DISABILITY, UNDEREMPLOYMENT AND SOCIAL CHANGE

by

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A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy

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Abstract

Informed by the disciplines of disability studies and interpretive sociology, and using the social model of disability and the collective identity model, this dissertation pursues an investigation of underemployment. Underemployment, conceptualized as the underutilized skills and knowledge of the employed and unemployed, occurs at higher levels amongst disabled persons than among non-disabled people (Canada, 2009). Semi-structured interviews with 14 underemployed disabled people were conducted, to investigate the experiences of disabled persons who worked in the fields of education, computer, healthcare, fitness, environment, travel, social work, government and non-government agencies. In addition, Canadian social policies were analyzed to address the research questions:

1) How do disabled workers understand and address experiences of underemployment?

2) How do organizations and social policies account for underemployment amongst disabled persons?

3) How can practices which acknowledge and enhance collective identity be used to address underemployment and advance the disability movement?

4) How can underemployment amongst disabled persons be addressed at the organizational level?
The texts of these narratives and Canadian social policies were analyzed using a critical interpretative textual analysis approach. The analysis demonstrates the depths of the negative consequences of high levels of underemployment resulting from structural, environmental and attitudinal barriers. Such consequences include lack of opportunities for recognition, compensation, promotion, accommodations, and career fulfillment, as well as poor mental, physical, emotional and social health. This research study is unique as it reveals the struggles that disabled persons experienced in work contexts, their narratives of resistance, and their recommendations for socio-political change to build more inclusive work environments.
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Dedication

Dedicated to all individuals and collective identities who are committed to social justice.
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<tr>
<td>ADA</td>
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<td>ALS</td>
<td>Amyotrophic Lateral Sclerosis</td>
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<td>AODA</td>
<td>Accessibility for Ontarians with Disabilities Act</td>
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<td>ARCT</td>
<td>Associate of the Royal Conservatory of Music</td>
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<td>ESL</td>
<td>English as a Second Language</td>
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<td>FSHD</td>
<td>Facioscapulohumeral Muscular Dystrophy</td>
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<td>ISAR</td>
<td>Integrated Accessibility Standards Regulation</td>
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<td>Ontario Human Rights Code</td>
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Chapter 1

Introduction

Underemployment is a chronic feature of the labour market which affects all segments of the population. It can be defined as “all dimensions of the wasted ability of the workforce, as they apply to either job holders or the unemployed” (Livingstone, 2004, p. 55). These dimensions point to the discrepancies between the requirements of a particular job, and the abilities and credentials of an individual. Often, the abilities and credentials exceed the requirements necessary to complete the tasks and responsibilities of a particular work role. In Canada, while one quarter (24.9%) of the working-age non-disabled population experienced underemployment, nearly half (46.5%) of disabled persons experienced the same circumstances (Canada, 2009). Disabled Canadians are currently underrepresented in the workforce. They are experiencing underemployment, whether it is in the form of unemployment, employment or involuntary part-time employment. Disabled Canadians also experience underemployment in the form of underutilized skills or unmet potential in the job market (Officer, 2009).

Annual income and life-time earnings can be affected by underemployment. The Canadian census comparative data from 2001 to 2006 reported that the average salary for working-age disabled adults has actually decreased by .3% ($30,490 in 2001 to $30,380 in 2006), while the working-age non-disabled adults received an increase of 7% (or over $2,400) in average salary from $35,670 in 2001 to $38,150 in 2006 (Canada, 2009). There was also a notable gender gap, whereby disabled women earned approximately $11,000 less than disabled men (Canada, 2009). These statistics only begin to reveal the negative impact of underemployment as well as the necessity for further analysis.
Officer (2009) was able to identify three distinct factors which can contribute to underemployment or inadequate employment among disabled workers – credential discrepancies, skill/performance inequities and subjective factors, such as conceptions of fit between the work and the job. A credential gap occurred when individuals’ credentials did not match their jobs and this was found in 34% of the disabled workers. About one-third (34%) reported a performance gap such that they were not able to use their skills or knowledge on the job, while nearly half (47%) reported that there was a subjective gap in their fit to the job and found limited options for a better one. These responses, as reported by Officer (2009), from disabled workers indicated that they faced limited opportunities to realize their potential. Consequently, reduced applications of their skills and abilities in the workplace resulted in barriers which hindered their career advancements.

In thinking about disability and underemployment, there seems to be an accepted or taken-for-granted attitude about the resultant annual incomes which indicates a gap in full-time work and annual salary between disabled persons and non-disabled persons. These facts about disabled Canadians may initially appear to be regularly occurring, however, the current state of underemployment amongst disabled persons may be deemed to be socially produced. What is accepted by society as natural, and generally unexamined, are employers’ human resource practices, employment policies, inaccessible workspaces, inaccessible transportation, and individual attitudes that devalue disability. Based on these prevailing circumstances, I would suggest that society in general, and organizations in particular, bear much of the responsibility for the ill effects of the untapped potential amongst disabled persons who choose to participate in paid work. Thus, underemployment that results from barriers which are produced by taken-for-granted attitudes, and both intentional and unintentional actions by organizations and policy makers need to be investigated.
To define the scope of this project, this research will focus on underemployment in paid work settings and includes review of relevant literature on disability and work. While the broad dimension of work includes paid and unpaid work consisting of volunteering in communities and household work which includes housework, family care and self-care (Eichler, 2008; Livingstone and Sawchuk, 2004), this study focused on paid work. This chapter will introduce conceptual frameworks which will offer perspectives on the areas of disability and work. Following the conceptual frameworks, I will then offer an overview of the subsequent chapters on literature review, data interpretations, and concluding discussions.

My perspective has been informed by the social model of disability (Oliver, 1990; UPIAS, 1976) which states that disability is a social phenomenon that includes social, political, cultural and architectural barriers which marginalize persons with impairments. The individual condition is the impairment and the disability is socially constructed, whereby “Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from society” (UPIAS, 1976, p. 14). While I will discuss the social model of disability (Oliver, 1990; UPIAS, 1976) in greater detail in the conceptual frameworks section of this chapter, I turn now to a brief explanation of how this model has influenced my understanding of disability as an identity issue of social and political importance.

People who use the social model of disability emphasise and examine the social, political, cultural, spatial, and architectural environments which can produce oppressive social relations. Such work also supports the necessity for both an “identity politics” and a “collective identity.” Identity politics is a critical component of the disability rights movement which has been influenced by the civil rights and women’s rights movements of the past, and aims to address the needs of an oppressed minority group (Barnatt, 2008; Shapiro, 1993). Identity politics focuses
on the possibilities for social change through the empowerment of disabled persons. In understanding the difference between the individual and a collective identity, Shakespeare (1996) wrote that “Identity therefore connects the social and the personal and involves the individual putting themselves in a collective context” (p. 99), and he goes on to say that he believes that there is a “symbiotic relationship between individual and collective” (p. 110). Oliver (1994), one of the originators of the social model of disability, emphasised the need for a collective identity for social change:

…individuals must transform themselves through collective action, not be transformed by others who know what’s best for them or what’s best for society. Empowerment is a collective process of transformation on which the powerless embark as part of the struggle to resist the oppression of others, as part of their demands to be included, and/or to articulate their own views of the world. (p. 16)

In relation to my current research study, the intersections of collective identity and the underemployment of disabled persons is interesting because I hope to find a new way of understanding underemployment, by exploring the causes of this taken-for-granted social phenomenon. Knowing that the Canadian census data depicts a gap which shows that underemployment exists at a higher rate amongst disabled persons than non-disabled persons, this research includes investigating work experiences amongst disabled persons, and consequently, seeking out ways to address this concern of underemployment amongst disabled persons. My interest is to examine organizational practices and social policies that contribute to this social phenomenon, and research ways to reduce this disparity between disabled and non-disabled persons who choose to seek paid employment. This project will take a critical sociological approach and will ultimately address the question of how to reduce the existence of underemployment among disabled persons. In recalling the definition of underemployment from
the opening paragraph to mean “all dimensions of the wasted ability of the workforce, as they apply to either job holders or the unemployed” (Livingstone, 2004, p. 55), this project will aim to uncover how abilities are being wasted or underutilized in paid employment and to show how this underemployment is related to the social structures that work to oppress disabled people.

This study on underemployment contributes to the scholarship of disability studies, work, human resources, education, gender studies, and public policies, and will result in a greater understanding of how disabled persons have been marginalized in work contexts and how to begin to address the normative, taken-for-granted behaviours of organizations, that perpetuate the devaluation and exclusion of disabled persons. The intersection of disability and underemployment is an area which requires further research and analysis unto itself. While answers to the causes and solutions of underemployment amongst disabled persons are the primary concern of this study, disability and underemployment interlocks with social issues including human rights, racism, gender equity, and poverty. From addressing social concerns to contributions to the research literature, this study entitled “Disability, Underemployment and Social Change” meaningfully connected with disabled persons, through the interview process, in order to value their lived experiences and to explore their collective narratives so that all people can re-imagine the potentials for work. Thus, in my investigation of underemployment, this research will explore social constructions of disability, social relationships to the individual and collective identity of disabled persons, and exclusionary practices which have resulted in the marginalization of disabled persons in the workforce. This research concludes by developing new perceptions of employment and underemployment to influence the workplace to better embrace a diverse workforce which includes both disabled and non-disabled persons.
With the current data on the labour force for disabled persons, there is a need to address their future prospects. There is growing interest (England, 2003; Fawcett, 2000; Kemper, Stolarick, Milway & Treviranus, 2010; Shah & Priestley, 2011; Williams, 2006) in the area of disability and work as a result of employment legislation and the issue of access to job opportunities, increasing the number of disabled persons in the labour force, and improving the economic conditions of disabled persons through paid employment. In order to pursue these various interests, this research project focuses on the current underemployment of disabled persons in the work force by investigating the following research questions:

1) How do disabled workers understand and address experiences of underemployment?
2) How do organizations and social policies account for underemployment amongst disabled persons?
3) How can practices which acknowledge and enhance collective identity be used to address underemployment and advance the disability movement?
4) How can underemployment amongst disabled persons be addressed at the organizational level?

Just before we turn to the conceptual frameworks, I will first address the use of language. In understanding disability, there is a need to differentiate the phrases “studying disability” and “disability studies” (Titchkosky and Michalko, 2009). The former aligns itself with the medical model, in that there is a knowledge base accorded to the studying of the conditions of impairment such as the causes, diagnoses, symptoms, etiologies, consequences, and prognoses. The study of disability belongs to the scientific realm of enquiry about individual conditions. In contrast, disability studies evolved from a multi-disciplinary approach including the fields of sociology, education and equity studies on how disability is being constructed, written/not written about, theorized, and talked about in various forms including education, culture, media,
Disability studies provide a direct critique on the individual/medical model, and allows for the identity of disabled persons to voice their own lived experiences. Titchkosky (2003a) emphasises that “disability is being regarded by some researchers as a place to speak and learn about the human condition” (p. 161). Additionally, in the field of disability studies, “at minimum, it conceives able-bodiedness as a culture in need of critical analysis and because it conceives the standpoint of disability as an opportunity to provoke such an enquiry” (Titchkosky, 2003a, p. 168). In an alignment with the social model of disability and disability studies, this paper will use the phrase “disabled persons” rather than “persons with disabilities” to refer to disabling social factors which pose barriers to individuals in their everyday encounters. When the word “impairments” is used, it will refer to an individual’s visible or invisible condition.

**Conceptual Frameworks**

Conceptual frameworks can offer a perspective on a particular social issue. In this section, I will discuss the conceptual frameworks which have shaped my understanding of disability and its linkages to underemployment. The conceptual frameworks which have informed my research questions are the social model of disability and the collective identity model, as opposed to an individual model of disability. Before detailing these models, I turn to a discussion of what it means to be individualized.

In the individual model of disability, a disabled person embodies a medical condition, a diseased body that needs to be diagnosed, treated, and returned to the normative order as stated by experts in medicine and education. The individual or the medical model focuses in on the body as that which disables individuals. In the individual model of disability, non-disabled
persons “see themselves in terms of ‘normality’ with a skewed medical view of health…disabled people are seen as ‘abnormal’, ‘deviant’, ‘people with special needs’, etc.” (Finkelstein, 1998, p. 30). This social construction of disability perceives disabled persons as ones who must be either cured or rehabilitated within the medical institutions or cared for through the welfare system.

These conceptions led to the rise in the medical professionals who studied disability as an individual or biomedical condition with the goals of either curing or rehabilititating the individual’s condition and bringing the person back to society to assume the normality of “abled-bodiedness” (Finkelstein, 1998, p. 32). When a cure or rehabilitation was not possible, then the prevailing social stance was to care for the individual through supports including family, institutions and welfare. The focus on function has affected eligibility criteria for programs such as workers’ compensation, social insurance or social assistance schemes. Workers’ compensation is closely linked to the individual biomedical model since it is based on the nature and degree of loss. Social assistance programming supports strategies for national efficiencies to reduce poverty since limited economic means can also lead to disease, crime, delinquency, and immorality resulting in higher health care and social service costs for the government. Canada’s social security system is also based on individual function which can pose barriers to access including complex rules, inequities due to a reliance on administrative discretion, and lack of integration and coordination between different levels of governments.

A critique of this model (Bickenbach, 1993; Prince, 2009) concerns the reduction of disablement to an economic problem which involves the supply side of the labour market and does not account for the demand side of the economic equation. Based on the individual model, the integration of disabled persons into the labour force will be to address economic and market needs, and not take into account the environmental barriers or Bickenbach’s now-outdated and
potentially problematic phrase of the “handicapping phenomena.” Both individual approaches – biomedical and functional – place the expertise of disability into the realm of assessments conducted by medical professionals; characterize disability as a biological condition; depict disability as a personal responsibility; focus on the individual as the unit of analysis for research and policy development; and identify the individual as the primary point of intervention (Rioux & Valentine, 2006). This greater understanding of the individual biomedical and functional models informs my research by setting the boundaries and separating out the rhetoric, practices, experiences and solutions which are focused on personal problems as opposed to social responsibilities.

In contrast, in the social model of disability (Oliver, 1990; UPIAS, 1976), the focus is on environmental conditions and systemic factors by addressing increased control over services and supports, and eliminating social, economic and physical barriers. The responsibility now belongs in the social realm with the need for individuals, organizations, and governments to eliminate barriers. According to the social model of disability, society sets up barriers that include attitudes, policies, physical facilities, technology, learning environments, work opportunities, and cultural representations. These barriers are disabling, and in this sense, disabilities reside outside of the individual. Thus, according to the social model of disability, the disabling barriers are outside of the individual who has a single or multiple impairments. The UPIAS’s (1976) statement, which is foundational for the social model of disability, emphasises the difference between disability and impairment:

In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairment by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. Thus we define impairment as lacking part or all of a limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary
social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical impairment is therefore a particular form of oppression. (p. 14)

Common characteristics of the evolved social model of disability assume that disability is not inherent in the individual; recognize impairment as a difference rather than an anomaly; prioritize changes to the political and social environments; identify the inclusion of disabled persons as a public responsibility; and focus on the social structure as the unit of analysis for research and policy purposes (Rioux & Valentine, 2006). In the evolution of the social model of disability, the rights approach is a consequence of an individual in relation to society whereby economic, social and political policies can be reformulated. By identifying disability as a rights approach, changes can lead to greater accessibility, independent living, equal benefits, protection of the law and improved quality of life. This concept can then better address the concerns of stigma, to meet the needs of disabled persons, and to acknowledge the person with an impairment or impairments. With this interactional approach and a move towards rights, an additional model needs to be engaged to not only identify how social policies are constructed, but more importantly, how these policies impact disabled persons. These policies can then begin to be changed through the work of collective identities. The following section will now turn to the collective identity model as theorized by Alberto Melucci (1996) to support a disability rights movement to influence change.

The social model of disability provides a framework to understand the location of disability and disabilities, and reveals the problems found in society. While the social model identifies “what is disability?” and “what are the barriers?” it is limited in working through the processes to dismantle the hegemonic understanding of disability as an individual condition which can be solved by the individual. Along with the social model of disability, the collective
identity model can provide a companion framework in theorizing about disability, underemployment and social change. According to Melucci (1996),

Collective identity is an interactive and shared definition produced by a number of individuals (or groups at a more complex level) concerning the orientations of their action and the field of opportunities and constraints in which action is to take place. (p. 77, italics in the original)

Thus, individuals or groups who have shared values can join together to work towards a common purpose. This common purpose will influence their actions and the contexts which are chosen for their collective activities. Collective identity is the formation of a group of participants who can then join together for “collective action.” According to Melucci (1996), collective action is “meaningful behaviour” and can be defined by

A set of social practices (i) involving simultaneously a number of individuals or groups, (ii) exhibiting similar morphological characteristics in contiguity of time and space, (iii) implying a social field of relationships and (iv) the capacity of the people involved of making sense of what they are doing. (p.18)

The three causes for the development of collective identities and collective actions can be identified as a need for solidarity, to address conflict and/or a breach of the limits within a social system (Melucci, 1996). There may be a need for individuals to come together in solidarity due to a crisis or a need for change whether it is to address employment issues, social behaviours or natural disasters. In contrast to crisis, conflict can emerge when there is an argument over limited resources. The limits of a social system which can also be referred to as “the limits of compatibility” (Melucci, 1996, p. 24) are the variations, elements and relations which maintain its structure. When the collective action addresses these limits, and when the action is the mobilization of the social actors, it is called a “social movement.” Specifically, according to Melucci, a social movement is characterized by solidarity, engagement in conflict to address
valued resources, and actions to challenge the power and limits of a system. Thus, the disability movement which arose in the United Kingdom (Oliver, 1990; UPIAS, 1976) is a critical example of a collective identity that worked towards removing barriers which prevented disabled persons from full participation in society. In Canada, the disability movement arose in the late 1960s as a result of a dissatisfaction of available disability services among disabled persons, with particular influences from the American independent living movement and the Swedish Self-Advocacy Movement (Rioux & Samson, 2006).

This time period marked the empowerment and politicization of disability activists and organizations to influence policies, laws, and programming at all levels, which began the paradigm shift from identifying disability barriers residing in the social environments rather than individual impairments. The American movement took aim at identifying and removing the barriers found in social attitudes, education, legal and architectural barriers. Individuals with impairments demanded greater control over the organization and management of their services. Within the Swedish movement, groups of individuals with intellectual disabilities formed to assert their rights regarding issues that concerned themselves.

Within the literature Oliver (1990) and Melucci (1996) are contemporaries, however, they have not cited each other’s scholarship. This research is the first time that these two scholars, both of whom are sociologists, have been brought together. Their common interest on collective identity and collective action to advance the disability rights movement from Oliver’s perspective and to advance social movements in general from Melucci’s vantage point allows for an original approach to the prevailing social challenge of underemployment. Melucci does not write explicitly about the disability rights movement, but his understanding of social movements in general and the related components of knowledge, practices, relationships and
communications have provided analytical tools necessary to reveal the possible intersections of disability, collective identity and underemployment and thus to begin to critique the causes of underemployment and identify actions towards full employment.

While compatibilities exist between the two conceptual frameworks offered by Oliver and Melucci, there are also incompatibilities or distinctions of note between them. The development of the social model of disability was informed by a Marxist (Marx, 1954) perspective which focused on the sociology of collective behaviours within an industrial age. Specifically, social classes and their respective behaviours were interpreted against the structures found within capitalist modes of production. The relationships between the collective behaviours and the social structures were the phenomena being theorized. However, Melucci (1996) questioned the existence of a collective behaviour as a “phenomenon without its own autonomy from structural ‘determinants’” (p.15), and aimed to study collective identity and behaviours, not as starting points or empirical data, but as a resultant phenomenon which requires investigation. In other words, Melucci sought answers to these questions: What is a collective identity? How does a collective identity come to exist? Consequently, Melucci problematizes the taken-for-granted formation of a collective identity or a “we” as a result of individuals coming together to form a group. Through the collective identity model, Melucci offers an analytical tool to understand the complexities in collective identity development, the orientations of unified actions, and the power relationships within group dynamics.

With respect to this research study on disability and underemployment, Oliver provides a conceptual framework that he has called the “social model of disability.” The social model of disability is designed to enable people to understand the relationship between collective identities and social barriers. In effect, Oliver posits it is social barriers that produce disabled people. In
contrast, Melucci provides a conceptual framework that I will use in order to investigate the formation and development of a Canadian disability community. Taken together, both models offer common directions, yet different perspectives, on possible ways to address the complexities of underemployment. Melucci can be understood as steeped in a liberal tradition and Oliver in a Marxist tradition and thus as somewhat incompatible theorists upon which to ground a research project. However, through my interest in how to understand the barriers faced by disabled people that contribute to their status as underemployment, I have used these theorists to address both disabling barriers and collective identity formation necessary to begin to address such barriers.

Advancing Disability Rights, Equity and Citizenship

From the perspective of the disability rights movement, the social model of disability has been widely adopted as a conceptual framework which explains the marginalization of disabled persons. According to the social model of disability, society sets up barriers that include attitudes, policies, physical facilities, technology, learning environments, work opportunities, and cultural representations, however, it does not explain explicitly the role of the disabled person in the quest for social change. A collective identity can provide the knowledge, experience and context to build a foundation which supports social change to more readily reduce barriers for disabled persons in the future. In his thinking about collective identity, Oliver (1994) stated that:

it is necessary for oppressed groups to organise collectively to confront oppression. That inevitably means confrontation and conflict with powerful groups, interests and structures for there are few examples in human history of people willingly giving up power to others (p. 18)

In this passage, Oliver is calling disabled persons to unite, to resist the dominant ideology of non-disabled worldviews and disabling social structures which can result in marginalization and
oppression. To advance disability rights, equity and citizenship, the investigation of collective identity and the social model of disability can move discussions from being oppressed or marginalized persons to one which envisions the agency of disabled persons through a rights approach.

Furthermore, the social model of disability has been critiqued for having a disembodied view of disability, rather than an “embodied experience of impairment as an intercorporeal phenomenon” (Paterson & Hughes, 1999, p. 608). As an intercorporeal phenomenon, I consider the relationships between disabled and non-disabled persons. This recognition of embodiment is integral to the collective identity theory (Melucci, 1996) within the disability rights movement and the disabled community’s relations to society. This gap in understanding has resulted in researchers offering alternative theories to supplement the social model of disability. For example, Peters, Gabel and Symeonidou, (2009) argued for a need for a collective consciousness and common vision as vital components in the acts of resistance. They recommend a paradigm shift from disability as constructed by society to one that constitutes disability as a complex matrix of language, practices, body effects, disposition and aspirations. This matrix also points to the necessity of an embodied approach to collective identity formation. This paradigm of disability is better positioned to support transformation and social change rather than just explaining marginalization and/or oppression as in the social model of disability. This study supports the shift away from the original social model of disability from the 1970s towards the need for a revised 21st century model when social change is the sought after result.

Another researcher, Putnam (2005) also supports the need for a collective identity model to influence social change, and theorized the potential of a political disability identity which is comprised of different domains: self-worth, pride, discrimination, common cause, policy alternative, and engagement in political action. Self-worth is the belief that a disabled person has
the same value and productive contribution to society as a non-disabled person. Pride is the belief that impairment is part of the continuum of human difference, and not inherently negative. Discrimination is the belief that disabled persons are negatively stereotyped and treated differently compared to non-disabled persons. Common cause is the belief that disabled persons share common experiences and that the negative experiences could be modified through a common political agenda. Policy alternatives are the beliefs that opportunities to reduce or remove barriers can be influenced by public policy. The final domain which is engagement in political action is the belief that disabled persons can form a political constituency group, and their engagement in political action can result in effective policy change. All six domains support the collective identity model such that common cause, policy alternatives and engagement in political action can facilitate the development of a network of collective actors within and external to themselves. Specifically, the domains of self-worth, pride and discrimination as described by Putnam (2005) support Melucci’s (1996) argument for emotional investment as an integral factor in the emergence of a collective identity.

The development of social policies needs to be first, influenced by disabled persons, and second, to align with the social model of disability – the rights approach - to provide disabled persons opportunities to voice their lived experiences in the workplace and society to dismantle the hegemony of an ableist society.

Disabled people’s history needs to be viewed as part of an increasing struggle to establish and maintain positive self-identities. It is about developing self-respect, self-confidence and solidarity. This is part of their struggle for rights, choices and participation in society. (Barton, 1998, p. 58)

In reflecting upon Barton’s imperative on identity and change, a disability activist may choose to identify as a blind person or as belonging to the deaf community to assert the importance of the
impairment as an integral part of his or her self-identity. This act of naming encourages an identity politics which supports the disability rights movement. Appropriating the words which signify differently abled persons is an intentional act of resistance and of pride (Zola, 1993). Naming or self-identifying oneself can be an act of resistance against the pervasive negative associations with phrases such as the “challenged,” “afflicted with,” “suffering from,” “confined to a wheelchair,” or the “crippled.” Taking action also minimizes the “stigma [that] comes about from a process of generalizing from a single experience, people are treated categorically rather than individually and are devalued in the process” (Zola, 1993, p. 169). Pride comes from the insider knowledge gained from being different and having the embodied experience of living with an impairment.

In his critique of the absent citizens in relation to disabled persons, Prince (2009) calls for a shift in activism from stigma to identity politics which means “altering self- and societal-conceptions of people with disabilities from passive, deviant, and powerless to positive, self-created conceptions for themselves” (p. 121). This summation can be based on his earlier findings that participation amongst non-governmental actors can influence government collaborations based on two conditions: first, the nature of the policy is a public concern amongst governments, and second, there is a “readily identifiable client group organized in the policy sector” (Prince, 2001, p. 811). Thus, organizations which have disabled representatives to work with and for the disability community are necessary in the interactions with various levels of government to influence the planning, implementing, and evaluating of social policies related to the disability rights agenda.

To further a collective identity model which supports identity politics, there is a need for capacity building which includes reviewing and redesigning services and programs so that they
more fully respond to and include disabled persons and their families in decision making; contributing to policy discussions, program developments and reviews; and building a new generation of leaders for the disability community. Government policies have stalled and the disability rights movement can be strengthened to advance the agenda for disabled persons. The common understandings of the disability rights movement are to work against discrimination based on impairment, to feel the shared experience of exclusion, and to advocate for accommodations to attain a barrier-free society (Vanhalta, 2009). The collaboration of various impairment-specific and cross-disability organizations can strengthen the potential of the disability community. The value of solidarity and a collective identity is supported in the following passage:

Notable features of the disability movement today are, first, a solidarity expressed by honouring histories, leaving no one behind, and coming together around shared reform priorities; and second, a belief in civic engagement as a crucial way for breathing life into the vision of access and inclusion. (Prince, 2009, p. 207)

Two key features of the collective identity model (Melucci, 1996) are relationships and emotions. The relationships are both internal and external and result in interactions, influences, negotiations and decision-making within collective identities. Emotional investment is a necessity to strengthen the collective entity of disabled citizens. These key features of Melucci’s collective identity model support Prince’s recommendations for a new paradigm of citizenship engagement which may result in the installation of new government policies, the cultivation of working relationships between government and citizens, and recognizing disabled individuals in democratic polices and policy making.
Overview of Chapters

In the next chapter, *Chapter 2 Literature Review*, I reveal the social constructions of disability within neo-liberal work contexts, historically and currently, which have resulted in the marginalization of disabled persons in the workforce. I discuss disability, as conceptualized through the social model of disability, where it is understood that the problem faced by disabled people are the barriers found in the social environment such as attitudes, facilities, communications, policies, transportation and technology. Thus, the problem of disability does not derive from individual impairments. By applying the social model of disability, I aim to shift attitudes to make changes to the disabling context, rather than focusing on adaptations by the disabled person. An investigation of the historical and contemporary contexts informed the development of the theme of this dissertation, the overarching research questions and the specific interview enquiries.

In *Chapter 3 Researching Underemployment*, I detail the methods used in this research study. These methods aimed at investigating the complexities of disability, underemployment and social change. Prior to embarking on the study, I revealed my role and social identity in the research process, which is a critical action particularly when I embarked on interviews with participants. Considerations for a research ethics culture permeated from the development of the project to the recruitment and interview of the participants, and through the interpretation of the data. The data generated from the interview process were based on transcribed interviews, and were mediated by my interpretation of the meaning of the participants’ narratives as they revealed the complexities of underemployment and how they related to one another through their similarities, themes and differences. A critical interpretative textual analysis (Titchkosky, 2007; Smith, 1999), informed by disability studies, sociology and phenomenology, was my key method for data analysis and interpretation of the text from the transcribed interviews and social policies.
In Chapter 4 Developing Definitions of Underemployment, I provide an initial definition for underemployment which was shared with the interviewees as a starting place for a dialogue on their lived experiences. Through their interviews and through a critical interpretative textual analysis of the data, the theme of “waste” became apparent in the situation of underemployment amongst disabled persons. My analysis of the data resulted in an emergent definition which expands from the initial definition, and yet is still only an opening for a dialogue or conversation to offer a deeper understanding of the experiences and the impact of underemployment. The various work contexts have set up barriers for these interviewees in their full participation in the workforce. By limiting their job and career potentials, these individuals are being underemployed in the workforce and limited in their inclusion in society.

In Chapter 5 Stories of Disability and Underemployment, I relay the narratives of the interviewees who bear witnesses to their underemployment situations. By re-telling their stories, I share their voices and experiences with readers and employers who can potentially learn from these story tellers. Stories of disability and underemployment relay insights and emotions to alert readers, employers, policy makers and the public to the dire concerns of food, shelter and poverty, and circumstances of low self-esteem and poor career achievements. These stories which convey the lived experiences of the underemployed are told between people – with the hopes that a greater understanding can provoke actions towards social change. In the critical interpretive textual analysis of the interviews, evidence of the attitudinal, environmental and structural barriers was revealed.

In Chapter 6 Collective Identity and Social Policies, I explore the concept and existence of collective identity. A collective identity can support a set of behaviours to address the limits of the social system. Through solidarity, engagement in conflict and recognition of society’s
constraints, disabled persons can form a collective identity to act in meaningful ways to set in motion a social movement. In support of the social model of disability, this social movement then is termed the “disability rights movement” with a goal to dismantle the disabling barriers found in society. In this chapter, I address the ways in which the interviewees spoke of their roles in their public actions to advance the disability rights movement. I also deconstruct the hegemonic understandings of Canadian social policies to provide the backdrop for the past and current context for disabled employees and their relationships with their potential and current employers. In writing this chapter, I raise the possibilities of how disabled persons can be embraced as valued members of society. Governments at all levels need to consider creating and implementing policies, by engaging disabled persons to participate in related decision making processes. Thus, this chapter offers readers the opportunities to explore collective identity as it is experienced by the interviewees and how it is influenced by Canadian social policies.

In Chapter 7 Resisting Underemployment, I consider novel ways of thinking and actions which can be implemented to reduce or eliminate structural, environmental and attitudinal barriers. Amongst the structural barriers, attention and action must be paid to legislation, funding, entrepreneurship, incentives and awards. To address the environmental barriers, accessibility is required within transportation, the built environment and workplace ergonomics. Attitudinal changes are needed within workplaces throughout the different stages of employment ranging from recruitment, training, accommodations, networking, and leadership, and more broadly in cultural representations. By discussing the lived experiences of the interviewees, I identify possible actions and their accompanying benefits to address underemployment.

In Chapter 8 Final Reflections, as a concluding chapter, I reflect upon the research and journey which has taken place for this dissertation and how this new knowledge adds to the
scholarly literature. I offer this dissertation as an invitation for more dialogue on the ongoing challenges concerning disability, underemployment and social change. Ongoing dialogue can activate applications of this research and provoke thoughts on new directions for further investigation.

**Conclusion**

This chapter introduced the individual model of disability, social model of disability and collective identity model which informs the investigation of the prevalence of underemployment among disabled persons. The subsequent chapters will each illuminate a particular facet of this research study with the intent to address the research questions and begins to offer recommendations for social change. These research questions are:

1) How do disabled workers understand and address experiences of underemployment?

2) How do organizations and social policies account for underemployment amongst disabled persons?

3) How can practices which acknowledge and enhance collective identity be used to address underemployment and advance the disability movement?

4) How can underemployment amongst disabled persons be addressed at the organizational level?

These questions are important to ask and answer since underemployment results in negative consequences including financial burdens for disabled persons. Underemployment remains higher amongst disabled persons compared to non-disabled persons. I will now proceed to explore the meaning of disability, work and underemployment within the neo-liberal paradigm of organizations and society.
Chapter 2

Literature Review

Social perspectives on disability and work can be used in order to analyze the pervasive neo-liberal paradigm of work and its impact on disabled persons. This chapter reveals the changing nature of work as a consequence of capitalism. Specifically, the causes of underemployment within organizations will be revealed through a review of the literature. The review of recent studies subsequently informed the development of questions which were included in the interviews of this research study. This chapter provides the background information for this research project, and identifies gaps in the literature and the necessity for a new perspective and a detailed investigation on disability and underemployment.

Neo-liberalism, Capitalism and the Productive Worker

Neo-liberalism, as a predominant paradigm of work, focuses on profits as the main goal of an organization. To compete on the local, national and global markets, net profits are derived when revenues exceed expenses. Profits are maximized when expenses are consistently kept lower than revenues. On the human resources side of this economic model, profits are maximized through a greater intensification of work; specifically, workers are directed to work harder or longer hours for a set rate of pay. However, this profit oriented goal of an organization takes a toll on the human aspects of the organization and has been doing so ever since the early 19th century. The arrival of the industrial society in the 19th century had a profound effect on social relations and the value placed on the individual conceived as a productive unit and productive entity (Davis, 2002; Oliver, 1993). While earlier times, in an agrarian culture, allowed
for a slower, self-determined pace of work within a family unit, the factory work of the industrial age demanded “able” individuals to come under its required discipline and levels of production. However, the rise of capitalism resulted in “the new mechanism of controlling economically unproductive people” (Oliver, 1993, p. 51) by sending disabled persons to workhouses, institutions or asylums. Abberley (1997) clarifies the relationship between disabled persons and work in a capitalistic society:

Marx’s and Engel’s description of capitalism captures the way in which capitalism creates both disabled people and a concept of disability as the negative of the normal worker. It is labour power which workers sell to capitalists for a money-wage, and impaired labour-power that characterises and accounts for the specific character of disablement under capitalism. (p. 31)

The foundation of capitalism relies on productive labour which can generate surplus value or profit for the capitalists. Subsequently, a disabled individual may not be able to produce the surplus value to serve the capitalist’s desires and capitalism has done little to enable structures of production that allow for disabled workers. The intensification of the working day did not provide the flexibility for individuals with impairments to reach their potential to provide surplus value in a capitalist mode of production. Furthermore, machinery became a widespread adjunct to factories to speed up production which intensified the work despite some changes to the workday, which included a shorter working day.

This neo-liberal framing of production, and thus, the economy is aligned with the medical or individual model of disability since it focuses on productive labour and how each person can produce surplus value. If a person had an impairment, the prevailing options were to become rehabilitated, cured or segregated. In contrast, the social model of disability offers a perspective to critique society’s acceptance of the dominance of capitalism (Abberley, 1998; Barnes & Mercer, 2005; Marx, 1954; Marx and Engels, 2002; Oliver, 1993). Disability results from
capitalism’s exploitation of labour, the reproduction of unemployment, and reduction of the collective power of labour by pitting the employed against the unemployed, and the more fully employed against the less fully employed and, even, the wage earner against the volunteer. Consequently, disability becomes reinforced as an individual problem, rather than a social one, as individuals, organizations and society in general adhere to the normative acceptance of capitalism as a prevailing paradigm of working with and relating to disabled persons.

In reflecting back on the narrow focus of a neo-liberal economic theory which presupposes that an individual’s contribution to society is through productive labour and surplus value, work needs to be re-considered. Work is currently being re-conceptualized by sociologists (Eichler, 2008; Livingstone & Sawchuk, 2004), in that value should be placed on paid and unpaid work. The broader definition of work includes paid, volunteer, and household work which includes housework, family care and self-care (Eichler, 2008; Livingstone & Sawchuk, 2004). These recent conceptions of work support Abberley’s (1997) earlier observations that there seems to be an identity of who you are with the work you do which transcends capitalism and socialism into the concrete utopia of the future to constitute a key element of humanity, and a key need for human beings in all eras. (p. 32)

A broader understanding of work amongst individuals, families, employers, and social support organizations can provide the shifts in paradigm from a social construction of disability which is merely based on economics and capitalism to one that facilitates opportunities for disabled persons to choose work according to their own terms, and to assert their “rights of human ‘being’ against the universalization of the human ‘doing’” (Abberley, 1997, p. 39). Disabled persons can then be considered valuable members of society whether they choose either paid or unpaid work, or a combination which best suits their interests and potential, and facilitate their rights to be
citizens within their communities. Prince (2009) critiques the prevalence of “absent citizens” within the Canadian context in general and the employment scenarios in particular. Underemployment amongst disabled Canadians remains an urgent concern which needs to be questioned and requires further investigation. Understanding that there are still many existing barriers, disability studies critiques and calls for changes to work and society that include changes to the form of interpersonal encounters, organizational practices, and political frameworks. The changing nature of work and how disabled workers can be enabled in the long term needs to be questioned. Theorizing about new work paradigms can include “the struggle for less intensive and extensive working conditions” (Roulstone, 2002, p. 638). While organizations have seen the rise in the use of technology within various work contexts, some of which can increase accessibility and support a more inclusive workplace, it can, however, like the machinery of the industrial age, continue to intensify the workday without regard for the human being at work. Furthermore, globalization, with competition amongst multi-national companies, can exacerbate the work scenarios amongst disabled persons, as neo-liberal governments shift social responsibility from the public system to the private individuals. Social policies which are connected to economic policies may lead to budget constraints and privatization, resulting in increased marginalization and exclusion worldwide (Rioux & Samson, 2006).

Thus, as the neo-liberal economic model of production locates disability in the individual and when the worker cannot produce surplus value or a profit, this person is then deemed to contribute less to the capitalistic goals of an organization. This understanding of production does not allow flexibility for the differences amongst disabled persons, and is in contrast to the social model of disability which locates barriers within the social, not in the individual. Barriers are not internal to individuals but external, such as work-place attitudes, machinery, facilities,
technology, and transportation. Rather than valuing a person solely on the quantity of their productive labour, work needs to be re-conceptualized to include paid and unpaid work. Expanding what is considered work or valued work will occasion a better chance of providing disabled persons with inclusive and optimum environments. More opportunities need to be made available as rights offered to all citizens of society, in this case, the Canadian work contexts.

**Contemporary Perspectives on Underemployment**

In this section, I will investigate the literature that discusses the causes of underemployment in the employed workforce. The literature on the employment-job gap can provide information and the language for underemployment amongst non-disabled and disabled persons. In researching the employment-job gap, Livingstone (2004) identified six dimensions of underemployment. They are the talent use gap, structural unemployment, involuntary reduced employment, credential gap and subjective underemployment, all of which will be discussed subsequently.

First, Livingstone’s research suggests that the talents of large numbers of the population, especially youth from poorer social-economic backgrounds, are being wasted in the school systems which result in inequitable job opportunities. This phenomenon, which the researcher has identified as the “talent use gap” (Livingstone, 2004, p. 56), results from a difference in educational attainments of higher and lower social classes. Under-representation at higher educational levels is found among lower socio-economic groups and other marginalized groups including women, visible minorities and disabled persons. This talent gap results from the compound effects of discrimination by class, race, sex and gender attributes such that in the most recent age group that has had time to complete their schooling, nearly 60 percent of white males from professional family origins have obtained a degree while only 7 percent of black females
with fathers who were industrial workers have done so, a ratio of more than eight to one (Livingstone, 2004, p. 59).

Second, structural underemployment is a concept that indicates that there is an excess number of job seekers relative to available jobs, resulting in an inadequate supply of jobs for the number of people who choose to seek paid work. Factors affecting structural unemployment include machines which can eliminate labour intensive jobs, demographic shifts which allow older workers to have longer careers since mandatory retirement is no longer legislated, and a continuing increase in immigrant workers. With regards to disabled persons who receive disability benefits, they are limited to the number of allowable work hours without losing their disability support income.

Third, involuntary reduced employment refers to work which can be found in non-standard or contingency jobs such as part-time jobs. Part-time employment, which averages about 15 hours per week, is often a form of underemployment since 25%-90% of these workers from North American and European surveys have indicated that they would prefer full-time employment (Livingstone, 2004, p. 70). While the demographics of part-time workers are students who need to combine work with studies or women who combine work with childcare and/or eldercare, many of the surveyed participants would prefer full-time work. Additionally, temporary full-time work such as short-term contracts, casual or piecework also falls into the category of underemployment. Characteristics of part-time jobs or temporary full-time positions often consist of lack of job security and poor compensation. Underemployment is prevalent amongst such jobs since employees rarely have the opportunities to use their full set of knowledge and skills.
Fourth, the credential gap results from the mismatch of educational attainments of workers to the actual credential requirements for entry into jobs. According to McDowell (1991), about 20% of the labour force is overqualified or underemployed, while 20% are under qualified. A surplus of qualified workers exists at all credential levels from high school to university. Similarly, a review of a 14 year period from 1982–1996 shows that underemployment persists amongst 20% of the Ontario labour force (Livingstone, 2004). The trend shows an increase in underemployment in the Canadian non-disabled population which sits at 24.9% (Canada, 2009).

Fifth, underemployment exists as a “performance gap” when employees who have attained certain levels of skill do not have opportunities to apply these same skills or requirements on the job. In Ontario, 40-60% of underemployment amongst employed individuals results from a performance gap and has continued to increase in the past 25 years (Livingstone, 2004, p. 82). The trend indicates that the educational attainments are continuing to increase beyond the actual requirements of jobs in North America. Further to the general statistics, Livingstone also identifies that underemployment is common among workers between the ages of 18-24 (about 60% of this age bracket), university graduates, visible minority employees, and women. However, this study does not identify the prevalence of underemployment due to a performance gap amongst disabled workers, and thus there is a need for further investigation.

Finally, the sixth point involves “subjective underemployment” which is based on perceptions of employees’ fit to their jobs, their feelings of opportunity to use skills on the job, and their sense of entitlement for a better job. Research has found that 40% of the Ontario labour force indicated that they had skills which they would like to use on the job but currently don’t (Livingstone, 2004, p. 88). These sentiments are particularly common among highly educated,
younger respondents; however, this perception was also echoed among a third of the older respondents with elementary school education. As for entitlement to better jobs, these sentiments were high amongst a majority of the 18-24 year old respondents, women, visible minorities, and employees who held lower occupational class jobs.

These six discrepancies which are used by Livingstone (2004) in order to characterize the education-job gap amongst non-disabled persons provide the preliminary set of questions or concerns for further investigation, and thus supplies me with the language to support my research of the education-job gap amongst disabled persons. Interview questions which were developed probed the interviewees’ understanding of underemployment and the six dimensions of underemployment, and these enquiries included: What does underemployment mean to you? Could you provide a couple of examples or stories? Based on these examples, how did these scenarios make you feel? What did you do about these situations? What have you experienced in terms of actions, practices, and policies to address underemployment in your workplace? What opportunities have you missed that may somehow be connected to your impairment or disability? Do you understand this as a form of underemployment? Why/why not?

Additionally, themes which have emerged from the dimension of subjective underemployment can provide further insights into the existing scholarship. Interviewees were asked about their feelings of subjective underemployment which Livingstone (2004) has identified as “perceptions of the fit of your qualifications to the job; feelings of opportunity to use your knowledge and skills on the job; and sense of entitlement to a better job” (p.85, italics in the original). According to Livingstone (2004), the rate of subjective underemployment ranges between 20%-40% amongst the non-disabled employed workforce, and higher amongst the highly educated and younger workers than older workers who have elementary schooling (p. 88,
31

95). There is yet one more way that Livingstone’s work guided this research project. Following the interviews, the transcribed data were reviewed and analyzed according to the six categories of underemployment. Thus, these categories were used so that my research could begin to provide an understanding of underemployment experiences among disabled persons, and thus, answers the initial research questions on the roles and impact of organizations, social policies and collective identities. I turn now to a consideration of other critical sociological work being done in the area of underemployment.

Disabled persons are often underemployed as a result of social discriminations which results in less opportunities for promotions and decision making. England (2003), who studied disabled bank employees, found that “social justice is at least as much about the quality of the social relationships as it is about statistical effects” (p. 445). Thus, organizations need to think, develop and monitor strategies to enhance the everyday informal social relations with employees in order to attempt to ensure that work environments are inclusive; inclusivity and equity cannot solely be measured by the number of employees hired from an underrepresented group. In alignment with the social model of disability, change needs to be steered away from the individual and towards the involvement of organizations to reduce barriers to the inclusion of disabled workers.

Based on individual interviews and focus groups, some research has shown that disabled Canadians identified discrimination and labelling as primary barriers to success in the labour force (Shier, Graham & Jones, 2009). Other research suggests that less than 10% of disabled persons said that they were included in organizational decision making processes (Officer, 2009). Disabled bank employees cited many strategies to optimize their employment engagement which included working from their strengths, asking for accommodations, finding good managers,
building webs of support, finding ways to keep up, and keeping work light through humour (Church et al, 2008). While these strategies do not directly address the education-job gap in finding the best job for the education level of a disabled person, these recommendations could pave the way for a more inclusive workplace at the same time that changes are made to the organizational environments which will be addressed in the next section.

In relation to the current research project, information on the education-job gap guided the development of the interview questions and support an understanding of the data gathered from the interviews. During data analysis of the interviews, the stories of the interviewees were analyzed according to the dimensions of underemployment and how these experiences have been influenced by organizations and their social environments. The categories of the different types of education-job gap provided an analytical tool and the language, as a starting place to build upon and expand from, and to gain the insights to relate the research project back to the larger body of scholarship on underemployment.

In a broad survey of over 170,000 participants between 1979–1994 in the U.S.A. (Dooley & Prause, 2004), underemployment or inadequate employment was found to have health implications similar to unemployment which led to incidences of low self-esteem, maladaptive responses such as increased alcohol consumption and dependency, increased occurrences of depression, and a higher prevalence of maternal stress which resulted in low birth weight babies. In hypothesizing the mediators of these possible health conditions as a consequence of underemployment, Dooley and Prause (2004) have indicated that a decline in income can reduce the workers’ personal agency to plan and affect a healthy lifestyle, and trigger other stressful life events such as separations or divorces. Furthermore, a workers’ job insecurity can impact their perception and optimism about the future in general and can potentially affect mental health
which are linked to the psychosocial functions of employment (Dooley and Prause, 2004). Thus, loss of status, time structuring and collective work towards a common purpose resulting from unemployment or underemployment can lead to mental health consequences. To investigate the impact of underemployment on health, some probing interview questions of my study included: Has underemployment influenced your health? Yes or no? If yes, how has underemployment impacted your health in any way (i.e. physically, mentally, emotionally, socially)? How have you addressed these health concerns? With underemployment and health being linked in previous research, the answers to these health related questions provided current understandings of the impact of underemployment on health, and strengthened the need for social change, in the desire to seek out integrated broad and specific solutions for the well-being of disabled persons, including the physical, mental, social, emotional and economic components of the self. Therefore, by making use of such probing questions, my aim is to begin to answer the research question which explores the impact of underemployment: How do disabled workers understand and address experiences of underemployment?

Organizational Environments

A review of the literature on organizations and their relationship to disabled persons also guided my development of the interview questions and the understanding of the resultant data from the transcribed interviews. My current research project investigated the depth and breadth of this impact of underemployment on disabled persons. This section will highlight explanations for limited advancement opportunities.

Some research suggests that non-disabled employers were reluctant to recommend a disabled employee for promotion if they expected a low performance as a result of the employee’s impairment (Collella & Varma, 1999). Potentially, the stereotypes based on the
impairment and the job-fit can impede a disabled employee from receiving opportunities for feedback, training and promotion. The researchers, Collella and Varma, concluded that disabled persons may progress through work organizations more slowly than their non-disabled counterparts in similar jobs, or not at all. Often jobs had limited advancement opportunities, such as call centre or clerical jobs.

A number of organizational factors such as token status, “out-group” status, lack of role models, lack of mentors, and lack of critical feedback deterred advancement opportunities (Jones, 1997; Naraine & Lindsay, 2011). In addition, these factors can influence the employers and co-workers’ attitudes towards disabled persons. Token status individuals are treated as representatives of a particular category and as little else. Often individuals with a token status do not have access to the informal networks of an organization. Without access to informal networks, opportunities for meeting important contacts and socializing are missed. In addition to being the numerically rare, “out-group” status may also be felt by disabled persons. While “in-group” status individuals “enjoy the sponsorship, role modelling, and mentoring of a supervisor and are assigned more challenging job assignments, are allowed job discretion, and participate in decision making” (Jones, 1997, p. 64), in contrast, “out-group” members are not able to access these opportunities. A lack of role models in the workplace limits the ability for disabled persons to learn about effective behaviours in the workplace. This lack of role models also translates into a lack of mentors.

Even when there are potentially non-disabled mentors who can be recruited for the role, mentors tend to want to choose mentees for high visibility projects. Often, disabled persons are not recruited by their supervisors for key assignments because co-workers, or even mentors fear the higher risk of failure; the prevalent belief was that any failure by the disabled mentee could
reflect poorly on the mentor (Collella & Varma, 1999; Magill-Evans, Galambos, Darrah & Nickerson, 2008). Without these high visibility opportunities to showcase their knowledge and skills, disabled persons are often passed over when career advancement opportunities arise. Even when disabled persons attained senior management positions, they still found barriers to learning, risk-taking, decision-making and stretch assignments and thus, in realizing their own potential (Wilson-Kovacs, Ryan, Haslam & Rabinovich, 2008). This study attributed these barriers to a paternalistic working environment which rarely recognizes accomplishments or provides constructive feedback on performance and consequently, their absence limits opportunities to improve performance for future promotions. “Moreover, this culture has an uninformed and unsupportive attitude to disability, which is not only detrimental to career progression but also conducive to discrimination and hostility” (Wilson-Kovacs et al., 2008, p. 714). Discrimination is exacerbated when training opportunities are not made available to disabled persons (Balser, 2002).

Different societal responses to impairments can affect work situations. Some researchers suggest that one predictor of employment is the type of impairment individuals have, for example, developmental motor impairments such as spina bifida or cerebral palsy. People with these impairments felt stuck with employment options and also felt the limited opportunities in advancement (Magill-Evans et al., 2008). Gender was a significant variable, with females experiencing more underemployment. In another study which investigated women with multiple sclerosis (Dyck & Jongbloed, 2000), work conditions which support continuous employment included the ability to take sick time when needed, an understanding employer and supervisor, understanding colleagues, flexible hours or reduced work hours. Adelman and Vogel (1993) found that employers of employees with learning impairments perceived that these staff required additional time to complete work, requiring additional work assistance and monitoring for
potential errors in the assigned projects. Work relationships were thought to be strained by employers when non-disabled workers worked with individuals with mental health conditions, which resulted in a wide variety of negative responses from the non-disabled workers including being over-protective, scrutinizing, insensitive, and dismissive of their colleagues to varying degrees (Gates, 2000).

Employees with invisible impairments often encounter the dilemma of disclosing or passing, and then the need to deal with the unintended or unwanted consequences. In disclosing their impairment, employees may be subjected to the loss of work or may not be provided with reasonable accommodations if they cannot prove the condition to be severe enough for those who manage resources to allocate them differently. Accommodations to physical surroundings such as furniture, parking and adaptive equipment were more readily supported than requests for changes to the work environment such as work schedules, job functions, and personal assistants; accommodation requests coming from lower job status employees who were deemed more expendable by employers had less positive outcomes than individuals who held higher level jobs and deemed more valuable to the employer (Harlan & Robert, 1998). Prior to securing employment, the interview process during employee recruitment can evoke anxiety amongst disabled candidates especially when they have to decide whether to disclose and risk discrimination (Duckett, 2000).

For these reasons, as part of the research ethics protocol, I asked the interviewees to provide a pseudonym and all identifying features of their workplaces were changed to ensure confidentiality. The interviews were conducted in private spaces located in mutually agreed locations between the researcher and the participant. Some emerging questions which probed the impact of organizations on underemployment amongst disabled persons and the exploration of
solutions to address these situations included: What have you experienced in terms of actions, practices, and policies to address underemployment in your workplace? What opportunities have you missed that may somehow be connected to your impairment or disability? Do you understand this as a form of underemployment? Why/why not? Have you connected with any other disabled person at work? How has this relationship assisted you in navigating your work? Are there groups or networks to address the concerns of underemployment? Have you joined any of these ever? Why/why not? What were your activities? What do you think could be done about underemployment as it affects workers who have impairments? What are the limits and potentialities of your individual and group efforts? Have you tried to raise consciousness about underemployment in the workplace? How have you tried to raise consciousness and/or make changes about underemployment in your workplace? What networks, resources and/or training do you need? The answers to these questions will provide a greater understanding and possible solutions to reduce underemployment amongst disabled persons.

As the labour force ages, the work environment will need to be more accommodating towards health conditions and impairments. Work environments will need to be addressed and questioned on how they are meeting the needs of a diverse working population, and not vice versa, whereby employees are asked to fit themselves into the existing work contexts. With the older population being comprised of more women and visible minorities, there is additional discrimination as disability intersects with a multitude of identities including age, gender and race (Kampfe, Wadsworth, Mamboleo, & Schonbrun, 2008). Organizational environments which embrace a culture of diversity and are committed to equity can influence the appropriateness of different behaviours between employees, the adoption of diversity awareness programs, and the development of organizational and government policies regarding diversity and employment equity (Spataro, 2005).
This background knowledge in the current research on organizational practices provides insights into some of the potential causes for underemployment, and information to probe for clarifications or details during the interview processes with disabled persons. While persons with invisible impairments may choose to not disclose their condition, this information also informs the design of the research protocol. Specifically, the criteria for selection were for persons with visible and/or physical impairments to self-identify their impairment. Individuals with invisible impairments may not want to participate in this study since they may or may not want to disclose their conditions due to the potential risk of social stigma.

Conclusion

An understanding of the social constructions of disability can provide the historical and contemporary contexts for the marginalization of disabled persons in the workforce. Through the lens of the social model of disability, disability is located in the social environment which includes barriers such as attitudes, facilities, communications, policies, transportation and technology. This model then shifts the problem away from the disabled individual and has the potential of shifting dominant attitudes to make changes to the disabling context. This paradigm shift is asking non-disabled persons to view disability differently, and to work against the dominant perception of disability as an individual problem which needs to be cared for, cured, rehabilitated or segregated. This literature review reveals that an education-job gap exists amongst disabled persons at a greater percentage than amongst non-disabled persons. While individuals can implement strategies to survive in the current workplace, organizational changes currently fall short of providing an inclusive workplace for disabled workers. Further research is required in the investigation of jobs, organizations and social policies to understand the prevalence of underemployment to foster fulfilling careers for disabled persons who choose to seek paid work.
The social model of disability identifies barriers to disabled people to becoming full citizens. When disabled persons gain access to work, then paid employment needs to be assessed for its accessibility. In thinking about historical and current perspectives on work, neo-liberal economic systems focus on the productive value of individuals. The hegemonic imperative to “earn” to become a productive member of society resulted in the marginalization of disabled persons in a capitalist society. With the current changes in technologies, productivity can be enhanced whether it results in paid or unpaid work. Technological advancements may better equip the world to embrace a diverse labour force; however, technology and globalization under neo-liberal organizations and governments may yet again focus on disability as an individual issue rather than a social concern for the rights of diverse citizens. A society which is theorized through a limited lens such as the individual model of disability, and its ties to neo-liberal systems of production, needs to include new ways of thinking which are more multi-disciplinary in scope.

The current literature reveals the persistence of the negative treatment of disabled persons in the workplace. More research is required to provide greater understanding of individual and collective identity and their roles in advancing disability rights. A supportive work environment can have the potential to enhance the self-empowerment and agency of the disabled worker. The realization of a person’s potential and the use of his/her skills and talents can generate a satisfied workforce, and more importantly, an empowered individual who can imagine many paths in the world of work.
Chapter 3
Researching Underemployment

In this chapter, I highlight the research questions which will be used to investigate disability and the social issue of underemployment as a phenomenon which requires investigation. I need to consider my positionality as researcher, especially since my prime research method will be an interactional process whereby I conducted interviews with disabled persons. My positionality is integral to my interpretation of the texts from the data which resulted from the transcribed interviews and the selected social policies related to employment. Following how I interpreted the texts, I highlight the potential of narratives and how data can be organized and represented as possible ways to resist underemployment. I now turn to my concern about underemployment and my research questions.

The rate of underemployment is higher amongst disabled persons compared to non-disabled persons according to the Canadian census data (Canada, 2009). To investigate this social concern, my research examines organizational practices and social policies that reflect this phenomenon. I do so in order to explore the meaning of this disparity between disabled and non-disabled persons who choose to seek paid employment both for those who are underemployed and identify as disabled and for all others who want to work towards change. Thus, in my investigation of underemployment, I explore the social construction of disability, society’s relationships to the individual and the collective identity of disabled persons, and exclusionary practices which have resulted in the marginalization of disabled persons in the workforce.

This research project focused on the underemployment of disabled persons in the workforce by investigating the following research questions:
1) How do disabled workers understand and address experiences of underemployment?

2) How do organizations and social policies identify and account for underemployment amongst disabled persons?

3) How can practices which acknowledge and enhance collective identity be used to address underemployment and advance the disability movement?

4) How can underemployment amongst disabled persons be addressed at the organizational level?

This chapter will discuss the influence of disability studies, my perspective as a researcher, the details of the research project, the adherence to ethical codes, and how the data were interpreted and represented in meaningful ways.

**Investigating the Phenomenon of Underemployment**

An investigation of the work experiences of disabled persons is critical to the understanding of the social construction of disability, and can be understood through a critical interpretive textual analysis informed by phenomenology, which begins with “a heedful, mindful wondering about the project of life, of living, of what it means to live a life” (Van Manen, 1990, p.12). A critical interpretive textual analysis is an enquiry into the lived experiences of humans. When this textual analysis is applied to the area of disability studies, we are directed to turn our focus not only on the lives of disabled persons, but on all who engage in interpretation. This enquiry moves us towards a greater commitment to the world that we are interested in. We become engaged. We become committed. We become a part of this world of our interest. Van Manen (1990) informs us that “the act of researching – questioning – theorizing is the intentional act of attaching ourselves to the world, to become fully part of it, or better, to become the world” (p. 5). This intentional process will consequently lead us to a deeper understanding and greater
meaning of the world in which we live. This research of our interest in the world is not our conception or our reflection upon it, but as a process of clarifying and writing about the world as it is, as it exists.

Underemployment is the current phenomenon which requires investigation. Even though I began with a concrete definition of “underemployment,” this was only a starting point in the interview process. Instead, we discussed the interviewees’ experiences and the impact of underemployment, and explored these through their personal stories. Through a critical interpretative textual analysis of the transcribed interviews, I aimed to learn more about barriers and began to find potential solutions to address the high levels of underemployment amongst disabled persons. In Merleau-Ponty’s (2004) description of phenomenology, he says “The world is not what I think but what I live through” (p. xviii). This form of living will raise our consciousness of our society. The world already exists. We need to be made consciously aware of it to find its meaning since “all consciousness is a consciousness of something” (Merleau-Ponty, 2004, p. xiv).

Phenomenology, according to Merleau-Ponty, discloses the world, reveals its mysteries, and brings the truth into being. To be able to turn disability inquiry away from traditional practices or towards something new, we need to engage ourselves in the question of: what is disability? *In the case of my particular study, we need to ask: what is underemployment through the life of disabled people?* We need to come to an understanding of what disability is and how it is perceived by employers and policy makers. Through understanding we can also find meaning in the world of disability, and how individuals negotiate in a society that is dominated by the individual model approach, that medicalizes the body as having gone wrong, treating it as a problem requiring medicine, rehabilitation or adaptation. In contrast, the social model of
disability indicates that disabilities are the social, environmental and political barriers which persons with impairments encounter on a daily basis. The social model is a conceptual framework that can be enhanced by a phenomenology informed analysis since it requires observations of the everyday activities and encounters of people and their interactions with people and their surroundings.

Text, from these transcribed interviews and social policies, will direct our gaze towards actual activities that we can see and experience in our everyday world, and forms a contemporary context for discourse about a particular topic. Titchkosky (2007) provides further insights on the social enquiry of text in the following passage:

[A]ny act of noticing is a social act, which has the effect of constituting meaning of the difference so identified, as this difference interacts and acts upon our perception of it…This difference lies in the fact that a critical analysis can bring to attention how disability appears, the grounds of that appearance, as well as the various interpretive slants, such as acceptance or critique, of the current appearance of disability in our lives.

(p. 24, 25)

I interpreted the texts from the interviews, and in so doing, I searched for the meaning of disability and underemployment, and explored ways to influence change at the social level. My interpretations were mediated by my perspectives, which have been influenced by disability studies scholars (Barton, 1998; French, 2001; Garland-Thomson, 2012; Michalko, 2002; Oliver, 2006; Prince, 2009; Shapiro, 1993; Titchkosky, 2007; Zola, 1993). I will now share these perspectives in the next section.

Researcher’s Positionality

Interviewing is an interactive process and can be shaped by my social identity, as suggested by Edwards (1993): “Researchers need to recognize that their own sex, race and class, and other social characteristics, in interaction with the interviewees’ own social characteristics
and experiences can increase or lessen the sensitivity of their research topics” (p. 195). In the initial recruitment phase, through the promotional poster and informed consent letter, the potential interviewees learned about my social identity as a graduate student or, more specifically, as a Ph.D. candidate from the Ontario Institute for Studies in Education at the University of Toronto (OISE/UT). I disclosed my name, and “Susan” usually signifies a person as a female gender with which I do identify. Upon responding to the enquiries, the potential interviewees learned more about me when they enquired about my academic background, work experiences, and relationship to the disability community. I divulged that my academic background stems from physical education and health, and sociology and equity studies, with Master’s degrees in both. My work experiences are informed by and lead to questions related to equity and diversity programs and initiatives. I work directly with students who are registered with Accessibility Services, and members of the student group “Students for Barrier-free Access” at the University of Toronto’s St. George Campus. I am an active member on equity committees on campus and within the Faculty of Kinesiology and Physical Education, which address practices and policies related to accessibility, ethno-cultural, gender and sexual orientation concerns. I identify as non-disabled, according to the social model of disability. I am Chinese Canadian. By disclosing my identity, I provided the potential interviewees entries for questions, or a way to build rapport prior to their agreement to becoming a research participant.

I entered into the lives of interviewees to learn about their lived experiences as disabled persons. By sharing my social identities, this reciprocity aimed to reduce the power balance between the researcher and participant, and can be instrumental in eliciting more information (Edwards, 1993). While I am not able to provide strict reciprocity since my lived experiences are different from my participants, “complementary” reciprocity (Johnson, 2001) in the form of self-disclosure or some related information may reduce the differences, and allow for a connection at
the interpersonal level. The amount of self-disclosure may vary from one person to another but should be sufficient enough to build a level of rapport and comfort between the researcher and participant to allow a story to be told in a respectful and safe environment. Additionally, “good rapport is signalled by emotions that feel harmonious and cooperative, and trust can commonly be discerned through eye contact, facial expression, and bodily idiom” (Johnson, 2001, p. 109). Not relying on normative versions of the bodies’ communicative abilities, allowed me to maintain good rapport. Where there may be sensitive content which may elicit emotional responses, Edwards (1993) suggests a final debriefing to restore the disturbance to equilibrium: “The ‘giving’ of yourself may be especially important” (p. 193).

In an initial enquiry, one potential interviewee who eventually became a research participant was curious as to my academic background, and whether I was disabled or not. In finding out about my physical education and health background, she related to me from that perspective, since she had also taught physical education prior to her current work role. She would then know the language that I was familiar with. She wanted to know whether I had a physical impairment or not. If I had, this interviewee would then know the level of understanding that I would have had in navigating the local transit system. If I had experience with the accessibility of the public transportation system, she would have been brief on this work-related question. Since I did not have the experience of navigating the public transit system with a physical impairment, this interviewee provided a detailed context of her transportation experiences in Toronto, Canada. As a final debriefing, all of the interviewees were given opportunities to offer their “final thoughts or comments” as a way to bring the interviewees back to equilibrium and to provide closure to the interviews on their terms, which allowed them time to reflect on what was said or needed to be said to wrap up their engagement with the research topic and questions.
The Research Project

To disrupt the treatment of all disabled persons as the same, I investigated how underemployment was experienced amongst persons with different impairments. A mixed method strategy (Morse & Niehaus, 2009; Tashakkori & Teddlie, 2003) using a critical interpretive sociological approach with qualitative interviews and textual data provided both breadth and depth to the research investigation on disability and work. I conducted a critical interpretive textual analysis of semi-structured interviews of disabled workers. Further inclusion criteria included those who had been employed for at least five years, and self-identified with a visible and/or physical impairment or impairments. This approach is a unique contribution to the literature by locating disabling barriers in both the workplace and social policies.

First, semi-structured interviews were conducted amongst adults (18 years and older) who have a physical and/or visible impairment or impairments, worked for at least five years in the labour force and are English speaking. Participants who were 18 years and older would understand the purpose of the study and be in a position to consent to this research project. Due to social stigma, choosing physical and visible impairments as selection criteria may increase the instances of discrimination by employers in relation to the employees with physical and/or visible impairments. Five years of employment may also provide a sufficient time period for promotions or the noticeable lack of them in this timeframe. Participants may also be able to provide their perspectives on their workplaces and opportunities for networking, and the potential or actual development of a collective identity. English was chosen as the language of
the interviews since this is the one that I am fluent in. In-depth 90 to 120 minute interviews were scheduled either in-person or over the phone with the participants.1

To engage my research participants and place them in the foreground, I conducted the interviews to learn about their perspectives. Time was allocated for the participants to ask any questions and provide the answers on the related research project as an aim to provide an opportunity for agency and co-creation. A digital recording of the interviews was transcribed and analyzed. The individual interviews aimed to uncover meaningful and realistic solutions for underemployment amongst disabled persons through their lived experiences as social phenomenon. Interviews of disabled persons who are employed in the workforce provided insights into the lived experiences of underemployment. The interviews also provided them with the agency to recommend changes within organizations and social policies.

The recruitment process resulted in 14 interviews which were conducted between January 26th, 2011 to November 8th, 2011, consisting of people who self-identified as males (4), females (9) and one as queer; they ranged in ages between 26 and 62 years old. The group’s ethnicity consisted of 10 Caucasians and 4 visible minorities. The interviewees worked in the fields of education, computer, healthcare, fitness, environment, travel, social work, government and non-government agencies. The work experiences ranged from 0 to 35 years. While the inclusion criteria included 5 years of employment, there was one interviewee who wanted to share her

1 Appendix A consists of the recruitment poster for the research project. Appendix B contains the recruitment text for emails and telephone script. Appendix C contains the information for the informed consent. Appendix D contains interview guide with questions which addresses individual identity, collective identity, organizational policies and practices, and social policies. Appendix E consists of the Ethics Approval letter from the University of Toronto’s Office of Research Ethics.
version of underemployment, as an unemployed person seeking full employment as a social worker. The group had both visible (i.e. visual and mobility) and invisible impairments (i.e. dyslexia and anxiety). The group’s highest educational attainment levels consisted of 5 college diplomas/certificates, 4 bachelor degrees, 3 masters, and 2 doctorates. The collective voices provided clarity on the knowledge, practices, relationships, and communications which revealed strategies and opportunities for the disability community to dialogue and work with employers, communities and governments to address underemployment and disability rights.

**Ethical Codes**

Ethical issues needed to be considered throughout the research process. In a chapter on ethical issues related to interviewing, Kvale (1996) outlines the ethical considerations during the seven stages of the research process: thematizing, designing, interview situation, transcription, analysis, verification, and reporting. In this section, I will define the specific stages and connect them to this current research study, along with the ethical guidelines for the respect for human dignity and risks versus benefits according to the Tri-council Policy Statement (Canada, 2010).

Thematizing ensures that there is a specific purpose to the study, and that there is an intent to improve the human condition. This research study investigates the nature of underemployment amongst disabled persons with specific investigation on the current barriers and lived experiences within work places. Uncovering answers to the research questions may suggest ways to improve the human condition, including recommendations to alleviate the instances of underemployment, to reduce the number of disabled persons living on limited funds, to address the health impact of poverty, and to disseminate the findings to employers and policy makers.
Designing the research study along ethical guidelines took into consideration the different elements: informed consent, securing confidentiality and making known the potential consequences of participation for the participants. The informed consent form was written in a direct language which outlined the investigators, purpose, process, confidentiality, and risks and benefits of the study. The informed consent also indicated the option for the interviewees to withdraw at any time or refrain from answering any questions without consequences. The informed consent was applicable throughout the interview process and provided provision for the interviewee to ask questions at any time throughout the research process. The current study poses no known risks to the participants. Confidentiality was ensured through the use of pseudonyms in reference to the interviewee and his/her place of employment, and the storing of data in locked spaces.

The interview situation continued with the aim to provide respect for human dignity, by first reviewing and then by obtaining a signature on the informed consent form. The interviewee is assured of confidentiality by having him/her choose his/her pseudonym and how best to disguise his/her place of employment. One potential interviewee was very concerned about legal ramifications if I were to disclose the name of his place of work, which was a multi-national computer organization. As noted in the last sentence, the type of service provided is identified without naming the specific workplace. While the research aim was for anonymity, one interviewee insisted on using her real name which then revealed the networks which she was associated with.

I first recorded the interview with a digital recorder and also took field notes. With the transcription process, which is intended to be a “loyal written transcription of an interviewees’ oral statements” (Kvale, 1996, p. 111), I then transcribed the field notes onto my laptop, and
filled in the blanks by listening to the recordings several times to capture a complete written transcription of the interview. Analysis of the transcribed data questions how critically the text can be analyzed and whether the interviewees have any roles in how the statements are interpreted. The interpretation of data was conducted by the researcher; the interviewees did not play a role in the interpretation of the data. The sum of the interviews provided a set of textual data to answer the research questions in the form of emerging themes and specific examples.

Verification ensures that the researcher is accountable for the security and verification of the data. The data were secured by the researcher in a locked space. The data were verified by tracing back to the transcribed recordings and the field notes of the researcher. Finally, in the reporting process, there is an issue of confidentiality and the consequences of any published reports. As indicated in the informed consent, the names of the interviewees and their work places were protected by pseudonyms with the exception of one interviewee who gave explicit permission for the use of her real name. General descriptions were given with references to their professions. Thus, throughout the seven research stages, a commitment was upheld to respect human dignity through the practice of autonomy such as informed consent; welfare by maintaining privacy and confidentiality; and fairness by understanding the levels of vulnerability. This research study progressed forward by embracing this research ethics culture as part of the scholarly process.

**Meaning Making**

By exploring the connections between the collective identity model and the social model of disability, I probed the interviewees with questions based on these conceptual frameworks in order to gain a greater understanding of this concept of collective identity in its current existence and its potential for organizational and social change. The benefits of a model of collective
identity are numerous. Collective identity brings a conceptual lens to collective action and a
dynamic view of it, while attending to the discourses within the system of collective action (such
as processes of mobilization, organizational structure, and models of leadership) and outside the
system (such as relationships with competitors, supporters, adversaries, political systems, and
political controls). While the discourses offered by Melucci (1996) can be useful analytical
themes as starting points, the qualitative nature of this research project also offered the
opportunity to uncover discourses within and outside of the system which may be specific to the
collective action of disabled employees. To connect the conceptual frameworks to the research,
the 14 interviewees were asked questions so that they could provide clarity on the knowledge,
practices, relationships, and communications found within their work environments. Answers to
these interview questions are how I researched potential practices, strategies and opportunities
for the disability community to dialogue and work with employers and organizations to address
underemployment and disability rights. The interviewees provided meaningful and realistic
solutions for employees and employers, to address underemployment amongst disabled persons
through their lived experiences.

This research study investigated the individual and collective identity of interviewees
who were asked how their work environments have affected their current jobs and career
developments. The interviewees were also asked whether they have chosen to network with other
individuals who have impairments in their efforts to influence their work environments or career
paths. Both the social model of disability and the collective identity model informed the research
methods, the interview questions, and interpretive analyses of the data of this study. For
example, specific questions included: What have you experienced in terms of actions, practices, and
policies to address underemployment in your workplace? Have you connected with any other disabled
persons at work? How has this relationship assisted you in navigating your work? Are there groups or
networks to address the concerns of underemployment? Have you joined any of these groups? Why/why not? If yes, what were your group’s activities?

For my meaning making of the data, whether it is from the interviews or the government documents, Wolcott (1994) provides a succinct distinction amongst the stages as description, analysis, and interpretation. Description answers the question “what is going on here?” and is based on the observations of the researcher. Analysis identifies the essential features and begins to answer the questions “why is this not working?” or “how can we do this better?” Interpretations aim to connect meanings and contexts, by answering the questions, “What does this all mean?” or “What is to be made of it all?” (Wolcott, 1994, p. 12).

The descriptions for this research study derived from the transcribed notes from the interviews, the initial demographic profile of the interviewees, and my field notes following each interview which included my reflections. While the interview questions which probed for answers to the purpose of the study as to “what’s going on?” the demographic questions provided context for the conversations. Demographic questions relay information on age, gender, education, work status (i.e., full or part-time employment), self-identified impairment(s), and field of work. My written reflections following the interviews connected me back to the research questions, allowing me to consider the salient comments made from each interview.

Analysis began with the first interview. During analysis, I re-read the transcribed interviews to investigate the common themes which emerged from the textual data, and to analyze the common words and phrases for their meaning to identify the current barriers and potential solutions to underemployment. Interpretation is the stage of the meaning making process which connects the interviews back to the social, which in this research includes work places. In discussing writing, Richardson (2000) provides insights into the value of language in
research inquiry: “Understanding language as competing discourses, competing ways of giving
meaning, and of organizing the world, make language a site of exploration and struggle”
(p. 929). Rather than analyzing the interviews, or rather the texts of interviews, as isolated
incidents, the language from the transcriptions can convey what is happening in terms of
workplaces and in relation to society. This process is informed by a phenomenological and
sociological approach as I explore the everyday work experiences of the interviewees as they
interact with people, spaces and systems.

To be able to make sense of the stories and to organize the data, I draw from the
frameworks offered by Rosemarie Garland-Thomson’s (2012) article on The Case for
Conserving Disability and Sally French’s book entitled Disabled People and Employment
(2001). The stories from the interviewees can offer new ways of knowing and learning about
disability, as they convey their experiences through their words, emotions and embodiment. In
addition, their lived experiences can offer insights into the social relations between disabled
persons and non-disabled persons. These stories can be “listening devices” (Frank, 1995, p. 76)
which can be applied to disability stories as told by the interviewees in this research study. By
carefully listening to the interviewees’ experiences, insights and emotions, I aimed to investigate
the meaning of the different narratives.

The Role of the Story Teller

Narratives can conserve disability as a generative resource in several ways: as a narrative
resource, as an epistemic resource, and as an ethical resource (Garland-Thomson, 2012). As a
narrative resource, disabled individuals can contribute to the cultural work of telling self-stories
which can lead to self-understanding, identity formation, and community inclusion. As an
epistemic resource, disability can contribute to knowledge making through their embodied
cognition and experiences. The embodiment of the disabled individual offers a distinct way of knowing the world in comparison to the non-disabled individual. As an ethical resource, Garland-Thomson argues that disability is a gift and offers opportunities for psychological and character development amidst non-disabled individuals. In support of the conservation of disability as an ethical resource, the additional opportunities to practise flexibility and openness to uncontrolled forces can provide new ways to “build solidarity with others, cultivate human sympathies, and create an open human community in which we live in ‘the given world’ that the present bequeaths rather than a ‘a gated community writ large’ of our scrupulously managed future” (Garland-Thomson, 2012, p.348). As a narrative resource, the interviewees from this study offered insights into the identity of disabled persons, and how they were included and excluded from their workplaces and communities. As an epistemic resource, they provided their embodied perspectives and experiences as they encountered either accommodating or inflexible work contexts. As ethical resources, the interviewees often were in positions to educate employers and colleagues to follow the law when necessary, but more importantly, how to act and react in the face of difference; in other words, how to interact with another human being.

As for the role of the storytellers, Frank (1995) asks the question: what do we call ourselves? He answers that we are witnesses rather than survivors. Witnesses can provide testimonies, and he argues for the role of testimonies:

Testimony is distinct from other reports because it does not simply affect those who receive it; testimony implicates others in what they witness. This reciprocity of witnessing requires not one communicative body but a relationship of communicative bodies. (p.143)

My interviewees are witnesses to their experiences with disability and underemployment in the various work contexts. By telling their stories they will be able to implicate others or rather,
reveal the social relations within the work contexts such as co-workers, supervisors and managers as these relate to the social production of their experiences. Furthermore, Frank emphasizes that

If people could believe that each of us lacks something that only another can fill – if we could be communicative bodies – then empathy would no longer be spoken of as something that one “has for” another. Instead, empathy is what a person “is with” another: a relationship in which each understands herself as requiring completion by the other. (p.150)

This resonance forms between the story teller and the listener, or in thinking about the different senses and as a more inclusive term, an engaged individual. The story teller has something to share as a result of her embodiment of impairment with the understanding that each person will experience the world differently. There is much to learn as the engaged individual begins to feel the different experiences and unique nuances of each story. The engaged individual is also “becoming” in the listening or engagement with the stories. In this research study, my interviewees are the story tellers and I am their listener. I record and transcribe their stories, and then in turn, need to interpret these stories to new audiences who are also the readers of this chapter, and future presentations. In “becoming” and in interpreting, I listen carefully to the details such as words, tones, pauses and emotions of their stories, to come to a deeper understanding of what underemployment is and how it is experienced in the various work contexts. I then translate my understanding into new text which is my way of meaning-making for new audiences.

As Frank concludes the final chapter of his book, he writes;

The first lesson of thinking with stories is not to move on once the story has been heard, but to continue to live in the story, becoming in it, reflecting on who one is becoming, and gradually modifying the story. The problem is to truly listen to one’s own story, just as
the problem is to truly listen to others’ stories. (p. 159, italics in the original)

My repeated listening of the recorded interviews and my re-reading of the transcribed texts allowed me to continue to live with the stories (and this is why I spoke of how phenomenology informed my work in the earlier section of this chapter). I then turned to my research questions to gradually interpret these stories. The choice of stories, shared now with future readers, helps me to develop ways to make sense of these people’s experiences of underemployment. While it is not within the scope of this research project to share each word that was uttered by each interviewee, I focused on the texts which resonated with me. While the selection of the specific narrative passages are only excerpts from the transcripts, they will allow us, both myself and new audiences, to live with the stories once again, to empathize with the individuals, and become someone a bit different from the person who did not hear the story. If these stories are told to provoke empathy, and possibly changes in work environments, then these stories have done much to be testimonies to disability and underemployment.

To investigate the potential social barriers, the research question asks: How do organizations and social policies identify and account for underemployment amongst disabled persons? The SEA acronym (French, 2001) which can be identified as structural, environmental and attitudinal barriers provides the framework to sort through the data from the interviews to locate the potential sources of and solutions for underemployment within organizations. Specific details about the frameworks and their applications will be discussed in the data interpretation chapters.

Following my interpretations, I considered methods of knowledge dissemination to be able to enter into conversations and dialogue with employers and policy makers about social change. My audiences may include academic researchers, policy makers, organizations, and the
general public. While it may be well-known that a limited number of people read a Ph.D. dissertation, my goal as a researcher is to share my findings beyond the university spaces. I also complement my research dissertation with a lyrical or poetic representation of my research experiences to expand my influence in the public sphere. Lyric enquiry, which blends lyric and research (Neilson, 2008; Zwicky, 1992), can convey the experiences of the interviewees through a poetic form “to explore and communicate to others an issue, dilemma, or phenomenon” (Neilson, 2008, p. 96). To support lyric enquiry, Neilson (2008) emphasises that

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\text{As our research increasingly reaches into the public domain to investigate a myriad of social phenomena, a reaching that is often motivated by a desire for social justice, we can look to lyric enquiry to make the research accessible and memorable, and we hope, to foster agency and action. (p.99)}
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In his discussion of phenomenology and Merleau-Ponty’s influence on language, Van Manen (1990) writes that “phenomenology, not unlike, poetry, is a poetizing project; it tries an incantative, evocative speaking, a primal telling, wherein we aim to involve the voice in an original singing of the world” (p.13). Poetry, in representation, can be an authentic reflection of the world it aims to portray. We will discover the world, as Van Manen (1990) says, “\textit{in the words, or perhaps better, in spite of the words}” (p.13, italics in the original). In the presence of words and through its absences we will gain a better understanding of the lived experiences. During the interviews, what was said and what was not said uncovered meaning on their experiences of underemployment.

Richardson (2000) expands on the concepts of presence and absence in her support of the role of poetic representation: “Poetic devices – rhythms, silences, spaces, breath points, alliterations, meter, cadence, assonance, rhyme and off-rhyme – engage the listener’s body, even if the mind resists and denies” (p. 933). Lyric inquiry began with the first set of transcribed
interviews by drawing out the riveting words and phrases which represented the experiences and emotions of the employees and their lived experiences. This process contributed to the ongoing interpretation of the text and the phenomenon. The lyric enquiry or poetic representation also supports an ongoing self-reflexive accounting in my role as researcher. Consequently, the texts from the interviews can effectively relay and emotionally resonate with different audiences, while creating “evocative representations” (Richardson, 2000, p.931) for the greatest impact for social action and transformative change.

Conclusion

This chapter highlights the research methods which will be used in order to investigate the complexities of disability, underemployment and social change. Prior to embarking on the research project, I needed to understand my role and social identity in the process, particularly when I embarked on interviews with human participants. I also needed to consider and apply the research ethics culture throughout my research as an integral part of what I do as a researcher. I have discussed how I outlined my research questions, as well as how I considered how to approach my work by taking a mixed methods approach in connecting the lived experiences of disabled persons to their work contexts and social policies. I explored ways to relay and convey the mental, emotional, physical and social impact of underemployment to individuals in workplaces, governments, and the general public to be change agents and supporters, and ultimately, to affect change. This research project aims to be well-grounded as I shared my considerations on perspectives and ethical codes as a researcher and for the different stages of the research process. This research project will now turn to meaning making of the data which will begin to reveal how workers with impairments understand underemployment in the next chapter.
Chapter 4
Developing Definitions of Underemployment

Exclusionary work experiences can result from society’s attitudes towards difference in the physical features, cognitive processes, and/or emotional characteristics in individuals. Such attitudes can impose boundaries and limits on disabled persons which may constrain the potential of individuals who are deemed different from the normative culture. These attitudes result in the underemployment that is prevalent among disabled persons. Nearly half (46.5%) of disabled persons experience unemployment which is much higher than the one quarter (24.9%) of the working-age non-disabled population who are in the same predicament (Canada, 2009). In this chapter, the definition and impact of underemployment will be explored through the work experiences of some of the interviewees who represent members of the part-time or precarious work force, unemployed, full-time employed, and recently retired. The narratives of the paid work experiences include representations from different fields including education, restaurant, health, computer, entertainment and non-profit. A critical interpretative textual analysis of the narratives began to provide answers to the research question: How do workers with impairments understand and address experiences of underemployment? By the end of this chapter, I will offer a new definition of underemployment based on the lived experiences of the interviewees.

At the beginning of the research interviews, the participants were provided with a working definition of underemployment. This definition is as follows: “all dimensions of the wasted ability of the workforce, as they apply to either job holders or the unemployed” (Livingstone, 2004, p. 55). The interviewees were asked specifically “What does underemployment mean to you? Could you provide a couple of stories or examples? Based on these examples, how did these scenarios make you feel? What did you do about the situations?
To begin to clarify a definition for underemployment as it intersects with disability, the narratives of the interviewees from Patsy, Larissa, Margaret, and Craig provided the much needed insights and perspectives

**Experiences of Underemployment**

**Patsy**

Patsy is a 57-year-old female who juggles her role as a line cook, program director and university lecturer, and has been on the receiving end of exclusionary practices many times. She identifies as a “WASP” (White, Anglo-Saxon Protestant). She has an auto-immune condition, and she uses a cane and wheelchair for mobility purposes. She holds a Ph.D. in education. Patsy attributes underemployment to attitudes towards impairments which often begin with self-identification at the initial hiring processes. She expresses concern that self-identification can elicit negative consequences which can affect:

- how you self-identify when you’re applying for a position and perhaps self-identifying as a person with a disability, but I found that it doesn’t always work to my advantage. You know because if that’s known then they’re less likely to hire me. I mean if I appear to have a fully able-body, and have great energy and all that stuff, they’ll hire me. Then I can tell them later that they’re with a crip.

Patsy understands the consequences of disclosure. If she appears to be a fully able-bodied individual who can fit into the normative, dominant culture of able-bodied others, then the hiring process becomes less of a barrier. Initially passing as able-bodied and then disclosing herself as “crip” or a person with a physical impairment can be one way to access employment. She needs to think carefully about her social relations with potential employers and choose non-disclosure over disclosure as an effective strategy for accessing an interview, and consequently, possible employment. Her situation reflects the extra work that she does for impression management to avoid stigma (Goffman, 1963) and to minimize her own difference to allow others to feel at ease.
In Patsy’s encounters in various work contexts, accommodations seem to be minimal or absent even when she disclosed her health condition and mobility needs. Patsy indicated that when she was conducting tours for an art gallery; for example, the supervisors were not pleased when she requested a stool in her role as tour guide for the adult programs. The employers did not provide a stool for Patsy based on their limited understanding or lack of tolerance of difference. Patsy interpreted the consequences of her request:

There was some iffyness about whether or not I could actually lead a tour group when I was in a wheelchair. So while no one would come out and say anything, you knew it was sort of this unsaid thing.

In this case, able-bodiedness was the imperative in the public sphere of the art gallery. The art gallery aligned itself with the dominant culture which understood impairment as a negative characteristic, not by its overt comments, but by its silence. As a site for cultural education, the art gallery could have done otherwise. By disrupting the dominant notion of the absence of disability, the art gallery could have offered up a stool for Patsy to bring disability into the forefront, and as a welcomed entity in a public space. As the public look at the art exhibitions, Patsy and her stool could have also been a representation of disability which may have engaged audiences to think differently. More importantly, it could have also provided the art gallery a form of activism to educate the public that disability has made an appearance and is a part of our society. Unfortunately, in this instance, the art gallery missed its opportunity to educate the public and to play a role in shifting the dominant understanding of disability. Patsy’s choice of disclosing her self-identity seems to collide with society’s intolerance for the appearance of disability.
In a second job, she currently manages to work as a line cook and this involves the preparation of food such as cutting up vegetables for salads and for cooking purposes. For this role, she was given a stool as an accommodation. As Patsy says,

> Basically all I get at the restaurant is a stool. In that situation, you know, the whole philosophy within that whole industry is suck it up. So beyond that, like for example, I’m told I work from 10:30 to 2:30, I rarely leave by 4:00. So there is that issue with boundaries and limits, which I think make further accommodations challenging.

Like everyone else, disabled persons have to “suck it up” and work within the inflexible conditions of the food services industry. This message, along with the token accommodation of a stool, indicates that Patsy is being asked to fit into her work environment, or leave. This situation reinforces the lack of recognition of rights of disabled persons, especially when Patsy indicates that the “whole philosophy within the whole industry is to suck it up.” Moreover, this statement dismisses difference and ignores the presence of disabled persons who may require varying types of accommodations. If the mindset is on a labour force which allows for an average worker, then there is little aptitude for figuring out ways to address the unique needs of workers. Thus, the work environment continues to be unwavering in its ability to or not to address the needs of the individual, so the individual must make adjustments to fit in to be able to conduct the job responsibilities. Specifically, Patsy has to be adaptable to the physical environment as well as the long work hours. Unfortunately, the physical toll of being asked to work long hours and to “suck it up” deleteriously affects Patsy’s health:

> And I can barely handle that… ‘cause it’s physically exhausting. It’s like something for the young kids too. But they’ve got more resilience than I do, and I find, you know, my shoulders killing me by the end of the day. I can’t stand for long. It’s pretty hard. I just come home and go to bed.
Patsy forces herself to be adaptable to the physical environment as well as the long work hours. She is barely coping physically since she feels the aches in her body, the physical exhaustion, and the need for immediate rest when she returns home. Her physical exhaustion affects her quality of life, both physically and mentally. These physically taxing work conditions are not only limited to the work itself, but results in a work-related scenario which necessitates immediate bed rest. As Patsy tells us, “I just come home and go to bed.” This imbalance between work, rest and life can exacerbate an individual’s health. As Patsy compares her resilience to her younger co-workers, she notices the difference in her physical abilities, yet this difference continues to be ignored in multiple sectors of employment. This working condition points to the inflexible environment of policies and procedures which can push an employee with impairments beyond his or her physical and mental limits. A more flexible work practice would be better attuned to the needs of the disabled individuals and address the much needed accommodations for an improved workplace and a healthier employee.

While Patsy exhausts herself working multiple jobs, she also feels the stress and impact to her health as she lives on minimum wage.

And you can’t save ‘cause you have to work your frickin’ ass off to make minimum wage. So you’re living on fifteen hundred dollars a month. So I think it’s the stress of having to do that kind of work, being treated poorly at work that makes it even more difficult. So you know if you have a disability or you have a health issue it’s just going to be exacerbating.

Minimum wage signifies coverage for basic necessities, and not necessarily be conducive for a person’s well-being, especially when a person has physical impairments or health issues. For Patsy, additional expenses include mobility devices such as her cane and wheelchair, medicine such as prednisone, and necessary health care such as massage therapy sessions. Based on her average wage of $12.00/hour, she needs to work over 30 hours per week to make her monthly
income of $1500. While she wants to live well and to work productively, underemployment restricts her from high levels of wellness and fulfillment. Consequently, Patsy has strong opinions on what underemployment means to her:

I’m being paid very little for doing an enormous amount of work, or that the work that I’m doing, or I’m not allowed to progress in any ways. Like I’m not being acknowledged for what I’m doing or paid for what I’m doing. So for example, working for the Women’s Program Centre I’m doing an inordinate amount of work for virtually no money, and similarly at the university.

Her work role at the Women’s Program Centre is that of a Director which translates into overseeing the whole program, writing grants for funding, supervising interns and work-study students. Patsy’s words express concerns for the lack of acknowledgement and for being undervalued in these precarious work situations, whether it’s the ability to make more money or move up the career ladder. Again, like the accommodations, this undervaluing and lack of acknowledgement is prevalent across many fields, and as exemplified by this case study, incidences can be found in public organizations, private restaurants, and educational institutions. Underpaid work creates greater stress amongst individuals when they have to cobble together multiple jobs to meet their basic needs. Limited term or contract jobs are culprits too. They do not provide the long-term financial stability through steady employment. In contrast, competitive pay and steady work can lead to a higher income resulting in a less stressful life for both disabled and non-disabled employees.

Patsy works many hours for very little pay and this draws attention to the complexities of identity. While one of her identities is connected to her employment as an educator with a specialization in women’s programs, such work is limited in both its availability and in the financial compensation it provides. As a disabled female worker who has multiple social identities which are further complicated by her socioeconomic situation, her living standards and
career potentials are hampered. Limited opportunities are available for her to realize full employment using her specialized knowledge and skills. This is especially true as this relates to class issues. Throughout her interview, the concept of socioeconomic class was raised several times. Her health, for example, could be better if she had more funds.

Like we’re living, you can’t get ahead. You’re living on less than minimum poverty level. What am I saying? You’re living what’s considered the poverty line. And, of course it’s going to have an impact on your health... I can’t afford it and I’m supposed to be getting a regular massage treatment. I haven’t been able to go ‘cause I can’t afford it.

Patsy connects her current life situation to living below the poverty line, and at an impasse without improvement. The word poverty conjures up images of a lack of the basic necessities of life, which include food, clothing and shelter. When it’s related to “not getting ahead,” the reality indicates that there are not any immediate solutions to this dilemma. Patsy is forced to seek employment at the same time that she is working multiple jobs so that she can meet her basic needs of food and shelter. She needs to think about affordable solutions. These solutions are commensurate with her income. Thus, if her income becomes even more limited, her affordable solutions will necessarily need to be at a lower standard in terms of food and shelter. Lower standards in food can result in a limited variety of foods, and may need to include food suppliers such as the food bank. Limited standards in shelter can range from her own place to a low-income housing unit. Complementary health care to support the health and well-being of a person with an auto-immune condition is out of reach when the condition of living at the poverty level necessitates a narrow focus on the next meal and next month’s rent. Changes in her income can dictate what she can and cannot afford, or whether she will or will not meet her basic needs. Thus, underemployment is exemplified in this case as a social determinant of health, when low
wages lead to compounding effects such as lower standards in nutrition, housing, and health care.

As a result of underemployment, she is stressed both physically and mentally, which exacerbates her existing health condition.

So I never know where the next job is coming from, and I, I’ve never had a steady job because I work professionally. So the stress of constantly looking for work and working at a variety of different jobs is both physically and emotionally challenging when you’ve already got disabilities to deal with.

While Patsy prefers to “work professionally,” by which I understood her to mean that she would like to work in the field of education, with a specialization in women’s programs, she has been forced to work multiple jobs since not one job pays sufficiently to meet her basic needs. She is reluctant to stop working in her multiple jobs, since the alternative would be the Ontario Disability Support Program (ODSP). Receiving funds would provide her a similar amount of funds compared to her multiple, low-paying jobs, but in her case, she is choosing her professional work and re-confirming her identity through her work over being an ODSP recipient. For some individuals who cannot work, ODSP would then be a choice for funding basic needs such as food and shelter, while it can be a restrictive policy for others, like Patsy. Thus, Patsy is wasting her professional potential as an educator since she is forced to work in numerous jobs which neither use her talents nor pay her market value for her education expertise and creative roles.

In thinking through the potential for change and a transformation of society’s engrained understanding of disability, Patsy strongly recommends a paradigm shift:

Because the assumption is oh well you’ve got a disability, somebody else is looking after it. Instead of saying, you know we have to understand that this is the make-up, that there is not this
homogeneous make-up of society. You know we are quite diverse so let’s create a space that’s welcoming for everyone.

In this excerpt, Patsy indicates that there is still the prevalence of the charity model of disability (Withers, 2012; Stiker, 1999) which indicates that disabled persons will be cared for by society, whether it is through family members or social welfare. However, like Patsy, many disabled persons are choosing to seek paid employment. Thus, the employment space needs to be accommodating and recognize that homogeneity is no longer the order of the day, but diversity is coming into the workforce. Diversity in gender and ability/disability needs to be thought of and planned for if there ever is the hope for employment equity. By following on Patsy’s recommendation to “create a space that’s welcoming for everyone,” the intersection of gender and disability needs to be represented. Within organizations, this intersection can be created for recruitment materials, discussed as a topic for raising awareness within human resources training, and realized in the hiring and retention of disabled women as role models for future employees. Opening up employment opportunities and providing for the necessary accommodations for diverse employees will also decrease the negative health impact which is currently being experienced by disabled workers. Like Patsy’s experiences, this next section will highlight excerpts from Larissa’s interview which also depicts underemployment conditions due to social barriers such as attitudes, environments and structures and through her descriptions, I will continue on the path to further developing the meaning of the concept of “underemployment.”

Larissa

Larissa is a 58-year-old female, Ukrainian Canadian writer and consultant. She holds a Master of Arts in English and American literature. She identified as blind and says that this blindness was congenital. Larissa is currently working on a contract with a women’s directorate
gathering and managing information to produce educational resources for the public. While she welcomes full-time work, she is limited to working on a contract. As a writer and consultant, Larissa felt excluded and generally ignored as a result of her impairment when opportunities arose and her skills could have been utilized for transcription purposes, as depicted in the following passage:

This writing thing when they were looking for people to do transcripts I was not even given a try. You win some you lose some. I can live with that. The fact that they did not ask me put my nose out of joint. I do not have faith in the work that we are doing. If you are not doing it right in your committee, how are you doing it right in the field? Everybody's offended about racial equity and I feel disability is getting left behind.

Larissa’s skills to do transcription work were ignored by her employer. Her colleagues did not acknowledge her abilities nor actively seek her services. Larissa’s “nose was out of joint” and rightly so, especially since this was a women’s directorate and intended to support women of all abilities. In fact, she notices that disability concerns and issues are being left behind or less important than equity concerns such as racial issues when she says, “Everybody’s offended about racial equity and I feel disability is getting left behind.” Larissa’s precarious work influences her thoughts on underemployment, which to her means “lost time in getting any job.”

Underemployment shows up in different ways, and she found this when she was treated, in her words, like a “token blind person”:

Another way that I see underemployment, like on this particular contract after Saturday, I feel that I am the token blind person. They can show for the government that there is a blind person sitting on the committee. Like going into this committee, they were asking: “What kind of contributions do you have that we can use?” I have not been given any real work. I get paid $250 for every meeting that we go to and sit, and really do nothing.

Larissa is included and can be counted by her committee as a representative of disability for any government reporting. She feels that her presence is regarded as but a token representative. In
this sense, the “waste” of underemployment as defined by Livingstone is lived by Larissa as a form of self or professional diminishment. She is not being consulted with despite the fact that she was brought in for her expertise and lived experiences with blindness. As she continued in her interview, Larissa emphasizes that

I went to school as an adult. I had three children, and a shift worker to manage. I still did my fourth-year and master on scholarship. It was not easy. I feel insulted that I am not given the opportunities that merit not only the education that I did but the quality of the student and scholar that I am.

However, she is simultaneously excluded since she is not necessarily valued as a spokesperson with knowledge and experiences to share. She does not want to just sit and get paid an honourarium for her presence. She wants to be acknowledged for her ability to contribute to meaningful discussions and be counted on to do so, rather than counted as a number for employment equity reporting purposes only.

Underemployment is insulting, reveals Larissa, but that only scratches the surface of the personal-social-economic impact of limited income due to part-time employment. Despite her academic credentials, she does not receive opportunities which match her knowledge or skills. As a result, for Larissa, both her health and social spheres are affected:

I am a borderline diabetic. I have to buy cheaper food. I don’t have the money that I do, you need to buy fresher fruits and vegetables. By the end of the month, I am buying things that I would rather not be eating.

In this reflective passage on the impact of underemployment, Larissa conveys the angst of her limited means for basic necessities such as food. Knowing that healthy food choices are a necessity for her health, in this case diabetes, there is no choice or control due to the limited funds; she eats food that may be filling for her stomach, but may not necessarily meet her nutritional needs. When she emphasizes the timeframe of a month,
this indicates a cycle of healthy and poor eating habits, and potentially where she can get her food. She would be stocking up with fresh food at a local supermarket at the beginning of the month, and then resorting to a low variety of canned goods by the end of the month. However, fresh foods such as fruits and vegetables are essential for well-balanced meals over the course of day, a week, a month and ultimately, continuously on a long term basis.

For Larissa, her health is being wasted. Multiple dimensions of health – physical, mental, emotional and social – are compromised in her current state of underemployment.

Socially, I can’t. A lot of women who have split-up find a little job to be able to go on trips or go to concerts, and stuff. You can’t do things like donate to charity or church to feel like a full part of society. I struggle with depression. I worry and struggle with my finances. I have had to put in applications into Toronto housing. Because the money that I was supposed to be investing for my old age runs out, I won’t have any. It affects how you dress. I am used to having designer clothing. I don’t buy designer clothing anymore, and I now shop at Value Village.

In addition to her concerns of diabetes on her physical health, she has at times had to deal with her mental health condition such as depression. She is constantly stressed as she worries and struggles with her finances. Her emotional health is compromised when she feels that she is disconnected from society and cannot contribute to charitable donations. Limited funds also curtail her social roles such as going out with friends. She also expects to dress in a certain way which appeals to herself and society’s expectations. While she shares in her interview that she was used to buying designer clothes, she alludes to living in a different socioeconomic class. Currently, she is now limiting her purchases to shopping in a place which is more affordable. Shopping for second-hand clothing at Value Village may be an interesting experience for some, but in Larissa’s case, it is now a necessity. As her finances become more compromised, she also has to consider government housing which will allow her to pay a reduced rent while living with
limited means. As a disabled person, she is being denied her rights to expand her contracts as a writer and consultant. Larissa flounders within the structural inequity of poverty, while she faces discrimination and marginalization from potential and current employers who limit her opportunities to work using her own talents. Furthermore, hope for the future is bleak since she needs to take care of her immediate basic and health needs, and yet, she reluctantly accesses her retirement funds to make ends meet for her basic needs. A comfortable retirement is slipping from her thoughts of the future. Consequently, underemployment undermines her current health, and can be a culprit in her potentially compromised state of health in her retirement years.

The question of underemployment also leads Larissa to tell me about her grandchildren and her retirement.

I can't take my grandchildren, like if I want to go to the movies with my two little grandsons. I can’t offer them what a normal grandmother could offer them. These are just things that a working person would take-for-granted.

Feeling less than a full part of society is a role that Larissa feels deep concern about. Her social health is compromised when she finds herself limited in her social role and identity as a grandmother. She is burdened by her own expectations for herself, and society’s expectations of what a “normal” grandmother could provide. Notice how Larissa understands underemployment to be tied not only to self-understanding but also to interpersonal relations. Her barriers include her battles with organizations and attitudes. As a disabled person, she is being denied her rights and desires.

Thus, we can see how underemployment is not a simple state of affairs but a complex social position interconnected to all other aspects of life that is accompanied by multiple and complex forms of waste or laying waste to human potential and well-being. This is further
exemplified when we meet Margaret who shared her narrative and addressed additional social barriers such as public transportation and government policies.

Margaret

Margaret is a 46-year-old Canadian who identifies as queer and is a teacher and accessible design consultant. She holds a master degree in special education and a certificate as a music teacher -- Associate of the Royal Conservatory of Music (ARCT). She has multiple sclerosis with multiple mobility impairments and uses, at different times and places, a power wheelchair, a walker, a quad cane, and a manual wheelchair. Margaret says, “I am variably and mobility impaired. In other words, I am fine one minute and then need my power wheelchair the next.” She describes the emotional impact of underemployment and how she would accept a pittance of food for her services:

How would you feel with three degrees? I would still be upset. I actually don’t earn anything in a month or get groceries. I get honorariums or people give me groceries. If I take half, that wouldn’t even cover my transportation costs. What I have been doing is borrowing a friends’ car, parking right in front of places, at least I would get an honourarium, I did some special ed work 2 1/2 hours, and transportation one hour each way, plus prep time. I get the princely sum of $30, that’s an honourarium under ODSP standards; if they are to hire someone else today it would be $60/hour for the 2 ½ hours right. I do a certain number per year. I am happy to get it. It’s far less than the value of the work. I am happy to get it. No one will hire me. I am allowed to keep that. That means I am only getting a few dollars here and there. Most people just give me groceries, a loaf of bread, so that I would have some food to eat. Fully qualified teacher, master’s degree, extra qualifications in special education and ESL, variety of teaching subjects and levels, will work for food. (long pause) That’s me. I consider that underemployed.

Margaret wants to work and is qualified to work in her field. However, the lack of employment has forced her to accept less than the regular wage rate for her specialized skills in special education. As she continues on in her interview, Margaret reveals that the current rate of tutoring
is now $15-$20 per hour, while she receives $5-$10 in things, such as “a couple cans of soup, that’s five dollars, for the same two hours of work.” Her succinct description of herself, “Fully qualified teacher, master’s degree, extra qualifications in special education and ESL, variety of teaching subjects and levels, will work for food” strikes to the core of the impact of underemployment.

To survive and acquire the basic essentials of life, Margaret has to sacrifice her own self-worth. This fully qualified teacher will work, and yet, not being able to receive a fair wage in a competitive job market, she is forced to work for food. Basic needs such as food are even difficult to be met in this scenario. Undervalued, not being able to secure basic essentials, and limited by the systemic funding protocols of the provincial government, Margaret finds herself upset, and definitely living below the poverty line.

If you don’t have the money, you cannot leave your house; you are house bound. If you cannot have food to eat you can get sick. If you can’t afford the medication that you require, you can get sick, you can die. I am lucky that I have a unit. As my disability worsens, I would have to leave. I used to have home care. Then it would be home care if I cannot manage my home; it’ll be 72 hours in a diaper. If I had been employed to my capabilities, I would have had benefits and more income.

The lack of income triggers a cycle which can spiral into ill health, dependence, and death. Here we come face-to-face with the full meaning of waste that is produced via inequality and underemployment as indicated in Livingstone’s (2004) definition. Margaret signals her concern for food, medications, housing and independence when “you don’t have the money.” The short sentences punctuate the impact of her concerns which can result in her dependency of being left in a diaper for 72 hours. Whether she suffers from the lack of medications or food, or the bacteria from bedsores, there is the likelihood of death lingering not far from these dire situations. The lack of employment and the accompanied minimal income sends a message of doom as she
copes with her daily survival. Emotional health can be further affected by social interactions found in both social and work contexts.

Even in social interaction, if people see my cart because people would speak to me like this, [in a very slow pronunciation of each each word] “would I like some water?” Some say, why can’t I think now? I can think. I cannot walk. They will be invited to the holiday party for academic reasons. They are having a get-together at the cottage. They have to ask how can I be accommodated. I have friends who are gainfully employed, but socially excluded. Work promotions is not just based on work. It’s based on social, unless they want a token at that level.

The interactions in the work and social contexts relay scenarios which can range from disrespect to lack of understanding to oppression. Margaret’s interaction with an individual who speaks to her slowly while deliberately enunciating every word conveys a lack of understanding that physical impairment is not necessarily tied to a cognitive difference. As Margaret retorts, “I can think. I cannot walk.” Lack of understanding can impact the social aspects of work which involve get-togethers and functions, and often result in feelings of “social exclusion.” The networking that is found in work-related social functions can address issues of underemployment. However, if there are not deliberate or committed moves to provide accommodations or support, the disabled employee will remain in the margins, and not be recognized for promotions. Again, the different talents are being wasted when they are not shared within organizations. This wasted talent will not be able to contribute to the ideas which can be beneficial beyond organizations, while their unique knowledge can also permeate into general society. “Disability generates circuits of meaning-making in the world,” writes Garland-Thomson (2012, p.344). Specifically, the disability experiences presented by the interviewees can “contribute to knowledge-making as an epistemic resource” (Garland-Thomson, 2012, p. 345). The way the interviewees live and work in the world through their unique ways of knowing
can be shared with their colleagues and employers. In the next section, Craig reveals his encounters with his employers and his unique perceptions on his entrepreneurial and creative pursuits.

Craig

Craig who is a musician and piano tuner just turned 60. He had worked 23 years for a disability organization where they manufactured mops and brooms. His blindness was acquired when he accidentally hit his head as a 9-year-old child growing up in Jamaica and his retina was detached. As an employee of the disability organization, Craig along with 17 other workers wanted to buy the business but was not allowed to purchase the service by the management. The manufacturing unit was eventually sold to a company outside of the province, to a company in Quebec. Craig said, “It made me personally feel displeased. I guess we could have taken it to a lawyer to stop selling it.” Craig was displeased with the outcome of these negotiations with management but he could not explain the exclusion. Thinking back about the situation, he indicated that he and his co-workers could have sought out legal support and action to stop this apparent discrimination by the disability organization. Although he was stopped in his pursuit of ownership of a manufacturing company, he turned to his other skills which lead him to the music industry.

Craig’s entrepreneurial spirit continues to be nourished as a musician who plays with his four person band to the tunes of movies, old times, folk songs, and gospel music. The work is part-time, not full-time. Craig says, “I sing and play and do percussion in a band. We get paid accordingly. Mostly we have been doing work for charity organizations. So we don’t ask for a big pay.” While Craig would like to book more musical gigs which would translate into a
greater income, he emphasizes that it would not be good for his finances and the other band members already had other jobs. Furthermore, he says,

    In the last five years, my band, we have been playing at one point quite regularly and we could have been doing much more, but some of the members were not willing to go further. So that was….More playing would mean more income….I was not pleased about this. I thought at one point, we could really have been very busy and making lots of money.

However, greater income would increase his monthly rent since he lives in co-op housing that currently provides him with a subsidy. Despite his entrepreneurial and creative spirit, Craig and his musical band are limited by a disability support system which paradoxically intends to support their financial circumstances, but in reality, curtails their potential earnings. In his words, “I am not pleased” was his emotional response to the limiting situation, but in reality there’s more since he noted that he is living with the understanding of lost potentials. Their musical talents as a band were being wasted as a result of an inflexible system which punishes those who want to pursue paid work to optimize their living conditions and expand on their creative pursuits.

    Upon reflecting on underemployment, Craig describes it as “not getting the work that I am qualified to do or it could be in a situation wanting a full-time and only getting part-time work that I would like to be doing.” While he would like to have more opportunities to be a musician, he continues within the music field with his part-time work as a piano tuner. Craig says, “I still do piano tuning and people call me. I do not do it on a steady basis right now.” He understands that he is underemployed, but between calls for music gigs and piano tuning, he is also constrained by organizational and social policies on housing which can limit his opportunities for full-time employment.
The social environment between himself and those who he encountered in the workplace affected Craig’s career path. He could have been an entrepreneur. But, the attitudes of the former management of the disability organization did not believe in the skills of the collective of 18 people who had the experience in manufacturing mops and brooms. He could have been a full-time musician or piano tuner. However, government policies on disability funding support constrains and limits the amount of income that he can make without jeopardizing his basic need of housing. Inflexible attitudes and strict policies can certainly hamper the career aspirations of disabled persons.

Defining Underemployment

Stories provide testimony as the interviewees witness and provide their lived experiences of underemployment. Reaching into retirement savings and selling their primary residences are strong indicators that there are no savings from their current employment. These stressful situations arise when there is no buffer zone for the future, especially when there is no immediate solution to living at or below the poverty line. Both Craig and Larissa are also capable of more, but their employers set the limits. Craig wanted to be an entrepreneur and co-own the manufacturing unit for the disability organization. Larissa just wanted to be given the opportunity to bid on a transcription contract, but was not told about it. How do boundaries, limits and exclusions intersect? Based on these examples, exclusion arises from employers’ narrow perceptions of what the skills and abilities are amongst disabled persons. Success can arise when skills and abilities are matched with opportunities. Craig could practise his business skills if he had more marketing opportunities. Larissa could benefit from some word-of-mouth referrals for her writing skills. Patsy could practise her creative skills as a program director if there was better funding opportunities. For the ones who have paid work, their employment is
sporadic in nature and based on single or short term contracts. They have to work multiple jobs to meet their financial requirements for their basic necessities of life.

An initial definition for underemployment was shared with the interviewees as a starting place for a dialogue on their lived experiences of disability and underemployment. The initial definition of underemployment was introduced as “all dimensions of the wasted ability of the workforce, as they apply to either job holders or the unemployed” (Livingstone, 2004, p. 55). In light of these complex understandings and in using the words of the interviewees, I will propose a new understanding of underemployment which can be developed as:

*The underutilized skills and knowledge of the employed and the unemployed*, and is often accompanied by the lack of opportunities for recognition, compensation, promotion, accommodations, and career fulfillment, in relation to structures, environments and attitudes of exclusion which lead to negative consequences for people’s mental, physical, emotional and social health.

This emergent definition which expands from the initial one is still only an opening for a dialogue or conversation to gain a deeper understanding of the experiences and the impact of underemployment. This expansion identifies the multiple factors which contribute to the lack of opportunities amongst the employed and unemployed. Furthermore, this expanded definition relays the deleterious health consequences of underemployment, to underscore this social challenge. Trying to encapsulate the richness of the data in a succinct definition can limit a conversation, however, by adding the broad categories of structures, environments and attitudes of exclusion to the definition allows for more characteristics to appear as research emerges and evolves in this discussion on disability, underemployment and social change.

\[^2^\] Underemployment exists along a continuum of the employed and unemployed. This research study focuses on the existence and complexities of underemployment amongst the employed.
Conclusion

Just as researchers need to be fully aware of what “waste” actually means in the day to day lives of underemployed people, so too do employers need to be aware of the rights for accommodations according to the human rights legislation that might help stave off this waste. Rather than hiding away the disabled employees, employers need to bring disability to the forefront in practices and policies. While adherence to legislation can provide an often minimum level of change, it is a commitment to equity which can compel and inspire paradigm shifts. The focus on human rights which encompasses disability rights needs to move beyond acceptable standards according to the dominant culture. The change needs to be above and beyond the minimum standards, and be acceptable to the individuals who embody difference and enter the workplace. Being able to pursue a fulfilling career with competitive pay can go a long way in addressing the physical, mental, emotional and social health of disabled persons. The health ramifications are complex and can negatively impact the individuals as employers turn away from these skilled workers. Underemployment results in many forms of waste: wasted talent, wasted health, wasted ambitions, wasted spirit and wasted potential. Society, in the form of the various employers, has set up the barriers to these interviewees in their full participation as contributing citizens to the workforce. By limiting their job and career potentials, these individuals are being underemployed in the workforce, and unnecessarily excluded from their contributions to society. Often, and unnecessarily, disabled persons are rendered invisible as potential employees or contract workers. Their underemployment only allows them to be partially included in the workforce, and in turn partially included as contributing citizens in society.
Chapter 5
Stories of Disability and Underemployment

Narratives can conserve disability as a generative resource rather than as a liability. Garland-Thomson (2012) theorizes a set of arguments which support disability as a narrative resource, as an epistemic resource and as an ethical resource. Disability can contribute to the understanding of identity and community. Disability, as embodiment, can be a way of knowing and learning. Disability as ethics can provoke an understanding of the social relations between disabled and non-disabled persons. The stories from the interviewees illuminated examples of the various generative resources. In Garland-Thomson’s interpretation, she notes that stories according to Frank’s *The Wounded Storyteller* (1995) may transform “the tragic narrative of disability as isolation into the comic narrative disability as belonging” (2012, p.345). Thus, stories signal the opportunity for inclusion, meaning-making and learning as opposed to being excluded and dismissed. While I do not assume that disability and illness are synonymous, I do believe that Frank’s approach to studying stories is useful to my work. These stories can be “listening devices” (Frank, 1995, p. 76) which can also be applied to disability stories as told by the interviewees in this research study. By careful listening, we can draw upon their experiences, insights and emotions to think through the dilemma of underemployment. French’s (2001) framework provides the details to the potential sources of underemployment which can be identified as structural, environmental and attitudinal barriers.

This research project on disability, underemployment and social change invited potential participants to tell their stories. On the recruitment poster, the following three questions aimed to generate interest and entice involvement in this study: Are you a person with a physical/visible disability? Do you have a story to tell about underemployment, currently or in the past 5 years?
Have your abilities been wasted or underutilized in your paid work? These questions resulted in 14 interviews and multiple stories of underemployment. To be able to make sense of the stories and to organize the data, I draw from the frameworks offered by Rosemarie Garland-Thomson in her article, The Case for Conserving Disability (2012), and Sally French’s book entitled Disabled People and Employment (2001). This chapter will begin with an introduction to the framework for the data analyses and interpretation which is the SEAwall of institutional discrimination, and then move to the critical interpretive textual analysis of the stories of underemployment as presented by the interviewees. Now that the benefits have been established for the need for narratives, I will now turn to more details on the data analyses by turning to the “SEAwall of Institutional Discrimination” (French, 2001, p. 13-14).

**SEAwall of Institutional Discrimination**

A disability studies approach to this study aims to identify the barriers in the social environment of the interviewees. In my interpretation of the transcripts, I aimed to identify the social barriers which may include attitudes, technology, facilities, transportation, and communications. A critical interpretive textual analysis of the transcriptions of the interviews pointed to the barriers, assumptions and taken-for-granted incidences found in the normative practices of the lives of employers and employees. These analyses provided a deeper understanding of underemployment that is being experienced by the individuals as they navigated their workplaces or aimed to find work. With an aim to locate the barriers in the social environment, I turned to the model which is informed by the social model of disability (Oliver, 1990; UPIAS, 1976) and reflected in the research shared in Sally French’s (2001) book entitled Disabled People and Employment. This book was based on earlier conceptions of social barriers (Swain, Gillman & French, 1998). In her research of the lived experiences of physiotherapists
living with visual impairments, French shared a model entitled “the SEAwall of Institutional Discrimination” (p. 13-14). The acronym “SEA” reflects structural, environmental and attitudinal barriers.

French describes a wall of bricks and cement to reflect barriers which were found in places of employment and stemmed from structural, environmental and attitudinal levels. The structural level was depicted by French as the macro-system or the foundational level which included the hierarchical power relations and structures which disempowered disabled persons, the denial of human rights and opportunities such as education and work in relation to disabled persons, and the welfare policies which could have a negative impact on socio-economic class.

In the middle of the SEAwall, there were the environmental factors which included four kinds of barriers: ableist language, institutional policies and regulations, professional practices, and inaccessible physical environments. For example, these barriers can take the form of rigid timetables and inflexible practices, ensconced in policy and regulation and reflected in everyday language, such as “office hours are from 9-5.” As disabled employees prepared for work and interact with society, these barriers included transportation, parking, office equipment and work spaces.

The top level of the SEAwall depicted attitudes or prejudices which had three components: cognitive, emotional and behavioural. The cognitive component reflects the lack of understanding of disability in general, and the skills and knowledge of disabled persons in particular. The emotional component revealed the feelings of non-disabled persons when they interact with disabled persons, and feelings ranged from fear to respect in any of these encounters. The behavioural component reflected the actions of non-disabled persons towards
disabled persons. These negative attitudes and actions explained some of the discrimination found in hiring practices in the cases of underemployment.

This SEAwall of barriers was influenced by or “cemented by ideologies of ‘normality’ and ‘independence’” (French, 2001, p. 14). These ideologies then can provoke tensions as non-disabled and disabled persons negotiated the social settings of work environments. Thus, this metaphor and acronym of the SEAwall pointed to possible barriers in the workplace, and in turn, this model guided the critical interpretive textual analysis to seek out the barriers found in the narratives of underemployment.

Organizational and Social Policy Factors

This section will begin with Margaret and Michelle who will share their stories as they experience work on the receiving end of social policies. Then, the interviews from Mable, Bear, Remi and Mary will be introduced as they share their narratives, through which we will be better able to notice and think about the experiences in their respective workplaces.

Unemployment, as an extreme form of underemployment, can be witnessed through the narratives shared by the interviewees. The job search poses many barriers and thus needs to be examined as additional factors such as the built environment and transportation can contribute to high levels of unemployment amongst disabled individuals. These lived experiences will then be investigated to reveal the barriers found in the social environment.

Margaret

In discussing barriers to employment, Margaret who is the special education teacher and accessible design consultant needed to address the built environment in her interview before she could even begin to talk about her unemployment experiences. Margaret says:
This is a mid-size wheelchair. The door that we came through so easily, the doors here are 44” wide. You have built environments which are legally accessible but practically inaccessible [doors]. This excludes a lot of people. This is huge in terms of employment.

For example, in Ontario, the building codes require 36 inches or 90 cm. for the width of doors, but many wheelchairs cannot pass through. A door which has adhered to the building code and meets the legal requirements may yet be inaccessible to many people who use wheelchairs which are wider than the 36 inch or 90 cm minimum standard. The availability to accessible workstations and washrooms are necessary features for a disabled person to consider, if a job is offered. If a door is meeting legal requirements but does not meet the accessibility requirements of an employee who uses a motorized wheelchair, then a certain type of disability is not expected, and not imagined to be a member of a productive workforce.

This legislation stems from the attitudes of the committee who first worked on the access standards and then passed through the different levels of government approvals. As a critique on the development of legislation, one then wonders who represented the disabled users, and whether any of the voiced representations were taken into consideration in the development of the legislation which was intended to promote access. If a disabled person drives, the workplace must also have wheelchair accessible parking spots which allow for the unloading of assistive devices, walkers or wheelchairs. If a disabled person does not or cannot drive, then there is reliance on an accessible public transportation. Margaret shared some stories on the dismal state of accessible public transportation. Her experiences highlight the unreliability of the transportation.

I have no reliable way to get anywhere unless I have a privately owned wheelchair van. That’s a huge expense. I can throw my hands up like this [arms are lifted up in the air]. I have to rely on
the City Trans Bus. There are huge problems with booking things. Either you have to have a pre-book service. Say I wanted a teaching job part-time starting at noon and ending at 4pm. In fact, I had a teaching job at 12 and ended at 3. I arranged to arrive at 9:30 and I was still late.

Even when Margaret was able to find a teaching job which suited her skills, she could not depend on a reliable source of transportation to get her to work on time. Unreliable transportation was a “huge problem.” She also had to allocate more time to be able to get to work. Knowing that bookings could delay her arrival times, she had to arrange to be at work hours before she was scheduled. If she had to average out her wages over the time that it took her to get to and from work in addition to the actual hours that she taught, she would no doubt be making a less than competitive rate for her teaching hours. The alternative of using her own wheelchair van also posed a barrier since she emphasized that it was a “huge expense.” In thinking about the poor service of the public transportation system, Margaret considers the negative impact of it for teaching:

If I had taught in the public system, I would have been fired, and it is also illegal for a teacher to be late in Ontario and I could have lost my teacher’s license. I could lose my job or certification, and never teach again because of missing transportation. Often they came late to pick me up or often they would not show up, and then I would have to pay for a private wheelchair taxi to take me home.

As a teacher, Margaret highlights the consequences of being late. She could have lost her qualifications as a result of the unreliable or missing transportation. The system needs to be changed to upgrade this service for individuals who require accessible transportation. This upgrade may require more resources as in the increase in the number of vehicles or drivers to support this service. When Margaret uses her mid-sized motorized wheelchair, there are

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3 Pseudonym is used for public transportation system
limitations on the types of vehicles which can transport her, and these need to be accessible vans. While she has tried riding in delivery trucks, these are not ideal since the suspension systems of trucks are worse than the ones found in vans. Her condition also requires that transportation vehicles have air-conditioning; otherwise, she could be prone to a fatal consequence: “I have asthma, MS and a heart condition, I can die.” Seeking employment can have its benefits, but the related barriers to employment, such as the built environment and transportation need to be explored and navigated prior to meeting potential employers in a job search. Despite being well-qualified in her fields of special education, music and accessible design, Margaret’s life conditions which are complicated by the built environment and accessible transportation deter her from finding and sustaining a work level to adequately meet her basic needs of food and shelter.

Her story is complex with so many factors that it is challenging to find a starting place for change. In the application of the SEAwall of Institutional Discrimination, the barriers are revealed at multiple levels. These inadequacies demonstrate a flaw in the structural level whereby Margaret is left powerless as a disabled person amidst the bureaucracy of the public transportation system. Within the environment level, physical barriers appear time and time again, in the form of doorways and sidewalks, which can impede her access to work, even before she gets to work. At the attitudinal level, there needs to be better practices when the transportation system is booked to ensure that there are timely arrivals and pick-ups for disabled persons to get to work on time. Margaret’s story bears witness to the dilemma of disability and underemployment as it intersects with social barriers and attitudes. I will now turn to Michelle’s story to listen to the concerns found in unemployment and identify the additional structural, environmental and attitudinal barriers.
Michelle

Michelle is a 27-year-old White female who is currently unemployed but is trained as a social worker. She has a Master in Social Work degree. She has cerebral palsy and uses an electronic wheelchair. Michelle has been looking for work for a year and a half now. While she is motivated to find work, she is very clear on the kind of paid employment that she is looking for: “I am looking for a career just like anyone else.” She contrasts a career with job placements which do not use a person’s skills, such as being a greeter at a big box retail chain. She relays some of her interview experiences:

I have been to interviews where they would have gone and put me through the whole interview and at the very end they would give me a list of physical restrictions or requirements which I could not do. They’ll put me through the whole interview and then I’m sorry we are looking for someone who can drive. Driving would not be on the listing. Things like heavy lifting or shovelling snow. I don’t want to make assumptions, but for them to give me a list after an entire hour of interview, it seems discriminatory. It wasted my time and theirs.

Michelle’s interviews have left her to believe that many of the interviews have been discriminatory, and a waste of time for both the employer and the interviewee. It is evident that this discrimination leads to the production of a list of physical requirements which excludes Michelle from being a potential candidate for the job. This list of requirements can only be produced by employers who have negative attitudes of disabled persons. In their biased assumptions of the skills and knowledge of disabled persons, the employers may fear that the candidate may not be able to fulfill the responsibilities of the job, and rather than providing an opportunity, the employer chooses to act on this fear and remove the opportunity altogether. Similarly, in various studies, supervisors opted not to offer work opportunities due to a fear of
failure on the part of the disabled employee (Collela & Varma, 1999; Magill-Evans, Galambos, Darrah & Nickerson, 2008). Often, a lack of work opportunities are based on misconceptions that disabled employees are less productive that non-disabled ones, as well as on the lack of knowledge about the availability of accommodation options (WHO, 2011).

Job descriptions need to accurately reflect the responsibilities of a posted position. If driving or shoveling snow were essential duties which would then have to be written into the posted job description, Michelle may not have chosen to apply or interview for that specific job. Additionally, interviewers need to present themselves in a way that is fair to both non-disabled and disabled job candidates, rather than displaying bias against disabled populations. When Michelle enters an interview with her wheelchair, she has experienced patronizing smiles, rather than receiving a genuine interest in hearing about the skills and knowledge that she has to offer to the job:

There’s been interviews where I walk right in and knew I would not get the job based on the expressions on their faces. They would go ahead with the interview, but they would do it through their smiles and they are patronizing me.

Self-disclosing can be a difficult choice, as it can place the disabled person in a “double-bind situation where disclosing her identity subjects her to public and institutional scrutiny” (Cheuk, 2012, p.27). The dominant narrative of disability in the public sphere is a stigmatized identity. With this pervasive stigma, employers may not have the attitude or mindset to listen to Michelle’s skills and talents for job postings. Again, Michelle wastes her time and is confronted with negative attitudes of employers who will not provide the opportunity for disabled persons to use their skills and knowledge. To take care of her mental health and cope with the stress from looking for work, Michelle also chose to volunteer so that she can at least use her skills in a
meaningful way. Her volunteer work at a disability organization enhanced her sense of well-being. She says, “I would have a lot worse attitude about this situation. It’s been a year and a half. At least I am doing something and getting at least a ‘thank you’.” Michelle tells her narrative as she continues to seek out a career which can use her abilities. Despite her added credentials, interviews are scarce. Employment is not available. As she continues to seek work in which the decisions are out of her control, she tries to add some coping strategies to the situation. The coping strategies exist as volunteer work for Michelle as she contributes to her disability organizations in different ways while at the same time applying her knowledge and skills.

The social barriers are primarily located in the attitudes of potential employers who discriminate from the outset as a consequence of disability making an appearance in the workplace. Within the attitudinal level of the SEAwall of Institutional Discrimination, there are three components: cognitive, emotional and behavioural prejudice. The employers may have been assuming the capabilities of the disabled interview candidates as a form of cognitive prejudice. Rather than listening to the knowledge and skill sets of the candidate, the employers may have already pre-judged the abilities, and consequently, underestimated the talents of the potential employee. The employers demonstrated an emotional uncertainty when they did not offer employment to Michelle, despite her qualifications and suitability for the various jobs. The interviews demonstrated behavioural prejudice, especially when they smiled, patronized and went through the motions of an interview, without seriously considering the candidate. Having located some of the structural, environmental, and attitudinal barriers, I now turn to additional narratives, which will provide some lessons learned through the various work experiences.

I will now share an account of Mable, Bear, Remi and Mary’s experiences of underemployment through their various workplaces which include the health, computer and education fields. They tell their stories as learning experiences for others.
Mable

Mable who is a 60-year-old Caucasian female works as a teacher, coach and fitness instructor. She was a former nurse. She has dyslexia, anxiety, depression, mild bipolar and ADHD, and a visible facial condition. She holds bachelor and master degrees in the performing arts, specializing in dance. Mable also experienced changes in technology and work intensification which forced her to change careers.

And I think that everybody would be healthier if we worked in an environment that was a little friendlier to dyslexics. It would improve everybody’s because you need to slow things down. You need to. We need to give people workloads that can be done in seven hours. We need to have fun and laugh a little at work. And those are all dyslexic-friendly things, but they’re also everybody-friendly.

Companies’ policies and structures could align themselves and their resources to becoming every-body friendly by slowing things down and by scheduling a manageable workload. Mable is bearing witness to her experiences within her quest narrative. Her quest which is the lessons learned include giving recommendations on how to create friendlier and more accessible workplaces. These recommendations need to then be turned into company policies that can limit the workloads per seven hour shift. Nursing has changed, Mable informs me throughout her interview.

Doing my nurse’s notes was incredibly... was.... It was a real difficulty... it was a real.... I knew that if I didn’t get my assessment when I did it first thing in the morning, I was going to stay late and do it in the evening at the end of shift. So I often stayed late: and people laughed you know, I’d sit there with my 14th coffee of the day, and you know they’d laugh at me, and it was ok in those days because... I had one patient... it wasn’t, you know... I was so good at my job that was... they considered.... Often I had the sickest patient, and often the reason I was writing my notes (they thought) and I thought, was because I was so busy
looking after the patient, and I was. I was acclaimed as a very thorough nurse; I had rave reviews all the time on my evaluations because I was so thorough and so detailed.

The attitudes in the nursing stations did not support Mable’s desire to meet her responsibilities of taking care of her patients and charting her notes. While she stayed late and drank copious amounts of coffee as coping strategies, “people laughed” and “they’d laugh at me.” The laughter was directed at Mable. It was not necessarily the type of joyful laughter that one enjoys in a social setting. The laughter, amidst her colleagues, revealed a lack of understanding and respect for Mable as she worked with her dyslexia. Writing, as Mable admits, is “a real difficulty.” While she acknowledges her colleagues’ opinion of herself as a thorough and detailed nurse, Mable continues to work without disclosing that she has dyslexia. She passes as a non-disabled person, while working harder than her colleagues to stay the course of upholding her responsibilities as a non-disabled nurse. However, as the work environment changed, Mable needed to develop new ways to cope and work even harder to pass as non-disabled. This next passage reflects an intensification in workload and consequently, exacerbates Mable’s ability to work as a nurse.

Plus we started having two patients in the units. I was focusing on the meds. I was focusing on my patient’s medical condition…. If I knew who was following me that would dictate what I would do. So I would, you know, I always give the meds on time and did the vital signs you know, all that kind of stuff. But if I knew there was a... like there were nurses that ... they bathed their patient no matter what shift they were working, I wouldn’t wash my patient, unless of course they were dirty, …but I started to not be able to do all my tasks, and I’d be late, and my charting never got done on time. I just couldn’t handle the workload.
Mable was very much patient-centered and the 1:1 patient to nurse ratio worked for her, until the work intensified. With double the patients, she would also have double the charting that was required of her and she would have to write or input these notes into the computer system. Admittedly, Mable says, “my charting never got done on time.” Mable enjoyed her patient interactions, and focused her strengths on patient care rather than on charting records. She managed her work by ensuring the essential duties like medications were given and vital signs were taken, but routinely left the bathing of patients to other students. She was often busy with the liaison components of her job when she organized the resources, pastoral care, and family visits. The intensification of her job as a result of the changes on the demands of nursing resulted in a work load and pace that was difficult to maintain. Consequently, Mable left nursing to practise in a different field of work.

She transitioned from full-time work in the year 2000 to contract work as a dance/fitness instructor, but with limited success. Writing and technology continues to be her nemesis as she needs to write advertising text on her computer to promote her professional services, and to access the internet for job opportunities and networking. She feels that computer technology can be a cause for her underemployment. Mable says, “I’m not on the internet enough. I’m not doing the job searches.” She mentions Facebook which is a social networking website, but dismisses it quickly since she prefers to connect with friends and acquaintances via the telephone. Mable draws from her memory to share her stories of underemployment. While she was qualified in nursing and decided to leave the field, her new career aspirations as a dance instructor and fitness have not allowed her to reach her potential. There are times of joy when she does teach. In her interview, she enthusiastically stood up from her seated position and demonstrated how she would teach her aqua fitness students with enthusiastic high kicks and confident arm punches. Her desire now is to teach, and to do so more often.
As she transitioned from a nursing to dance/fitness career, Mable’s narrative teaches lessons of struggle and adaptability within work settings, and changes with the times to seek and find more amenable work, while facing underemployment due to attitudinal and environmental factors on a regular basis. At the attitudinal level, her colleagues demonstrated cognitive prejudices in the way that they laughed at her and her abilities to work. The changes in technology are a part of the environmental barriers which can intensify and create barriers to work whether it is the context of patient care or marketing purposes. Organizational practices which fall under environmental barriers also need to be considered when there is choice with the potential of fitting everyone into the same role, or potentially, creating flexibility within job descriptions to fit the talents of different employees.

**Bear**

Turning to another field of work, underemployment also occurs in computer technology. Bear is a 58-year-old French Canadian male who has worked for a multi-national computer company for 32 years as a programmer analyst. He identifies as blind and navigates his surroundings using a white cane. He has been forced into retirement due to technology and work intensification. The company knew that Bear was not able to read a document when he first started in the workplace, so the employers provided people to read for him. He received weekly folders filled with memos. There would be a lot of files and a person was hired to read his memos aloud and fill out any necessary forms. As time went on, in 1994, they started to roll out e-mail access to managers. With the screen-reading software programs, Bear was able to read the email texts. Before his recent retirement, the computer company was implementing internal processes that Bear could not perform because he could not use the software. Bear says,
They would say that you have always been resourceful. Some of it was terribly graphical. I cannot do it. Some of the reason was the product being used in the development. Could I have sued them? This was frustrating. I came very close to that. What are the chances of winning? I thought about this. I want to live a long life. I have a pension so I left. These were products that X made themselves so X was responsible. Something has happened in industry in the past 10 years. They would say that it's not true. It’s not true that they are not out to get disabled people. They are out to get everybody. I told you of the billable utilization of people, and the very brutal calculations, and the very brutal use of people.

Changes in technology could have kept accommodations in mind but that was not the case at this company “X.” The additions of more graphic components prevented the screen readers from doing their job in order for Bear to be able to understand the text and software. In addition to the changes in software development, the for-profit computer company intensified work production to be competitive in a global market. Being part of a brutal calculation, Bear sought retirement over diminishment; but diminished he nonetheless felt, to the point that he came close to, or considered suing the computer company. In the quest for accommodation, a person may rise to the occasion after an interruption which may later become an opening for something new. Bear’s interruption or opening is the ever increasing work intensification in the computer sector. He was not going to be able to work in such a non-worker friendly environment and decided that he had sufficient funds within his pension to retire early. As Bear says, “they are out to get everybody,” tells me that the average worker needs to produce for this computer company which operates in a capitalistic society. According to Abberley (1997), “capitalism creates both disabled people and a concept of disability as the negative of the normal worker” (p.31). Thus, for individuals who cannot produce at the level of the average worker, these individuals are deemed unnecessarily “disabled” or a problem within a competitive society. Bear could have worked longer into his career if the workplace was more conducive to accessible work conditions. Bear explains work intensification using the phrase “billable utilization” or BU, and
indicated that work hours increased with a concomitant increase in the percentage of productive hours per person:

BU the way that you calculate 36.5x 52 weeks, 72% of that the rest of your time is through vacation, we will give you 3 weeks of education time. Just before I retired, it all had changed. We went from a 37.5, then to a 40 hour week...To make up the time, you would need to make up the time with 44 hours per week. Because of my diversity background and I told them that they could not legally do this. I was a rebel. I have a sense of fair play and somebody has to say something. I got fed up with them. They really deserve to be sued but I don’t have the money or power to do that. I thought through the whole thing and finally retired. I have spoken to the people after I have left, the billable now is 100%; now they have to work 46-48 hours, 40 hours is paid and 6 to 8 hours is unpaid. If you do not work these hours, we will move the job to India. They move the job to India anyway. They work for a lower salary. Today, they have to put in 50, 54 to 60 hours per week anyway.

The competitive nature of the private sector increases the expectations for a productive workforce. Bear gave the example of a 40 hour work week prior to his retirement to a change to 48 hours per week within a six month period. To keep up with the expectation of 100% of productivity for the 48 hours, employees need to put in even longer hours – 50 to 60 hours – to keep up with productivity quotas. This intensification in work cannot be healthy for a non-disabled workforce, and as Bear found for himself, intolerable for a person with an impairment. Bear used the word “brutal” to describe his work environment: “the very brutal calculations and the very brutal use of people.” The implementation of these work conditions is a structural barrier which places very little regard for the welfare of employees. Work intensification translates into productivity and revenue for a multi-national company which has as its main goal, profit in a global market. Employees are replaceable in this global market mentality. As Bear indicates in his interview, as a Canadian worker, he could easily be replaced by a worker from India. The company can pay less and demand higher productivity per person. When a lower
salary is part of the productivity equation, the lower expense would result in a higher profit for the company. Capitalism, in this case, depicts a structural barrier for both non-disabled and disabled workers.

The job environment is changing through technology, production quotas, and possible layoffs. In this work environment, Bear felt like playing fair was a rebel’s position and this is the work environment he is trying to make sense of in his own underemployment. An unsustainable version of work seems to be contrasted to his current situation. At the time of his interview, he had just recently retired, and it did give him a new chapter in his life, and can be considered “an opening” within the quest narrative. He was considering opening up a consulting company to provide accessibility training for organizations with his son. He stated that “I want to live a long life.” By thinking of an entrepreneurial venture, he shares his lesson that he wants to continue using his skills in a productive manner to add quality to his desired long life, but on terms that are not counted in brutal billable hours. The workplace environment can negatively impact individuals’ relationships to their work.

In thinking about the SEAwall of discrimination, the experiences at the company shed light on their environmental barriers which included institutional policies, professional practices and inaccessible physical environments, and the structural barriers which re-enforced power relations. The need for greater production to meet a global market resulted in institutional practices to continually increase the intensification of work. The organization did not consider the care of their employees who were asked to work beyond the billable hours, and threatened them with job loss if they were not productive. This threat can also be constituted as an imbalance in power dynamics between the senior administration of the company who decide on the vision, direction and strategies for the company, and the employees who have to either
continue to work in brutal conditions or leave. The use of technology can be an aid or a hindrance; in the latter case, if the technology results in adaptive technology which is not suited to an individual’s needs, then it is a waste of time and money for all parties. While this waste can also be found in educational institutions, this next story shared by Remi also highlights the exclusionary nature of her work environment in a university research setting.

Remi

Remi, is a 50-year-old East Indian female who has congenital low vision. She is a post-doctoral fellow working as a researcher at a university and has a doctorate in education. Remi finds that she misses a lot of networking opportunities in her workplace. Her colleagues, who are non-disabled and younger tend to not include her in coffee breaks or lunches. Access to these opportunities could translate into access to information. With her visual impairment, she cannot just rely on posters and signs. She needs to be on email information lists to formally learn about the organization’s news or connect with colleagues informally to learn about current events or job opportunities. Networks also provide a form of support for job opportunities. Remi says:

You need to develop allies to get promoted for the workplace. You need people to support you. You need information. You need to get connected to others. It’s harder for me than other people.

Allies can act as references or mentors. By knowing the work of their colleagues, allies can provide the needed references on professional conduct and work habits. Allies can also become informal or formal mentors to provide information, to assist with navigating the workplace, and to be a supporter to champion opportunities which provide the right fit of skills to the job. As Remi says, “You need people to support you.” A support can also translate into having a friend at work, just someone to talk to, and this basic but necessary relationship seems to be missing
from Remi’s work situation. While there is an independent nature to Remi’s work as a researcher, she realizes that there are aspects of her work which require some interdependent relationships. These relationships can provide information and important connections, although their development can be a challenge for Remi who has visual impairment. This interdependent relationship can be nurtured or avoided altogether, and is grounded in the attitudes of her co-workers. As an attitudinal barrier, what are the cognitive, emotional and behavioural prejudices?

The difference between Remi and her co-workers can account for some of these barriers. Remi’s co-workers are younger, tech-savvy and non-disabled:

I feel I miss out on lunch times because I am in a lab with young people. They do not feel that they can relate to me. These are undergraduate students, all in their 20s and the oldest is 30. I am sort of left out of lunch dates and coffee dates. I feel odd there. I am the only one who is 50. Everyone else is under 30. There is a big generation gap. It’s noticeable. I try to fit in. I try to be chatty and stuff. I don’t fit in. They talk. They are tech people. High tech. They all know the technology and I’m a little bit behind.

In contrast to her co-workers, Remi is older, “a little behind” in technology, and has a visual impairment. She indicates that “they do not feel that they can relate to me.” By highlighting the apparent differences, there seems to be a need for a greater understanding and awareness on how to create a more inclusive environment which embraces difference. Whether this is in the form of training workshops or one-on-one discussions, there needs to be a space created for such interactions. While Remi’s supervisor understands difference and accommodations, the supervisor can take a lead role in changing the work environment to address the concerns, but also to welcome difference as a perspective which can provide ideas and thoughts which are different from one’s own. While “there is a generation gap” as Remi notices, it would be the role of the supervisor to at least begin the bridging of this gap, and to influence some of the behaviours of the younger workers. Small gestures such as invitations to coffee breaks or lunches
can begin the conversations that embrace diverse perspectives and support an inclusive work environment.

Remi is providing voice to the situations of disability and underemployment from the perspective of a low vision employee. Her story bears witness to barriers such as limited networking and access to information. Her lesson to us is that greater efforts need to be made by the organization to find ways to bring employees together for socializing and networking purposes. These efforts can begin to remove the cognitive prejudices or assumptions about disabled persons, and adjust the employees’ behavioral practices to move towards a more inclusive one. Greater awareness needs to be made to ensure that all employees have access to important notices such as job postings and current events. These workers revealed their experiences of underemployment. Public attitudes, lack of accommodations, changing technology, work intensification and limited networks contributed to underemployment which resulted in shortened careers, changes in careers, and limited job opportunities. The next interviewee shares her experiences of underemployment and work contexts which can provide hope and possibilities for inclusion.

Mary

Mary is a 41-year-old female Canadian who is self-employed as a registered massage therapist, copy editor, transcriber, and restaurant server. She holds an honours bachelor degree, majoring in English literature, and a certificate in massage therapy. She identified as blind from birth, and uses a white cane for navigation. She enjoys the variety in her work, since she finds full-time work “a bit daunting,” and has decided that she has not found work that she would like to do for eight hours per day. Mary is confident in her abilities in her various job roles, but the marketing component which requires her to seek out clients and is necessary to support her
profession as a fully employed successful massage therapist has been frustrating for her. It takes her time to identify effective marketing strategies, find ones that she is comfortable with, and follow through with ones that are accessible to her. In her massage therapy role, she needs to identify community events in which she can promote her services, and interact with the public in a visual way. Examples of her community events include an elementary school’s holiday celebration which invited vendors and service providers to set up exhibit booths to showcase their products and services, and an outdoor arts and crafts market which had display areas along a well-travelled street in her neighbourhood. With body work such as massage therapy sessions, Mary informs us that potential customers often want to have a sense of who the therapist is before being touched by the professional, and yet, she finds this process is unproductive when individuals get mentally side-tracked when they meet her and encounter her blindness. In her experiences at community events, Mary has found that sometimes people will either know or not know that I’m blind when I’m at a community event, and if they don’t know, it makes it awkward because they’re not understanding why I’m not making eye contact with them, so they’ll just drift away, and if they do know, there’s often a discomfort about having to engage, how to engage with me directly, and so that experience has been discouraging, and daunting, and frustrating.

It seems ironic that at a community event, where people meet, greet and perform social niceties, Mary should be made to feel discouraged and frustrated. She has made the effort to be a part of community social events, but the practice is not reciprocated. Based on Mary’s experiences, eye contact seems to be the taken-for-granted behaviour to make an initial connection at community events, and yet when it does not happen, people drift away and are not comfortable enough to engage with her. A community event conjures up a process for people to become familiar with one another. To know one another can be one route to understanding the needs of one another, and to engage with someone who is different. Thus, the initial connection from community event
participants, rather than eye contact, might be a verbal or kinesthetic cue to greet Mary. If the people at the community event choose to become more familiar with Mary, then there would be less of the awkwardness, of being next to someone who is different and in this case, who is blind.

In a social setting that has fewer interactional demands, blindness is more neutral when Mary offers her copyediting and transcription services. As for her copyediting and transcription services, she found her work through referrals. The initial job began with her copyediting a friend’s Ph.D. dissertation, and then her services were shared amongst an academic community of students and colleagues. Word-of-mouth referrals seem to be the best marketing strategy for this service. The referrals, the computer and the internet mediate these services. There is minimal in-person social contact since the initial communication can be made via the computer or the phone. For the transcription services, digital recordings are uploaded onto an internet website where Mary listens to the words, and then transcribes them into written text. The work does not require in-person contact, so blindness is not encountered by a normative culture in this process. Blindness does not make an appearance to the clients, in the computer and internet modes of communication, to cause Mary to become frustrated, or her client to feel awkward.

In contrast to navigating in a sighted world as a massage therapist, copy editor and transcriber, Mary also works as a server for a unique dining experience which values blindness as an asset and darkness as an experience. Mary feels very differently when she works at this “Dinner in the Dark” setting:

Definitely as a server because all of the other servers are blind or visually impaired. That’s actually been incredibly empowering and stimulating and satisfying at the same time. That’s been a really powerful experience for me, and it’s helped me to feel very comfortable in my workplace, and to feel a sense of confidence because I’m not the exception in my workplace. I’m the rule as it were. Yes, and I’m the piece without which the place isn’t going to happen, and so that’s a very unique position for me to be in. Of
course when I first started there, my co-workers were incidental in training me and helping me learn how to do the job, how to do the job properly, but, just being in an environment with many other blind and visually impaired people has been really great, and they’re all obviously outgoing, energetic, confident to some degree, competent people, because they’re doing a job too, and that has been really good for me in many ways.

Blindness is not merely accepted but respected in this setting where the public is invited into a location which has been set up to embrace the experiences of darkness. Mary says, “I’m the piece without which the place isn’t going to happen, and so that’s a very unique position for me to be in.” This uniqueness lies in being respected, being wanted, and being a part of a community. Blindness appears in this setting and this identity is embraced by the servers and patrons. The non-blind patrons accept their inability to navigate in the dark and are guided to their tables by the blind or visually impaired servers. The patrons eat, drink and socialize in the dark. The patrons experience blindness as an excursion away from their normative lives where blindness is more often than not, as Mary has described from the community events, awkward and discomforting occasions. Mary’s multiple work commitments juxtapose her between inclusive and exclusive work environments.

Further into the interview, Mary elaborates on her positive thoughts about being a server:

what it’s like for me to work in an environment like the “dinner in the dark” restaurant, it highlighted for me how important it is to feel like the norm, and not like the exception, and so, like I say, I’m not sure where I’m going with that, but just that always trying to fit into an able-bodied workplace can be exhausting and maybe, routine dulls that and maybe I just haven’t had a long enough job in one place to experience that ease, but I think that always accommodating yourself to the community around you is tiring, and being in a community or a workplace where everyone’s like you is quite relaxing and empowering.

Working in an ableist normative setting takes a great amount of energy, as Mary describes how “always trying to fit in to an able-bodied workplace can be exhausting.” Her reprieve from the
normative world at this novel concept of a restaurant gives her a rare opportunity to “feel like the norm, and not like the exception.” In contrast, when she is probed further about the relaxing and empowering nature of her work as a server, Mary describes how she can interact with her colleagues without the customers knowing. For example, when her colleagues are busy seating guests, she may just pick up a basket of dinner rolls to save them a trip to the kitchen, and then touch her colleagues to indicate that she has a basket for them. For Mary, she comments that:

The guests are oblivious to this interaction because it’s dark, and servers do this for each other all the time. It’s smooth, efficient, helpful, seamless and completely unique. I can interact with my colleagues without having to mediate the sorts of things that I usually have to with sighted people.

The serving experience in the dark is also empowering. She notices that

Being in the dining room with a few dozen sighted who are trying to function in complete darkness provides a unique opportunity for me to feel like the most competent and capable person in the room. I have complete freedom of movement and action; they don’t.

Mary is constantly adjusting to her different work contexts, and as she transitions from one place to another, she has found a job which can offer her feelings of empowerment, freedom, and competence. As Mary describes these emotions, she is providing insights into characteristics of an ideal job. How can roles be reversed more often? How can disabled persons feel like the norm, rather than the exception? How can workplaces be re-imagined to reduce the hard work of fitting in, or alternatively, how can workplaces be more inclusive? How can we reduce or eliminate exclusionary practices? Answers to these questions will be explored when we proceed to solutions for underemployment. In the meantime, these questions do provoke thoughts on the possibilities of new jobs or workplaces which can be made more relaxing and more empowering and which can be found for all employment seekers.
The community in this restaurant setting contrasts with the one for marketing purposes in Mary’s role as a massage therapist. This “dinner in the dark” community provides Mary the opportunity to fit in and “to feel like the norm and not the exception.” The physical and emotional ease of an inclusive environment, as Mary says, is “relaxing and empowering,” unlike the strain of trying to fit into an able-bodied workplace that can be exhausting and tiring. Rather than using energy for the actual work, much is then used to just fit into the workplace.

In thinking through the research question of “How do organizations and social policies identify and account for underemployment amongst disabled persons?”, this particular interviewee provides examples of what can go wrong and what can be very right in work contexts as she balances a variety of jobs in her quest to work full-time hours. Mary’s role as a massage therapist relies on her ability to make contact with potential clients.

The normative culture in an ableist society causes interruptions in communications and understanding between Mary and her community of potential clients. In contrast, Mary’s role as server allows her to use her abilities to navigate in the dark, in a setting in which she feels competent and capable, moving with ease amongst her co-workers and patrons. This specific context can provide cues to what can be implemented in an environment which is inclusive for blind or low vision individuals. Familiarity with surroundings and collegiality amongst co-workers are evidently important for Mary to work in her role as a server. By telling her stories about her different work contexts, she has shared an example of a quest narrative which allows her to recall incidences of inclusion and exclusion, provides her perspective as a blind person and in solidarity with others with similar conditions, and inspires hope with how she feels as server working in an accessible and inclusive environment.
Applying Disability as a Resource

Rather than thinking about disability as lack or limit, Garland-Thomson (2012) argues for a new perspective: “a reading of disability as a potentially generative source rather than unequivocally restrictive liability. In other words, what I consider is the cultural and material contributions disability offers to the world” (p.341). She personally acknowledges her eclectic, rather than systematic argument, and yet her perspectives bring to the forefront how we can perceive disability as multiple resources: narrative, epistemic and ethical. As a narrative resource, disabled individuals can voice their lived experiences and offer themselves and others greater opportunities for self-understanding, identity formation, and community inclusion.

The stories from Mable, Bear and Remi corroborate on the barriers which appear in organizations to unnecessarily induce underemployment. They identified public attitudes, technology, work intensification, and lack of social networks as prime culprits in the barriers to employment amongst disabled individuals. As with the nature of these narratives, there are lessons to be shared, taught and learned. All these stories provided lessons which can be learned to minimize or eliminate barriers to underemployment, and to increase the social relations within work contexts. The interviewees offered insights on how they can be better accommodated and included within their work communities.

As an epistemic resource, disability can contribute to new understandings and knowledge making through the embodiments of disabled individuals which are distinct from the way non-disabled individuals learn about the world. As a blind server, Mary found joy and ease when she located the right place to work, namely the “Dinner in the Dark” restaurant. These revelations point to what can be otherwise, provoking readers and researchers alike to ask: What can full employment imagined to be? As Garland-Thomson (2012) states: “Disability occurs when the
shape and function of bodies come into conflict with the shape and stuff of the world” (p.342). However, when Mary promotes her massage therapy sessions at neighbourhood events, her embodiment of blindness comes into conflict with the world, which in her case, includes the non-disabled individuals whom she encounters as clients and potential clients. For her profession as a registered massage therapist, her way of knowing the needs of a client will differ from a non-blind colleague. This difference is not better nor worse, but is just another variation in how one comes to understand the world.

As an ethical resource, disability is a gift and offers opportunities for psychological, character and flexibility development amidst non-disabled individuals. The narratives shared by Margaret and Michelle were difficult for them to tell since each interviewee expressed their emotions through changes and breaks in their voices, and sometimes tears. These stories also seemed to go on and on, since there did not seem to be a relief to their circumstances of underemployment which resulted in limited funds, food, health and opportunities. It was challenging listening to their stories as the interviewer, since I felt lost, not knowing how I could help, and the responsibility of how much research can assist them in the future. In the narratives of Margaret and Michelle, an endless list of barriers, often resulting from social policies, and generally, from social attitudes, have located these qualified and yet underemployed individuals far from their personal goals and career aspirations. As ethical resources, their situations provoke non-disabled persons to learn from and in conjunction with disabled individuals so that there can be better opportunities for employment through greater accommodations throughout the human resources recruitment processes, and through accessible transportation and built environments. Thus, disability as it appears in our everyday life offers immense resources to the world as we learn about and through the stories of the interviewees.
Conclusion

By relaying their stories, with their narratives, signs, pauses, and tears, the interviewees are witnesses to these underemployment situations which in turn will allow others to share in their stories. Readers and employers can then empathize with these story tellers who tell their stories in the hopes that they may feel the need and be compelled to make changes to the situations of underemployment amongst disabled individuals. Stories are between communicative bodies, which allow resonance between the narratives that are told and the emotions that are evoked. The stories are provocative, as one listens to the story, lives with the story, relates to the emotions, and in the final analysis, moved by the story to take action within one’s spheres of influence, whether that be actions taken within local work contexts, community organizations, or global multi-nationals.
Chapter 6
Collective Identity and Social Policies

Social change is dependent on the understanding that disability is not an individual problem. However, to affect social change, there needs to be a paradigm shift from the dominant individual model to a social model of disability which locates disability outside of individuals and specifically, in their social environments (Oliver, 1990; UPIAS, 1976). As one of the originators of the social model of disability, Oliver (2009) says, “We cannot build a better world for disabled people unless we can create a democratic movement in which our collective views can be advanced” (p. 183). To be a catalyst for change, Michalko (2002) states that

Disability can now be understood from the perspective of politics. It is more than merely a private happenstance that must be suffered in the realm of privacy; it is also a public matter that must be suffered in and through the polis. Disability is not an exclusively individual issue; it is a collective one. (p. 6)

This concept of collective identity can be a force for change and be critical in a democratic movement and in this case, the disability rights movement, to break down the barriers to employment amongst disabled persons. To analyze the existence of a collective identity which can in turn support the action for changes, Melucci’s (1996) framework identified three necessary components. First, the process of collective identity involves cognitive definitions; rituals, practices, and cultural artifacts; and cognitive understandings constructed through interactions. Examples from disability organizations could include working definitions of impairments, information brochures, and conferences. Second, the process of collective identity also refers to a network of active relationships between actors who interact, communicate, influence, negotiate, and make decisions. For example, disability organizations may exist as non-profit organizations that work with a volunteer board, communicate through websites, and use accessible technology for communication purposes as different modes of active relationships.
Finally, emotional investment is an integral factor and is required of a collective identity to feel part of a common unity. Within the Canadian disability movement, activism has focused on “a politics of cultural recognition, a politics of socio-economic redistribution, and a politics of democratic representation” (Prince, 2009, p.200). These political struggles focus on the prevailing barriers that disabled persons are not recognized fully across cultural signifiers such as social policies and public documents; through resources such as employment, income, education and housing; and their “misrepresentation or marginal voice in elections, policy development, and decision-making processes” (Prince, 2009, p. 12-13). The application of Melucci’s framework will facilitate the identification of the existence of a collective identity amidst the narratives shared by the interviewees.

In comparison to Melucci’s framework, Swain and French (2008) have identified similar key notions for collective identity development: active engagement, shared identification and tension arising from social constraints. First, collective identity requires active engagement at the individual or collective levels to support an ongoing process of identity formation and maintenance. Specifically, people need to be involved for a collective identity to exist, and this may or may not happen due to existing barriers such as time, transportation and money amongst disabled persons. Second, collective identity requires a form of “shared identification with some people and not others” (Swain & French, 2008, p.67) and this can be reinforced through social events, common understandings, and symbols. For example, social events which offer accommodations for individuals who use wheelchairs may have the internationally recognized symbol on the promotional brochures and websites. Finally, a collective identity results from the “tension between the control the individual has in constructing his or her identity and the social constraints of limiting and determining identity formation” (Swain & French, 2008, p.67). This
tension also aligns with Melucci’s key process of emotional investment being needed for collective identity development.

The Swain and French, and the Melucci frameworks, both foster abilities to focus on the active engagement and the social interactions which are aligned with the building of networks; the symbols and meanings which connect with practices and artifacts; and the tensions which are aligned with emotional investments. In addition to these overlapping notions, Swain and French (2008) do add one more point, and indicate that: “In affirmation of identity the personal becomes social/political and the political becomes personal” (p. 67). Thus, a collective identity is a necessary construct when barriers which hinder individuals need to be addressed at the social and political level. Consequently, social-political changes matter at the organizational and social levels, and can greatly benefit individual lives. The collective identity framework from Melucci will be applied used to investigate the research question: How can practices which acknowledge and enhance collective identity be used to address underemployment and advance the disability movement? Following a critical interpretive textual analysis of the interviews, I will turn to prevailing social policies to investigate their roles in their relationship to collective identity, the disability rights movement, and employment.

Collective Identity Narratives

I will now introduce you to Ray who is an environment technician, and Anne, who is a retired high school teacher. Both of their stories exemplify the concept of collective identity.

Ray

Ray finds his job searches disappointing. He is a 26-year-old male Caucasian who works as an environment technician, and returned to school to earn a diploma in land and water reclamation. He has Amyotrophic Lateral Sclerosis (ALS) which is also commonly
known as Lou Gehrig’s disease. He uses a power wheelchair, and self-identifies as a “quadriplegic.” Ray’s work would require him to work in the field and in the office. He managed to get to three interviews, but as soon as he disclosed, in his term, his “illness,” Ray says, “as soon as that happened, it just…the interest level died.”

When I came out of college I wanted to do whatever work I possibly could do. Like at that point in time, I could still do a large part of the job. Some field work I still would have been able to do. I still would have been able to look after the office end of it, and if I would have been able to get employed right away, I may have been able to maintain a job for probably up to two years before fatigue would have become an issue with my illness. But unfortunately I was not able to get into…. Like there wasn’t any…. I just couldn’t find anyone that had an interest, ‘cause it was…. Like having to say that I had a neurological disease, like it was just like... “Ah no, we don’t really have a spot available,” is what ended up happening. So like there are…. Like I did have years of experience in the field; like I still would have been of use to a company. Like there’s a lot of things I was familiar with. It wasn’t as if I couldn’t have contributed somehow to a company.

In this excerpt from the interview, Ray points to the potential employers who did not have any interest in his knowledge, skills and experiences as an environment technician. Ray emphasized that he could have contributed to the company especially if it was office work. He believed that he could have been a productive worker as opposed to the potential stigma of an unproductive one, when he said “I still would have been of use to a company.” According to the employers, a position was no longer available although up to the point of Ray’s disclosure there was a job opening. He encountered discrimination against his impairment which was invisible at the time of job interviews. As noted by Titchkosky (2003a, p.79), “there is a strange politics of normalcy surrounding those who bear the mark of difference.” While Ray may have initially passed for “normal” in his public representation to the potential employers, his verbal self-disclosures offered up an identity that was different. These experiences exemplify “interactional work,
[which] conforms to the normal sense that disability is simply the negation of ability and is a position defined by lack” (Titchkosky, 2003a, p.76). In shifting a private identity to a public “outing,” problems which are often associated with a socially stigmatized identity can arise such as violence, dismissal, denial, broken relationships and loss opportunities (Cheuk, 2012; Goffman, 1963; MacLachlan, 2012). Instead of providing an opportunity, the potential employers focused on the part of the job responsibilities which would exclude Ray from the workforce. When probed about why the potential employers would not offer him a job, Ray says, “the majority of the work that they were looking for was a person to hire in the field.” This fact, which was relayed by the potential employer to Ray, could have been an act of fear of impairments, a poor attitude towards accommodations, or a case of discrimination against disabled persons. Whether the job requirement truly reflects the role, as in the necessity for field work as a required duty, employers need to consider the abilities of the interviewees. Without consideration for the actual skill sets of the individuals, the job hunt can become futile for many, especially if there is no hope for an employer to imagine a work role being filled by a disabled person. These individuals are then left with time which needs to be filled, bills to be paid, and self-esteem lowered every time an employer says “no” to a disabled job candidate.

Ray reflects on his missed opportunities as a result of his unsuccessful job searches:

Probably looking at salaries of $60,000 to $80,000, so I’m missing that sort of wage revenue. The fulfillment of having a successful career is another thing that I’m missing out on. The other part of it is, you, all of the sudden depression is another major thing that you have to deal with! When you look at everyone else’s life that’s happening and yours isn’t.

The lack of paid work has resulted in a loss of potential income, an unmet career potential, and a negative impact on mental health. Paid work is not available for Ray, after two years of job
searching. Ray compares what his colleagues are making in current wages, and notices that he is worth at least $60,000 to $80,000 on the competitive job market. However, he is not able to attain these salary levels since job offers have eluded him. In addition to his physical fatigue, Ray needs to address his mental health – sudden depression – through his practices of yoga and meditation. His mental health is also complicated by his emotional health, especially when he relays his thoughts on the situation: “I definitely miss out on self-worth. It’s definitely…it’s just not there anymore.” His current dilemma is a result of the attitudes amongst the potential employers who have cost him his environment technician career, his potential earnings, his poor health, and his low self-worth.

Despite his lack of paid employment as a consequence of encounters with various social environments, Ray has chosen to volunteer as an ambassador and spokesperson for the ALS society’s major fundraiser. His role was to give a speech to address people who have ALS and share his experiences. When asked about collective identity and connecting with others, he replies:

Like the only thing that I’ve actually been able to come across is like through the ALS Society, like I volunteered, and it helped them in a few ways, but that has its own limitations as well. What I did this year was, I was the ambassador for their major fund-raiser. Basically what it was is I worked with the organizing committee to help organize the event itself, and as well, I had to kind of I was their poster boy for the year type thing and come up with a speech to try and inspire the people with the disease and give them hope. It was definitely a stretch out of my norm: something I normally wouldn’t have done, but, it didn’t bother me, like I was comfortable with it.

By coming forward to be a spokesperson for the fundraiser, Ray was contributing to the development of a collective identity amongst individuals with ALS. In applying Melucci’s
(1996) collective identity framework for an analysis, this case study can exemplify the three components: cognitive definitions or rituals, practices and cultural artifacts; a network of active relationships and its constitutional parts; and emotional investment. First, the fundraiser would act as a cultural practice to bring the individuals with ALS to come together as a collective. The promotional posters, invitations, programmes, and web site pages would act as artifacts to indicate to the general public that this organization exists on behalf of its members. Second, Ray was asked to be an ambassador and spokesperson for the ALS society. While he did not provide details of who invited him to become involved, both the members of the society and the organizers of the fundraiser would have constituted the active relationships to support the development of a collective identity for individuals with ALS. Finally, the emotional investment was hope. Ray shared his stories to provide hope for other individuals who also had ALS. For example, volunteering is helpful for Ray in a small way:

It isn’t anywhere near the same as being able to go out and be employed and pursuing a career, but the bit that I’ve managed to volunteer with the ALS Society and that sort of thing is part of it. The rest of it is just a struggle to deal with day to day.

While Ray continues to lament about the lack of employment and the loss of a career, he does share his hope and his gratitude as he identifies his volunteer work, his yoga and meditation practice, and his wife’s support. However, there is a tension with volunteer work and creative work, since “these activities facilitate social participation but do nothing to improve the material conditions of disabled people” (Hall & Wilton, 2011, p. 878). While the ALS Society has attributes of a collective identity, Ray’s experiences indicate that they are taking a charity model approach to disability, rather than addressing the social-political barriers. His statements about being a poster boy for their annual fundraiser indicate that the charity model is being adhered to through the ALS Society.
Still, amidst the social barriers, specifically the attitudes of potential employers, Ray was able to seek self-worth in his wellness journey through the ALS Society. He provides voice through his speeches as he recounts his condition and feels compelled to tell others. He recollects his stories, connects with others who have ALS, and acts as a spokesperson to share his experiences through his disability organization. In tandem with the unpredictability of his ALS condition, his narrative demonstrates the interruption in his life as a result of ALS, but it has also been an opportunity for him to share his lessons on life with others, a life with and through ALS.

The next interviewee also shares a narrative to provide further information on collective identity formation and the experiences of underemployment. In contrast to the previous stories from Ray, the purpose of this collective identity in relation to muscular dystrophy takes a human rights approach and is aligned with the social model of disability.

**Anne**

Anne is a 58-year-old female Canadian who had worked in the education field for 26 years. Her roles included high school teacher, department head and curriculum developer. She has had muscular dystrophy for over 42 years, and uses a combination of braces, a walker at home, and a scooter for mobility. She holds an honours degree in science and a Bachelor of Education degree. Anne was forced to retire early from her career as an educator due to a lack of accommodations, in what she has described as a “hostile” and “indifferent” environment. She worked full-time until the last 3 years of her career, and required accommodations for the past 10 years. Anne requested that her own name be used, as well as the identification of the FSHD network.
years as a high school classroom teacher and curriculum developer. Anne had enhanced her qualifications by training to be a guidance counselor, foreseeing that she might need accommodations with respect to the physical demands of her job. She also trained in co-operative education for the same reason to add another qualification to her education in anticipation of her body’s physical changes and abilities. Classroom teaching, as she described it, is “very physically demanding in terms of walking around, bending, picking up things off the floor, etc.” In contrast, co-operative education did not require classroom responsibilities, but needed administrative work which connected students to possible community members who would provide the students with learning experiences in the workplace. Although she was also trained in guidance counseling, Anne decided not to pursue that particular role and its related responsibilities.

Anne believed that she made a successful transition into co-operative education by splitting time between classroom teaching and co-operative education 10 years prior to retiring from her employment. Her work demands changed in the last five years of her career when administration brought a new principal to the helm. As Anne was coping with a medical leave at that time, she also had a discussion with the new principal to propose possible work arrangements as she intended to return to full-time work. Her proposal was to ideally return to a full-time co-operative education role, or as a second option, to return to a part-time role teaching at 80% of a full-time position. Showing a lack of understanding of accommodations, the principal countered the proposals with an offer for a full-time teaching assignment, and even suggested that she teach physical education based on her qualifications. Despite the fact that physical exertion could negatively impact her health condition of muscular dystrophy, Anne reluctantly accepted the offer of a 100% teaching assignment role, and eventually had to reduce her workload to 80%, then to 60%, and then finally, she had to go on medical leave due to an
inability to meet the physical demands of the classroom job. Since the administration did not provide accommodations, Anne found that she was falling regularly, and as proof of her accidents, she had accumulated a large file folder filled with written reports for each of her falls. Anne experienced her underemployment as unnecessary part-time work and a shortened career:

I was on disability for the last, I say 2 ½ to 3 years of my career. It was not my choice. I would have liked to have worked to the end of my career, and insurance ultimately paid for someone, which in my way of thinking they shouldn’t have had to have paid. I should have continued to be employed and pulled that employment wage.

Rather than having to be paid through an insurance company, she would have liked to have continued to work on her terms, which in this case would have been a part-time appointment. This lack of options or more importantly, lack of accommodations, forced her to take an early leave from her teaching career. The lack of choice impacted her career earnings as well, as she states that she could have worked to earn her wages. If she were able to continue with her employment or career earnings, she would not have had to rely on insurance payments. She would have been independent and contributing to the educational field rather than waiting for her monthly insurance payments. This lack of choice can be deemed a form of disempowerment amongst disabled persons, and is a component of structural barriers which affects the power relations between disabled and non-disabled persons (French, 2001). Society, in this case, the educational institution, did not allow her to live an independent life. She had no choice since the educational institution was offering an inflexible way of working within a high school setting.

With retrospection and in learning more about her rights, Anne would have liked to have addressed the administrators more directly:

So how is it a hardship for you to assign me back to doing a job I was doing before I left on medical leave? I should not have been
reassigned when I came back, to a more physical demanding job, which is what you did. Legally, it’s my understanding that it is against the law. But I didn’t get to that point of strength and knowledge for some time, because I was trying to do my job, and I was exhausted when I went home, and I would fall. Towards the end of my career I was filling out accident reports almost every day.

In this excerpt, the administrator assigned her to a more demanding teaching role compared to what she held prior to her medical leave, which was a less physically taxing cooperative education position. This decision from the administration needed to be legally challenged, but as Anne says, she was too exhausted to follow through and was not aware of her rights at that time. Her teaching role exacerbated her physical condition, which resulted in her daily falls on the job and the extra paper work of filling in accident reports. Her encounter with administration reflected a rigid system and an oppressive attitude on the part of the principal.

Anne had proposed cooperative education as well as acting as a resource person for students with impairments. She offered her potential skill sets to her workplace, but the principal neither listened to her needs nor understood her legal rights for accommodations under the Ontario Human Rights Code (OHRC). Employers are required to provide accommodations without undue hardship, or unless they are “unduly” costly or dangerous to health or safety (Ontario, 2012). Finally, two years into the negotiations for accommodations, Anne wrote a letter to the education board, citing the legislation and outlining the violations of the code. A reply from the local district school board offered Anne a guidance position, not a cooperative education role. Anne declined the offer in light of the timing of the offer, the negotiations, her training, her interests, and medical condition:

So I was ultimately offered a job that I had trained for maybe 6 to 7 years prior, that I had never done, two years into a process that had taken a lot of energy and literally fighting to get, and it had cost me more in terms of my physical ability. By that point my mobility
was much more difficult. Part of the medical prognosis is physical stress on the muscle which will cause it to deteriorate at a faster rate and I knew that, so I was actually taking on a workload that I knew ultimately if I continued, would cause my disease to progress more rapidly.

Anne emphasizes the toll it took on her body when she was going through the negotiations process. The energy which was expended over two years was more than just physical. One can only imagine the frustration that she was feeling while she was fighting administration, and living with the concern for her personal health since extra physical stress would have a negative impact on her muscular dystrophy condition. Thus, Anne’s case of underemployment resulted in many consequences as a result of her interactions with the high school administration. As she emphatically shares her thoughts, she informs us that

My 80% that I was working, and then eventually 60% because I remained in the classroom, so we had to keep rolling it back because physically I couldn’t handle it, was underemployment. If I had maintained a position in co-operative education which is the position I left when I went on medical leave, actually I carried one class and the rest was co-op when I went on leave. If I had switched to full-time co-op and dropped that one class, I believe without any exaggeration I would have been able to finish my career: fulltime 100% employment, doing my job 100%.

In this excerpt, Anne had a counter solution to what she was given. Knowing her body well, she believed that she could have worked full-time on her terms. These were very specific terms as to the position but this option could have been better than the one which asked her to work in a position which was physically taxing and detrimental to her health, and one which she had to reduce gradually to a point of not working. This option from administration seems to be forced, rather than needs-based, which would have required the principal to have at least listened to the possibility of a solution which addressed her need for accommodations. There are legal rights to accommodations; there are also human rights to address here. With a more caring attitude and an increased understanding of the duty to accommodate from the principal, there would have been a
better chance of discussing and finding a solution which could have been amenable to both parties.

While Anne is now officially retired, she is saddened that she could not have finished her career on her terms, with her personal and professional interests in mind. Anne’s social relations with administrators who lacked empathy and knowledge resulted in solutions that were too little, too late in her decision making process. She now takes her accumulated knowledge of employee’s rights and volunteer time to mentor others who are currently experiencing similar circumstances. Anne had to push herself to her physical limits, and then had to reduce her teaching role to 60% of a full-time role because, she emphatically believes, that she was not accommodated. Had she been given a more sedentary position such as a co-operative education role, Anne believes that she could have worked to her career potential, and not have her career unduly shortened as a result of her supervisor’s lack of understanding of the legal rights regarding accommodation.

In thinking about collective identity, Anne was the only one of the interviewees who actively formed an organization to become a resource for others like herself. Anne formed the Facioscapulohumeral Muscular Dystrophy or FSHD Network in 2003 as a response to the gap in information, research and support in Canada as it related to this health condition. Currently, Anne shares that the FSHD network has 70+ members. Some of the highlights of the organization include: access to contact information for 50 people with FSHD across Canada, assistance with workplace accommodations and personal advocacy, a speakers network, sharing and exchange of used equipment such as canes, commodes, etc., a three day conference in 2004, production of a documentary entitled “Assumptions” (Harland, 2009), and establishment of a fund with $65,000 being donated in 2011 to the Alberta Children’s Hospital for a research study
entitled “A Multi-Centre Collaborative Study on the Clinical Features, Expressive Profiling and Quality of Life of Pediatric Facioscapulohumeral Muscular Dystrophy.”

I set up this organization. I have been asked many times to make it into a not-for-profit, bigger, you know political activities organization: no. That’s not my mandate. My mandate is to help people with their daily lives, to mentor them, to help them get equipment with knowledge and information that I got through my excessive journey: to quickly give that to them so that when you’re in a position of compromised health or disability that leads often to emotional disability ultimately because you can’t deal with everything, and depression because you’re going through a death every time you lose another...If it’s a progressive disability, every time you lose a function it’s like another death. So to quickly give support and specific information to individuals is my mandate.

Anne’s FSHD network fills a resource gap within Canadian society. She is the resource for many people who need knowledge and information about this particular health condition. She draws from her journey to be able to become a mentor for daily living. She understands the condition and she has experienced social and systemic barriers. The condition can affect a person physically, mentally and emotionally. She emphasizes that “every time you lose a function it’s like another death.” The constant change in the many dimensions of a person’s well-being is taxed and extended, and even more so in the face of a society which limits or does not provide for accommodations, or has a low tolerance for difference. Anne aims to make a societal difference by addressing the barriers as well as by being a cultural guide for others, to better navigate the work contexts and social systems. She draws from her work experiences to mentor others to request their rightful accommodations in the workplace. Anne has shown how she has lived her life with muscular dystrophy, and how she decided to use her experiences to support and mentor others who are living with FSHD. As she reflects on the lack of accommodations in
her workplace, and then later learning about the rights available to her through legislation, Anne combines her experiences and knowledge to teach others how she witnessed her encounters of underemployment.

In applying Melucci’s (1996) collective identity framework for an analysis, this case study can also exemplify the three components: cognitive definitions or rituals, practices and cultural artifacts; a network of active relationships and its constitutional parts; and emotional investment. There were a number of cognitive definitions to the FSHD network; the conference, the website and Anne’s video documentary entitled “Assumptions” are all components of a collective identity. She fostered active relationships through her educational conference and membership base. Her emotional investment was high as she continued to maintain her relationships with the new and current members of her national network to help them navigate the vast amount of information related to accommodations and the formidable barriers of everyday living. Anne found it necessary to form a collective identity to provide information and hope for others living with FSHD. Her network also formed a clear example of a collective identity in action, with Anne playing a pivotal role as a cultural guide and mentor. Her formation of a collective identity was also characteristic of a new social movement, in this case, the disability rights movement. These characteristics, which are attributed to disability politics, “include the self-organization of people with disabilities, an emphasis on non-economic or post-materialist values of identity, and alongside local and national concerns, an international outlook (Prince, 2009, p. 121). Furthermore,

Canada’s disability community favours terms such as obstacles, inclusion, equality rights, and citizenship, rather than the oppression and domination, a language more common in British Disability politics or the language of minority group and civil rights in American disability politics. (Prince, 2009, p.121)
In returning to the research interviews, the narratives of Ray and Anne are difficult to listen to as they deal with their barriers of exclusion and rights found in their everyday lives. They have not “overcome” their physical impairments, but have learned to live with their collective identity as disabled persons. In recalling Michalko (2002), and Swain and French (2008), the personal becomes social and political, and the political becomes personal. Both Ray and Anne are choosing to think and feel beyond their individual impairments to become change agents as members of a collective identity to voice change. They are not overcoming disability in the ordinary sense according to the individual model of disability, but live with and through their impairments as their unique ways of experiencing and engaging the world. They have used this collective identity as a tool to assert their human rights, to be in solidarity with others with the same conditions, and to educate others to think about and feel the need for lives worth living.

Collective Action and the Disability Movement

Both Ray and Anne’s narratives show that the health conditions which caused their physical impairments and interruptions in their lives lead to lessons for collective identity formation. By living with these physical impairments and their related emotional impact, these experiences have been turned into informative stories to guide others to better understand their own situations while living with their respective conditions and their encounters with the social-cultural attitudes and barriers found in everyday life in general, and in organizations in particular. These interviewees live with their physical impairments, and while they have their daily physical and mental struggles of daily living, they push on with their lives as they give voice to and with others who have not had the opportunities to speak for themselves. Currently, they both seem to feel a responsibility to assist others in their pursuit of life, volunteer work and happiness. In return, their generosity as tireless volunteers has provided the opportunities for them to gain back
some of the self-worth that they had lost in the job hunting and employment retention phases of their lives.

By connecting the collective identity that they have participated in for a particular cause, both Ray and Anne have played a role in a social movement, and in this case, the disability movement. According to Melucci (1996),

A social movement is the mobilization of a collective actor (i) defined by specific solidarity, (ii) engaged in a conflict with an adversary for the appropriation and control of resources valued by both of them, (iii) and whose action entails a breach of the limits of compatibility of the system within which the action itself takes place. (p. 30)

The collective actors in these two case studies are individuals with Amyotrophic Lateral Sclerosis (ALS) which is also known as Lou Gehrig’s disease, and Facioscapulohumeral Muscular Dystrophy (FSHD). Ray and Anne are working in solidarity with their disability organizations and networks to share knowledge and assert their rights as disabled persons. They are actors within a disability movement which consists of a multitude of members. As identified by Prince (2009), there are five sectors which form the Canadian disability community: service organization, interest groups and coalitions, disability movement organizations, a constitutional category of citizens, and a research and knowledge production network (pp.5-133). Service organizations which provide support and volunteers for disabled persons, also include specific-impairment organizations which provide psychosocial support, social activities, and legal and family support. Interest groups tend to work on influencing policies, legislation and budget. Disability movement organizations are active in asserting a disability identity, and questioning the normative practices in society. As recognized citizens within the Canadian Charter of Rights and Freedoms, disabled persons can exert and legally defend their constitutional rights. Finally, the research sector of the disability community contributes to the production of disability
knowledge, and can be a critical role in addressing the social barriers, including access to paid employment.

In returning to both groups of collective actors, as represented by Ray and Anne, these constituents of the disability movement are fighting against the structural, environmental and attitudinal barriers which hinder them from paid employment. The need for both networks to exist is supported by other non-profit disability organizations which give voice to disabled persons; to advocate for systemic change and to shape policy; to provide links to a collective voice of solidarity and hope; to create strategies for resource mobilization; and to secure financial support (Hutchison, Arai, Pedlar, Lord, & Yuen, 2007). Similarly, Peters, Gabel and Symeonidou, (2009) and Putnam (2005) argued for the need for a collective identity to work in solidarity towards a common cause for social change. In identifying the common causes within the Canadian context, Prince (2009) finds that “The main contours of disability activism concern the pursuit of respectful inclusion, adequate social security, and an authentic democratic voice” (p.11). Common causes lie in the beliefs that disabled persons share common experiences and that the negative experiences could be changed through a common political agenda and engagement in political action, with potential impact on social practices and policies.

In returning to the social concern of underemployment, the context of the work environment is governed by the federal, territorial and provincial policies which are intended to support disability rights. However, the overt and covert attitudes of employers have rendered qualified individuals either underemployed or unemployed. Often the catalyst for change through collective identity resides in the existing levels of underemployment, and yet, the burden of responsibility needs to be shared amongst both disabled and non-disabled individuals. When disabled individuals are not able to work in organizations, they cannot influence the policies and
practices of the workplaces. At a minimum, the federal, territorial and provincial policies need to be recognized and implemented to support the inclusion of disabled persons within the paid labour force. In thinking about how “text enters into the coordination of people’s activities” (Smith, 2012), I now turn to investigate the public documents which shape the lives of disabled and non-disabled persons.

**Canadian Policies and Causes of Underemployment**

A critical analysis of texts of Canadian policies can determine how these policies construct disability by making use of the perspectives on disability and normalcy. These normative, and often narrow, perspectives could assume that all is well and is serving all members of the community. However, we need to explore these social policies more closely. What do these texts say about disability? What do they not say about disability? Texts can reveal much about social relations (Smith, 1999) and can be extrapolated to the understanding of how society is constructing disability in its midst. Language names events, emotions, values, and beliefs, thus, the use of language is powerful. Prince (2009) suggests that “As cultural scripts, policy documents communicate certain values, cast specific roles, and convey particular models of people and communities” (p. 7). Consequently, cultural interpretations and understanding of disability can be shaped by the many government documents which circulate at the social and organizational levels. A number of government documents have attempted to enhance the opportunities for disabled persons. The text found in social policy documents can be analyzed to understand their construction of disability and how they work within organizations. If the understanding of disability resides in the dominant medical model, then forthcoming documents may just be a reproduction of previous social policies. A disruption of these texts, through critical analysis, can be the opportunity to address reproductions, and pave the way for more
transformative social policies which understand both the social model of disability and the collective identity model. In addition to a critical interpretative textual analysis of the documents, these social policies also informed the questions that were asked of disabled interviewees. Specifically, the interviewees were prompted to reflect on the role of these policies in the prevention and removal of barriers within their work environments.

One of the initial government documents was entitled “Equal Citizenship for Canadians with Disabilities: The Will to Act” (Canada, 1996) and prepared by the Federal Task Force on Disability Issues. This document was followed up with two vision papers entitled “In Unison: A Canadian Approach to Disability Issues” (Canada, 1998) and “In Unison 2000: Persons with Disabilities in Canada” (Canada, 2000). From 2002 to 2009, Canada produced annual reports to record the experiences of disabled persons and changes over time. The most recent “Advancing the Inclusion of Persons with Disabilities 2009” (Canada, 2009) which includes comparative data from 2001 and 2006 will be critiqued. The following section will proceed to highlight how Canadian policies accounted for underemployment amongst disabled persons by setting up disability as a personal problem rather than a social issue, by touting the rhetoric of citizenship and inclusion without accountability, and by enumerating barriers to employment without commitment to change.

Disability as a Personal Problem

The document “In Equal Citizenship for Canadians with Disabilities: The Will to Act” (Canada, 1996) was tasked to answer the question: “What is the federal role in the area of disability?” by the Ministers of Human Resource Development Canada, Finance, Justice and National Revenue. Before the Task Force on Disability Issues was able to answer this question, they also had to clarify the vision for inclusion, suggest recommendations from this vision, and
then provide short, medium and long term strategies. They were able to draw over 2000 people from across Canada including representatives from twenty national disability organizations to attend 15 forums for discussions. From the feedback, disabled Canadians wanted visionary leadership, common principles and values, input into policies and decision making, a decent standard of living, a common approach to disability issues which is sensitive to individual differences, government accountability, predictable funding for disability-related organizations, and equality of outcomes (Canada, 1996). These goals were identified by disabled persons as ways to enhance inclusion, and were realistically grounded in the lived experiences of existing barriers which needed to be eliminated. The disabled persons raised concerns over the shifting of government funding to private responsibility; the prevalence of poverty; the lack of mobility across Canada due to the separate government offices which support disability-related services; and the inadequate support for disability organization, and public ignorance. The lack of action on disability-related programs resulted in the common phrase of “Just do it!” amongst the participants (Canada, 1996, p. 6).

While the forum participants wanted some action to be taken, any action at all, the federal government constructed disabilities as an individual matter. Consider the title of the report, “Equal Citizenship for Canadians with Disabilities: The Will to Act.” Titles are generally written to reflect the content and understanding of the report. In thinking about the individual model of disability, the report uses the phrase “Canadians with disabilities” and resorts to the detachment of the impairment to the person. The word “disabilities” in this case is not identified as anything from the social environment, but is used as a condition of the individual. Individuals seem to be acceptable for inclusion only when their disabilities, or more specifically, impairments can be distinct or separated from the person. As strongly stated by Titchkosky (2007),
Person-first language is typically used to emphasize personhood, as well as the conditionality of disability, and the idea that disability and persons ought to be separate….Thus, in the battle for recognition and human rights, people-first language codes may reconfirm the notion that there are some people in this world whose humanness is debate-able. (p. 196)

When this person-first terminology dominates the report, the prevailing message conveys the understanding that impairments are an individual matter and not necessarily a need for the federal government to address social accommodations. In some cases, accommodation is required to allow a disabled person to work in a modified workspace with adaptive equipment, or an accommodating workplace which has addressed architectural barriers such as stairs. The use of this particular person-first language relays how the government wants Canadians to understand disability. In speaking about language and labelling, Stiker (1999) emphasises that, “To name, designate, point out, is to make exist…and manipulate it, in our minds and in our conversations! But, quite to the contrary, language operates, transforms, creates” (p. 153). Person-first language aims for inclusion, a form of inclusion that attends to the person, while excluding or erasing the appearance of any impairments. Disabilities, as it is interchangeably understood as impairments in this individual model of disability, are not considered integral to the person’s identity, but as a mere attachment, which can be ignored in the process of transforming or conforming disabled persons to the normative order of an ableist society.

Citizenship and Inclusion

In returning to “The Will to Act” government report, what does equal citizenship mean in the context of the title? According to the report, “Citizenship offers a sense of belonging in one’s country and gives each individual the right to participate in society and in its economic and political systems” (Canada, 1996, p. 9) with a complete set of rights such as civil rights to offer freedom of speech, political rights to offer the right to hold office or vote, and social and
economic rights to offer full participation to all those who call a country home. A core principle of citizenship, as stated in the report, is inclusion along with equality, and opportunity to achieve equal outcomes. What does inclusion mean? The report turns back to the individual and indicates that “every government program should, as a matter of principle, incorporate the individual and particular needs of persons with disabilities in the very core of its design” (Canada, 1996, p. 12). Rather than constantly turning back to address the individual differences to address underemployment, the development of policy needs to take an outward look and focus on structural systems and policies that become barriers to disabled persons by being too complex, too evaluative and non-integrated across government levels.

In moving on to another government document, “In Unison: a Canadian Approach to Disability Issues” (Canada, 1998) was developed as a vision paper by the Federal/Provincial/Territorial Ministers responsible for social services. The report defines the Canadian approach, values and principles of inclusion and citizenship. It then reveals the vision for what it has deemed as core building blocks of inclusion to be disability support, employment and income. An accountability framework concludes the report. The title conveys a pan-Canada perspective to “disability issues.” While the integrated approach is welcomed, the word “issues’ already suggests a problem, a negative set of conditions which need to be dealt with. Quite easily the title could have read “In Unison: A Canadian Approach to Disabilities” to move forward with a neutral stance on the topic. Rather than solving problems, the report could be presented as new opportunities for social policy renewal. The vision is to ensure full participation of disabled persons in all sectors of Canadian society, and the achievement of this vision is the responsibility of all Canadians. I now turn to the investigation of social policies to reveal how they can influence the understanding of work for disabled persons.
Employment and Workplaces

Inaction can account for problems in underemployment. “The Will to Act” report outlined strategies and timelines for change. While the report was dated 1996, it recommended changes to be made by the year 2000. Strategies such as incorporating disability-based analysis in the design of policies, a timetable to systematically examine policies, complementary policies to ensure implementation, mechanisms to deal with accountability, and including meaningful input from the disability community were outlined over 10 years ago, but are not fully realized yet. The report’s chapter on work which is titled “The Opportunity to Work – Labour Market Integration” (Canada, 1996, p. 50) immediately conveys the value of work, and at the same time, the neo-liberal influence of the productive individual, and further adds that:

Work is important. Our consultations and research told us that this is among the top concerns of Canadians with Disabilities. It is important for the dignity of individuals. People told us about the dignity of work, the sense of accomplishment it brings them, its value to the community and to society, and the way it contributes to a sense of belonging. The tangible benefits of income, learning, and participating in the goals of an enterprise give us a sense of control over our destiny. Work is fundamental to one’s sense of well-being and to citizenship. (Canada, 1996, p. 50)

This passage specifically refers to paid work, and does not take into account unpaid work such as volunteering. Thus, the underlying principle behind these statements would be to urge people to work for an income so that they can become productive and contribute to the Canadian economy. As a corollary, paid workers can participate in the goals of a society. If one works, one can achieve citizenship, however, what if an individual is not able to participate in paid work? Then, does this person find citizenship elusive or unattainable? As stated in the body of the report, “many of the barriers to employment and independence are the result of policies, regulations, guidelines and administration that simply ignore the individual circumstances of women and men
with disabilities” (Canada, 1998, p. 51). Individual differences should not matter if there were
correct policies in place to address all differences. Again the “The Will to Act” report points
back to the individual, in aligning with the individual model of disability while not addressing a
society which has not imagined the possibilities of a continuum of differences amongst citizens
who may need to access policies and services.

One participant from the Halifax focus group, which was facilitated by the government,
thought of work in broader terms including volunteer work:

> We do not want to sit in our communities, in our houses, being
> unemployed for our entire lives. We must get out there and we
> want to work. And we want to contribute to the economy, and
> contribute to the communities in whatever capacities we can,
> whether that means working or participating in volunteer activities.
> (Canada, 1996, p. 51)

This excerpt was selected from the thousands of forum comments to highlight the benefits of
being a productive individual through work, and yet, this comment also indicates that the
spectrum of work could also include volunteer or unpaid work that was not included in the
regular text of the report. Does that mean that the government continues to place the
responsibility of disability on the individual? The government would assume less responsibility
for income support if more disabled persons gained employment. Through these statements, the
government maintains its predominant adherence to the individual model of disability and
chooses not to focus disability as a social construction of barriers.

In a token gesture to the social model of disability, consideration of social factors appear
on one page out of a document of 112 pages, that briefly states in 43 words:

> All sites offering employment services and programs to
> unemployed Canadians and those who are out of the workforce
> must be fully accessible. This includes architectural and safety
> considerations, accessibility of technology, information and
services, and the attitudes of staff and contract service providers. (Canada, 1996, p. 69).

As a foundational government document to understand the role of the federal government, the report “In Equal Citizenship for Canadians with Disabilities: The Will to Act” (Canada, 1996) has constructed disability as a separate entity from the person, an individual matter, an individual difference, a potential productive worker, and one who is minimally influenced by social factors. These conceptions may have contributed to the underemployment of disabled persons. In contrast to the meaning conveyed by the text of this report, a new way of thinking could have discussed the polar opposites of the current results. By guiding a discourse through a different path, there may have been greater potential for the integration of disability as integral to identity, as the re-conceptualization of productivity and work, as the re-imagination of the continuum of differences, and as the evaluation of social barriers to underemployment. A new way of thinking, potentially opposite to the current texts, as shown in this report, could have resulted in different findings and different recommendations to address equal citizenship, and spurred the will to act of government rather than being stalled at the social policy level.

The report, “In Unison,” (Canada, 1998) speaks about a holistic and multi-sectoral approach to reform, plus ongoing dialogue with the disability community. The new approach embraces active measures to support employment. These include the necessary support incomes, independence, shared responsibility, identification of work skills, incentives for employment and volunteer opportunities, portable benefits and services, and a person-centred approach. The report, however, ends with yet again, an alignment with the individual model, as it concludes with an appendix on the International Classification of Impairments, Disabilities and Handicaps. These policies may not result in progress unless they are measured, thus an accountability framework is indicated in this report as a method for tracking progress. Phrases such as “key
performance measures” and “annual report” (Canada, 1998, p. 1) are highlighted in these brief, two paragraph suggestions for an accountability framework. As a blueprint for change, the language which hovers over “could produce” or “could explore” needs to be stronger to emphasize the necessity for an accountability framework, and not merely a suggestion, in the aim to advance the disability agenda. Key performance indicators and outcomes in the social realm with specified timelines and responsibilities need to be identified as markers of progress.

In the report “In Unison 2000: People with Disabilities in Canada” (Canada, 2000),” the introduction to employment highlights the objectives and policy directions in bold font. The stated objectives include reduction in income support programs, promotion of access training programs, increase in the availability of work-related supports, education of employers to provide accommodations, and enhancement of work and volunteer opportunities. While there are encouraging signs to support employment amongst disabled persons, one major concern is the government’s interest in reducing the income support programs. This planned action tends to place the responsibility of disability back onto the individual rather than society which include government policies and programs.

The policy directions support the concept of accommodations, measures to off-set work-related disability costs, greater support for community economic development and self-employment, and enhanced access to education, training and transition opportunities (Canada, 2000). One of the current barriers to underemployment involves income programs that impact on work. Disincentives to work such as classification of individuals according to their impairments include higher welfare payments for more severe impairments as deemed by medical professionals. As the report indicates, the classifications could be out-dated since adaptive equipment may provide for a modified job or workplace.
The subsequent report, “In Unison 2000” (Canada, 2000), highlighted informative stories to support practices to address disability supports, employment, and income. This report portrays the government’s “dual-consciousness of disability.” Titchkosky’s (2003b) analysis of “In Unison 2000” defines the meaning of this phrase:

A dual-consciousness of disability as a biological condition (individual thing), and as a distinct population (group), governs the conduct of governments and makes possible the conscious grouping together of people with very different embodied experiences into one problematic population in need of a unified, consistent, and coherent set of programs and services. These procedures target individuals who are conceived of as excluded because of “their” capacity and “their” lack of supports.” (p. 524, italics in the original)

In highlighting disabled persons who have found work, the government depicts how the biological condition can be overcome. The thoughts from a couple of the participants from the focus groups which were held as part of a consultation process were highlighted within the report. For one example, the report highlighted Brenda Lea’s narrative and her employment experiences as a resource worker in a summer program for disabled children. Brenda will “undoubtedly…contribute to continued positive change for herself and her community” (Canada, 2000, p. 1). Similarly, through the words of another focus group participant, Collette Lacroix’s story tells readers that she has been diagnosed with a developmental disability, and she has been working as a communications department clerk and earning a competitive salary (Canada, 2000). In the translation of these stories to a report which is intended to influence future practices, the welcomed members of the disability community, include only as a single identity, which Titchkosky (2003b) has termed, the “abled-disabled” (p. 526). Emphasizing “ability” and dismissing embodied differences, amounts to a limited and exclusionary version of “workers with disabilities”. According to the report, only when disabled persons have found productive work and contributing to society are they then included into the normative order of society.
The second part of dual-consciousness whereby the government continues to relate to
disability as a difference results in groups, surveys, data, and reports which portray differences
from the “normal, able citizens.” While the non-disabled “are invested with an unquestioned
ability to participate, to work – to be a normal citizen” (Titchkosky, 2003b, p. 532), disabled
persons are counted by the government as a group with “disadvantages” which needed to be
remedied. Specifically, the report pointed to the individual differences, and again, emphasised
the normative and problematic common understanding that disability remains an individual
concern. Both “In Unison” and “In Unison 2000” continue to construct disability as an individual
bio-medical matter which resides in the individual, but if this impairment can be overcome to
allow individuals to become the “abled-disabled,” then disabled persons are not excluded, but
included as productive, contributing citizens and become role models for others. According to
the report, disabled persons were less likely to have full-time, full year work than non-disabled
persons; disabled women were the most likely to have gone without work all year; and the
unemployment rate was nearly double that of non-disabled persons (Canada, 2000).
In focusing on this transition of overcoming to normalcy, the government document minimizes
the necessity of questioning the social factors of disability. How can this normative perception be
transformed? As Titchkosky (2003b) writes,

To conceive of disability as part of the movement of life, and as
something all persons are indeed interpretively engaged by, would
cease to invest normalcy with its taken-for-granted status. To begin
to understand disability as connected to, and revelatory of, the
human condition would begin to disrupt the normal order of the
built environment, of knowledge production, and of interaction,
and even economic interaction… (p. 534).

Thus, rather than highlighting role models of the “abled-disabled,” narratives for future
government reports need to showcase practices which do not merely depict how individuals have
overcome their impairments but feature best practices of social conditions which generate a respect for difference, within a broader understanding of productivity and work.

In the Government of Canada’s more recent progress report on disability, “Advancing the Inclusion of People with Disabilities 2009” (Canada, 2009) aims to detail the employment experiences of disabled persons. Findings from the report indicate that there has been some progress made since 2001, with a 4% increase from 49.3 to 53.5% employment rate amongst working-age disabled Canadians in 2006 based on the census data. In contrast, non-disabled working-age Canadians experienced an employment rate increase from 73.8% to 75.1% over the same period. Of the disabled Canadians who were employed, just over half (54.7%) were employed year-round.

The employment chapter of this report highlights the employment rate, the year round employment, workplace accommodations, and unpaid employment/volunteering. The report is counting numbers and percentages to convey the magnitude of the employment concern, but by doing so, it is also labelling disabled persons as problems and making a statement about the individuality of this concern. Is the government choosing to absolve itself of responsibility for disabling factors? If the government is more mindful of the social factors, what needs to be counted is not the unemployment rate but the changes that have been made to the social environment such as training programs to build disability awareness amongst non-disabled employees, the universal design of buildings, the accessibility of public transportation, and availability of adaptive technologies. In a similar annual report which proposed funding partnerships between the federal and provincial/territorial governments, other social factors which could denote progress but are not yet counted include job coaching and mentoring initiatives, wage subsidies, accessibility job placement networks, and self-employment (Canada,
2006). Additionally, social policies which can support public education and employer programs to address attitudes towards disabled persons and to educate on the barriers and experiences of disabled employees can reduce the stigma, discrimination and labelling which results in underemployment (Shier et al, 2009).

Modifications can be counted and categorized into two social factors: resource specific whereby the job is modified or assisted with computer technology, or physical/structural which would result in changes to handrails, workstations or accessible washrooms. In the comparative data, the results are discouraging since in 2006, 70.2% of employed working-age disabled adults with requirements had all of their resource-specific needs met, compared to 79.9% in 2001 (Canada, 2009, p. 3). In contrast, 49.1% of individuals with physical or structural modification requirements indicated that all of their needs were met in 2006 which was a decrease from 76.1% in 2001 (Canada, 2009, p. 3). The main reason for their needs not being met was due to the costs of the disability supports (Canada, 2009), thus an increase in income in the form of employment or income support can readily increase access to these aids and devices to ease activities of work roles and daily living.

In the same report, education and income are summarized. The majority of disabled persons (74.6%) had earned a high school diploma or higher, with more women (24.8%) attaining a diploma than men (18.3%). In the trades, more men (19.2%) received trade or apprenticeship certificates than women (10.8%). Once in the workplace, some of the barriers to training and potentially career advancement included inaccessible locations, ill-adapted course formats, denial of opportunities by employer, inadequate transportation, lack of time and high costs of courses (Canada, 2009). The annual average salary of disabled working-age adults continues to be less than that of non-disabled working-age adults based on the comparative
census data from 2006 and 2001 (Canada, 2009). While employment income is only a source of income for half of the working age adults, the primary source of income for a majority (55.7%) of disabled women was government transfers. In the intersections of employment and income, 37.2% of employed disabled adults had self-rated their health as very good or excellent, in comparison to the 25.1% of unemployed disabled adults. The 2009 annual report highlighted progress in employment rate and education, lack of change in income, and even worse, some regression in disability supports. Each of these indicators intersect with the other, and in turn, they all can impact on the health and well-being of disabled persons. Notably, employed non-low income disabled persons perceived a higher health status than their non-employed low income counterparts.

In this review of the text of social policies, Canadian social policies can be causes for underemployment as they construct disability as a personal problem, define characteristics of citizenship and inclusion, and imagine work contexts for disabled persons. Where there is some progress, there is still a large gap between employment rate and income between non-disabled and disabled persons. In thinking back to the collective identity stories of Ray and Anne, they provided some solutions for social change, but their limited information then prompted me to turn to the texts from Canadian social policies to investigate how they can become solutions, rather than remain causes for underemployment.

**Canadian Policies and Solutions for Underemployment**

Throughout the Canadian policies which were reviewed in the last section, common themes emerged and revealed how social policies caused underemployment. However, social policies can be and need to be prominent forms of solutions to the problem of underemployment. In thinking about a conceptual framework which fuses the revised social model of disability
using the rights approach in conjunction with the collective identity model, I explore the social policies on employment, unemployment and underemployment which are written about disabled persons by policy makers. Governments at all levels must create and implement policies by engaging more disabled persons as key informants and policy makers to assert their rights to speak and participate in decision making, to think through the access to social resources, and hear the democratic voices of all in a concerted effort to advance full citizenship. This next section will explore the rhetoric of equality, citizenship, a Canadian for Disabilities Act and accountability as they appear in the documents, how they relate to each other, how they relate to collective identity and how they can address underemployment.

**Equality**

“The Will to Act” report recommends a disability policy framework which supports the purpose of the Canadian Charter of Rights and Freedoms and ensures constitutional equality. This equality is further itemized and defined: “The goal of equality means that self-determination, autonomy, dignity, respect, integration, participation and independent living must be the effects of *all* federal programs, laws and activities” (Canada, 1996, p. 26, italics in the original). The report envisions an “inclusive labour market” which begins with programs and services which are designed in consultation with disabled persons, with employers who can provide accommodations for employees during the regular course of hiring and retaining practices. The report uses the phrases “equity in participation” and “equity in outcomes and results” (Canada, 1996, p. 57) which embraces fairness and a commitment to serving disabled persons proportional to their representation in the working age population, including work delivered by organizations of and for disabled persons.

Equality is a critical goal of the social model of disability (Bickenbach, 1993; Rioux & Valentine, 2006). Yet, as outlined by these authors, there are different forms of equality such as
equality of respect, equality of opportunity, equality of result/outcome, equality of capability, and equal treatment. There are three which overlap and this section will address equal treatment, equal opportunity and equal outcome. Equal treatment may be a reasonable strategy, however there is a marked difference between “the right to equal treatment versus the right to be treated as an equal” (Bikenbach, 1993, p. 240). If there are different individuals, and their needs are unique, then equal treatment could undermine their dignity, rather than preserving it.

Equal opportunity takes into account social factors by ensuring that barriers are minimized to allow for fair access. Equal outcomes can follow equal opportunities such that disabled persons will have access to the same results as non-disabled persons. In contrast,

Inequalities involve, or lead to, differences in wealth, power, access to resources, status, social role, and other indicia of social importance and individual well-being and self-esteem. Inequalities are more than mere differences because they inevitably involve some form of ranking based on normative distinctions of virtue and vice, superiority and inferiority, worthiness or worthlessness. Whereas differences create distinctions, inequalities create stratifications. (Bickenbach, 1993, p. 232)

In terms of social policies and the deconstruction of the word equality and its different meanings, a more meaningful word may be introduced to the discussion. The term “equity” was introduced in “The Will to Act” (Canada, 1996, p. 57) with the phrases “equity in participation” and “equity in outcomes and results” but it has not reappeared in the more recent government vision and accountability reports. Social policies need to embrace equity, not equality, to set forth a guiding principle which advocates for fairness, respects differences and prevents inequalities. Imagining equity in society can then provoke and permeate discussions based on fairness while embracing differences.
Citizenship

“In Unison’s” objectives for full citizenship are “to make as inclusive as possible all domains of Canadian society” and “to mobilize all sectors to enhance the full and equal partnership of persons with disabilities” (Canada, 1998, p. 1). The accompanying policy direction is stated as “policies that promote access to generic programs and services for all Canadians, including persons with disabilities” (Canada, 1998, p. 1). Citizenship can have different meanings and results for disabled persons. Rioux and Valentine (2006) have developed a matrix which aims to identify the impact on social policy when the models of disability also intersect with concepts of equality and disability. According to their matrix model, equality falls along a continuum ranging from equal treatment, to equal opportunity to equal outcome, with the former aligning closer to the individual model and the latter aligning more with the social model of disability. Furthermore, concepts on disability can be identified as civil disability, charitable privilege, and citizenship status.

Civil disability is characteristic of the individual model of disability and its biomedical and functional approaches. The concept of civil disability focuses on providing care for an individual, translating into “paternalistic decision making, politics, programs and services which include institutional living, segregated education, and sheltered workshops” (Rioux & Valentine, 2006, p. 57) which attends to the unchanging condition of the individual. Thus, along the matrix model continuum, equality results in equal treatment. Charitable privilege offers care and treatment and is based on benevolence and on forms of paternalism. These actions acknowledge the individual’s impairment as well as the impact of the social and physical environment such that “Goods and services, such as a medical care, housing, welfare, and therapeutic services, are provided to the individual not as a matter of right but as a matter of charity and compassion” (Rioux & Valentine, 2006, p. 58). Understanding disability as a charitable privilege falls into the
realm of both the individual and social models of disability. Consequently, there is a social responsibility to care for or to provide supports for individuals as a result of impairments. In contrast, citizenship status is based on human rights and equal treatment (Rioux & Valentine, 2006, p. 58). Citizenship status is not limited to human rights and equal treatment.

According to Prince (2009), citizenship can be identified in more detail with five elements which include “the discourse of citizenship, legal and equality rights, democratic and political rights, fiscal and social entitlements, and economic integration” (p. 17). The discourse of citizenship can be found in the Charter of Rights and Freedoms, social policies, popular culture and mass media. Legal, equality, democratic and political rights are closely tied to institutions which include “the legal system and judiciary, the Charter of Rights and Freedoms, the electoral system, the legislative, executive, and administrative branches of government, and disability organizations” (Prince, 2009, p.17). The social element of citizenship includes education, health care, social services, and income security, while economic integration focuses on access and mobility in the paid labour market. As part of disability activism, employment is critical to full citizenship, as Prince (2009) states that

A core element of the struggle for ‘access’ means access to paid labour. The economic dimension of full citizenship assumes gainful employment, rather than the alternatives of sheltered workshops or voluntary service masquerading as competitive and fair wage-based work. (p. 182)

Citizenship status confirms that society needs to have a better understanding of disability rights within the social model of disability. By identifying the elements of full citizenship, disabled individuals can be better equipped to fight the existing barriers to participation, and seek their rights to speak, act, imagine, negotiate, re-think and influence social policies which have been both causes and potential solutions to underemployment.
Canadians with Disabilities Act

“The Will to Act” (Canada, 1996) introduced the concept of a “Canadians with Disabilities Act” which could support the broad interpretation of citizenship rights in areas that fall under federal jurisdiction back in 1996. The report even outlined a five year action plan to include statements of principles and values, enforcement and reporting mechanisms, and a review of the proposed Canadians with Disabilities Act. Time has passed and yet there still are no signs on the federal front for a national legislation to advance the disability agenda. The benefits of a Canadian Disability Act may positively impact telecommunications, employment equity and human rights. However, it would be limited under the provincial legislations which oversee programs and services such as employment, education and health. With two distinct levels of jurisdiction, there would be a need for intergovernmental collaboration. Based on the development of “In Unison” and “In Unison 2000” reports, there were proposals for collaborations at the various levels of government, and dialogue to be continued amongst the Federal, Provincial and Territorial Ministers responsible for social services. If social policy has not achieved sufficient progress, then this recommended legislation could do more by setting the standards for the achievement of noticeable change alongside social policy statements and recommendations. Standards followed by progress reports would then set the stage for improved public accountability to limit or remove social barriers for disabled persons.

Accountability

Public documents are merely inventories of existing programs and policies. They could be more effective in the social processes for change. In Prince’s (2009) critique, he states that:

They could be robust accountability documents by including evaluations of results against objectives, over time, and by engaging interested publics of the disability community around possible new initiatives and/or reforms to current programs and
delivery systems, through online consultations, roundtable meetings, and other processes. (p. 214)

Rather than using government discourse as “technologies of stratification” (Prince, 2009) to set boundaries to include and exclude individuals by evaluating, labelling, ranking and monitoring disabled persons, these reports could disrupt the normative order and move away from normalcy, and yet social policies have reached a point where they continue to pre-dominantly repeat their understanding of disability as an individual matter. The government policies have articulated equality, citizenship, a Canadians with Disabilities Act and accountability as vision and strategies for inclusion as far back as 1996, and the government still has not moved in a responsive pace to address underemployment. This response is disconcerting when it affects approximately half of the disabled persons who are of working age, and affects the intersections of income, lifestyle, and health and well-being.

A new model of citizenship engagement is proposed by Prince and exemplifies the theoretical discussions of Melucci on internal and external relationships. This new model identifies seven levels of engagement (Prince, 2009): 1) at the intra-community level, there is engagement within the disability community; 2) at the cross sector level, disability groups are engaging with other groups from the voluntary sector; 3) at the community-political executive level, disability groups are engaging with cabinet ministers and city councillors/mayors; 4) at the community-legislative level, disability groups are engaging with legislative committees and individual members; 5) at the community-judiciary level, disability activists and groups are engaging with the courts, human rights commission, and tribunals; 6) at the community-public service level, engagement would be amongst disability representatives and public servants; and 7) at the community-intergovernmental level, engagement would be based on structures and processes which would realize a collective policy vision. This model of multi-level engagement
supports the need for a variety of stakeholders as essential in the movement of ideas and the realization of plans (Thun, 2007). Thus, citizenship engagement begins with and welcomes the dialogue amongst disabled persons, and between the disability community and policy makers to talk through and about rights, equity and citizenship. By embracing diversity, citizenship rights and engagement, social policies can move beyond mere rhetoric to the will to act by connecting with the wider political community to aspirations of belonging and participation.

In the areas related to underemployment, the dialogue can address topics including social policies, employment practices, architectural barriers and cultural habits. For example, when disabled persons and activists formed a collective identity and called themselves the United Disabled Consumers (UDC) in Hamilton, Canada, they were able to focus attention on common interests, including employment, transportation and physical-access issues to influence the social policies within municipal politics, and subsequently engage in provincial discussions as part of the Ontarians with Disabilities Act (ODA) Committee (Kitchin & Wilton, 2003). It is through discussions from representative groups such as the UDC and ODA activists which can generate new ideas and work through potential tensions stemming from difficult discussions. Despite the many perspectives which need to be heard and appreciated, tense moments within a disability dialogue can be valued and embraced as a time for new learning. In recalling Melucci’s (1996) collective identity framework, tension can be a creative space for thinking, feeling, and engaging. Tensions, which often involve emotions, can then spark new ways of imagining what can be possible, of what can be otherwise, with the full engagement of disabled persons who through their collective identities and through their experiences of disabilities and impairments, can then be respected and empowered to share their ideas and action plans for meaningful changes.
Policy directions to address underemployment can then follow a new paradigm which is based on the fusion of the social model of disability with the collective identity model to champion for citizenship status, citizenship engagement, equity in participation and outcome, and public accountability. A disabled person, as a Canadian citizen, can then expect to receive legal, social and economic rights with opportunities to engage in social and political levels of planning, decision-making, monitoring and evaluating. Citizenship engagement is an essential process and goal, particularly when the achievement of equity lies in the participation of a variety of stakeholders. Rather than just reporting at the government levels, public accountability means that disabled persons will have the opportunity to monitor progress and express concerns when performance indicators have not been reached. This new terms of reference could then better serve disabled Canadians who can expect employment as a right, choose from diverse work options, access work accommodations, participate in policy discussions and directions, and experience progress through realized action plans and accountability reports.

**Accessibility for Ontarians with Disabilities Act**

A national disabilities act does not yet exist, but the collective identity of disabled persons and their activism have resulted in legislation to establish standards to remove barriers and promote inclusion in the province of Ontario. The documents of the Ontarians for Disabilities Act (ODA) and the Accessibility for Ontarians with Disabilities Act (AODA), and the Integrated Accessibility Standards Regulation (IASR) exist as artifacts of a collective identity which signal the work of an active disability rights movement. These legislations have established the long awaited standards which are required by public and private organizations to reduce social barriers and promote access for disabled persons. Accountability and compliance are key elements of these legislations. I now turn to the development and meaning of these legislations for disabled persons and their access to employment.
On December 5, 2003, Ministers responsible for Social Services approved the *Multilateral Framework for Labour Market Agreements for Persons with Disabilities*. The Multilateral Framework outlines the commitment of governments to work towards ensuring that persons with impairments can participate successfully in the labour market. The goal of the Multilateral Framework was to improve the employment situation of disabled Canadians by enhancing their employability, increasing the employment opportunities available to them, and building on the existing knowledge base (HRDC, 2003).

In response to this agreement, the province of Ontario passed the Ontarians with Disabilities Act in June 2005. While the Act was passed, organizations have plodded through the removal of barriers. As of January 2008, the Ontario government passed the first of five standards under the Accessibility for Ontarians with Disabilities Act (AODA). The five standards are: customer service, information and communications, employment equity, transportation and built environment. Non-compliance to these standards will eventually result in penalties for the organizations which receive complaints regarding their failure to comply.

Accessible employment policies and training requirements include accessible employment policy statements, accessible employment policies and employee training. The requirements from recruitment to hiring include job postings, accessible recruitment information and communications, and assisting potential employees. Retention requirements include individual accommodation plans, job orientations, performance management, career development and advancement, and accessible information for retention purposes. Once these AODA employment standards become law, organizations will have two to five years to document their compliance and the specific timelines are dependent on the number of employees, and the private or public nature of the organization. Koyabashi (2002) emphasises
“progress in breaking down barriers is part of creating the hiring practices that will see more members of designated groups hired and promoted, the rate of cultural change is hastened once the numbers begin to shift” (p. 246). A change in culture may be facilitated by the removal of barriers and the recognition of diversity as a benefit to organizations, however, what is the role and impact of the current social policies on underemployment amongst disabled persons?

Within Ontario, the passage of the Integrated Accessibility Standards Regulation (IASR) (OMCSS, 2012) as part of the Accessibility for Ontarians with Disabilities (AODA) legislation is targeted at “developing, implementing and enforcing accessibility standards in order to achieve accessibility for Ontarians with disabilities with respect to goods, services, facilities, accommodation, employment, buildings, structures and premises on or before January 1, 2025” (AODA, 2011). Five areas which require standards have been identified: customer service, information and communications, employment, transportation, and built environment. The AODA employment standards, filed in June 2011, were developed alongside the information and communication, and transportation ones to now form the 87-page “Integrated Accessibility Standards Regulation.” The format of the regulations document is divided into five distinct parts: general, information and communications standards, employment standards, transportation standards, and compliance.

Part I General of the IASR clearly states that the scope of the legislation applies to the three key areas; it is “not a replacement or a substitution for the requirements established under the Human Rights Code” or any other related legislation, and pertains to public and any other organizations which provide goods, services and facilities to the public and third parties. Obligated organizations have been given a schedule for compliance by establishing accessibility policies and plans, with a phased in approach from January 1, 2012 to January 1, 2015. The compliance process begins with the Government of Ontario, followed by large public sector
organizations with 50 or more employees, small public sector organizations with fewer than 50 employees, large organizations with 50 or more employees, and then finally small organizations with fewer than 50 employees. The stated schedules for compliance prompt an immediate leap to the consequences of non-compliance. Part V Compliance states that penalties can range from $200 for minor infractions, to $2,000 for major ones. Penalties for corporations can range from $500 to $15,000 for non-compliance. A minor contravention addresses administrative procedures. A moderate contravention addresses organization preparedness, while a major infraction relates to an incident which includes but is not limited to the health and safety of a disabled person. If the organization offends repeatedly, the fines also go up based on their reporting history.

The general and compliance sections of the IASR seem to offer disabled persons new regulations to support their pursuit for accessible communications, employment and transportation. While organizations may need to address these new regulations, disabled persons had these rights since the establishment of the law under the Ontario Human Rights Code (OHRC) in 1962. Specifically, the OHRC (2012) states that

Every person has a right to equal treatment with respect to employment without discrimination because of race, ancestry, place of origin, colour, ethnic origin, citizenship, creed, sex, sexual orientation, gender identity, gender expression, age, record of offences, marital status, family status or disability.

After 50 years since the establishment of the OHRC, organizations still need to be regulated to prepare for accommodations for disabled persons, with a schedule for compliance and with penalties for non-compliance. The appearance of this document reflects a society that still acts as a barrier to the rights of disabled persons. By developing accessibility policies, accessibility plans, and training workshops on the standards according to the regulations in the
document, organizations are deemed to be performing accessibility. They are complying, but compliance does not convey an understanding of human rights. Compliance means meeting standards, but are they only minimal standards?

In returning to the specific requirements in the IASR, this section will now turn to its Employment Standards. This 12-page section lists a range of topics from scope, schedule, recruitment, accessible formats, workplace emergency, return to work, performance management, career deployment and redeployment. In the scope and schedule section, the standards apply to the employers of obligated organizations but not employees, with an implementation timeframe from Jan. 1, 2013 to Jan. 1, 2017. These timeframes signal a notable time lag time of one to two years between the accessibility plans and the future realization of these standards. While organizations may think that they have time to address and adjust to the standards, disabled persons have every right to complain about lack of progress or illegal treatment when they consider the OHRC. Under the OHRC, organizations already are legally bound to a duty to accommodate (Ontario, 2012). According to the social model of disability, it is exactly their failures to accommodate which both delay and hinder the removal of employment barriers for disabled persons.

Accessible formats and communication supports are required accommodations for employees who request them. For accessible formats to be made available, accommodations can only be made available through the thinking and planning processes of organizations. When information is required to do the work and to learn about the work culture, it is mandatory for employees to have this information in accessible formats. Whether it is large print or adaptive technology, employees have the right to reveal and relay their need for accommodations without discrimination. For the safety of employees, there is a standard for workplace emergency response information. Since this standard is a matter of life and death, the timeline was set for
the same date as of January 1, 2012 for all employers. This is a priority standard and can provide
reassurance for a safe workplace for all disabled employees who may require accommodations
and assistance during an emergency.

These individual accommodation plans are to be documented with input of the employee
requesting accommodations. Both disclosures and documentations signify an increased level of
surveillance of the employer upon the disabled employee, which raises the question: When does
the disabled employee deserve the right to privacy? The extra documentation can result in extra
work for the employer, and add to the perception of the employee as an additional burden. Rather
than everyone learning about accommodations, the disabled employee will be singled out to be
the “other” – the exception to the normal worker. This standard emphasizes difference, with
disability being different from others. Rather than training employees on the range of
accommodations for communications and emergencies, these standards return to the individual
model of disability by addressing the difference or impairment, and not necessarily the
marginalization and oppression of a disability identity as a result of the dominant attitudes in
society.

The Employment Standards of the IASR offer 13 requirements which can influence the
human resources cycle of recruitment, to employment, to career development. The recruitment
standards require job postings and interview processes to notify candidates that
“accommodations are available upon request” (OMCSS, 2011, p.16). While this statement can
provide the aim for inclusion, it may not consider that public disclosure is a difficult choice for
many disabled persons. A request for accommodations necessitates the disclosure of a disability
identity, whether visible or invisible, which may result in less than welcome consequences for
the potential employee. The consequences, as presented earlier in this chapter, can range among
denial, dismissal, or lack of opportunities. However, there is potential for more. Revelation of a disability identity can contribute to the social relations of disclosure to emphasize that disability does exist, and can be a productive worker in a move towards accessibility in work contexts. Disclosure can support the move towards a collective identity, as an action of solidarity and which “entails a breach of the limits of compatibility of the system within which the action itself takes place” (Melucci, 1996, p. 30). A disclosure then would expand the boundaries of who will be included as part of the labour force. Something other than the “average worker,” which is the dominant expectation of current work environments, can start to be expected, and perhaps, even accepted in more progressive workplaces.

Within the employment standards, employers need to inform employees of the “provision of job accommodations” and that employers “shall develop and have in place a written process for the development of documented individual accommodation plans” (MCSS, 2011, p.17). With the lack of disabled employees in the workplace, there is an urgent need to invite representatives from either the workforce or the disability community to guide the development of these documents, which will in turn direct the accommodation practices within the organizations. Another welcome addition to the Employment Standards is a section on career development and advancement, with the aim of facilitating an employee’s success. While the strategies of career development for disabled persons include job movement for a higher pay, greater responsibility, or higher level, or any combination of these, there needs to be a certain amount of skepticism as to how many employees can actually access these opportunities, and thus necessitate the employer to provide these options. Currently, the employment rate of disabled persons (53.4%) falls short of the non-disabled counterparts (75.1%) in Canada (Canada, 2009).
These employment standards have come into existence as a result of the advocacy work of disability organizations and activists to provoke social responsibility towards inclusion. The documented standards exist as artifacts of a collective identity which signals that an active disability rights movement is flourishing. In Ontario, the Accessibility for Ontarians with Disabilities Act (AODA) Alliance, which represents disabled persons who are working towards a barrier-free Ontario, is using the AODA and the IASR documents to voice their concerns to the provincial government. Their letter to the premier specifically asks, amongst numerous questions on compliance and enforcement of the AODA and the IASR, “What specific plans does your Government have for enforcing the requirements of the Integrated Accessibility Regulation?” (Lepofsky, 2013). The AODA Alliance reminds the government of their political promises which were made in writing in three elections in 1999, 2003, and 2011, and states that

We recognize that enforcement must be coupled with other strategies to best ensure that the AODA is effectively implemented. However, without effective enforcement, we fear that any other strategies would pale, as the AODA would fade into voluntary legislation that your Party rightly condemned as inadequate, during the previous Harris government. (Lepofsky, 2013)

As Chair of the AODA Alliance and as a person with a visual impairment, David Lepofsky has written this letter on behalf the organization to represent disabled persons as part of a social movement to change Ontario. In addition to email updates to the AODA Alliance and the organization’s website, Lepofsky urges disabled persons and allies to take action and engage in political activism by calling members of parliament and by using social media such as Facebook and Twitter. In recalling Swain and French (2008)’s point that “In affirmation of identity the personal becomes social/political and the political becomes personal” (p. 67), disabled individuals can address their concerns about unemployment and underemployment as social-political issues in a concerted effort to change the status quo in organizations. Prince (2009)
supports the notion of this personal shift to the socio-political when he writes that, “Disability activism, in the Canadian context, is a form of social liberalism that emphasises not only individual self-development but also community and the rights of groups” (p.26). Furthermore, “liberalism with a social outlook relates to a rights-based advocacy for equal treatment under the law” (Prince, 2009, p. 182). As in the case of the AODA Alliance (Lepofsky, 2013), the advocacy work of this collective identity can be examples of disability activism or social liberalism which have taken actions to persuade governments and employers to respect the rights of the disability community, to think about accommodations, and to create spaces for difference. Disabled persons as a collective identity can influence and change the cultural scripts of policies and legislation. Consequently, as cultural scripts, Canadian policies and Ontario legislation which have entered the public sphere and offer the potential and power to shape the social relations of disabled and non-disabled persons can be critical solutions in advancing the goals of disabled persons and the disability movement.

Conclusion

The identity of a person or collective is interwoven with the complex relationships which we have as we encounter society, and how it subsequently reacts to a collective identity which moves disability beyond a personal matter. The collective identity is a part of a personal and social-political interface whereby the thoughts, feelings, histories and experiences of individuals encounter the social-political of who becomes accepted or excluded in a work environment. Collective action can push the boundaries of who is accepted and address the abilities of disabled persons. Consequently, collective actions resulting in the disability movement can gain greater traction and momentum, with “civic engagement as a crucial way for breathing life into the vision of access and inclusion” (Prince, 2009, p. 207). By pushing the limits and acting together
as engaged citizens of a society in need of changes, more disabled individuals can become members of the workforce if they choose this option, and more employers will have the opportunities to interact with this potential employee group. A reform priority would be to dispel the employers’ fears and assumptions about disabled persons. If it cannot be accomplished at the interpersonal level, then legislative documents are needed to include enforceable standards to move the general public to become a more inclusive society. The combination of a collective identity and collective actions channeled towards a particular cause such as the disability movement can have the potential of dismantling some of the barriers found in underemployment.

Canadian policies play a major role in accounting for underemployment and a limited one in providing solutions. Despite social policies which have existed for over two decades, disabled persons are unemployed and underemployed to a greater extent than non-disabled persons. Many disabled persons are relegated to low paying jobs and living in poverty, with disabled women being amongst the most marginalized. Disabled persons are underrepresented in managerial and professional positions. To address societies which disable persons with impairments, there needs to be changes at the local and macro levels. In this research study, I consider the local levels of work organizations, and the macro levels of national policies and provincial legislation. Work organizations and society-at-large require national and provincial policies and legislations to develop accessible environments and become accountable for change. To reduce the discrimination and stigma, workplaces need to change. Much education in the workplace is needed to reduce and eventually, eradicate these barriers to success at work.

Engaging disabled persons by valuing their collective identity as places from which to begin a discussion on rights, equity and citizenship, to consult on widespread social policies, and to learn with and from lived experiences can pave the way for the achievement of human rights
in a more equitable society. This chapter recommends a conceptual framework which fuses the revised social model of disability using the rights approach in conjunction with the collective identity model to emphasise the interactions between the two to foster synergistic relationships between disabled persons and policy makers, with the emotional passions to advocate and deliver meaningful actions and results. By deconstructing the hegemonic understandings of Canadian social policies, the re-imagination of new possibilities to embrace disabled persons as valued members of society can begin. Work, including both paid and unpaid dimensions, needs to be considered as valuable productions and contributions to society when disabled persons conduct their lives living within a normative society. Meaningful and productive work can then be an individual choice, rather than what is predicted, expected and measured by society. Governments at all levels must create and implement policies, by engaging disabled persons to assert their citizen rights to speak and participate in decision making, not as an adjunct practice but as an integral process in a desire to address rights, equity and citizenship. Complexities and differences in our social identities are our current realities as human beings. In a desire to create a better world, and to specifically reduce chronic underemployment, a collective disability identity interacting in harmony with a renewed citizen-centred social policy environment can be more empowered to express differences, address inequities, influence government policies, and advance social change.
Chapter 7
Resisting Underemployment

The social model of disability points to structural, environmental, and attitudinal conditions as barriers to full employment (Gillies, 2012; Shier, Graham & Jones, 2009; Swain & French, 1998). The structural barriers include the inflexible policies and procedures surrounding accommodations, and the limits imposed on employment opportunities such as the Ontario Disability Support Program (ODSP). The environmental barriers can be found in built facilities and the transportation system. Negative attitudes are prevalent amongst organizations as employers and co-workers either ignore the presence of disabled persons or include them only as token representatives. Additionally, many employers demonstrate poor attitudes when they do not comply with legislation pertaining to accommodations.

With their observations about workplace, Michalko and Titchkosky (2010) tell us that Disability does disrupt all social institutions. Rather than conceiving of this disruption only as a problem in need of a solution, it can be understood as a space through which the normative order can be “viewed,” understood, and ultimately changed. As teacher, disability is a “good problem”. (p. 122)

I turn to the interviewees with their lived experiences of the “good problem” of disability to guide me in thinking through the normative spaces in the work contexts, with the aim of learning more about their circumstances, and ultimately, suggesting changes to the current structures and systems. To address these barriers, the interviewees for this research study were invited to express their ideas on solutions to underemployment. Their narratives provide insights on how to improve the current dilemma of underemployment amongst disabled individuals, and begin to
offer recommendations to my final research question: How can underemployment amongst disabled persons be addressed at the organizational level?

The recommended actions from the interviewees have been organized into a framework which addresses the three main barriers -- structural, environmental and attitudinal -- and their respective components (French, 2001). I have organized these recommendations as ways to resist underemployment: structural actions include legislation, funding, entrepreneurship, incentives and funding; environmental actions include accessible transportation, environments and ergonomics; and attitudinal actions can be enhanced through human resources recruitment, organizational training, accommodations, networking, support groups, allies, and media representations. These recommendations are not offered as an exhaustive list, but act as an opening for organizations to think about, rally around and act upon to enhance accessibility.

I will now begin to outline the details of these recommendations, starting with structural barriers and actions.

**Actions Against Structural Barriers**

Structural barriers exist despite the existence of accessibility legislation and funding programs which are intended to address the needs of disabled persons. In fact, the existence of certain funding programs, which will be explored in detail later in this chapter, limits opportunities for individuals to reach their full potential. This section will investigate the factors which contribute to these limits and recommend actions to expand these boundaries.

**Legislation**

Employment for many disabled persons has been in the form of job placements whereby minimal skills are required. Since the late 1970s through the legislation of the Ontario Human Rights Code (OHRC) (Ontario, 2012), disabled persons have had the right to work. More
recently, the provincial government of Ontario passed the Accessibility for Ontarians with Disabilities Act (AODA) in 2005 with the aim of “developing, implementing and enforcing accessibility standards in order to achieve accessibility for Ontarians with disabilities with respect to goods, services, facilities, accommodation, employment, buildings, structures and premises on or before January 1, 2025” (OMCSS, 2011). The employment standards, filed in June 2011, have been developed alongside the information and communication, and transportation ones to now form the “Integrated Accessibility Standards Regulation” (IASR).

Most of the interviewees for this research study have not felt the positive impact of the passage of this new legislation since these interviews were conducted during 2011, and most employers were just being made aware of the new standards. However, the opinions of the interviewees can shed some light on the future success of the new legislation, as presented by the following interviewee.

Penquin is a retired civil servant who has worked in the provincial government for 23 years and is a 62-year-old Caucasian male who is blind from birth. As an activist, he is fully aware of the AODA and says that it is “woefully inadequate since it has no enforcement process” and continues sarcastically, “it has actually had positive impact based on how little it says and how little it requires.” In other words, Penquin believes that the AODA standards are not sufficient in their requirements in meeting the needs of disabled persons, and will not be adhered to due to the lack of compliance processes. While the original OHRC was established in 1962 (OHRC, 2012), he believes that the amendments to the OHRC in 1979 provides the legislation to support disability rights within work contexts. Penquin, along with other disability activists, was instrumental in the passage of the amendments to the OHRC since he worked hard in the 1970s to lobby the government to include disability rights within the provincial legislation. He believes
that any discrimination can then be taken up through the OHRC, or the Canadian Charter of Rights, section 15, which clearly outlines equality for each person under Canadian law.

While Penquin comments on the new legislation which he believes is inadequate, he does acknowledge that the Ontarians with Disabilities Act (ODA) does require organizations to report action plans, and forces municipalities to think about disabling issues. He says, “It was easy to ignore our needs in the first place. At last, they have put us on the radar screen.” From action plans to enforceable standards, the ODA and now the AODA and IASR, are legislated by the provincial government to ensure public and private organizations in all sectors are taking immediate actions to remove barriers to employment, and enhance opportunities for work for disabled persons. The IASR is current legislation, with its new passage and renewed commitment to accessibility for all, may address the barriers to information and communications, employment equity and transportation. However, if there is non-compliance with the IASR, it will become yet another document with minimal impact on the reduction of underemployment rates amongst disabled persons.

Michelle, who is a social worker, shared her doubtful sentiments about the new legislation:

If you want these to be effective you cannot write it on a piece of paper for people to know what to do with them. You need public education so people can understand why there are these standards. Changing perspective on how Ontario thinks about disability. I don’t think that we are there yet.

Consequently, legislation can state the legal standards but more public education is required for compliance to these new laws to be realized. The general public needs to understand the benefits and the actions which need to be taken to transform visions into reality. Each standard must be translated through public education so that realistic plans can be developed and implemented at
the organizational level in accordance to the legal requirements. Accessibility audits by representatives from disability organizations can support compliance (WHO, 2011). Public education can be paid for by the government and disseminated through different modes of communication such as radio, television, billboards and websites. Legislation can be a catalyst for the discussions, education and actions, but it will take the collective efforts of disabled and non-disabled individuals to begin to make changes at the personal, organizational and social levels. These collective efforts can potentially build momentum from the personal levels of disabled persons and allies to influence practices and policies at the organizational level, which may in turn influence the broader society in terms of awareness, perspectives and actions.

**Funding**

The ODSP provides income support for some disabled persons who are working limited hours or are unemployed due to an impairment or impairments. The amount that is received per person per month is intended to cover the basic needs and shelter allowance. The basic needs are defined as food and clothing, while the shelter allowance is meant to help cover rent or mortgage payments, heat, utilities (hydro, water), property taxes, home insurance, and condominium fees (Ministry of Community and Social Services [MCSS], 2012). The income support formula from the website of the MCSS (2012) indicates “How earnings affect your Income Support:

1. We look at your net monthly earnings. This is the money you earn from work minus your mandatory deductions, such as income tax, Canada Pension Plan and Employment Insurance contributions and union fees.

2. We calculate half of your net monthly earnings (50% is exempt).

3. From the amount in step 2, we deduct part or all of your monthly child care and disability-related work costs that you report to us.

4. We subtract the final amount in step 3 from your Income Support amount.

5. We give you an extra $100 Work-Related Benefit.
Thus, the number of hours worked by an individual can affect the total amount of ODSP income support that a person can receive. If a person earns more, there will be a greater deduction from the government funded income supports. With additional financial concern, one interviewee is working part-time because he does not want his income to affect his co-op housing arrangements. Craig, who is a musician, says:

Right at this present time, part-time may be best for me as a full-time job would probably not be so good for my finances. Because I live in a co-op housing and I am eligible for subsidy. If I go back to work, then my rent will go up.

Craig would have liked to have worked more hours as a musician, but because of the ODSP formula he is limited to working part-time hours since he does not want his income supplements or rent payments being affected. Thus, the funding formula is restrictive and needs to be changed to prevent those who can work more from being penalized. Additionally, a number of the interviewees recommended that the ODSP restrictions be modified so that they are allowed to work more hours and to not be taxed heavily on the earned income. The current formula for financial compensation are disincentives for disabled persons who are able to work but are concerned about the claw-back from the government on their ODSP income. Once a person pursues a full-time position with a steady income, the ODSP recipient would no longer be eligible for support payments. However, once the person is finished with the job, if it is on a contract basis, he or she would then need to go on employment insurance which would not cover the ODSP eligible expenses. They could lose their benefits such as reduced payments for batteries for electric wheelchairs or for the actual adaptive device. For example, Michelle who is a social worker says, “My chair requires two batteries - $200 each. Without ODSP, then its $400. It’s still scary. When you are on ODSP, you get your main device covered. If you lose ODSP,
you do not get it covered.” In reflecting on the structural barrier and the concerns of going on and off of the ODSP, Michelle shares that

It should not be such a struggle for people who want to work. There’s a bias in the system. I was rejecting it because of stigma. Not only would I be giving up a job, there’s no real transition there.

Similarly, Patsy, who is a line cook and university instructor, juggles multiple jobs since she had opted out of ODSP and needs to make sufficient income for her everyday expenses of food and shelter.

The ODSP uses a one-size-fits-all system which does not meet the different needs of its recipients. Some individuals may require greater flexibility to the basic allowances for food, clothing and shelter. As pointed out by Michelle, assistive devices need to be taken into consideration into the formula. Such changes to the funding program can then better address the underemployment situations amongst disabled persons. Potentially, with a more flexible ODSP program, there may be less of a stigma in accessing these funds. This perception adds to the burden of stigma which is commonly attached to a disability identity.

In addition to the ODSP, increased funding through provincial government and non-government agencies can also support the self-managed Attendant Service Direct Funding program which embraces the concept of living independently within one’s own community by providing the opportunities for disabled persons to employ contractors for attendant services (Centre for Independent Living Toronto, 2013). This independent living movement which began in the United States in the 70s, and moved to the Canada in the 80s, aims at working with disabled persons to “Live with dignity in their chosen community; participate in all aspects of their life; and control and make decisions about their own lives” (Independent Living Canada, 2013). While the current maximum of attendant services allowed is 90 hours per month (Centre
for Independent Living Toronto, 2013), tactics which were used in the early days of development of the direct funding model can be re-implemented. Tactics may include speaking directly with key government officials or preparing a comprehensive position paper as part of a framework for change, which was aligned with the aims of the independent living movement to promote self-esteem and self-determination amongst disabled persons (Yoshida, Will, Parker & Locker, 2006). In thinking about the maximum allowance of 90 hours per month, this number translates into the equivalent of four hours of attendant services per day. If a person chooses full-time employment, the direct funding needs to be made flexible to allow for the potential of attendant services, in both the home and work environments. An evidence-based position paper which can argue for an increase in direct funding and the maximum hours allowed can potentially address the social issue of underemployment, and the need for attendant services for some individuals to be better equipped to integrate themselves into their communities, specifically through places of work.

**Entrepreneurship**

While there are funds through the ODSP, there are potentially other sources for employment. In speaking with Craig, who is a musician, he says, “I think the money that agencies receive from government can be used to start businesses to help people find employment. That way other people can find employment.” Rather than using the time and money to find jobs for individuals, he recommends that the various disability support agencies start businesses or companies such as call centers, recycling businesses, and secretarial services. As Craig says,

> From where I worked, they can subcontract from companies. The companies are very glad to do that. The companies do not have to come up with benefits or space. Companies are glad to do that.
Subcontracting would be very good. Start to do work for other companies.

Craig is suggesting an entrepreneurial role for the agencies. Rather than finding jobs for individuals in the community, disabled persons can seek jobs within these agencies which have created a business model within their operations. There is potential in this idea. Agencies would need to evolve to think of having an expanded organizational mandate, and the professional skill sets of staff would need to match this entrepreneurial direction. These agencies which are now newly formed subcontracting companies can provide individuals with the job experiences, whether they choose to work there for a short time or over a longer period. These jobs can provide a suitable transition for individuals who want to eventually seek work outside of the agency, while working inside to gain knowledge, skills sets, and an income. An entrepreneurial model can be another solution to mitigate the high rates of underemployment.

**Incentives and Awards**

Legislation necessitates compliance, and can result in penalty fees for non-adherence to the standards. However, another way to actualize change can address actions towards greater accommodation and can be rewarded in the form of external motivators. Remi, a research fellow, suggests that the government provide an incentive for organizations to subsidize part of the salary of a disabled person. This payment would allow time for the employer to orient the employee to the workplace, while the new staff person would also have an extended period to adjust and ascertain the appropriate accommodations. This longer adjustment time frame is also recommended to address probation periods which are often only three months in length. Thus, a longer probation period can provide additional time for a new employee to become oriented and accommodated to the workplace. In addition to these incentives, Remi suggests that employers can be given recognition, whether through an article in a print or in an online format.
In the world of business, people would want to compete. Put the article in the paper, in one of the business papers. Set up a Facebook site for those who do a good job, twitter, there are so many social things for people who want to keep on top and compete.

Recognition, in the form of an organizational award or press release, can be a strong motivator to initiate a change cycle. The good will that can be generated from these initiatives may distinguish an organization or corporation as a socially responsible leader in its field. The actual changes can also showcase the organization to be a role model for others to follow and implement in their own settings, new ways for providing accommodations and realizing inclusion.

To summarize this section, actions to address structural barriers can begin to make changes to underemployment. Compliance to existing legislation, changing funding criteria, broadening employment to include entrepreneurship, and recognizing organizations through incentives and awards can all contribute to actions within the structural component. The next section will investigate the environmental barriers and actions to address underemployment.

**Actions Against Environmental Barriers**

The environment can pose barriers to employment if individuals are not able to travel to their work places or are limited once they arrive in their work contexts. The interviewees Margaret, Anne and Remi will reveal the concerns and actions regarding transportation and the built environment.
Accessible Transportation

Accessible transportation is a necessary factor in the removal of barriers to employment. Employees need to find accessible and efficient transportation to be able to get to and from work on time. Margaret, who is a teacher and accessible design consultant, criticizes the transportation system as a barrier to employment and a factor in underemployment. Margaret is dependent on public transportation. Despite the pre-arrangements that she makes, reliability is an issue for accessible transportation for her. She reveals how important a timely arrival and departure of the accessible transportation is for her job when she does substitute teaching, but also the traumatic consequences of the absence of a scheduled ride. As a result of her lateness, she could lose her teaching certificate. Margaret emphasizes the impact of an absent ride: “What actually happens, once or twice I had to stay in the school building or sleep in the park across the street. Is that any way for a teacher to live?” From the financial impact of having to pay for a wheelchair cab to the survival issue of having to sleep outside in the cold winter, Margaret’s confidence in her local transportation system is low. Thus, public transportation poses a barrier to steady employment.

The additional work of getting to workplaces needs to be addressed. Public transportation systems need to be reviewed. New policies and procedures need to be implemented and evaluated as to their success to ensure that the travel requirements of disabled persons are being met. During the revision for more reliable accessible transportation systems, representation of the targeted users must be a part of the consultation and deliberation processes to ensure that their needs are being met. The mere existence of an accessible transportation system may not be aligned with the clients’ needs and expectations. Service standards, policies and procedures can improve the availability and reliability of accessible transportation systems to reduce the work
that disabled persons have to do even before they get to their actual workplaces for paid employment.

**Built Environment**

Organizations need to have accessible entrances, washrooms, parking areas, and workspaces to provide the opportunities for a more inclusive work environment. Within Ontario, the built environment must adhere to the accessibility standards which are itemized within the AODA and the Ontario Building Code. However, while there are building standards, they are also code minimums. For example, the code minimum for doors is 36 inches, but in Margaret’s case, when she uses her motorized wheelchair she needs a 44” door and not a 36” door to access her place of work. Margaret says,

They meet all the codes and yet not be accessible. These are huge barriers to employment. You can have a building that is wheelchair accessible, but then half of the people cannot access it. And yet, it is legally accessible in the eyes of the law.

The limitations of the building codes can be disputed with the OHRC which can require accommodations for mid-sized wheelchairs. Margaret continues on with her explanation as she compares the building code for doors and the rightful accommodations through the OHRC. During her interview, Margaret was able to show pride in the 44” doors which she helped design within her cooperative housing unit compared to other doors which she has encountered in her everyday life. When there is no flexibility to the building codes, then access can be an issue and become barriers for many. The built environment needs to be considered even before workplace related legislation takes place; it begins during the discussion of new accessibility acts.

Even when there were public forums before the passage of the legislation on the AODA, there needed to be a greater awareness for accessibility. Anne, who is a retired high school and
cooperative education teacher, said that as part of her advocacy work she started her speech in the public forum on the AODA with the following passage:

I would just like you to, before I begin I would just like you to acknowledge/recognize that there are very few people here today with visible disabilities. There are a few people with electric wheelchairs and scooters. And they’re in the next room, by the way which is inaccessible, but that doesn’t mean there’s a lack of interest. They couldn’t make it today because it was just too hard logistically to get dressed, to eat, to physically come, and then to worry about…

As her voice trails off, she is referring to accessibility and the inaccessibility of the spaces for this public forum which was intended to focus on accessibility legislation. Interested members of the general public were forced to listen and participate from a distance, in another room, due to the inaccessible spaces. Interested participants were also away due to the extra physical work that accompanies disabled persons who desire to travel to places. For this particular meeting, Anne had enquired about accessible parking prior to the meeting and when she arrived, there was not one available. The accessible entrance was located to the rear of the main entrance. As part of accessible event planning, the administrators of the event needed to plan ahead for more accessible parking and locate a space which was accessible for all. Anne was asked to stand up as part of the regular protocol for the opening of the public forum, but due to her muscular dystrophy she was not able to. She purposely used her scooter as a symbol of her impairment and in her representation of the muscular dystrophy community. Even when disability is the focused topic of conversation, actions for accommodations are deemed lacking for this specific public forum on the AODA, and once again, is indicative of the lack of awareness amongst non-disabled individuals in everyday reality.
Ergonomics

In further thinking about the built environment, ergonomics of the workplace need to be considered. Remi, who is a research fellow, tells us:

Every disability should have an ergonomic consultant to assess the work station. Every office is different. That can be part of the training and the accommodations. The employer does not want to work on this. There needs to be some assistance with accommodations for the initial accommodations. It could be part of the accommodations. Every couple of years it should be assessed again.

Part of the ergonomic assessment would include a review of the adaptive technology required for computer and phone work, access to entrances and washrooms, and location of the office. For example, Anne, who was the high school and cooperative teacher, was addressing strategies to cope with her health condition, negotiating for accommodations, learning about her legal rights, and proposing recommendations to keep herself fully employed. The physical demands of the cooperative education and the proximity of its office to the necessary amenities such as washrooms and photocopiers would have eased the physical demands on her body. She knew, for example, that she had to travel 150 steps from her classroom, whereas the office for cooperative education would be next door to the photocopier. The ergonomic consultation, thus, is a dialogue on needs assessments and accommodation strategies between the employee and employer, with the potential aid of an ergonomic consultant who is also versed in adaptive technology, accessible work stations, and inclusive work sites.

In summarizing this section on the environmental barriers to underemployment, changes need to be made outside and inside of workplaces. Transportation systems need to be more reliable to allow individuals to get to work on time. Once individuals get to their workplaces, spaces must be accessible including doors, washrooms and hallways. Ergonomic workstations
are necessary to facilitate the roles and responsibilities within a particular job. Having investigated the environmental solutions, the next section will explore the barriers and actions with respect to attitudes.

**Actions Against Attitudinal Barriers**

The interviewees encountered barriers at different stages of employment such as interviewing for jobs, juggling multiple jobs, and trying to retain steady employment. They encountered negative attitudes from potential and current employers, resulting in unemployment or underemployment in all the circumstances. In thinking about possible changes, Larissa, who is a writer and consultant, is emphatic about the need for equity:

> When people are talking about equity and awareness, the very first thing that needs to change, and I don’t know how you do this, is to get people to understand that there is a real human being in here. I don’t see but I more than understand the world. I take the time to. By the time you get reading all the stuff that I have, I have a good grip about what’s happening in the world. I made it my business to do that. And so don’t underestimate my ability, and you know to talk to me as an equal.

The attitudes of society need to change to be more understanding and respectful as a move towards treating disabled persons as equals and to support human rights. Larissa emphasizes that “there is a real human being in here.” She gives cues on how to achieve this. She takes time to read the world, and so in turn, society also needs to take the time to read and understand disability. In reading disability, using the social model of disability, this would translate into noticing barriers which are imposed by society onto disabled persons with impairments. Supporting human rights would result in not only noticing but actively removing the barriers found in society. Thus, to be able to shift the cultural paradigm from one which favours ability to
one that recognizes the disability as a social phenomenon requires understanding, time and activism.

Respect for diversity is a fundamental value in the move towards a greater understanding of human differences. Larissa shares her opinions from the perspective of blindness:

So I think blind people need to be in my stream of thinking in terms of understanding, without overemphasizing the limitations. We do have limitations. So all we are asking for is an equal playing field. I would like to have that expressed. It’s the playing field that needs to be equal. No two people are equal, whether they can see or not. You may have dark hair and I have light hair. That does not mean that you are worth more and that I am worth less. It just means that we are different.

As Larissa acknowledges, there will be limitations which will be encountered both in work and social contexts. However, if we are committed to equity in attitude, we also need the diligent practice for accommodations to level the playing field of work. This fairness in the field of work returns us to the acknowledgement of difference, and when there is difference, disabled individuals have the right to accommodations according to the prevailing legislations of the Canadian Charter of Rights, the OHRC and the AODA, whether it is in the form of adaptive technology, flexible work hours, and/or accessible parking spaces. Being able to pursue a fulfilling career with competitive pay can go a long way in addressing the physical, mental, emotional and social health of disabled persons, and provide movement towards employment equity and a reduction in underemployment.

Anne, who is a high school and cooperative education teacher, tells us that:

A person with a disability, in addition to everything else that anyone else would have to deal with: a grumpy spouse, a child who’s 16 and doesn’t want to come home by curfew, like in
addition to everything that everyone deals with, you have the additional baggage or issues of a disability, and the limitations and the challenges that that brings with it. So some days guess what: you’ve got much more attitude than maybe you should have, and it’s not necessarily positive attitude. And so I guess as I say, I would expand that to be: whose attitude causes problems? Yours, mine and ours.

In this passage, Anne emphasizes the extra work that accompanies the lives of disabled persons. While there may be the daily family responsibilities, it is not surprising that emotions may run high because of the limits imposed by society’s attitudes. Changes in social attitudes take time and the right media. Such shifts in attitudes can begin with awareness targeted towards non-disabled persons. An awareness raising campaign could begin with promotions and advertising by the government and cross-disability organizations. The interviewees provide their perspectives on awareness raising through the media in the following section.

Media Representations

Ray, who is an Environment Technician, recommends that promotions and advertising in the media should focus on the abilities rather than the impairments amongst disabled individuals:

the more socially aware that the general population is about people and their disabilities and their capabilities! Like everybody focuses on the disability of people, but maybe we should also pay just as much attention to what they’re capable of instead of always concentrating on the negative.

While Ray would like to focus on the abilities of disabled persons, Michelle emphasizes that they should not be seen as special interest groups:

I have seen something cool in the states. They have the ADA [Americans with Disabilities Act]. TV ads in the states, they are really funny – making it not special interest. It’s on TV. In Canada we do not have this. Need to not make it special interest either. I think that’s the difference between groups who have not made it special interest, but can benefit the community as a whole. We need to bridge the gap.
Programs and initiatives which can “bridge the gap” and benefit both the disabled and non-disabled communities could include strategies as diverse as flexible work hours, and curb cuts and wedge ramps. Flexible work hours can address employees who have child care responsibilities, or need to rely on accessible transportation. Curb cuts can be helpful for individuals who push baby carriages, grocery carts or walkers, or wheelchairs users. While curb cuts are permanent installations which require more time and money, a grassroots organization based in Toronto, Ontario, such as Stopgap.ca (Stopgap.ca, 2012), has recently launched a project to build wedge ramps for local businesses to ensure more people can access stores, whether they use a wheelchair or pull a grocery cart. These wedge ramps are built to bridge the gap for stores and businesses which have a single step in front of their main entrances. These examples of flexible work hours, curb cuts and wedge ramps which can benefit the whole community are valuable for both disabled persons, and non-disabled persons, and can be recognized or written about more often in the media. These projects are newsworthy and can involve the media to build awareness regarding the disability community. Broader social marketing campaigns through governments and disability organizations can use media to change the attitudes on stigmatized issues (WHO, 2011).

Anne, who is a retired high school and cooperative education teacher, adds a comment on the potential purpose of media representations:

I think that there needs to be public, as in media campaigns on the television and on the radio with respect to mm... legal requirements, legal responsibilities. I don’t think that it should be simply a focus on rights, but responsibilities as well.

Both the legal rights and responsibilities point to the adherence to the existing legislation in the form of the AODA, the OHRC and the Canadian Charter of Rights. Meeting or exceeding the AODA standards would support the rights of the disabled persons and the compliance
requirements of the employer. Both the OHRC and the Canadian Charter of Rights do not allow for discrimination, and address the “duty to accommodate.” Employers need to be aware of and comply with their legislative responsibilities as fair employers who respect employment equity and diversity.

**Human Resources Recruitment**

Employers may not know the best way to recruit disabled employees. As a social worker, Michelle shares her experiences:

> There’s been interviews where I walk right in and knew I would not get the job based on the expressions on their faces. They would go ahead with the interview, but they would do it through their smiles and they are patronizing me.

Despite the fact that she met the qualifications to be shortlisted to get to the interview stage, Michelle did not expect to get the job once she appeared as a potential employee who uses a motorized wheelchair. In this case, based on their facial expressions which relayed that someone is an unexpected participant, the interview committee needed some sensitivity training.

Disability awareness training can provide the forum and initiate the dialogue for change in the various stages of employment: recruitment, management and promotion.

Employers or employee groups who are recruiting potential candidates for a job opening need to think through and plan for accessible interview sessions and workplaces. Recruitment begins with the promotion of career opportunities within an organization. For an employer to share their value on diverse employees, they can express this through promotional avenues such as websites or brochures. Both the text and images need to relay diversity amongst the employees and a commitment to inclusion. The job descriptions need to include a statement on employment diversity and equity. A statement on accommodations can be included in both the
job description and the call for an interview. Whether a person needs the accommodations or not, this statement signals the possibility of an accessible and inclusive culture in the workplace. If these practices are in place, the hiring committee needs to then expect applicants and interviewees from the various candidate pools, including the disability community.

Organizational Training and Development

In reflecting on a more inclusive model, Patsy, who is a line cook and university instructor, emphasizes that, “Until we change the work paradigm in this culture, it’s always going to run counter to people with disabilities.” To support a cultural shift, a number of the interviewees suggested that training be made available for the employers and employees within an organization. Awareness training may focus on the abilities of disabled individuals, the rights of disabled individuals according to the various legislative acts, the multitude of accommodations that are available, and the issue of attitudes as a major barrier within workplaces. Disability awareness training can address the social barriers of attitudes which can stem from fear or assumptions about disabled persons, and begin a discussion on the social model of disability. Similarly, Shier et al. (2009) found that awareness programs about the barriers and experiences of disabled employees can reduce the stigma, discrimination and labeling which results in underemployment. Such training can also provide the forum to initiate the dialogue and open up the space for change in the various stages of employment: recruitment, retention, and promotion. Employers need to be aware of the rights for accommodations according to the human rights legislation. While adherence to legislation can provide an often minimum level of change, it is a commitment to equity which can compel and inspire paradigm shifts which address human rights to move beyond acceptable standards according to the dominant culture. The change needs to be above and beyond the minimum standards, and be acceptable to the individuals who embody difference and desire to enter the workplace. Further
organizational development can support interested employees to write articles for the organization, or to attend disability specific workshops and conferences to be able to share this new information with their work colleagues.

**Accommodations**

Under the OHRC, employers have a “duty to accommodate.” Each accommodation needs to be specific to the employee so that she or he can work effectively, and in order to not waste money on inappropriate purchases. Sometimes, administrators just purchase some adaptive item which they believe to be the right accommodation without consulting with the employee. Thus, the employee and employer need to have a detailed discussion on accommodations as to what would work best for the individual and the job responsibilities. Suitable accommodations, as in the case of Mable, who is a former nurse and current dance and fitness instructor, allowed her to have a writer to take notes to support her work as a dance instructor when she evaluated her students. When she was artistic director of a theatre company, she told them what she needed to support her work and they accommodated her needs: “I’ll be on your board, but you need to.... I need a sidekick slash secretary person. So I always got it. I doubled up with somebody.” Similarly, Bear, who worked at the international computer company, worked with a receptionist to read him his notes. Both Remi and Rachel worked well in their respective roles as researcher and receptionist once they acquired screen readers for their computer related responsibilities. Unfortunately, not all employers are aware of their duty to accommodate. If they did know, then individuals would not feel that they were asking a favour of their supervisor, as evidenced in Margaret’s case:

How many times will you ask your boss for a favour? How many times will you want to disturb the resource? Why would something so important reside in the individual? I did not want to rock the
boat. I was hurting myself by not asking. In that corporate culture, you should not disrespect the employer. You do not want to rock the boat or make waves.

Margaret’s sentiments are aligned with the social model of disability when she says, “Why would something so important reside in the individual?” Rather than making the accommodations request an individual matter, the onus then is on the organization to comply with accessibility legislation and demonstrate best practices to address the accommodation needs of a new employee. When left to the individual, accommodation becomes an individualized discussion with an immediate supervisor. When it is an individual matter, the adherence to accessibility legislation and equitable practices may not transfer from one supervisor to another, if their values differ with respect to employment equity. In contrast, accommodations need to reside as legislation, policies and procedures which are followed throughout an organization to be effective.

Sometimes, although employers want to accommodate, they do not address the accommodations effectively to meet the needs of the individuals. Larissa shares her experiences:

The biggest problem in the workplace is that employers are looking for a standard. What is the standard for a blind person? They’ll look it up in a book. They will look up that this person needs a large print screen and yellow edges on the desk. She’s going to need all things related to visual cues. Those accommodations do not mean anything to me. All those visual cues are meaningless to me. I need all things in braille and voice. My needs are different. You can contrast all you want, but it’s not going to help me.

Taking time to learn about the needs for accommodations is crucial in the effective decision making for the purchase of adaptive devices and/or design of ergonomic workstations. If it is an incorrect purchase of an adaptive device, it becomes a useless expense for the employer and the employee. Furthermore, the employee would still not have the adaptive device to do his or her job in the most productive manner. Larissa emphasizes that the wrong decision “costs all of us. I
either can’t do the job or there’s too much stuff on my desk. Either way I feel bad.” The issue is not a personal one since it is the duty of the employer to accommodate. However, because of the lack of knowledge the employee may need to bear the brunt of ineffective decisions.

**Networking and Support Groups**

Many of the interviewees commented on the lack of networking and support groups in the field. In her place of work at a university, Remi, who is a research fellow, says,

> I miss a lot of networking opportunities. I often miss information because I don’t always get access to the information. Because of my disability, you can’t read posters and signs, and don’t know when events are. I may not be on lists. It’s not easy for me to check websites every day to see what’s happening. That’s a big problem – access to information. It affects the job hunting skills. And the networking. You need to develop allies to get promoted for the workplace. You need people to support you. You need information. You need to get connected to others.

Remi laments the lack of networking opportunities. Much of it is due to the social attitudes about disability, but she is also experiencing intersections of disability with gender, race and age which complicates the situation of being alone in the workplace despite working amongst a group of researchers. In relation to the experiences for persons with blindness or low vision, the lack of social inclusion can be attributed to some barriers which include a failure to recognize co-workers, an inability to obtain food and drink without assistance, difficulty in eating while managing guide dogs, the need to rely on colleagues to navigate within social settings, and travel to and from such work functions (Naraine & Lindsay, 2011). Networking not only serves the social needs of employees, but it is also critical for career mobility. In her work context, Remi lacks access to both of these benefits found in networking and inclusive work practices.
Margaret, who is a special education teacher and accessible design consultant, relays her thoughts about her blind friend who does not have the advantages of a social network at work.

I have a computer techy [blind] friend, and he says he is the “mole in the building.” They can be in a cubicle, a forgiving environment. It was a self-described description. That’s how they perceive other people seeing them. But what if you are more exposed to the public?

Hidden away, but still working in a cubicle is neither conducive to work team collaborations nor to job promotions, especially if one is seen by colleagues and perceived by oneself to be a “mole in the building.” The word “public” is not to be ignored in this passage, since this conjures the greater potential for social interaction. “What if” there was a greater exposure to disability by the public. The presence of disability can go a long way in disrupting how an organization is perceived both internally and externally. Difference can then be the frontier upon which an organization can build its diversity platform as an employer of choice, a place where people will choose to work and do service with.

The work relations need to also change by valuing different perspectives during work team collaborations, and providing networking opportunities by inviting disabled colleagues to social functions. Rather than leaving the work practice to individual networking, the organizational culture can start to think more about collaborations. Concerted efforts can be made to create work teams or working committees. Each employee needs to feel that he or she is part of the work community. Potentially, this can be a buddy or mentor at work, and can extend to include social events with work colleagues. These initiatives can be the catalysts for change towards a more respectful and inclusive society which embraces human rights and equity for all. To realize such a change, each employee of an organization must make an effort and commitment on how his or her individual effort towards equity and inclusion can support an
organization’s ability to embrace disabled people who can provide valued skills and different perspectives within the workplace. In sum, the attitudinal barriers can be addressed through an organizational commitment to equity and diversity by hiring, retaining, recognizing and promoting disabled persons.

Roles of Allies

To strengthen the impact of promotions and education, one suggestion was to include a celebrity spokesperson to support the cause. Remi, who is a research fellow, advocates having a high profile person rally behind the movement for change. She says: “We must have high profile people in Canada or in the States to have a name to support either group of people working for a cause.” Allies can be in the form of celebrities to support the disability movement in general, or a specific disability initiative. While celebrities can attract attention and interest, they cannot do such work alone. They do need allies, who often identify as non-disabled persons and support a particular cause or initiative in partnership with disabled persons. Additionally, Patsy, who is a line cook and university lecturer, supports having allies, and says: “I think one of the strengths too is people who are able-bodied or in positions where they’re able to speak in solidarity with the disability community.” Attitudes can also begin to change through advocacy by allies who are members of a leadership team of an organization. They will be instrumental in embedding the values of equity, diversity and inclusion in the organizational mission or mandate, and developing key roles to realize these values. Allies within an organization add to the capacity building efforts to support the planning, development and implementation of new equity ideas towards greater inclusion.
To increase the public understanding of disability and its associated barriers, research needs to continue to investigate the impact of social barriers including environmental and attitudinal barriers, the quality of life and well-being of disabled persons, and the effective interventions to enhance inclusion in various contexts (WHO, 2011). Research on these social issues needs to include disabled persons as researchers and research participants, especially when such engagement broadens the opportunity for epistemic and ethical knowledge on a particular topic of discourse (Garland-Thomson, 2012). Dedicated disability research centres associated with universities have been critical to knowledge production and dissemination, which have included collecting and analyzing the lived experiences of disabled persons; investigating the roles and responsibilities of the public, private, social economy and family and friends; and researching the work integration of persons with mental health conditions (Prince, 2009). The follow-up to research findings is knowledge dissemination. While the findings of research is often limited to discipline specific journals and conferences, knowledge dissemination in support of disability activism needs to aim to reach the disability community to support engagement and change. The disability community which can consist of service agencies, special interest groups, researchers, disabled persons and allies can then use their respective networks and communication tools to work towards the common goals, as articulated by Prince (2009), of recognition, re-distribution and representation.

To summarize the recommendations to eliminate attitudinal barriers, action plans can address: media representations, human resources recruitment, organizational training and development, accommodations, networking and support groups, identifying allies, and research. All of these can contribute to the awareness raising and cultural shifts within work contexts. The readiness of an organization for these changes may dictate the priority or choice amongst these
different recommendations. A wholehearted adoption of multiple methods to change attitudes may capture the attention and interest amongst non-disabled persons on the road towards employment equity and diversity.

Conclusion

The stories shared by Penquin, Craig, Margaret, Anne, Ray, Patsy, Larissa, Rachel and Remi show that there are many changes which can be addressed in the various work fields including the education, not-for-profit, computer and environment sectors. Even the stories shared by Margaret and Patsy show that there can be changes to attitudes in the public sector which includes the transportation systems and service industries. While legislation has been around since 1962 in the form of the OHRC and includes new legislation such as the IASR in 2011, the interviewees were skeptical about the level of compliance to these legal requirements. Greater adherence can provide the catalyst for employers to take notice of some of the necessary changes to facilitate employment which will in turn address barriers relating to information and communications, employment equity and transportation. With the passing of the IASR in 2011, the legislation signifies a written commitment to ensure that public and private sectors are compliant by a set deadline. Only time will reveal the impact of the legislation on the lives of disabled individuals who are able to choose and find paid work.

Stories of disability and underemployment can provide the much needed narratives to provide an understanding of the facts and emotions, which can alert readers, employers, policy makers and the public to the dire concerns of food, shelter and poverty, and circumstances of low self-esteem and poor career achievements among disabled persons. These stories between communicative bodies provide the inter-human connections and empathy needed to catalyze paradigm shifts and social change. The social model of disability can provide insights into
barriers to both employment and actions to resist underemployment. By attending to the structural, environmental and attitudinal barriers, new ways of thinking and doing can be implemented to reduce or eliminate these barriers. Amongst the structural barriers, attention must be paid to action on legislation, funding, entrepreneurship, and incentives and awards. To address the environmental barriers, accessibility is required within transportation, the built environment and workplace ergonomics. Attitudinal changes are needed within workplaces throughout the different stages of employment expanding across the continuum from recruitment, training, accommodations, networking, and leadership, and more broadly in society through media representations. As expressed by the interviewees, their lived experiences are valuable conduits to identify many possible actions to eliminate underemployment, and consequently, to improve the lives of disabled persons who desire to work to their full potential.
Chapter 8

Final Reflections

I began this investigation supported by my growing interest in disability studies as a new lens to perceive the world. I dwelled in the intersections of disability studies and work, and found the phenomenon of underemployment. My journey embarked from a set of research questions which provided opportunities to meet with and learn from disabled individuals and their lived experiences. My research draws from disciplinary foundations, concepts and analytical themes from three fields: critical disability studies, interpretive sociology and social policy analysis. In this final chapter, I will reflect on the meaning making of the stories which have been shared in the texts which were derived from the transcribed interviews, and the themes which emerged through my critical interpretative textual analysis of social policies related to disability and underemployment. I will also reflect upon how this journey contributes to the scholarly literature in disability studies and the sociology of work. I will then ponder emerging questions for future research, but for now I return to the phenomenon of underemployment and its related texts.

The Phenomenon of Underemployment and Texts

Underemployment persists as nearly half of disabled persons who are seeking paid work encounter it. These occurrences cannot be taken-for-granted especially when the stakes are so high for disabled persons. My current research study has provided insights into the following questions which prompted this journey: 1) How do disabled workers understand and address experiences of underemployment? 2) How do organizations and social policies identify and account for underemployment amongst disabled persons? 3) How can practices which acknowledge and enhance collective identity be used to address underemployment and advance
the disability movement? 4) How can underemployment amongst disabled persons be addressed at the organizational level? In search for answers to these research questions and through critical interpretative textual analysis of the texts of stories and social policies, the high stakes resided in the lives which were being wasted when career potentials are unfulfilled, when social roles are diminished, when health is in danger, and when living conditions are close to the poverty line.

Specifically, in work contexts, disabled persons experienced underemployment in the form of marginalized identities, lost opportunities, limited incomes and wasted energies. The concern about stigma often deterred the interviewees from full-disclosure, and yet, when they fully disclosed about their physical impairments, their fear of having a marginalized identity was realized as they often encountered insensitivity or even worse, negativity to their physical appearances and/or requests for accommodations. Negative attitudes towards disabled individuals are prevalent in the workplace: employers and co-workers often either ignore the presence of disabled persons or include them only as token representatives as they perform their job responsibilities (Canada, 2009; Jones, 1997). Individuals with token status may stay in the same job for a long time, as they do not have access to the informal networks within an organization and miss opportunities to socializing with important contacts for job mobility. According to the interviewees, they also encountered attitudes in the workplace that did not respect their knowledge, skills and abilities for neither their current jobs nor their needs to be accommodated for social functions.

The interviewees shared stories about lost opportunities. While many of their educational backgrounds including Master’s and Doctoral degrees qualified them for positions as educators in higher education, consultants in specialized fields and senior level government workers, they were all underemployed either working below their potential, working part-time (often outside
their field of expertise), and having shortened careers. Additional consequences include lack of opportunities for recognition, compensation, promotion, accommodations, and career fulfillment. The notable culprits include public attitudes, lack of accommodations, changing technology, work intensification and limited social networks.

Limited incomes from undervalued or part-time work severely affected the social class of the disabled persons interviewed: they shared stories of using food banks and second-hand clothing stores, which affected their self-worth. Furthermore, their inability to meet the expectations of society by joining friends for social functions, fulfilling a grandmother’s role, or contributing to society in a meaningful way through charities or within their particular profession affected their emotional well-being and self-identity. In addition to the prevailing conditions attached to underemployment, their present difficulties were intensified when they had to think about and felt stressed about their futures, especially when they had already dipped into their retirement savings or had no means to contribute to a more secure financial retirement.

Competitive wages and steady work enable a higher income and a less stressful life for disabled and non-disabled employees. In contrast, underpaid work generates more stress when a person needs to work multiple jobs to meet basic income needs. Limited term or contract jobs also generate stress, because they do not provide long-term financial stability. The reduced income that results from underemployment can diminish an employee’s personal agency to plan for immediate and long-term needs and to live a healthy lifestyle. The impact of low and uncertain income can increase the prevalence of depression, and trigger other stressful life events such as separations or divorces (Dooley & Prause, 2004). Job insecurity can also affect perceptions and optimism about the future in general, and can potentially affect mental health conditions that are linked to the psychosocial functions of employment.

Underemployment also leads to wasted energies for individuals who have little to spare.
Many disabled employees spend a lot of time trying to negotiate their work contexts so that they can fulfill their job responsibilities. Employers are often not receptive to accommodation requests. Energies used to educate and inform current supervisors about accommodations are necessary to ensure the work environment is adjusted to the needs of the disabled employee, but when these energies are expended and are not accommodated, they are simply wasted. Consequently, disabled employees often try to perform their best within work contexts with minimal accommodations.

These stories, which were generously told by the interviewees, can alert both the disabled and non-disabled communities to the complexities of underemployment. For the disabled community, this sharing can facilitate the building of a collective identity to learn, to engage, and to act against barriers to full employment. As a collective identity, possibilities arise to find more actions to address and resist underemployment. Structural, environmental and attitudinal actions can be implemented within work contexts to shift the mindset of employers of disabled employees to perceive them, not as individuals with minimal capabilities, but as ones with career potentialities spanning a range of knowledge and skills. A collective identity can be a singular disability type which represents a common form of impairment, or it can be cross-disability based when groups representing multiple forms of impairments join together to advocate for new social legislation such as the Accessibility for Ontarians with Disabilities Act (OMCSS, 2011).

In learning about the underemployment experiences, I investigated the understanding between communicative bodies, between story teller and those who are engaged by the story. As Frank (1995) reminds us, “not to move on once the story has been heard, but to continue to live in the story, becoming in it, reflecting on who one is becoming, and gradually modifying the story.” (p.159, italics in the original). These stories are also told as ways of “belonging,” writes Garland-Thomson (2012). In thinking about becoming and belonging, my own life has changed
as the stories have lived with me while I listened to the interviewees’ concerns and hopes during the interviews, and many times over through the transcription process. The stories revealed the need for a belonging that is commonly elusive in our mainstream society. As a disability studies researcher, my role then is to carefully engage, and attend to how I am responding to and interpreting these stories, and how I can best relay their rights to belong as disabled persons to others.

In thinking about the interviewees, I am inspired to share my original lyrical representation of their commitment to the disability movement:

*Hope in Collective Identity*

I move with my body
as it travels at a different pace.
I speak with my mouth
as it seeks the words to express
I share with you my emotions
as we explore new ways of being in this world.
I connect with you in a collective identity
in motion,
in words,
in feelings,
in hope.

A lyrical representation is one way of conveying understanding and meaning between communicative bodies. In this instance, the sequence would be story teller, receiver, and now engaged individuals. Zwicky (1992) tells us that “Lyric speaks of, and to, a wholeness that is not merely additive” (p. 120). My lyrical representation is a composite of lived experiences, not merely its individual parts. It is my hope that my interpretations of the narratives can be offered in multiple ways to facilitate the sharing of the stories, to assist others in listening and becoming, through critical interpretative textual analysis and lyrical representations. As we are reminded, the aim of this form of interpretation is then to use “lyric enquiry to make the research accessible and memorable, and we hope, to foster agency and action” (Neilson, 2008, p.99). Understanding
through meaning making exists through the phenomenon of the lived experiences of underemployment, the stories told, the interpretation of the texts, and the opening which provokes an emotional resonance amongst new audiences to take action.

Knowledge Creation and Impact

Often people may refer to their work as a second home, perhaps because of the time they spend there, or even more likely, how they feel in their surroundings. Michalko (2002) describes his conception of a home in the following passage: “Whenever we conceive of a place as home, we feel at home there and we know, ‘by heart,’ that the place welcomes us. We know, by heart, that we belong in that place, and that it belongs to us” (pp. 17-18, italics in the original). Yet, it is often a struggle to belong at work as a disabled person. These struggles are necessary to educate non-disabled persons who have built up barriers in the environment, and may not have done so intentionally. A disability identity is “valuable and worthwhile” and these struggles are political, not individual (Michalko, 2002, p. 39). The political urges both disabled and non-disabled persons to question the prevailing employment practices. The political resides in demands for accessible spaces and transportation. Political stances translate to assertive actions, be it in the form of peaceful demonstrations, written communications to politicians, and/or legal claims due to discrimination. My scholarly work then also becomes political, in seeking room for change and making space for difference. My next original lyrical representation takes a stance on the need for work places to provide the structure and the feel of home for disabled persons.
Finding My Home at Work

My home, a space of relaxation
With my family and disabilities
My work, a place of marginalization
With my colleagues and potentialities
My body feels tired, my legs feel weak
My arms feel the fatigue of reaching overhead
My legs are walking slower
My movements are becoming smaller
I ask for your understanding
Forego your stares and attention
As I enter my work, in my space,
With my tasks and aspirations

This lyrical representation recalls the experiences through expressed words and feelings; “the memory becomes poetry replete with the lesson to be learned” (Maracle, 2012, p.15). I offer my poem as an observation on the relationship between work and home, and between the employer and the employee. Poetry, like stories, can strengthen the body, as Traditional Teacher Lee Maracle shares her insights: “The memory then becomes a spring board releasing the spirit and freeing the person to muster their courage to go out and about in the world free of fear” (Maracle, 2012, p.15). The interviewees shared their stories with me and they wanted to let others know of their experiences through this research study. In speaking their stories out loud and in sharing them with me, I hope that they have also gained some courage to move more freely in a normative society which does not always offer a welcoming home for difference.

Through this dissertation, I embarked on a research project to seek out the barriers which result in a dis-ease in the workplace, as well as the possibilities to promote ease in the same contexts. This research has been a journey which began with an exploration of the definition of the term “underemployment” and resulted in a more comprehensive definition. This expanded original definition of underemployment is:
The underutilized skills and knowledge of the employed and the unemployed, and is often accompanied by the lack of opportunities for recognition, compensation, promotion, accommodations, and career fulfillment, in relation to structures, environments and attitudes of exclusion which lead to negative consequences for people’s mental, physical, emotional and social health.

This definition captures the consequences of the interviewees’ work experiences. Through the stories of underemployment, I have offered deeper insights into the troubling complexities of underemployment. Through an original combination of the social model of disability and the collective identity model, I have provided insights on what constitutes a collective identity, and how this can strengthen the disability movement. Organizations such as the AODA Alliance and the FSHD Network epitomize the collective identity formation of disabled persons to address their respective causes. Their personal concerns have become political as they use their knowledge, networks and technologies to address social change, including barrier-free workplaces.

In recalling Chapter 7, actions against structural, environmental and attitudinal barriers can be taken to resist underemployment. To address structural barriers, actions can be implemented to enforce legislation, advocate for more flexible funding, increase opportunities for entrepreneurship, and motivate employment equity through incentives. Environmental barriers can be addressed through accessible public transportation, built environment and workplace ergonomics. Attitudes amongst employers, organizations and policy makers can be influenced throughout the different stages of employment expanding across the continuum from recruitment, training, accommodations, networking, and leadership, and media representations.

To confront exclusion and move towards inclusion, the social-political changes embrace disability politics to break down these “bricks” which are the structural, environmental and attitudinal barriers. However, the “cement” which holds these different layers of discrimination
in place is based on “ideologies of ‘normality’ and ‘independence’” (French, 2001, p. 14). Thus, disability politics advocates for the inclusion of disabled persons and collective identities as critical to this change in ideology, towards a new normative order which embraces difference. Disability politics through an alliance of advocates, allies and researchers are vital in breathing new life into organizational practices and social policies which can deconstruct normality and advance socio-political changes to address underemployment amongst disabled persons.

Disability cannot remain an individual problem if inclusion requires a paradigm shift of the social and political sphere in which we live. The move towards inclusion requires perceiving and embracing disability as generative resources (Garland-Thomson, 2012): narrative, epistemic and ethical. As a narrative resource, disabled persons can offer greater understanding of identity and community inclusion through their lived experiences. As an epistemic resource, the embodiment of a physical or visible impairment can offer new knowledge about work contexts and our world. As an ethical resource, disability can offer new understandings between disabled and non-disabled persons.

While Chapter 7 is dedicated to identifying actions which can address underemployment, I offer them as starting places, and not as a comprehensive checklist for any particular organization. As I have learned from the interviewees, one or a few persons cannot speak for others with the same impairment. Each person is different. Thus, each accommodation needs to be customized and personalized. Accommodations begin with a mindset which opens up the space for difference and discussion. Accommodations can also build upon the minimum requirements as detailed in legislation and social policies. Whether it is human resource practices or building codes, adherence would provide for movements towards change. The interviews were conducted within the existing context of the AODA customer service standards and the
AODA Integrated Accessibility Standards Regulation (IASR). Time will only tell whether the AODA has made an impact on the lives of individuals and their employment opportunities.

**Moving Forward**

As I think about the future of research and organizational practices, I turn to the role of disability studies in the investigation of work and underemployment. As Titchkosky (2011) writes about the role of disability studies and organizational practices, she says that “the work of critical theoretical approaches, such as disability studies, is not generated solely by what it fights (patriarchy, racism, capitalism, able-ism); what links us can also be explored in generation, renewal, genesis, and natality” (p.127). Disability studies can be a starting point to address attitudinal, organizational, social and systemic barriers, and I have investigated the phenomenon of underemployment with this lens. Furthermore, disability studies which, in its multi-disciplinary nature, has provided the opportunities to explore stories, social policies and lyrical representations as texts. These texts can generate new solutions and renew discussions on the concern at hand. These texts can also be places to think again about new research and practices. While I have offered some interpretations of the lived experiences of underemployment through the preceding data interpretation chapters, I would need to enter a “third space” (Bhabha, 1994) to further explore the implications of disability and underemployment. What is the research concern in this third space which resides between the now, and the not yet? A place which requires research resides in “social intersectionalities,” as it is termed by Prince (2009). This approach would take into account initiatives with three key considerations: by continuing to advance the rights of disabled persons and being inclusive of all individuals with their various types of impairments; by attending to the needs of targeted groups such as women or ethnic communities and ensuring that disability is taken into account along with various social identities; and by including disabled and non-disabled populations within all policy and research
developments. By recognizing social intersectionalities, this approach avoids “essentializing disability” and acknowledges disability as a “factor in the stratification order of human societies” (Prince, 2009, p. 189). Specifically, future research on the concerns about disability, underemployment and social change, can ask questions which may include: What are the experiences of disabled persons and underemployment when they identify with more than one marginalized social identity, for example, women, Aboriginal, Indigenous and/or visible minorities? What are the experiences of both disabled and non-disabled persons as they navigate the prevailing systems in organizations and society? How do the work experiences differ between different generations of disabled employees as a result of changing technology and social media? More questions arise from the current research as one study ends and the possibility of a new one begins.

## Conclusion

In coming to the end of this research, I consider the themes which have emerged from my investigation of disability, underemployment and social change. I have come to a deeper understanding of underemployment as a complex social issue, which is manifested by a framework consisting of structural, environmental and attitudinal barriers. While such a framework facilitates the categorization of the barriers which range from faulty social policies to inaccessible transportation to negative attitudes, disabled persons often encounter more than one of these challenges in their search for paid employment. Often, it’s not the search for one job, but a repeated process which requires persistence and stamina from individuals to participate in numerous interviews and work at multiple jobs to earn sufficient wages to cover basic survival costs such as food, shelter and clothing. Consequently, the impact of underemployment and situations of poverty often complicate a disabled person’s mental, physical, emotional and social health. Such complex situations may be reasons for individuals, organizations and governments to turn away from the phenomenon of underemployment, and more commonly than not, leave it as an individual problem, rather than addressing this social issue. However, underemployment
cannot remain as an individual problems and be reliant on personal solutions, especially when we consider what is at stake for individuals and communities who are marginalized within work contexts, living at or below the poverty line, and discriminated against for being different. Embracing difference requires a change in mindset for many people. Rather than thinking about difference as the “other,” the paradigm shift in society needs to be that of inclusion. Rather than an antagonistic approach to inclusion as to why disabled persons should be included in the workplace, I would recommend further thinking and exploring on “How can we include disabled persons in the workforce?” for individuals who want to enter the paid work force. As we aim to embrace difference within a paradigm of inclusion, we can then direct and facilitate dialogues to include re-writing policies, addressing discriminatory practices, training people, enforcing legislation, and requesting accommodations. Paradigm shifts can be seen as seismic challenges, however, if we can begin with nodes of influence among disabled persons, allies, and collective identities, there is hope for change. I offer my thinking and writing of the possibilities:

*Ripple Effects for Change*

On the edge of the lake
I feel the calmness of the water
I feel a need to disturb this stillness
I pick up a pebble and toss it into the water
I notice my little pebble setting the water in motion
A ripple effect emerges

I pick up another pebble and toss it in another direction
Another ripple effect emerges
I take a handful of pebbles and toss them in with all my might
These pebbles—difference, inclusion, accessibility, attitudes, belonging, allies, rights, disabilities—they are my change makers

They land in many places and directions
Multiple ripple effects emerge
And the ripples touch the many shores
My friends join me, my allies too
In unison, with purpose, we happily toss our pebbles
To stir this once-still water
We sense the noticeable changes
I imagine these nodes of influences as pebbles tossed into still waters, which can set in motion far-reaching ripple effects. These nodes of influences can begin at any level, so that a personal mind shift which embraces difference and inclusion can affect both the organizational and social levels; and vice versa, organizational practices and social policies which embrace difference and inclusion can influence personal perceptions. The greater number of nodes of influence, or the greater number of change agents, can create a greater impact on the normative ways of the social understanding of disability and underemployment. These ripple effects can disturb our otherwise ableist society, to affect changes across personal, organizational and social levels. Beginning with text in the form of research questions about a social phenomenon, then engaging with the text of narratives and social policies, I now end with text in the form of provocative words – complexity, difference, inclusion and change – as they point to and offer meaning and hope to the social-political relations among all human beings.
References


Fawcett, G. (2000). Bringing down the barriers: the labour market and women with disabilities in Ontario, Ottawa: Canadian Council on Social Development


Varul, M. Z. (2010). Talcott Parsons, the Sick Role and Chronic Illness, *Body & Society*, 16 (2).


Appendix A

Recruitment for Research Project

Research Project Title: Disability, Underemployment and Social Change

Are you a person with a physical/visible disability? 
Do you have a story to tell about underemployment, currently or in the past 5 years? 
Have your abilities been wasted or underutilized in your paid work?

Please contact Susan Lee ss.lee@utoronto.ca or 416-978-5655 for an interview.

Interviewee criteria:
• 18 years or older
• self-identify with a visible disability
• worked in paid employment for over 5 years
• English speaking
Appendix B

Recruitment Email Text and Telephone Script

I. Email Text

Dear (name of contact):

I am Susan Lee, a graduate student from the Ontario Institute of Studies in Education at the University of Toronto. I am conducting a research project entitled: Disability, Underemployment and Social Change.

This research study that examines the interconnections amongst disability, underemployment, organizational practices and social policies. Results from the study will contribute to the scholarship of disability studies, workplace learning, collective identity and social change.

The study addresses the limited research on the causes and solutions of underemployment amongst disabled persons. Underemployment is defined as “all dimensions of the wasted ability of the workforce, as they apply to either job holders or the unemployed” (Livingstone, 2004, p. 55), and this project intends to research how an individual’s abilities are being wasted or underutilized in paid employment.

The criteria for the selection of research participants include:

- adults 18 years or older
- self-identify with a physical/visible impairment/disability
- worked in paid employment for over 5 years
- English speaking

If you do identify with one of these roles, would you be interested in participating in this project? Would you know of other contacts who may be interested in this study? Please find attached an electronic version of the recruitment poster. Please contact me if you have any questions.

Sincerely,
Susan Lee, Ph.D. candidate
Principal Investigator
II. Telephone Script

Hello (name of contact):

I am Susan Lee, a graduate student from the Ontario Institute of Studies in Education at the University of Toronto. Would you have a few minutes to discuss a research project now? (Alternatively, I could call back at a more convenient time.)

This research study examines the interconnections amongst disability, underemployment, organizational practices and social policies. Results from the study will contribute to the scholarship of disability studies, workplace learning, collective identity and social change.

The study addresses the limited research on the causes and solutions of underemployment amongst disabled persons. Underemployment is defined as “all dimensions of the wasted ability of the workforce, as they apply to either job holders or the unemployed” (Livingstone, 2004, p. 55), and this project intends to research how an individual’s abilities are being wasted or underutilized in paid employment.

The criteria for the selection of research participants include:

- adults 18 years or older
- self-identify with a physical/visible impairment/disability
- worked in paid employment for over 5 years
- English speaking

May I send you an electronic version of the recruitment poster? What is your email address? Are there other contacts who would be interested in receiving a copy of the recruitment poster?

Thank you so much for your time.
Appendix C

Informed Consent for Research Project Title: Disability, Underemployment and Social Change

Researcher: Susan Lee, Ontario Institute of Studies in Education at the University of Toronto, Department of Sociology and Equity Studies

Supervisor: Dr. Tanya Titchkosky, Ontario Institute of Studies in Education at the University of Toronto, Department of Sociology and Equity Studies

Purpose of the Study
You are invited to participate in a research study that examines the interconnections amongst disability, underemployment, and organizational practices. This project intends to research how an individual’s abilities are being wasted or underutilized in paid employment.

Methods
Study participants are asked to participate in one to two 60 – 90 minute audio-taped phone or in-person interviews which will be transcribed for textual analysis. Participants will include individuals who self-identity with a physical/visible impairment or impairments, who have worked at their current place of paid employment for at least 5 years, have experienced underemployment, and are 18 years and older. Participants may be asked for a follow-up call to clarify any questions pertaining to the interviews.

Confidentiality
Completed audio transcripts will be securely stored in a locked filing cabinet to which only the principal investigator will have access. Anyone who is hired to transcribe the data will sign a confidentiality agreement as further protection of the data, which will be erased following the transcription of the interview.

Benefits and Risks
Study participants will have an opportunity to share solutions to address underemployment amongst disabled persons at the organizational and social policy levels. There are no known risks involved in participating in this study. Participation is voluntary, and participants can withdraw from the study at any time without consequences simply by contacting the researcher. Any data associated with a research participant who has withdrawn from the study will be destroyed and all the identifying features will be changed to protect anonymity.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Research Ethics Board
If you have any concerns or complaints about this project you may contact any of the following:
Susan Lee email: ss.lee@utoronto.ca phone: 416-978-5655
Dr. Tanya Titchkosky email:tanyatitchkosky@oise.utoronto.ca phone: 416-978-0451
University of Toronto Office of Research Ethics email: ethics.review@utoronto.ca phone: 416-946-3273

Research Consent

<table>
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Appendix D

Interview Guide

I. Introduction
Thank you for agreeing to participate in this research project on “disability, underemployment and social change.” My working definition of “underemployment” is “all dimensions of the wasted ability of the workforce, as they apply to either job holders or the unemployed” (Livingstone, 2004, p. 55), and this project intends to research how an individual’s abilities are being wasted or underutilized in paid employment.

I will review the informed consent and the process before you sign it. With your permission the interview will be recorded and transcribed for analysis. I will be asking you for a pseudonym which will be used to protect your privacy in the written portion of this research. Feel free to ask any questions before, during or after our interview session and you can withdraw from this research project at any time. You may withdraw from or refuse to a question at anytime. Do you have any questions before we begin?

II. Demographics
Let’s begin with your choice of a pseudonym and some demographic questions and it is important to remember that none of this information will be used in ways that break confidentiality protocols:
Pseudonym:
Age:
Gender:
Ethnicity:
Title at work:
Name of Organization:
Field/Industry of Organization:
Years at current place of work:
Full-time or part-time work: ________________ # of hours per week of paid work:
Self-identified impairment:

III. Interview Questions
We will now begin with the questions.
1. Please describe your role and responsibilities at your paid work.
What are your thoughts on full-time work?

2. How are accommodations perceived in your workplace?

3. What does underemployment mean to you? Could you provide a couple of stories or examples? Based on these examples, how did these scenarios make you feel? What did you do about the situations? Clarify whether these feelings fall into any of these categories: “perceptions of the fit of your qualifications to the job; feelings of opportunity to use your knowledge and skills on the job; and sense of entitlement to a better job”.

4. How do you identify with this statement?
I feel that I am underemployed at my work.
Strongly agree
Agree
Neither agree or disagree
Disagree
Strongly disagree
5. What have you experienced in terms of actions, practices, and policies to address underemployment in your workplace?

6. What opportunities have you missed that may somehow be connected to your impairment or disability? Do you understand this as a form of underemployment? (Why/why not?)

7. Have you connected with any other disabled person at work? How has this relationship assisted you in navigating your work?

8. Are there groups or networks to address the concerns of underemployment? Have you joined any of these ever? Why/why not. What were your activities?

9. What do you think could be done about underemployment as it affects workers who have impairments? What are the limits and potentialities of your individual and group efforts?

10. Would you describe any of the ways that the new Ontarians with Disabilities Act and other related policies/legislation are having an influence in your workplace?

11. What do you think about the new policy and issues of underemployment? How can your group efforts support the realization of a barrier-free Ontario in the workplace?

12. How have you tried to raise consciousness and/or make changes about underemployment in your workplace? What networks, resources and/or training do you need?

13. Overall, what do you think would need to be improved from your perspective as a person who self-identifies with a physical/visible impairment?

14. Has underemployment affected your health? Yes or no? If yes, how has underemployment affected your physical, mental, emotional and social health in any way e.g. physically, mentally, emotionally, socially? How have you addressed these health concerns?
PROTOCOL REFERENCE #25930

December 17, 2010

Professor Tanya Titchkosky
Sociology and Equity Studies in Education
OISE/University of Toronto
252 Bloor St. West
Toronto, ON M5S 1V6

Ms. Susan S. Lee
Sociology and Equity Studies in Education
OISE/University of Toronto
252 Bloor St. West
Toronto, ON M5S 1V6

Dear Professor Titchkosky and Ms. Lee:

Re: Your research protocol entitled, "Disability, Underemployment and Social Change"

<table>
<thead>
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<th>ETHICS APPROVAL</th>
<th>Original Approval Date: December 17, 2010</th>
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<td>Expiry Date: December 16, 2011</td>
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<td>Continuing Review Level: 1</td>
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We are writing to advise you that the Social Sciences, Humanities and Education Research Ethics Board has granted approval to the above-named research study under the REB's delegated review process. Your study has been approved for a period of one year and ongoing projects must be renewed prior to the expiry date.

All your most recently submitted documents have been approved for use in this study.

Any changes to the approved protocol or consent materials must be reviewed and approved through the amendment process prior to its implementation. Any adverse or unanticipated events should be reported to the Office of Research Ethics as soon as possible.

Please ensure that you submit an Annual Renewal Form or a Study Completion Report 15 to 30 days prior to the expiry date of your study. Note that annual renewals for studies cannot be accepted more than 30 days prior to the date of expiry, as per federal and international policies.

If your research has funding attached, please contact the relevant Research Funding Officer in Research Services to ensure that your funds are released.

Best wishes for the successful completion of your project.

Yours sincerely,

Dean Sharpe, Ph.D.
Research Ethics Board Manager--Social Sciences and Humanities