Defying the Odds: Growing Up & Growing Older with a Lifelong Physical Impairment (Cerebral Palsy)

by

Laura Roberta Moll

A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy
Graduate Department of Rehabilitation Science
University of Toronto

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Abstract

Purpose: The purpose of this study was to explore the experience of individuals who are aging with a lifelong and/or early-onset physical impairment. Method: A qualitative methodology was utilized consisting of narrative inquiry informed by the Life Course Perspective. The life course perspective is a dynamic approach that encompasses multiple theories including sociology, human development, and aging, highlighting how social, historical, and cultural contexts shape people’s lives. Narratives are storied ways of knowing and communicating that people use to organize events in their lives and make sense out of their experiences. Nine community-dwelling individuals (3 men; 6 women), aged 26-70, with mild to severe Cerebral Palsy were recruited using a combination of purposive and snowball sampling. Multiple (3-4), in-depth interviews were completed with each participant in order to co-construct their life stories. The data analysis was iterative. NVIVO 8 was used to organize the data, supporting a systematic comparison of emerging themes and categories, as well as the central plot that weaves the participants’ experiences together. Findings: “Defying the Odds” emerged as the central narrative that weaved together their experience of growing up and growing older. Their narrative is depicted through the trajectory of the
disordered body that manifests itself in peaks and valleys. Their narrative is also weaved together by three central threads: Achieving a Sense of Belonging, Overcoming being Seen but not Heard, and Striving for Self-Reliance. “Normalization” emerged as a key recurring theme in the participants’ life stories. The focus of rehabilitation on "normalizing" movement, particularly walking, during childhood can lead to social psychological challenges as well as problems later in the life course as people encounter increasing fatigue and decreasing functional abilities but no longer have access to rehabilitation services.

Implications: Theoretically, the disordered body needs to be reconceptualized in ways that are more positive. Conceptualizing a theory on aging with disability needs to be pursued. Clinically, we need to work towards developing a continuum of care across the life course with a focus on long-term maintenance and prevention of secondary health problems.
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Chapter 1. Introduction and Literature Review

1.1 Introduction

A relatively new field of study in social gerontology is disability and aging. Disability is a term that describes the challenges faced by individuals with physical or cognitive impairments that may affect their ability to perform multiple activities of daily living, which in turn may have an impact on their ability to participate in mainstream society (World Health Organization, 2002). Until very recently, our understanding of disability and aging was limited to the onset of disability in old age, or aging and disability (Gilson & Netting, 1997; Putnam, 2002; Tremblay et al., 1997). However, in the presence of advanced medical technology and increased life expectancy, many individuals with a lifelong or acquired physical disability are now reaching middle and old age, or aging with disability (Kemp & Mosquida, 2004; Priestley, 2003). Despite these advances in life expectancy for people with lifelong disability, we have limited knowledge about the supports and resources that are needed to maintain the functional independence, psychosocial wellbeing and quality of life of these individuals as they transition into adulthood, and old age (Hilberink et al., 2007; Lankasky, 2004; Zaffuto-Sforza, 2005).

Over the past thirty years, there has been a growing awareness of the issues of aging for individuals living with physical impairments acquired in late adolescence and young adulthood as a consequence of conditions such as polio, spinal cord injury (SCI), and traumatic brain injury (TBI). Ten and twenty years after completing rehabilitation, in mid-life, many are encountering declines in function and secondary health problems that are usually associated with aging. The functional declines associated with aging coincide with
limitations in activity (activities of daily living [ADL] and instrumental activities of daily living [IADL]) and threaten these individuals’ ability to participate in daily life and continue to fulfill the roles and responsibilities associated with work, social, family and leisure activities (Colantonio, Ratclif, Chase, & Vernik, 2004).

Even less attention has been paid to issues of aging for those individuals aging with lifelong physical impairments such as spina bifida and cerebral palsy (CP) (Bottos, Feliciangeli, Sciuto, Gericke, & Vianello, 2001; Hilberink, et al., 2007). The experience of growing up and growing older with lifelong physical impairment (aging with disability) is different from that of aging and acquiring physical impairment in adulthood (aging and disability). Individuals with lifelong physical impairments may not have had the same opportunities as others without impairment to achieve traditional social milestones (such as graduating from high school, embarking on a career, marrying and having a family); establish strong social support networks (through work, family and friends); and, accumulate the financial resources needed to support themselves in old age (Wilkins & Cott, 1993). Furthermore, the patterns of physical and psychosocial adaptation individuals with lifelong physical impairments achieve in early life may not be suitable for maintaining long-term independence due to changing abilities with age, changing life circumstances, and changing access to support and resources such as health care and rehabilitation.

The narrow scope of the current research on aging with disability presupposes that the foundation of the quality-of-life and well-being of an individual living with lifelong physical impairment rests on the achievement of functional independence while paying much less attention to a multitude of factors that contribute to overall well-being such as developing social, psychological, and intellectual capacities (Priestley, 2003; Wiart L. & Darrah, 2002). Further, by placing the emphasis on functional independence the focus of research on aging
with disability locates the source of difficulties encountered within the individual, ignoring the important role of the social environment in shaping the experience of growing up and growing older with physical impairment. It is this gap that I address in my research.

1.2 Thesis Statement & Research Objectives

The purpose of this study is to explore the experience of individuals growing up and growing older with lifelong physical impairment with particular attention paid to the contribution of factors external to the individual such as institutional, political, social, and economic factors. Specifically, the research objectives are: 1) To achieve an in-depth understanding of what it is like growing up and growing older with lifelong physical impairment; and 2) To identify and describe how the people and institutions with which individuals with lifelong physical impairment interact have an impact on their unfolding lives with respect to the construction of biography, self-identity, and patterns of adaptation (Giele & Elder Jr., 1998; Priestley, 2003).

In the remainder of Chapter 1, I describe my positionality and reflexivity, provide an overview of conceptual approaches to aging and to disability, and review the literature on aging with disability.

1.3 Reflexivity & Social Positioning

My interest and commitment to completing a dissertation in this area is reflected in my own life-long personal and professional involvement in the fields of gerontology and disability. I have over 30 years of experience living with physical impairment resulting from a traumatic brain injury (TBI) sustained in childhood, and ten years working with disabled students and seniors as a professional social worker. Who I am as a social worker and a researcher with a childhood onset physical impairment is a product of the attributes of my
own life course. Being a researcher with physical impairment, I could be considered an insider. I am, however, very cognizant of the fact that growing up in a white middle class Jewish community, and obtaining both undergraduate and graduate degrees, may be a very different experience than that of other persons with physical impairments. I was also concerned that my social location could have a negative impact on the dynamic of the research process and even foster ambivalence on the part of the participants (even though my own journey was filled with challenges and barriers). Another concern I had at the outset of this research was whether I would be able to manage my own beliefs about and experiences with disability during all phases of the study. Despite these challenges, being a researcher with physical impairment underscores my interest in exploring the intersection of people with bodies with impairments, and the social environments in which they grow up and grow older.

From an academic and research perspective, my interest in aging with disability emerged from an absence of theories and perspective on this topic. During the 1990s, research in gerontology identified the emergence of a crisis for individuals growing older with disability, as many were reaching old age without the presence of health care professionals and resources to meet their needs. They are competing for the same resources that seniors require, though at a much younger age. During the completion of my diploma in gerontology I found gerontology to be an area of research that was just beginning to address the issue of aging for the many people who have benefited from life-saving practices following illness or injury (Gilson & Netting, 1997; Kemp & Mosquida, 2004; Neysmith, 1999). I also felt this issue was important because our understanding of aging with disability has been limited to normative theories of aging, which were conceptualized ignoring the experience of disability and pathologizing it.
1.4 Conceptual Approaches to Aging with Disability

Before reviewing the literature on aging with disability, some important conceptual issues need to be addressed. I originally set out to study aging with disability. However, the concepts of “aging” and “disability” are problematic because the disciplines of psychology, sociology, gerontology, and medicine define them differently (Heinz & Marshall, 2003; Oliver, 1998; Priestley, 2003). In the following section, I identify the conceptual issues with the terms “aging” and “disability” and explain why I reframed my study as growing up and growing older with lifelong physical impairment.

1.4.1 Conceptualizing Aging: the Life Course Perspective

Aging is a dynamic process that involves physical, social, emotional, and intellectual development of an individual over time. That is, aging involves the simultaneous physical development or evolution of an individual from being dependent on others for one's well-being to developing skills and abilities that enable individuals to perform as autonomous human beings who are able to fulfill the roles and responsibilities associated with adulthood. Adulthood is accompanied by several social, psychological and physical changes that occur with age (McPherson, 1998).

The life course perspective is the dominant theoretical perspective in gerontology today, having gained increasing attention over the past 30 years. It focuses on the dynamic and transactional relationship that takes place between individuals and their environments, and social, institutional, and political structures that are contextually and historically situated (White Riley, 1998). Social structures include family, friends, and coworkers. Institutional structures include family, schools, work, and community organizations. Political structures
encompass the policies associated with education and health care that exist during different decades (Giele & Elder Jr., 1998).

The life course perspective provides a theoretical framework for studying the influences—individual and environmental—that shape the life experience of an individual, including the transactional relationship that takes place between individuals, and individuals and their environments, over time. It is embedded in theoretical pluralism, encompasses human agency (making decisions about their lives and acting upon them), and explains the elements that contribute to the formation of self-identities and adaptation over time (Giele & Elder Jr., 1998; Patton, 2002). This perspective identifies elements at the micro, macro, and mezzo levels of organization that influence personal biographies, and the meanings that individuals ascribe to significant life events and transitions at a particular point in time (Giele & Elder Jr., 1998; Priestley, 2003).

Using a life course perspective, aging with disability is thus conceptualized as the interaction that takes place between the individual living with a physical impairment and their environment, including social, institutional, and political structures (Giele & Elder Jr., 1998). Conceptualizing aging in this manner allows one to explore aging with disability from two vantage points: how living with lifelong physical impairment affects the experience of living across the life course; and, how living across the life course influences the experience of living with lifelong physical impairment.

1.4.2 Conceptualizing Disability

Similar to aging, the concept of disability has multiple interpretations and definitions. Within the medical model, disability is considered a biological characteristic that deviates from the norm and is considered a problem within the individual (Oliver, 1998; Priestley,
In contrast, the social model of disability views disability as a limitation of opportunities to take part in normal life of the community and is due to physical and social environmental barriers rather than functional limitations within the individual (Oliver, 1996). One perspective sees disability as inherent in the individual with physical impairment, whereas the other views disability as being socially created. In other words, a person with physical impairment is not automatically “disabled”.

Currently the most widely used conceptual model in rehabilitation is the International Classification of Functioning (ICF). In the ICF, disability is an umbrella term referring to how a health condition or disease impacts on the body structure and functioning of an individual and how this in turn influences a person’s ability to engage in activities and participate in mainstream society (Kielhofner, 2004; Oliver, 1996; Stewart, 2002). The three key concepts are: Impairment (problems in body function or structure such as significant deviation or loss); Activity Limitation (difficulties an individual may have in executing activities); and, Participation Restriction (problems an individual may experience in involvement in life situations). The ICF also recognizes the impact of environmental and individual (attributes) influences. The ‘environment’ is conceptualized as the physical, social, and attitudinal environment in which people live and conduct their lives: domains include products and technology; natural environment; support and relationships; and attitudes, services, systems, and policies.

The ICF was developed in an effort to overcome the narrow conception of the International Classification of Impairments Disabilities and Handicaps (ICIDH), which failed to acknowledge the role of the environment in disability (De Kleijn-De Vrankrijker, 2003; Hurst, 2003). The ICF was also seen as a solution to overcoming the limitations of earlier models of conceptualizing disability by including or emphasizing some components while
omitting or de-emphasizing others (Morris, 2001; Nagi, 1965, 1991; Vebrugge & Jette, 1994). Although environmental factors have been given greater prominence in the ICF than in the ICIDH, the ICF still places less prominence on the significant role of the environment as a component of disability than do other models (e.g., The Disability Creation Process Model), instead placing greater emphasis on individual aspects of functioning at the level of body functions and structures, activities, and participation (Fougeyrollas, Noreau, & Boschen, 2002). The medical model is grounded in a philosophy of normalization that expects individuals to adjust to their physical impairment and external environment without the environment making any adjustments for them. Consequently, there is a strong relationship between functional independence and full participation.

Even though the ICF represents a comprehensive framework for understanding and describing the experience of disability, it continues to be fraught with problems. It still harbors a biomedical orientation, since health is associated with the cure or elimination of illness and disability, and this is extremely problematic for the disabled community at large (see Bury, 1996, Lutz and Brown, 2005, Morris, 2001). The model is also not ideal for studying change over time (living with a disability and then aging) or studying the relationship that exists between an individual and their environment (Bury, 1996; Fougeyrollas, et al., 2002; Schneider, Hurst, Miller, & Ustun, 2003; Simeonsson, Lollar, Hollowell, & Adams, 2000; Stewart, 2002).

The Social Model of Disability (SMD) was developed by Michael Oliver (1996) in order to provide an alternative explanation to the individual and/or medical model that located the problem of participation in the individual with the physical impairment which was/is considered a personal tragedy (Barnes & Mercer, 1996; Thomas, 1999). SMD advocates that it is not the impairment that imposes restriction in participation in mainstream
life. Rather, society imposes physical, structural, and attitudinal barriers to full participation. The SMD provides a framework that identifies the societal and environmental forces that manage, and impede, an individual’s ability to adjust to and successfully live with a long-term impairment. That is, the SMD places emphasis on how the environment mediates between the individual with a physical impairment and significant others, which impacts the processes he/she engages in to make sense of their experience. Therefore, the patterns of adaptation to which a person adheres are not regarded as a consequence of his/her residual impairments, but a reflection of the structural, physical, and attitudinal barriers he/she encounters as he/she tries to reconstruct his/her life by resuming previous roles and responsibilities. Examples of how the environment disables the lives of people living with physical impairments include failure to provide access to community services that support independent living, suitable housing and transportation, and a modified work experience (including flexibility in hours, and alternative work environment).

While the SMD explains how macro forces impact the lives of people living with physical impairment it has been criticized for ignoring the role of the individual and the embodiment of physical impairment on the experience of living with impairment (Barnes, Mercer, & Shakespeare, 1999; Morris, 2001; Oliver, 1996; Thomas, 1999). Ignoring the significance of impairment diminishes our understanding of the complexities and multifaceted attributes associated with the experience of living with a physical impairment. Many disabled activists and scholars are advocating for the need to research the experience of impairment and disability (Morris, 2001; Thomas, 2002).

The ‘significance of impairment’ is captured by Crow (1996) who argues:

*Suppression of concerns related to impairment does not mean that they cease to exist or suddenly become more bearable. External disabling barriers may create*
social and economic disadvantage but our subjective experience of our bodies is also an integral part of our everyday reality (p.59).

Morris (2001) similarly argues:

We need to write about, research, and analyze the personal experience of our bodies and our minds, for if we don’t impose our own definitions, and perceptions, then the non-disabled world will continue to do it for us in ways that will continue to alienate and disempower us (p.10).

These arguments emphasize how important it is to include impairment in the study of disability (Bury, 1996; Lutz & Brown, 2005; Morris, 2001; Thomas, 1999).

The challenges embedded in these models inspired me to conceptualize and implement a study that would attempt to overcome their limitations and bridge the gap that exists between individuals and their environments. This was undertaken by conceptualizing a study on aging with disability that focused on researching how the experience of impairment and disability (social environment) impacted the unfolding lives of individuals living with a physical impairment, within a life course perspective. The life course perspective is fundamental to this study because of the multiple factors it considers that intersect with both individuals and their environments. This study began with researching the experiences of individuals living with lifelong physical impairment—reconceptualized as “growing up and growing older with lifelong physical impairment”—which emerged during the completion of data collection and the unfolding analysis. Growing up and growing older captured the experience of aging with disability as well as the experiences of individuals living with lifelong physical impairment.
1.5 Literature Review

Two main bodies of research have addressed issues of aging with disability. These studies have been approached through one of two lenses.

1) The first lens is the biomedical lens which considers deviations in physical functioning as a problem located within an individual that requires medical intervention and/or rehabilitation to eliminate impairments and/or improve physical functioning (Oliver, 1998; Priestley, 2003). These predominantly clinical and psychological studies are quantitative and tend to be grounded in the assumption that there are normative patterns of physical functioning characteristic of all human beings (Coyle, Santiago, Shank, Ma, & Boyd, 2000; Oliver, 1996). This tendency to focus on individual attributes ignores other factors that have an important impact on aging with disability.

2) Constructivist approaches constitute the second lens that has been used to enhance our understanding of the experience of aging with disability. Constructivist approaches view aging with disability as not limited to individual attributes but also recognize the role of the social and cultural contexts in which individuals live (Morris, 2001; Oliver, 1998). This lens considers the existence of multiple realities and is predominantly associated with the use of qualitative approaches such as phenomenology, grounded theory, or narrative inquiry (Harrison, 2006; Nochi, 2000; Oliver, 1998; Tighe, 2001).

These two bodies of research on aging with disability are reviewed in the following section.

1.5.1 Biomedical Approaches to Aging with Disabilities

A body of clinical and psychological research has been undertaken to expand our understanding about aging with disability, particularly with respect to the early declines in functioning that individuals with acquired physical impairments confront as they age. Many
studies have addressed persons with impairment and disability acquired in young adulthood caused by conditions such as spinal cord injury (SCI), polio and TBI. Only a few studies address persons with lifelong physical impairment resulting from conditions such as Cerebral Palsy (CP) or Spina Bifida.

All of the clinical studies reviewed focused on assessing the physical functioning of individuals with impairments through self-reports on physical health and psychological well-being, and completing comprehensive physical, neuropsychological, and/or psychological examinations (Charlifue, Lammertse, & Adkins, 2004; Coyle, et al., 2000; Dean, Colantonio, Radcliff, & Chase, 2000; Lammertse, 2001). Longitudinal and cross-sectional approaches have been used for assessing functional abilities and limitations in relation to one or multiple domains of life. The focus of these studies is often on the degree to which individuals with impairments deviate from normal physical functioning (Davis, 1995; Hughes, 2009; Oliver, 1998). Health care utilization was also explored in many studies (Bottos, et al., 2001; Charlifue, et al., 2004; Hilberink, et al., 2007; Krause & Coker, 2006).

In a thirty year follow-up study of individuals with SCI, Krause and Coker (2006) found that individuals with SCI experienced improvements in functional adaptation and other areas of their lives and were able to maintain these achievements for approximately ten to fifteen years following their injury and the completion of rehabilitation. These individuals tended to be satisfied with their lives both personally and professionally. However, at the last follow-up many participants in the study had experienced declines in function and one or multiple health related problems including pressure sores, urinary tract infections, fractures, pain, and fatigue. These changes impacted their personal and professional lives. Many participants required more assistance with personal care. The increased need for assistance tends to coincide with aging and decline in functioning (Andrén & Grimby, 1999; Hoofien
D., Gilboa A., Vakil E., & Donovick PJ., 2001; Krause & Coker, 2006; Masson, 1996). Hospitalization and re-hospitalizations to treat these problems were not uncommon and tended to increase with an increase in years post-injury (Krause & Coker, 2006). Accessing other types of health care was challenging for these individuals. Many community services and programs were difficult to obtain when needed because of an absence of health care professionals trained and experienced to work with adults with long-term impairment such as SCI. These findings are consistent with findings from earlier studies (Coyle, et al., 2000; Lammertse, 2001).

Of the small body of clinical research on aging with lifelong physical impairment that does exist, researchers have found that many of these individuals are unable to maintain the functional independence they achieved from rehabilitation during their childhood and adolescence. Research on CP has found that adolescents and young adults encounter difficulties with walking and changes in musculoskeletal structures which contribute to pain and fatigue. Many are unable to retain the functional abilities they achieved after many years of rehabilitation. Loss of ability to walk due to pain and fatigue is encountered sometimes even before adulthood (Andrén & Grimby, 1999; Bottos, et al., 2001; Hilberink, et al., 2007; Strauss, Ojdana, Shavelle, & Rosenbloom, 2004; Zaffuto-Sforza, 2005). These findings are significant because traditionally CP has been thought to be a condition that is relatively stable over time.

Within the biomedical lens, the quality of life that individuals experience in the presence of disability has been primarily determined through psychological assessments. These studies assess specific domains associated with psychological well-being including social support, coping abilities, life satisfaction, employment, and quality of life in order to predict and/or identify the impact of aging with a long-term impairment. The findings from
these studies are very diverse. While many of these studies have found that severity of disablement and time since injury in the case of acquired impairment do not necessarily decrease quality of life, in other instances they do (Anderson, Vogel, Chlan, Betz, & McDonald 2007; Dean, et al., 2000; Engberg & Teasdale, 2004; Hoofien D., et al., 2001; Liem NR., McColl MA., King W., & Smith KM., 2004). The outcomes of these studies may be so diverse because the psychological well-being of individuals with impairment and disability is mediated by the extent to which they are able to participate in meaningful activities, have meaningful interpersonal relationships, and cope with the challenges that life presents to them (Furukawa, Iwatsuki, Nishiyama Masaki, & Uchida 2001; Jahnsen R., Villien L., Stanghelle JK., & Holm I., 2002; Murphy, Molnar, & Lankasky, 2000; Zaffuto-Sforza, 2005).

For instance, Hoofien, Gilboa, Vakil, and Donovick (2001) assessed how well people cope with and adjust to the effects of their traumatic brain injury (TBI) ten to twenty years post-injury. Seventy-six individuals with moderate to severe TBI were evaluated in six different areas of their life: mental processes involved in knowing, learning, and understanding, physical abilities, symptoms of mental problems, social and familial relations, and community integration, and level of independence in daily routines. Identifying the presence or absence of continuous and/or new difficulties with a person’s cognitive abilities (e.g. the ability to initiate an activity, changes in memory, and information processing) was sought, as well as the relationship of his/her family to the family member with TBI. Changes in cognitive and physical performance, participation in work, and independent living tended to be more profound for individuals with severe TBI as compared with the consequences of moderate TBI. Many of the individuals and families reported experiencing depression and poor psychosocial functioning. These challenges were accompanied by increased emotional
and physical burden for caregivers. The individual with TBI is grappling with his/her own issues (disability related and psychosocial), while his/her caregiver is burdened with the challenge of caring for a person with behavioral, cognitive, and emotional attributes. These challenges increase as both the caregiver and person with TBI age.

Schanke (1997) described the complexities and temporality associated with psychosocial well-being in a 5-year prospective study of 63 polio survivors who had experienced symptoms of post-polio. The psychosocial well-being of most participants was compromised when they first experienced declines in functioning associated with post-polio, especially after living for many years without significant problems. However, for the most part, the participants felt that they had adjusted to the changes that resulted from post-polio at the five-year follow-up after attending a post-polio rehabilitation program.

These findings are important to individuals with lifelong impairments. There is a misconception that adjustment to early onset disabilities prepares one to cope with the secondary health problems and declines in functional abilities associated with aging. Declines in function disrupt former patterns of adaptation and participation in activities related to work, family, daily living, and leisure (Andrén & Grimby, 1999; Harrison, 2006; Zaffuto-Sforza, 2005). These losses can be just as significant for an individual with a pre-existing disability as they can for a person who experiences disability for the first time in old age (Schanke, 1997).

1.5.2 Summary of Biomedical Research on Aging with Disability

The clinical and psychological studies reviewed are useful for identifying the changing functional abilities of individuals living with impairment. They increase our awareness of challenges associated with aging with disability, however, they do not address
the impact of these changes on the day to day lives of people with long term physical impairment. That is, it is important to understand the experiential impact of functional deterioration on psychosocial well-being in order to establish and implement policies and programs to meet the changing needs of persons aging with disability. Further, some of these studies highlight one of the biggest challenges that accompany aging with disability – lack of access to medical care and rehabilitation.

1.6 Aging with Disability through a Constructivist Lens

Studies of aging with disability using a constructivist lens are from the field of health care and rehabilitation, social science, and sociology of the body (Galvin, 2005; King GA., Cathers T., Polgar JM., MacKinnon E., & Havens L., 2000; Sandström, 2007). Research conceptualized within a constructivist paradigm provides researchers and clinicians alike with a more in-depth understanding of the experience of living with physical impairment (Goodwin & Comptom, 2004; Sandström, 2007; Tighe, 2001). As with the clinical and psychological research, much of the research on aging with disability has focused on persons with disability acquired in young adulthood following Spinal Cord injury or Traumatic Brain Injury and much has been written about the adjustment to disability and chronic illness.

1.6.1 Adjustment to Chronic Illness and Disability

The narrative inquiry approach to research has been used by several researchers studying the experience of adjustment to chronic illness and disability. Many authors have studied the experiences of people living with disabilities using narrative perspectives based on the illness narratives conceptualized by Arthur W. Frank. According to Frank (1995), people with chronic illnesses tend to use one of three narratives — a restitution narrative, chaos narrative or quest narrative — to make sense of their experiences and communicate
them to others. Frank believes that people who adhere to restitution narratives are focused on recovering from their disabilities and returning to their pre-disability existences. These individuals usually are unable to conceive of living a meaningful life with their disability. People who adhere to chaos narratives view existence with their disabilities as empty and hopeless. They see their lives as having been dramatically and permanently disrupted. They may even hold the view that life with a disability is a life not worth living. Unlike those who adhere to restitution and chaos narratives, people who adhere to quest narratives have a positive outlook on life with physical disability. They don’t reject the physical, personal and psychological changes that are consequences of their physical disabilities. In fact, some take the view that they have been given a second chance at life, while others embrace their new circumstances as an opportunity to make a positive difference in the world.

Nochi (2000) used narrative inquiry to explore the experience of individuals with traumatic brain injury and Smith and Sparkes (2004) investigated the life histories of men with spinal cord injuries. Both found that people who adopted a restitution or chaos narrative had more difficulty moving forward with their lives than those who adopted a quest narrative.

Adoption of the quest narrative is a positive step in the recovery process following acquisition of a disability because it helps people cope with the profound changes in their lives and develop new interests (Frank, 1995). Those who get stuck in restitution or chaos narratives can face significant challenges in coping and moving on. According to Ville (2005), these challenges can include difficulties in reintegrating into the community and returning to the workforce.

The way that people reconstruct their lives is contextually situated and influenced by the meanings they ascribe to their circumstances (Williams, 2000, p.43). People attach different meanings to chronic illnesses based on factors such as cultural mores, the
significance of the disruption, the stage of development of the illness and the severity of the disablement that the illness has and will eventually cause (Livneh & Antonak, 1997). In other words, the responses and orientations of people with physical impairments are not static; they vary over the course of the illness and treatment trajectories.

It is also important to note that the orientation of people with acquired disabilities tends to change over time as they move through the healthcare system and the rehabilitation continuum of care. Adoption of the quest narrative can occur at different stages along the road to recovery. Some people adopt it early; others must first work through challenges associated with their disabilities or let go of previously adopted restitution or chaos narratives that stand in the way (Ville, 2005).

Bury coined the phrase “biographical disruption” to describe the experience of the transition to chronic illness and disability for persons who acquire impairments (Bury, 1982). Bury developed the concept of biographical disruption to describe the processes people experience and engage in when physical impairment resulting from chronic illness permeates all aspects of their lives, including the ability to fulfill responsibilities and aspirations associated with school, work, family, parenting and leisure activities (Bury, 1982) Other authors have identified this process as loss of self (Charmaz, 1983) and biographical accommodation (Corbin & Strauss, 1987).

Frank’s illness narratives are consistent with biographical disruption (Bury, 1982) as they both describe a process individuals go through when they experience a crisis in biography as a consequence of illness and impairment. The timing and trajectory of the process a person goes through will be different from one individual to another. They are linked at three levels: the meanings that individuals assign to the onset of disability through a process of appraisal and interpretation; their interpretation impacts how they react
emotionally which determines the narrative and/or identity they adhere to at a particular point in time; the narrative or identity they adhere to influences the resources and supports (instrumental and emotional) they seek to reconstruct their lives. It is important to note that the ways in which a person recasts his/her biography is also mediated by the perceptions of and interaction with significant others. Consequently, the interaction that takes place between the individual and self, and the individual and significant others can either impede and/or support identity reconstruction. That is to say, that a person who adheres to either the restitution or chaos narrative may find it more difficult to explore new opportunities and identities that would incorporate their disabled self due to the stories they are telling themselves and how they see themselves through the eyes of others. These individuals therefore may cling to the restitution and/or chaos narrative for a temporary or extended period of time. Individuals who interpret their experience positively will likely have an easier time recasting their biography in meaningful ways that incorporate their abilities following illness/injury. For those individuals who adhere to a quest narrative the adjustment process for living with a physical impairment a little more smoothly. However, adhering to the quest narrative doesn’t ensure that these individuals will not encounter other challenges as they progress through life.

The concepts of illness narratives and biographical disruption provide theoretical frameworks for understanding the complex processes individuals go through when confronted with chronic illness and impairment. However, they are limited in their application to the experience of living with lifelong disability. People with congenital impairments don’t experience biographical disruption as people with acquired chronic illness and impairment do (Williams, 2000). People with lifelong impairments don’t have a sense of a non-disabled self as they have only ever had the experience of living with impairment.
Persons who are born with a congenital disability consider their circumstances as being normal as they do not know any other way of living whereas individuals who acquire a disability as a result of illness or injury distinguish who they are by identifying with life before and after becoming disabled (Lankasky, 2004; Sandström, 2007). For people with lifelong physical impairment and disability the challenge is not biographical disruption, rather it is biographical construction. Individuals who have lived their entire lives with physical impairment may not have had the opportunity to develop the internal and external resources necessary to successfully negotiate the world around them and construct their lives in meaningful ways.

1.6.2 Aging with Disability

Over the past fifteen years, there has been a gradual growth in qualitative studies that provide a more in-depth understanding of the complexities associated with the experience of aging with impairment and disability; however, they continue to be small in number. These predominantly qualitative studies have also found that individuals living with long-term physical impairment experience difficulties maintaining physical functioning and independence in part due to the demands that they are placing on their bodies and in part due to the barriers to accessing services and resources they need to maintain their bodies and prevent secondary health problems (Lutz & Brown, 2005; Neri MT & T. Kroll 2003; Tighe, 2001).

Harrison (2006) found that the achievement of functional adaptation to the consequences of polio provided her participants with the incentive to pursue personal and professional goals and aspirations by willing the Body to Achieve Potential, while Conflicts between Self and Body were confronted when the women began to experience declines in
function due to post-polio in later adulthood. These changes coincided with not being able to engage in personal and professional activities in the same way they did when they were younger. These changes also threatened their self-identity and earlier successes they had achieved because they were losing control of their bodies (Harrison TC. & Stuifbergen, 2005).

Among Harrison’s (2005) forty-one participants (55 and 65 years old) aging with childhood onset paralytic polio many encountered a number of secondary problems as they aged. Chronic pain, fatigue, muscle weakness, and respiratory problems the compromised physical and psychosocial patterns of adaptation that were achieved at an earlier time in their lives. Her findings also reveal that the positive outcomes associated with rehabilitation have short-term benefits given that individuals with impairments are reaching old age. That is to say that once individuals complete rehabilitation, they return to their communities without knowing what to expect as they grow older or equipped with the information or resources they need to maintain their achievements long-term. This creates a problem because medical and rehabilitation practices that were provided to facilitate the recovery from polio for instance emphasized the achievement of normative functional adaptation.

Goodwin (2004) explored how six women with physical disabilities (cerebral palsy, 2, acquired brain injury with muscular weakness, one and spinal cord injury, three) between 22 and 37 years old experience their bodies as they age, and the meanings that they attach to these experiences specifically as they relate to engaging in physical activity. She found that remaining physically active and engaged in living was regarded as being important to the overall well-being of her research participants. Staying physically active (including ADL and IADL) was considered important because it served as a mechanism that would prevent
and/or prolong the onset of secondary health problems and declines in function and therefore support the physical and social-psychological well-being of an individual.

The physical changes individuals experience disrupt former patterns of adaptation, both physical and psychosocial, and interfere with being able to participate in roles and responsibilities associated with school, work, family, and leisure (Lankasky, 2004; Lo Surdo, 1997; Murphy, et al., 2000; Neri MT & T. Kroll 2003). Strategies that support success in earlier years may not be as helpful when one’s functional abilities change later on in adulthood or middle adulthood (Harrison TC. & Stuifbergen, 2005; Lankasky, 2004). For example, the presence of pain and fatigue for example takes away a person’s ability to exercise control over his/her body which interferes with daily living (Harrison TC. & Stuifbergen, 2005; Tighe, 2001). It’s important to note that the altered body’s ability to support an individual in daily living changes from day to day and week to week as it is mediated by the number of responsibilities and activities he/she is engaged in. A heavy work schedule one week can place more stress on the body than weeks characterized by a lighter agenda. Sandström (2007) explored how physical disability is experienced by twenty-two community dwelling individuals with cerebral palsy, and how it impacts their everyday lives. She found that there was diversity among participants in how they experienced their bodies on a day to day basis. These perceptions of embodiment reflected the diverse ways in which their bodies supported and/or hindered their abilities to engage in daily living and participate in mainstream social life.

The trajectory of living with a physical impairment can be unpredictable and unfolds differently for individuals living with the same or different conditions (Goodwin & Comptom, 2004; Harrison, 2003; Lankasky, 2004; Lutz & Brown, 2005; Tighe, 2001). This
experience can be exacerbated when secondary health problems unrelated to the primary condition develop.

1.6.3 Lived Experience of Impairment

There were a group of other studies that explored impairment and disability in everyday life (Galvin, 2005; Lutz & Brown, 2005; Sandström, 2007). While these studies didn’t focus specifically on aging with disability, they identified and reinforced how the individual, social, and environmental issues individuals with impairments confront impact their bodies, the construction and reconstruction of their self-identity, as they grow up and grow older. Research found that living with a physical impairment was thwarted by not having access to resources they need to manage life on a day to day basis, not having control over their condition, inaccessible health care, and limited opportunities for social participation (Galvin, 2005; Lutz & Brown, 2005; Tighe, 2001).

All the studies found that participants encountered one and/or multiple environmental barriers at different times in their lives that made living and aging with impairment difficult (Galvin, 2005; Harrison, 2006; Harrison TC. & Stuifbergen, 2005; Tighe, 2001). For instance, difficulties accessing information, knowledgeable and caring professionals, health care and educational support programs on a consistent basis made it difficult for adolescents and young adults with cerebral palsy to achieve their potential through developmental and social milestones (Darrah, Magil-Evans, & Adkins, 2002). This challenges them in developing the skills they need to successfully transition to adulthood and being able to negotiate the world around them.

Neri (2003) found that access barriers to health care have a ripple effect on living and aging with a physical impairment. Barriers to health care affected five areas/domains of their
lives: physical, psychological, and economic (additional health care costs and loss of income due to illness), social, and independent living (declines in abilities to engage in activities of daily living and/or work or both, and increased dependence on others). That is to say that the consequences associated with access barriers to health care were very complex, overlapped, and impacted one another.

For instance not having access to physiotherapy for acute conditions, the maintenance of functional abilities and prevention of secondary problems would often coincide with physical deterioration which impacted a person’s ability to care for themselves, complete ADL and household activities, as well as taking off work. Some individuals also experience secondary health problems that could not be improved when treatment was available. In other instances, many individuals experienced declines when repairs to durable medical equipment (DME) could not be done in a timely manner. Failure to access what they needed had a significant impact on their psychosocial well-being, as the circumstances created unnecessary physical and financial consequences that could not be regained once lost.

1.7 Summary of Research on Aging with Disability

Clinical and psychological studies reveal that aging with a long-term physical impairment is a problem that needs to be addressed. These studies are useful for identifying the functional abilities of individuals living with impairment. They also increase our awareness of challenges associated with aging and disability however, it is difficult to ascertain how these changes impact their lives. That is, it is important to know the experiential impact of functional deterioration on psychosocial well-being in order to establish and implement policies and programs to meet their changing needs.
Even though there is extensive research on this topic it tends to be episodic. What is also problematic is these kind of studies assesses people at different time points, while missing the years in between (plateaus and stability), as well as the context and circumstances that contribute to positive/negative changes in one’s life. Despite these limitations, more research of this kind is desirable as individuals living with impairment need to be followed throughout their lives or from the time of onset in the same way that a healthy person goes for a yearly checkup. One of the biggest challenges that individuals with long-term physical impairments confront is not having access to medical care (gender specific issues) and rehabilitation because the physiological declines are not identified as acute problems that will lead to a beneficial outcome.

Studies that examine aging with disability through a constructivist lens add to our understanding of the findings from the clinical and psychological studies. The qualitative studies on living and aging with disability, these studies reveal that the experiences of individuals with congenital and acquired physical impairments (as I conceptualized) are connected by several attributes. Physiological declines and secondary health problems are experienced early in life. Their needs change over time. Patterns of physical and psychosocial adaptation achieved through rehabilitation are threatened by aging with a physical impairment. They encounter access barriers to health care and rehabilitation. Prevention of physiological deterioration and the onset of secondary health problems could be achieved by the provision of health care and rehabilitation across the life course. These practices would correspond to the changing needs of the individual at a given point in time. These linkages suggest the need for a shift in the philosophy or approach to care that places more emphasis on conservation and prevention, rather than the achievement of normative patterns of
functioning in order to maximize the independence and long-term well-being of these individuals (Harrison TC. & Stuifbergen, 2005; Lammertse, 2001; Liptak, 2008).

Even though we have achieved a more in-depth understanding about aging with disability, and the associated social-psychological issues there is still a great deal of work to do as the narrow scope of the current research on aging with a disability presupposes that the foundation of the quality-of-life and well-being of an individual living with a physical impairment and disability rests on the achievement of functional independence when there are in fact a multitude of factors that contribute to the overall well-being of these individuals (Lutz & Brown, 2005; Priestley, 2003; Sandström, 2007; Steadman-Pare, Colantonio, Radcliffe, Chase, & Vernich, 2001; Tate & Broe, 1999) as reflected by many of the qualitative studies that were included in this review. The well-being and quality-of-life of an individual living with physical impairment and disability also involves enhancing social, psychological, and intellectual capacities.

1.8 Chapter Summary

In this chapter an overview of the issues associated with aging with disability were identified. Clinical and psychological research using a biomedical lens shows that individuals with early onset physical impairments are at risk for experiencing declines in former patterns of physical functioning that were an outcome of the rehabilitation they received following and illness or injury, or diagnosis of their condition (congenital origin). These disrupt their ability to engage in activities they value and fulfill their personal and professional roles and responsibilities. However, studies using a constructivist lens reveal that social-psychological adjustment to physical impairment is a dynamic process that is not limited to the achievement and maintenance of functional adaptation.
The review of the literature revealed that many individuals are unprepared for dealing with these changes which has a negative impact on their social-psychological well-being. Furthermore, many individuals do not have access to health care and/or rehabilitation that would support them in managing their physical well-being and preventing secondary health problems.

The study I conceptualized and implemented is intended to fill a gap in the literature on aging with lifelong physical impairment as well as extend our understanding of this experience by moving beyond explanations that are limited to examining physical changes in functioning. I believed that this was one component of a larger picture. That is, I was interested in the role that other factors such as change over time, support of a social network, and access to instrumental and tangible supports and resources contributed to the experience of aging with disability.

In Chapter 2, I describe how I used the life course perspective and a constructivist paradigm to inform the design and implementation of my study. Specific attention is given to describing the recruitment process I undertook and how data collection and analysis were structured and managed through the use of narrative inquiry and analysis. I also identify methodological issues associated with data collection.
Chapter 2. Methods

2.1 Overview of Chapter

In this chapter, I describe the theoretical framework and methodological underpinnings of this work. First, I describe the epistemological and ontological stance within which the study is situated (social constructivism). Second, I identify and describe the theoretical perspective I chose to conceptualize this study and its significance (Life course perspective). I describe the concepts that are central to this perspective and that figure in the analysis of my data. Third, I identify and describe the methodological approach I undertook (narrative inquiry) and explain why I chose to study persons with lifelong physical impairment as a result of Cerebral Palsy. Fourth, I describe the specific methods that I used beginning with data collection. I describe the process I engaged in to recruit research participants and co-construct their life stories. I highlight the methodological issues I encountered in collecting my data. Fourth, I describe the process I engaged in to analyze my data.

2.2 Epistemological and Ontological Stance

Designing a qualitative study begins with the selection of a paradigm. A paradigm describes a set of assumptions that describe a specific way of looking at reality (Schwandt, 2000). There are a number of different paradigms a researcher can select from when engaging in a qualitative inquiry. That is to say, a researcher can examine the same issue using different approaches (Patton, 2002; Schwandt, 2000). Situating one's research in a particular paradigm provides the building blocks for how the inquiry is framed which informs the kind of approaches that will be appropriate to use for data collection and analysis (Patton,
The complex and dynamic attributes associated with living with a physical impairment situates my research in a social constructivist paradigm. Social Constructivism

Constructivism is a term that describes how knowledge is produced. According to this paradigm, knowledge is socially constructed through a process of interaction that takes place between an individual and his/her social environment. This knowledge contributes to the formation of a person’s self-identity. Social construction is a continuous process that individuals engage in to make sense of and adapt to their life experiences. These experiences are historically and culturally situated (Atkinson, 1998; Schwandt, 2000). This paradigm reinforces the heterogeneous nature of living with a physical impairment and can broaden our understanding of the forces that influence it. The ability to make sense of the complexities associated with this phenomenon is grounded in the ontological and epistemological assumptions attached to this paradigm. These include the recognition that the experience of living with a physical impairment is unique for individuals living with the same condition. What distinguish the heterogeneous nature of an individual’s experience are the multiple elements that influence it. Therefore, the nature of a person’s reality is grounded in relativism, multiple voices that emerge through specific and constructed realities (Patton, 2002; Priestley, 2003).

Second, knowledge about living with a physical impairment emerges through co-construction, a process of interaction that takes place between individuals, an individual and his/her environment, and through the collaboration of the researcher and participant (Atkinson, 1998; Rodwell, 1998; Schwandt, 2000). That is to say, individuals ascribe meaning to their experiences through the interpretation of events they encounter through their interactions with others. These experiences are conveyed through stories that are constructed and reconstructed as individuals progress across the life course (Atkinson, 1998; Frank,
1995). This philosophical orientation depicts the complexities associated with the experience of disablement and the mediating forces that permeate its evolution.

2.3 Theoretical/Methodological Underpinnings of the Study

The experience of individuals living with lifelong physical impairment was conceptualized within the context of a constructivist paradigm and the life course perspective. Constructivism and the life course perspective converge on two levels. First, the experience of an individual is socially constructed through a process of social interaction between individuals, and through the interaction that takes place between an individual and their environment. Second, the nature of these experiences can be understood within the context in which they are produced and situated, historically and culturally (Giele & Elder Jr., 1998). Attention was given to both of these processes in data collection and analysis.

The Life Course Perspective provides a lens through which we can achieve a broader understanding of the impact of forces external to individuals on their experiences with impairment and disability as they grow up and grow older. This perspective is dynamic because it is grounded in multiple theoretical frameworks such as sociology, human development, and gerontology, which recognize multiple influences on the unfolding lives of individuals.

There are four concepts central to this perspective: 1) individual agency (individuals actively construct their lives through their interactions with significant others; 2) changes in time and space (temporality); 3) significant life events (social milestones, marriage, death, divorce, job loss), and 4) linked lives (connections with family, friends, and the social environment) (Giele & Elder Jr., 1998). Attention is given to how historical, social, and cultural contexts shape people’s lives in time and space which gives credence to the fact that
the circumstances and needs of people change as they grow up and older. This perspective also considers the role of institutions, policies, and practices, and how they shape the construction and reconstruction of self-identity and biography.

Within the context of this study, the role that health care, rehabilitation and education play in the lives of people with physical impairments is a central focus. Specific attention is given to the ways in which these institutions govern the body as a way to improve or eliminate disability through normalization. Therefore, this perspective enables us to consider the experience of impairment and disability as a complex phenomena that is not strictly an individual problem, as there are other forces external to an individual the impinge on their full participation in mainstream social life. It can also be used to answer some of the following questions:

What role do health care and rehabilitation play in shaping the lives of people with impairments? Does their role support/impinge living with a long-term impairment? How do cultural and medical beliefs about the body impact the opportunities and/or barriers individuals’ experience? Do changes in time and place improve the life experiences for people with impairments? Life course research has been undertaken using quantitative or qualitative approaches or a combination of the two (Giele & Elder Jr., 1998).

The attention that this perspective gives to the process of aging through the concept of change over time contributed to my decision to use this perspective to explore the experience of aging with disability. However, it extremely difficult to study since it converges with multiple research traditions in the fields of gerontology and life span development which conceptualize aging very differently (O’Rand, 1998). Furthermore, aging is a complex process that is challenging to research. Independently, aging is considered a dynamic process that involves the physical, social, emotional, and intellectual development of an individual.
That is, aging involves the simultaneous physical development and/or evolution of an individual by transitioning from being dependent on others for one's well-being to developing skills and abilities that enable individuals to perform as autonomous human beings who are able to fulfill the roles and responsibilities associated with adulthood. It is the complexity of this process that I hoped to capture in this study. Aging was therefore conceptualized as the interaction that takes place between the developing individual living with a physical disability and his/her environment, and social, institutional, and political structures (Giele & Elder Jr., 1998).

Conceptualizing aging in this manner permits me to explore aging from two vantage points: how living with a disability intersects with the achievement of developmental tasks and milestones across the life course; and, how aging influences the experience of living with a disability. Special attention was given to how living with a physical disability influences physical, social, psychological, cognitive, and intellectual development across the life course (White Riley, 1998). Hence, the life course perspective provides an organizing framework for exploring the elements that contribute to shaping the self-identity of an individual as well as the patterns of adaptation he or she adheres to at different points in time, and in response to different life experiences. It also provides us with the opportunity to identify how disability is socially constructed across the life course and how that in turn influences the experiences that individuals living with a physical disability may confront at different stages of development.

2.4 Research Method

Taking a life course approach provided the opportunity to identify and describe the role of multiple forces that intersect with the unfolding lives of individuals with lifelong
physical impairment. Consequently, I felt that the best way for me to explore this phenomenon was by designing a retrospective qualitative study using narrative inquiry and analysis.

2.4.1 **Narrative Inquiry**

Narrative inquiry is a qualitative method that supports an in-depth exploration of individuals’ life experiences (Clandinin & Connelly, 2000; Kohler-Riessman, 2008). Narrative inquiry is compatible with the constructivist paradigm and provides rich data that enhance our understanding of the individual stories participants share, as well as highlighting the central and meta-narratives that link participant experiences together.

Narratives are used as a mechanism for organizing events in one’s life and making sense out of one’s experience. The researcher is interested in why participants tell their story in a particular way, conveying certain emotions, including some details while omitting others (Kohler-Riessman, and 1993, 2002). How a story is told demonstrates both the differential impact and the significance that individuals ascribe to different life events, and through their interactions with significant others, and their external environment. The central and meta-narratives that are embedded in individual participant narratives lead to the construction of a common or central narrative within which there may be one or multiple meta-narratives (Kohler-Riessman, 2008).

I felt that using this method would be beneficial to learning about the stories my participants would share, achieve an in-depth understanding about how they make sense of their experience and interpret the world around them, and their place in it. Finally, I believed that this approach would be useful in conceptualizing their experience of growing up and growing older. This is reflected in the experience of living with a physical disability. For
example (Thapar, Bhardwaj, & Bhardwaj, 2001) found that although individuals may share the same chronic condition they will likely experience different levels of impairment and disability which will in turn have an impact on other areas in their life in different ways. Learning about these patterns of adaptation is one of the areas to which attention was given. Both the form and content of participants’ stories were an important part of the analysis. The form that their stories take reveals shared and unique experiences participants had with impairment and disability, while analysis of the content identifies emerging themes and specific examples.

2.4.2 Rationale for Choice of Persons with Lifelong Physical Impairment as a Result of Cerebral Palsy

Cerebral Palsy (CP) is a term given to a lifelong neurological condition that results from damage to the brain due to loss of oxygen prior to or during the birth of a child or during an early period in childhood and can also result from a head injury. It manifests in difficulties with balance and coordination and can impact one or all four limbs. It may be accompanied by one or multiple learning and/or developmental impairments. Difficulties with speech and cognition (information processing) may accompany this condition, as well as developmental disabilities. Physical rehabilitation is used to help children with cerebral palsy (CP) to achieve optimal physical functioning in order to enhance their independence and participation in mainstream social life (Bottos, et al., 2001; Kielhofner, 2004). There is extensive research on CP in childhood and adolescence which views CP as a pediatric condition that is stable over time. Most of this literature is based on the assumption that individuals with moderate to severe CP experience the greatest benefits from health care and rehabilitation during childhood and experience little or no improvement during adulthood (Bottos, et al., 2001).
Despite advances in health care, the incidence of cerebral palsy has not declined over the past thirty years. According to the International Cerebral Palsy Society (2011), there are approximately 17 million people around with cerebral palsy; there are over 60,000 Canadians living with cerebral palsy (Ontario Federation of Cerebral Palsy, 2010). However, it is difficult to know how many individuals are experiencing declines in functioning, as a national directory does not exist (Strauss, et al., 2004; Zaffuto-Sforza, 2005). Many individuals living with this condition lead full lives, in the areas of school, work, family, and leisure. However, many individuals with CP are at risk for and have encountered problems as adults that interfere with participating in daily living, which can impact social-psychological well-being. Despite the emergence of these issues, there is a dearth of research on aging with CP.

Expanding our knowledge of aging with CP was important to me to gain a better understanding about how adulthood and aging are experienced by individuals with this condition. It was also important to challenge the assumption that CP is predominantly a pediatric condition and, thus, increase our awareness of the changing needs of individuals with lifelong impairments. CP is a lifelong condition that may be accompanied by improvements early in the lives of individuals, as well as plateaus and periods of declines due to acute and/or chronic conditions that accompany the primary condition. Achieving this recognition could change the ways in which we think about people with impairments, and the practices that are used in health care and rehabilitation to treat and manage their conditions across the life course.

Similar to the research on aging with acquired physical impairments, our understanding of aging with CP has primarily focused on the physical challenges that individuals encounter: increased spasticity, pain, fatigue, loss of strength, declining mobility,
and musculoskeletal deformities, especially in the joints (Bottos, et al., 2001; Haak, Lenski, Hidecker, Li, & Paneth, 2009). Other health problems that have been identified include bowel and bladder difficulties, respiratory problems, and problems with oral hygiene.

The experience of individuals with lifelong physical impairment such as CP is unique from four standpoints: 1) Many of these individuals have received health care and rehabilitation from infancy up to late adolescence without having access to medical care once they transition into adulthood; 2) There are very few health care professionals who have the training, knowledge, and experience in working with adults with cerebral palsy. 3) Medical environments are not accessible to assess and treat the health care needs of these individuals (Bottos, et al., 2001; Hilberink, et al., 2007; Neri MT & T. Kroll 2003; Tighe, 2001). 4) Research on adolescents and young adults are finding that declines in functioning in relation to walking and needing assistance with some personal care begin as early as late adolescence and young adulthood (Andrén & Grimby, 1999; Bottos, et al., 2001; Hilberink, et al., 2007; Kemp & Mosquida, 2004; Strauss, et al., 2004; Zaffuto-Sforza, 2005).

2.5 Data collection

2.5.1 Boundaries of the Data Collection

This study was designed around the completion of multiple interviews (orientation interview plus 3 or potentially 4 interview sessions) with 8 to 10 individuals living with cerebral palsy between 45 and 70 years old, in order to achieve an in-depth understanding of their experience. This age span was chosen in order to learn about their experiences during multiple phases of their lives. The justification for this sample size is grounded in the guidelines associated with narrative inquiry. Narrative inquiry can be undertaken by interviewing a small group of participants depending on the objectives of the research being
undertaken. Some studies may focus on one or two cases where the researcher meets with each participants many times. This supports the collection of rich data by studying their experience in-depth with a focus on understanding and interpretation of the meanings embedded their narratives. The interviews may represent units of analysis or researchers may use the interviews to reconstruct narratives from the transcripts (Clandinin & Connelly, 2000; Kohler-Riessman, 2008; Lieblich, Tuval-Mashiach, & Zilber, 1998). This study was designed to meet with participants multiple times which would provide a rich source of data.

In order to participate individuals had to be able to read, write and/or speak English. Each session was approximately 1 1/2 to two hours. Individuals with communication impairments (difficulty being understood by others who use a communication device or other assistive technology to assist with expressing him/herself) were also encouraged to volunteer. Individuals living with cerebral palsy who had a history of significant intellectual disabilities and/or psychiatric problems were not included in the study.

Narrative inquiry is usually undertaken by interviewing a small number (typically 6-15) of participants multiple times (Clandinin & Connelly, 2000; Kohler-Riessman, 2008). The sample size in this study was limited to 8 to 10 individuals in order to develop a comprehensive, in-depth understanding of the participants’ experiences across the life course (Kuzel, 1999; Patton, 2002).

2.5.2 Recruitment

After I obtained approval from ethics at the University of Toronto in August 2006, I contacted the executive directors for the Ontario Federation of Cerebral Palsy (OFCP) and the Ontario March of Dimes to send them a flyer about my study (Appendix A, p138). A
request was made to have this information posted in their newsletter and on their website. Individuals interested in the study were requested to contact me directly.

Information on my study was posted on the message board at OFCP while the Coordinator of Research at the Ontario March of Dimes approached prospective participants who contacted me if they had an interest in participating. Three participants were recruited from this process. In June 2007, I attended a conference (FICCDAT) where I met a few prospective participants and was provided with a few names of other individuals who might be interested. Overall, thirteen people expressed interest, two chose not to participate after several follow-ups. As I engaged in the recruitment process I was meeting individuals living with secondary health problems who were younger than thirty-five. Consequently, my age range was expanded in order to include their experiences.

2.5.3 Orientation Session

Individuals who expressed an interested in participating attended an orientation session to provide them with an overview of the study and to determine their eligibility to participate. The purpose of the orientation session was to review the objectives of the research, review the consent form (Appendix A, p138) and the expectations associated with participation in the research. Informed consent was obtained written or orally, depending on the abilities of the prospective participant. The orientation session was also an opportunity to assess the participants’ willingness and ability to meet the demands of the research and to ensure that they could be understood (especially individuals with augmentative difficulties who did not use a communication device). Background information (Appendix B, p139) was obtained from each participant.
2.5.4 *Life Satisfaction Chart*

At the orientation session, the participants were provided with a copy of the Life Satisfaction Chart (Clausen, 1998) to be completed prior to the first interview. The Life Satisfaction Chart was developed by John Clausen (1972) to capture significant attributes across the life course of individuals when engaging in longitudinal studies. It is a grid on which participants chart significant life events and individuals at different phases in their lives. They are also supposed to rate the level of satisfaction at each phase (Appendix C, p141).

The chart was designed to be used in clinical or semi-structured interviews for compiling life reviews or life stories (Back & Bourque, 1970; Clausen, 1972). It was designed as a grid where a person could plot significant social milestones and events that took place at different phases of their lives and rate the satisfaction associated with these experiences. It is also used a strategy to facilitate recall of experiences in their lives. Instead of using a grid I constructed a chart that included these ideas.

I used the chart as a strategy to facilitate the interview process so that participants could reflect upon significant life events, experiences and people that have impacted their lives prior to the actual interview process. I also sent them an electronic copy so they could write down their thoughts and feelings as well. This was important to capitalize on their strengths and abilities while enhancing their participation in the process. I also wanted to provide individuals who could not participate in the traditional interview format with the opportunity to do so. Research has found that individuals with moderate and severe cognitive or communication impairments are not considered to be good candidates for health research because of challenges they have in engaging in and completing the research process.
Participants were given 2-3 weeks to complete their Life Satisfaction Chart following which the first interview was scheduled.

2.5.5 The Interview Process

Most participants were interviewed in their homes. Two chose to be interviewed in their workplace. Three participants were interviewed on the phone as they lived outside of Ontario (British Columbia and Alberta). At the first interview the purpose of my research was reiterated to facilitate the telling of their stories. Using the guidelines of narrative inquiry, an interview guide was not used to learn about their experience. Rather, I used a primary question that was supplemented with encouraging participants to elaborate on experiences they identified in their life satisfaction chart. The primary question I posed was, “What is it like living with cerebral palsy?” I wanted to learn what it had been like growing up and growing older with cerebral palsy in order to achieve an in-depth understanding of their experiences and how aging has impacted their lives. Probing questions were used to support this process. The questions that were selected were intended to be used as a reference on an as-needed basis to assist participants in describing and elaborating their experiences (Atkinson, 1998; Rodwell, 1998) There was no intention to use every question with each participant, since some participants required little or no assistance in providing a comprehensive account of their experiences. Examples of some of these questions can be found below:

2.5.6 Probing Questions
What was the experience like for you?
What happened next?
Tell me more about that
Can you elaborate?

2.5.7 Supplementary Questions
How would you describe your childhood? Adolescence? Adulthood?
Who and/or what (i.e., transition or life event) has contributed to influencing who you are today and in what ways?

2.5.8 Closure Questions
Is there anything that we’ve left out of your life story?
Do you feel you have given a fair picture of yourself?
What are your feelings about this interview and all that we have covered?

2.6 Data Analysis
The first step in a narrative analysis is to construct a single narrative or life story for each participant based on the multiple interview transcripts. I reviewed all of the interview transcripts for each participant and constructed a single narrative for each participant that was chronological and captured important experiences, significant events and key relationships. The process of developing the individual narratives was iterative and began with the first interview. Participants were actively involved throughout. They reviewed their own narratives to ensure that I had captured their stories and were given the opportunity to expand or clarify different segments. Every effort was made to preserve the meaning of the original texts by using the participants’ words and keeping grammatical editing to a minimum.

The second step the analysis involved in-depth analysis of the individual life stories or narratives in order to identify the overall or common shape and content of the narratives.
Once the individual narratives were completed and had been reviewed and approved by the participant the analysis of the narratives proceeded as follows: First, each narrative was reviewed considering the context, content, and form of story being told. Next, each stage of development (childhood, adolescence, young adulthood, older adulthood) was reviewed independently to identify emerging themes, group categories together to form sets, and begin to explore relationships that exist between categories within and across stages of development. Attention was paid to identifying individual and collective attributes, as well as the historical, political, social and cultural contexts in which the participants’ experiences were situated. NVIVO 8 was used to assist in the organization and management of the data.

The process I engaged in for analyzing the data involved two components: constructing participants’ life stories and then analyzing their life stories involving multiple processes and strategies. The next two sections provide a detailed account of these processes and some of the emerging findings.

2.6.1 Constructing Narratives

Narratives were constructed from three sources of data: background information, Life Satisfaction Chart, and the interview transcripts. They were structured chronologically according to the Life Course. Headings were created from the transcripts that captured experiences, significant events, and relationships that shaped their narratives as they grew up and grew older with cerebral palsy. The transcript, page, and line # were all documented so that I could keep track the decisions I made in selecting one statement over another as I reconstructed their stories.

The first narrative provided a template for organizing the data for the narratives that followed. More headings were added with each narrative as some headings did not capture
every participant’s experience. Even though I started each narrative with the same headings, they all took different shape and structure. This was partially due to variation in the details that participants were willing to share with me. Some participants provided extensive details about different events and experiences, while others were less descriptive in the telling of their stories.

Every effort was made to preserve the meaning of text by using the participant’s words and keeping grammatical editing to a minimum. In order to achieve continuity of a participant’s story, redundancies were omitted using “…” words that were changed or added were placed in brackets (Kohler-Riessman, 1993, 2008). Both my interest in this topic and my own experience with impairment and disability informed the inquiries I made and how I constructed their stories. It was important to me that the participants’ voices be heard rather than my own and so each narrative was written as though my participants were telling their own stories. After the narratives were constructed, participants had the opportunity to review them to ensure that they captured who they were, the headings used, and retelling of their story. Preserving the words of my participants improved with each narrative that was constructed.

This study was designed following the guidelines of narrative inquiry (Atkinson, 1998; Clandinin & Connelly, 2000) as well as including the use of adaptive technology and reasonable accommodations such as extra time (more than 3 interviews), and using a scribe. Despite this careful planning, I encountered challenges immediately during the first interview with my first participant. She provided facts about her life without being able to provide in-depth accounts of her experiences. She requested additional questions to assist her in sharing her experience during the first interview. She also found it difficult to expand on experiences she wrote about in her life satisfaction chart. There may be at least three explanations for
these challenges: 1) She had never participated in this kind of interview process and/or been asked the questions that were posed; 2) She found it difficult to recall and reflect upon her experiences due to mild cognitive issues and therefore found it difficult to share more elaborate details of her experience; and 3) Some individuals are more detail oriented in the telling of their story while others focus on providing facts.

The challenges that I encountered during the first interview facilitated modification of the interview process as well as implementing strategies that would support participants in the telling of their stories. A comprehensive overview of the challenges and strategies that were used support participants in the telling of their stories can be found in Appendix D (p143).

2.6.2 Narrative Analysis of Participant Life Stories

After all the individual narratives were constructed I engaged in four different phases to analyze and interpret my data. Field notes were kept for each phase of the analysis to track new developments and changes as the analysis became more in-depth:

Phase I: I reviewed three transcripts to identify emerging themes during the co-construction of participant life stories. I then reviewed each narrative to identify categories embedded in the text (pencil and paper). My data were analyzed by considering the context, content, and form of the story being told. I identified both individual and collective attributes. Broad categories were identified which linked together a central narrative “Defying the Odds”.

Phase II: All of the life stories were imported into NVIVO 8 to organize the data into the categories that emerged from the first analysis. The categories were then re-organized into four stages of life (childhood, adolescence, adulthood, and old age). A list of my code scheme can be found in Appendix E (p145).
Phase III: Each stage of the life course was reviewed independently to identify emerging themes, group categories together to form sets, and begin to explore relationships that exist between categories within and across the life course. Consideration was given to how the experience of growing up and growing older with childhood onset impairment is influenced by context and historical periods, the linkages that individuals have with family and their community. This means that being able to fully participate in mainstream society is influenced by meanings individuals assign to their interactions with others. Past experiences are used to make choices about the future. Early life experiences contribute greatly to identity formation and the opportunities and resources a person may have available to him/her. The concepts, categories and themes were integrated in a coherent manner.

Phase IV: The final phase involved the write-up of the findings of the analysis of the participants’ life stories. The narratives were reviewed again line by line in order to achieve a comprehensive account of the data and increase the rigor of my analysis. Linkages between my emerging findings and existing research were made. Strategies used throughout the process included:

* Both context (including historical point in time and the context in which the narrative was constructed) and text were incorporated into the analysis and interpretation.

* Comparing attributes, concept, and themes

* Identifying unique attributes (negative cases) that have social significance

* Reflexivity

Engaging in this process for analysis was helpful for identifying preliminary themes that permeated different phases of participants’ life course, as well as the central storyline/narrative that linked their experiences together.


2.7 **Emergence of the Defying the Odds Narrative**

The Defying the Odds narrative began to emerge during the process of data collection, the co-construction of participant life stories, and the preliminary analysis of the themes and categories that were embedded in their stories. Initially five themes emerged from this process:

1. Little or expectations for a meaningful existence
2. Self-identity
3. Achieving belongingness
4. Overcoming being seen but not heard
5. Becoming Self-reliant

Attributes of these themes can be found in the Glossary of Terms (Appendix F; p153). As the analysis unfolded, it became apparent that a narrative captured the participants’ experiences by weaving together these five themes. The narrative did not have a name until I achieved a more in-depth analysis of the data. Nonetheless, it was apparent to me very early on in this process that there were attributes of my research participants’ narratives that were not captured by the illness narratives conceptualized by Arthur Frank (Frank, 1995). During the middle phase of analysis, their narrative was first conceptualized as “Against all Odds” and was later reconceptualized as “Defying the Odds”.

“Defying the Odds” is a narrative that builds on the quest narrative conceptualized by Frank (1995). It unfolds in one of three ways:

1) A person with lifelong physical impairment grows up in a loving family and a supportive environment that are then not supported or reinforced in the external environment. He/she encounters attitudinal, physical and structural barriers that he/she breaks through resulting in personal transformation in one or multiple areas of their lives (personal,
social, and vocational), which supports the achievement of independence (which varies depending on the severity of one’s disability) and may also involve making a difference in the lives of other individuals confronted with similar circumstances (Quest narrative).

2) Other individuals come from families where their needs for love and support are not met. They then encounter a society that does not value them making it difficult for them to access the social and educational, vocational and health care opportunities they need to manage life as an adult with lifelong physical impairment. Many individuals confronted with these circumstances are able to transcend the negative forces they have encountered by being able to achieve independence while encountering challenges in achieving meaning in other areas of their lives due to the absence of a strong foundation.

3) Other individuals find themselves in an ongoing struggle to maintain their independence and quality of life as adults after overcoming the negative expectations, opportunities and experiences of growing up with physical impairment due to the conceptions society imputes on them with respect of what they need to. While individuals confronted with these circumstances may achieve success and meaning in their lives they may take ten steps forward and then three steps back because of other mitigating circumstances that are outside of their control.

While the origins of growing up and leading an independent and meaningful existence may be different, the experiences of these individuals are linked as much by the external forces that impinge on living with a physical impairment as the impairment itself. That is to say living with a lifelong physical impairment is not as difficult as having to negotiate the barriers and challenges that are confronted in the external environment.

In the Results Section (Chapters 3 and 4), I outline “Defying the Odds”, the central narrative that emerged from the analysis of participants’ life stories. Chapter 3 begins by
providing an overview about how the narrative emerged and was conceptualized. The central characters will be introduced which is then followed by describing the early years of the participants’ lives. Their narratives unfold by tracing how their disordered bodies were managed by the institutions the participants interacted with as they grew up and grew older. The narrative is divided into two parts: Growing Up (Chapter 3); and Adulthood and Growing Older (Chapter 4).
Chapter 3. Growing Up with Lifelong Physical Impairment

3.1 Introduction

Defying the Odds was the central narrative that emerged from the analysis of the life stories of the nine participants who shared their experiences for this study. Chapter 3 focuses on Growing Up with Lifelong Physical Impairment. Chapter 4 focuses on Adulthood and Growing Older.

3.1.1 Overview of the Defying the Odds Narrative

The Defying the Odds narrative depicts the notion that individuals with lifelong physical impairments possess an inner drive to create a life for themselves even when adversity is confronted on a regular basis. Adversity takes the form of little or no expectations for achievement, being defined by their impairments, growing up without social, emotional, and instrumental support that contributes to developing a positive self-concept, and skills and abilities needed in adulthood. It also includes not having access to social and educational, and later, vocational, opportunities that support their development and overall well-being. People with lifelong physical impairment have the capacity to see the ability and potential within themselves that is not apparent to the outside world. The external forces they confront often thwart their efforts to participate in meaningful occupations.

Defying the Odds refers to the challenges that people with lifelong disability encounter growing up and growing older and the ways in which they overcome or resist biomedical and cultural discourses about the normal body and impairment. They challenge
and resist the discursive and non-discursive practices that the institutions of medicine, rehabilitation, and education use to manage and regulate their bodies, and the ways in which their lives are constituted, meaning the experiences and opportunities they are given to achieve their full capacities. Discursive practices refer to the role of knowledge (scientific) and institution (health care and rehabilitation) and education in constructing the lives of people with physical impairments (along with management and regulation of the disordered body) (Turner, 1992). Non-discursive practices capture the embodied experience of impairment, more commonly known as the lived experience of impairment, which considers how the body and individual subjectivity are constructed and reconstructed through interactions with “others” (Turner, 1992). Both sets of practices overlap with one another and occur simultaneously as peoples’ lives unfold and are reflected by the primary and secondary characters they encounter at different phases of their lives. The primary and secondary characters throughout the narrative include their parents, extended family, health professionals, and educators.

Figure 1 (Appendix G; p156) illustrates the main phases and challenges encountered in the Defying the Odds narrative as the participants grow up and grow older with lifelong physical impairment. The meta-narrative that weaves the Defying the Odds narrative together is “Striving for a life with Meaning & Connection” which consists of three threads: Achieving a Sense of Belonging; Overcoming Being Seen but not Heard; and, Becoming Self-Reliant.

Growing Up encompasses the years when individuals with disordered bodies are identified and labeled and find their narratives shaped by institutions of family, medicine, rehabilitation and education. There are four phases to the Growing Up phase of the Defying the Odds narrative: 1) The Appearance of the Disordered Body; 2) Assessment and Labelling
Disordered Bodies; 3) The Normalization of Physical Impairment; and, 4) Struggling to Fit In. Growing Older encompasses the adulthood years when individuals with disordered bodies strive to maintain the gains they made Growing Up. The four phases to the Growing Older phase of the Defying the Odds narrative are: 1) Making a Place for Themselves in the World; 2) Living on their Own; 3) Disruptions in Self-regulation of the Disordered Body; and 4) Abandonment of the Disordered Body.

3.2 The Participants

The central narrative that emerged from the analysis was constructed from the experiences of 9 individuals, six women and three men living with mild to severe communication, and physical impairments from cerebral palsy. What follows is a brief overview of these individuals. Each participant has a pseudonym to protect his or her identity. Refer to Appendix H (p157) for an overview of their background attributes.

Participants’ life stories were distinguished by the severity of their condition. Two of my participants had severe communication and physical impairments: Fred (54) uses a bliss board to communicate with the assistance of an interpreter. He lives on his own with the support of attendant care. He is close to his family and actively engaged in his community in a variety of volunteer, and education programs. Cathy (70) had been widowed for a few years when she was interviewed. She had been married for over 27 years and led an active and independent life with her husband who also had CP.

Three participants had severe to moderate physical impairment and used a wheelchair, and other mobility aides to get around at home and in their communities: Vanessa (35) was involved in volunteer work with seniors and living in her family home. She was unable to find a job after completing college due to physical and attitudinal barriers in the environment
coupled with declining health that limited her participation in a variety of activities. **Geraldine** (61) was retired at the time of her interview but was very busy taking classes in the community. She loved working with children and enjoyed a brief career as an early childhood education assistant. **Robert** (61) was retired after working over twenty in community services. He spends his time volunteering.

Two other participants had mild to moderate physical impairment and used a wheelchair and/or forearm crutches, while two other participants had mild physical and communication impairments and managed without the use of mobility aides. At the time of their participation, both **Suzanna** (47) and **Marni** (26) were living in their own apartments. Suzanna was working part-time, while Marni was attending graduate school. Both Suzanna and Marni had a twin sister. **Michael** (54) was retired at the time of his participation in the study, but actively involved volunteer work and workshops (classes) in drama and singing. **Natalie** (43) was a mother of three, divorced, and attending graduate school.

The remainder of this chapter is devoted to describing the growing up years of the Defying the Odds narrative.

### 3.3 The Appearance of the Disordered Body

There are physical capacities that people acquire as they mature that enable them to control and regulate their bodies in order to perform certain skills and abilities that contribute to society through participation in roles such as student, parent, worker and citizen (Foucault, 2003/1973, Turner, 1992 #248). These basic physical abilities include being able to sit, stand, walk, and regulate and control physiological processes on a day to day basis. These attributes are considered as “normal” functions or body techniques that people learn to manage as they mature (Merleau-Ponty, 1962; Turner, 1992). A body is considered
disordered when an individual has paralysis of one or multiple limbs, which alters the appearance of the body and interferes with being able to control and manage physical functioning and normal physiological processes. These bodies deviate from the norm and are difficult to control and regulate (Seymour, 1998; Turner, 1992). The economic, political, social, and cultural contexts in which people with disordered bodies exist impact the ways in which they are treated through biomedical intervention, rehabilitation, and education, as well as the experiences and opportunities within which they engage (Hughes, 2009; Sullivan, 2005).

The Defying the Odds narrative begins at birth when participants encounter their first medical crisis due to a high risk pregnancy or complications during the birthing process itself. Medical intervention is required for all participants in order to stabilize their physical well-being. Parents and extended family are the primary characters in participants’ lives at this stage of the narrative. Health professionals enter briefly at this early time to resolve the crisis.

All participants experienced varying degrees of brain damage as a consequence of loss of oxygen to the brain. In most instances, participants told stories of entering the world prematurely with the umbilical cord wrapped around their necks. Fred recounts the dramatic nature of his birth and delivery:

All was fine during the nine months of my mother's pregnancy. She went into labour on a Saturday morning and then at supper time all the labour pains stopped. At about 1 a.m. Monday morning, the doctor decided to take her to the delivery room so he could take me out. It turns out I was stuck in the birth channel from Saturday to Monday morning and my brain did not get enough oxygen during this time. That's why I have CP. In all it had been 49 hours since my mother's labour began! When I was finally born, I had great difficulty breathing.
Doctors did not think that I would live. My Uncle and Aunt came to the hospital before seven in the morning to help my father baptize me. Later I was baptized again at church. After I was a few hours old, the doctor suggested I be taken to the Children's Hospital. My father was told that he could transport me in his car with a portable incubator so I could breathe. They sent a nurse along to help. When we got to the hospital, the staff would not allow the incubator from the other hospital to be taken in. So I was left lying on the table while my father filled out hospital admission papers! I needed oxygen badly as the person in charge didn't seem to realize that. My dad was very worried and angry because I was gasping for air for an hour and a half. This was an emergency but the staff was not treating it as one.

Fred’s story illustrates the key role of his parents in defying the odds of his difficult birth by resisting the negative attitudes of the health professionals concerning his breathing difficulties. Although not so dramatic as Fred’s story, all participants told stories of difficult births. Natalie conveyed,

At birth my umbilical cord [was] around my neck ... for about 2 minutes. I lived in an incubator for about 2 weeks after birth (4.7 lbs).

Once the baby’s medical condition was stabilized, parents were sent home without knowing or realizing that their children may face challenges with respect to their physical functioning. As Fred said,

My father knew there were complications during my mom’s labour but he didn't know what was happening to his baby as a result.

As months passed all participants were confronted with new odds that manifested in failure to begin to display the ability to regulate and control physical abilities characteristic of their age. For most, the disordered body began to appear between six and nine months. Parents became concerned when their children didn’t display, or if they had difficulty
mastering, one or more of the following abilities: grasping, smiling, making sounds, sitting up without being supported, rolling over in bed or on the floor, beginning to crawl, stand, and take their first steps. For instance, Cathy recalled:

When I was little, my parents were concerned because I wasn’t developing at the same pace that other children were at my age. I wasn’t able to talk until I was three or four, and few except my parents could understand me. At the same time I began to crawl which remained my only means of self-navigation. At five maybe, I walked (after a fashion) with someone hanging on to me or was carried everywhere.

3.4 Labelling the Disordered Body

The next stage of the participants’ narratives involves parents searching for answers to the problems their sons or daughters are displaying. This search invariably leads them to the institution of medicine and the world of health care and rehabilitation. At this point the children are brought under the medical gaze of health professionals, beginning with a physical assessment that is judged against normative standards of physical functioning and appearance (Davis, 1995; Foucault, 2003/1973; Kielhofner, 2004).

It is here that the thread of Being Seen but not Heard begins. Being seen but not heard is a common experience for the participants that begins when they are children and their parents and health care professionals make decisions for them. This thread then follows them throughout their lives. The kind of decisions that others make for them can hinder having their personal and social needs met, especially for those with a severe impairment. Parents tend to value the expertise of professionals they come into contact with and make decisions for their children without including the child as part of the process. From the time they are very young, these individuals are given little or no opportunity to convey their needs or feelings, or to be included in decisions that will impact their lives.
The medical gaze perpetuated the feelings of *being seen but not heard*. The gaze of health care professionals negatively impacted their sense of self and devalued their existence through its legitimation of normalcy. All participants would encounter these experiences in different social contexts throughout their lives; however, this experience was extremely profound in health care and rehabilitation. For instance, Marni recalled,

I remember this one time and I wasn’t particularly older this time but I was a little bit younger, but one time they’re like oh your shorts are too long and my mom took my shorts off so I’m in my underwear. I think they should maybe pay attention to that a little bit more like asking, I know parents are supposed to have the consent but also asking the person that they’re seeing. I don’t know if they ask children that, like they should but I don’t know if that happens in practice. I just kind of felt like I was on display...... This doesn’t even sound bogus to me but I think if I was trying to explain this to a doctor it might sound bogus to them, but when you’re on display like that you’re not on display for them to say good things about your body, like they’re pointing out things that are deficits, right. And you can hear what they’re saying whatever, disrupted gait or atrophy of like this part of the body or that part of the body and you know it’s not good but not all of those terms are explained to you in that moment. [It] just made me feel really nervous and perhaps silent.

The children will continue to be scrutinized and judged against the standards of normality as they grow up. *Being seen but not heard* was particularly an issue for Fred and Cathy who were extremely vulnerable to misconceptions about what they wanted or needed at a given time because of how difficult it is to understand them. The most significant difficulties they encountered were outside the home when they interacted with people who did not know them and were unfamiliar with the strategies they used to express themselves. Living with severe physical and communication impairments made other people who Fred and Cathy met at different points in their lives assume that they are unable to make decisions
for themselves. It is through the professional gaze, knowledge and expertise that the participants are assigned a label (Green, Davis, Karshmer, Marsh, & Straight B., 2005) for the physical challenges they were displaying. The label that was assigned identified both the condition and its attributes (e.g., spastic CP).

Labelling is used as a mechanism to identify the kinds of programs and/or medical technologies that can be implemented to improve and/or eliminate participants’ physical impairment so they would conform to normal standards of functioning. Labelling the disordered body is beneficial because the health professional can make recommendations for medical treatment such as orthopedic surgery and/or physical rehabilitation to improve the physical functioning of the individual with physical impairment. However, the use of labels establishes parameters on how much and/or how little a person is expected to be able to achieve, what he/she needs, and determines the extent to which he/she will be able to lead a normal life.

Being labelled disabled or physically impaired carries certain conceptions and assumptions about a given subject that are by no means positive. Having a physical impairment is a devalued physical attribute that is stigmatized by able-bodied persons and perceived as being associated with inability and/or lack of potential (Davis, 1995; Goffman, 1963; Green, et al., 2005). Being stigmatized coincides with segregation and discrimination, which limits the opportunities of individuals possessing the negative physical attribute to fully participate in mainstream social life. This experience is also accompanied by being perceived as non-human, as incapable of being productive, or as having the same needs as their able-bodied counterparts. These discourses are reflected in the life stories of the participants in this study.
Most participants were assessed and received a diagnosis during their first year of life (Suzanna, Marni, Fred, Geraldine, Michael, and Vanessa). In general, participants who were diagnosed early in their lives lived in urban areas where their parents had access to health care professionals who were familiar with cerebral palsy. In contrast, Robert, Cathy and Natalie were diagnosed much later. The timing of obtaining a diagnosis was influenced by when they were born, where they lived, and the medical expertise that was available to them. For example, Robert began to experience problems during the polio epidemic in the early 1950s. Many of the local doctors his mother took him to see were familiar with polio but not with the difficulties he was experiencing. Robert recalled,

My mother took me from specialist to specialist, but the doctors didn't know what was wrong. My uncle suggested a specialist in Baltimore where he lived. I was four or five when I was diagnosed with cerebral palsy.

Cathy was eight when she was diagnosed. She grew up on a farm outside of a large city. It was difficult for her parents to find a doctor until they took her to a specialist in the city who provided them with a name for her condition, as well as access to services and programs that could help her improve her functional abilities and manage life with impairment. Consequently, her parents sold their farm and moved closer to the city so she could benefit from these programs. Natalie, who lived in a rural area in her early years, also did not have access to health professionals familiar with her mild form of CP and was not diagnosed until she was three.

Putting a name or label to the physical and social delays and difficulties their children were displaying had a significant impact on parents in two distinct ways: on the one hand, the diagnosis provided them with an explanation for the difficulties their sons or daughters were experiencing. However, at the same time concerns associated with the long-term outcomes
that accompanied the diagnosis were raised. The way that parents embraced or resisted these medical discourses was key to shaping the participants’ narratives.

It is here that we pick up the thread of *Achieving a Sense of Belonging* that weaves through the Defying the Odds Narrative. Needing and wanting to belong begins and is shaped within the family context, and depend on how families accept or reject the discourse of disability. The need to be loved and accepted—first within the context of their families and later among the people they interact with outside of the home—is very important to all the participants because it contributes to supporting a positive self-concept, belief in one’s self-efficacy, and overall emotional well-being. Having confidence in oneself also contributes to providing an individual with the strength and resources (both internal and external) to deal with the trials and tribulations that show up at different times in their lives.

Many health care professionals attached a bleak long-term outcome for improving the impairments associated with the child’s condition, as well as lower expectations for being able to achieve his or her potential and any kind of meaningful existence. The prognosis and guidance they offered permeated the family and later education professionals. As a result, many participants felt they were discouraged from achieving their full potential as children, thereby making it difficult for them to survive in the world as adults. Geraldine captures these ideas when she said:

> [Some] people who have a disabled child only think that the only thing that they need to do is protect that disabled child. No! They need to teach the disabled child how to survive in the world. They think they’re doing the right thing by coddling the disabled child, but they’re not because the disabled child is going to be an adult and living in the world and having to learn how to survive in the world without them.
As the primary characters in their lives at this point in the narrative, the ways in which parents dealt with having a child with a disability, and the decisions they made, significantly shaped their son/daughter’s narrative. Parents’ responses to having a child with a physical impairment are crucial to the experience of growing up and growing older with impairments because the paths the participants take throughout life have their origins in the patterns of interactions within the context of the family. Before children with impairments connect with health care professionals, school, and children their own age, their first social network consists of their families which are the first and primary source of nurturing their sense of self.

### 3.4.1 Acceptance or Rejection: Parents’ responses to the labeling of the Disordered Body

All the parents accepted the medical label but had different responses to the diagnosis. In the first response, acceptance of the disability discourse and rejection of the child, parents were only able to deal with their child’s medical needs and seemed unable to respond to their child’s needs for love and acceptance. Several participants told stories about feeling as though they were a burden to their families and not feeling loved and accepted because of their impairments. These experiences are captured by Geraldine who stated that,

> I had two older brothers and a sister. A fourth child was not needed or wanted. I was the youngest for 11 years until my stepsister was born. I was six when my parents divorced. Very little time was given to me.

Some participants tell stories about their parents finding it difficult to engage with them when they were little because they had difficulty accepting that they had a child with a long-term chronic condition. In some ways having an impairment influenced how parents related to their son/daughter on an emotional level both physically (hugging and kissing) and
verbally (providing encouragement, love and support), and engaging in activities together.

For instance, Robert stated,

Although I was not in a wheelchair or had speech impairment, but being a disabled child I think there were guilt feelings from my parents. And I think it was a strain financially on my dad, like visits to the doctor. When I was little it was difficult growing up in my family because my parents weren’t there for me emotionally. Let’s say I wanted to toss around a ball with my dad or go fishing and do things like camping and stuff like that, he didn’t do it. And I always thought, well, maybe he didn’t want to it around me, but it turned out that he didn’t do it with any of my brothers. But I wanted to do more things with my dad. He was there for me, but he wasn’t. Like, he worked very hard, but I would have like to have been ....closer.

In contrast, in the second response, resistance to the disability discourse and inclusion of the child, participants tell stories about their parents embracing their children despite disability and supporting them in being the best that they could be. Both Cathy and Fred tell stories of their parents investing a great deal of time and energy in their children’s lives and trying to make them feel part of the family. This was not limited to meeting their daily needs, but also seeking community support and resources to enhance their abilities, as well as socializing them with others (family and children) so they could experience life like other children their age. Even though they were dependent on their family for everything, they felt loved and accepted from the time they came into the world. As Fred said,

My family and I often lounged on the living room floor and played games like Monopoly and cards and we spent time together. Everyone who played the game sat on the floor and helped me, which felt very inclusive—like we were all on the same level. Someone would roll the dice, someone else would move the game pieces and we all played together. I was very dependent on my family and all my family members helped me.
During childhood many participants described being close to other relatives besides their parents who also encouraged them and had a positive impact on their sense of self. As Geraldine recalls,

I was very attached to my older sister. She understood me better than anyone else in the family. Since our mother wasn't stable, my sister took on the role of surrogate mother. She was really special to me because she maybe wasn't as critical of me as the rest of the family. She was the emotional cushion she was the one that nurtured me more than anyone in the family… She was more excepting of me as a total person. I just wasn't this thing, this annoyance that happened to have a disability

Robert’s identity was nurtured through his experiences with his extended family, especially his Uncle (father’s brother) and grandparents (mother’s parents) who provided him with a great deal of love and acceptance during his childhood and adolescence that supported a positive self-esteem. He recalled that,

Most of the love and affection I received was from my grandparents (mother's parents). My aunt and uncle made me feel really good. They always gave me a lot of confidence. When my uncle came to visit me he was very interested in what I was doing. He liked the same things as me. He provided me with a sense of belonging and being loved.

Both Marni and Suzanna have non-disabled twin sisters that they were very close to growing up. Suzanna considered herself lucky as a child that she had a twin sister because they shared a birthday, and she always had someone to play with when she was little. Similarly, Marni still considers her sister to be her best friend and someone who has been an ongoing source of support and love even in adulthood. Her presence has helped her to live with her circumstances and put no limits on what she could do in life as she grew up. She conveyed,

When we were younger, for example, there were sometimes kids that would invite my sister to a party
or something and they wouldn’t invite me. But my sister ….she would always kind of be, “Well, I want to go to your party, but I want to go to your party if my sister could come”.

3.5 The Normalization of Physical Impairment

Following diagnosis and labeling, recommendations were made by the doctor for the child to receive rehabilitation. The medical and rehabilitation discourses children and their parents encountered located their problems in the individual (Oliver, 1998), which means that the individual with the impairment has to participate in rehabilitation and work hard at trying to achieve “normal” physical functioning (Hewitt, 1991; Sullivan, 2005).

At this point, the plot line of all of the participants’ narratives changes dramatically, as having a permanent physical impairment expands the cast of characters involved in their lives to include rehabilitation specialists who have strong influence on the shape of their narratives. Entering the disciplines of health care and rehabilitation means that they are surrendering themselves to the expertise and practices of these health professionals in order to enhance their long-term physical well-being and life experience. Little do they know how the influence of health care and rehabilitation professionals’ knowledge and power will shape their narratives long-term. That is, the kind of programs and services from which they may benefit are decided by the outcomes of the medical examination and assessment of their physical functioning. Their physical functioning is measured against standards of normal physical functioning that individuals the same age are capable of in the absence of physical impairment.

Even though physical rehabilitation offered hope for participants and their parents, the mere possession of physical impairment cast them in a negative light that associated them with being less capable than able-bodied individuals. These assumptions were reinforced
through the use of two practices. First, health care professionals that participants and parents came into contact with expressed low expectations of achievement and felt the children possessed little or no potential for participating in mainstream social life. These assumptions reflected cultural beliefs about the body, as well as the medical discourse on impairment which both value the healthy normal body. Secondly, the health care professionals that participants came into contact with were concerned with engaging in medical practices such as orthopedic surgery that would fix the disordered body so that it would be able to benefit from physical rehabilitation to enhance physical functioning and bring it closer to normal standards. It was not uncommon for some participants to undergo orthopedic surgery to correct atypical musculoskeletal structure, or reduce spasticity before they reached physical maturity. Consequently, the management and regulation of disordered bodies was achieved through a process of physical rehabilitation and education.

For the most part following diagnosis almost all parents took their children to receive physical rehabilitation in order to improve their physical abilities. The focus was on transforming the body to one that conformed to normal standards of functioning and appearance. For the participants of this study, rehabilitation usually involved engaging in one or multiple therapies such as physical therapy, occupational therapy and/or speech sometimes two or three times a week. The emphasis of these therapies was on achieving functional abilities and/or patterns of adaptation considered age-appropriate. Some participants used assistive devices such as splints, braces, or walkers, or forearm crutches, for a short and/or extended period of time to improve their functional independence. A great deal of emphasis was placed on normalizing their experience by trying to eliminate their physical deficit and in particular learning to walk. Although the participants acknowledge the results they were able to achieve through rehabilitation, they felt pressured to conform to
a notion of “normal” that they found difficult to achieve. This is captured by Marni’s experience when she was a child,

I think it was very good for them to do those things in terms of like it's helped me do very practical things for myself from a medical standpoint. I can do a lot of things physically and I'm physically a very strong person as well. So I think all of these things are great you know because I can wear a backpack and walk to the post office and things like that. At the same time though I think there's this whole business of normalcy and the idea that we're going to try to make this child walk as close as possible like as close as possible like the normal body or the idea of the normal body.

The emphasis that rehabilitation placed on normalizing their physical differences was a challenge because no matter how much progress they made physically, their bodies didn’t look or function in the same ways as their able-bodied counterparts. The physical image they were being encouraged to achieve did not reflect the image they saw in the mirror or how they perceived themselves. As Marni describes,

I went to physio often which I liked sometimes. Other times I think that it negatively impacted on my body image. I think there was too much emphasis on “Walking like a Princess”. I never felt like a Princess.

For many participants learning to walk was delayed for some months and for some years. Some considered learning to walk to be one of their greatest achievements because it was highly valued by those around them who felt that more opportunities would be made available to them if they could walk. Many parents hoped that their child would be able to walk independently like other children their age. For instance, Geraldine wanted to go to school like her older brothers and sister. She recalled her mother saying to her,

"How can you possibly go to school because you don't know how to walk?" At that very moment I got up from
the floor where I was sitting and walked for the very first time.

The frequency that these children received one or multiple services such as Physiotherapy, Occupational Therapy, or Speech Language Pathology was influenced by the severity of their impairment and the availability of programs and services in the communities they lived, as well as the value parents attached to receiving these services, and the financial resources they had. As Marni said,

My mother tried really hard to take me to physio and she invested a lot of energy and stuff when I was really young to do those things effectively.

The progress that many children displayed from the physical rehabilitation they received was encouraging to their parents because their children’s future looked brighter. These achievements made them believe that their children could have “normal” lives, especially those with mild to moderate impairments. In contrast, learning about the possible outcomes they could expect from their children sometimes blinded parents from acknowledging their son or daughters needs and aspirations by either being overprotective and/or discouraging them from achieving due to the difficulties associated with their condition. For example, Suzanna felt that her parents might have neglected her rehabilitation as they could not accept her disability:

When I was little my contact with doctors was very limited. I went to a rehabilitation centre for children with disabilities for physiotherapy for a short time when I was three. I didn’t see a doctor very often, ... I saw an orthopedic surgeon at the hospital for my legs. I believe my parents thought that my legs and feet were in good condition and that there was no need to see a doctor for my CP often. I think they felt they could take care of it themselves. I did think that not taking me to see a doctor for my CP often was a little negligent on their part, even though it did seem to me too that I was in good shape
in regards to my CP. I believe part of the reason they didn’t want to take me too often was because they didn’t want to be reminded that it was a permanent disability and that I would never walk like my sister.

While so much attention was being given to improving their physical abilities, participants felt that other needs were being overlooked or minimized due to the pervasive belief that having a physical impairment such as not being able to walk is associated with not being able to have a meaningful life or be happy. They felt that the rationale behind rehabilitation was misleading for two reasons: achieving functional independence did not necessarily coincide with being integrated in mainstream social life, nor did it lead to enhancing participants subjectivity as continuing to possess atypical physical attributes compromised their interactions with family members and significant others.

Many felt that the focus on achieving physical normality overshadowed their social psychological development. Geraldine felt the difficulties she encountered growing up had less to do with her physical impairment than with the stigma and pathology that able-bodied individuals attach to it. She stated,

...in the era that I grew up in (early 1950’s) it was all about the disability, it wasn’t about who you were as a human being. ... I am not just my disability. I have a mind, a heart, and a soul. Professionals in the era that I was raised in weren’t thinking along those lines. They were only thinking of the physical aspect of, you know, the fact that you had a physical deficit or something.

Even though participants confronted so many odds at an early time in their lives they still found ways of being defiant and exercising their agency. That is, all participants benefited from physical rehabilitation as becoming more independent made other experiences and opportunities possible. Participants with moderate to severe impairment who could not walk
achieved greater independence using a chair which gave them more freedom to move around and manage activities of daily living.

Their success and accomplishments challenged the medical assumptions and expectations associated with physical impairment because participants wanted more out of their lives than managing their physical conditions. Consequently, all participants resisted the low expectations and the lives that were constituted for them by the experts. They wanted more for themselves, intellectually, academically and socially. However, the intersection of dominant discourses and medical and rehabilitation practices thwarted their efforts to bring meaning to their lives and achieve their full capacities in order to manage life as adults. Their interaction with others also contributed to this process. That is, it was not uncommon for participants to feel inadequate and have a low self-esteem despite their achievements, as it was hard not to internalize the negative responses they received from others, as well as the negative ontology associated with impairment. As they grew up, these feelings were reinforced and/or exacerbated by how they were treated within their family as young children. Failure to conform to normal body function through rehabilitation impacted how others related to them.

Both the successes and challenges participants encountered through the rehabilitation process and their interactions with others contributed to the emergence of the third thread, *Becoming Self-reliant*, which is associated with achieving functional independence that goes beyond being able to walk. The desire to *Become Self-reliant* was a gradual process that was characterized by multiple achievements that extended beyond the medical management of the participants’ conditions. *Becoming Self-reliant* was an integral part of becoming functionally independent, as it included acquiring the abilities they needed to achieve self-efficacy and make decisions about what they want and need to support them in being able to participate in
Becoming Self-reliant included but was not limited to being able to engage in activities of daily living with/without the support of attendants. Cathy described it is being able to control your life, which included being able to go to school, work, socialize, and live in the community on one’s own. She said,

Therapy used to emphasize walking above everything else. I don’t believe it is the primary goal. [I think the primary goal should be] communication, being able to express yourself and your needs, and feelings, so you can control your environment. Not being able to control your environment is demoralizing. That should be encouraged in whatever way you can figure out rather than the conventional way. But even in controlling your environment there are ways in which you can figure it out. For example, I can’t turn the light switch on with a power bar. Look for alternative ways. I boil a tea kettle or a cup of tea. I can boil a coffee maker and use the kettle to get hot water without pouring it. [So, finding] alternative ways of controlling your environment [is really important]--

3.6 Struggling to Fit In

The participants’ determination to overcome the limitations of their disordered bodies and Become Self-reliant begins to appear when they start school. Their narratives begin to diverge depending on whether they attended segregated or special schools for children with disabilities or whether they were integrated into mainstream schools. In both cases they would encounter new characters in their lives that would support and/or hinder the acquisition of skills and abilities that extended beyond the mastery of physical functioning emphasized in rehabilitation. The cast of characters expands further to include teachers and other children with/without impairments who would move to the foreground of their lives. These new social worlds to which they were exposed greatly influenced their subjectivity and life direction. Even though they went in different directions, they were all continuing to
grapple with overcoming *Being Seen but not Heard*, continuing to strive to *Become Self-reliant*, as well as *Achieve a Sense of Belonging*.

Respondents followed one of two pathways during their early school years: 1) the pathway that involved attending a school for children with disabilities and then transitioning to the public school system at adolescence (segregation); and, 2) the pathway that involved being integrated into the public school system from day one (integration). These two different pathways resulted in differences in the learning and social opportunities they engaged in which had both short and long-term impacts on their lives particularly in terms of *Achieving a Sense of Belonging* and *Becoming Self-reliant*. Which pathway they took had less to do with their physical abilities than the availability of specialized pediatric services and the decisions their parents made.

### 3.6.1 Segregation: School for Children with Disabilities

Segregation of children with disabilities into separate schools was recommended to most of the parents as the best way to improve the participants’ physical functioning and enhance their education. This was the experience of participants who grew up prior to or during the Independent Living Movement, as well as those who grew up afterwards. The reasoning attached to segregation was that they would find it difficult to enter a regular school as educators were not trained or experienced to meet their needs. Mainstream schools were also not physically accessible for children in wheelchairs. Consequently, all participants were encouraged to go to a pediatric rehabilitation facility where they would receive comprehensive physical rehabilitation. Another component of the program was having access to onsite education with professionals who were trained in working with children with physical impairments.
Five participants, Geraldine, Suzanna, Fred, Vanessa, and Michael, attended school for children with disabilities from the beginning. Their parents were told that going to a segregated school would be beneficial to their children because they would get the physical rehabilitation they needed, they would have access to a therapeutic pool (which was recommended for Vanessa), and they would get an education. Participants who went to special schools for the disabled had an opportunity to be with other similarly-aged children who also had physical impairments. On the one hand, this was important for them to develop a Sense of Belonging, in this case, finally meeting with other children with disabilities. Michael felt that going to a school for children with disabilities was a very positive time in his life because he had many friends that he connected with and maintained into adulthood or until their deaths (as some had progressive neuromuscular conditions). Michael stated,

I was lucky, because all the kids in my class were all the same age. So, for us, you know, I guess because there were no expectations, and I was with a group of muscular dystrophy and we were all the same age. I was on the student council. When we went on field trips we all had to raise money. So, we – I mean in a lot of ways people had ... misconceptions of [the school for children and residence for adults with disabilities]. I mean the teachers really didn’t do stuff for us.... There were things we did at [the school for children with disabilities] that if we went to a regular school we would have been observers.

Both Geraldine and Suzanna also had friends at the schools they attended however, they both found attending a segregated school challenging socially. When she was 12, Geraldine’s family decided to move to another neighborhood in the city in which they were living. Her mother took her out of the school that she was attending to go to another school for children with disabilities where she didn’t know anyone and didn’t find that her classmates were very nice to her. Suzanna had friends from school; however, she didn’t have
any opportunity to socialize with them outside of school because they all came from different parts of the city which made it difficult for parents to coordinate spending free time together. Suzanna felt she was discouraged by her parents from forming her own circle of friends. She spent most of her free time with her sister and her sister’s friends. Though she didn’t accompany them into the community as her parents didn’t think it was necessary, and she had difficulty walking and using the bus or subway. She said,

I spent most of my free time at home either playing with my sister and her friends, or listening to music, reading, or watching TV. My friends from school for children with disabilities did not live close by so we couldn’t see each other outside of school.

While rehabilitation in childhood focused on “fixing” their bodies, participants were more interested in experiencing life, like any child. For example, Michael said,

Even though we were segregated we watched the same TV shows. We were kids. We just wanted to do things like our brothers and sisters and what we see on TV, when we listened to the radio.

Many participants who were segregated felt disadvantaged because they felt that they didn’t learn what they needed to know so they could do well when they transferred to the public school system for junior high and/or high school or both. As Suzanna stated,

“When I was in primary school I did learn a lot there, but I found that I didn’t learn enough. My sister was learning a lot more in her own school. She was learning chemistry, French, gymnastics and biology. Courses like biology, and physics were not available at my school. We were only taught the basics. Had I known early in my education that I was being taught at a slower pace, I would have gone a much quicker pace because when I left the school for children with disabilities I was behind my classmates in what I knew. The teachers at my special school influenced my parents and my parents said, oh, well, you’ll never go to university and stuff like this.”
Participants felt that more time was spent on learning skills that would enable them to manage their ADLs and physical therapy so that they could achieve functional independence rather than teaching them skills and abilities they would need as they grew up.

Vanessa stated,

[Growing] up with CP I was thrust always into going to some kind of physiotherapy and doing all that kind of stuff. So, it’s like I could easily get in and out of the shower myself and get dressed and do all of that sort of stuff. I could manipulate my body where I could even put my, I could even lift one leg up to put it on my knee.

Most felt they didn’t learn the skills they needed to prepare them for life because expectations were low as to what they could accomplish. As Michael said,

I really didn’t learn anything when I was at school because we weren’t taught to think about doing anything with your life.

### 3.6.2 Integration: Mainstream Public School

The four participants (Marni, Natalie, Cathy and Robert) who were integrated into the regular public school from the beginning also had difficulties to contend with that had an impact on their acquisition of knowledge and abilities, and their subjectivity. These participants were able to benefit from a more comprehensive education that could potentially support the acquisition of skills and abilities they would need in life and pursue a higher education and employment. However, they did not Achieve a Sense of Belonging as expressed by some who attended segregated schools. Rather than encountering other children with disordered bodies, they were often the only children in the public school with functional difficulties which only served to emphasize their differentness.

Robert, Marni and Natalie were able to start school at a time consistent with their chronological age, while Cathy started school when she was nine in part due to not obtaining
a diagnosis until 8, and it was difficult to find a suitable placement for her where her needs could be met. All of these participants had learning difficulties associated with their condition that were not identified or properly dealt with which negatively impacted their self-esteem and subjectivity. For instance, Robert did well in some subjects but poorly in others. He recalls,

I was good in writing subjects and history and literature, but I was really bad - like I had to see everything black and white. And now they are finding that in some cases it’s a learning disability from the CP, like not being good in math. It seems like there are so many that have cerebral palsy that are weak in math subjects. But I’m not sure if that was the case. And then a few teachers were frustrated with me because they thought that if I can do well in some subjects, why can’t I ....do well in all subjects. And also in my beginning years I went to parochial school. ...I had a half day with Hebrew and bible studies, like the Torah ......and then English and ...all the regular courses. I’m glad that I had the background, but sometimes I think it was more difficult in the beginning years. Also in my school years I failed Grade 5, and ....Grade 8, and that to me was very embarrassing. My self-esteem was pretty low. I was really always hard on myself. I wanted to do the best that I could and there were some times I couldn’t understand why it wouldn’t sink in.

For Cathy the learning process was slow and she needed assistance with everything. This had a huge impact on her life. She stated,

I went to a regular public school where I had lots of girlfriends. But I could only do a little at a time, so I kept getting older and older in comparison to my classmates. It didn’t have a good impact on me. It had an emotional impact. ...That is, I looked young for my age; so it was easy to conceal my real age but extremely frustrating to not be able to keep up. My desire to learn overpowered me through my school years....[I was unable to complete my courses in the same time frame as my peers because I needed
assistance with everything (including writing, reading, and completing homework)].

The challenges that Cathy and Robert encountered made it difficult for them to keep up the same pace as their classmates. Marni said that she was grateful that her parents did not follow her doctor’s recommendations to send her to a school for children with disabilities and sent her to public school instead. She said,

My parents aren’t...they don’t challenge authority much, but I know that my mom must have challenged someone because I know the recommendation was for me to go to a [school for children with disabilities]. [The best thing about going to public school was] I got to be with my sister. It was a huge thing for me.... Maybe if I had gone to [the school for children with disabilities] as a child maybe I would have reflected on that as like a positive experience, maybe.... I know people who have gone to that school and similar schools and think that it was really helpful for them. But like for my adult self, the reality is it’s not considered like an OAC or grade twelve education and so it would have been really hard for me, and not impossible, like I also did my Master’s with some people that went to the [school for children with disabilities].... . It wouldn’t have been impossible but I think I would have been...I’ve always competed with my sister a little bit and I think I would have been disappointed. If I went a segregated school it would have been significantly more difficult—but not impossible—to attend university. Certainly if I went to a segregated school I would not be doing my Master’s at the age of 26. I think children who go to a segregated school have a harder time attaining the so called regular high school diploma right, because they’ve been accommodated but also not necessarily encouraged to reach their potential.

Even though Marni was able to keep up with her classmates, her efforts were thwarted by not receiving the assistance, support, and accommodations she needed to minimize the impact her impairment had on her learning aptitude. This was also compounded by an absence of
continuity in her education. Her family moved several times during her childhood and adolescence, which meant once she became comfortable in a school it was time to leave and start all over again somewhere new. Natalie was able to go through school without encountering many difficulties especially before she went to high school. She was able to maintain the same pace as her classmates.

Achieving a Sense of Belonging and acceptance was challenging at first because there weren’t many students with disabilities at the schools they attended if at all. Having a disability combined with not doing well in school made a participant stand out in the crowd. It was not uncommon for them to be ridiculed and rejected by their peers, leaving them with feelings of isolation and a low-self-esteem. Robert had vivid memories of this.

It was hard to kind of make friends in school but I got along pretty good. Sometimes I was teased... Sometimes I stepped on people’s toes going upstairs so people, ...students stayed away from me. I went to some large schools and... I was kind of like loner in school unless there was some sporting event. So, my early years of school were more like being isolated and it was difficult to have friends.

Cathy, Natalie and Marni also found it difficult to feel as though they belonged, particularly in the beginning. They were set apart because of their impairment and/or not being able to move forward with their lives at the same pace as other children their age which was characteristic of the experiences of most participants. Being teased or bullied was very common. For instance, Marni recalled,

I have a lot of friends at this time (age 11-12) but I am also physically bullied by a group of boys. One day they kick me down the stairs (there is no elevator) at school. I am knocked out, and I have to go to the doctor.
Growing up with a physical impairment did not immunize these children from experiencing and wanting to have the same experiences as other children without impairments. This is especially true for individuals with severe physical impairment. Unfortunately *Achieving a Sense of Belonging* through opportunities to form meaningful friendships and intimate relationships are not encouraged because these individuals are perceived as being undesirable and not needing of benefiting from these things. Many professionals as well parents may discourage the fulfillment of these needs as they feel that the individual has enough to contend with in managing daily living and school. These perceptions continued to marginalize their experience as they fail to demonstrate competencies that are characteristic of the healthy normal (Goffman, 1963; Hughes, 2009; Morris, 1999). Many found that even though they had achieved functional independence, they were not granted the right to participate in mainstream living. The responsibility for change and adjustment continued to be placed on them. At the same time the environments in which they were interacting did little to accommodate their needs either physically or emotionally. For instance, the odds were against those participants who were integrated into the regular school system especially when environments were not physically accessible. They felt that they were not really wanted due to their small representation, social rejection, and difficulty accessing the resources and supports both tangible and instructional to meet their learning needs.

The participants’ narratives converge again when they all were integrated into the public school system for high school. Now both groups had to contend with the issue of *Achieving a Sense of Belonging* with maturing, able bodied classmates. In addition, the previously segregated group had to address issues of academic differences and different academic expectations. Further, the sense of belonging they had achieved in the segregated
school was lost. Michael was very connected socially when he was going to school for children with disabilities where he had many friends and played an active role in school activities. After transitioning to the public school system, his sense of belonging diminished because there wasn’t anywhere for he and his friends to go so they could continue to maintain their relationships.

Participants were often much older than their non-disabled classmates. This age difference increased in a few instances when some participants had to repeat a course or grade because of difficulties they had mastering the curriculum. Even though integrated education was supposed to offer students with disabilities with better learning experiences than they had in the past, it didn’t help that a student may have been the oldest one in the class. As Michael says,

> When I was in school, a lot of us stayed there for two or three years, it wasn’t that they wanted us there. There was nowhere to go. I was 18 when I went into...Grade 10. It would never happen now, but at that time, you know, I know the principle and vice-principle really had trouble (knowing what to do with us).

The social rejection that many experienced had a profound negative impact on their self-esteem. It was not uncommon for participants to feel as though they didn’t really matter, that they didn’t belong and that there was nowhere for them to go. In Geraldine’s case this was quite literally the truth. She did not have the benefit of attending high school, as there actually was nowhere for her to go. When she completed Grade 8 at age 15, she was informed that she was too young to leave school and would have to return to a class where she was the oldest student. She found having to stay in school devastating. She says,

> They allowed me to graduate from Grade 8 at 15. ...it was like a rural school. ...that was fine. But then it was decided, because I wasn’t eligible to quit school
or leave school, I was to be put into another class. But the only special class that was available in this rural area... was another class of mixed children who were labeled slow, but yet again 9 year olds. Not that there’s anything wrong with 9 year olds but I was nearly 16. I hated it. I hated it with a passion. I didn’t want to be with 9 year olds at 15. So, it was like, it was emotional torture for me.

Some participants felt that having a physical impairment excluded them from participating in extracurricular activities associated with the schools they attended as well as those that were unrelated to school. Vanessa and Suzanna experienced significant physical, social, and academic challenges that negatively impacted their education experience and social-psychological well-being. Suzanna describes how she felt like an outsider because of assumptions made by others about her limitations, and her own difficulties connecting with others,

It was so difficult for me to get into a normal social situation with my peers. I found it was like trying to break through a brick wall. I had trouble finding out about parties, or getting in with the people I wanted to socialize with. For me, “brick wall” describes a force holding you back... For instance there were parties going on after school (high school) and I didn’t know what steps to take so I could go (which I was invited to). It was hard for me to decide what the first move was to find out about these parties and other social activities... I was kind of stuck when it came to trying to change my social situation. I always seemed to come up against a brick wall, when I asked myself how to resolve this problem.

This analogy to a brick wall highlights how separate the participants felt from the able-bodied students. Not only did they feel separate; they felt powerless to change the situation. Brick wall also refers to the idea that you don’t think you have the power to change something. It’s like your destiny is, it’s whatever you’re doing, and whatever you’re allowed
to do, and that’s the only thing you can do, and if you try to change it, someone would get
mad at you or maybe say that you couldn’t do it.

3.6.3 The Brick Wall

The notion of “Brick Wall” is not limited to social experiences, as it may also represent other physical barriers or misconceptions that impinge on being able to participate in activities they value and/or fulfill their aspirations. It may be interpreted that a brick wall impedes resisting and challenging misconceptions about impairment and disability, as well as low expectations. Encountering a brick wall can also act as a motivator to resist these forces especially when individuals have dreams and aspirations they want to achieve. This was the response of all participants; however, participants have found it challenging to break through some brick walls more than others. The diverse paths that participants took are a manifestation of this metaphor.

Both Suzanna and Vanessa felt that these experiences were exacerbated by their parents validating their exclusion rather supporting them in meeting their personal and social needs. For example, Suzanna wanted to fit in and have a boyfriend but she didn’t have the skills she needed to achieve these outcomes. She remembers,

My mom wasn’t too keen about taking me to the mall to find a dress for me to wear to school and she always told me that I looked just as good in slacks and not to worry about it. But if I could have worn a dress everyday to school and put on eye make up like all the other girls in school, I would have had more confidence when it came to boyfriends. (I have difficulty putting on eye makeup because of my CP). But I don’t know, my parents thought maybe boyfriends were for other girls to worry about who didn’t have a physical disability.
From a young age Vanessa felt that her parents socialized her to believe that forming friendships with kids her own age wasn’t important. She was also taught not to inconvenience other people especially when she needed physical accommodation to be included. These ideas were embedded in her mind and impacted her as a teenager. She said,

I would get invited to so-and-so’s house and even though their house had a few stairs, they’d say don’t worry, we’ll handle it, we’ll find a way to get you in. And then my parents would say, ‘Well, you know...’. I remember hearing things like, ‘Do you really want to go and put them through all that trouble and all of that sort of stuff?’ So, that part of it had a lot to do with it too. Like you grow up with - it’s surprising how even if you forget about those things, they’re still deep seated in you. Like, if it’s too much trouble, you know, why bother for just me. You know, and I’ll go and do something else.

Achieving a Sense of Belonging within the family, among peers, and within communities spans the life course of all individuals. The fulfillment of these needs during childhood and adolescence provides a foundation for achieving self-confidence and self-affirmation, both of which are necessary for forming and maintaining meaningful relationships with others. Academic challenges combined with not fitting in and having impairments during adolescence created an emotional crisis for some participants that manifested in being depressed and feeling socially isolated.

For Fred attending public school was difficult not only because he needed help with everything, but because of the overwhelming feelings of social isolation he had as a result of not being able to experience life like other boys his age. He conveyed:

In general, my teenage years were not a highlight in my life. They should have been, but instead I feared being alone and I was depressed a lot. Everyone around me seemed to be having a good time but I sometimes wanted to die. "Why me?", I thought, "why did I have to be disabled?"
Like many teenagers, his warm, inclusive family became a prison rather than the liberating support he felt as a young child.

Sometimes being at home made me feel really trapped. I felt isolated and sheltered by my family's love. It is very hard for parents to let go of a child with a disability.

But unlike other teenagers he had few options to fit in.

I desperately wanted to be treated like everyone else. I wanted to socialize like a normal teen but people who I knew didn't understand who I was inside and I was just beginning to understand myself.

In contrast to Fred’s story, Cathy wasn’t socialized with other children before going to school. Going to school made a significant difference in her life because she was able to experience life outside of her home and feel good about herself due to the activities she was able to engage in with the help of her classmates. Her sense of self was enhanced when she had the opportunity to participate in social activities with other children and later adolescents with disabilities. The participants’ inability to achieve significant social milestones, along with environmental and attitudinal barriers impinged on being able to achieve acceptance, self-affirmation, and cohesion with significant others.

Fred, Geraldine, and Suzanna articulated not knowing what it is like to be able-bodied; however, they had a keen sense of what it was like to be different and devalued because of their impairments. These feelings were generated by a combination of the reactions of others they interacted with, low expectations, and the lack opportunities for them to experience life like other teens their age. Also, their experience of Being Seen but not Heard, and not being able to Achieve a Sense of Belonging contributed to their emotional distress. For instance, Vanessa found that part of what contributed to her depression was the
incongruence between the way she was treated in school and the way she was treated in the community. She said,

...part of it too was this feeling of belonging....I attracted a lot of people..... But a lot of times I felt like, I was in a group of 20 people around me and I felt so alone. And then came the time, like I’d be out at the grocery store with my mom or somewhere, you know somewhere on a weekend where you might actually happen to see somebody from school that you know. [It] was like I existed in school but not outside of school and people, if they made plans with me, I get this call, “I’m sorry, I can’t go today.” And it’s fine when it happens once, and then it happens twice, and then it happens three times. Okay, you think, well, life is like that. But then it starts happening 10, 11, 12, 13, 14, 15 times and you’re like, “Okay, what’s wrong with me?”

Each of the participants used different strategies for coping with their circumstances. For example, Vanessa and Fred used positive self-talk. As a teenager, Vanessa used to tell herself,

You know what, for me, I can’t explain this, all I know is I used to almost get a sense of like, if you will, I don’t know if you can call it a voice, like an internal part of me that said, “Okay, you know what, if you can just hold on and get through this for some reason, life will get better as you go along.”

Despite sometimes feeling stifled by his family, Fred found that their love and support helped him to deal with the social-psychological impact of his experience with “others”.

I was able to deal with the frustration and despair associated with having CP by talking with my parents and sisters. At our dinner table we had a routine of discussing things and not leaving the table until they understood what I was saying.

It was difficult for participants to find the emotional support they needed to deal with these issues as they were often interpreted by professionals as being exclusively related to
difficulties adjusting to their impairment as opposed to a combination of impairment and disability related issues, another example of *Being Seen but not Heard*. For instance, Vanessa was sent to see a psychiatrist to treat her depression. Her depression was treated with medication without considering the broader issues that were contributing to her difficulties. For the most part professionals they came in contact with tended to assume that the issues they were grappling with were related to difficulties adjusting to their impairments rather than recognizing the impact of reactions by significant others and the ways in which their lives were being managed and regulated. These assumptions are reinforced by the difficulties professional experts have/had in educating them to be independent and possess the knowledge, skills and abilities necessary to both manage their physical well-being, their day to day responsibilities and activities they value.

By the time participants reached late adolescence, many transitioned into adulthood without having the knowledge or experience of advocating for themselves, and taking responsibility for their own lives. There was no one there to teach them what they needed to know as the dominant discourse interfered with supporting them in the process of self-efficacy, and self-mastery.

### 3.7 Chapter Summary

The purpose of this chapter was to describe central themes that motivated participants to resist and challenge the odds they confronted during the Growing Up phase of their narratives. Being born with cerebral palsy presented each participant with personal challenges that would influence their ability to participate in age appropriate activities and begin to develop achieve their potential as they grow up. The experiences and opportunities they had were also impacted by the institutions and discursive and non-discursive practices
they came in contact with as they grew up. The next chapter describes the participants’ experiences of adulthood and growing older with a lifelong physical impairment.
Chapter 4. Adulthood & Growing Older with Lifelong Physical Impairment

4.1 Introduction

The next phase of “Defying the Odds” narrative is late adolescence and transitioning into adulthood. The thread of Overcoming being Seen but not Heard picks up again as participants begin to consider what kind of lives they will lead when they finish high school. This thread is interwoven with Becoming Self-reliant which represents their desire to make decisions about what they want and need in their lives. As they transition into adulthood the participants’ narratives diverge once again as they strive to achieve independent lives involving the pursuit of higher education leading to establishing careers, living on their own, forming meaningful relationships leading to marriage and families of their own. This chapters highlights how their pursuits are thwarted by the odds they encounter in being able to self-regulate their bodies (with/without attendant care) and how the abandonment of the disordered body by the institutions of health care and rehabilitation, as well as the changing structure and function of family and friends contributes to their struggle to maintain a Sense of Belonging, challenges their efforts to Overcome Being Seen But Not Heard, and diminishes their ability to continue to Be Self-reliant as they grow older.

During adulthood, participants encountered three significant turning points that impacted being able to manage and participate in life in profound ways. As they approached late adolescence and the completion of high school, many participants found themselves with nowhere to go to engage in higher education and pursue a career. Their transition into young adulthood coincided with not being eligible for health care and rehabilitation services and programs they had received as they grew up. In many instances participants’ found
themselves without having an adult health provider as those linkages were not coordinated by their pediatric physician, and/or they did not exist or were difficult to find. That is, it was difficult to find a doctor or services that specialized in treating adults with cerebral palsy.

During this phase of their lives resistance manifests itself through the actions that participants take to construct places for themselves within their social environments by resisting the negative conceptions associated with their potential to be productive, contributing members of society. This phase of their lives is fraught with incongruencies between resisting the dominant discourses they encounter and succumbing to them. However, their experiences as adults demonstrate their continued resilience as they deal with and overcome the discursive and non-discursive forces they encounter as they grow older.

In late adolescence and early adulthood participants’ encountered significant shifts in the primary and secondary characters involved in their lives. The institution of rehabilitation and the professionals attached to it receded into the background. Even though participants wanted to make their own place in the world, they felt that they were left unprepared for adulthood in two ways: 1) all the care and treatment they received growing up had been done to them and for them without including them in the process. Consequently, they lacked the knowledge or experience to continue to regulate their bodies and maintain their physical health and emotional well-being. 2) They had limited opportunities to participate in mainstream social life due to their inadequate preparation for adulthood with no where for them to go.

4.2 Making a Place for Themselves in the World

By middle to late adolescence, both the threads of Overcoming being Seen but not Heard and Becoming Self-reliant were very important to participants. These threads
manifested in their commitment and determination with/without the approval of “others” to play an active role in making decisions about their lives that included and extended beyond the management of their disordered bodies. They wanted to decide where and how they lived, become employed, and participate in mainstream social opportunities just like their able-bodied counterparts. They all resisted the low expectations that were imputed on them and became actively engaged in making decisions about choice of living circumstances and pursuing a post-secondary education. Being able to achieve some or all of these outcomes varied among participants because of the nature of their impairments and the social, cultural, and political contexts in which their lives as adolescents and young adults unfolded.

The desire to participate in productive work was important to all participants. However, their poor academic competence coupled with the extended time needed to acquire certain skills and complete activities meant that they had little potential to compete in the job market. When at school, participants were often excluded from exploring prospective careers or having dreams and aspirations that they could achieve according to their strengths and abilities. They felt that their aspirations were not considered as being important by those around them and that professionals had no expectations for their future as adults.

During middle to late adolescence, the central narrative of participants began to diverge again in two distinct ways: 1) some participants began to pursue a post-secondary education without being able to finish; and moved into a community residence for people with disabilities; and, 2) other participants completed college/university, becoming gainfully employed, and lived on their own from the time they started school or work. In both instances participants resisted the non-discursive and discursive forces they encountered in order to actively engage in making decisions about their lives and plan for adulthood.
After completing high school Cathy, Fred, and Michael attempted to pursue a college or university education however, they found themselves unable to complete a program that would lead to gainful employment as there weren’t programs in place to meet their needs. Cathy found life circumstances intervened making it impossible to continue with a course she could complete at her own pace. In contrast, Michael went on to teach a program on disability awareness for the public school board which began from a one year government grant. The program was successful and received funding for ten years. Being able to engage in paid work was challenging in part due to the negative attitudes towards hiring people with disabilities and the lack of training for a specific career. Nonetheless, they were actively engaged in activities focused on increasing awareness about living with a disability, and advancing the rights of people with disabilities in the areas of education, accessibility (transportation, physical environments), and independent living. Both Cathy and Fred were very active as volunteers, disability activists and educators on a number of disability issues including accessibility, transportation, and educating society about the experience of living with disability. Fred also became a consultant in his forties to a Life Care Planning Program for a community organization for people with disabilities. Achieving these milestones enhanced their Self-reliance, their Sense of Belonging and being able to engage productive activities. The paths they took to accomplish these milestones were often thwarted by attitudinal, physical and financial barriers.

4.2.1 Living on Their Own

Being able to live in the community away from the family home was important to all participants because they wanted to experience life like their able-bodied counterparts as well as being able to actively construct how they live their lives personally and socially. For the
most part, moving out of their family homes supported them in exercising their agency, *Becoming Self-reliant*, and enhancing their *Sense of Belonging*. The expectation for asserting control over one’s life was reflected in Cathy and Fred’s experience during late adolescence.

Towards the end of adolescence, Cathy and Fred took the first steps towards achieving their independence by moving out of their family home. It was important for both of them to have control over decisions made about their lives, as well as being able to live their lives like other people their age. They both had the support of their parents. Fred first moved out of his home when he was 17. He went into a group home for adults with physical disabilities that had just opened. He said,

> Living there was not what I expected. I needed to be in control of my life, but the staff was trying to control me. This made me very angry. I wanted to tell the staff that I wanted to be in control of my own life. Instead of finding independence, I ended up feeling lonely. I needed my family’s support more than ever because they were my only connection to sanity. I wanted to go home. I felt like nothing was ever going to change; like I was going to exist in misery for eternity and none of the staff seemed to notice.

Eventually Fred returned home. Even though this experience had a poor outcome, he never gave up the desire to try again to live on his own under different circumstances, which he would do once again with the support and encouragement of his parents.

During the late 1960s a residence for adults with disabilities opened and offered Cathy and Geraldine, and later Michael, the opportunity to live on their own away from their families. The importance of being in control of one’s life was conveyed by Cathy.

> I applied thinking that there would be a long waiting list. And I was accepted two weeks later. I wasn’t really ready to move but my boyfriend had been put into a chronic hospital with no consultation. His parents made the decision for him without asking him.
I wanted to be able to make the decision for myself. So I decided to move and thought that a change of place might be good for me, so I moved. My parents were not happy about my decision. Dad sat at the table and cried. I asked, “Don’t you want me to go?” “Well it is your decision and you have to do what you think is best for you.” Even though my application was accepted very quickly, I thought it would be good for me as I was really depressed.

Even though moving out of their family homes offered them the independence that Fred was hoping to find in the group home, living there presented its own set of challenges with which Cathy, Geraldine and Michael grappled. For example, Cathy said,

When I moved into the Residence it was a completely different lifestyle, which helped me to get out of the depression. Living there opened up a whole new experience for me. Some of it was good and some of it was bad. I was among 55 disabled residents and I had more social interaction with them...I was able to get out in the community more to go to entertainment, and make friends within the residence. It was difficult for me at first because I am an only child. I wasn’t used to having people around me all the time. It was a little disconcerting as we each had a room of our own...which was small. And it wasn’t sound proof, so I could always hear the hubbub in the hallway. There were rules about what we could and couldn’t do. The opposite sex couldn’t visit in other people’s rooms. If people came to visit you had to keep your door open. That was hard.

Michael also found it difficult there because he was among a small number of residents who were in their late teens or early twenties, with the majority being over forty. Despite the challenges they encountered living there it tended to be a stepping stone towards new experiences and greater independence which led to later living in the community in their own apartments. Even with the restrictions that were placed on interacting with other residents, according to Michael,
I’m sure when it’s summer a lot of people got romantically involved and they found places to be involved. Now, I’m sure they knew what was going on, but they just overlooked it. Because I think, looking back ... the administration, they just wanted people to become more independent. weren’t allowed to have liquor in the building. And it’s not like you don’t go overboard and end up disrupting things. ... They allowed things to happen, because I think,... they knew it was going to happen regardless ....[Also,] it was loneliness...

While living in the residence appeared to offer them greater independence their lives continued to be regulated by the administration and health care professionals managing the institution, which challenged their desire to manage their own lives. Despite these boundaries, the participants who lived there were able to achieve a Sense of Belonging, resisted the restrictions placed on them by exercising their agency and enhancing their ability to Overcome Being Seen But Not Heard by voicing their needs and aspirations, as well as learning to Become Self-reliant within the policies that governed their lives.

Fred, Cathy, and Michael were also the first generation of individuals with disabilities to move into supportive housing in the community. Consequently, Cathy married her boyfriend who came to residence shortly after she moved in. Their life together would span thirty years.

Robert, Geraldine, Natalie, Suzanna, Vanessa, and Marni all achieved diplomas or degrees at college or university. Everyone but Vanessa was successful at obtaining employment following the completion of his or her education. The trajectory of their career paths was diverse. Their careers span between five and twenty years. Suzanna, Marni and Natalie are still working. In order to have a positive high school experience and improve her emotionally well-being, Vanessa resisted her mother’s decision to remain in the Catholic school, she transferred to a public high school in Grade Eleven which increased her sense of
belonging. She also took the initiative to explore career options that she might be suitable for when representatives from colleges and universities came to her school. She would go on to college to complete a Diploma in Radio Broadcasting but would find it difficult to obtain long-term employment due to impairment and disability related issues. Nonetheless, the actions she took represent her attempts to Overcome being Seen but not Heard and Becoming self-reliant. Going to college had a positive impact on her self-identity and being able to exercise individual agency. She said,

I really grew up that way because I had to put myself out there and say, “Hey, you know what, this is me and in order for me to work accordingly or properly within this program or whatever, I need to do this or this is what I need to help me along.” And, you know, everybody was more than accommodating. But it was a big step for me to have to go out there and say, hey. You know, because I’ve always had people advocating on my behalf, whether it was my parents or other teachers or physiotherapists or occupational therapists, whoever it might have been. I was a lot more confident than I was four years before.

Despite beginning to learn to be her own advocate while in college, once she left college she encountered barriers to finding and maintaining long-term employment for which she was not prepared.

[Even though I went to college,] I didn’t really know how to advocate for myself in terms of trying to get a job, because I was never really taught how to do that. Because even though I went to classes on how to write the right resume and how to write the proper cover letter and how to make cold calls and how to do that, see, what applies to someone who is able bodied doesn’t necessary apply to somebody who is disabled. I don’t know, especially being in a wheelchair, do you disclose and do you say that you’re in a chair and are you wheelchair accessible … I didn’t know exactly what I would need in terms of what would help me function properly in a work environment and I didn’t know what that proper work environment was. …
The difficulties she encountered meant that her desire to move into her own apartment would be financially difficult, which left her with feelings of frustration and sadness associated with the significance of her life and all the difficulties has and continues to grapple with. Many individuals her age were living in their own apartment, and feels that even though she is an adult her parents continue to treat her like a child. Not being able to work has at different times been frustrating because as an adult a person’s identity is attached to what he/she does professionally which also provides social opportunities she will not have. Despite these challenges she appreciates what she has and will deal with things as they come.

Natalie and Marni were also successful in Defying the Odds by attending college or University. After raising her children Natalie went to college to train as a special needs teaching assistant which she worked as in a public school for several years before going on to complete undergraduate and graduate studies (including a Masters and Ph.D. Marni also went to university completing her BA and a Masters at the time she was interviewed. Suzanna lives in her own condominium which her parents contributed to as they were concerned that she may not be able to afford her own home. Robert and Michael live in supportive housing units, while Marni resides in her own apartment.

4.3 Disruptions in Self-regulation of the Disordered Body

The participants’ early socialization was fragmented and did not offer them the same experience as their able-bodied counterparts that led to marriage, family, employment and other resources that their able-bodied counterparts could draw from when they grew older and encountered impairment in later life. During young and middle adulthood, the institutions, professionals, and family members which were in the foreground of their early
lives receded to the background and in some instances could not be counted on for instrumental and/or social support.

Many participants found that they began to encounter difficulties in physical functioning in young and/or middle adulthood, several years earlier than traditionally experienced by individuals who grow older without the experience of impairment. The difficulties participants experienced as a consequence of their disordered bodies was overshadowed by having to cope with and adjust to changing life circumstances such as the changing structure and function of the family, dealing with the death of loved ones and friends, as well as more limited social and vocational opportunities as well as financial resources. Many participants have encountered changes in the structure and function of the family with respect to providing care, resources or support, as well as continued companionship where families were close. What Sense of Belonging they had been able to achieve in young adulthood was threatened by these losses. For example, Michael outlived many of his friends as he transitioned into adulthood which further contributed to feelings of loneliness and isolation while Geraldine outlived her closest siblings.

Quite often the participants felt they were unprepared to deal with these circumstances and had nowhere to turn for guidance and support. For instance, Cathy lost both her parents a few years after she got married. The impact was devastating. She and her husband lost two of the most important people in their lives. She said:

We knew nothing about funeral arrangements or selling a house or any of that. Even though we didn’t know what to do, we didn’t want anyone taking over and I was afraid of letting people know too much of anything, as [outside of our friends and my parents, we didn’t have anyone to turn to for support]. Even though I was devastated by the death of my parents, they were extremely good in nurturing self-reliance.
Fred and Robert’s networks of interaction had diminished as they have gotten older. For Robert, the people who made a difference in his life as a child and adolescent are gone, and his parents and siblings have moved on with their own lives. All his siblings moved to different provinces and his retired parents recently left the city he resides in to live in a retirement home close to his sister. Both Fred’s immediate and extended family have diminished in size during young and middle adulthood. While he has a social network, the opportunities that brought meaning and fulfillment to his life are no longer there. His father is his only surviving family member with whom he still has a close relationship. However, his ability to care for Fred is more challenging as they both grow older. There are two issues with which he is confronted: Who will be there for him when his father is not able to care for him? How will he be able to maintain his current life style and have his needs met by people who don’t know him?

Even though Vanessa still lives with her parents in a home that has been adapted to her needs, she worries about where she will go when they are no longer around or able to maintain their current residence. However, to worry about the future diminishes her ability to live in the present. In order to cope with these issues she puts them away in the back of her mind while living in the present and appreciating what she has.

The difficulties participants encountered as they grew older were characterized by a general slowing down that was accompanied by pain associated with changes in their musculoskeletal structure and fatigue. This occurs many years before they reach old age and are in the prime of their lives. For most participants these changes had a gradual onset in their early thirties or mid-forties with a profound impact on their ability to engage in activities of daily living that they were once able to complete on their own in a timely manner. They also experienced disruptions with work and being able to participate in
activities the valued (with friends and family). Some significant changes that participants’
cited were losing their ability to walk and having to rely on a wheel chair both in and outside
the home, and no longer being able to use public transportation due to difficulties managing
the stairs and/or boarding the bus or subway.

The general slowing down is characterized by changes in endurance and ability to
engage in and complete basic ADL or IADL, and professional and personal roles and
responsibilities. Vanessa said,

[A] lot of things start in my early 30s. Like I just
found out that – I naturally just started to slow down
with things. I used to do everything on my own. Like, get out of bed, get dressed. Take my showers.
Transfer. I can do everything really easily, but what
ended up happening was, there was one day I was sort
of like okay, I did everything like I normally do, I
got showered, I got dressed and everything, and
instead of it taking me an hour, it took me two and a
half hours. And I’m like, wait a minute, but I did
things like I normally do, where did all the time go?
And then all of a sudden it just started going from
there. And that’s just the way it’s been. So, it’s
just something I just have to deal with.

The general slowing down that participants associated with growing older coincided
with a significant life transition or turning point that was facilitated in one of two ways.
Most participants surmised that they began to experience these changes after many years of
carrying out their lives without having taken better care of their bodies and pushing
themselves beyond their beyond their limits. Some participants found that in their quest for
establish their lives as adults they began to encounter changes in their physical functioning
which they never expected to encounter just as they were in the midst of finishing college or
university and beginning to start their careers. Many noted the onset of one or multiple
secondary health issues and/or a new impairment such as dystonia. For example, Cathy
recalls beginning to slow down and require more help after continuing to maintain the household responsibilities that her husband was unable to resume after finishing his BA as he had gone from being able to walk independently and drive a car to using a wheelchair and needing assistance with activities of daily living. Suzanna began to slow down and experience problems after developing cancer, and having maintained a full and busy schedule for many years without achieving balance in her life or caring for her body and getting the rest she needed. Robert and Michael had similar experiences in the sense that they kept a regular pace with the jobs they had for many years without having support in the workplace or getting the rest they needed.

4.4 Abandonment of the Aging Disordered Body

The changes that participants encountered due to declines in physical functioning were often dealt with in isolation as they did not have access to the same programs and services they received growing up. Many also found that when they had acute health problems requiring a doctor’s attention, the physicians did not have training or experience with adults with cerebral palsy which made it challenging to have their needs met. Yet as adolescents and young adults they were still held accountable for the physical problems they were encountering. They were perceived as not trying hard enough when experiencing fatigue or chronic pain interfered with being able to walk without the use of mobility aides or withdraw from daily routines. Unfortunately, the concept of long-term maintenance wasn’t and continues to be absent from the medical radar. They were not taught how to care for their bodies and maintain their functional independence. For instance, Vanessa said,

I wanted to have some form of physio and everything like this, because I had stopped going at that point to the…Fitness Centre. So, somehow, because of connections she had, she set me up at …, over here,
...Hospital, as an outpatient just for some physio. And it worked out for a little while, because at the same time I also found out about conductive education through a friend of mine at ...that I had met, you know, at the time. So, anyway, I got into Conductive Ed and I was doing the physio. But with the physio, because I’m not there in terms of rehabilitation, it’s sort of like just to keep what you have going, within three months it was like, we don’t want to see you anymore. Because I don’t have a situation where like you know I got into a car accident and I’m trying to walk again or something like that. I’m only trying to stay with what I have.

They also found it challenging to have their health care needs addressed because professionals were not experienced in treating their condition, and often perceived their complaints as being associated with their impairment, or found that their needs and experience were completely ignored when trying to have their health issues addressed. Marni has grappled with these issues all of her life and shared one experience she found stressful in dealing with her kidney problems.

...in the summer I had a test to determine bladder function or something. Like it was a kidney related test at a [hospital] and I called in advance to tell them that I had a physical [disability] and I needed...it was an invasive test, ...so I wanted to make sure that they were up and up on that, and the secretary had said, “Oh, you’ll be fine...”. No one really explained to me like what exactly they were doing or like what would happen beforehand and then it was very... And I know one of the nurses had said like very quickly, “Do you have polio?” I was like, “Oh my God. No, I don’t have polio” and it wasn’t like “Oh my God, how can you make that assumption?” It was like...I can think really quickly on my feet and it came to me quickly that if the assumption was that I had polio, then I can spread my legs out as far,...like I’m perceivably to them a lot more flexible than if I had cerebral palsy right. So what had happened was they almost dislocated my hip and they were holding down my legs until the catheter was attached and I was extremely uncomfortable and I think that whole process
contributed to an infection like in the weeks following. When I know that very simple, simple things could have been done to make that a whole lot easier....

These experiences challenge participant’s ability to regulate their bodies, *Overcome being Seen but not Heard*, and continue to *Be Self-reliant*.

### 4.5 Chapter Summary

This chapter highlighted the pathways participants took to constructing a place for themselves in society as adults. The progress they made during earlier phases of their lives contributed to the level of preparedness they underwent to be able to negotiate life as adults in the areas of post-secondary education, work, meaningful relationships, and family.

The experience of participants diverged along two distinct pathways: one involving work and volunteer activities without having completed a college/university education, and moving into either a group home or residence for people with disabilities; or completing a college or university education that led to gainful employment and living on their own in the community. Embarking on either pathway challenged their ability to maintain a *Sense of Belonging* and *Overcome Being Seen But Not Heard*. This phase of their lives is overshadowed by the intersection of adulthood and aging. The changes they experience as a consequence of declines in functioning, leaves them feeling abandoned in the absence of access to health care and/or rehabilitation resources and programs that may help them in the maintenance of former patterns of physical functioning and the prevention of secondary health problems that disrupt being Able to engage in ADL and IADL, activities related to work, leisure and family.

In chapter 5, a theoretical understanding of the meanings embedded in their life story is described. Specific attention is given to describe the disadvantages associated with
normalizing physical impairment through the processes of rehabilitation. Linkages will be made between how the body is conceptualized during different phases of life relates to the manner in which professional institutions, and non-discursive and discursive practices are used to regulate the disordered body and life experiences and opportunities individuals possessing these bodies are granted. The economic, political, health care and rehabilitation implications will be identified.
Chapter 5. Discussion

5.1 Introduction

The purpose of this study was to explore the experience of aging with lifelong physical impairment and disability with particular attention to the contribution of factors external to the individual such as institutions such as family, rehabilitation and education. I chose to study the experience of individuals growing up and growing older with Cerebral Palsy using Narrative Analysis informed by the Life Course Perspective.

The main finding of the study is the identification of a common narrative, “Defying the Odds” which depicts the inner drive of individuals with lifelong physical impairments to create a life for themselves even when faced with adversity in the face of biomedical and cultural discourses about the “normal” body and impairment that the institutions of medicine, rehabilitation and education use to manage and regulate their bodies. Defying the Odds consists of Growing Up (when their disordered bodies are labeled and their narratives shaped by the institutions of family, medicine, rehabilitation and education) and Growing Older (when they attempt to find a place for themselves in the world and manage an ageing disordered body). Throughout they are striving for a life with meaning and connection as they try to achieve a sense of belonging, overcome being seen but not heard and become self-reliant.

The findings of this study underscore that growing up and growing older with a lifelong physical impairment is extremely complex and multifaceted, and changes over time. The experience of the participants from this study reveal that having a lifelong physical
impaired impacts the unfolding of their lives at many different levels (individual, social, cultural, institutional, political and economic) which influences the kinds of opportunities they have in life. As their lives unfold, many participants are not able to achieve “normal” standards of physical and social functioning at the same pace as nondisabled individuals. Being able to participate in mainstream social life is also hindered by having a body that is difficult to control and regulate despite having benefited from physical rehabilitation while they were growing up. As they age, most participants are confronted with functional deterioration and secondary health problems in young adulthood or midlife that impacts multiple areas of their lives and threaten their long-term physical and emotional well-being. Functional declines associated with aging coincide with limitations in activity (ADL and IADL) and threaten their ability to participate in daily life and to continue to fulfill the roles and responsibilities associated with work, social, family and leisure.

The remainder of this chapter is divided into five sections: 1) describing how the findings of this study relate and add to the existing research on aging with disability; 2) identifying how Foucault augments the Life Course Perspective and adds a different perspective to our understanding and interpretation of the findings of this study; 3) highlighting implications of the findings of this study for rehabilitation theory and practice; 4) describing the strengths and limitations of this study; and, 5) identifying directions for research that could be undertaken in the future that will continue to enhance our understanding of individuals aging with lifelong physical impairment(s).

5.2 Contributions of the Findings of this Study to Existing Knowledge and Literature on Aging with Disability

Traditional theories of aging focus on normative aging whereby individuals are born into the world and progress through a series of physical, social, cognitive, emotional, and
intellectual development that lead to mature, control, and self-regulation of their bodies which reinforce normative standards of production leading to a meaningful life as adults in the areas of work, family and leisure. As they grow older they experience changes in roles and responsibilities as they approach the age of retirement and beyond (McPherson, 1998). With increasing age there is a greater risk for having health problems and/or becoming disabled after leading healthy lives. Depending on the impairment that occurs, an individual’s ability to manage daily living and social participation is compromised. Even though seniors do not have the same demands that they had when they were younger, encountering impairment at this phase of life continues to be pathologized by health care professionals leading to practices that are oriented to restoring individuals to who they were before impairment permeated their lives. The experience of individuals with lifelong impairment is disenfranchised partially due to pathologizing impairment, and failure to account for the trajectory that characterizes their lives when theories of aging were being conceptualized, which is very different from able-bodied people.

When individuals with lifelong impairment transition to adulthood, many are just beginning to fully participate in mainstream social life or are fully engaged in roles and responsibilities associated with adulthood when they begin to experience increased fatigue, musculoskeletal changes and pain that disrupt these activities and former patterns of physical functioning. For many participants these changes coincided with a significant life event or transition that they did not have support or resources to use to deal with them. In many instances, their complaints go unheard because of an absence of health care professionals and services to respond to their needs. The changes they experience can lead to more serious problems that if untreated in a timely manner cannot be improved and diminishes their physical and emotional well-being. It is apparent from the participants’ narratives that their
lived experience of growing up and growing older is simultaneously shaped by both discursive ideologies and socially constructed through their interactions with their external environment and a variety of people they come in contact with at different phases in their lives.

The experience of the participants suggests that the aging process unfolds very differently for them than it does for individuals without physical impairments. What is distinctly different for individuals with physical impairments is the delayed achievement (or non-achievement) of typical physical and social functioning that has an impact on their ability to have the opportunities and experiences that are paramount to the construction of self-identity, self-efficacy and biography. Limited opportunities to socialize and participate in typical life events such as work, education and family leave them with limited personal and social resources to address the issues of adulthood and aging as compared to people who reach old age without ever having experienced impairment and disability.

The unfolding of the participants’ lives suggests that it is difficult to distinguish between adulthood and growing older because these phases of their lives overlap with one another and are shaped by earlier phases as well as the personal and disability related issues with which they contend. The differences in the unfolding trajectories for persons with lifelong physical impairment are in part due to differences in their bodies’ structure and function, but also are due to social and cultural discourses that influence how both aging and disability are conceptualized and how these issues are responded to at different phases in people’s lives.

For example, striving to overcome being seen but not heard and achieving a sense of belonging are lifelong struggles for the participants and very problematic as they transition from adolescence to adulthood. Despite their achievements in education and rehabilitation
many continue to experience social oppression and are devalued (Lutz, 2005). Many participants found themselves with nowhere to go after finishing school both socially and vocationally. Other studies of aging and CP have also found this transition very challenging as many people with lifelong physical impairment lack the experience and opportunity to achieve their potential and build capacities that would enable them to manage life as adults (Beresford, 2004; Hilberink, et al., 2007; Neri MT & T. Kroll 2003). Providing these individuals with skills and programs to facilitate this process is often not possible or comes about late in the process (Bottos, et al., 2001).

5.3 How can we interpret these findings? Contributions from Foucault

I did not set out to engage in a Foucauldian analysis of growing up and growing older with physical impairment. However, as the analysis progressed I found the Life Course Perspective was limited in providing me with being able to describe my data theoretically, particularly with respect to the barriers and challenges in the external environment. The Life Course Perspective was very beneficial for collecting data and organizing participants’ experiences in life stories. It was also useful for attending to other forces that impact the lives of individuals with lifelong physical impairment. However, as the analysis unfolded, I found it increasingly difficult to use the Life Course Perspective to explain the relationships that existed between two central themes that emerged from my analysis: normalization and disability as well as being able to identify and describe how these concepts enhance our understanding of the experience of aging with disability.

I found myself struggling with conceptualizing normalization as it relates to the participants’ experiences. In some of my readings on disability Foucault was cited. I began to read some papers and books with a focus on disability. I found that Foucault’s concepts of
Bio-power, Governmentality, Normalization, and Resistance provided me with insight into how institutions, policies and practices especially medicine and education, manifest in the lives of individuals with physical impairments. These concepts provided a way to understand how the central concepts in the Life Course Perspective shaped the lives of my research participants and the central narrative “Defying the Odds”. Furthermore, some of Foucault’s concepts helped me to interpret and make sense of normalization (a central theme from my analysis) and the experience of impairment and disability.

Four concepts were used to interpret the underlying meaning and significance of “Defying the Odds”: Normalization, Bio-power; Resistance, and Governmentality. Normalization involves a group of individuals conforming to specific standards of behavior that are valued and reinforced by a group of individuals in positions of power. Being able to meet these standards contribute to maintaining order and diminishing the occurrence of chaos. Bio-power refers to the knowledge, practices, technologies and discourses that are used to regulate individuals’ lives. Resistance is not formally defined however it represents the diverse ways in which individuals challenge the practices and discourses that are used to regulate their lives (Danaher, Schirato, & Webb, 2000; Spitzack, 1992; Sullivan, 2005; Tremain, 2005). It is the management and/surveillance of these individuals that constitutes Governmentality (Danaher, et al., 2000).

Theoretically, Foucault’s concepts of Governmentality, bio-power, normalization, and resistance are helpful for enhancing our understanding of why individuals with lifelong physical impairments’ encounter physical declines so early in their lives. These concepts also support an interpretation of the impact that political, economic, and institutional forces have on people’s lives. Furthermore, these concepts also explain the relationship that exists between normalization and disability.
Governmentality (Danaher, et al., 2000) constitutes the management and/surveillance practices that are used with individuals in a given society. Bio-power is a concept that includes the institutions, discourses, and practices that are used to regulate and transform the lives of individuals who deviate from normal physical functioning and appearance (Hewitt, 1991). With respect to individuals with physical impairments health care and rehabilitation professionals use their knowledge to control the lives of these individuals by working towards the achievement of “normal” physical functioning. Possessing a healthy and physically able body is necessary to support capitalist modes of production (Tremain, 2005). Conforming to normal standards of physical functioning is also associated with being granted the rights and responsibilities of citizenship (Hughes, 2009). According to Foucault, when the actions of individuals are regulated, resistance is a natural response to practices and beliefs that a group of individuals may disagree with (Foucault, 2003/1973; Sullivan, 2005). Foucault doesn’t define resistance. However, it may present itself in diverse ways depending on the circumstances that confront different groups of individuals.

Defiance is interpreted as resistance that participants and sometimes their parents engaged in to recast discourses, cultural beliefs, and practices that is attached to disability (Tremain, 2005; Turner, 1992). Foucault was interested in the impact these elements had on subjectivity. Subjectivity refers to identity (Hewitt, 1991; Turner, 1992). The significance of these concepts to aging with disability within a life course perspective and normalization and disability is reflected in an interpretation of the deeper meaning that is embedded in the Defying the Odds narrative.
5.3.1 Foucault and the Life Course Perspective

Traditional theories of disability and of aging cannot explain the phenomenon of aging with disability as they tend not to account for the experience of these individuals in ways that explain the complexities associated with the experience as well as the multiple forces that interact with individuals which support and/or impinge upon achieving and maintaining independence across the life course. Theoretically, a Foucauldian and Life Course Perspective provide a lens through which we can conceptualize and understand the complex dynamics that impact the experience of growing up and growing older with a lifelong physical impairment by including and expanding beyond explanations limited to changes in physiological functioning. There are concepts that are central to both perspectives that reveal the complexity associated with the experience of impairment and the multiple forces that shape that experience. The Foucauldian perspective accounts for the impact of discourses and institutions in the regulation of the body that is shaped by time and space. While the Life Course Perspective also considers the impact of time and space on the unfolding lives of individuals, it also recognizes the interaction of individual agency, discourses and institutions situated in historical and cultural contexts that shape individual lives that is temporal in nature (Foucault, 2003/1973; Priestley, 2003). With respect to the current study, cultural beliefs about physical impairment combined with medical discourse and the medical management of disordered bodies significantly influences how participants are treated as well as the agency they exercise to live their lives and fulfill their needs.

When they reach adulthood the promise of being able to lead a “normal” life after benefiting from rehabilitation during childhood and adolescents backfires and is for many very short lived compared to the efforts put forth to achieve what they did. Childhood and adolescence provided the foundation for transforming damaged bodies into ones that
conformed to a standard norm in physical functioning which would pave the way for individuals with impairments to be granted the rights and responsibilities of citizenship (Davis, 1995; Hughes, 2009). At the same time individuals with lifelong physical impairments are told that their bodies have no potential and therefore they are conditioned to possess little or no expectations for a meaningful existence or to strive towards their potential. Despite these assumptions, many individuals benefit from rehabilitation and achieve functional independence that supports participation in mainstream social life. Nonetheless, they still have physical attributes that deviate from the norm which governing institutions use to marginalize their experience in the areas of school, work, leisure, and family.

The assumptions and perceptions of physical impairment perpetuated by cultural beliefs and medicine suggest that the normalization of physical impairment diminished the participants’ rights and opportunities to full citizenship because the emphasis placed on physically transforming their bodies interfered with being socialized in the same ways as their able-bodied counterparts. This was problematic because they did not acquire the skills and knowledge they needed to participate in activities related, to school work, and leisure as adults. By the time they did reach adulthood many participants had achieved functional independence which supported them in multiple areas of their lives. Nowhere during the process of receiving rehabilitation or health care did they feel that they been taught how to manage their disordered bodies (Seymour, 1998).

When the participants transitioned from pediatric to adult care there was no one to whom they could turn to address issues related to their health and medical condition (Hilberink, et al., 2007; Tighe, 2001). They were raised to believe that the health care and rehabilitation practices they engaged in while growing up would allow them to experience a
normal life and independence as they grow older. The medical and rehabilitation discourse and practices that were used to transform participant lives created a paradox. The paradox of normalizing their physical functioning rests on the assumption that achieving “normal” physical functioning leads to acquiring permanent control and regulation of one’s body which coincides with being granted the rights and responsibilities associated with citizenship (Beckett, 2006). Rehabilitation is considered successful by eliminating the presence of physical impairment rather than learning to embrace one’s physical structure, being supported in striving to achieve physical, cognitive, intellectual, and social potential, and care for their bodies. Consequently, failure to maintain functional independence is perceived as an individual problem, by not trying hard enough, rather than recognizing that the ability to regulate and control one’s body is a temporary condition that shifts across the life course and is mediated by circumstances and situations in which individuals engage.

Not having access to health and rehabilitation when they transitioned into adulthood was driven by the increasing cost of these services, and resources needed to live with physical impairment as well as the ontologies attached to the disordered body. That is, even though participants benefited from these practices, they continued to be stigmatized for their physical attributes and were also regarded as unsuitable for making any worthwhile contribution to work and worthy of being given the rights and responsibilities associated with citizenship (Hughes, 2009). Their experience suggests that since their bodies could not be completely normalized, they were not considered a worthwhile investment, which enhances our understanding of the absence of services and programs during adulthood and as they grow older (Hewitt, 1991; Hughes, 2009; Sullivan, 2005).

It seems apparent the regulation of impaired bodies through a process of rehabilitation hinders rather than supports the well-being and productivity of society as a collective body.
For individuals with lifelong impairment, rehabilitation is used as a mechanism to control their lives by denying them agency and failing to recognize the potential that lies within disordered bodies. Receiving a diagnosis was a significant turning point for all participants, not because it gave parents an understanding about what their child was grappling with, rather it determined what their future would look like with/without treatment. Regardless of what path they would take living with a physical impairment was going to be difficult. Their bodies were manipulated to improve their functional abilities of which their potential was achieved by the time they reached adulthood. That is according to health professionals, the bodies of adults with physical impairment as a consequence of cerebral palsy cannot be transformed to meet the norms of physical functioning (Bottos, et al., 2001; Zaffuto-Sforza, 2005).

The absence of adult services for people with lifelong impairments disenfranchises their experience of growing older and reinforces their false sense of citizenship, as issues they confront that are related to their condition and attitudinal and structural barriers limit their participation in daily living as adults. It also serves to protect health care and rehabilitation by covering up the short-term outcomes that accompany the normalization of physical impairment, while perpetuating the credibility and power, and benefits of their practices. Children with physical impairments may possess the potential to achieve physical adaptation to their condition, however, their physical structure does not support engaging in a normal existence long-term when they don’t have access to knowledge, resources and accommodations that will enable them to care for their impaired bodies as well as manage their physical and emotional well-being. Failure to address their needs seems to contribute to increasing the financial burden of people with impairments including health care costs, as well as disorder rather than stability among the collective body because society is unable to
confront the fears associated with impairment, especially being able to lead productive lives and be happy with the bodies we have. It is apparent from the unfolding of participants’ lives that Foucault’s conceptualization of power/knowledge and resistance give credence to the central narrative that shape their lives including the five themes that weave together their narrative.

5.3.2 The Underlying Meaning of Defiance

The ways in which the body, power/knowledge and medicine are conceptualized and the cultural and social influences that overshadow them, enhances our understanding of the deeper meaning that is reflected in “Defying the Odds”. That is, the Odds reflect the components that impinge on participant lives, while defiance could be regarded as representing Foucault’s resistance to the impact the odds have on their lives. Resistance is also reflected by their efforts individually and collectively to challenge pre-existing assumptions and misconceptions about impairment and disability as well as challenging the dominant discourses. In this study, their resistance is hindered by discursive ideologies and power arrangements that make achieving their potential and maintaining their functional independence as they grow older more difficult than is necessary.

The power that health care and rehabilitation professionals exercise in working with individuals with impairment facilitates resistance to conforming to the normal body. Foucault also believed that power/knowledge is accompanied by resistance. Resistance manifests itself in many different forms. There were two kinds of resistance prominent in this study. The first is defying the physical and social expectations that were imputed by health care and rehabilitation professionals on participants with mild to severe forms of cerebral palsy. All participants received a poor prognosis with respect to overcoming the limitations of their
impairments and leading a normal life. The second form of résistance was challenging pre-existing conceptions of what is considered “normal” and how important it is for people with impairments to be given the same rights as their non-disabled counterparts, and be treated with respect and dignity. This form of resistance is associated with two achievements. The first is finding creative ways of managing daily living, pursuing an education and becoming employed. The second achievement involved pursing personal friendships and intimate relationships leading to a family and children. These achievements were an outcome of resistance that manifested itself in the “Independent Living Movement”, which many participants either actively contributed to or grew up during its implementation.

Being able to lead a normal life was something that all parents wanted for their children and was reinforced by the dominant ideology. Being able to participate in life like children without impairments is facilitated by normalizing their physical impairment through a process of rehabilitation. Transforming the disabled body into one that functions normally provides the foundation for becoming entitled to the rights and responsibilities associated with full citizenship. Emphasis placed on normalizing their experience ignores their embodied experience of living with paralysis and accepting their circumstances as “normal” for them. For the most part, they are encouraged to embrace who they could become by achieving normal physical functioning instead of being encouraged to embrace and value who they are as they are and strive to do the best they can with what they have. Participants found that the practices that were used to achieve “normal physical functioning did not coincide with being able to participate in mainstream social life because of continuing to possess characteristics of the disordered body. Their desire to experience life like their able-bodied counterparts facilitated resistance to the low expectations and control professionals were trying to impute on them. The resistance manifested itself in striving to get a
comprehensive education, engaging in social opportunities, becoming employed, having families of their own, and living in the community. Resisting these practices and discourses came at a cost because many participants extended themselves over and above their capabilities which had a negative impact on their bodies and emotional well-being.

Devaluing the physical embodiment of paralysis appears to serve the best interests of the government and society, as it reinforces the beliefs and values associated the discourse on normalcy, and the high health care costs associated with impairment. People with impairments don’t necessarily experience long-term benefits from improved physical functioning as an outcome of rehabilitation. After many years of rehabilitation individuals with lifelong impairment receive interferes with addressing other areas of skill acquisition and personal needs that are fundamental to living an independent life in adulthood. Unfortunately, the marginalization of individuals with impairments through the use of Bio-power is strongly tied to and reinforced by the cultural discourses on the body. For instance, all participants found that professionals they encountered in medicine, rehabilitation, or education used their knowledge and training to make decisions about what they needed, could or couldn’t do without including them in the process which was accompanied by alienation and frustration. The decisions that were made gave them little or no control over the experiences and opportunities they would have at different phases in their lives.

5.3.3 The Power of the Cultural Context

Historically cultural beliefs about the body heavily influence what physical characteristics and behaviours are acceptable to society as a whole. This even holds true today. Our society is overly obsessed with the achievement and maintenance of physical perfection. We are constantly bombarded with images in the media of young, thin, healthy,
and physically attractive men and women. The fear of growing older is reflected in anti-
aging campaigns and products as well as a variety of cosmetic practices that can restore and
prolong youth (Hughes, 2009; Seymour, 1998; Turner, 1992; Wendell, 1996). Let’s not
forget the messages that are conveyed to the public at large about how caring for one’s
physical health and well-being can lead to a long and healthy life that could prevent the
experience of disabling conditions resulting from strokes or heart disease.

Cultural beliefs play a significant role in the attributes and roles associated with being
male and female. Men are generally perceived as physically strong and attractive, possessing
the abilities to work, marry and parent children, while perceptions of women are associated
with being perceived as possessing physical attributes which are attractive and feminine, and
provide her with the ability to marry, bear children, and raise a family. These perceptions are
regarded as a natural part of the cycle of life (Davis, 1995; Priestley, 2003). Those men and
women who live with impairments are not valued in the same way as their able bodied
counter-parts. Having a physical impairment prevents or disrupts the normal functioning of
the body. Normal functioning includes three attributes: the regulation of bowel and bladder
functioning as an individual matures, engaging in bodily techniques (Mauss, 1979), including
the ability to sit up, stand, walk etc., as well as being able to maintain physical appearance
by caring for one’s body (Seymour, 1998). Even though people with physical impairments
have damaged bodies that may be considered disordered because of the absence of regulation
(Seymour, 1998), they still have a body and experience their bodies through physical
embodiment (Turner, 1992). However, the inability to control and regulate one’s body is
devalued and associated with negative attributes.

Individuals with disordered bodies are perceived as unattractive, possessing a life not
worth living, as well as lacking the attributes that are valued and necessary for contributing to
the work force as adults (Davis, 1995; Seymour, 1998; Turner, 1992). Consequently, many children with physical impairment are not socialized like their able-bodied counterparts as they are perceived as not needing social/intimate relationships or possessing the abilities to become mothers and fathers, and parent children. Positive attributes associated with impairment are rarely talked or written about despite the fact that many people with physical impairments have achieved successful and meaningful lives that include work, love, acceptance, and family.

Two ontologies inform the lived experience of physical impairment: the foundationalist and the anti-foundationalist perspectives. In the foundationalist perspective, the embodied experience and sense of self are shaped by forces external to an individual such as the discourses they encounter (Turner, 1992). The individual is considered passive. The anti-foundationalist perspective considers individuals to actively engage with their environment, and discourses which contribute to the social construction of the embodied self (Turner, 1992). The significance of these perspectives is they bring our attention to the complexities associated with moulding and transforming themselves as they grow older.

The emphasis that society places on physical perfection is historically rooted in the birth of industrialization first in Europe and later across North America. Capitalism required workers with healthy functioning bodies to meet the demands of production which led to an increase in wealth and the accumulation of materialism. Anyone who was unable to be part of the workforce because of illness/disability was considered a burden to society. The origins of medicine during the 18th and 19th century developed treatments that focused on the elimination of disease and illness (Foucault, 2003/1973). Medicine had and continues to have a prominent influence over society that is not limited to the elimination of disease and illness.
Foucault’s analysis of the role of medicine reveals that it is one of multiple institutions (along with education and the penal systems) whose professional expertise is used to transform individuals’ deviant characteristics/behaviours so they conform to acceptable normative patterns, and into acceptable subjects, for the common good and maintenance of order in society. Foucault considered the impaired body as being docile due to its abnormal attributes and unregulated functioning. Individuals were therefore expected to surrender themselves to the medical experts to improve or completely eradicate their physical abnormalities (Danaher, et al., 2000; Foucault, 2003/1973; Tremain, 2005). It is through their knowledge and power that they regulate and control the lives of individuals with disordered bodies. The process of normalization is used as an apparatus to transform their bodies (Danaher, et al., 2000; Heyes, 2007). Participants were expected to embrace these practices and discourses, as it entitled them to receive support and resources to help them transform their bodies. They were also considered compliant by receiving treatment and/or surgery or both to improve their circumstances.

As medicine and technologies advanced in the 20th century, greater wealth was being accumulated in a capitalist economy, and people were experiencing improved health and living longer than the generation before. Improved sanitation and advances in medical technology contributed to life saving practices, and increased life expectancy. Despite these advances, individuals continued to encounter illness and impairment which were sometimes an outcome of medical life-saving practices including cerebral palsy, cardiovascular disease, and stroke. Individuals confronted with these circumstances continued to be at the mercy of medicine not just to improve their circumstances but to restore order in society. Even if individuals benefited from medical intervention, their experience was silenced, and they tended to be marginalized from mainstream social life. The experts tended to think that they
knew what their patients needed, felt, or experienced. Also, they were, and continue to be, denied full citizenship because of their circumstances. In fact, many participants felt that mobility was one of many capacities they wanted to achieve. Being able to learn to communicate with or without a communication device, as well as being able to read and write was considered just as or more important than being able to walk.

The significance of cultural beliefs is that they perpetuate normalcy and the rights and exclusion of individuals with physical impairments. It will become clear that the continued advancement of medical technology including the availability of rehabilitation currently contribute to legitimizing the dominant ideology of normalcy and supporting partial or a false sense of citizenship even when individuals with impairments are successful at achieving functional independence (Hughes, 2009).

5.3.4 Citizenship

Being a citizen is associated with being granted certain rights and responsibilities. Some of these rights include receiving an education, health care, family benefits, being socialized to expand and contribute to society through family and work. Receiving these opportunities is strongly influenced by possessing a healthy functioning body. Being treated as a citizen means that children will receive the support and resources they need to achieve physical and social milestones that participation in school, work, marriage and children. Consequently, being born with a healthy body is desirable and possesses the attributes that entitle that person to the full rights of citizenship (Davis, 1995; Hughes, 2009; Priestley, 2003). When a child is born with impairment he/she doesn’t meet the physical norms that society attaches to the body. Possessing a damaged body is devalued because it will be difficult for them to experience a productive life and contribute to their community through
work. Since they cannot function in the same way as their able-bodied counterparts, they are not considered to have the same needs, or be entitled to the same rights and opportunities associated with citizenship. Consequently, their lives are controlled and managed by institution (medicine, rehabilitation, education) which uses their professional expertise to marginalize their experience by impinging on their participation in mainstream social life. By doing so, they perpetuate their dependency on others rather than supporting them in acquiring the skills and knowledge they need to manage life with impairment (Davis, 1995; Wendell, 1996). The dynamic relation between health care and rehabilitation professionals is verified by Foucauldian concepts of knowledge and power that disadvantage individuals with impairments. Health care professionals have the knowledge and skills to treat, improve, and/or eliminate their physical impairments. Their power is in their knowledge which plays a significant role in the regulation or governance of people with impaired bodies (Foucault, 2003/1973). This kind of regulation is directed towards transforming the damaged body into one that functions “normally” by being able to achieve self-control as one matures (Foucault, 2003/1973). These practices are designed to improve the physical well-being of an individual, when in fact their primary objective is to legitimate normalcy and marginalize the experience of individuals who deviate from the norm. According to Foucault, the perspective of individuals with illness/impairment needs to be considered in order for health professionals to effectively meet the needs of their clients/patients. For the most part, the experiences of individuals are silenced as possessing a damaged body leads many professionals that they come in contact with to assume that don’t know what they need or want, and are unable to describe the embodiment of their physical condition. Consequently, they become helpless and dependent of the knowledge and guidance of health professionals to improve their life circumstances which would lead to being entitled to full citizenship
According to Lupton (1997), Foucault’s intention was for medicine to have a positive impact on people’s lives by empowering them with knowledge and being the best they could be. She states:

From the Foucauldian perspective, power as it operates in the medical encounter is the disciplinary power provides guidelines about how patients should understand, regulates and experience their bodies. The central strategies of disciplinary power are observation, examination, measurements and compare a set of individuals against an established in one bringing them into a field of visibility. It is exercised primarily through direct coercion or violence (although it must be emphasized that these strategies are still used from time to time), but rather through persuading the subjects certain ways of behaving and thinking are appropriate for them (p.99).

While Lupton considers these practices as being facilitative, this intention is and continues to be very misleading and oppressive with the absence of agency and recognition that very few people conform to the normative standards associated with physical abilities and appearance. Consequently, failure to meet these standards can create dissonance within and among individuals with impairments which facilitates resistance which is a characteristic attribute in my participant narrative. The dissonance is grounded in medicine and rehabilitations failure to meet the long-term needs of people with physical impairments when cultural beliefs continue to perpetuate normalcy which is legitimated and reinforced by these practices. The next section examines how these practices and discourses impact aging with disability.

### 5.4 Implications for Rehabilitation Practice

Other studies have identified persistent health and musculoskeletal problems in young adults with cerebral palsy (Sandström, 2007). The experience of participants in this study reveals that early onset declines are characterized by what many describe as a “general
slowing down” that interferes with and/or disrupts daily living and fulfilling the personal and professional roles and responsibilities they have/desire.

The participants in this study felt that rehabilitation is helpful for enhancing their physical functioning; however, it does not prepare them to achieve capacities that will enable them to manage their condition while navigating life as adults. Similar to other studies, participants in this study encountered declines in functioning in young or middle adulthood changes (Andrén & Grimby, 1999; Bottos, et al., 2001; Charlifue, et al., 2004; Harrison TC. & Stuifbergen, 2005; Liptak, 2008). They felt that they did not have the knowledge and resources (personal, financial, health care, or rehabilitation) to deal with these changes. Consequently, by the time they transition into adulthood they begin to slow down without having access to comparable services they received as children and adolescence.

Many found it difficult to find accessible health care and care providers with knowledge and training to respond to the issues that adults with lifelong physical impairments confronted (Darrah, et al., 2002; Hilberink, et al., 2007; Neri MT & T. Kroll 2003). Over the past thirty years, advances in rehabilitation have enhanced the functional outcomes for people living with impairments from illness and injury. Yet from a rehabilitation perspective, funding and services are mainly available to individuals whose condition is labeled acute since these individuals with acquired impairments are considered to have the potential to achieve a successful recovery and to be reintegrated into their communities (Hammel, 2006).

Experts working with the participants in this study were guided by the same assumptions with one unique difference: individuals with lifelong impairments were considered to possess the greatest potential for improvements in functional abilities during childhood. As a result, the participants had little or no access to rehabilitation in adulthood.
Other studies have also found that the physical improvements that clients/patients made in rehabilitation during childhood are perceived by rehabilitation specialists to support individuals for the remainder of their lives (Bottos, et al., 2001; Kemp & Mosquida, 2004; Lankasky, 2004; Wiart L. & Darrah, 2002). What is significant about these findings is that they reveal that cerebral palsy should no longer be considered a stable condition, as individuals living with the condition were informed by their doctors when they were young.

Within biomedical and rehabilitation frameworks the primary focus is on assessing functional abilities that are measured against a normative standard that if achieved and displayed coincides with being granted the right to participate in mainstream social life, or being able to engage in life (Oliver, 1998; Schneider, et al., 2003). Achieving these norms are unrealistic especially when they are socially constructed and perpetuated by cultural beliefs that serve to legitimate the beliefs of a dominant group of individuals who decide what is normal/abnormal in physical representation, structure and function of the body (Hewitt, 1991).

The physical changes participants experienced in early adulthood suggests that living with a disordered body requires ongoing maintenance in addition to engaging in practices needed to maintain their physical health and well-being. The absence of services and programs for individuals with lifelong physical impairment seems to be a political and economic issue. That is, they possess bodies that are devalued and not suitable to participate in productive work. This suggests that stakeholders and health care professionals may regard rehabilitation as a waste of time and money since when completed; many of these individuals will not be able to return to productive work. Even though many participants didn’t like their lives revolving around the management of their conditions growing up, many feel as though they have been abandoned and neglected as the changes they grapple with impinge on living
and enjoying life to their full potential. This is reflected in the misconception that professionals may have about individuals with lifelong impairments having the knowledge, skills and resources to successfully manage their bodies as adults and lead full lives.

These findings suggest two key implications for health care and rehabilitation practice are: 1) the need to develop and implement a continuum of care across the life course. A continuum of care is not limited to providing young adults with impairments with the knowledge and skills they need to transition from pediatric to adult care. This approach should be predicated on ensuring that these individuals have access to the comprehensive services and level of expertise they encountered growing up. While some individuals may not require the same level of care received in the past, other individuals may require them due to the temporal nature of living with physical impairment. While it may not appear to be cost effective, it is more cost effective to ensure that these individuals have access to trained and experienced professionals, resources and technologies they need to engage in meaningful occupations, and manage life with physical (including their general health and emotional well-being) many years following comprehensive pediatric rehabilitation.

The second important practice issue is to reconceptualize the meaning of prevention for people with pre-existing impairments, as well as the practices that are used to reduce health care problems and costs. This issue aligns very closely with the one preceding it. The difficulties that participants in this study encounter suggest that prevention needs to be considered as practices and procedures that focus on maintenance of physical functioning through intermittent rehabilitation (will vary from one individual to the next), or access to new mobility aides due to changing needs. Prevention has another component that focuses on reducing the early-onset of secondary health problems and impairments secondary to their primary condition, which could be facilitated through the availability of a continuum of care.
5.5 Implications for Theory

From a theoretical standpoint, the first issue that needs to be addressed is to reconceptualize the disordered body. This would involve incorporating more positive attributes associated with impairment with the recognition that potential does exist within the disordered body, can be nurtured, but must also be cared for. Caring for the disordered body means that there will likely be additional practices, resources, and technologies that need to be used to achieve their physical potential and preserve their independence, which extend over and above the practices that individuals without impairments have to engage in.

This process would also involve moving away from the philosophical approach to rehabilitation that places emphasis on ambulation as being a means to an end in and of itself. A philosophical approach that emphasizes the achievement of other capacities such as communication, self-advocacy, as well as other unique abilities should not be ignored. Being able to walk should be complimented by using mobility aides that will enable individuals to maintain their independence while still being able to engage in meaningful occupations that extend beyond activities of daily living. By taking this approach, there is recognition that potential exists within the disordered body and life can be meaningful. This approach would enable individuals with disordered bodies to maximize their physical potential with the awareness that there are limits on how far they can go without properly caring for and managing their bodies. That is, there are additional practices that individuals with impairments need to engage in to maintain their bodies long-term.

The second important change that needs to occur is to construct a theory on aging with disability that considers the trajectory of living, and growing up & growing older with lifelong physical impairment. This is important because the existing theories on development and aging do not adequately depict the unfolding lives of people with lifelong physical
impairment. Their experiences of growing up and growing older with physical impairment are distinguished from their able-bodied counterparts by not having had the same experiences and social opportunities that provide the foundation for being able to engage in life and negotiate the world around them as adults. Even though many individuals with disordered bodies are slower to achieve some physical and social milestones, or don’t achieve them at all, it is important to account for the trajectory of their lives as we cannot fully address their changing needs as they grow up and grow older by limiting our understanding to the trajectory of a given medical condition. The Defying the Odds narrative suggests that there are limits to medical intervention. More research is needed to identify and achieve a greater understanding of what they are to reduce health care costs increase the autonomy and long-term outcomes of individuals with lifelong and early onset impairments.

5.6 **Strengths and Limitations of this Study**

The approach that was taken to explore the experience of aging with disability provided an in-depth understanding of the multiple factors external to the individual that impact growing up and growing older with disability. This study revealed how non-discursive and discursive practices intersect with one another and shape the unfolding lives of individuals with physical impairments. A great deal of consideration was given to use a combination of strategies to achieve rigor for both data collection and analysis. This meant that the strategies I employed would support a high level of accuracy in compiling participant life stories using a life course perspective. During analysis, several I used several strategies to identify the form of the narrative emerging from their life stories, emerging themes and categories, as well as the deeper meaning embedded in their collective narrative “Defying the Odds”. These processes were iterative. The strategies I employed included:
1) Memos where kept to track methodological issues encountered and strategies used to resolve them, trace decisions made in constructing participant life stories (why certain text were selected over others), trace emerging themes and central narrative as well as interpretive insights. 2) Multiple interviews were undertaken to increase the accuracy of the information being collected (when reflecting on many years of one’s life specific details may be difficult to recall in the beginning, and are retrieved in later interviews). One of the challenges associated with constructing life stories using the life course perspective is being able to achieve coherence and consistency throughout participant life stories because some details about certain events may be difficult to remember when participants are being asked to recall events from many years ago. 3) Member checking was used by having participants review their narratives to ensure accuracy, and expand on sections that needed more detail or clarifications. Participants also provided feedback on emerging themes (from the first phase of analysis).

Even though this was a rigorous and in-depth study, it was fraught with some shortcomings. First, it is important to recognize that even though the experiences participants shared to co-construct their life stories were comprehensive; they do not include all details of their lives, as their telling was impacted by the contexts in which they chose to share their experiences with me as well as the working relationship we formed together. Second, I argue that cultural beliefs held by society about the “disordered body” impacted the unfolding lives of my research participants. All of my participants grew up in middle-class Canadian families and they have all been involved in disability culture at different points in their lives. As such, my participants represent a specific middle-class Canadian cultural context. Finally, traditional research using a life course perspective also involves interviewing significant others who constitute participants’ support network (including family, friends, and co-
workers) as these relations provide insight into how their lives are linked with others who positively or negatively impact their biography and subjectivity.

5.7 Dissemination
There are many potential audiences for this work including other researchers (writing papers, presenting at conferences), clinicians, people with disabilities, and in particular, CP, and decision-makers. The strategies for dissemination include:
1) Teach a course on Aging with Disability (Theoretical Foundations of Aging with Disability). This course is appropriate for current students pursuing careers in health care and rehabilitation (professionals and paraprofessionals). Students will learn about individuals living with lifelong and acquired impairments (such as CP, MD, ID, AIDS, Crones, SCI, and TBI).
2) A workshop or series of workshops on aging with disability will be designed and facilitated for seasoned health care and rehabilitation professionals who did not receive this knowledge and training early on in their careers.

5.8 Future Research
Even though this study provides researchers and clinicians with increased awareness on the issues that adults with cerebral palsy contend with as they age, there continues to be a dearth of research on individuals aging with childhood physical impairments (Liptak, 2008). There are four directions that can be pursued using either quantitative or qualitative methods or a combination of the two: 1) Needs assessment; 2) rehabilitation Program Design and Evaluation; 3) Longitudinal Research involving long-term follow-up; and 4) Research with a focus on prevention of secondary health problems (this would include education on what to expect as they grow older and rehabilitation to support long-term maintenance).
1) Needs assessment: Continued research on identifying the needs of individuals with childhood impairments is important for constructing theory on living and aging with
disability, as well as expanding our understanding of their needs at different phases of their lives. For instance, the findings of this study can be built on by exploring the experiences of adolescents with lifelong physical impairments. This would be beneficial as it could give clinicians and researchers a better understanding of their trajectory, needs, and gaps in services and experiences that need to be addressed to support them in achieving their full potential.

2) Rehabilitation Program Design and Evaluation: There have been several studies that have found that the achievement and maintenance of the ability to walk throughout the lives of individuals with CP is very challenging (Bottos, et al., 2001; Lankasky, 2004; Liptak, 2008; Zaffuto-Sforza, 2005). Consequently, it would be beneficial designing and implementing a rehabilitation program (as a pilot study) that encourage the achievement of mobility in the form of walking without it being the ultimate goal. Children will be encouraged to use mobility aids to minimize fatigue and increase independence, by offering them the opportunity to achieve other capacities in order reach their physical, cognitive, intellectual, and social potential.

3) Longitudinal Research involving long-term follow-up: While longitudinal studies are extremely expensive to engage in they provide valuable information that could positively impact the lives of the individuals and phenomenon being studied. Longitudinal design should be considered to follow individuals across their lives or from the point of their illness or injury. Long-term follow-up is important to support long-term maintenance, to prevent secondary health problems, and to respond to their changing needs as they grow older. Having this option available would provide them with access to new equipment and resources that are needed to support them in participating in meaningful occupations.
5.9 **Key Message**

When doing research on individuals with impairments it is very difficult to make decisions about programs and services that will be beneficial to them if research studies focus on either the experience impairment or environment independently. Living with impairment is temporal. Both the individual with impairment and their external environment intersect with one another thereby making it difficult to separate them from each other.
References


Appendix A

Graduate Department of Rehabilitation Science

UNIVERSITY OF TORONTO, FACULTY OF MEDICINE

Consent Form

I, __________________________ will participate in research on the experience of living with a physical impairment across the life course. I agree to complete three to four interview sessions (1 ½ to 2 hours long) to provide Laura Moll (Primary Investigator) with an in-depth account of my experience of living with cerebral palsy. I give Laura permission to audiotape all interview sessions for the purpose of transcription for analysis of the information collected. Laura has informed me that my name will not appear in the transcripts or any publication that results from this study. I also know that the audio-tapes of my life history will be destroyed after Laura’s research is published. I know that sharing my life experience will improve our understanding about what it is like living with cerebral palsy, and may also in improve rehabilitation programs and policies to meet the life long needs of individuals living with CP. Even though sharing my experience doesn’t pose any significant threat to my well-being, I know that recalling some life experiences may be upsetting to me emotionally. I will be able to receive counselling to deal with these issues if I want to. I have been informed that I will receive a gift certificate from Indigo for my participation in this study. I have the right to withdraw from the study at any time and have my life history removed from the write-up and publication of this research.

I have read the overview of this study and understand my rights and responsibilities as a research participant.

Signature: __________________________ Date: __________________________

Witness: __________________________

Contacts
Laura R. Moll, MSW, RSW, CGT, CBE
Ph.D. (Student), Primary Investigator
Moll.laura@torontorehab.on.ca
(416) 597-3422 ex.(7866)

Cheryl Cott, Ph.D., Supervisor
cheryl.cott@utoronto.ca (416) 978-0301

Jill Parsons, Research Ethics Officer
jc.parson@utoronto.ca (416) 946-5806
[Flyer]

The Experience of Living with a Physical Impairment: A Life Course Perspective

Overview of Research

**Primary Investigator:** Laura R. Moll, Ph.D. (Student)
**Supervisor:** Cherly Cott, Ph.D.

The purpose of this study is to explore the experience of individuals living with a physical impairment across the life course. The experience of living with cerebral palsy will be used as a model for investigating the experience of physical impairment across the life course. There are two objectives I hope to accomplish in this study:

- To describe how social, institutional, and political influences impacts on the developing individual living with a physical impairment.
- To identify how these elements contribute to and shape the experience of an individual, and patterns of adaptation he/she adheres to at different stages across the life course.

**Participants: Rights and Responsibilities**

There are two parts to this study. The first involves completing the Life Chart (Appendix C), and participating in three to four interview sessions in order to put together an accurate account of your life. Interviews will be tape recorded and transcribed for analysis. Before interviews begin, participants will be given a life charts (plot significant events, life transitions) which they will complete and can bring to the interview to facilitate discussion (Giele and Elder Jr., 1998). The anonymity of research participants will be protected by omitting their names from transcripts and any documents used for publication. The audio-tapes of his/her life history will be destroyed after Laura’s research is published. Sharing your experience will improve our understanding about what it is like living with cerebral palsy. It may also contribute to improving rehabilitation programs and policies in order to meet the changing needs that you and other individuals have from childhood to old age. Sharing your experience doesn’t pose any significant threat to your emotional well-being, yet recalling some life experiences may be upsetting to you emotionally. In order to deal with these issues you will be referred for counselling support if you want to. You have the right to withdraw from the study at any time and have your life history removed from the write-up and publication of this research. In appreciation for your participation, you will receive a $30.00 gift certificate from Indigo.
Appendix B

The Experience of Living with a Physical Impairment

Background Information

1. Name:
2. DOB:
3. Impairment:
4. Secondary Health Problems:
5. Martial Status:
6. Education:
7. Occupation:
8. Living Arrangements:
9. Support System:
## Appendix C

### Life Satisfaction Chart (Clausen, 1993)

<table>
<thead>
<tr>
<th>Stage</th>
<th>0-6</th>
<th>7-12</th>
<th>12-16</th>
<th>16-18</th>
<th>18-25</th>
<th>25-40</th>
<th>40-64</th>
<th>64-70</th>
</tr>
</thead>
<tbody>
<tr>
<td>Childhood (0-6 year)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Adolescence 12-16</td>
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<td>16-18</td>
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<tr>
<td>Young Adulthood 18-25</td>
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<tr>
<td>Adulthood 25-40</td>
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<tr>
<td>Middle Age 40-64</td>
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<tr>
<td>Old Age 64-70</td>
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</tbody>
</table>

In the space provided list significant life events during each stage of development:

- Important people in your life, including parents, sibling, friends, mentors
- Milestones (important achievements)
- Challenges (personal, circumstance, people)
- Life Roles and Responsibilities (student, sister/brother, parent etc..)
Individuals will then rate their level of satisfaction at each stage of development. This chart is a descriptive account of a person’s life. (Each participant will have two weeks to complete it before meeting for the first interview.)

On a scale of 1-10 rate your level of satisfaction at each stage of development. This can be completed on separate paper.
# Appendix D

## Interviewing People with Communication & Physical Impairment

### Table 1

<table>
<thead>
<tr>
<th>Interview Process</th>
<th>Challenges</th>
<th>Strategies</th>
</tr>
</thead>
</table>
| **Orientation Interview**              | • Time frame (some participants needed more than 2 weeks to complete the BI and LSC.  
                             • Some participants needed assistance to complete the pre-interview tasks (disability related issues). | • Extended time was provided to accommodate the abilities and limitations that participants had.  
                             • Encouraged to capitalize on their strengths (written/oral expression) – word processing  
                             • I acted as a scribe to assist with the BI and LSC |
| Provide overview of study              |                                                                           |                                                                           |
| Time commitment, Withdrawal & Confidentiality |                                                                           |                                                                           |
| Obtain informed Consent (written or verbally) |                                                                           |                                                                           |
| Provided a BIS and LSC to be completed (prior to first Interview) |                                                                           |                                                                           |
| **Session 1**                          | • Participants found it difficult to share a detailed account of their lives only using a primary question (requested more questions):  
                             • “What has been like growing up and living with cerebral palsy?”  
                             • Encountered difficulty reflecting upon their experience.  
                             • Some found it difficult to elaborate beyond what was in their chart  
                             • Participants may have not had experience telling their story the way that they were being asked | • Provided participants with supplementary questions (further areas of inquiry) two weeks prior to the next session for reflection  
                             • Participants were encouraged to write down their thoughts and feelings  
                             • Managing fatigue-check in with participants after an hour to see if they are comfortable continuing unless they bring it up before the hour |
| Reiterate the objective of the study   |                                                                           |                                                                           |
| Explore and expand upon events, experiences, and significant others (LSC) |                                                                           |                                                                           |
| Use Probing Questions intermittently   |                                                                           |                                                                           |
| Length of Interviews: 1-2 hours        |                                                                           |                                                                           |
| **Session 2**                          | • Continue to probe and expand on areas that need to be clarified  
                             • Explored further areas of inquiry (questions generated from reviewing previous interview) | • When interviewing a person who is nonverbal it is important to use a variety of strategies.  
                             • Provide the participant with questions in advance so that he/she can review it with someone who understands him/her and is very familiar with the communication tools and strategies he/she uses.  
                             • Record responses in writing and/or word-processing  
                             • Arrange one or two sessions with the participant and |
| Communication Impairments              | • Hard to understand due to slurred speech and difficulties with pronunciation  
                             • Takes a long time to express themselves (usually in short sentences  
                             • There is often a need to repeat what is said as well as spell a word  
                             • Understanding what is being said takes a long time and can be tiring for the participant and researcher |                                                                           |
- Address the participant in all correspondence even though he/she will have assistance with this process.
- Clarify and paraphrase responses to the topic under investigation
- Be patient and take the time to listen
- Clarify things that are difficult to understand
- Paraphrase what is said to verify what is being said (this strategy enables the researcher to expand on the facts that are being provided

<table>
<thead>
<tr>
<th>Session 3</th>
<th>Narratives were not always ready for the third interview session</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Probed further areas inquiry&lt;br&gt;• Review participant’s narrative (from first 2 transcripts)</td>
<td></td>
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</tbody>
</table>

| Session 4 & 5 (as needed) | |
|----------------------------| |
Appendix E

Emerging Categories Cumulative Listing

Preliminary categories

(May-August 2008)

Little or No Expectations for a Meaningful Life

This theme describes the perceptions and interactions of significant others with the person with a physical impairment as he/she grows up.

- Professionals and parents had little or no expectations for children with disabilities to have the potential to grow up and lead productive and meaningful lives. This view impacted the opportunities for these children to develop the skills and abilities that they would need to negotiate the world around them.

My Disability does not define who I am

- People with physical impairments felt that the people they interacted with (including health care and educational professionals and some family members) them as though their disability defined who they were.
- This theme also captures met and unmet needs.
- They were not treated as human beings who had thoughts, feelings, and needs.
- Most participants went to schools specifically for children with disabilities where the emphasis was placed on achieving functional independence (part of the curriculum involved physical and occupational therapy).
- There was less emphasis on academic achievement and the curriculum was not at the same standards as the public school system.
- Many who entered the regular school were inappropriately placed in grades that did not correspond to their chronological age, which had implications for intellectual, cognitive, and social development, as well as psychosocial well-being. In the absence of supports and resources to meet their needs many found themselves watching their peers move
forward with their lives while they stayed behind to develop the academic skills they needed for a future adulthood that did not include developing *interpersonal relationships* that would lead to marriage or a family, post-secondary education, or a career that would provide them with meaningful and productive existence. Developing *life skills* was seen as more important especially for individuals who were children and adolescents prior to the independent living movement. This was even true for two participants (Delia and Donna) who grew up during the independent living movement. There was a feeling of social disconnectedness, and being devalued as a human being. In short having a disability meant inability.

*Gaps in development and other areas of life*

- Emphasis was/is placed on achieving functional independence. Health care and educational professionals, as well as parents impose the process of normalization through the use of surgical procedures designed to eliminate physical abnormalities, and support physical age appropriate development so that they can walk independently without the use of assistive devices such as a scooter or wheelchair.

- Children with lifelong physical impairments are not taught to embrace their physical impairments as a normal and acceptable part of who they are. They are taught that they are not okay as they are. This is reflected by messages that they get from their surrounding environment.

- Many individuals were not taught to become self-advocates. It’s not uncommon for the needs of these individuals to be imputed, as many of them were not asked about what they wanted or needed, rather they were told.

- They are not educated about their physical condition, its consequences, as well as long-term outcomes and management.

- The absence of preparedness to deal with normal life transitions (developmental, death of a parent, illness (self or others), divorce, and aging.

- Absence of continuity and availability of health and rehabilitation services needed to maintain physical health and well-being, as well as independence as one ages. The experiences of my participants revealed that they require these supports and resources on a regular and/or intermittent basis beginning in early adulthood.
When emphasis is placed on helping children with disabilities achieve the functional abilities associated with normal development other areas that need to be developed are compromised. These achievements may take place slowly which impacts when they begin school, how quickly they can acquire age appropriate skills and developmental tasks. The supports and resources he/she needs and are available also influence whether or not a person with a disability moves forward with his/her peers or stays behind. Even

**Self-reliance**

The absence of support, encouragement, and a life plan forced all participants to take control of their lives by creating their own lives. This involved rejecting negative expectations and poor prognosis.

**Social/Developmental transitions-Off Time/On Time**

This category captures how having a physical impairment impacted the timing of developmental and social transitions. Policies, programs, and available resources also contribute to the timing of these transitions and are closely linked to impairment. Some participants started school late because he/she did not accomplish developmental milestones consistent with a readiness to begin school. Another issue that many have contributed to these circumstances is disability related issues including inaccessible building, absence of resources, program or services and teachers trained to meet the learning needs of these students, which hinders the development of age appropriate skills and abilities. With no where to go some students are kept behind while their peers move on with their lives (needs to be reconceptualized) See Geraldine, Vanessa, and Cathy’s narrative. Being off time poses significant social-psychological implications

**Physical barriers**

Captures the environmental barriers individuals encounter and their impact on participation as well as having basic needs met (housing, health care, social environments)

_Brick Wall_ (Suzanna’s Narrative) describes the difficulties encountered with fitting in socially.
Social-psychological Impact
Describes the emotional impact that the experience of disability (environmental barriers) has on the well-being of an individual.

Nowhere to Go
Capture the notion that there is both an absence of readiness or place for people with impairments in society. Examples include school (unable to support and meet learning needs, limited work opportunities, absence of health care, and accessible housing).

Adaptive strategies
Strategies individuals use to engage in meaningful personal and professional occupations.

Dreams and Aspirations
Personal dreams and aspirations (parallel able-bodied peers) with are mediated by impairment and disability related issues. For example, schools may not be physically accessible or have the resources available to meet the needs of students with moderate to severe physical impairments. Transportation may be an issue that impedes full participation in daily living, work, and leisure. Attitudinal barriers may also limit opportunities. See Vanessa, Geraldine, Cathy & Robert’s narrative.

Being with my peers (social needs)- Cathy’s Narrative
Emphasizes the importance attached to being with peers (with or without impairments). Developing a sense of belongingness is desired.

Being born with a disability is different

Personal Needs- Cathy’s Narrative
Intellectual, social, education and information (specific to each stage of development as well as one’s physical condition), being able to communicate
Challenges with residential living-Cathy’s Narrative
This category describes some of the disadvantages associated with living in a community residence for people with impairments. Rules are established without asking or considering the needs and desires of those individuals residing there.

Unmet Needs
Areas of knowledge, skills and development that were neglected due to perceptions of inability and/or potential because of having a physical impairment

Being self-reliant
Engaging in meaningful activities, and without relying on the assistance of others

Making a Difference
To engage in work-related or volunteer activities that a person is passionate about and gives him/her the opportunity to touch the lives of others; Enhancing society’s understanding about the experience of disability

Hard Work
Describes the work related activities participants were involved with and gave them purpose and meaning in their lives (Cathy, Fred, Geraldine, Susanna, and Robert)

Managing Significant Life Events
Describes how participants deal with life events that their able-bodied peers are taught to deal with as well as events and experiences that no one is prepared for (death of a loved one, personal health); see Cathy, Natalie, Marni, Vanessa’s narrative

Being Seen but Not Heard
Individuals with disabilities are provided with what they need without people taking the time to listen to what they want or need
Interdependence
Refers to moving through life with support that is reciprocal and mutual (spouse, friends, attendants). See Cathy, Vanessa, and Natalie’s narrative.

Declines in physical health and well-being
Physical changes encountered that impose restriction on activities (ADL and IADL) and participation.

Adjusting to Physical Declines
Involves physical and psychosocial adjustment to changing abilities
There is an increasing need for assistance with ADL and IADL, and the social-psychological impact of not being able to engage in activities that he/she could do without assistance.

Intimate and Meaningful Relationships
This category captures the importance attached to having close relationships with friends and family, a spouse, or boyfriend/girlfriend and the positive impact on one’s life. It emphasizes the need for belongingness and intimacy

Barriers to managing physical Declines
Financial, and absence of health care services, programs and professionals experienced and trained in meeting the needs of people with impairments

Barriers to Independent Living
May include physical, and financial (impairment and disability)

Physical Impairment
A description about how one’s impairment impacts daily living. The attributes of his/her condition.

Social Challenges
Difficulties forming and maintaining meaningful relationships
Cultural & Social Influences
Forces that impact a person’s journey through life (negative and positive)

Familial Changes
Tracing changes in the structure and functioning of a family and its impact on the life of an individual. (Fred and Natalie’s narrative)

Health Problems- From Natalie’s narrative
Acute and chronic conditions, the experience of health care and rehabilitation, including the orientation of health care professionals, health care as a dehumanizing experience (Cathy, Marni, and Vanessa)

Making Sense of It all- Natalie & Cathy’s Narrative
Reflections on why things are the way they turned out to be.

Physical Challenges
Capture the experience of how impairment restricts a person in engaging in certain activities or can do them, but with some difficulty.

Personal Growth and Development- Natalie’s narrative
Certain life experiences contribute to a person is today

Confidence & Self-esteem (Natalie’s Narrative)
Attributes of a person’s self-identity and experiences and/or significant others contributing to this orientation. Even though certain relationships are time sensitive, they can have a positive/negative impact on personal growth and development (divorce, death of a loved one).

Doing it on My Own
Refers to dealing with significant life events without others, and knowledge, training, support and guidance when confronted. See Cathy, Natalie, Vanessa, and Geraldine’s narrative.
Living on My Own (Susanna’s narrative)
Describes a person’s living circumstances
Gaps- Why did Cathy begin school so late?

The Way things are
What is or isn’t taking place with respect to meeting the needs of people with disabilities, especially problems that have been identified in with different programs and services have not been resolved.

Managing Daily Living
Describes how individuals live on a day to day basis and the strategies they use to negotiate their lives, including everyday activities and those involved in their lives.

My life was going in a different direction (Natalie)
Personal and professional changes that alter the quality of interpersonal relationships

Moving On (Natalie)
Describes making changes that will enhance a person’s life(Vanessa, Geraldine, Cathy)

Personal Challenges
Difficulties that are encountered with impairment and/or disability that hinder daily living

Coping Strategies
This includes the psychosocial strategies individuals use to cope with their lives (including declines in functioning).

Having Meaning in my Life
Relationships, social and professional activities)
Appendix F

Glossary of Terms

Central Narrative: Defying the Odds
The narrative depicts the notion that individuals with congenital physical impairments possess an inner drive to create a life for themselves even when adversity is confronted on a regular basis. Adversity takes the form of little or no expectations for achievement, being defined by their disability, growing up without social, emotional, and instrumental support that contributes to developing a positive self-concept, and skills and abilities needed in adulthood. It also includes not having access to social and educational, and later, vocational, opportunities that support their development and overall well-being. They have the capacity to see the ability and potential within themselves that is not apparent to the outside world. Defiance represents the diverse ways in which they resist and challenge the dominant discourses that are used to regulate their lives

Meta-Narratives

Achieving a Sense of Belonging
This meta-narrative describes their lifelong struggle to feel loved and accepted within their family, and achieve inclusion and validation among their peers. Being accepted by others for who they are is important as it contributes to developing self-confidence, and a positive self-identity. It is fundamental to long-term adjustment to life with physical impairment.

Overcoming Being Seen but Not Heard
This meta-narrative describes how individuals with disabilities strive to overcome being treated as objects and like a child as they grow up. They grapple with always being provided with what they need without people taking the time to listen to what they want or need.

Striving for Self-Reliance/Becoming Self-Reliant
- The absence of support, encouragement, and a life plan forced all participants to take control of their lives by creating their own lives
- Breaking through and down barriers
- Taking control is mediated by contextual forces including not having needs met within the family, living in emotionally and physically abusive environments

Peaks & Valleys
Represents the meta-narrative that describes the trajectory of growing up and growing older with a physical impairment

Agency
Describes a person who acts on his/her own behalf to change circumstances he/she is unsatisfied with
Aging with a disability
Depicts the experience of individuals with physical impairments having worked so hard during childhood and adolescences to achieve functional independence so they can participate in mainstream life, including educational, vocational and social activities, only to reach adulthood and find themselves slowing down, overcoming by fatigue, and declines in their abilities to activities of daily living, that was easier in the past. Some individuals who could walk independently when they were young felt as though they over stressed their bodies because there was so much pressure to walk, because using a wheelchair was considered a sign of weakness. Consequently, they felt that being able to use a wheelchair would have enabled them to preserve their overall physical strength and well-being longer so they could maintain their independence. It seems that they were guided by the philosophy that states “use it or lose it”. In fact many of these individuals find themselves overusing their bodies which often coincide with other strains and pains which may endure after a person’s ability to walk ceases, which has been the experience of many individuals living with CP.

The impact of aging with a disability is demonstrated by a 61 year old and a 36 year old woman who both find their lives significantly compromised by the functional declines they have experienced. The functional limitations they both encountered govern their personal, social and professional pursuits. For example, Denise (36), completed college but was unable to pursue are career in her field of training because there weren’t jobs that could accommodate a person in a wheelchair, and it was difficult to pursue another vocation because it was difficult to achieve a balance between managing her fatigue, getting the rest she needs, engaging in her ADL, and commuting to and from training/work in a reasonable amount of time. Gerry (61), completed college for ECE which she thoroughly enjoyed, and had a short career due to fatigue and physical decline.

For these individuals, participation is dictated by fatigue and the condition of the body. Activities (ADL and leisure) that could once be completed in a relatively short period of time, now take more effort and a longer time period that is usually followed fatigue or exhaustion (e.g., once being able to get dressed in a half hour and now taking an hour and a half to two hours, or participating in a leisure activity that enjoyable, now causes exhaustion {i.e. baking}).

Bio-power
Refers to the knowledge, practices and technologies that are used in the management and transformation of subjects and bodies to conform to societal standards of behavior; Engaging in suitable behaviors that support work productivity and increasing the wealth and resources of their communities

Changes in time and space
Refers to the changes in roles and responsibilities, as well as experiences change over time as they grow up and grow older
Defiance
Resistance that participants and sometimes their parents engaged in to recast discourses, cultural beliefs, and practices that is attached to disability

Disability
Refers to the social and environmental barriers that impede the participation of individuals with physical impairments in mainstream life

Discourse
Represents the language and patterns of thought that are associated with different institutions and bring meaning to the situations and subjects they encounter

Governmentality
Describes the practices, institutions and discourses that are used in the management and/surveillance of individuals who deviate from the norm

Impairment
Refers to changes in the physical structure and functioning of the body

Life course perspective
A dynamic approach that encompasses multiple theories including sociology, human development, and aging highlighting how social, historical, and cultural contexts shape peoples lives. Narratives are storied ways of knowing and communicating that people use to organize events in their lives and make sense out of their experiences

No Where to Go
Captures the notion that there is both an absence of readiness or place for people with impairments in society. Examples include school (unable to support and meet learning needs, limited work opportunities, absence of health care and accessible housing)

Resistance
Refers to the diverse ways in which subjects challenge the practices and discourses that are used to regulate their lives

Self-Identity
Refers to who individuals perceive themselves through the others they encounter in their daily lives

Social-psychological Impact
Describe the emotional impact that the experience of disability (environmental barriers) has on the well-being of an individual

Subjectivity
Refers to the self-identity of an individual
Appendix G
Appendix H: Research Participant Attributes

Background Information Summary Table
Sample Size: 10 (4 men; 6 women)
Age Range: 26-70 years old

Table 2

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<td>Walk independently with/without mobility aides (cane; walker, crutches)</td>
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