minority (37 percent) of people with early onset disabilities feel they need more formal education, despite the fact that they have had more time to adapt to having a disability and the potential to prepare in advance?

Although the literature is far from integrated and few studies exist, people with congenital or childhood-onset disabilities are likely to have their educations restricted, disrupted or delayed. Absences from school, resulting from hospitalization or health care treatment, may also result in social isolation and poorer grades if children are not provided with tutoring during those absences or an education system that can address those needs. Studies from the U.K. suggest that educational segregation may also result in poorer educational outcomes (French, 1993; Leicester & Lovell, 1997; Morris, 1996), affecting employment status and earnings in adulthood. The exception appears to be those who have extensive familial support (parental advocacy, financial resources, insistence on mainstream education).

Those with an onset in adulthood may retrain or return to school, but the literature suggests that working age men are more likely to receive retraining and more likely to be trained in higher paying occupations in comparison to women (Albrecht, 1992; Canadian Abilities Foundation, 2004; Vash, 1982). Albrecht (1992) documents how the type of rehabilitation a person receives varies by age of onset. His research indicates that income

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[2] The study does not define the term student, or provide any information indicative of age of disability onset.

benefits and rehabilitation are given initially to those deemed capable of returning to work (usually male and between the ages of 20 to 45) followed by those "deserving of support" but unable to return to the labour force (1992). Typically, working-age males are the primary recipients of vocational rehabilitation. Among older people, the emphasis is on rehabilitation that returns a person to normal functioning and independent living (Albrecht, 1992). When women receive vocational counseling, they are channeled into clerical type, lower paying occupations, while men are directed towards skilled-technical, higher paying occupations (Vash, 1982). The allocation of rehabilitation resources to select groups of people is often a reflection of gender stereotyping and the personal biases of rehabilitation specialists and those in similar positions of power (Albrecht, 1992; Morris, 1991; Vash, 1992). After the onset of a disability among working adults, men may have the opportunity to retrain in well-paying occupations, and women may be encouraged to seek clerical work, or, in the alternative, focus on rehabilitation which is directed towards maintaining a home (Blaxter, 1980; Vash, 1982).

3.4 Disability and Work

A review of the literature on the work lives and employment outcomes of women and men with disabilities indicates that there are numerous studies addressing variations by gender, but almost none comparing variations by age of disability onset. As a result, we know little about the work experiences and outcomes for people with early onset disabilities largely because they are not differentiated in the research. Typically, the research and qualitative studies examine the outcomes of the work lives of those with adult onset disabilities, that is those who work full-time (most often men), while very little literature documents the employment outcomes of those whose disability may be present from birth or childhood, or those who are not in the labour force at the time of the onset (women who may chose family work over paid work, those attending secondary or postsecondary school). There is research to support the finding that labour force status at the time of the onset has a direct effect on the formal financial support and resources that are available after the onset (Roeher Institute, 2004). Those who are not in the labour force at the time of the onset have comparatively fewer financial options, yet little research addresses this issue in relation to disability and paid work. Employment barriers such as work disincentives, poor accommodations, and discriminatory employer attitudes have a direct influence on work lives of people with disabilities. In the balance of this section of the review, I discuss variations in employment status, outcomes and earnings by gender from several quantitative studies, and then present findings on the variations by age of onset.

There are numerous quantitative Canadian studies and publications based on the 1986 and 1991 Health and Activity Limitation Survey and the 2001 Participation and Activity Limitation Survey which address the differences in labour force status, employment and unemployment rates, and earnings among women and men with disabilities. The studies' findings are consistent in so far as working age[3] men with disabilities earn more, have higher employment rates, and lower unemployment rates in comparison to working age women with disabilities. The same studies also report that, in comparison to non-disabled women and men, women and men with disabilities earn less, are less likely to participate in the paid labour force, have significantly higher unemployment rates and lower educational attainments (Fawcett, 1996, 2000 ; Roeher Institute, 2004). The surveys also show that working age men with a disability are much more likely to participate in the labour force than

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[3] Statistics Canada defines working age as those who are aged 15 to 64.

are disabled women. Disabled men's participation rate is 15.7 percentage points higher than disabled women, with women's participation rates at 48.5 percent and men's at 64.2 percent (Fawcett, 1996). In 1993 and 1994, about 57 percent of disabled women of working age were not in the labour force, in comparison to only about 15 percent of non-disabled women (Fawcett, 2000). Among working age men with a disability about 46 percent were out of the labour force in comparison to only 3.1 percent of non-disabled men (Fawcett, 2000). Findings from a 2003 survey (Canadian Abilities Foundation, 2004) of 1,200 working age Canadians with physical disabilities, who were either in the labour force or who had worked in the last five years, indicate that 56 percent of the participants were employed and 44 percent were unemployed. Of those who were employed about 61 percent were employed full-time, 27 percent were employed part-time and 12 percent were self-employed. Unemployment rates for the non-disabled population range from 7 to 12 percent. The effect of part-time work is reflected in lower average annual earnings for people with disabilities. Among all working age men with a disability, employment earnings in 2000 averaged about $15,800. For working age women with a disability, the comparable value is $10,200. For non-disabled men and women, average annual earnings in 2000 are about $31,400 and $20,200 respectively (PALS, 2001). Thus working age men and women with disabilities on average earn about half as much as non-disabled men and women.

Other statistical evidence shows that the presence of a disability is a strong indicator of unemployment and poverty, regardless of gender. In an Ontario study of persons with disabilities, aged 15 to 64, 36.2 percent of women and 34.1 percent of men live in poverty. This is twice the rate in comparison to non-disabled women and men (Fawcett, 2000). For those who were not employed, the poverty rates for women and men with disabilities increase to 45.4 and 47 percent respectively (Fawcett, 2000). One reason may be that women and men with disabilities are more likely to live alone. About 30 percent of women and 29 percent of men with disabilities are sole income providers. This is almost double the rate for non-disabled women (at 17.3 percent) and men (17.8 percent) (Fawcett, 2000). It is clear that the presence of a disability negatively affects employment, participation in the labour force, and earnings, and that women with disabilities often fare far worse than men with disabilities, and in comparison to non-disabled women.

In terms of age of onset, the research tends to address the work experiences of those who are already in the labour force, that is, those with adult onset disabilities, and the consequences of the disability on their work lives (Roeher Institute, 2004). Several studies indicate that the onset of a disability among working age adults is a factor which necessitates a temporary, or permanent, departure from the paid labour force (Blaxter, 1980, Riley et al, 1994; Smith, 1985), or a period of physical rehabilitation and/or schooling, with the goal to re-enter the paid labour force or to return to pre-disability levels of functioning (Albrecht, 1992). A Canadian study (Canadian Abilities Foundation, 2004) indicates that 69 percent of the respondents who became disabled as adults made career changes following the onset of the disability; men (75 percent) are more likely than women (62 percent) to make a career change, and those with pre-existing work experience are more likely to return to work and receive employer accommodations. Some research suggests that pre-existing work experience and the relationship built up over time with employers may foster a return to work because employees may directly negotiate a return to work with their former employers (Albrecht, 1992; Blaxter,1980). That is, pre-existing work experience, job knowledge and transferable skills are valued by employers. Other research indicates that higher levels of educational attainment are associated with the incidence of returning to paid work (Canadian Abilities Foundation, 2004; Fawcett, 1996, 2000). However, higher educational attainment is often associated with sedentary work (less physically demanding) and may be an indicator of work more suitable for a person with a physical disability.

Some qualitative studies on the work lives of persons with physical disabilities indicate that gender influences the expectation of returning to paid work and the likelihood of returning to work. Blaxter`s (1980) study indicates that medical, vocational and government agencies are instrumental in this process, and encourage men to return to work while the legitimated role for women may be to stay at home. Thus men are more likely to return to work. Some research indicates that those who are young adults (under the age of 25 at the time of onset), male, married (an indicator of informal support) and/or working in the paid labour market are more likely to return to work, less likely to be unemployed , and more likely to resume postsecondary schooling (Albrecht, 1992; Creek et al, 1987). As Albrecht (1992) argues, most vocational retraining for adults is geared toward working age males.

While gender may play a role in returning to work, there is research to indicate that employer accommodations and attitudes, and work disincentives, influence employment outcomes among people with disabilities, regardless of age of onset (Canadian Abilities Foundation, 2004; Roeher Institute, 2004). Employer accommodations can range from providing (transfers to) administrative or light duty jobs, graduated work programs, appropriate or ergonomic equipment, accessible work spaces, flexible hours, part-time employment, working at home to job sharing. As Wendell (1996) notes:

> Many more people with disabilities would be able to work, for example, if they could work part-time or flexibly, so that they could manage their work despite having more fatigue, pain and/or interruptions for medical procedures than the average non-disabled worker. People with disabilities are often forced to work less than they

> could, or at less creative and demanding jobs than they are capable of doing, because of inflexible workplaces. (p. 48)

The Canadian Abilities Foundation (2004) study also indicates that 70 percent of its 1,200 respondents require some work place adjustments or accommodations in order to work, and 81 percent report the ability to work full-time with suitable work place accommodations. The same study also reports that employer attitudes towards people with disabilities is a significant barrier to employment. The Roeher Institute (2004) reports similar findings. About 95% of the respondents reported that accommodations are (quite or extremely) important forms of support in the work place.

Another barrier to employment among people with disabilities are work disincentives. As reported in several studies (Canadian Abilities Foundation, 2004; Roeher Institute, 2004; Fawcett, 1996, 2000) the withdrawal or loss of disability-related supports during the transition to employment is a major issue affecting the decision to work. Disability-related supports include medical costs or medications, subsidized housing or transportation, wage indemnity benefits from private insurers, Canada Pension Plan Disability Benefits, Workers' Compensation Benefits ,and government social assistance programs (Roeher Institute, 2004). Fawcett's (2000) findings indicate that women with disabilities often must choose between enforced dependency, or risk losing existing disability-related services and funding if they find paid work but cannot secure employment on a long-term basis. As a result, women with disabilities remain underemployed or out of the labour force.[4] Respective findings from Canadian Abilities Foundation (2004) and the Roeher Institute (2004) indicate that 20 and 21.4 percent of the respondents were

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[4] Fawcett (2000) reports that 77 percent of female lone parents with a disability rely on government transfer payments as the major source of family income.

discouraged or reluctant to work because they could lose their disability benefits and supports. This dependence on disability benefits and support was of significant concern to about 48 percent of those who had not worked at all in the last five years (Canadian Abilities Foundation, 2004).

Income benefits received by women and men are directly affected by their attachment to the labour force and status at the time of onset, which is germane for those with adult onset disabilities. Only those who are strongly attached to the labour force (i.e. work full-time for more than two to six years) have access to income benefits from the Canada Pension Plan, public (superannuation) or private pension plans, Medical Employment Insurance, Workers' Compensation and/or private wage indemnity plans. While these income benefits do not mitigate all financial hardships for those deemed unable to work, men report smaller drops in income (Roeher Institute, 2004). Those who are self-employed, work part-time (typical of women) or unemployed are also more likely to report lower income benefits. For those who are not in the labour force at the time of the disability onset (women choosing unpaid work over paid work, students, those with early onset disabilities) income benefits are limited to government social assistance programs. As a result, access to income supports will vary by labour force attachment and status, and often by gender and age of onset.

Decisions about choosing paid work over unpaid work have faced several generations of non-disabled women with children or who want children, but what are the implications for women with disabilities? For non-disabled men, strong attachment to the paid labour force s associated with traditional and contemporary expectations of male roles as breadwinners and the primary financial support in families (Murphy, 1990; Priestley, 2003). If many men with disabilities are precluded from this traditional role, what are the implications? The literature does not appear to address the unpaid work careers that people with disabilities may have. In 1991, about 20 percent of people with disabilities, who were not in the labour force, were active in volunteer work compared to 25 percent of the Canadian population (Fawcett, 1996). While Fawcett (1996) asserts that volunteer work is an indicator of willingness to work, it may also be an alternative career for people with disabilities.

3.5 Disability and Marriage

A review of the literature on the impact of gender and disability on marriage suggests confounding results and is fragmented. In addition, I have not been able to locate studies examining persons with physical disabilities that address differences by gender and age of onset. Studies often are based on the experiences of disabled men (Creek et al, 1987; Oliver et al, 1988; Parker, 1993; Thompson, 1981) or persons with spinal cord injuries (Brown & Giesty, 1986; Creek et al, 1987; Kreuter, 2000). Another limitation is paucity of literature addressing the marital lives of those with congenital or childhood-onset disabilities, suggesting that they simply do not marry or form families. While some research indicates that the presence of a disability affects marital status or stability regardless of gender, other literature suggests that women with disabilities are more likely to be divorced or single (Fine & Asch, 1988; Morris, 1991), implying different rates of marriage and divorce among women and men with disabilities. As noted by Parker (1993), "despite lots of literature on marriage, there is very little information about disability and marriage and family life more generally" (1993, p.566).

The issue of marital status is important because it influences who women and men will rely on for personal, social and financial support and care in the event of a disability (Olsen & Clarke, 2003). Views on how marriage, or its stability, is affected by disability and gender are linked to women and men's traditional roles as *homemaker* and *breadwinner* respectively. Some literature suggests that when a wife becomes disabled, this is more likely to end the union because of the perception that she cannot be a nurturer, care giver, parent, lover and/or homemaker (Fine & Asch, 1988; Matthews, 1983, Morris, 1991, 1992; Ridington, 1989a,1989b). Other literature suggests that when a husband becomes disabled, it is more likely to adversely affect the marriage and family because of a severe drop in income, the disruption to day-to-day family life if the husband is at home permanently, and/or the wife must return to the paid labour force (Blaxter, 1980; Murphy, 1990; Parker, 1993; Thompson, 1981).

Morris (1991) and Fine and Asch (1988) suggest that women with disabilities are more likely to separate, divorce, or be single because their traditional roles as care givers, nurturer, and attractive (sexual) partners are questioned if they have a physical disability, or, in the alternative, they are exempt from all female roles. Fine and Asch (1988) also note that women with disabilities are less likely than their male counterparts to occupy traditional female roles, especially those associated with marriage and parenting. As a woman with a spinal cord injury, Morris (1989) notes that "[s]ome of us find that a relationship with a man is under added strain following our disability because our roles as women are so bound up with caring for a male partner. Some men find it very difficult to take on the caring role" (p. 85). However, research by Murphy (1990), Parker (1993), Thompson (1981) and Blaxter (1980) suggest that when men are no longer able to maintain the traditional role of primary breadwinner in the family, then the marriage is at greater risk of dissolution. Blaxter's (1980) study also finds that a wife's disability is less likely to radically alter the family's way of life because women manage their households with varying degrees of formal and informal help.

Her findings reinforce the idea that if women and men's traditional roles of housewife and breadwinner remain the same, the marriage will remain stable. A study by Creek et al (1987) indicates that role ambiguities are also experienced by men and the loss over the male role that is tied to earning the family income. Kreuter's (2000) study of 49 spinal cord injured men and women indicates that the dual role of care giver and lover may alter the nature of the marriage and may have a negative impact on the relationship. While it is difficult to generalize about how the traditional roles of women and men with disabilities affect marital stability, there is evidence to show that the presence of a disability can affect the integrity of a marriage.

The literature also indicates that women with disabilities are less likely to marry (Franklin, 1977; Kutner, 1987), more likely to marry later (Franklin, 1977), less likely to be accepted as marital partners (Clarke and Olsen, 2003; Helmius, 2004; Morris, 1991; Nancoo, 1993; Thompson, 1981), more likely to be single parents (Fawcett, 1996; Kutner, 1987), and are more likely to be single, divorced or separated than men (Fine & Asch, 1988; Franklin 1977; Matthews, 1983), with separation occurring most frequently within five years of the disability onset (Peterson, 1979). Brown and Giesty's (1986) study and Kreuter's[5] (2000) review of the quantitative literature indicates that, among women and men with spinal cord injuries, the presence of a disability has a greater negative effect (higher risk of divorce) on the marital status of women than men. Of the forty-five women in Matthews' (1983) study, only five were married and over half reported no intimate relationship since the onset. According to Matthews (1983), 99 percent of married women who become disabled are

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[5] An earlier study (Kreuter et al, 1998) on spinal cord injured women and men indicates no gender differences in divorce rates, however the participants also had brain injuries.

divorced: the analogous figure for men is only 50 percent. Matthews' source, however, is unknown and its validity difficult to assess. Among the young women and men with severe physical disabilities in Blaxter's study (1980), three men became engaged during the survey year and all of the women were single. One of the reasons for the gender differences may be explained by the fact that the men became engaged to their care givers, which suggests that women's traditional roles as care givers may bolster the viability of marriage for men with disabilities. The study by Creek et al (1987) indicates that most men with spinal cord injuries consider themselves to be burdens to their wives (or prospective partners), but there is no evidence that the presence of a disability increases "marital disharmony" or divorce. Blaxter's (1980) study, however, indicates that a higher number of men (eight) compared to women (one) reported that their spouses left as a result on the onset, yet it is unclear why these outcomes occurred.

With regard to age of disability onset and marriage, the literature addresses marriages occurring after the onset (post-disability marriages) and marriages that predate the onset (pre-disability marriages). In cases where the onset predates the marriage, the disability is perceived to have less strain on the marriage because the disability is known to both partners and both people have more realistic views of what to expect (Kreuter, 2000; Thompson, 1981; Vash, 1981). Oliver (1981) reports that non-disabled people contemplating marriage to a person with a disability are counseled to reconsider, and cautioned that care giving demands will strain the marriage. However, it is unclear if this would contribute to increased cohesion in marriages or discourage marriages to persons with a disability. Also, there is nothing to indicate if marriages occur later in life in comparison to marriages among the non-disabled. According to Vash (1981), "marriage after disability is a *fait accompli*, statistics show that the chances for success are greater than for marriages established previously" (p. 84). The rationale behind this perspective implies the marriage will not have to endure the difficulties associated with the acute stage of illness or disability, and both partners make commitments in the face of known disability-related conditions. This view, however, implies that disability itself eclipses all other marital issues, and trivializes the experiences that people with disabilities may face socially and systemically. There is no evidence to indicate that the social, financial or personal issues affecting a non-disabled couple will not have the same weight for a couple where one spouse is disabled. Thompson's (1981) study appears to support the idea that if a disability predates the marriage, it will be less likely to cause marital problems. Three of the (paralyzed) men report that their disability caused a divorce from their first wives, but that no problems existed in their second marriage. Other literature suggests that if a disability is acquired prior to a relationship, then there is a greater chance that the disabled person will be female, since traditional, female roles associated with dependence and passivity are more conducive to marriage (Gibbons, 1986). Similarly, if a woman marries after the onset then she is more likely to have a disabled spouse in comparison to similarly disabled men (Fine & Asch, 1988). However, the study by Kreuter (2000) indicates no difference in marital stability between post-injury and pre-injury marriages of those with spinal cord injuries.

Overall, there is very little literature which discusses the marital lives of people with congenital or childhood-onset disabilities, or those who remarry after the onset, with the exception of several small scale studies. None of the literature discusses the experiences of men disabled since birth or childhood. Rousso's (1988) study of 46 women indicates that of those disabled prior to adolescence, 80 percent are single and in their thirties. Simon's (1988) study of never-married, retired women indicates that four women disabled from birth report that their disability is the reason why they never married. A nation-wide study of 246 Canadian women with a disability by DAWN (Ridington, 1989a) shows that 50 percent of the participants with congenital disabilities were single. While few in number, these studies indicate that women disabled from birth or childhood are less likely to marry in comparison to non-disabled women. Matthews' (1983) study suggests that women disabled after adolescence have an advantage socially and sexually, because they are likely to know how to handle social situations, talk to potential partners, and build relationships.

Some literature indicates that when a marriage predates the onset, it is at greater risk of dissolution since the onset of a spouse's disability may socially, economically and emotionally alter the basis of the relationship to which both people made commitments (Vash, 1981). Although the personal, social and economic roles and well-being of a person can be dramatically altered with the onset of a disability, a careful review of the literature suggests that it is the lack of income, resources, support for care, and prognosis which are largely responsible for the dissolution of a marriage. As noted earlier, several studies find the primacy of the men's ability to earn income, or to have an independent source of income, as central to the stability of the family unit (Blaxter, 1980; Parker, 1983;Thompson, 1981). Studies involving couples (Blaxter, 1980; Parker, 1983) and men (Thompson,1981) indicate the greatest strain on the marriage occurs at the time of the onset, or during extended periods of hospitalization, and conclude that increased financial support and counseling would ameliorate the stresses experiences by couples. Other literature suggest that if a marriage is "under strain" or "unstable" before the onset of a disability, then this is a more likely factor affecting the dissolution of the marriage (Burnstein, 1985; Finkelstein & French, 1993;

Morris, 1989). Other research indicates that the onset of a disability brings a couple closer together and strengthens the marital bond (Blaxter, 1980; Parker, 1993; Peterson, 1979; Thompson, 1981; Vash, 1981).

Among pre-disability marriages, the literature also indicates that there is a greater likelihood of divorce among younger (under 40 years old) compared to older persons with disability (Blaxter, 1980; Peterson, 1979), and the older a person is, the less likely they are to remarry if divorced (Thompson, 1981). Parker (1993) reports that older couples are more accepting of caring for a partner and that the reasons they provide care to their spouse stem from their sense of loyalty, duty and responsibility. Yet, Parker also reports that one third of the disabled spouses with a disability had contemplated ending the marriage about four years after the onset.

While the data is limited, women disabled at birth or from childhood may be less likely to marry than non-disabled women. For men, there is no information about marriage and early onset disability. The literature also suggests that the presence of a disability affects the occurrence of marriage, but not its stability, while women with disabilities, regardless of age of onset, are more likely to be single and more likely to divorce or separate when the disability occurs after marriage in comparison to men. When marriages fail, and intimate relationships end, changes in women and men's traditional roles appear to be a factor, yet this may be mitigated with financial resources, counseling, professional care givers and social support.

3.6 Parenting with a Disability

The literature on parenting with a physical disability[6] is generally qualitative and predominantly focuses on women's parenting experiences. Reviews of the literature in several studies report that research on disabled parents tends to focus more on the parent's ability to parent than parenting itself (Ducharme, 1993; Fine & Asch, 1988; Morris, 1991; Olsen & Clarke, 2003; Thomas, 1997; Vash, 1981). One basic premise underlying this perspective is the belief that a person with a disability cannot assume the role of a care giver (Blackford, 1999; Grue & Laerum, 2002; Morris, 1991; Olsen, 1996), or, in the alternative, that it is inappropriate for a person who has an attendant (and therefore needs help) to have a child (Morris, 1996; Olsen & Clarke, 2003), despite the use of nannies and full-time care givers by non-disabled parents. Women, as the primary care givers in most families, are particularly susceptible to the negative attitudes surrounding parenting with a disability (Fine & Asch, 1988; Morris, 1991; Thomas, 1997). Disabled women report greater levels of scrutiny and surveillance by non-disabled people (Grue & Laerum, 2002; Olsen & Clarke, 2003;Thomas, 1997), or , in the alternative, are told that the desire to become a parent is irresponsible or selfish (Olsen & Clarke, 2003; Thomas 1997) because they are incapable of caring for a child and thereby burdening society (Morris, 1991; Olsen, 1996). *Perceptions* of dependence, neediness, helplessness and incompetence, associated with the presence of a physical disability, continue to influence people's (particularly women's) parenting experiences and decision to have children. Yet non-disabled views of parents with physical disabilities fail to adequately theorize persons with disabilities as responsible, nurturing care

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[6] In this research, I have excluded literature addressing issues concerning parenting and persons with intellectual disabilities.

givers (Killoran, 1994; Kocher, 1994) and reveal nothing about the day-to-day living and care provided to children and the relationship they have with their parents (Olsen, 1996). As Ducharme (1993) notes:

> More than any other single issue, questions regarding contraception, birth and child rearing seem to separate people with a disability from those without a disability. ...The beliefs that people with a disability are unable to conceive and raise a child are as pervasive today as they were twenty years ago. ...Most would question the ability of people with disabilities to serve as strong role models for their children. Such assumptions are typically based on a lack of information as well as prejudice toward people with disabilities. (p.185)

Despite the negative stereotypes and ignorance surrounding parents with physical disabilities, and the effects they allegedly have on their children, women and men with disabilities have children and parent them. This research asks if this varies by age of disability onset and gender. A review of the literature, which is predominantly based on women, describes two main patterns based on age of disability onset. If a woman has children and becomes disabled, her ability to raise, nurture or care for her children is questioned, and recognized as a difficult, but plausible role (Hardesty, 1987; Kocher, 1994; Olsen & Clarke, 2003; Thomas, 1997). If a woman is disabled and wants to become a mother, her ability to raise, nurture or care for her children is denied, and interpreted as selfish and unrealistic (Killoran, 1994; Kocher, 1994; Morris, 1991; Thomas, 1997). Other literature suggests that women with genetically inherited disabilities, which are present prior to parenthood, are commonly encouraged to terminate pregnancies (Olsen & Clarke, 2003; Thomas, 1997). The paradox facing people with a disability lies in the social and cultural construction and meaning of adulthood, which includes parenthood and the responsibility of raising and caring for children (Priestley, 2003), yet many persons with disabilities are denied this right, or deemed irresponsible if they choose to have a child. Even though there may be very different issues facing parents who are disabled prior to having children, and parents who already have children when they become disabled, there is no statistical information to indicate how many parents are disabled, or how age of disability onset and gender may affect the subsequent life course events such as childbirth, adoption and parenting.

Despite this paucity, several qualitative studies provide important insights about parenting with a disability, and, in some cases, how this may vary by gender and age of onset. Olsen and Clarke's (2003) study of 67 parents with disabilities suggests that when a disability diagnosis follows the birth of children, parents are less likely to see their disability as an obstacle to their experience of parenting. Grue & Laerum's (2002) study indicates that for women with a physical disability since childhood, the birth of a child is the defining transition to adulthood and womanhood, and becoming a parent means being perceived and treated as an adult by other people for the first time. Grue and Laerum (2002) also report that "depending on when a woman had become physically impaired", having a child meant affirming their gender, or "recapturing a lost gender" (p. 676). Thomas' (1997) study also indicates that when women are disabled prior to childbirth, they report advice and pressure from medical professionals and family to refrain from having children, or not have any additional children. For those women disabled from birth or early childhood, Thomas (1997) reports that they are encouraged not to have children because of the potential to pass on a hereditary condition to the child.[7] Several authors (Helmius, 2004; Olsen & Clarke, 2003) report that women, disabled from birth or childhood, are told that they are be unsuitable marriage partners, and therefore will never be parents. As a result, Helmius (2004) argues

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[7] Of the four women with congenital disabilities in Thomas' study, all had one child or more.

there are deficiencies in sexual education for adolescents growing up with a physical disability based on the belief that "encouraging the sexual development of a disabled young woman might entail too great a responsibility" (p. 105). Olsen and Clarke (2003) report some variations by gender when couples made a decision to have more children insofar as medical professionals are much less likely to offer advice or counseling if the father is disabled and the mother is non-disabled, and that disabled mothers report good care and support from medical professionals, but that the information is directive rather than supportive.

The literature also indicates that the lack of resources, reduced income, environmental barriers, limited support and prejudicial attitudes among health care professionals tends to impact parents with disability more than having a disability per se (Olsen & Clarke, 2003). Parents report their care, interaction and relationships with their children change due to reduced physical strength, energy or fatigue (Hardesty, 1987; Lyons & Meade, 1983; Matthews, 1983). Others note that inaccessible buildings or recreation sites (Thompson, 1981) and the lack of practical and personal support from peers, family (Thomas, 1997) and the medical profession (Report of the Equity Committee on the Interim Regulatory Council on Midwifery, 1993) makes parenting with a disability difficult. Qualitative Canadian studies on mothers with a disability (Blackford, 1999; Matthews, 1983; Ridington, 1989a) all indicate that poverty, low incomes, lack of support, isolation, high child care costs, and lack of accessible housing and transportation are the greatest problems facing mothers with a disability. Women with physical disabilities report that health care professionals question their ability to raise and care for a child (Killoran, 1994; Kocher, 1994; Thomas, 1997) as opposed to providing strategies, support or referrals (Hale-

Harbaugh, 1978). Another concern is related to information about pregnancy: women are not told what is common or uncommon during pregnancy and find it difficult to get accurate information. Women with a disability are often encouraged to end a pregnancy or counseled not to have children at all (Matthews, 1983; Shakespeare et al, 1996; Thomas, 1997).

Fathers are largely absent from the literature on parenting with a disability. Insofar as the studies acknowledge the presence of children, they do not comment on the father's role as a parent (Creek et al, 1987; Thompson, 1981). Quantitative research is also limited. Only Fawcett's (2000) research provides statistical information on parenting. Her findings indicate that about 10 percent of women with disabilities are lone parents compared to about three percent of men (Fawcett, 2000). Thus, women with disabilities may be three times more likely to be single parent in comparison to men. The paucity of men's experiences in the parenting literature[8] and the general lack of statistical information, is quiet testimony to the need for more research and exploration of parenting with a disability.

3.7 Summary

This review of the research literature has shown that there is limited research directly addressing how age of disability onset and gender affect the work trajectories, educational attainment and outcomes, marriage and family formation. While some life course research has explored how the presence of a disability may alter subsequent life course outcomes, little has explored those experiences within the context of gender, of age of disability onset, or variations by generation. Typically age of disability onset and gender are addressed separately in the research literature, resulting in little concensus about how the presence of disability may affect life course experiences and outcomes of women and men. This is

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[8] For information and references on intellectually disabled fathers and mothers parenting experiences see Hanna Bjorg Sigurjonsdottir (2004).

apparent in the literature on marriage and family formation, where the presence of a disability has the potential to discourage or disrupt marriages, or constrain childbirth. Research on the work lives of people with disabilities addresses the work experiences of those with adult onset disabilities, or does not make distinctions. Likewise, little is known about educational outcomes among people with early onset disabilities. Statistical research indicates that women with disabilities have lower incomes and rates of employment, and are more likely to be single parents, compared to men with disabilities. Despite considerable research examined in this review, numerous gaps remain regarding long-term life experiences and outcomes for women and men with early and adult onset physical disabilities.

CHAPTER 4 — METHODOLOGY AND ANALYSIS

4.0 Introduction

This research is based on twenty in-person interviews conducted with ten women and ten men with a physical disability. Sections 4.1 to 4.6 review the participant research criteria, the sampling procedures used to select participants (sampling design), the characteristics of the participants, the design of the interview guide, the interview process, and the interpretation and analysis of the in-person interviews. The interviews collected data on life histories and anticipated life paths (Elder 1985, 1991) through a structured and semi-structured interview schedule (see Appendices C and D). A pilot interview was conducted and the findings from that interview are included in the research results. The information gathered in the interviews are qualitatively analyzed to identify themes regarding subjective feelings on how a disability has affected people's lives in terms of work, schooling, relationships and family, typical and unique experiences, and personal well-being. The interview findings are used to compare and contrast the experiences of women and men in relation to the age of onset of the disability.

4.1 Participant Research Criteria

It is important to acknowledge the differences among types of disabilities and their varied impact on the lives of persons with disabilities – socially and functionally. Having a disability can pose common social experiences of institutionalized exclusion, poverty and discrimination, yet persons with disabilities have differing experiences and outcomes (Fine & Asch, 1993). Those with physical, psychological or intellectual disabilities, face very different personal and social issues. In order to limit the issues that are associated with different types of disabilities, this research focuses on persons with physical disabilities affecting motor skills, stamina, strength and co-ordination (e.g., multiple sclerosis, cerebral palsy, arthritis).[9] Participants were required to be age 19 or older, had to be disabled for at least two years prior to the research, and to have the onset of the disability to occur prior to age 45. To clarify the concept *age at onset*, a distinction is made between *early* and *adult* onsets. For the purposes of this research, an *early onset* disability is defined as a disability acquired by age twelve and includes congenital disabilities. A *late onset* is defined as a disability acquired after age twelve and up to age 45. With regard to acquired disabilities, a distinction is made between a disability resulting from an accident or trauma, and a disability resulting from organic pathology, disease or with no known cause (e.g., multiple sclerosis). Those whose disability is the result of a trauma or accident are excluded from this research.

4.2 Sampling Design

This research applies purposive and snowball sampling procedures (Babbie 1989; Mason, 2003; Yow, 1994) based on the criteria outlined in Section 4.1. Participants were referred through four sources: the Society for Students with a Disability at the University of Victoria, the DisAbled Women's Network of Vancouver, B.C. Rehab (the administrative body of George Pearson Hospital), and from participants who were interviewed and provided personal referrals. One woman was not referred; contact with her was made through a chance interaction at a restaurant. Table 4.1 summarizes the referral sources, the number of people referred, and the number of research participants by referral source.

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[9] Although blindness, low vision, and hearing loss are defined as physical disabilities, persons with these disabilities are excluded. Persons with a mental or intellectual disability (e.g., schizophrenia or Down's Syndrome), a head injury or Acquired Immune Deficiency Syndrome are also excluded.

Table 4.1

Summary of Referral Sources

Referral Sources	Number of People Referred	Number of Research Participants
Society for Students with a Disability	6	4
DisAbled Women's Network (DAWN)	5	3
BC Rehab	5	5
Personal Referrals	7	7
Chance Meeting	1	1
Totals:	24	20

After obtaining the names of potential research participants, people were contacted by telephone to discuss the research, confirm the participant criteria, explain how the interview would be conducted, and answer any questions. Those contacted were informed that the interview would be in-person, taped, and may take up to four hours. If concerns arose over the length of the interview, the person was advised that the interview may be conducted over several days, or with breaks. Issues of confidentiality were reviewed, and persons were informed that all participants would sign an informed consent form (see Appendix A) and an interview release form (see Appendix B) to stipulate restrictions and conditions concerning the use of the information provided in the interview. Of all those referred, one person did not meet the research criteria, one declined to participate and two could not be contacted.

A total of 22 people were contacted, and 20 (who met the criteria) were provided with a copy of the informed consent, interview release form and interview guide (one for those with congenital disabilities and one for those with non-congenital disabilities) (see Appendices A, B, C, and D respectively), and encouraged to review these before consenting to the interview. A follow-up telephone call was made and all 20 people agreed to an interview. The high response rate was likely due to the efforts of those providing referrals.

It took 12 months to find ten women and ten men who met the criteria.

4.3 Characteristics of the Participants

Of the 10 women and 10 men interviewed for this research, four women and five men have an adult onset disability, and six women and five men have an early onset disability. The participants' range of physical disabilities include cerebral palsy, post-poliomyelitis syndrome, multiple sclerosis, arthritis, muscular dystrophy, degenerative disc disease, dysgraphia, fibromyalgia, and one requested the disability be kept anonymous. The participants ranged in age from 21 to 78. The median age was 35 for the early onset participants and 45 for the adult onset participants.[10] Table I (see Appendix E) summarizes the participants' pseudonyms, age at disability onset, their age, education attainment, marital and work status at the time of interview, and whether they had a child (or children).

The participants report a variety of cultural and ethnic backgrounds. Participants are of Asian, Indo-Canadian, European and Canadian ancestry. In general, participants had high levels of education, that is a minimum of some postsecondary education. Among the early onset participants, all but two had attended or completed postsecondary schooling, and four participants had university degrees. However, among the adult onset participants, only five participants had attended or completed postsecondary schooling, and four had educational attainments of high school or less. The variation in educational attainment between early and late onset participants is, in part, explained by generational differences and expectations regarding education for those born prior to 1950 and those born later. Of the four adult onset men born prior to 1950, two did not complete high school, one had a high school diploma, and one had some trades training. Table 4.2 shows the participants' educational attainments.

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[10] The age range of each group was 21 to 54 (the early onset participants) and 33 to 78 (the adult onset participants).

Table 4.2

Participants' Educational Attainment by Age of Disability Onset

Age of Disability Onset	High School or Less	College and/or Some Postsecondary Education	Completed University Degree(s)
Early Onset Disability	2	5	4
Adult Onset Disability	4	5	0
Totals:	6	10	4

At the time of the interviews, the participants' marital status and the presence of children varied by age of disability onset. Adult onset participants are more likely to have been or be married, or have children. For example, all but one (woman) of the adult onset participants report having children, while none of the early onset participants have children. Of the adult onset participants with children, only two participants (a woman and a man) had children after the disability onset. One women and man with an early onset are married, and one early onset woman is in a long-term relationship. Eight of the early onset participants (four men and four women) have never married, and are single or dating. However, given that four of the early onset participants (one woman and three men) were in their twenties at the time of the interview, they would be unlikely to be married or have children, although likely to cohabitate. In contrast, three early onset women, in their 30's to 50's, had never married or cohabited, suggesting that the women are more likely to be single than their non-disabled age peers. Among the adult onset participants, one woman and two men are married, one man is widowed, and one woman and two men are divorced. One woman is single and one woman is in an *alternative, common-law relationship.* Fourteen participants lived alone (excluding their attendants) or resided in a care facility on a full-time basis. Table 4.3 shows the participants' marital status at the time of the interviews.

Table 4.3

Participants' Marital Status by Age of Disability Onset

Age of Disability Onset	Divorced or Widowed	Married	Long-Term Relationship But Not Cohabitating	Single (Never Married)
Early Onset Disability	0	2	1	8
Adult Onset Disability	4	3	1	1
Totals:	4	5	2	9

Of all the persons interviewed, only one man (early onset) reports that he has not had any form of paid employment, other than paid honourariums. All nine adult onset participants were employed on a full-time basis at the time of onset of the disability. At the time of the interviews, only two early onset participants were in the labour force, and the remaining eighteen participants were out of the labour force. Of those participants out of the labour force, five were university students. Table 4.4 shows the participants' labour force status at the time of the interviews.

Table 4.4

Participants' Labour Force Status by Age of Disability Onset

Age of Disability Onset	Employed or Self-Employed	Unemployed	Out of the Labour Force: Students	Out of the Labour Force: Other Reasons
Early Onset Disability	1	1	2	7
Adult Onset Disability	0	0	3	6
Totals:	1	1	5	13

4.4 Design of the Interview Guide

The in-person interviews were collected using an interview guide developed through the collaboration of the author, two women with congenital disabilities and two women with acquired disabilities. However, none of these women were interviewed for this research. The development of a sensitive and comprehensive interview guide would not have been possible without the considerable feedback and guidance of these women. Incorporating and relying on the experience and personal expertise of these women was critical to the success and validity of the interview guide (Mason, 2003; Barnes, 1992; Oliver, 1992).

Two separate interview guides emerged – one for persons with a congenital disability and one for persons with a non-congenital disability.[11] Both interview guides consisted of a structured interview schedule,[12] designed to collect basic demographic information and outline the participant's family, work, and education history, and a semi-structured interview schedule, designed to gather detailed, personal information on each participant's life history. The structured interview schedule asked questions on age, place of birth, natal family membership, parent's work and education, the presence and age of children, marital status and history, educational attainment, employment status, volunteer activities and income sources helped sketch a preliminary biographical profile and time line. Based on this information, subsequent questions in the semi-structured interview schedule could be more thoughtfully directed towards each participant's personal circumstances and background.

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[11] It was not until the interviews were transcribed, and I had commenced analyzing the transcripts, that I came to realize that the experiences of the three women whose onset occurred in elementary school were more similar to those participants with congenital disabilities. Hence the interview guides are (awkwardly) titled "Proposed Interview Format for Those with Congenital Disabilities" and "Proposed Interview Format for Those with Non-Congenital Disabilities."

[12] The same structured interview schedule was used for all participants.

The semi-structured interview schedule consisted of open and close ended questions in a sequenced order, verification questions, and questions asking participants to describe events, experiences or feelings. Questions in the semi-structured interview schedule asked about the occurrence, interruption or timing of personal life events, careers and goals. Other questions asked participants to define concepts (e.g., meaning of disability), provide examples (e.g., elaborate on an experience), and discuss issues not covered in the interview. The questions were ordered to facilitate the participant's biographical history based on the preliminary information gathered from the structured interview schedule.

The design of the two semi-structured interviews schedules were similar. However, questions in the (semi-structured interview) schedule for participants with congenital disabilities collected information from the time when participants could recall their earliest memories. Questions in the schedule for participants with non-congenital disabilities collected information from about one to two years prior to the disability onset. A pilot interview was conducted with one woman who had an adult onset disability to test the flow and wording of the questions and to determine the approximate length of time required for the interview. No changes were made to the interview guide.

4.5 The Interview Process

All interviews were conducted in-person and all but one participant were interviewed in their residences (one participant requested to be interviewed in a mall). On average, the interviews lasted four hours, with a range from about two and one half to twelve hours. Many interviews were conducted over several sessions to accommodate the participants' personal schedules.

The interview process consisted of an informal discussion to build rapport.[13] After the informal discussion, the informed consent and interview release forms were reviewed and verbal consent to tape the interview was obtained. The interviews were orally administered. Responses to the semi-structured interviews were manually recorded and taped; the responses to the structured interview schedule were not taped. At the conclusion of the interview, participants were asked to sign two copies of the informed consent, complete the interview release form in duplicate, and provided with a copy of each document. Participants were also asked if they wished to maintain contact with me after the interview and if I could ask them more questions after transcribing the interviews. Nine participants (five women and four men) requested to maintain contact with me, agreed to answer more (clarifying) questions, and/ or wanted to see how the information from her/his interview would be used in the research. These requests were noted on the interview release form. Later, when the interviews were being transcribed and analyzed, those participants were contacted by telephone, e-mail or in-person for further clarification and feedback on topics discussed during the interview.

With the in-person interviews, I prefer a method that relies on the exchange and sharing of experience and ideas (Abu-Lughod, 1993; Minister, 1991; Oakley, 1993). Oakley (1993) advocates that the relationship between the interviewer and interviewee be one of reciprocity and familiarity, emphasizing a more equal and balanced style of interviewing (Shakespeare, 1996). Yow (1994) describes this as a shift from the research relationship of objective, authoritative researcher and subject to one where both the researcher and

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[13] To facilitate rapport, I assured participants they were free to speak on any topics they wished to discuss (such as issues not addressed in the interview), and candidly answered all questions about me or the research. Another way I built rapport was to acknowledge the participants' contribution with a small gift to thank the them for their time and generosity.

participant have knowledge of the situation as well as deficits in understanding. The thinking and methods used in this research eschew the detached stance of neutrality and perceive the participants involved in this project as collaborators and experts, not subjects (Stacey, 1991).

In this research, the goal of in-person interviews is to provide a forum for the participant to express, define, describe and give meaning to the experiences, events and daily activities of significance to her/him in her/his own terms (Anderson & Jack, 1991; Morris, 1992). This means suspending the logic and order of the interview guide as needed to allow the participants to articulate a series of non-linear events and experiences, or to take a line of enquiry in the direction appropriate for them. In other instances it means that questions flowed in both directions. The use of open-ended (general) questions encourages the voice of the participants (Shakespeare, 1996) and allows them to choose, explain and define which experiences are important to them (Anderson & Jack, 1991; Yow, 1994). Overall, I attempted to use interview techniques (interpersonal skills) which could make the participants feel comfortable and empowered. This includes being compassionate, respectful and supportive of their views and experiences.

The participants' reactions to an interview style that focused less on questions and more on the interactions (Stacey, 1991) was met differently. In a few cases, this approach made the participant anxious, therefore the more traditional approach of neutrality and “simply asking the questions” was the most appropriate interview strategy. Also , there was a difference between the women and the men. Generally, the women were more comfortable with me and more at ease with discussing personal experiences. The women were much more inclined to focus on their personal relationships, particularly with children, (ex)spouses, (ex)partners or (ex)lovers. The men I interviewed tended to focus on "the things they had done" and tended to report less discriminatory experiences than the women.

4.6 Analysis of the Interviews

The analysis of the in-person interviews began by selectively transcribing and printing the taped interviews. Discussions about household pets, movies or shows, interruptions from phone calls, attendants or family, were noted but omitted from the transcripts. Each transcript was reread in conjunction with the tape to verify the transcript as an accurate representation of the interview. In doing the qualitative analysis, I aim to fairly and honestly represent the experiences of the participants, and collaborated in the analysis process with nine of the participants (Oliver, 1992; Shakespeare, 1996). One technique to achieve this was to provide the transcribed interview for the participant to comment on or edit. Select portions of the transcripts were highlighted to indicate which portion of the interview might be used in the thesis. This was done with four participants (two women and two men) who expressed the interest to review her/his transcript. Copies of the transcripts were sent by mail (one woman), or I met in-person with the participant and read (usually portions of) the transcripts to them. This resulted in two of the transcripts being edited and a request to omit an account of a particular experience from the research. Another technique was to contact participants by telephone to review and clarify some of the issues discussed during the interview. This was done with five participants (three women and two men) and resulted in minor editorial changes to three of the transcripts. The remaining eleven participants did not want to be involved in the research after completing the interview.

Initially, the analysis of the transcripts began by identifying general, although tentative, themes regarding the participants' perspectives and experiences of their education, work, relationships, family life, and "personal takes" on living with a disability. After additional reviews of the transcripts and interview notes, attention was given to addressing any divergent or similar experiences that were particular to their sex and/or age of onset. However, after extensive reviews of the taped interviews and transcripts, it became clear that most participants repeated or emphasized certain themes and events, and these in turn became starting points for analyzing, collating and building themes. Attention to this latter process allows patterns to emerge from the interviews, rather than selecting data to fit into a preconceived schema, and requires ongoing reflection and reflexivity of the interviews and the process of analyzing them. Reflexivity is necessary, not only because of the unquestioned biases and assumptions inherent in the researcher, and her effect on the research process, but also because the analysis process can usurp the experiences of participants and construe findings to support pre-existing hypotheses and theories (Adams, 1995; Mason, 2003; Stacey, 1991). For example, although I asked specific questions about the kinds of formal and informal support the participants used, it was apparent in the transcripts that "support" was spoken of throughout the interviews, and was an integral part of their personal relationships and networks which sustained them through difficult transitions or coping with change over time.

After some themes were identified, excerpts from the interviews were compiled according to each theme. A further review of the initial excerpts was performed noting the areas of commonality and the points of departure. Often this meant reviewing the transcripts several times, and repeatedly listening to the tapes over time to see if any new themes emerged from the interviews. At this point it was possible to collate the interview findings into five main themes: definitions of disability; experiences in the schooling system; relationships, family and parenting; alternative and traditional work trajectories; and transitional events unique to persons with disabilities.

4.7 Biases and Limitations

Limitations specific to this research include the decision to focus on people with physical disabilities and the resulting exclusion of people with intellectual, psychological and/or other types of disabilities. This research does not address the experiences of people with disabilities which are the result of trauma or accidents. None of the participants are of Aboriginal, Middle Eastern or African descent. More disability research needs to incorporate disability issues with ethnicity, class and race, however, this research does not ameliorate this. I had difficulty finding people with congenital disabilities. As a result most of the men with congenital disabilities are in their twenties or early thirties, and have not yet married or cohabitated, or had children, so assessing the effects of the disability on family formation for them is untenable. None of the participants' (initial) disability onset occurred in their adolescent years (aged 13 to 18), which may have resulted in very different life course trajectories and outcomes. This research examines the participants' biographical time, that is looking at their experiences of individual time (education, work) and family time (relationships, marriages, births)(Mason, 2003) within the context of social and historical circumstances. However, due to the limited number of participants, their wide range of ages (21 to 78), and the variability in historical circumstances, it was difficult to disentangle the effects of gender, age of disability, and generation on the participants' experiences and outcomes. For example, education policies prior to the mid 1960's advocated segregated education for children with disabilities. Therefore, the early onset participants who were born prior to 1962, and who were mostly women, were more likely to be educated in segregated schools, than those who were younger (born after 1965), regardless of gender.

While all the participants were influenced by social and historical circumstances (policies and social institutions), and made decisions affecting their lives within the dictates and constraints of those circumstances, it was not possible to determine whether a participant of a different gender, or age (generation), would have had comparable experiences or outcomes.

Often, narratives have social lives, and their meanings shift as narrators address different audiences and situations. I acknowledge that my presence may have influenced what I was told and what I understood. I cannot escape this. With regard to the analysis of the interview findings, I was the only person who read the transcripts. It may be that another person would identify different themes or draw on different material as presented in the transcripts. Presenting the findings as themes and issues raised by the participants meant that much of the literature and research on disability could not always support, corroborate or refute the experiences of the participants, and the meanings they attached to those experiences and events. These gaps attest to the importance of studying the lives of persons with disabilities throughout the life course, and recognizing that variations by gender and age of onset may be capable of explaining or contextualizing only some of those experiences and events.

CHAPTER 5 — RESEARCH FINDINGS

> The idea that expertise may grow as much from lived experience and reflection as from 'objective' academic study is still far from being universally accepted. (Altman, 1994, p. 28, quoted in Campbell & Oliver, 1996, p. 46)

5.0 Introduction

This research explores how age of disability onset and gender affect the life course experiences of twenty people with physical disabilities in three areas – education, work and family formation. Specifically, it examines the variations in life courses trajectories and outcomes in terms of gender and age of disability onset regarding schooling and work careers, marriage and childbirth, and where relevant, details the timing of subsequent life course transitions. It also examines the formal and informal support participants utilized, and how policy provisions affect life course trajectories and outcomes. This chapter is organized according to the themes which emerged from the interviews. Section 5.1 presents the participants' definitions of *disability* and preferred terms. Section 5.2 examines education trajectories and outcomes by age of disability onset and gender. The education experiences of the early onset participants reveal significant delays and disruptions to the completion of secondary and postsecondary school, especially for women. In Section 5.3, the participants' work trajectories are presented, revealing distinct paid and unpaid work trajectories by age of onset. I also review how policies, attitudinal barriers and work disincentives affect the participants' work trajectories. Section 5.4 examines how the participants' marital status is affected by government policies and/or gender role expectations, reviewing variations by age of disability onset and gender. Section 5.5 discusses the participants' family status, and experiences regarding child birth and parenting are presented. Sections 5.6 reviews the life course transitions unique to persons with physical disabilities. Section 5.7 summarizes the chapter's findings.

5.1 Definitions of Disability

How we define and give meaning to a word cannot be understood outside of the larger social and cultural context in which people conduct their lives. The strength of words lies in their ability to ideologically invoke concepts and legitimate actions and beliefs. The terms disability and handicap do not lie dormant in our vocabularies, but create social categories of people whose status is constructed and whose treatment is justified on perceived physical characteristics and/or abilities as interpreted by the disabled and non-disabled alike. For these reasons, it is important to provide the participants' definitions for the term disability, and what they think when they hear the words "disability" and "handicap." Most participants view disability as requiring strategies and creativity for everyday living.

> ...whatever people say, there's always another way of doing things. My meaning for disability is another word for being inventive or creative. (Carrie, age 35, congenital disability)
>
> I always think disability refers to something or some part of your life where you either need to acquire or look at a different strategy for doing an activity of daily living. (Hailey, age 42, adult onset disability)

Others perceive disability as restrictions or specific limitations which they experience, but many articulate these restrictions as imposed by their surroundings - the physical and social environment.

> It can mean restriction. You do things differently. You go about moving about your world differently. (Ann, age 60, adult onset disability)
>
> It's not so much myself, it's the environment. (Pierre, age 26, congenital disability)
>
> Something that affects your ability to function on a daily basis. (Jemma, age 37, congenital disability)
>
> Anyone with a specific impediment that affects their daily life, and probably almost everyone has one. (Michael, age 21, congenital disability)

> A functional limitation. I don't see it as a handicap. I see structural barriers and attitudinal barriers as handicaps. I see disability as some kind of functional, physiological limitation, but given the proper support systems, the limitations are arbitrary. They can change. (Simone, age 41, adult onset disability)

> I think of some kind of impairment that is different from what normal would be, and restrictions in lifestyle and a different life experience. (Alaura, age 39, childhood onset disability)

Participants report that the term disabled is acceptable but the term handicapped is derogatory. Several discuss how they feel about the terms, how the terms should be used, and the preferences they have.

> I have a lot of biases. I tend to like to use the term *persons with disabilities*. I don't ever like to see anyone, and this is part of myself being someone with a disability, as referred to as *the handicapped*. I feel handicapped is not the same connotation as disability, and that everyone in life has a handicap to some extent. And yours might be, for instance, learning to play the piano. You can never learn to play the piano (laughter), but that doesn't mean that you have a disability. I feel handicapped is a very degrading type of statement. [pause] Whereas, I feel disability can be used in a very respectful manner to denote any range of disability. (Hailey, age 42, adult onset disability)

> I don't even like the term *disability*. It's like dis-ability. It's this whole *ability* and *not able*. I really don't like the word *handicapped* as used to designate a person. A person has a disability; an individual has a disability. They're not disabled individuals, and definitely not handicapped individuals, but society can certainly handicap them. But it's pretty hard to figure out another term for disability. (Simone, age 41, adult onset disability)

> I prefer *disabled*. *Handicapped* for me, I think of golf, you know, I've got a handicap and so on. I like the term *disabled*. I hate *challenged*, it's a stupid euphemism. ...You just need a straight forward word like disability. ...I hate the term *enabled*. And I hate it when everybody says, were all disabled in some way. Get a life! ...I have to work really hard to get around my disability. I feel that a disability is something that a person must work to get around and should damn well be given credit for getting around or overcoming! (Angela, age 26, childhood onset disability)

Most of the participants say that they prefer the terms woman/man/person with a disability, or a term that specifically refers to their disability, such as a person with cerebral palsy. Other preferred terms include *person with a physical impairment or limitation*, *physically* *challenged* or a *person with a physical restriction.* Conversely, some participants say that terms used to define disability are nothing more than labels. They stress the importance of recognizing people with disabilities as people with just another physical attribute.

> I'm not really into labels. I'm a human being just like everybody else. (Pierre, age 26, congenital disability)
>
> I prefer the term *person.* (Erik, age 33, congenital disability)
>
> I'm a person made up of many things. [My disability] is only one component of me. (Kim, age 35, adult onset disability)

Based on the wishes of most of the participants, I use the terms woman/man/person with a disability, or disabled persons. In this thesis, *disability* refers to physical impairments, and *disability* may also be the result of disabling structural, social and cultural environment in which a person conducts her/his day-to-day living.

5.2 Reading, Writing and Rehabilitation - Education Experiences

Growing up in Canadian society means that most people will be educated and socialized in public or private schooling systems. Access to education is an individual right and a social obligation, yet people with physical disabilities are not always granted the same rights and society's obligation to educate everyone is compromised by funding, the inconsistent provision of resources and accommodations, teacher attitudes, and policies which often fail to adequately address the needs of "special needs students" (Roeher Institute, 2004). The literature, although limited, suggests that children with disability often have academic requirements subordinated to therapy (Barrera et al, 2005; Saxton and Howe, 1997), have poorer grades compared to non-disabled children (Barrera et al, 2005), are taught more rudimentary skills (French, 1996), and lack in class support which restricts, or ends, education careers (Blaxter, 1980). Therefore, the educational experiences and outcomes of the children with disabilities may vary considerably among themselves, and in comparison to non-disabled children (Roeher Institute, 2004).

In this research, nine of the eleven participants with early onset disabilities report delays, disruptions, and problems completing elementary or secondary schooling, or accessing schools. In comparison, the education trajectories and outcomes of the adult onset participants were less likely to be affected by the disability onset since most participants had completed school at the time of the onset. However, after the onset, three adult onset women chose to return to university to further their education, altering their education trajectories. None of the men, however, report returning to school after the onset.

In the following section I present and compare the educational experiences and outcome of the early onset participants. I examine how education trajectories are disrupted and delayed, affecting the timing of school completion. Also I review their experiences in mainstream and segregated schools, and accommodations in school. Finally, I discuss the experiences of the adult onset women who chose to return to university.

5.2.1 Participants with Early Onset Disabilities

Among the participants interviewed for this research, education trajectories, outcomes, and subsequent transitions related to secondary school completion and postsecondary school attendance varied considerably by gender. In addition, of those with an early onset disability, those with a childhood onset (as opposed to a congenital) disability, are the most likely to experience delays and to drop out of the mainstream school system. All of the participants with a childhood onset are women. Overall, women were more likely to experience segregated schooling (childhood and congenital disability) and to participate in segregated schooling for a longer duration than were male participants (the two men with congenital disabilities who were put into segregated schooling were "mainstreamed" by elementary school). Gender appears to be a much stronger factor in schooling experiences than is generation among early onset disability participants. Table 5.1 below summarizes the education experiences and outcomes of the eleven early onset participants.

Table 5.1

Summary of Education Experiences and Outcomes of Early Onset Participants

Pseudonyms	Attended Segregated99 School for Children with Disabilities?	Entered Mainstream School By	Delayed in Completing Secondary Schooling?	Dropped Out of Mainstream School System?	Recovery, Therapy or Surgery Disrupted Schooling?	Difficulty Physically Accessing or Traveling to School?	Completed Requirements for High School Diploma?	Attending or Attended University?	Attending or Attended College?
Childhood Onset Disability:									
Angela	No	Kindergarten	Yes	Yes	Yes	No	No	Yes	No
Alaura	No	Kindergarten	Yes	Yes	Yes	No	Yes	Yes	No
Alice	No	Kindergarten	Yes	Yes	Yes	Yes	Yes	No	No
Congenital Disability:									
Jemma	Yes	High School	Yes	No	Yes	No	Yes	Yes	N.A.
Carrie	Yes	High School	Yes	No	No	Yes	Yes	Yes	Yes
Lilia	Yes	High School	Yes	No	Yes	No	Yes	No	Yes
Michael	No	Kindergarten	No	No	No	No	Yes	Yes	N.A.
Erik	No	Kindergarten	Yes	No	No	No	Yes	Yes	N.A.
David	No	Kindergarten	No	No	No	Yes	Yes	No	Yes
Frederick	Yes	Elementary	No	No	Yes	No	Yes	No	Yes
Pierre	Yes	Elementary	Yes	No	Yes	Yes	No	No	No

Note: N.A. refers to participants who attended university but did not attend college prior to attending university.

As Table 5.1 shows, despite delayed completion of secondary schooling, or the failure to obtain secondary school requirements, all the women, except one, were able to attend college and/or university. The one woman who did not attend university or college cites the lack of accessible transportation to university in the 1960's. Among the men, four were able to complete high school and subsequently attend college or university. The one man who did not complete his high school requirements was discouraged from attending postsecondary school for a credited program.

Delays and Disruptions in School

While men and women with early onset disabilities ultimately are equally likely to attend university or college, the impact of delays or disruptions in completing high school is more marked for women. Of the six women, one graduated from high school at age 19 (one year delay), three completed high school at age 21 or 22, and two left school before graduating. In comparison, the men are much less likely to experience educational delays, and none left the secondary school system. A delay refers to attending school later than one's age peers, due to late entry, or being held back for a grade. A disruption refers to time missed in class or a lack of continuity in schooling (switching schools). Delays or disruptions in schooling were the result of missing school after surgery (and no homework assigned while recovering), segregated schooling (with lower academic standards and an emphasis on therapy over school attendance), and mainstream schools that lacked the resources and knowledge to effectively teach and accommodate students with a physical disability. Although Jemma was one year behind her age peers, she explains that being a few years behind in school was a common experience for many children with a disability in segregated schools in the 1970's.

> I spent a lot of my day in therapy, so because of that I was a year behind in school. I'm bright. I'm exceptionally bright. Most kids were like two, three, four years behind because they would be hospitalized from surgery and stuff, and they'd fall even more behind, right? (Jemma, age 37, congenital disability)

Lilia's experience was similar. Despite repeated surgeries and hospital stays, she was never given school work to complete while recovering, resulting in the loss of two years of secondary education.

> That whole year, between the time I was fourteen and fifteen, was a lost year [in school]. They, they didn't know what they were doing. ...They just did too much surgery, too fast, and they ended up causing me so much pain, I just didn't even want to bother sitting in a wheelchair anymore. I spent a year in the hospital - in and out, in and out. (Lilia, age 44, congenital disability)

Pierre recalls that there was a greater emphasis on therapy ("making him normal") than on his academic education, even though he attended school in the 1980's.

> They weren't ready for someone to be educated and use it. The system is more set up to worry about making you look better - making you normal. It's this whole scenario about fixing you. That's the big focus: I need to fix you. And, so instead of concentrating so much on the educational part, it's "I'm gonna sit you down and going to keep pushing you over until you stop getting pushed over." (Pierre, age 26, congenital disability)

Once mainstreamed, Pierre was behind his age peers academically and was unable to complete his secondary school requirements in his last year of high school. Eric recalls being denied entrance into the mainstream schooling system which resulted in starting school one year late.

> My mom tried to put me into kindergarten and the principal said, "Look he can't walk. Therefore, obviously, we can't let him into the school system if he can't walk." So, I was registered in the segregated system. There were a number of segregated classes around so I could have bussed. I wouldn't have to walk to school. So, my mom said, "Well, we'll be back." Now she put me in daycare for another year and we started walking to school. It was about 42 houses from my house to school. She would shove me into the stroller and take me home. ...but the next year, I remember, every day we would walk to school. So people were waiting for 18 months for a trial period in the kindergarten ... Fortunately, I had a wonderful kindergarten teacher, who was the epitome of a wonderful grandmother. Grey-haired, a little bit plump, kind, kind

> lady with little wire-rimmed glasses. So, anyways, she was just delighted with me. ...So when the 2-month review came up, you had this little grandmother-type character saying to the principal, "Of course this little boy can be in the kindergarten. Where else do you want him?" So, it was pretty hard to really argue with that kind of logic at all. (Erik, age 33, congenital disability)

It is worth noting that two men, who were not delayed in the completion of their schooling, report that their parents became familiar with the principal of the local school and report good accommodations early in their elementary school years. This is consistent with the literature which indicates that strong parental support increases educational attainment among children with a disability (Barrera et al, 2005).

Segregated and Mainstream Schooling Experiences

Three women, with congenital disabilities, report they attended mainstream school by grades ten or eleven, but did not detail the reasons why it took so long to enter the mainstream system. In contrast, the men were either mainstreamed from kindergarten onward, or by grade six. Those who were mainstreamed in kindergarten report that their parents were very strong advocates, which was crucial to their entry into the public school system.

> Education, I got what I wanted, but at the initial stage we fought really hard to get it. The key is getting in at the beginning. (Erik, age 33, congenital disability)

The most salient conclusion reached by several participants was the significance of parental advocacy and family support, and how this furthered educational goals. Pierre, who did not meet his high school requirement, had no parental advocacy or support.

> My friend ..., he's a lawyer. He has Muscular Dystrophy and lived with his birth parents his whole life, and he got into the regular education system right away. He's older than I am, and when it comes to integration, for me that happened when I was 10 years old (1980) and I had to push for it. When he was going to school there wasn't integration at the time, but his parents demanded that he had to be in the regular system. So he got to be part of that right off from kindergarten up and it's because he had supportive parents that said: I want the best for my kid. He may have physical

> disabilities but that's it! He's going to be a part of it. He had parents that had to fight for a good 10 to 12 years, at the beginning and all the way through, of dealing with the school system. (Pierre, age 26, congenital disability)

Frederick (age 47, congenital disability) describes his experience of segregated schooling as, "Very protective. No competition. Politically powerless." As a result, most participants are strong advocates of mainstream schooling, especially those who were held back for grades or had their education delayed and disrupted. However, a few participants feel that mainstream schooling is not a favourable way to educate all children with disabilities, and cite the lack of infrastructure, teaching staff and resources and the possibility of social and political isolation. Angela, who left the public education system after her onset at age 7, felt strongly about ineffectual environments and support for children with disabilities in mainstream schools.

> Integrating disabled people in the classrooms ... I think it's a bad idea. People need a peer group and very often those children are isolated in the classroom, and then when you see them coming together at university or in social groups it's such a relief for them just to see and associate with other people with disabilities. I think every case is different, but many times children are put into a classroom without adequate support and basically left in the corner to vegetate. I think that's the tragedy with integration, and I think we'll end up seeing fewer disabled students in university in ten years. (Angela, age 26, childhood onset disability)

Several participants echo the same concerns regarding the social isolation experienced by children with disabilities who are mainstreamed, and who do not develop peer groups with other persons with disabilities. As Jemma notes:

> Integration is double-edge sword. It is good on the hand that people accept disabled people as people. What is bad is disabled people become isolated from other disabled people, so they hit eighteen or nineteen, and they don't know. They don't have contacts in the disabled community about where to go, how to access stuff, and what's happening is a lot of groups like the B.C. Coalition, The Voice, are not attracting younger members, and part of the reason is with people who are disabled, but in this time, in this economic climate, it is critical that they band together because if not, they're not going to have a voice against the cuts in service that my husband's generation and my generation fought to implement. So this integration is having all

> kinds of different repercussions that people are not acknowledging. (Jemma, age 37, congenital disability)

She concludes that young people with disabilities need to have both disabled and non-disabled friends, and draws attention to the difference between the two.

> I think you really need a balance. I have disabled and non-disabled friends and that's it, because you can't deny you're disabled, but you cannot isolate yourself from the able-bodied community. You have to have a foot in both worlds. (Jemma, age 37, congenital disability)

Of the five participants who attended segregated schools, the women report that their experiences in the mainstream system were positive and offered a change of pace to the segregated education system. Many participants report that they developed close friendships and peer groups in the segregated and mainstream school systems, although the transition to mainstream schools jeopardized these. Of all the participants, one man and one woman report that segregated education was detrimental to their educational goals.

Accommodations at School

Germane to all the participants' education experiences and outcomes are the accommodations, or lack there of, in the public education system - be they attitudinal or environmental. Some participants had more difficulty accessing school buildings or getting adequate assistance, than getting an education. In other cases, the attitudes of the principals, teachers and school administrators either hindered or facilitated the participants entry into the mainstream school system and school rooms. David, who did not report any delays in the completion of his schooling, cites the attitudes of the school principal as key.

> There was a time when the [elementary] school I was in was going to be closed down. They were going to move to another school that was close by, but it wasn't accessible, so my parents looked into enrolling me in a special school. The principal said, "No way. If we're going to move we're going to take your son. If he has to be in a wheelchair, we'll make a ramp for it." So they did. (David, age 28, congenital disability)

However, not all schools were able to accommodate the participants. Three women, whose onset occurred while in elementary school, report that the schools could not accommodate their education needs after the onset. Alice, who re-entered the public school system in the 1950's, recalls a complete lack of accessibility and attendant care. As a result she left the public school system.

> The idea was I would to go to high school. It would've been grade nine and my brother was a grade ahead. So my parents talked to the principal - of course there's stairs all over the place in the school - and the idea was to arrange classes so that there would be as many classes on the main floor as possible, but they couldn't do it. ...So the idea was my brother and his friends would carry me up and down the stairs, ...then mom would have to come there at noon because I would have to go to the bathroom, and then come and pick me up again. There was no transportation. ...This was mom, getting me ready, putting me in the car, lifting the chair and put in and all your school supplies, and then out there. Then my brother was responsible for me and to get me to class. ...So after two weeks, I got sick and the doctor said, "Look, if you continue this I will be very sick." He recommended that I did not go to school and take correspondence instead, because I simply wasn't strong enough to do that every day. (Alice, age 54, childhood onset disability)

After completing elementary school, David and Pierre report that they could not physically access local high schools, and had to attend an accessible school across town only to experience the loss of friends and peers - their informal support system.

> I should have went to Eric Hamber with my friends. In my time, it wasn't accessible; at least that's what they told me. I really wanted to go to Eric Hamber because that's where my friends were going. I remember I just had the greatest two years with them. There were real relationships there, and those relationships were kept up for a while, but you're just kids. You start at a new school, you end up losing touch unless you carry on together. So, I ended up at John Oliver, and friendships were hard to find, but they were there. I lost a lot of my (pause), going through that year and a half, getting dicked around. I lost my ability to communicate. I was outgoing, but it took a long time to get going. (Pierre, age 26, congenital disability)

All of the participants indicate that they received some accommodation at mainstream schools mostly in the form of using equipment, such as a typewriter, or additional time to complete exams or tests. Several women and men say they learned how to type before they ever learned to write, and that their typewriters and personal computers became as much a part of their communication as other children's pens and pencils. Overall, the participants note that they required little in the way of accommodation except for the odd ramp, computer, or someone to set them up in class and some attendant care. Others, who had difficulty with note taking, made arrangements with classmates for photocopying or sharing notes. David and Pierre had personal attendants in school which was more commonplace in the 1980's, but David reports that funding for the attendant (and transportation) was often a struggle.

> After (junior) high school, I couldn't go to high school. It was inaccessible at the time. I moved to Vancouver, because we needed more accessible housing and so, if you're in Vancouver, you go to a Vancouver school. There were two accessible schools at the time, but we had to fight for attendant care. I need some attendant help, like setting-up in the classroom, taking notes, things like that. Big fight over that! Huge! The school board met with my parents and they were saying, "No. We can only provide this and that." My parents were so upset. It turned out, lucky for us, that they changed their mind. They gave me an attendant for more time than they were going to. (David, age 28, congenital disability)

Participants also cite the importance of teachers including them in day-to-day activities of the mainstream education system. Some participants report that the teachers were particularly understanding, or in extreme cases, highly ignorant and discriminatory.

> I would say I was really lucky with the (mainstream) teachers I had. I know that other teachers with other disabled people that were being integrated weren't having fun the way I was. My music teacher, he always included me and never made a fuss. He just let things go. He never paid any extra attention to me. He never put me in front of the class and said, "This is a special disabled person coming in today." I was just part of the class. I was lucky the physical education teacher really included me in everything where ever possible. He allowed me to think of things to do, and between me and the other kids, we'd figure it out. (Pierre, age 26, congenital disability)

> [I had] this psycho grade two teacher. She wouldn't allow me to use the typewriter. It made too much noise. So, as a result, I didn't actually start using the typewriter until grade three! But it was so funny when I got to grade three, I had a wonderful teacher. I had wonderful teachers every year except for grade two. I was so used to asking for permission to use the typewriter that for the first couple of days I asked every time I wanted to use it. To which she said, "This is your writing tool. You don't ask me for permission to write, so you don't ask for permission to type. You just do

> it." So that was the start where I learned how I would write. (Erik, age 33, congenital disability)
>
> I had this (high school) math teacher and he hands the test to me, and he goes, get this, he goes, "Oh, by the way, can you read?" Can you believe it! I was totally shocked! I just didn't know what to say, right? Yeah (laughter), but I got even (laughter). I (laughter) the first exam he gave, I got an "A"! (Jemma, age 37, congenital disability)

While the literature does not detail in-class and schooling experiences or highlight their unique experiences (e.g. typing instead of writing), there is literature to support the importance of accommodation in school (Matthews, 1983; Wendell, 1996). The attitudes of educational staff are crucial to determining the education experiences of all children, with and without disabilities. The participants' strategies and adaptations to the non-disabled schooling system reveal the extent of their creativity and perseverance despite prejudicial behaviour by some teachers, and highlight how little they actually require in the way of accommodations. As Wendell (1996) notes, "if schools, colleges, universities, and workplaces were designed or modified to be fully accessible, and if discriminatory practices were ended, the extra help that a person with a disability would need to meet her/his potential would not be very much greater than that needed by a non-disabled person" (p.50).

The literature reviewed for this thesis suggests variations by age of disability onset (congenital versus childhood onset) and gender are the most likely to affect the timing and occurrence of life events associated with the completion of schooling or completing school without delays or disruptions. While there is little literature to support the idea that boys are more likely to be mainstreamed than girls (Fine & Asch, 1988), gender appears to be a salient factor among the participants with early onset disabilities in this study. For example, men were either mainstreamed in kindergarten, or elementary school, while the women were not mainstreamed until high school. The men are more likely to complete secondary school on-time (with their age peers); the women are more likely to be delayed. Of the three women with childhood-onset disabilities, all three dropped out from the mainstream schooling system, despite educational experiences that spanned from the 1950's to the mid 1980's. Consistent with the literature, the participants who were not accommodated in school, or who have academic goals or achievement subordinated to ongoing therapy, hospitalization or medical treatment, report poorer educational outcomes, delays or disruptions completing school (Blaxter, 1980; Matthews, 1983; Berrara et al, 2005). Yet this may be mitigated by parents' resources and abilities to advocate for their children. Eight participants (four women and four men) attribute their academic success to their parents and families. Despite delays and poorer educational outcomes for some, the participants are well educated in the end (even if it took longer). The question then becomes, why do children with disabilities require well-off, well-educated parents to achieve academically? Based on the participants' reports, poor accommodations in schools, be it architectural barriers, poor transportation, the lack of resources available to teachers, or unfamiliarity with students with disabilities, disrupt and restrict the educations of children with disabilities.

5.2.2 Participants with Adult Onset Disabilities

For those with late onset disabilities, the decision to return to school or retrain may be influenced by existing financial support, resources, education and job skills. Although the literature suggests that men are more likely to receive vocational counseling and retrain in skilled, higher paying occupations in comparison to women (Albrecht, 1992; Canadian Abilities Foundation, 2004; Fine & Asch, 1988; Vash, 1981), this is not the case for the women and men with late onset disabilities who participated in this research. Of the four women and five men with late onset disabilities, three of the women (but none of the men) chose to retrain and attend university. Consistent with the literature, however, the women report that they did not use vocational counselors or government agencies to direct them in their new vocations. They relied more on their own research to secure financing and resources for their return to school (Fine & Asch, 1988; Vash, 1982). The women also report that they chose to retrain in order to return to the labour force.

All three women reported the need to retrain in order to support themselves and be financially independent (two of the three women experienced marital separation after the onset of their disability). For one woman who did not retrain, the decision to remain out of the labour force is the result of a wage indemnity plan provided through a unionized employer. All five of the men were working at the time of the onset, yet none chose to return to school. They report that employers either accommodated their needs, had existing wage indemnity plans or were physically unable to work, and therefore did not return to school.

The three women who returned to school report they were accommodated in postsecondary schools by instructors and other students. One woman also reports that she requested a lawn chair (which allows her to lie almost flat on her back) in her classes and was accommodated. However, one woman reports that the local college she attended left the disabled washrooms in disrepair for one full year. The women also report that they all were able to secure student loans, some specialized funding for students with disabilities, or had income from other sources, and these are important mechanisms that fostered their postsecondary schooling. Although limited in number, the women's experiences are consistent with the literature that suggests that support and resources, in the form of accessibility provisions, financial assistance (student loans), classroom or exam accommodations, and support from professors or students, allows people with disabilities to successfully pursue and obtain higher education — regardless of gender or age of onset. The fact that they returned to school in the 1990's may also constitute part of a growing trend and acceptance for adults to return to school and start a second career later in life. Less consistent with the literature, however, is the fact that none of the men needed or chose to retrain or receive vocational rehabilitation (Albrecht, 1992; Vash, 1991).

5.3 Employment Trajectories and Outcomes

The challenge of discussing the work trajectories and experiences of persons with disabilities arises from the use of concepts and definitions which have traditionally described the work trajectories and experiences of the non-disabled (usually men) aged 15 to 64, who are strongly attached to the paid labour force. Government policies, insurance programs, and social assistance for persons with disabilities predominantly assume that people with disabilities are unemployable (Morris, 1991; Roeher Institute,1992; Wendell,1996). The findings presented in this section show that these assumptions are often erroneous and that the participants actively engage in the process constructing both paid and unpaid work trajectories. In this section, I present the work trajectories and employment outcomes of the early and adult onset participants, and I examine how existing policies, access to resources and personal strategies, and the timing of their disability onset combine to influence the participants' work trajectories and outcomes.

5.3.1 Participants with Early-Onset Disabilities

Work disincentives and the inability to find "suitable" work are the most common reasons why the early onset participants were not in the paid labour force, self-employed or unemployed, despite high levels of educational attainment. However, this did not prevent the participants from establishing long-term unpaid careers as full and part-time volunteers, consultants, lobbyists, advocates, teachers, public speakers and managers or founders of disability organizations or cooperative living societies for people with disabilities. All the participants (except one woman), report that they work or had worked, although it was rarely for wages. Of the eleven participants, two (one man and woman) are students[14] (not in the labour force), one man is self-employed, one woman is unemployed, and four women and three men receive income from the government (e.g., B.C. Benefits).

At the time of the interviews, nine participants report part and full-time volunteer work and consulting. They report that they sit on boards, have helped establish or run co-operative housing associations, volunteer for organizations for persons with disabilities, give workshops, organize seminars and conferences, attend lectures and conferences to disseminate information for others, and many are involved in support groups and advocacy groups for persons with disabilities. Participants report they receive honouraria and minor fees for their work, but cannot earn income from employment without jeopardizing their attendant care, medical benefits, B.C. Benefits and/or related payments.

Several participants report that very few employers will hire a person with a disability, or accommodate their needs, even though their requirements may be minor, such as assistance with toileting, more flexible work hours, or accessible office space and equipment. Lilia's comment reflects this frustration.

> So there's only one big battle that I haven't been able to fight all these years, and I don't even think that I've got the strength to deal with any more, and that was that I was capable of working but I needed to be able to go to the washroom. There was no way for me to go to the washroom, so that meant that I couldn't be there all day, and I wasn't going to jeopardize my health for it. I have a serious kidney problem and if I don't empty my bladder every so often, I can get really sick. So what is it? Go out and prove you can work and get really sick, or take care of your health? ... All they

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[14] Those who are students report income from student loans, grants, bursaries, and financial assistance from their families.

> (the employer) would have had to do was hire somebody to help me out. (Lilia, age 44, congenital disability)

Others report attitudinal barriers and discrimination in the paid work force. Eric's decision's to become self-employed was the result of his inability to find an employer who would hire him, despite having two university degrees. Even when the participants have jobs, they are subject to *ableist* discrimination, making difficult work even more challenging. Alaura spoke of her experiences:

> As a worker – being the token gimp – was really, really bad. The assumption is: you're only there because you're disabled ; you're really not qualified; you don't have a (graduate) degree; you didn't take the same courses everybody else did; you didn't do as well, or what ever, you did okay. So therefore, you don't get the responsibility, you don't get credit, you don't get anything. You get treated like shit. People don't see you can do the science. ...It takes them a long time to come (pause). You have to be better. Like women have to be better than men. (Alaura, age 39, childhood onset disability)

While all participants report discrimination is a barrier to finding employment and/or in the workplace, seven participants report that work disincentives are the main reason they stay out of the paid labour force. Lilia and Pierre comment on paid work disincentives established through government policies and the Income Tax Act:

> And then, when I did want to go out in the work force, because I kept saying to people, for me to get off GAIN and to be able to be self-sufficient I would have to have a good enough job where I was paying for my own attendants and my own housing, plus paying all my bills, all the taxes. It would be impossible for me because I won't even be able to get started doing that because I wouldn't have the help to get started to do that. And what, I'm in my mid-forties! Am I going to bother now?! I mean, all I can do is make it better for people in the future. (Lilia, age 44, congenital disability)
>
> There's tons of disincentives to work. Definitely, just look at me. My attendant care per year is $60,000. So that means I have to make about $80,000 to $90,000 a year, if not more, because half of that goes to taxes. So really, just to come up with $60,000 I have to make $120,000. Plus, now I've got a mortgage because I can't stay in subsidized housing for $300 dollars a month. Now I'm looking at a $1,000 mortgage. All of a sudden transportation going to cost a lot more. Everything that I would be getting a little bit of a subsidy on would be taken away, which now I have to produce.

(Pierre, age 26, congenital disability)

Among the participants interviewed for this research, systemic work disincentives are the most crucial polices to influence and restrict their work trajectories and employment outcomes. Many participants openly acknowledge the futility of engaging in paid labour at the cost of losing their incomes, housing, attendant care and medical care. As a result most participants work in volunteer positions and report unpaid work trajectories.

According to the participants, government policies affected their choices and place them in a position where they have to choose between access to adequate attendant care, income, housing and medical care, or paid work. When participants work for pay, they report attitudinal and workplace discrimination. Disability does not prevent people from working, but the failure to accommodate workers with a disability, attitudinal barriers and work disincentives do.

5.3.2 Participants with Adult-Onset Disabilities

My findings indicate that the timing of the onset of disability is critical because the adult onset participants had existing work histories and were more likely to work after the onset and/or to receive work related income benefits. Following the onset, three distinct work trajectories emerged, which also varied by gender. The work trajectories and employment outcomes following the onset were also influenced by historical economic conditions, and by financial resources and work related benefits to which the participants had access.

One work trajectory reported by three participants was the complete discontinuation of paid work following the disability onset. In this situation, one man and woman, whose onset occurred in the 1990's, had the benefit of being employed in unionized occupations, and were entitled to long-term disability benefits and Canada Pension Plan (CPP) disability benefits. As the receipt of their income benefits is conditional upon the complete inability to work, they have not returned to work, or attempted any return to work.[15] They also cite unpredictable health and fatigue as reasons that they cannot return to part or full-time employment. One man, who was a skilled labourer, experienced the disability onset in the 1950's when disability plans or wage indemnity programs were uncommon. He was unable to return to work and reports he had to rely on "sickness insurance" and modest government provisions after the onset.

A second work trajectory consisted of an initial withdrawal from paid work after the onset, a period of physical rehabilitation or hospitalization, followed by a return to either full or part-time employment. This trajectory was reported by three men who experienced the onset in the 1950's and early 1960's, and did not have any wage indemnity plans through their employment. Despite extended periods of rehabilitation, the men report they were highly motivated to return to paid work and were able to re-enter the labour force. Their post-disability work trajectories were influenced, in part, by the existing economic conditions in the late 1950's and early 1960's, when the economy was experiencing continued growth and there was a strong demand for labour. Other historical events, like the polio epidemic of the 1950's and World War II, resulted in larger numbers of people with physical disabilities in the population, and, as a consequence, in the labour force. Two men were able to return to full-time work, however, only one continued to work full-time until his retirement, the other eventually left the labour force in his 40's due to his health. One man returned to work on a part-time basis, and was able to secure entry level jobs. All three men advised that their

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[15] Both reveal that they could not work, even on a part-time basis, without risking the loss of their disability payments.

employers knew of their disability and made work place or job specific accommodations for their needs. As a result, they were able to work following the onset. Peter reflects on his experience as a worker with a disability.

> Well, they all knew. I don't think it ever was an issue. It became well known in the industry, over a period of time. Mind you, there's been people in the industry who I've talked to over the phone for years – 10 or 20 years – and never met them, and if we did happen to meet then they might be a little surprised. On the telephone they might not necessarily know I was in a wheelchair, but it's never really been an issue. (Peter, age 63, adult onset disability)

A third work trajectory is reported by three women. They report that they continued to work for a period of less than two years following the onset, and eventually withdrew from the paid labour force to attend university. Two women indicate that they used their disability benefits for as long as they required, and chose to return to school. Both worked for a limited time following their diagnosis, and note their supervisors were supportive of them and their needs once the symptoms became more acute. Hailey describes her experience:

> I switched over from a community to a desk job, but that was something that had just fallen into place anyway, and that was great, because I was working for a community agency that dealt specifically with persons with intellectual and/or disabilities. ...Had I been working in another type of venue, it might have been very difficult. Had I not been working for the person I was working for, it might have been very difficult. (Hailey, age 42, adult onset disability)

The third woman was self-employed. She also continued to work until her symptoms became acute, and then returned to school. She was able to receive Canada Pension Plan disability benefits, but she had to supplement her income with student loans, grants and any funding available for person with disabilities. The women report that the decision to return to school was prompted by the desire to transition to another career that was less physical in nature and could accommodate part-time employment. They all felt they could work on a part-time basis, but not meet the physical demands of full-time employment.

The reasons for returning to work, leaving the paid labour force and/or returning to school were influenced by a range of factors: the strong economy in the late 1950's and early 1960's which fostered a high levels of labour force participation; the accommodations people received from their employers; the need to work (even part-time) to support a family; absence of wage indemnity plans; periods of hospitalization and rehabilitation; the receipt of long-term disability benefits; and the decision to choose less physically demanding work. Regardless of gender, the participants whose onset occurred in the 1980's or 1990's, all report forms of wage indemnity and long-term disability benefits. These worker-related benefit programs provided the participants with an income when they needed to withdraw from the paid labour force, and gave them the time and security to consider alternate work careers and personal goals. For those without wage indemnity plans, participants reports that they relied on their own resources (family, friends and savings) for support, and, in some cases, the accommodation of employers if they return to the paid work. For others, whose onset occurred in the 1950's or 1960's, a strong economy helped foster re-entry into the paid labour force if their health allowed it.

5.3.3 Summary

My findings indicate that age of disability does affect work trajectories of people with disabilities, although variations by gender are less apparent. In this research, the adult onset participants are more likely report paid work trajectories and/or retraining to re-establish paid work trajectories, following the disability onset, while early onset participants are very likely to report unpaid work trajectories. While all participants report that decisions to work (paid or unpaid), are affected by personal (educational attainment, skills and personal ability) and socio-economic factors (availability of work, rates of pay), or historical circumstance (the economy in the 1950's and early 1960's; work-related wage indemnity polices in 1980's and 1990's), policies affecting disability related income and benefits (work disincentive), attitudinal barriers and employer accommodations greatly influence work trajectories, experiences and outcomes. The findings also indicate that the participants had very unique paid and unpaid work histories, regardless of age of onset or gender, and the literature does not reflect this.

5.4 I Do — I Don't: Marriage, Relationships and Disability

The interview findings indicate that most of the participants are aware of how funding for disability related income, subsidized housing and attendant care can be affected by their martial status. Those who were single and rely on government funding, are the most likely to indicate that they cannot marry or they will lose funding. This is a concern and consequence for four women and two men with early onset disabilities, and one woman with an adult onset disability. Thus it appears that the presence of a disability may influence subsequent life course events such as marriage, or in the alternative, delay marriage and increase the likelihood that disabled people will remain "single." Another implication is that people with disabilities may not cohabitate even if they are in long-term relationships.

5.4.1 Participants with Early Onset Disabilities

Of the eleven participants with early onset disabilities only two are married and cohabitating (and do not have children), one woman is in a long-term relationships but does not co-reside, and the remaining participants (four women and four men) are single and dating. Several of those who are single or in a long-term relationship note that they are reluctant to enter marital or common-law unions. Regardless of their gender, they express concern over the loss of government funded attendant care, and related income assistance and housing, if it is known that they have a partner who may assist with day-to-day care or income. Again regardless of gender, many chose to remain single since they believe cohabitation and/or marriage will jeopardize their current arrangement. Pierre's views reflects this:

> And the big dreams are to get married and have kids, but I need to have the money flow. I want to be able to support my kids. I want my wife not to have to do all the work if she's able-bodied or disabled, but even if I do marry an able-bodied person, I don't want her to have to do it all. I want the supports in place so that I can take my 50 percent of the share. ...Then there's the issue if I do get married. What happens to my services and that kind of stuff? I mean I don't know if I'll be able to fight it or not. I've never been in that position. As far as I understand it, as soon as you get married, it's expected that the wife will take care of everything. Common-law is okay, but as soon as you make that marriage it all disappears. (Pierre, age 26, congenital disability)

In a subsequent interview, he notes that he and his girlfriend (both have CP) could not live together because they would have their current attendant care hours reduced based on the assumption that they could "share" an attendant, ignoring that they both require their own attendant and lead active, separate lives. He also notes that they cannot surrender their wheelchair accessible apartments, because if the relationship does not work out, then one of them may not find proper accommodations. He concludes that he is forced to keep his relationship clandestine and does not have the unrestricted choices that many non-disabled people take for granted. Carrie reports a similar story about a friend with a physical disability who married a non-disabled man.

> She lost her allowance and everything else. [You're] penalized for having relationships, and encouraged to be single, (pause) isolated. (Carrie, age 35, congenital disability)

She notes that if she would ever marry her boyfriend, she would not disclose this to the public funding agencies which she relies on for income and attendant care. Alice chose a long-term relationship over marriage for "economic" reasons.

> He doesn't want to get married and neither do I. The point is, and this is a really bad thing in our system, that if you get married they are liable for every cost of everything. So if I were to move in with him, and if we were to be married, we would have no help because he earns too much at his work. I need full-time help, and I need someone around all the time, then he would either need to retire and stay at home and look after me, and he doesn't want to do that. He likes working, and once you're in the union it's not hard work. So we'd have to pay for wheelchairs, my prosthesis, my back brace - this is not cheap stuff. And I say, "Why? Why would we do that?" I guess if your income levels are not enough, you might be able than get some assistance. For someone like me I need a ventilator - those are extremely expensive - and the one that I have is about ten thousand dollars, plus the supplies for it. He knows all this kind of stuff and it's a never-ending drain. (Alice, age 54, childhood onset disability)

As noted earlier, the literature on the marital lives of people with early onset disabilities is limited, especially for men, and with few qualitative studies (Matthews, 1983; Ridington, 1989; Rousso, 1988; Simon, 1988). This literature indicates that women with congenital or early onset disabilities are predominantly single. My research also points to the fact that age of disability onset affects the timing or occurrence of life course events such as marriage, cohabitation, and the dissolution of those unions. Not only this, in this group of participants, less they are likely to cohabitate. The one woman and one man married at ages 34 and 44 respectively, which are 6 and 16 years later than the average age of first marriages for non-disabled women and men respectively. Furthermore, my findings suggest that those with early onset disabilities, who rely almost entirely on government funding for most of their day-to-day needs, have either chosen not to marry, or note government funding and provisions influence their decision about future marriage. This finding suggests that government policies are often centrally implicated in the choices available to or decisions reached about marriage and cohabitation for those with an early onset disability.

5.4.2 Participants with Adult Onset Disabilities

The literature suggests that marital stability (pre-disability marriages) may be compromised by the onset of a physical disability, and that women are more likely than men to experience divorce or separation following the onset (Fine & Asch, 1988; Franklin, 1977; Kutner, 1987; Morris, 1991, 1996). My findings suggest that the adult onset women are more likely to report that the disability ended their marriage or common-law relationship, while men report the disability did not affect their marital status. That is, they either remained married, or if their marriages did end, cited other reasons.

At the time of the onset, four men and two women were married, one woman was in a common-law relationship, one woman was single, and one man (who was nineteen at the onset) was single. At the time of the interview, two men and one women remained married, one woman is in an *alternative common-law relationship*, one woman is still single, and three men and one women are divorced or widowed. Among the those who are divorced or widowed, none report they have remarried or entered into another long-term relationship.

Two women report their marriage or common-law union ended as a result of the disability onset and the challenges it posed to their relationship. Simone and Ann comment on the male-female roles in intimate, heterosexual unions, and how the disability fundamentally changed the relationship.

> ...my partner did not want to be the person who was making the money. I mean, I was making money, he was making money. It was when he needed money it was no problem. It was when he needed emotional, touchy-feely understanding, that he did not know how to touch on those issues. It was almost like he didn't have the background. He was quite typical, I think, of a lot of men. He didn't mind taking the role of the financial supporter - the breadwinner - but he was really worried if he was going to be [pause],the whole business of I'm leaving if you have a baby in a wheelchair. It was like he would be the care giver. ...When I look back on it I go: Is this why 99 percent of all marriages break-up when the woman has a disability? Why is that? This was my experience, that he just didn't know what to do. If I didn't know what to do I would go and find out. I would go to counselors. I would go and seek out information. If I was living in an intimate relationship with someone I would go and do that, but he didn't. And I'm just thinking: That's almost a gender difference. (Simone, age 41, adult onset disability)

Ann reports a similar experience and outcome when her husband abandoned her emotionally, financially and socially.

> I think my husband was sort of fed up with being married (pause). I guess when he realized that I couldn't work any more. ...He never liked to work; he could make a fortune in his business, but he hated it. I was always there to pick-up the slack, so finances were going down. He opted for losing equity in the house. He did that and then came a time when he was very abusive and threatening. I never minded. To me we were in a partnership, right, and it doesn't matter what I make, what I don't make, and what you make, what you don't make. But still, that was hard - especially being called a ball-and-chain for crying out loud! (Ann, age 60, adult onset disability)

One man married following the onset of his disability. He married when he was in his late 30's, which was considerably later than most men in the 1960's. He reports that the marriage ended for reasons unrelated to his disability, and notes that his former wife knew about the disability before they married. Although, another man's disability onset post-dated his marriage, he also states that the disability was unrelated to the marriage ending.

Two men and one woman report that their marriages endured all the changes brought on by the onset. The woman reports that her husband was supportive of the financial, social and physical changes brought about by the onset of her disability. The men report that they relied considerably on their wives to maintain the family's strength, unity and endurance. In fact, both men simply state that they could not have done it without her. Andrew (age 78, adult onset disability) wrote the following in his own autobiographical account.

> My wife had a great burden to carry; the load of responsibility for the children and the daily requirements of living was overwhelming. How she did it, nagged at me constantly because I felt so badly about not being able to contribute. Her devotion to the family and myself was constant throughout all the years, and still is.

Consistent with some of the research literature is the finding that women are more likely to divorce or separate following the onset of a disability and to attribute this to the disability onset; two women report that their disability onset resulted in the end of their marriage or common-law relationship. Among the men who divorced, neither report that the disability influenced the decision to end the marriages. Although one man's disability onset pre-dated his marriage, the union end. This outcome is less consistent with the literature which suggests higher marital cohesion when a disability pre-dates marriage.

5.5 Bringing-Up Baby: Childbearing and Parenting Experiences

The family status of the early onset and late onset participants are markedly different. Specifically, none of the early onset participants have children, while eight of the nine adult-onset participants have children (one woman does not). However, the participants' life course *age and stage* are among the factors which explain some of this difference. For example, six of the late onset participants had children prior to the disability onset, while the early onset participants in their 20 and 30's are planning to do so. In the following I review the factors affecting family formation among the participants by age of onset and gender. I also review childbirth and parenting experiences and outcomes for the adult onset participants, and draw on their accounts to illustrate how the non-disabled and medical views of parenting with a disability have influenced outcomes.

As noted earlier, the early onset participants do not have children. The most notable absence of children is among the four women ranging in age from mid 30's to early 50's, who report that because they are not in a relationship (marriage or cohabitate) due to policy disincentives associated with marriage or cohabitation (discussed earlier), they had not had children. These women report that they had thought of having children, however, their personal circumstances did not make it feasible. For five participants, who are either in their twenties or early thirties and had not married or cohabitated, the absence of children is unremarkable, and three say it is their intention to have children, or, in the alternative, to adopt children. In contrast, the one woman and man, who are married, say that they do want children.

Among the adult onset participants, six had their children prior to the onset, and one man and woman had children after the onset. Of the six who had children prior to the onset, only one woman reports that she wanted more children, and one woman reports her only child died at age six. The remaining four indicate that they were happy with the number of children they had, and the onset did not influence the decision to not have more children. Of the two who had children after the onset, one man had his only child in his forties (the result of a marriage in his late 30's), and one woman, Ann, delayed child birth based on medical advice. Ann was advised by her doctor to delay her pregnancy well into her late thirties.

> It was recommended that I should not get pregnant, because of getting heavy when you have a baby. ...I really wanted a child and I was around 30 or 31, but then it wasn't to be, so I just carried on. (Ann, age 60, adult onset disability)

She became pregnant and successfully delivered a healthy girl, but notes that her doctors advised against pregnancy because of her age and disability, despite earlier advice to delay child birth. One woman, who raised an adolescent son, reports that she terminated a pregnancy as a result of the medical advice she received. Simone was "advised" to end a pregnancy she wanted to keep.

> Well, I was told that I was going to end up in a wheelchair and that it wouldn't be a good idea for me to carry. I was thinking, this is not a good thing that I am pregnant, but the fact of the matter is I would never plan to have another child. So, to me this was almost like a gift. I didn't want to have a abortion. I had made my promise to myself: Good for other people but not good for me. But my GP, my neurologist, and my partner said, "If you go through this, I don't want to have the responsibility for a woman in a wheelchair with a child." I have never quite forgiven him for it. That was a major reason that we had split up. So I went fine, and had an abortion, and subsequently found out a couple of years later that this was common, and that women do go through and have babies, but this was a common response by the medical profession. Again, this *ableist* kind of society. And granted it would have been rough. I was scared because what they were telling me, the horror stories of what was

> going to happen to me if I carried this baby full-term, were lies. It's a possibility, worst case scenario, but they were using scare tactics to control me, as opposed to try and find out what's in place and give me choices. And I could have possibly gone out and found more information. It just a matter of, "Okay you find out you're two and a half months pregnant, you've got to make a decision real quick!" So that was a rough time, but the experiences that I see, from what I gather, researching and speaking to people, it's echoed over and over again with women. (Simone, age 41, adult onset disability)

She is the only participant to state that she wanted more children and that society's reaction to the disability significantly altered her decision to have a second child. She reports that her son was a teenager at the time of the onset, and that she was deemed capable of looking after an adolescent, but not an infant. Her account is similar to others' (Killoran, 1994; Kocher, 1994; Saxton, 1994; Matthews, 1983) who report inadequate medical or practical advise and encouragement to end pregnancies. Both Ann and Simone's accounts are indicative of the power of the medical community to influence the lives of disabled women, and society's belief that disabled people should not, or cannot, be parents (Morris, 1991; Thomas, 1993).

While none of the participants report that they were denied the opportunity to parent their children, some report that some people thought they were not capable of parenting. One man had a child after the onset, and later raised his daughter as a single parent. Peter describes the process of getting custody of his daughter and the concerns others had about his ability to raise her.

> Well, I had to convince a judge that I could do it. There was some apprehension on some people's part - friends mostly - the judge was relatively easy. I told him my mother had volunteered to move in with me at the time, and look after the child, and that got me over that hurdle. But there were friends, work related and others, neighbours who actually offered to take my daughter and raise her. So they were obviously concerned about my ability to perform the function. I guess they felt that if I couldn't look after myself, how could I look after her, but they hadn't seen me at my best. So, I politely declined and that was the end of that. I've often thought about that (pause), and about how (pause) generous those people were, making that offer. (Peter, age 63, adult onset disability)

He reports that he hired a series of live-in homemakers, and successfully raised his daughter with their support and his parenting skills. Often people with disabilities are treated as incapable of parenting because they are not perceived as care givers, and non-disabled thinking fails to acknowledge that "parenting" can be augmented through the use of attendants or professional help (Morris, 1991; Olsen,1996; Olsen & Clarke, 2003). The use of nannies, and similar professional child care, by non-disabled parents is rarely interpreted as the inability to parent, yet appears to be such an indicator if utilized by people with disabilities.

At the time of the interviews, two women and two men became single parents, one had visitation rights to his children, and two remained married. Parenting, whether or not a person has a disability, poses many challenges and requires strategies for the day-to day care of children (Hardesty, 1985; Kocher, 1994;Olsen, 1996; Olsen & Clarke, 2003). For those whose disability onset occurred after the birth of their children, parenting with a disability also meant transitioning to new roles and redefining the meaning of *parenting* (Kocher, 1994). Simone recalls how her relationship with her adolescent son, and her parenting, began to change once she started to experience some of the effects of the disability.

> I was always playing hockey with the kids, and going skiing with my son, and I found that I couldn't share in those things with my son anymore. ...I couldn't do as much with him and I was getting further and further away from him at a time when I felt that it was really important for us to occasionally do neat stuff together. I had to really rearrange, redefine what quality time was with my son, but he wasn't used to it. ...And I found I couldn't do any of those things with him, and that distressed me because I thought I was losing my son. Like, he was no longer with me. I was so fatigued all the time. So that whole business of family and losing it. So there was career and children. I felt like the dream of the type of parent and the family that I had to work so hard (pause). I felt that it was crumbling. (Simone, age 41, adult onset disability)

For some parents, like Jonah, the onset of the disability meant they spent more time at home with their children, and they became more involved in child rearing and parenting.

> You know, I didn't really appreciate how much work it was to look after a child, let alone two. Initially, my wife's mother came to help us because it was just too much for her. A real eye opener. Mind you, eventually, I saw it as an opportunity to spend time with them and teach (pause), but that took a while, you know. (Jonah, age 33, adult onset)

For Edward, the transition to becoming a parent with a disability was "very manageable." However, the transition to becoming a single parent with a disability was devastating. He reports that the death of his wife, declining financial resources, failing health and stamina, and the lack of attendant care and community support influenced him to have his children adopted by a close family member. His situation is a reflection of society's inability to provide disabled parents with the support and resources they need, and how people with disabilities must often rely on their own resources and family to cope with dramatic personal changes. Overall, the adult-onset participants report that their families are *the* most important support system.

Among the participants interviewed for this research, women are more likely to report that the disability affected family formation. Among early onset women, family formation was affected by the absence of marriage or a partner, and the consequent decision not to have a child. For two women with adult onset disabilities, family formation was affected by either delaying child birth or ending a pregnancy. Men were less likely to report that the disability affected their family formation, because they were too young to have children, or, in the alternative, already had children at the time of the onset.

5.6 Life Course Transitions Unique to Persons with Disabilities

A salient theme emerging from all the interviews centred on the unique transitions the participants experienced as a result of having a physical disability. Within the life course perspective, transitions mark a change in roles or statuses, which are socially shared or recognized and occur throughout a person's life time (Hagestad, 1990). Social institutions, laws and policies provide formalized rites of passage which temporally delineate and coincide with transitions, but what about transitions which have not yet become part of the culture and everyday life of the non-disabled? In this section I review the participants' unique transitions which include learning they had a disability (in the case of congenital and childhood onset disabilities), receiving a diagnosis, major surgery, changing from a manual to an electric wheelchair, and/or moving to an institution, or living independently.

5.6.1 Learning About Being Disabled: Early Onset Experiences

In interviewing the participants with congenital or childhood onset disabilities, it was my intention to discuss when they became conscious of their disability and if that knowledge acted as a transition. However, the participants with congenital disabilities were only able to retell stories told by their parents, or foster parents, regarding the first time they were diagnosed, and many do not even recall being told about their disability as children.

> As much as I was able to understand, my parents told me. I mean I was a four-year-old kid. They never kept it a secret from me. (Frederick, age 47, congenital disability)

> I don't remember first learning about it, because like I said, I was born with it. So, I don't know any different. (Jemma, age 37, congenital disability)

Other participants spoke of when they first experienced the feeling that they were different.

> You just know. People start calling you names and you don't have the friends that other people do. Then it really comes home that you're different, but before, until grade one or so, I had no problems. None that I can recall anyway. (Michael, age 21, congenital disability)

> When did I first realize I was disabled? I've always known I was disabled. Then I started realizing there was a difference that denies my rights. The most profound thing probably was when I was denied to go play with somebody around the neighbourhood, because their mother didn't want me to play on the lawn since she was afraid I would get into an accident. (Carrie, age 35, congenital disability)

In contrast, the two women with childhood onset disabilities were conscious of and accepted their disability long before their families, therefore the disability onset acted as a transition the not only for the women, but for their families as well. Alice describes her experience.

> I had other childhood diseases like the measles, chicken pox and other sicknesses. You are sick for a while, and then got better. So the in the beginning this was just another sickness, but thinking back about it. ...I found that for me I accepted it first, understood the reality of it. It was more difficult probably next for my friends, and the most difficult for my family, my parents. Because after I went home, and I'm not the only one who's been through this, but people are always looking for a cure. (Alice, age 54, childhood onset disability)

Alaura's experience was traumatic because the adults (medical profession and parents) failed to acknowledge her symptoms, resulting in mistreatment until the diagnosis.

> I was a kid doing kid things. It was gradual. It became painful and I fell down a lot in grade three or four, I think. It was misdiagnosed as psychosomatic so that it had a really traumatic effect. It still does today. I don't trust physicians. I don't trust my own (pause), you know, "Am I feeling this?" A lot of doubt because of the way it was treated. We had a really incompetent physician who said it was psychosomatic, and who said you should treat children with psychosomatic illnesses by neglecting them. "Ignore her. She'll stop it." So the ignoring process was really awful and scary (pause). So you're in a lot of pain. You're having a hard time walking, and what we do with you is we tell you to go to the basement and sit there with the lights out. At least six to eight months [went by]. It got to the point where I couldn't take three or four steps without falling down. So it became so obvious that everyone could look at you and say, "That kid just doesn't seem to be walking even though she tries really hard." (Alaura, age 39, childhood onset disability)

5.6.2 Getting the Diagnosis

The adult onset participants report that the onset of the disability was one of the more profound and life transforming events they experienced, comparable to marriage or the birth of children. Many report it changed their dreams and aspirations about their future, and the perspectives they had about themselves. For Hailey, the onset was life altering and meant lifestyle changes, but she did not view her situation as a tragedy or insurmountable challenge.

> Going back to school was one of them, working. I had always had those sort of expectations, but I didn't see them crumbling. I didn't see them (pause). I didn't think

> unrealistically because again it goes back to the fact of growing up with someone who did balance disability and a career. So, I looked at it more from a pragmatic point of view, like: What will I need to manage a house, managing my time, my energy, that type of thing - like selling my car and buying a jeep-type vehicle that was easy to get into. (Hailey, age 42, adult onset disability)

The adult participants report that an aspect of the transition is dependent upon securing an accurate, medical diagnosis. Participants with disabilities such as arthritis, multiple sclerosis, spinal disease, or fibromyalgia are more likely to report misdiagnoses, or times when they struggled with their doctors to get an accurate diagnosis. Hailey describes her experience of trying to get a diagnosis as a one-year gauntlet.

> I was gradually getting extremely stiff and having a lot of pain, and finding it difficult [to work]. Of course at that time it was right around the onset of the new diagnosis of Chronic Fatigue Syndrome. So I went through a year of very frustrating (pause), you-must-believe-me-type-syndrome. And, then got a halfway diagnosis from a rheumatologist here in town, but because I was lucky, very fortunate for growing up in Vancouver, and I also had a cousin who's a doctor. So I just phoned him up and said, "Okay, give me a list of XYZ rheumatologists in Vancouver. Like I'm out of here!" (laughter) I've done the year, and I'm fed up, and I want some sanity in my life. (Hailey, age 42, adult onset disability)

Simone and Edward report they received preliminary diagnoses which suggested their symptoms were the result of stress, or were psychosomatic.

> Well, I was diagnosed in February 1980, but pre-diagnosed *crap*. The reason I say crap is because medical science told me it was all in my head and they were wrong. (Edward, age 48, adult onset disability)

> I couldn't feel a thing from the waist down and it took them, let's see, November, December, probably about six or eight months - I'm a little foggy on this - to actually take me seriously. Like, it finally took me to go into emergency to get to get into the hospital for these people who were doing the testing to take me seriously. I was told it was stress. I was told I had nerve problems. I was told that I was working too hard. I was getting it from the medical people, and then I was getting it from my partner, and my son. It was, "You're depressed, and that's why I was having this problem," or "You want attention," or "You're lazy. What are you doing? You haven't cooked dinner tonight." It was really hard for me. So that first year before I was diagnosed was really, really rough. (Simone, age 41, adult onset disability)

As a result, the diagnosis is often described as a period of relief or validation. Hailey describes the experience of her diagnosis.

> Relief. Huge relief that I wasn't a neurotic! (laughter) Enormous relief, enormous. I can honestly say I practically danced out of there (laughter). It was strictly, strictly on: "Great, I'm not off my rocker. Someone will believe me." Isn't that awful? ...The easiest way I can describe it is a weight had been lifted off me. ...I can honestly say it was almost like a turning point. (Hailey, age 42, adult onset disability)

Simone relates her perspective on the importance of receiving a diagnosis:

> It's really important to get diagnosed. That's what I think, (pause) unfortunately unless it's the wrong diagnosis. It gives people something to grasp onto, a starting point. That's why it's so hard for people who have symptoms for three years and they don't get someone to take them seriously. But the cost, I guess. (Simone, age 41, adult onset disability)

Participants report that getting a diagnosis is a significant transition because it legitimized their symptoms, gave them a prognosis, and marked the formal transition to being *disabled*. Getting a diagnosis is also important since it secures peoples' access to appropriate medical care, private or government benefits, and/or support from family and friends (Wendell, 1996).

5.6.3 Surgery as a Life Course Transition

Surgical intervention was a key transition for some participants, marking dramatic personal and social turning points. David describes the period of his life up to and after the decision to have a tracheotomy performed.

> I was getting more and more in need of using the ventilator during the day. So I had to put the mask on and I was stuck sitting in my room - this is in Pearson Hospital at the time - and ending up watching T.V., doing nothing. I was having difficulty eating as well because the energy it took to breathe was incredible. I didn't know this, but eating takes 20 percent of your energy. It's amazing. It's either eating or breathing, and you've got to breathe, so you don't eat. So I was getting really thin and I was getting sick of sitting in my room. So I said, "This is absolutely ridiculous, here on Ward 7 in Pearson just about everybody has a trachea. Look what they're doing and I'm stuck in this stupid room." I finally said, "Okay, let's go." It drastically impacted my life. It was incredible the difference. (David, age 28, congenital disability)

For Ann, the error of a surgeon left her with no support in her spine. As a result, she was unable to return to her former employment, lost her ability to earn income, and lost her home. Eventually she returned to university to complete a degree.

> You know, this is all very depressing, but I've been able to say, "Well, if it hadn't been for all this crap, I wouldn't be doing what I'm doing right now." I'm going through university and I'm working towards a different career. A career that in a certain way, I can help other people, and that's very rewarding. (Ann, age 60, adult onset disability)

Five participants report that surgery was an important transition because of the resulting outcomes it had on their health, or how it ultimately changed the direction of their life.

5.6.4 Challenging Perspectives of Wheelchair Use

Twelve participants use, or had used, manual and/or electric wheelchairs. For the non-disabled, the wheelchair represents the most visible symbol of disability and (alleged) loss of independence and freedom. Only infrequently are wheelchairs perceived as the energy-saving mobility devices that they are designed to be (Oliver, 1990). The participants who use(d) wheelchairs describe them as an important aid which they chose to use over others, or simply as the best aid they could find. Edward describes his initial feelings when he made the transition from a manual to an electric wheelchair.

> You know I will share with you a most, difficult, frustrating time of my life, and it wasn't when my wife died or my children went back to Alberta (pause). That was difficult, yes, but even more difficult than that was when I moved from a manual wheelchair to a power wheelchair. I mean for two years prior, I knew I was heading for a power wheelchair, and I was scared of a power chair, but not for the reasons you're thinking (pause). The main reason was that I would not be able to get around any more because of accessibility, and I would be stuck on my own. Now that frightened me. (Edward, age 48, adult onset disability)

In contrast, David reports that he welcomed his first wheelchair at age eight because he was finally able to keep-up with the rest of his family and friends.

> Sometimes, I just can't get over that, uhm, disabled people who are in manuals and they're losing their ability to manoeuvre like they could before, but they're resistant to go into an electric wheelchair. I'm thinking: Why? Are you nuts? I mean accept that you're getting worse and not waste your energy! I mean that's illogical. People are disabled and they're wasting valuable energy. Like this friend of mine, she found it more and more difficult to feed herself. She had hand movement, but with her hand could do beautiful art work. So I was thinking: Why don't you get your attendants to feed you? Save that energy for art, or whatever. It makes me think it's strange when people don't accept their own disability. (David, age 28, congenital disability)

Pierre notes that his wheelchair was his preferred mode of locomotion and that the other children in his school liked playing with him and his wheelchair. Two women and two men with congenital disabilities report that their wheelchairs served as a toy which amused or fascinated non-disabled children. Lilia fondly recalls her experience.

> The kids in the neighbourhood - they were so funny - they'd like to be with me because they thought my wheelchair was a toy (laughter). A neat toy! They liked pushing me around all the time. In fact, they wanted to play with me because I was different. If they wanted to push my chair, I just let them do it. (Lilia, age 44, congenital disability)

Despite non-disabled views of wheelchair use, often conceptualized as stigmatizing or as a loss of freedom, the participants provide insight into the personal importance of this mobility aid.

5.6.5 The Move Away and Changing Residences

Moving from one home to another means that we change the physical and social space that meets day-to-day needs and constitutes our sense of community. This issue was raised by twelve of the participants who either needed to move following the onset of the disability or who struggled to live independently. For those who had resided in a group home or institution, the move to independent living was an important personal milestone, symbolizing the *independence* associated with the transition to adulthood (Priestley, 2003). For Pierre, the move to independent living was a major transition because he rejected the government's protocol to move to a group home or institution, and chose to live on his own.

> You know, the system isn't really there to support us to live on our own. Its very much interested in you moving to another institution ,or group home, or something else, like Pearson Hospital. And those were all the options I had in front of me that they said I could do. I knew some big brother disabled people that were living on their own, and I said, "That's what I what to do." But they told me I wasn't being very realistic. So, this was when I was 18. I was already thinking about this stuff because they wanted me to. (Pierre, age 26, congenital disability)

Peter reports that it took sixteen years before he was able to live on his own.

> Pearson (Hospital) finally hired a lady who was trained in rehabilitative nursing and she was the first one in all those years that I was involved that I thought knew anything about at all about self-care and severe paralysis. She was the one who was able to teach me a lot of the tricks that I was able to do to be able to dress and undress, and get out of bed and into my wheelchair. It was so successful that in 1969 I moved to an apartment down in the swinging Westend and lived for two years on my own. I had a chap come in and help me in and out of the shower, two or three times a week. (Peter, age 63, adult onset disability)

Nine of the adult onset reported that they moved (to a new home or institution) following the onset of the disability. Despite the struggle to live independently, or the need to move to a new home or institution, the participants interviewed for this research indicate that moving was a significant transition they negotiated in the process of living with a disability.

5.6.6 Summary

My findings indicate that the transition from non-disabled to disabled is a significant, and disruptive, transition for the childhood and adult onset participants alike. However, those with a congenital disability indicate that the disability is a part of their identity and how they understand themselves. Almost all the participants believe that living with a disability provides insight and a unique view of life. Regardless of gender or age of disability onset, participants report that any intervention which increased their stamina (through surgery or electric wheelchair use) or personal independence (living independently) are important transitions. The meaning and value the participants' gave to these transitions highlights how living with a physical disability is a personal and social process. Negotiating unique disability-related transitions, is a process mediated by social institutions (medical profession, policy provisions, social networks, *ableist* attitudes) and individual agency and adaptation (struggles to get a diagnosis, decisions to live independently, or have surgery).

CHAPTER 6 — CONCLUSION AND RECOMMENDATIONS

6.0 Conclusion

This study has shown that there are important variations in life course experiences, trajectories and outcomes of people with physical disabilities in terms of age of disability onset and gender. Early onset participants report unique life courses compared to most non-disabled people, or to those disabled in adulthood, and were more influenced by disability policy provisions throughout the life course. Those disabled as adults report dramatic changes to their life course following the disability onset, and relied on very different forms of formal and informal support compared to the supports they relied on prior to the disability onset. In addition, women are more likely to report that the disability affected their marital status and family formation regardless of age of disability onset.

In terms of education, the early onset participants experienced delays and disruptions in completing secondary school requirements, and subsequent delays attending and completing postsecondary school. These experiences were reported by almost all the participants. While the overall educational attainment of early onset participants is similar, with many attending postsecondary school, this similarity discounts important differences between the women and men in terms of schooling experiences and trajectories. In comparison to the men, the women were all delayed in the completion of secondary school, were more likely to drop out of school, and/or more likely to complete university entrance requirements as young adults. Most of the women were born prior to 1962, while most of the men were born after 1962. This variation in generation may explain, in part, why women (congenital disabilities) had longer durations of segregated schooling, or dropped out of school (childhood onset disabilities), and men tended to enter mainstream schools at earlier ages. Although the men report strong parental advocacy, their experiences were, to some extent, part of a growing trend toward including children with disabilities in mainstream schools. Thus educational attainment among the participants was not affected by disability *per se*, however, but the result of social institutions and policies from the 1950's to the 1980's.

While some of the participant's experiences are consistent with the literature regarding delays or disruptions in school completion (Barrera et al, 2005; Matthews, 1993; Saxton & Howe, 1987), or compromised academic educations resulting from therapy (Barrera et al, 2005; Matthews, 1993), other schooling experiences, such as accommodations provided by school staff and administrators, are virtually absent. The participants' accounts are testimony to their tenacity in obtaining an education in a system often unable to meet their needs. Perhaps this accounts for the high proportion of participants who either attended or wanted to attend postsecondary school.

This study also shows that the education trajectories of adult onset participants are largely unaffected by the disability onset. Contrary to the literature (Albrecht, 1992; Blaxter, 1981; Canadian Abilities Foundation, 2004; Vash, 1980), the women in this study returned to university, while none of the men retrained to re-enter the work force. As women continue to exhibit strong attachment to the paid labor force, it may be that the women in this study are part of this ongoing trend. Two had their relationships end after the onset and report the desire to work and remain financially independent. The women's decision to return to school may also be part of a growing acceptance and trend among adults to retrain and to start a second career, even with an established work history.

The most unexpected finding in this study, and one not discussed in the literature, is the tendency for early onset participants to report long-term unpaid work trajectories, despite high levels of educational attainment. Similarly, the participants who were either self-employed or unemployed, also had university educations. While the research literature (Canadian Abilities Foundation, 2004; Fawcett, 1996; Roeher Institute, 2004) indicates that higher educational attainment is associated with higher employment rates among people with disabilities, regardless of gender, the experiences of the participants in this study suggest that systemic discrimination and policy provisions are more significant determinants of participation in paid work than is educational attainment; and explains the unique unpaid work trajectories and outcomes for the participants with an early onset disability.

Among the adult onset participants, the literature indicates a greater likelihood for employment after the onset if a person is employed at the time of the onset (Blaxter, 1980; Canadian Abilities Foundation, 2004; Creek et al, 1987) and if they are men (Albrecht, 1992; Canadian Abilities Foundation, 2004; Vash, 1981). This is borne out by the work trajectories of the men, and to a lesser extent, the women in this study. Although the men had educational attainments of high school or less, they re-entered the work force at a time when it was common for men to acquire on-the-jobs skills (1960's to the early 1970's). The women all worked for about two years, and subsequently attended university. Participants who did not return to work report they were unable to work, and two chose to rely on work-related wage indemnity plans rather than attempt to return to paid work.

Variations in gender and disability onset are the most pronounced when examining the participants' experiences and outcomes regarding family formation. Notably, the early onset women, who are in their late forties to early fifties, were more likely to be single (never married) and unlikely to cohabitate. They report that policies, which financially penalize them for marriage (financially interdependent relationships), kept them from marrying. As a consequence, they do not report having children. While research (Fawcett, 2000) suggests that there is high rate of single parenthood among women with disabilities , this was not the pattern observed for the women (with early onset disabilities) in this study who tended not to marry or cohabitate at all. The early onset participants, who were in their twenties and early thirties, report that they have not married, cohabitated or had children. However, based on their ages, this is not unremarkable, and it remains to be seen whether their aspirations to marry and have children will be realized.

The adult onset participants were more likely to be married and have children, since the onset had occurred after family formation. However, the adult onset women were more likely to report their relationships ended as a result of the disability onset. In comparison, the men cited other reasons for the divorce. The adult onset women also reported that they either delayed childbirth, or ended a pregnancy, as a result of the disability onset based on medical advice they received. These findings are consistent with the research literature indicating that disabled women are more likely to be single or divorced than men (Fine & Asch, 1988; Matthews, 1993; Morris,1991), and more likely than men to be discouraged from, or scrutinized if they chose to become parents (Grue & Laerum, 2002; Helmius, 2004; Olsen & Clarke, 2003;Thomas, 1997). Three adult onset participants in this research report overt concerns were raised about their ability to parent and care for a child following the disability onset. Their experiences are consistent with the literature reporting that people who have a disability and who choose to parent are perceived as incapable of parenting and care giving, and even deemed irresponsible when they choose to parent (Morris, 1991; Thomas, 1997).

Another unexpected finding in this study is the *meaning* participants gave to their own life course transitions. For the participants whose onset occurred in *childhood* or *adulthood*, the onset was a disruptive and difficult transition. Despite this, participants report the disability provides insight and a unique view of life. In comparison, those with *congenital* disabilities tended to report that the disability is a core part of their identity. Regardless of age of disability onset or gender, the participants valued wheelchair use and did not view it as a stigma. Among the early onset participants, wheelchairs would serve as *toys* when playing with non-disabled children. Surgery was a also a major transition, resulting in either freeing or debilitating outcomes. Another notable transition was the move to independent living, which symbolized the transition to adulthood (Priestley, 2003) among early onset participants.

This research shows that life course experiences and outcomes of people with disabilities is a complex process, influenced by the age of disability onset, personal decisions, formal and informal resources, policy provisions, and historical circumstances. In addition, there is the overlay of gender role stereotypes and socially constructed notions of femininity and masculinity, particularly in relation to family formation, cohabitation, marriage and childbearing. This is most acute for the early onset women born prior to 1962. This research indicates that people with disabilities make decisions about their lives as a consequence of policy provisions – disability-related supports and services, income support and/or replacement programs, educational funding – which restrict or foster choices and options available to people with disabilities. Remarkably, some policy provisions *for* people with disabilities are also responsible for disabling them – constraining their choices, and marginalizing them socially and financially.

6.1 Policy Recommendations and Implications for Future Research

Based on the experiences and responses of the participants in this study, several policy recommendations were made. Foremost among the participants' recommendations: delink disability-related supports and services from means (income) testing, especially for people who are entering or re-entering the paid labour force. Likewise, disability-related support, services and income programs must not discriminate on the basis of marital status, or assume spouses will provide support. Children with physical disabilities need the same academic educations as non-disabled children as a universal standard. Policies and funding need to be in place to accommodate disability-related education needs, be it improved school access (transportation, building access), in-class learning (attendant care, tutorial assistance) or supplemental schooling assistance for children receiving therapy, surgery and/or medical treatment. In addition, disability-related support, services and income programs must meet the real life needs of day-to-day living at all ages of the life course (in schools, in the workplace, in the home). To facilitate ease of access, one ministry, or administrative body, needs to co-ordinate and administer all disability-related programs, services and supports ("one-stop" shopping). Finally, educate the medical professionals to provide information, support, strategies and resources for people with disabilities who are considering childbirth, who are pregnant and who are parents.

It is important to know more about how the experiences and outcomes of the early and adult onset participants are the result of personal, social and/or generational circumstance. Large scale studies are needed to investigate the effects of gender, age of disability onset, and generational differences on the life course, and to understand the long-term effects of living with a physical disability. This research is the first step toward generating a greater understanding of the lives of people with disabilities and contextualizing their experiences within broader social institutions and policy provisions that influence the life course. While this study has shown how a physical disability may have an impact and change the life course, living with a physical disability is not a tragedy, but a challenge to the non-disabled and disabled alike to reconstruct the world to include and accommodation all people, at all ages, now and in the future.

Appendices

Appendix A

Informed Consent

The University and those conducting this project subscribe to and advocate the ethical conduct of research and to the protection of at all times of the interests of the research participants. This form and the information it contains are given to you for your own protection and full understanding of the procedures involved. Your signature on this form will indicate that you have received an adequate description of the research project in writing and verbally, that you have received an adequate opportunity to consider the information in the document and that you voluntarily agree to participate in the project.

Having been asked by Monika Fisher of the Department of Sociology and Anthropology of Simon Fraser University to participate in the research project regarding the impact of disability on one's education, and personal and work life, collected through the use of an interview guide and an oral history,

I understand the procedures to be used.

I understand that I may withdraw my participation at any time.

I understand that I can obtain a copy of the results of from the above named researcher.

I also understand that I may register an y complaint I might have about the research with the Chair of the Sociology, Dr. Ellen Gee, Department of Sociology and Anthropology of Simon Fraser University.

I agree to be interviewed on the condition that my responses are anonymous and confidential. If at anytime I would prefer some comments to be off-the-record, this request will be honoured.

Signature:____Date:____________

For ease of discussion, I would like to be able to tape record the interview. The tapes will be used for transcription only, and will be transcribed by myself or a research assistant. No-one else will have access to the tape. Also, if at anytime you would prefer the tape recorder to be turned off, for example, for off-the-record comments, this request will be honoured.

I agree for the interview to be tape-recorded. If at anytime I would prefer some comments to be off-the-record, this request will be honoured.

Signature:____Date:____________

Once signed, a copy of this consent form should be provided to you.

Appendix B

Interview Release Form

I ____ hereby give to Monika Fisher of Simon Fraser University this taped interview and grant her the right to use the information in this interview for her research to be used in her Masters thesis. The right for her to use this information is subject to the conditions listed below.

The specific disability(s) and restriction(s) for the release of this interview is/are:

1.____

2.____

3.____

4.____

I, Monika Fisher of Simon Fraser University, hereby agree to comply with the above listed disability(s) and restriction(s) concerning the data collected in the taped interview with the aforementioned narrator.

NARRATOR: ______________________________________

ADDRESS: ______________________________________

____

SIGNATURE: ______________________________________

DATE: ______________________________________

INTERVIEWER: ______________________________________

ADDRESS: ______________________________________

____

SIGNATURE: ______________________________________

DATE: ______________________________________

Appendix C

Interview Schedule
for Those with Non-Congenital Disabilities

Just to review what we discussed earlier in our phone conversation on (give date). Firstly, any and all information you give me is confidential and your identity is anonymous. In other words, only I will know who you are. If you feel there's information that will reveal your identity, then that information will be suppressed. Secondly, I will be transcribing some parts of the taped interview. Thirdly, I will keep the cassette tapes and be responsible for storing them in a safe place. If you would like a copy I will be happy to make one for you.

Also, this interview will take some time and if you feel that you are not up to finishing it, or you'd like to take a few breaks, please don't hesitate to tell me.

As you know, we are together today to discuss your life and your experiences as a person with (state specific disability). In particular, I'm very interested in your life history starting from around the time you recall that you knew you had (state specific disability) and up to the present. It may be that you won't remember everything that's ever happened to you, but that's okay. The things that are important to you are probably the things you'll remember. There are three main areas that I'll be focusing on during the interview. One area will be your family life, and the other two areas concern your education and work life. I'll also be asking you about the kinds of medical and professional services and help you've received and the ones you use now. At the end of the interview I'll be asking you about your opinions and ideas concerning the laws or policies which have directly affected you.

Just as a reminder to you, if you feel uncomfortable or offended by any question or discussion, <u>please let me know</u>. If this is the case about anything I ask you, I want to let you know that you have the right to refuse any line of enquiry.

Name of Narrator:____________________Date of Interview:____________________

<u>Introductory Questions:</u>

1. Sex. ________________

2. Date of birth. ________________: Therefore you are currently _____ years old?

3. Birthplace (Community, Reserve, Village or City, and Country). ______________

4. I'm going to ask you to tell me a little about who you lived with when you were growing-up. In particular, I'm interested in which <u>adults</u> in your life raised you and when? For example, when I was growing-up I lived with my mother and father until they separated and divorced when I was 11 years-old. After that, I lived with my father for 2 years. I then lived with my mother and her new husband until I was 17

years-old. (If the narrator states "my family", ask them to list all her/his "family" members. If the narrator indicates that she/he was institutionalized, get a brief history of where she/he stayed and explore this in detail during the interview.)

____

____

5. Who looked after you the most? ________________________________

6. Any sisters or brothers?

____No } If no, **go to question 8.**
____Yes } If yes, **go to question 7.**

7. Gender of sibling(s) and age(s).

Gender:	Age:
a-I.) ______________	a-ii.) ______________
b-I.) ______________	b-ii.) ______________
c-I.) ______________	c-ii.) ______________
d-I.) ______________	d-ii.) ______________

In the questions that follow include the appropriate references to the adults who the narrator grew-up with as discussed in question 4. This may include her/his mother, father, step-parents, the common-law spouse of a parent, extended family members and/or the person who looked after her/him the most.

8. Have any of the adults who raised you passed away? (PROBE: The people I'm thinking of would be .. refer to the persons discussed in question 4.)

____No } If no, **go to question 10.**
____Yes } If yes, **go to question 9.**

9. Who passed away and when? ________________________________

10a. What is/was your mother's education. __________________

10b. What is/was your father's education. __________________

If applicable:

10c. Stepmother's education. ________________

10d. Stepfather's education. ________________

10e. Person who cared for you the most - her/his education. ______________

11a. What is/was your mother's main occupation or work (eg. current work or last job) __________ (PROBE: So would that be her current work or her last job or ...?)

11b. What is/was your father's main occupation or work (eg. current work or last job) __________ (PROBE: So would that be his current work or his last job or ...?)

If applicable:

11c. Stepmother's main occupation or work __________________
(PROBE: So would that be her current work or her last job or ...?) ____________

11d. Stepfather's main occupation or work __________________
(PROBE: So would that be his current work or his last job or ...?) ______________

11e. Person who cared for you the most - her/his main occupation or work ___________
(PROBE: So would that be her/his current work or her/his last job or ...?) ________

12. What is your present marital status? I'll read you a list and please tell me which descriptions apply to you.

a.) ____ Single, never married. If single, **go to question 20.** Next page ----->

b.) ____ Common-law relationship. } **Go to question 13.**

c.) ____ Separated. } **Go to question 14.**

d.) ____ Divorced. }
} **Go to question 15.**
e.) ____ Widowed. }

f.) ____ Married. } **Go to question 16.**

13. When did you start living together with your common-law spouse? ________
Go to question 17.

14. How long have you been separated from your husband (or wife)? _________

15. How long were you married for? ___________

16. When did you get married? (i.e., date of marriage)___________

17. *For those who are living common-law...* Have you ever been married before? *For those who are separated, divorced, widowed or married...* Have you married more than once?

____ No } If no, **go to question 20**. Next page ------ >

____ Yes } If yes, **go to question 18**.

18. How many times? ______

19. Can you tell me when you were married and when that marriage ended? (For example: When did you separate and divorce? When were you widowed?)

Date of - Marriage:___________ Separation: ________________

Divorce:___________ Widow(er)hood: ________________

Date of - Marriage:___________ Separation: ________________

Divorce:___________ Widow(er)hood: ________________

20. Have you ever been in a common-law relationship before?

____ No } If no, **go to question 23**.

____ Yes } If yes, **go to question 21**.

21. How many times? ______

22. Can you tell me when you began living together and when you stopped living together?

Start Date (Month, Year):___________ End Date: ___________

Start Date (Month, Year):___________ End Date: ___________

If need be, repeat the information gathered from the narrator to ensure you are correct. So just to review your marital status, you are currently .... and you were ...

23. Do you have any children or stepchildren?

____ No } If no, **go to question 29.**

____ Yes } If yes, **go to question 24.**

24. How many children or stepchildren do you have? __________

25. Would you please tell me if you have a daughter, son, stepdaughter or stepson, and their/her/his age(s)?

Relationship: Age:

a-I.) _______________ a-ii.) _______________

b-I.) _______________ b-ii.) _______________

c-I.) _______________ c-ii.) _______________

d-I.) _______________ d-ii.) _______________

26. Do <u>all</u> your children/stepchildren live with you? / Does your (step)daughter/son live with you?

____ No } If no, **go to question 27.**

____ Yes } If yes, **go to question 28.**

27. Where do your children/stepchildren live and why? / Where does she/he live with and why?

____

28. Can you tell me why they/she/he live(s) with you?

____

29. Apart from yourself/and the family members you've mentioned, namely your (list family members), is the anyone else you live with?

____ No } If no, **go to question 32.**

____ Yes } If yes, **go to question 30.**

30. Who are they and why do you live with them?*Record the relationship (eg. friend, room-mate, parents) and the reasons for sharing the home.*

____

PROBE: So would you say that "you live with them" or "that they live with you"

or

____

31. How long have you been living with (state responses to question 30)?

____

32. What is your educational attainment?____________________

33a. When did you complete your (state level of educational attainment) education or are you still completing your education? ____________________. If she/he <u>has completed</u> her/his schooling, **go to question 34**.
If she/he <u>is still completing</u> her/his schooling:

33b. When do you think you'll finish ______________________________

33c. What degree, diploma or certification you have then? __________________

33d. Are you a full-time student or a part-time student or ...?

_____ Full-time student _____ Part-time Student

_____ Other, Explain ____________________________________

34. Did you ever discontinue your education for any reason?

____ No } If no, **go to question 41**.

____ Yes } If yes, **go to question 35**.

35. What were the reasons for discontinuing your education?

____

36. Did you resume your education?

____ No } If no, **go to question 37**.
____ Yes } If yes, **go to question 38**.

37. Why not? ____

38. Did you finish your education?

____ No } If no, **go to question 39**. (Be aware that the narrator may have returned to school and may be in the process of finishing her/his education)

____ Yes } If yes, **go to question 40**.

39. Why? ____

Go to question 41.

40. When did you finish your education?______________________________

41. Have you taken any other courses such as a first aid course or night courses over the last three years?

____ No } If no, **go to question 44**. Next page ------>

____ Yes } If yes, **go to question 42**.

42. Which courses did you take and when?

____Date:_______

____Date:_______

43. Are there any special reasons why you have taken those courses*(Note that the responses to questions 35 or 37 may already answer this.)*

Please explain.____

44. Have you attended any seminars, workshops, or conferences over the last three years?

____ No } If no, **go to question 47**.

____ Yes } If yes, **go to question 45**.

45. Which seminars, workshops or conferences did you attend and when did you go?

____Date:______

____Date:______

46. Are there any special reasons why you attended those seminars, workshops or conferences? *(Note that the responses to question 35 or 37 may already answer this.)*

Please explain.____

47. ARE YOU CURRENTLY DOING ANY VOLUNTEER WORK?

____ No } If no, **go to question 50.**

____ Yes } If yes, **go to question 48.**

48. Where are you volunteering and what are your responsibilities there?

____

49 How long have you been doing volunteer work there? ______________

50. ARE YOU CURRENTLY EMPLOYED FOR WAGES?

____ No } If no, **go to question 63.**

____ Yes } If yes, **go to question 51.**

51. What kind of work do you do? ______________________________

52. What is your job title? ____________________________________

53. How many hours do you work per week? ________________________

54. Where do you work (who is your employer)? If you are not comfortable with giving me this information I will understand completely. ______________

55. When did you begin working there? ______________

56. What is your current annual wage? Again, if you are not comfortable with giving me this information I will understand completely. ______________

For narrators with a congenital disability, proceed to question 60.
For narrators with a late onset of disability, proceed to question 57.

57. Did you get <u>this job</u> before, after or during the onset of your disability?

____ Before } If before, **go to question 58.**

____ During } If during, **go to question 58.**

____ After } If after, **go to question 60.**

58. Did any one at work know about your changing health status when you first began to experience some of the effects of your disability?

____ No } If no, **go to question 60.**

____ Yes } If yes, **go to question 58.**

59. Who knew? ____

60. <u>At present</u>, do your employer(s), supervisor(s) or co-worker(s) know of your disability?
60a. Employer(s) _____ Yes ____No }
60b. Co-worker(s) _____ Yes ____ No }**If yes for any of these, go**
60c. Supervisor(s) _____ Yes ____ No }**to question 61, otherwise**
60d. Other(s) _____ Yes ____ No }**proceed to question 62.**

61. Did you inform your employer(s), supervisor(s) or co-worker(s) of your disability?
61a. Employer(s) _______ Yes _______ No
61b. Co-worker(s) _______ Yes _______ No
61c. Supervisor(s) _______ Yes _______ No
61d. Other(s) _______ Yes _______ No

62. If yes or no, why? ____

63. ARE YOU CURRENTLY SELF-EMPLOYED?

____ No } If no, **go to question 71.** Next page ------>
____ Yes } If yes, **go to question 64.**

64. What kind of work do you do? ______________________________

65. (If applicable), what kind of business is it? ________________________

66. How many hours do you work per week? ________________________

67. How long have you been self-employed for? ________________________

68. Can you tell me what your net annual earnings are? If you are not comfortable with giving me this information I will understand completely.

____

For narrators with a congenital disability, proceed to question 80.
For narrators with a late onset of disability, proceed to question 69.

69. Were you self-employed before or after the onset of your disability?

____ Before } If before, **go to question 70.**

____ After } If after, **go to question 80.**

70. Were you self-employed in the same field?

____ No })
) **go to question 80.**
____ Yes })

71. ARE YOU CURRENTLY LOOKING FOR PAID EMPLOYMENT?

____ No } If no, **go to question 79.** Next page ----- >

____ Yes } If yes, **go to question 72.**

72. How long have you been looking for paid work? ____________________

73. What kinds of jobs have you been applying for? ____________________

74. When was the last time you worked for wages?

__________ Never } **go to question 80.**

__________ Date Last Worked } **go to question 75.**

75. What kind of work did you do in your last job? ____________________

76. Who was your last employer? ____________________________________

77. How many hours per week did you work back then? ___________________

78. What was your annual wage back then? _______________________

Go to question 80.

79. CAN YOU TELL ME WHY YOU ARE NOT CURRENTLY LOOKING FOR PAID WORK?

____

80. CAN YOU GIVE ME A COMPLETE LIST OF ALL YOUR INCOME SOURCES FOR THE YEAR _____? (If applicable, ask for the income sources of the spouse or common-law partner.)

____

____

____

81. Was this typical of your income sources in the last 5 years?

____ No } If no, please explain _____________________________________

____

____ Yes } If yes, begin taped interview.

Begin the taped interview.

Interview Schedule - Commence Taped Interview from Here on:

Terms of Reference:

1. What do you think of when you hear the word "disability"? (How do you define "disability"?)

2. How do you feel about the terms "disabled" and "handicapped"?

3. Are there terms which you prefer to disability or handicap?

4. For the record, can you tell me the name of the disability you have?

5. I don't know much about (state specific disability). Can you tell me more about it?

Life Path Prior to the Onset of the Disability:

Here is where I begin asking you about your life history. I would like you to tell me about what was going on in your life about a year prior to the onset of the (state specific disability). By this I mean the time when you were not aware you had (state specific disability).

6. How old were you at that time?

7. *At this point in the interview repeat the salient and relevant information the narrator provided in the first portion of the interview. This will help to locate the narrator in her/his personal time line (eg. child, teenager, young adult, etc.) and this will allow the narrator to correct you or to provide greater detail about her/his education, family, living arrangements and work.*

   Given what you've told me earlier, I'd say you: (state appropriate education level if she/he was of school age) "were in grade 10", or "just finishing your college diploma", or "had completed most of your formal schooling over 17 years ago"; (discuss the narrator's family status and living arrangements as you perceived it at that time - "you had just starting living with your common-law partner", and/or "your daughter was just born and your already had a seven-year-old", or "you were living with your parents", or "you were working at company X"... Is that an accurate description? What was going on at the time?

8. Just prior to the onset of the (state specific disability) do you recall how you saw your life unfolding back then? For example, what were your dreams and aspirations?

   (PROBES: ... with regard to schooling/education? ... work? ... family life?)

Onset of the Disability:

9. Would you say that the onset of the (state specific disability) was sudden or gradual?

10. When did you first begin to notice anything different about your health or your ability to do day-to-day work or activities? (i.e., symptoms)

11. How long before you sought professional help? (e.g. How long before you went to the doctor?)

12. If over 1 year: Why did you wait for (state period of time) before seeking professional help (e.g. going to the doctor?)

13. Initially, what did you think you had?

14. How did you find out you had (state specific disability)?

15. How long was it between your first symptoms and a medical diagnosis of (state specific disability)?

16. Were there any other medical opinions which were different? If yes, please explain.

17. Who told you had (state specific disability)? Was it a doctor, a nurse ...?

18. How were you told that you had (state specific disability)?

19. How did you feel about the person who told you had (state specific disability)?

20. Did you go elsewhere to learn more?

21. When you were first told that you had (state specific disability), how much did you know about it?

22. When you first found out that you had (state specific disability), what did you think would happen to you?

23. Were you scared?

24. Did you have any preconceived ideas or notions about (state specific disability)? If yes, Do you have any idea where those ideas or notions may have come from?

25. Do you recall anything else about the news of having (state specific disability)?

26. Initially, did the onset of the (state specific disability) have an immediate affect on your:
    a.) **If applicable**, schooling/education?
    b.) **If applicable**, work?
    c.) **If applicable**, family life?
    d.) day-to-day life (eg. where you were living)?

27. Did the onset of the (state specific disability) change your dreams and aspirations about what you were planning to do with your life? Explain.

28. When you first began to experience the effects of (state specific disability), what were some the frustrating experiences you had? If yes, What sorts of changes did you make?

29. Can you tell me about some positive experiences you had?

<u>Support and Resources:</u>

30. Initially, what kinds of medical or professional help did you seek out which was related to the onset of the (state specific disability)? PROBE: This could have been care or help from a doctor, social worker, government agency, or services like physical rehabilitation, a personal care attendant and physiotherapy.

31. What help did you actually receive?

32. What did you think of the help you received?

33. Did your medical professionals suggest any of these services or did you (or a family member or friend) pursue them on your own?

34. Did you pursue other forms of support of any kind after the diagnosis? PROBE: This could have been your family, alternative medicines, support groups or religious guidance.

35. <u>At present</u>, what kinds of medical care, professional help, or support do you receive?

36. What part do you feel your family and friends have played during the onset of the (state specific disability)? (PROBES: What kind of support have they offered? Who do you think provided the most support?)

37. Was there anybody else who influenced you - such as a mentor or role model?

Life Path After the Onset of the Disability to Present - Life History:

In the next part of the interview, I'd like you to tell me about your work, education and family history since the onset of the (state specific disability). This would be about the time when you had already been diagnosed and perhaps you had begun to make some changes in your life concerning your family life, your living arrangements, your education or your work. It might be easier for your to provide a year by year description, or if you'd prefer, you can tell me about your work history since the onset, then your education history and then about your personal and family history.

38. a.) Schooling, education, night courses, seminars - PROBES: What courses or programs were you taking or thinking of taking?; Where did you go to school?; Did it take longer to finish your schooling?

b.) Work and employment - PROBES: When did you get you first job? What kind of work have you done since the onset?; Which companies did you work for?; How long did you work for?; What kinds of work did you try to find?; How long was it before your next job?; So where did you work next and what did you do?; What kinds of financial challenges were you up against?

c.) Personal and family history - PROBES: When did you leave home?; Where did you first live?; Who were you living with? Were you dating?; What did you think about having children?; What were some of your family responsibilities - such as child care or caring for your parents?; When did you buy your home?

39. Have you ever felt that some people assumed that you were incapable of being a parent, student, worker or lover because of (state specific disability)? (PROBE: The people I'm thinking of might be family, friends and acquaintances, spouse/intimate friends/partner, co-workers and employers, medical professionals, and students or teachers.)

If yes: Can you give me some examples of these incidents?

40. Have you ever experienced discrimination? By discrimination I mean have you ever been denied access to or excluded from an opportunity, a job, a building, an education, medical care, child care, child custody and so on as a result of your disability, gender, race, ethnic background or age.

If yes: Can you give me some examples of the discrimination you've experienced? (Note that the responses to question 39 may have answered this.)

If no to both questions 39 and 40: **Go to question 44**.

41. **For those with a "hidden" disability:** Have you ever been concerned about being discriminated against if anyone found out that you had (state specific disability)?

    If yes: Can you tell me about it? **Proceed to question 42.**
    If no: **Proceed to question 44.**

42. Do you think that being a woman/man has anything to do with the kinds of experiences you've described to me?

43. What kinds of policies or laws do you think need to be implemented for the incidents you've described to change?

44. Looking back over the past few years, what would you say was the hardest thing about having (state specific disability)?

45. If you could change any of what has happened to you, what things would those be?

46. What do you think was the best thing about having (state specific disability)?

<u>Anticipated Life Path:</u>

47. What do you see yourself doing over the next few years in regard to family, schooling and work?

48. What choices would you like to make in regard to your family, schooling and work? (How would you like to see things unfolding in your life in regard to your family, schooling and work?)

49. What would need to change for this to happen? (e.g, Increasing social assistance, tutor for school, additional aides, own vehicle for transportation, increased social awareness, more accessible programs for vocational rehabilitation)

<u>Policies and Resources:</u>

50. Do you, or did you, belong to any support groups for persons with disabilities? Can you tell me about your experiences with them?

51. Are there any policies, practices or laws regarding persons with disabilities that have affected you?

52. Are there any current practices, policies or laws which you feel:
    a.) need to be changed?
    b.) are effective insofar as they address your concerns or needs?

c.) are ineffective insofar as they address your concerns or needs?

For example, I'm thinking of access to and funding for programs for re-training, funding for attendant care or homemakers, funding for accessible housing, or the adequacy of public transportation.

53. Are there any questions or issues which I have not addressed which you would like to discuss? If so, please tell me about them.

54. Are there any concerns you have about the questions and issues we've discussed? If so, please tell me about them.

Appendix D

Interview Schedule for Those with Congenital Disabilities

Just to review what we discussed earlier in our phone conversation on (give date). Firstly, any and all information you give me is confidential and your identity is anonymous. In other words, only I will know who you are. If you feel there's information that will reveal your identity, then that information will be suppressed. Secondly, I will be transcribing some parts of the taped interview. Thirdly, I will keep the cassette tapes and be responsible for storing them in a safe place. If you would like a copy I will be happy to make one for you.

Also, this interview will take some time and if you feel that you are not up to finishing it, or you'd like to take a few breaks, please don't hesitate to tell me.

As you know, we are together today to discuss your life and your experiences as a person with (state specific disability). In particular, I'm very interested in your life history starting from around the time you recall that you knew you had (state specific disability) and up to the present. It may be that you won't remember everything that's ever happened to you, but that's okay. The things that are important to you are probably the things you'll remember. There are three main areas that I'll be focusing on during the interview. One area will be your family life, and the other two areas concern your education and work life. I'll also be asking you about the kinds of medical and professional services and help you've received and the ones you use now. At the end of the interview I'll be asking you about your opinions and ideas concerning the laws or policies which have directly affected you.

Just as a reminder to you, if you feel uncomfortable or offended by any question or discussion, <u>please let me know</u>. If this is the case about anything I ask you, I want to let you know that you have the right to refuse any line of enquiry.

Name of Narrator:______________________Date of Interview:____________________

<u>Introductory Questions:</u>

1. Sex. __________________

2. Date of birth. __________________: Therefore you are currently ______ years old?

3. Birthplace (Community, Reserve, Village or City, and Country). ________________

4. I'm going to ask you to tell me a little about who you lived with when you were growing-up. In particular, I'm interested in which <u>adults</u> in your life raised you and when? For example, when I was growing-up I lived with my mother and father until they separated and divorced when I was 11 years-old. After that, I lived with my father for 2 years. I then lived with my mother and her new husband until I was 17

years-old. (If the narrator states "my family", ask them to list all her/his "family" members. If the narrator indicates that she/he was institutionalized, get a brief history of where she/he stayed and explore this in detail during the interview.)

____

____

5. Who looked after you the most? ______________________________

6. Any sisters or brothers?

____ No } If no, **go to question 8.**
____ Yes } If yes, **go to question 7.**

7. Gender of sibling(s) and age(s).

Gender: Age:

a-I.) ______________ a-ii.) ______________

b-I.) ______________ b-ii.) ______________

c-I.) ______________ c-ii.) ______________

d-I.) ______________ d-ii.) ______________

In the questions that follow include the appropriate references to the adults who the narrator grew-up with as discussed in question 4. This may include her/his mother, father, step-parents, the common-law spouse of a parent, extended family members and/or the person who looked after her/him the most.

8. Have any of the adults who raised you passed away? (PROBE: The people I'm thinking of would be .. refer to the persons discussed in question 4.)

____ No } If no, **go to question 10.**
____ Yes } If yes, **go to question 9.**

9. Who passed away and when? ______________________________

10a. What is/was your mother's education. ________________

10b. What is/was your father's education. ________________

If applicable:

10c. Stepmother's education. ________________

10d. Stepfather's education. ________________

10e. Person who cared for you the most - her/his education. ______________

11a. What is/was your mother's main occupation or work (eg. current work or last job) __________ (PROBE: So would that be her current work or her last job or ...?)

11b. What is/was your father's main occupation or work (eg. current work or last job) __________ (PROBE: So would that be his current work or his last job or ...?)

If applicable:

11c. Stepmother's main occupation or work __________________
(PROBE: So would that be her current work or her last job or ...?) ____________

11d. Stepfather's main occupation or work __________________
(PROBE: So would that be his current work or his last job or ...?) ______________

11e. Person who cared for you the most - her/his main occupation or work ___________
(PROBE: So would that be her/his current work or her/his last job or ...?) ________

12. What is your present marital status? I'll read you a list and please tell me which descriptions apply to you.

a.) ____ Single, never married. If single, **go to question 20.** Next page ----->

b.) ____ Common-law relationship. } **Go to question 13.**

c.) ____ Separated. } **Go to question 14.**

d.) ____ Divorced. }
} **Go to question 15.**
e.) ____ Widowed. }

f.) ____ Married. } **Go to question 16.**

13. When did you start living together with your common-law spouse? ________
Go to question 17.

14. How long have you been separated from your husband (or wife)? _________

15. How long were you married for? ___________

16. When did you get married? (i.e., date of marriage)____________

17. *For those who are living common-law...* Have you ever been married before? *For those who are separated, divorced, widowed or married...* Have you married more than once?

____ No } If no, **go to question 20**. Next page ------ >

____ Yes } If yes, **go to question 18**.

18. How many times? ______

19. Can you tell me when you were married and when that marriage ended? (For example: When did you separate and divorce? When were you widowed?)

Date of - Marriage:____________ Separation: _________________

Divorce:____________ Widow(er)hood: _________________

Date of - Marriage:____________ Separation: _________________

Divorce:____________ Widow(er)hood: _________________

20. Have you ever been in a common-law relationship before?

____ No } If no, **go to question 23**.

____ Yes } If yes, **go to question 21**.

21. How many times? ______

22. Can you tell me when you began living together and when you stopped living together?

Start Date (Month, Year):____________ End Date: ____________

Start Date (Month, Year):____________ End Date: ____________

If need be, repeat the information gathered from the narrator to ensure you are correct. So just to review your marital status, you are currently .... and you were ...

23. Do you have any children or stepchildren?

____ No } If no, **go to question 29**.

____ Yes } If yes, **go to question 24**.

24. How many children or stepchildren do you have? __________

25. Would you please tell me if you have a daughter, son, stepdaughter or stepson, and their/her/his age(s)?

Relationship:	Age:
a-I.) _______________	a-ii.) _______________
b-I.) _______________	b-ii.) _______________
c-I.) _______________	c-ii.) _______________
d-I.) _______________	d-ii.) _______________

26. Do <u>all</u> your children/stepchildren live with you? / Does your (step)daughter/son live with you?

____ No } If no, **go to question 27**.

____ Yes } If yes, **go to question 28**.

27. Where do your children/stepchildren live and why? / Where does she/he live with and why?

____

28. Can you tell me why they/she/he live(s) with you?

____

29. Apart from yourself/and the family members you've mentioned, namely your (list family members), is the anyone else you live with?

____ No } If no, **go to question 32**.

____ Yes } If yes, **go to question 30**.

30. Who are they and why do you live with them?*Record the relationship (eg. friend, room-mate, parents) and the reasons for sharing the home.*

____

PROBE: So would you say that "you live with them" or "that they live with you" or

____

31. How long have you been living with (state responses to question 30)?

____

32. What is your educational attainment?__________________

33a. When did you complete your (state level of educational attainment) education or are you still completing your education? __________________. If she/he has completed her/his schooling, **go to question 34.**
If she/he is still completing her/his schooling:

33b. When do you think you'll finish _______________________________

33c. What degree, diploma or certification you have then? ________________

33d. Are you a full-time student or a part-time student or ...?

_____ Full-time student _____ Part-time Student

_____ Other, Explain ______________________________________

34. Did you ever discontinue your education for any reason?

____ No } If no, **go to question 41.**

____ Yes } If yes, **go to question 35.**

35. What were the reasons for discontinuing your education?

____

36. Did you resume your education?

____ No } If no, **go to question 37.**
____ Yes } If yes, **go to question 38.**

37. Why not? ____

38. Did you finish your education?

____ No } If no, **go to question 39**. (Be aware that the narrator may have returned to school and may be in the process of finishing her/his education)

____ Yes } If yes, **go to question 40.**

39. Why? ____

Go to question 41.

40. When did you finish your education?____________________________

41. Have you taken any other courses such as a first aid course or night courses over the last three years?

____ No } If no, **go to question 44.** Next page ------>

____ Yes } If yes, **go to question 42.**

42. Which courses did you take and when?

____Date:______

____Date:______

43. Are there any special reasons why you have taken those courses*(Note that the responses to questions 35 or 37 may already answer this.)*

Please explain.____

44. Have you attended any seminars, workshops, or conferences over the last three years?

____ No } If no, **go to question 47.**

____ Yes } If yes, **go to question 45.**

45. Which seminars, workshops or conferences did you attend and when did you go?

_______________________________________Date:______

_______________________________________Date:______

46. Are there any special reasons why you attended those seminars, workshops or conferences? *(Note that the responses to question 35 or 37 may already answer this.)*

Please explain.____

47. ARE YOU CURRENTLY DOING ANY VOLUNTEER WORK?

____ No } If no, **go to question 50**.

____ Yes } If yes, **go to question 48**.

48. Where are you volunteering and what are your responsibilities there?

____

49 How long have you been doing volunteer work there? ______________

50. ARE YOU CURRENTLY EMPLOYED FOR WAGES?

____ No } If no, **go to question 63**.

____ Yes } If yes, **go to question 51**.

51. What kind of work do you do? ______________________________

52. What is your job title? ____________________________________

53. How many hours do you work per week? ______________________

54. Where do you work (who is your employer)? If you are not comfortable with giving me this information I will understand completely. _____________

55. When did you begin working there? _______________

56. What is your current annual wage? Again, if you are not comfortable with giving me this information I will understand completely. ______________

For narrators with a congenital disability, proceed to question 60.
For narrators with a late onset of disability, proceed to question 57.

57. Did you get <u>this job</u> before, after or during the onset of your disability?

____ Before } If before, **go to question 58.**

____ During } If during, **go to question 58.**

____ After } If after, **go to question 60.**

58. Did any one at work know about your changing health status when you first began to experience some of the effects of your disability?

____ No } If no, **go to question 60.**

____ Yes } If yes, **go to question 58.**

59. Who knew? ____

60. <u>At present</u>, do your employer(s), supervisor(s) or co-worker(s) know of your disability?

60a. Employer(s)	_____ Yes	____No }	
60b. Co-worker(s)	_____ Yes	____ No	**}If yes for any of these, go**
60c. Supervisor(s)	_____ Yes	____ No	**}to question 61, otherwise**
60d. Other(s)	_____ Yes	____ No	**}proceed to question 62.**

61. Did you inform your employer(s), supervisor(s) or co-worker(s) of your disability?

61a. Employer(s)	_______ Yes	_______ No
61b. Co-worker(s)	_______ Yes	_______ No
61c. Supervisor(s)	_______ Yes	_______ No
61d. Other(s)	_______ Yes	_______ No

62. If yes or no, why? ____

63. ARE YOU CURRENTLY SELF-EMPLOYED?

____ No } If no, **go to question 71.** Next page ------>
____ Yes } If yes, **go to question 64.**

64. What kind of work do you do? ________________________________

65. (If applicable), what kind of business is it? ________________________

66. How many hours do you work per week? ________________________

67. How long have you been self-employed for? ________________________

68. Can you tell me what your net annual earnings are? If you are not comfortable with giving me this information I will understand completely.

____

For narrators with a congenital disability, proceed to question 80.
For narrators with a late onset of disability, proceed to question 69.

69. Were you self-employed before or after the onset of your disability?

____ Before } If before, **go to question 70.**

____ After } If after, **go to question 80.**

70. Were you self-employed in the same field?

____ No })
) **go to question 80.**
____ Yes })

71. ARE YOU CURRENTLY LOOKING FOR PAID EMPLOYMENT?

____ No } If no, **go to question 79.** Next page ----->

____ Yes } If yes, **go to question 72.**

72. How long have you been looking for paid work? ____________________

73. What kinds of jobs have you been applying for? ____________________

74. When was the last time you worked for wages?

__________ Never } **go to question 80.**

__________ Date Last Worked } **go to question 75.**

75. What kind of work did you do in your last job? ____________________

76. Who was your last employer? ____________________________________

77. How many hours per week did you work back then? ___________________

78. What was your annual wage back then? _______________________

Go to question 80.

79. CAN YOU TELL ME WHY YOU ARE NOT CURRENTLY LOOKING FOR PAID WORK?

____

80. CAN YOU GIVE ME A COMPLETE LIST OF ALL YOUR INCOME SOURCES FOR THE YEAR ______? (If applicable, ask for the income sources of the spouse or common-law partner.)

____

____

____

81. Was this typical of your income sources in the last 5 years?

____ No } If no, please explain _____________________________________

____

____ Yes } If yes, begin taped interview.

Begin the taped interview.

Interview Schedule - Commence Taped Interview from Here on:

Terms of Reference:

1. What do you think of when you hear the word "disability"? (How do you define "disability"?)

2. How do you feel about the terms "disabled" and "handicapped"?

3. Are there terms which you prefer to disability or handicap?

4. For the record, can you tell me the name of the disability you have?

5. I don't know much about (state specific disability). Can you tell me more about it?

Early Experiences:

Here is where I begin asking you about your life history and experiences. I thought that you could begin with your recollection of when you first learned that you had (state specific disability) and if you could tell about your experiences during that time. If you'd prefer, you can tell me about any events that were important to you and that you'd like to tell me about.

6. How old were you when you were diagnosed with (state specific disability)?

7. Can you begin by telling me about the process of how you learned that you had (state specific disability)?

8. How old were you at that time?

9. What do you recall was going on in your life at that time?

9. How did you feel about the idea that you had (state specific disability?

10. Were you scared?

Early Education to High School:

In the next part of the interview, I'll be asking you about your schooling and education history. I'm interested to know where you went to school and what your experiences were in the education system. *If the narrator reported any discontinuations or disruptions in her/his education, appropriately explore this in greater detail in the following section if need be. Also, get a history of the narrator's education to her/his highest level of education up to high school and what challenges she/he faced in the education system.*

11. Where did you attend elementary school? (Can you tell me the names of the schools and where they were?)

12. What was it like for you in elementary school? (PROBES: Was that school a school for kids with disabilities? When did you go to school there? Were there any special arrangement made for you such as a tutor, an aide, special equipment, smaller classroom size, or...? Do you recall any of the teachers you had and how they treated you?)

13. Where did you go after elementary school?

14. What was it like there?

15. Do recall what some the attitudes of school mates and teachers were towards you or other people with disabilities when you were in school then?

16. **If applicable**, How did that make you feel?

Life Path After Early Education - Life History:

In the next part of the interview, I'd like you to tell me about your work, education and family history after you finished your secondary schooling (or highest grade completed if not grade 12). It might be easier for your to provide a year by year description, or if you'd prefer, you can tell me about your education history since you finished (state secondary grade completed), then your work history and then about your personal and family history.

17. a.) Schooling, education, night courses, seminars - PROBES: What courses or programs were you taking or thinking of taking?; Where did you go to school?; Did it take longer to finish your schooling? So, after high school did you consider attending a college, trade school or university?; Why or why not? How did/does the college/trade school/university accommodate your needs? Did/do you require any special equipment, a tutor or an attendant to attend school?

    b.) Work and employment - PROBES: When did you get you first job? What kind of work have you done since the onset?; Which companies did you work for?; How long did you work for?; What kinds of work did you try to find?; How long was it before your next job?; So where did you work next and what did you do?; What kinds of financial challenges were you up against?

    c.) Personal and family history - PROBES: When did you leave home?; Where did you first live?; Who were you living with? Were you dating?; What did you think about having children?; What were some of your family responsibilities - such as child care or caring for your parents?; When did you buy your home?

Support and Resources:

18. Do you recall what kinds of medical or professional help you received when you were growing-up? You don't have to recall everything that occurred, but were there any incidents which stand out in your mind? PROBE: This could have been care or help from a doctor, social worker, government agency, or services like physical rehabilitation, a personal care attendant and physiotherapy.

19. What did you think of the help you received?

20. Did your medical professionals suggest any of these services or did you or your family pursue them on your own?

21. Did you pursue other forms of support of any kind? PROBE: This could have been alternative medicines, support groups or religious guidance.

22. At present, what kinds of medical care, professional help, or support do you receive?

23. What part do you feel your family and friends have played? (PROBES: What kind of support have they offered? Who do you think provided the most support?)

24. Was there anybody else who influenced you - such as a mentor or role model?

Personal Perspectives:

25. Some of the people I've interviewed were adults when they became disabled. Since it seems a little odd to ask what you life was like before the (state specific disability), I though I would ask you if there were any times or moments when the (state specific disability) made you feel different?

26. How did you handle this?

27. What were some of the frustrating experiences that you had?

28. Can you tell me about some of the positive experiences you had?

30. Have you ever felt that some people assumed that you were incapable of being a parent, student, worker or lover because of (state specific disability)? (PROBE: The people I'm thinking of might be family, friends and acquaintances, spouse/intimate friends/partner, co-workers and employers, medical professionals, and students or teachers.)

    If yes: Can you give me some examples of these incidents?

31. Have you ever experienced discrimination? By discrimination I mean have you ever been denied access to or excluded from an opportunity, a job, a building, an education, medical care, child care, child custody and so on as a result of your disability, gender, race, ethnic background or age.

    If yes: Can you give me some examples of the discrimination you've experienced? (Note that the responses to question 30 may have answered this.)

    If no to both questions 30 and 31: **Go to question 35.**

    32. **For those with a "hidden" disability:** Have you ever been concerned about being discriminated against if anyone found out that you had (state specific disability)?

        If yes: Can you tell me about it? **Proceed to question 33.**
        If no: **Proceed to question 35.**

    33. Do you think that being a woman/man has anything to do with the kinds of experiences you've described to me?

    34. What kinds of policies or laws do you think need to be implemented for the incidents you've described to change?

35. Looking back over the past few years, what would you say was the hardest thing about having (state specific disability)?

36. If you could change any of what has happened to you, what things would those be?

37. What do you think was the best thing about having (state specific disability)?

<u>Anticipated Life Path:</u>

39. What do you see yourself doing over the next few years in regard to family, schooling and work?

40. What choices would you like to make in regard to your family, schooling and work? (How would you like to see things unfolding in your life in regard to your family, schooling and work?)

41. What would need to change for this to happen? (e.g, Increasing social assistance, tutor for school, additional aides, own vehicle for transportation, increased social awareness, more accessible programs for vocational rehabilitation)

Policies and Resources:

42. Do you, or did you, belong to any support groups for persons with disabilities? Can you tell me about your experiences with them?

43. Are there any policies, practices or laws regarding persons with disabilities that have affected you?

44. Are there any current practices, policies or laws which you feel:
    a.) need to be changed?
    b.) are effective insofar as they address your concerns or needs?
    c.) are ineffective insofar as they address your concerns or needs?

    For example, I'm thinking of access to and funding for programs for re-training, funding for attendant care or homemakers, funding for accessible housing, or the adequacy of public transportation.

45. Are there any questions or issues which I have not addressed which you would like to discuss? If so, please tell me about them.

46. Are there any concerns you have about the questions and issues we've discussed? If so, please tell me about them.

Appendix E

Participants' Pseudonyms and Demographics

Pseudonyms	Age at Onset	Age at Interview	Educational Attainment at Interview	Marital Status at Interview	Ever Had a Child?	Work Status at Interview
Participants with Early Onset Disabilities:						
Jemma	birth	37	University Degree	Married	No	Out of the Labour Force
Carrie	birth	35	University Degree	Single	No	Out of the Labour Force
Lilia	birth	44	College and/or Some Postsecondary	Single	No	Out of the Labour Force
Angela	10 to 11	26	College and/or Some Postsecondary	Single	No	Student
Alaura	7	39	University Degree	Single	No	Unemployed
Alice	11	54	High School or Less	In Long-Term Relationship	No	Out of the Labour Force
Michael	birth	21	College and/or Some Postsecondary	Single	No	Student
Erik	birth	33	University Degree	Single	No	Self-Employed
Frederick	birth	47	College and/or Some Postsecondary	Married	No	Out of the Labour Force
Pierre	birth	26	High School or Less	Single	No	Out of the Labour Force
David	birth to age 2	28	College and/or Some Postsecondary	Single	No	Out of the Labour Force
Participants with Adult Onset Disabilities:						
Hailey	31 to 32	42	College and/or Some Postsecondary	Married	Yes	Student
Anne	27	60	College and/or Some Postsecondary	Divorced or Widowed	Yes	Student
Simone	34	41	College and/or Some Postsecondary	In Long-Term Relationship	Yes	Student
Kim	31	35	High School or Less	Single	No	Out of the Labour Force
Andrew	34	78	High School or Less	Married	Yes	Out of the Labour Force
Peter	22	63	College and/or Some Postsecondary	Divorced or Widowed	Yes	Out of the Labour Force
Edward	32	48	High School or Less	Divorced or Widowed	Yes	Out of the Labour Force
Gerald	27	64	High School or Less	Divorced or Widowed	Yes	Out of the Labour Force
Jonah	28	33	College and/or Some Postsecondary	Married	Yes	Out of the Labour Force

The range of physical disabilities include: post-poliomyelitis syndrome, arthritis, multiple sclerosis, degenerative disc disease, cerebral palsy, dysgraphia, fibromyalgia, muscular dystrophy and one disability kept anonymous. The ran

Note: The educational attainment of *college or some postsecondary* includes those with completed college diplomas, some trades schooling, trades certificate, some college and/or some university education.

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