

Legally blind people's experiences of stigma in the context of the labour market:
Stories of adaptation and resistance

by

Martha Jansenberger
B.A., University of Western Ontario, 2007

A Thesis Submitted in Partial Fulfillment
of the Requirements for the Degree of

MASTER OF ARTS

in the Department of Sociology

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University of Victoria

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Supervisory Committee

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Abstract

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This thesis examines the labour market experiences of a purposive sample of legally blind people in a medium-sized Canadian city. Relevant literature on disability, employment and stigma is reviewed, providing context for the thesis. Thematic analysis of qualitative data gathered from 18 in-depth face-to-face interviews of legally blind working-age participants provide rich narratives of their experiences in the labour market and society at large. The participants' current and past employment situations are described and barriers to acceptance of their disability in the workforce are identified. Findings suggest that while perceived, enacted, and felt stigma constitute significant barriers to meaningful employment for the participants, many employ effective strategies to adapt to or resist stigmatizing treatment by others. Policy suggestions are provided to mitigate the impact of stigma on the lives of legally blind Canadians. The thesis concludes with suggestions for future directions of research in the area.

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Acknowledgments

I am deeply grateful to the funders of this research: Mitacs, the Disability Health and Research Network (DHRN), and the Sara Spencer Foundation. I would like to thank the University of Victoria for providing me with a graduate scholarship which allowed me to pursue my studies and participate in this research project.

I would also like to thank the 18 participants in this research project who shared their personal narratives with me. My goal in this thesis is to honour your lived experience and promote changes within the current model of disability in Canada.

Thank you to Zoe Lu for providing caring support, and solutions to all of the administrative challenges I brought to her.

A deep thank you to Dr. Cecilia Benoit and Dr. Andre Smith for providing ongoing encouragement, assistance, resources, and direction throughout this lengthy and trying process. I absolutely mean it when I say I would not have been able to complete this project without your support.

Finally, thank you to my friends and lovers, for believing in me when I did not, and pushing me forward when I was unable to do so myself.

Dedication

This thesis is dedicated to Sarah and Rebecca Jevnikar, in honour of your resilience.

Chapter One: Introduction

Introduction

In this thesis, I examine the reasons why legally blind people (LBP) experience lower employment rates and lower income than other people with disabilities and other working-age Canadians. I describe the employment situation of a sample of legally blind, working-age Canadians and examine the role that perceived discrimination might play in the employment experiences of the participants. Estimates place the unemployment rate of the legally blind population in Canada as high as 70-80% (O'Day, 1999; Shaw, Gold & Wolffe, 2007). This figure is considerably higher than the 6.8% reported by the general Canadian population (Statistics Canada, 2008). The significant disparity between these employment rates demands further examination.

The thesis is nested in a parent study that examined the experiences of LBP in relation to the labour market and which determined the unemployment rate to be significantly higher than other Canadians who identified as having a disability during the same period of time (Benoit et al., 2012). This parent study originated in 2008 as a result of collaboration between researchers from the University of Victoria and a coalition of legally blind people seeking to address perceived shortcomings in the current system of provincial support for the legally blind community. This community organization championed peer support and mentorship, building community among legally blind people, and rejecting the current standard of support. Its members saw the current model of support relied too heavily on the expertise of sighted people, an arrangement which

they felt removed agency from the legally blind and fostered dependency on social assistance and government disability pensions.

The organization's concerns about the employment situation stemmed from discouraging estimates of the rate of the unemployment among the legally blind population in Canada. This disparity in employment rates spurred UVic researchers and the community partners to collaborate on a research project which will be referred to as the "parent study" in the thesis. The objectives of the parent study were: (1) to produce an accurate statistical estimate of the unemployment rate among legally blind people in Canada based on Statistics Canada's Participation and Activity Limitation Survey (PALS) data; and (2) to contextualize this estimate using qualitative interviews with selected participants. Through examination of PALS data combined with 18 in depth, in person interviews with legally blind Canadians residing in Victoria BC, the parent study explored the relationship between disability stigma and unemployment. This thesis research is an off-shoot of that study, and specifically examines the stories of stigma's role in excluding legally blind Canadians from the workforce, an area that has been minimally researched until now.

Previous research on labour force participation for LBP has attributed low employment rates to personal factors such a lack of motivation, poor education and insufficient job-related experience (O'Day, 1999; Corrigan and Watson, 2002; Shaw, Gold and Wolffe, 2007). Shaw, Gold and Wolffe (2007) draw their study's sample population from youth, which they defined as anyone between the ages of 15 and 30 years old. Researchers would have been well-served to include a control group of sighted "youth" to act as a baseline standard for certain issues addressed in the study. The use of

a control group could have clarified whether characteristics like low job search motivation were the result of other demographic factors (such as age) rather than sight. This focus on younger participants also excludes an important contingent of legally blind workers- those that develop vision loss later in life, as well as individuals who have been in the workforce for an extended period of time. Because the Shaw, Gold and Wolffe (2007) study placed blame on the participants for their unemployment (citing a lack of motivation and qualifications), assessing the level of motivation among sighted youth in the same age range might have tempered these findings.

This type of research has also been criticized for blaming the disabled person for the challenges they face, focusing responsibility for low employment rates on LBP rather than the social, economic and legal systems that fail to accommodate their needs (Shaw, Gold and Wolffe, 2007). Attributing the disparity in employment rates to personal factors is consistent with a bio-medical understanding of disability which views the lack of physical functionality as the most significant barrier to accessing resources (Boorse, 1975, 1977). In recent years, a paradigmatic shift in disability research has resulted in greater attention to the lack of accommodations available to people with a disability and to the impact of societal factors such as employment barriers, discrimination and stigma on people living with a disability (Oliver, 1996; O'Day, 1999; Wendell, 1996; Tremain, 2005).

With support from community partners, UVic researchers sought to investigate the contribution of societal factors to employment disparity. In particular, consideration was given to the relationship between stigma and low rates of employment in the LBP population (Corrigan & Watson, 2002; Shaw, Gold and Wolffe, 2007). This relationship

was supported by findings in the parent study and became a focal point of this thesis research (Benoit et al., 2012).

Stigma: definitions and theoretical perspectives

Erving Goffman (1963: 3) wrote that stigma "spoils identities", and acts to bar individuals "from full social acceptance" and degrades them "from a whole and usual person to a tainted, discounted one". There are three main types of stigma: tribal stigmas- typically built around race or other similar identifying physical characteristics; behavioural stigmas- enacted when an individual deviates from behavioural norms; and bodily stigmas- based around observable deformities (Goffman, 1963). Groups that deviate from the dominant norms and values of society (whether entho-culturally, behaviourally, or physically), can become the subject of social exclusion and experience limited access to resources, such as housing, education and labour market participation (Benoit et. al, 2012; Link and Phalen, 2001). The concept of stigma will be further expanded in the remainder of this thesis; in particular, perceived, enacted, and felt stigma will be discussed. Perceived stigma refers to stigmatizing experiences that the marginalized person is aware of during social interactions (Link and Phelan, 2001). Enacted stigma refers to actual instances of discrimination, whereas felt stigma refers to the guilt and shame which limit a stigmatized person's social interactions in anticipation of discrimination (Scambler and Hopkins, 1986). The role of stigma in limiting full social acceptance, and access to the labour market for legally blind Canadians, underpins much of my thesis research.

Organization of the thesis

The relevant literature relating to legally blind individuals and their experiences in the work force is reviewed in Chapter Two. This chapter provides context for the findings that follow. I review information about the rates of labour force participation among the legally blind. I also discuss some of the previous literature, much of which focuses on personal factors (little motivation, education and job experience) as explanation for the low employment rate among the legally blind. Literature which acknowledges the role of societal factors in limiting access to the labour market for legally blind Canadians will also be presented, with particular attention to studies that examine the role of stigmatization. Disability policies from Canada and other countries are also considered. A theoretical framework for this research is provided at the conclusion of this chapter, including overarching themes of stigma, and conflicting models of disability. Chapter Three provides a description of the methodological process for the research project. In this chapter, the parent project is discussed in greater detail, and differentiation between it and the follow-up study is reiterated. Recruitment, sampling and data collection procedures are detailed. Also included in the third chapter is a section discussing some of the challenges faced during this research project; including the tension that developed between the community partners and the researchers, challenges with the transcription process, and difficulties faced as an “outsider” studying a marginalized population.

The findings section follows, wherein the interview protocol is reviewed and the specific questions used to draw the data for this study are discussed. Drawing from data collected during the participant interviews for the parent study, I focus on the participants’ labour market experiences; document their experiences with stigma in the

context of seeking and maintaining employment; and investigate the impact of perceived stigma on their motivation to engage with the labour market.

I report the findings in Chapters Four and Five. Chapter Four summarizes participant accounts of their employment experiences and the impact of perceived and enacted stigma in their lives in general and the labour market specifically. This chapter also examines how these factors have affected their motivation to seek employment and remain in the workforce. Perceived stigma is also reflected upon as it relates to the day-to-day microaggressions experienced by the participants.

Specifically, the fourth chapter reports on:

- 1) The ways in which participants responded to the personal and societal employment barriers they have faced while attempting to access and participate in the labour market and their beliefs about the impact of stigma on their motivation to seek employment;
- 2) The nature and extent of the barriers participants faced in seeking and maintaining employment; as well as attitudinal or behavioural barriers of their co-workers or managers. Enacted and perceived stigma as a barrier to labour market participation and satisfaction will be considered in this section;
- 3) The extent to which participants felt accepted within the workplace once employment had been secured;
- 4) The extent to which participants attribute the existence of these barriers to active forms of stigma and discrimination, or a lack of awareness, sensitivity or ignorance about the workplace capabilities of legally blind people;

- 5) The extent to which participants faced stigmatization in their day-to-day lives.

Chapter Four centres on two themes: perceived and enacted stigma experiences in the workforce. Building on the findings of the parent study around perceived stigma presented in the review of literature, participant narratives describing their experiences with stigma are presented.

Chapter Five presents findings on the responses to stigma as reported by participants. Specifically, the Chapter centres on the following issues:

- 1) The experience of felt stigma;
- 2) The impact of felt stigma on self-esteem and self-confidence.
- 3) The role of felt stigma in limiting the social network of LBP;
- 4) Resistance and resilience to stigma;

For the purpose of this thesis, resilience refers to the ability to overcome barriers to labour market participation, whereas disenfranchisement due to felt stigma reflects a withdrawal from the labour market stemming from the internalization of rejection and stigmatization. In general, the resilient participants in my sample enjoyed a higher rate of employment, and showed lower levels of perceived stigma in comparison to the disenfranchised group. This is indicated by their scores on the Devaluation-Discrimination Measure (adapted for the legally blind population) (Link, 1987; Link & Phelan, 1999; Benoit, 2012), as well as from their personal narratives.

In Chapter Six I present a discussion to expand on the findings. In this chapter, I summarize the findings on the ways that stigma acts as formidable barrier to employment

and how it is managed and overcome by the participants. I also discuss resistance and resilience in greater detail, and present some of the limitations of this study.

Chapter Seven concludes this thesis with an examination of current policies impacting access to the labour market for legally blind Canadians and, in light of the findings, suggest ways in which these policies could be improved to increase the rate of labour force participation for this population. In the conclusion, I reiterate the key findings and provide suggestions for further research.

A Note about Terminology

As language around disability is an evolving process, it is important to qualify the terminology used in this research project. At the outset of the parent study, our community partners suggested that concrete language around blindness was preferable to terms like “visually impaired,” “special needs,” and “low vision.” They believed that indirect terminology failed to honour the lived experiences of legally blind people, and implied shame around their condition. Their beliefs around language echoed similar arguments in the literature as illustrated here:

Language reflects conceptions of reality, or truth. As such, I feel the term ‘special need’ is no longer useful or constructive. To me, it is reflective of professional ownership where medical and educational definitions dominate the discourse. It jars uncomfortably with the discourses in the disability movement where new languages and metaphors are emerging in a creative burst of pride and assertion... if we are able to ‘move through’ identities, we can also adopt a similar approach to the use of special language, [one which] will make all language special. Thus ‘special’ becomes normality. (Corbett, 1996, pp. 32-33, 101).

In the interest of both accuracy and honouring the wishes of our community partners, the terms “legal blindness,” and “legally blind” are used throughout this thesis. “Legal blindness” is a term applied to a population of people with decreased vision. The criterion for this medically approved designation is defined by the government, and outlined in provincial legislation. All provinces quantify legal blindness as ranging from less than 20/200 vision in the person’s best eye to no vision at all (Hoppe, E., 1992). Depending on municipal, provincial and federal guidelines, being declared legally blind may entitle a person to a variety of government subsidies which vary between jurisdictions.

The term “disability” has also evolved over the last five decades. Originally, considered a catch-all word referencing medical impairments that limited a person’s ability to work in the formal labour force, it is now understood to reflect the broad scope of social, physical, and emotional challenges faced by individuals with a physical or intellectual limitation as they try to negotiate a world that has given little consideration to the needs of the non-able-bodied (Corker & French, 1999). The term disability has also been criticized for reducing the disabled population to a singular characteristic or master status, despite considerable variation in experience (Higgins, 1992; Kutner, 2007). This thesis was written with an understanding that experiences around disabilities vary considerably across personal circumstances. For the purpose of this research, my use of the term “disability” acknowledges the interplay between personal and societal factors resulting in diminished access to important social spheres as experienced by many individuals with physical or intellectual limitations.

Corker and French (1999) remind us that a new meaning of a word does not simply replace its predecessor; both tend to co-exist for an extended period of time, defining roles and delineating boundaries in the subject's relationships to other things and people, and becoming a matter of identity. The "disabled" identity is complicated, interwoven, and constantly evolving. As the authors posit, our understanding of language as a system of words with fixed meanings that everyone agrees upon should be challenged and reframed as a site of variation, contention and potential conflict; and the power relations and politics that exist within our system of language, which is central to our present social and economic organization, should be acknowledged. Through consideration of the limitations and power dynamics inherent in language, we are able to develop a more nuanced understanding of the complex meaning of terms like disability and blindness.

For the purpose of this research, as noted above, stigma is defined as a mark, attribute, behaviour, or reputation that associates a person with socially discrediting, undesirable characteristics or stereotypes, causing an individual to be classified by others in a rejected, negative way rather than in an accepted "normal" one (Goffman, 1963). Stigma disregards biography and complex life situation, resulting in discrimination, marginalization and/or social exclusion from important resources, such as housing, education and the labour market (Jones et al, 1984; Crocker et al, 1998; Link and Phelan, 1999). Menec & Perry (1998) further expand on the ways in which perceptions of morality impact experiences of stigmatization. Labour force participation refers to the percentage of adults over the age of 15 who have a job or business, or are unemployed but available for and actively seeking work. Unemployment rates refer to the percentage

of the population who are working age and lack employment but are seeking and ready for work. Underutilization rates refer to individuals who are working age and unemployed, but discouraged from looking for work or are involuntarily self-employed, or working part-time but prefer full-time work (Benoit, et al. 2012).

Situating the Thesis within the Parent Study

The parent study is a large, mixed-methods project aimed at examining the lived experiences of LBP people in relation to the labour market. Through examination of Participation and Activity Limitation Survey (PALS) data combined with 18 in depth, in person interviews with legally blind Canadians residing in Victoria BC, the study explored some of the barriers faced by legally blind people when seeking employment. Findings suggested that stigma played a significant role in the exclusion of this population from the labour market (Benoit et al., 2012). These findings provided a direction for further research, and inspired a follow up study which would form the foundation of my thesis project using the data I collected during the 18 participant interviews.

Another important finding from the parent study was the determination of a reliable unemployment rate for the legally blind population in Canada. It was discovered that the previously estimated rate was considerably inflated, with PALS survey data supporting a rate of 26.4%. Although this rate is significantly lower than previous estimates, it was still nearly four times the Canadian national average, and 2.5 times that of Canadians who identified as having any type of disability (10.4%) (Benoit et al., 2012). After determining an accurate unemployment rate for legally blind Canadians, the

partnership between researchers and the community organization we were working with began to deteriorate. The dissolution of our partnership with the community organization will be discussed in greater detail in Chapter Three. Despite the dissolution of our partnership with the community organization, the parent study produced valuable findings and direction for further research. With an interest in honouring the generosity of our participants in sharing their personal narratives, this thesis expands on the parent study by giving voice to a segment of this marginalized population of Canadians, with an aim to improve their current conditions.

Chapter Two: Review of Literature

Introduction

This chapter outlines a number of the emergent themes from the literature on LBP and the labour market. This literature review demonstrates that the legally blind population has experienced comparatively low labour market participation for a variety of reasons, including stigma and discrimination. A brief overview of some of the academic discourse and structural context around employment and legal blindness will highlight specific issues around education, visibility, and disability. Canadian policy related to blindness and disability will also be reviewed and compared to other international models. The literature review concludes with a synopsis of the theoretical framework guiding this research, touching on issues around stigma, and competing models of disability.

Literature explaining low labour force participation

Despite the implementation of employment policy aimed at achieving representative equality for disabled individuals in the workplace¹, estimates of the current Canadian unemployment rates for the legally blind community remain disproportionately high (O'Day, 1999; Shaw, Gold & Wolffe, 2007; Benoit et al. 2012). Prior to commencing the parent study, Canadian unemployment rates for the legally blind

¹ The Canadian Charter of Rights and Freedoms prohibits discrimination in the basis of disability, and guarantees equality and equal protection under the law. The needs of disabled workers must be accommodated by the employer, and termination based on disability is forbidden under the Charter (1982, s. 15:1).

population were estimated at 70-80%. This rate is significantly higher than the national rate of unemployment for the general population which fluctuated between 6% and 8.7% from 1999-2011 (Statistics Canada, 2011; Akyeampong, 2007; O'Day, 1999; Shaw, Gold & Wolffe, 2007). Although it was later determined to be an inflated estimation, this rate informed the North American research on employment in the legally blind community prior to 2012, and merits acknowledgment.

Historically, disability research has been criticized for its tendency to place blame on the disabled person for the challenges they face. Much of this blaming has been attributed to the “outsider” (able-bodied) status of past researchers, who have often been accused of using offensive, demeaning, and insensitive language while colonizing the stories of the disabled people they are researching (O'Day, 1999; Wendell, 1999; Tremain, 2005). A common narrative in the previous literature is that the legally blind population faces barriers to employment based on insufficient education, motivation, and work experience- all personal factors over which they have some degree of control (O'Day, 1999). Although these factors may determine employability in much of the general population, there is a lack of attention paid to other factors like (often costly) assistive technologies and devices that LBP may need in order to adequately function in the job role. This kind of oversight reflects the disparity between a bio-medical understanding of disability and one that accounts for the societal impact of a world built around the able-bodied, a subject that will be discussed in greater detail throughout this thesis. These studies (e.g., Shaw, Gold and Wolffe, 2007) also fail to recognize the source of low motivation- self stigma, or the internalization of negative, prejudicial attitudes leading to negative emotional responses and behaviours (Corrigan & Watson, 2002). The

following section will consider literature related the role of education and work experience for legally blind labour market participants.

Education and work experience

Research on LBP and labour force participation has examined the impact of insufficient education and insufficient job-related experience. One of the only studies done in the area was conducted by Shaw, Gold and Wolffe (2007) and surveyed 328 employed and unemployed blind and low vision² individuals between 15 and 30 years of age. Of the participants in their study, 29% were currently employed. Their findings suggested that increasing the level of education within the legally blind community was of paramount importance to improving employment levels. In spite of this recommendation, the article also acknowledged there is little disparity between the levels of education within the legally blind population when compared to the general public. This study relies on a definition of employability that fails to account for societal factors involved in employment, including the cost of accommodation devices and the impact of stigmatization on job search experience and motivation. Furthermore, a stronger understanding of the factors influencing employability could have been gained by including a sighted comparison group. This article fails to address the barriers to accessing the workforce that specifically relate to the legally blind population. The

² “Those who were categorized as blind had a visual acuity of between 20/1200 and no usable vision (no light perception), and those who were categorized as having low vision had a visual acuity of between 20/200 and 20/1200, as recommended by the World Health Organization (1973)” (Shaw, Gold and Wolffe, 2007).

research is informed by a simplified definition of employability that is based on a sighted, able-bodied population, resulting in blame being placed on the legally blind participants for their own exclusion from the job market.

In a study exploring employment barriers for blind and low vision individuals, O'Day (1999) attributed the low rate of employment within the legally blind community to personal, societal, and programmatic barriers, recognizing stigma as a significant factor contributing to low labour force participation. In her interviews with 20 unemployed blind and low-vision subjects (since birth or infancy) of varying ethnic, educational, familial, and class backgrounds, O'Day noted a relatively high level of educational qualifications among her participants. This finding is of particular importance considering all her participants were unemployed and collecting a government disability income at the time of the study; moreover, all of her participants expressed a desire for meaningful employment. However, by selecting a population of unemployed participants on disability, O'Day excludes LBP participants who could shed light on what has worked in terms of securing and maintaining employment. Establishing *how* social barriers have been overcome would assist in the development of strategies to help more LBP secure employment. Furthermore, in limiting the research population to individuals who were legally blind since birth or infancy, O'Day excluded people who experienced the onset of their vision loss later in life. This skews their findings toward a population that qualifies for governmental assistance in learning Braille, receiving mobility training, and other assistive technology, increasing their level of literacy, mobility and often confidence. Individuals who experience adult onset legal blindness rarely qualify for these governmental programs, and in some cases experience job

termination because of their inability to adapt to their loss of vision. On the other hand, O'Day's research recognizes the existence of personal (within the control of the subject) and societal (outside of the subject's control) barriers to employment, and the ways in which these barriers interface with each other. She rightly criticized previous disability research for placing blame on the legally blind individual, rather than problematizing the societal barriers they face in securing meaningful employment.

Visibility

Scott (1969) made an important contribution to the field of disability research, wherein he examined behavioral differences between sighted and LBP people. He referred to these mannerisms as "blindisms" and gave examples like tilting one's head so that their ear was facing the speaker rather than their eyes. He suggested that these unusual mannerisms could result in alienation from the sighted community. Scott's work around the visibility of disability factors into issues around stigmatization which contributes to the theoretical framework for this thesis, and is of particular importance in managing stigmatization. The extent to which one experiences stigma is largely determined by the saliency of their stigmatized characteristic; and in addition to "blindisms," the use of guide dogs, white canes, and other assistive devices, further contributes to the visibility of a legally blind person's disability.

Scott (1969) also criticized the disability industry, accusing this charity economy of exploitation and control over legally blind individuals. He advocated for the return of agency to LBP, and promoted the value of peer support and empowerment. Scott (1969)

is a pioneer in the field of disability research, and his personal circumstances informed much of his work. Many of the more recent academics have drawn from his contributions.

Disability

Wendell (1996) contributes a critical account of the disability literature from the standpoint of a previously able-bodied, now disabled individual. This qualitative, life-course account utilizes Goffman's work on stigma, but draws attention to some offensive language and generalizations Goffman uses in his analysis, attributing them to challenges within academic language during that era. Wendell discusses the implications of disability status in relation to obtaining employment, developing a social network, and maintaining a healthy self-image. This research acknowledges the role of internal and external barriers to accessing resources, and accounts for the differences in understanding issues around disability as an able-bodied person compared to a disabled person.

Wendell (1996) recognizes a concept that is often glossed over in disability literature – i.e., that disability status is experienced in different ways by everyone and as a result the generalizability of the content of any study is limited. For example, a LBP from a wealthy family, living in a city with an accessible transit system, would have considerably different experiences of independence and autonomy when compared to an impoverished person with the same condition, living in a rural area. Wendell's work accounts for intersectionality (the ways in which multiple marginalizing characteristics work together to impact the lived experience of marginalization), and sheds some light on the complexity of living with a disability. In her writing, Wendell presents a great deal of

information regarding her personal experiences, and makes a valuable contribution to the literature.

Policy Comparisons

In an Australian study of randomly selected, visually impaired participants, McCarty, Burgess and Keeffe (1999), found that 73% reported participation in the labour market. Such findings drastically differed from the Canadian employment statistics being reported at the time. The study concluded that. "...visual function was not a predictor of labour force status" (p.190), thus raising the question: "what is Australia doing to neutralize employment barriers for legally blind people that Canadians are not?" The authors examined Australian pension and disability policy as a possible factor contributing to the inter-country discrepancy in employment levels for legally blind individuals. Under the Australian model, the government does not conduct means testing³ when determining eligibility for a "blind pension," meaning that the legally blind population in Australia is afforded a net financial entitlement regardless of whether or not they work, and at no point is the pension clawed back based on earning a higher income. McCarty et al. (1999) suggest that this universal entitlement allows legally blind workers to afford accommodation devices which allow them to maintain their employment, whereas in British Columbia (and most of Canada), that entitlement is aimed at providing a living allowance and would be reduced should the recipient become employed. The article does not mention the comparative costs of the Australian model, therefore

³ Means testing is a process wherein the government determines eligibility for benefits based on a series of qualifications aims at determining whether the person (or family) could survive without the financial assistance.

implementing a similar policy in Canada would require a thorough review of the economic impact of such a strategy. Nevertheless, by accounting for the need to purchase assistive devices, and recognizing the impact on job-search motivation from the claw-back of disability pensions once employment has been secured, these authors present a more sophisticated interpretation of the labour market experiences of the legally blind.

However, more recent research (e.g., Benoit et al., 2012) suggests that employment rates for LBP might be comparable between Canada and Australia (26.4% vs. 27%), thus raising doubts about the validity of McCarty et al.'s argument (1999). Nonetheless, the authors do present an interesting and potentially viable policy alternative to some of the barriers to employment that legally blind people face (inability to afford assistive devices, lowered job search motivation due to disability pension claw backs). Another weakness in the McCarty et al. (1999) study is the lack of clarity around the term "vision loss" which was used throughout the article. In Canada, the definition for legal blindness is set out in "The Blind Person's Act" and includes individuals with no vision, or less than 20/200 in their best eye (Hoppe, 1992). McCarty and colleagues refer to a standard of vision of 6/60⁴ in determining whether a resident qualifies for the "blind pension," but throughout the remainder of the article the term "vision loss" is used in describing study participants (1999). As a result, the reader is left wondering if they are comparing the same population of legally blind individuals. Vision loss is a vague term, and in theory can describe someone with corrective lenses who operates with 20/20 vision when wearing their glasses; obviously, such a person would experience life in a

⁴ Equal to the Canadian standard.

different way than someone who relied on a white cane for mobility. The governmental support policies outlined in this study may not be as effective as they seem if the subject population is drastically different. All things considered, this article presents an interesting perspective, and moves towards developing a potential solution to the employment barriers currently faced by legally blind Canadians. Thus far, the literature review has suggested that internal and external factors play an important role in the labour market experiences of legally blind people. In the following sections, these themes will be expanded upon and a theoretical framework for some of the external factors will be developed.

Theoretical Framework

The literature relating to disability has informed the direction of my thesis and is presented below.

Bio-Medical versus Social Models of Disability

As noted above, in recent years the bio-medical definition of disability as observable deviations from biomedical norms of structure or function that directly resulted from disease, trauma or other health conditions (Boorse, 1975, 1977) has lost popular support (Bickenbach et. al, 1999). Although the medical component of disability continues to merit some consideration, increasing emphasis is being placed on the ways in which disability is enacted within a larger social context wherein the world is built around the able-bodied, causing the disabled to be excluded or restricted from accessing

the opportunities available to their able-bodied counterparts (Bickenbach et. al, 1999). Several theorists have employed Marxist principles in analyzing disability, identifying capitalist values as the root source of discriminatory behaviour which creates barriers to employment for individuals living with disabilities (Wendell, 1999; Fitzgerald, 1998). For example, Fitzgerald (1998) problematizes the commodification of the body in the human genome project. She argues that the Human Genome Project presents an opportunity for the genocide of “genetically defective” people, a situation which would further marginalize individuals with disabilities. Fitzgerald argues that capitalism and its commodification of the body informs the valuation of individuals on the basis of their contributions to the labour market. This perspective frames legally blind individuals as deficient and defective labourers.

Building on Fitzgerald’s criticism of capitalist ideology around disability, Tremain (2005) discusses how the “contemporary disabled person” has led to the creation of various institutions, experts, services, systems, and commodities to assist LBP. Like Scott, Tremain recognizes the economy that has been built around the “support” of disabled people, and challenges the notion that such a system is necessary, adequate, or sufficiently beneficial for the labeled individuals swept into it- particularly when comparing the costs and burdens they are inflicted with as a result of these systems. Tremain is critical of the current services because they subject the marginalized population to the expectation they learn special skills, shoulder the burden of adapting, and contribute their limited finances to accommodating their own needs in the labour market. Tremain believes that government, employers, and society constitute systems of oppression that need to be challenged in order for LBP to be empowered as full

participants in society and the labour market. Fitzgerald (1998) also suggests that visibly disabled people act as a "...constant reminder to the able-bodied of the negative body- of what the able-bodied are trying to avoid, forget and ignore" (p.154). This assertion links the issues of stigmatization and the visibility of disability discussed earlier, and supports Benoit et al.'s finding that stigmatization has a significant impact on the lived experiences of LBP (2012). Fitzgerald's work also explores the threat that the visibly disabled pose to our culture's self-embedded perception of perfection and control (1998). Fitzgerald draws attention to Western culture's fixation on perfection; however the application of her work requires further expansion. Fitzgerald's research is based on individuals from a variety of disability groups, and specifically emphasizes individuals who were born with genetically marked disabilities, a designation that applies only to a portion of the legally blind population (1998). Disability status is complicated, and many factors are involved in the way people experience this status in their day-to-day lives. As such, Fitzgerald's article (1998) is limited in its application to LBP because the vast majority of legally blind individuals experience their loss of vision later in life (World Health Organization, 2009), and often there is no obvious genetic marker.

Goffman's work on stigma (1963) provides important insights on the current treatment of blind individuals in the workforce, as well as in larger social settings. According to Goffman, stigma occurs when a person is defined based on an "attribute that is deeply discrediting" which reduces them "from a whole and usual person to a tainted, discounted one" (1963, p. 3). Goffman argues that stigma "spoils identities" and bars individuals from experiencing "full social acceptance" (1963, p. 3). A considerable amount of research has expanded Goffman's original findings. Of particular importance

to the theoretical framework informing this thesis, is Goffman's and other key researchers' conceptual thinking about enacted, felt, and perceived stigma. Scambler and Hopkins (1986) distinguished between 'enacted' and 'felt stigma'. "The former refers to overt discrimination against those with epilepsy on the sole grounds of their social unacceptability, while the latter denotes both a sense of shame and a companion fear of encountering enacted stigma." (Scambler, 2009). Felt stigma happens when a member of a marginalized group experiences fear and shame based on their *anticipation* of rejection or other barriers to access. An individual experiencing felt stigma will often try to conceal their stigmatized characteristic. As previously discussed in regard to blindisms (Scott, 1969), concealment is difficult for many legally blind people, especially those who rely on assistive technologies. Scambler and Hopkins (1986) suggest that an inability to conceal one's stigmatizing characteristic may result in social disengagement as a means of avoiding the negative feelings anticipated by the marginalized person. Other consequences of felt stigma include: "low self-esteem... strained and uncomfortable social interactions with potential stigmatizers, more constricted social networks, poorer life satisfaction, unemployment and loss of income" (Link & Phelan, 2001, p. 1622). Experiences around felt stigma presented as a common theme in the narratives of the participants in this study, and will be expanded upon in the findings chapters of this thesis. Scott's (1969) symbolic interactionist approach also sheds important light on the impact of stigma on the experiences of legally blind people: "these stereotypic beliefs about the blind have profound consequences for the self-concept of every blind man. He may internalize them as a part of his self-image, or he may reject them as completely false and misleading, but he cannot ignore them" (pg. 24). Scott's

work on the impact of stigma on the day-to-day experiences of legally blind people supports examining the role of stigma in explaining low labor force participation.

Perceived stigma refers to the perception that others are treating you differently because of a particular condition or behaviour, and is closely related to felt stigma. Unlike enacted stigma, perceived stigma does not involve the internalization of a devalued identity as a result of stigmatization. It simply denotes awareness of the actual stigmatization on the part of the LBP. The work of Link and Phelan (2001 & 1999) in the area of perceived stigma is particularly relevant to this thesis, as it was used in the parent study to establish a link between perceived stigma and the employment experienced of LBP.

Constantine & Dorazio's (2008) work on "microaggressions" provide a framework for understanding the ways in which marginalized populations face subtle forms of discrimination throughout their day to day lives. Microaggressions relate to the perceived, demeaning implications which are made towards marginalized groups, through words or actions, on a day-to-day basis. These (often seemingly well-intended) comments work to reinforce negative stereotypes of marginalized groups. Microaggressions are related to perceived stigma, and connect well with the work of Link and Phelan (2001 & 1999) discussed previously.

Menec & Perry (1998) compared the impact of the stigma associated with blindness to other "spoiled identities" (for example people with cancer, or AIDS). Their research established a level of stigma experienced by blind participants relative to other stigmatized groups. Menec & Perry (1998) found that stigmas ascribed to "uncontrollable" causes generate more pity, and a greater willingness to help than those

attributed to “controllable” causes. As such, they determined that the legally blind population was treated with more sympathy and understanding than other stigmatized groups who were often blamed for their stigmatized characteristics (for example, people with HIV/AIDS). Menec and Perry’s research primarily focused on attribution theory⁵ and how it applied to individuals with different types of spoiled identities; the study falls short of examining the barrier that stigma creates for a legally blind person in accessing social resources. This theme will be expanded upon in the findings chapters.

Link, Phelan and Dovidio (2008) also built on Goffman’s work, theorizing that the functions of stigma and prejudice in society include: “(1) exploitation/domination, (2) enforcement of social norms and (3) avoidance of disease. Link et al. also refer to these as keeping people down; keeping people in; and keeping people away” (p. 358).

Exploitation/domination, serves the powerful through reinforcing the current distribution of goods: less for some means more for the powerful. This part of the theoretical framework ties in well with Fitzgerald’s (1998) work mentioned earlier. By *enforcing social norms*, stigma functions to encourage conformity to social expectations and provide boundaries for acceptable levels of deviation from the norm. This phenomenon relates to Goffman’s theories of stigma and spoiled identities. Finally, *disease avoidance* refers to a fear from the dominant culture that the disability is somehow contagious, coupled with discomfort or disgust when being exposed to certain types of disabilities. This sentiment is echoed in the work of Fitzgerald that was previously discussed.

⁵ Attribution theory holds that humans seek order for their social world by explaining behaviours based on perceived physical traits (Heider, 1958).

Applying Link's Devaluation/Discrimination Measure

Link's work in the field of stigma examines the discrimination and marginalization of people with mental illness (1987). The development of Link's Devaluation-Discrimination Measure⁶ continues to be recognized as the most reliable, accurate measurement tool in determining the level of stigma that a marginalized group perceives for various kinds of spoiled identities (Mak, Poon, Pun & Cheung, 2007). This thesis will build upon findings discussed below which are derived from the use of this measure during the parent study to characterize the stigma reported by the legally blind participants. These findings from the parent study provide some context in which to situate the qualitative narratives the participants provided me around their experiences of stigmatization which I discuss in the findings chapters. The Link's Devaluation-Discrimination Measure (1987), "...assesses a respondent's perception of what *most other people believe...*" (Link, et. al, 2004, p.524) and thus offers of the degree of perceived stigma experienced by the participants. The table below (Benoit et al, 2012) shows the breakdown of responses to the questions about perceived stigma based on Link's devaluation discrimination measure (1987):

Table 1 Link's Devaluation/Discrimination Measure

Devaluation Discrimination Measure		
	Agree (%)	Disagree (%)
Most people believe that a blind or legally-blind person is just as trustworthy as the average citizen?	94	6
Most people feel that being blind or legally-blind is a sign of personal failure?	28	72

⁶ See Appendix A

Most people believe that a person who has been diagnosed as blind or legally-blind is just as intelligent as the average person?	56	44
Most people in my community would treat a blind or legally-blind person just as they would treat anyone?	50	50
Most people would willingly accept a blind or legally-blind person as a close friend?	61	39
Most young people would be reluctant to date a blind or legally-blind individual?	83	17
Most people think less of a person who is blind or legally-blind?	72	28
Once they know a person is blind or legally-blind, most people will take their opinions less seriously	61	39
Most people would accept a blind or legally-blind person as a teacher of young children in a public school	50	50
Most people would not hire a blind or legally-blind person to take care of their children, even if he or she had children of their own?	89	11
Most employers will hire a blind or legally-blind person if he or she is qualified for the job?	33	67
Most employers will pass over the application of a blind or legally-blind person in favour of another applicant?	83	17

Source: Adapted from Link (1987), originally published in Benoit et al., 2012.

Responses indicated a lower level of perceived stigma in two areas: one related to whether a legally blind person is considered trustworthy (94% agreed), and whether their legal-blindness is a result of personal failure (72% disagreed). These responses were consistent with a marginalized population whose stigmatized characteristic is seen as primarily physical, and separate from other elements of their lives; as well, these responses suggest that the participants believed the general population did not blame them for the acquisition of their stigmatized characteristic.

Because of this, we would anticipate that the participants would experience less apprehension than individuals with highly stigmatized characteristics like obesity (where the participant may be blamed for their circumstances), or schizophrenia (wherein the participant may anticipate being viewed as unpredictable and fearsome) (Schafer & Ferraro, 2011). This further suggests that participants would expect to experience less overt or enacted stigma and more perceived forms of stigma linked to a lack of understanding or ignorance about blindness and the capabilities of blind people.

This is indeed confirmed by the results on the other questions. For example, there were relatively equal division in responses when asked whether most people believed those with legal-blindness were as intelligent as the average person (56% agree) and whether most people in their community would treat a legally blind person in the same way they would treat anyone (50% agree). With regards to the measures specifically addressing issues of employment, most participants perceived moderate to high levels of stigma. Half of the participants disagreed that ‘most people would accept a legally-blind person as a teacher of young children in a public school,’ and 89% agreed that ‘most people would not hire a legally-blind person to take care of their children, even if he or she had children of their own’.

The final two measures touched on specific perceptions around labour market entry. Sixty-seven percent of participants disagreed that ‘most employers will hire a legally-blind person if he or she is qualified for the job.’ One participant reported consistent interview feedback from potential employers where she was told, she “came in a close second” in the selection process; she recounted that it had happened so many times now she no longer believed it. For the final measure, 83% of participants agreed

that ‘most employers will pass over the application of a legally-blind person in favour of another applicant.’ Once again, many participants spoke to the need for education in the labour market, “... having to educate potential employers because there’s a lot of misunderstanding about what blind people are capable of doing.”

Perceived stigma also extends to the participants’ views on how they expected others to behave toward them in relation to their personal lives. In particular, eighty-three percent of participants agreed that ‘most people would be reluctant to date a legally-blind person’, and 72% believed that most people thought less of a person who is legally blind. Sixty-one percent of participants believed their opinions would be taken less seriously if their legal-blindness was discovered, and many expressed the sentiment that people often talked down to them. Only a small majority of participants (61%) agreed that ‘most people would willingly accept a legally-blind person as a close friend’; as Mary, age 54 responded, “I personally don’t have any problem having friendships, but I know that there are a lot of lonely blind people.” This suggests that participants would expect greater difficulties with perceived stigma in their personal relationships—this source of personal perceived stigma could compound the stigma experienced in the workplace discussed below, thus further discouraging LBP from maintaining or seeking employment.

Based on this review of the literature, it is clear stigma plays an important role as in the lives of legally blind people. Building on the findings of the parent study, I deepen understanding of how stigma impacts LBP’s experiences seeking meaningful employment in the Canadian labour market by conducting an analysis of the stories of

participants' day-to-day experiences. To my knowledge, there had been no published research providing an experiential account of stigma as it relates to the legally blind population; this research project aimed to close that gap.

Summary

This chapter has presented an overview of some of the relevant literature related to disability, employment and the experiences of the legally blind. The eighteen participants in our study brought with them a diversity of educational, social, and employment experiences, creating a complex interplay between a variety of factors influencing their labour market experiences. The aim of this literature review was to provide a grounding context for why this research was conducted, and how the findings are interpreted. The literature suggests that:

1. Legally blind people face personal and societal barriers to employment that are reflected by the low rate of employment within the community;
2. Historically, legally blind people have been attributed blame for their low employment levels by disability theorists;
3. Several socio-structural factors including the disability support industry contribute to the stigma faced by legally blind individuals, and;
4. Stigma is a factor in the exclusion of legally blind people from the work force.

There is a need to problematize the systems that are in place which impede the employment opportunities afforded to the legally blind population. These systems include: the disability support economy, governmental assistance programs, and current

employment practices. Furthermore, changes to employment policy, as well as educational campaigns, may be of significant value in addressing the systemic barriers faced by legally blind individuals seeking employment. In order to fully understand the complexity of the situation, it is imperative that both personal and societal barriers to employment are considered, as well as, the interplay between the two. The next chapter provides details about the research methodology used for the interviews of legally blind, labour market participants in the Great Victoria Area.

Chapter Three: Research Design and Methods

The focus of this thesis is on the labour market experiences of legally blind individuals between 15 and 65 years of age residing in Victoria, British Columbia. The study is part of a parent study commissioned in 2008 by community partners who were concerned about the low level of employment among the legally blind population when compared to similarly educated individuals, with and without disabilities. Funded by the Canadian Federation of the Blind, MITACS (Mathematics of Information Technology and Complex Systems) and DHRN (Disability Health Research Network), the parent study analyzed national and local PALS (Participant and Activity Limitation Survey) data relating to employment rates for legally blind individuals. In addition, the parent study involved collecting and analyzing qualitative and quantitative interview data on the employment experiences of LBP from the Greater Victoria Region. The intent was to identify the factors that contribute to the disparity between employment rates for legally blind and sighted individuals in Canada, and what can be done to counteract some of these barriers. Unfortunately, the relationship between the researchers and community partners began to deteriorate after the investigators found a lower unemployment rate for the legally blind population than had previously been estimated. Because of disagreement over the validity of this estimate, the community partners withdrew from the study and the name of their organization was withheld from any publications, including this thesis.

To complement this quantitative estimate, face-to-face qualitative interviews were conducted with 18 participants about their labour market experiences. The intent was to

explain in more depth the disproportionately high rate of unemployment which had been estimated at 70-80% for this group (O'Day, 1999; Shaw, Gold & Wolffe, 2007). These interviews⁷ included a variety of demographic and experiential questions, including questions on barriers to attaining employment and barriers to meaningful employment if employed, and twelve questions based on Link's Devaluation-Discrimination Measure to determine the participants' experiences with stigma in their day to day lives. The community partners offered valuable feedback in designing the interview protocol, procedures, assisted with the recruitment of participants, and lent credibility to the research project within the blind community. They facilitated participant recruitment by supplying their organization's list-serve; members also provided valuable feedback and assisted with accessible language. As well, community partners provided practical advice which was helpful in organizing issues around consent forms; for example, they advised against translating our informed consent form to Braille because only 10% of legally blind individuals are Braille literate (Amato, 2002). The partners also assisted by acting as "test cases" for the interview protocol, and after some revision we developed a series of questions that satisfied all parties. We added questions related to the lived experience of LBP navigating the labour market and some questions provided space for the interviewer to adapt to the expertise of the participant through probing. The mix of open-ended and forced questions reflects a phenomenological emphasis on gathering narrative around the participants' lived experience and a concern for collecting information on the demographics and the social context of the participants.

My thesis research was guided by the following research questions:

⁷ Appendix B

- a) *To what extent does stigma act as a barrier in securing and/or maintaining paid employment in the employable blind population?*
- b) *To what extent is the legally blind community employable?*
- c) *What are the perceived employment barriers within the legally blind community?*
- d) *To what extent does the participant blame internal/external factors for barriers faced in the employment market?*
- e) *How have participants responded to the employment barriers they have faced?*
- f) *How and to what extent do legally blind people face stigmatization in their day-to-day lives?*
- g) *To what extent do participants feel accepted within the workplace, once employment has been secured?*
- h) *What are some workplace/policy/individual solutions to identified employment barriers?*

The interview protocol used a mixed-methods approach and consisted of 60 questions divided in four different sections: A) Personal Background Information, B) Employment Information, C) Experiences Seeking Employment, and D) Adjusted version of Link's Devaluation-Discrimination Measure (Link, 1987). Section A consisted of twelve, close-ended questions aimed at gaining demographic and skill-based information about the participant. Included in this section were questions relating to age, marital status, education, ethnicity, and income. These questions were important in establishing

whether there were intersectional patterns of marginalization present in the participants' lives. Also included in this section were questions specific to experiences of blindness such as: age of onset, whether they were collecting disability pension or other benefits, use of assistive devices, and Braille literacy. These questions provided important information about the participant's experience as a blind person. For example, individuals experiencing blindness later in life, qualify for fewer training programs than individuals who become blind early in life.

Section B of the interview protocol provided information about the participants' experiences in the workplace, and included several open-ended questions. The second section of the interview protocol asked questions about the participant's employment history, including questions relating to required assistive technology, current employment status, area of desired employment, issues surrounding underemployment, and the extent to which participants considered their legally blind status a barrier to professional success. Of particular interest to this thesis were questions 9, 14, 16, 17, and 18. Questions 9 focused on the quality of the participants' work experiences, whether they found it meaningful, satisfying and challenging. This question generated interesting narrative around underemployment and job satisfaction which will be discussed in the findings chapters. Question 14, 14a, and 16 asked participants whether they believe they faced any barriers in maintaining employment. These questions also generated rich narrative data about the participants' experiences. Question 17 and 18 asked the participant whether they believed they were treated unfairly by their employers and co-workers. These questions shed some light on the participant's experiences of discrimination within the workplace.

Section C pertains to the participants' experiences around seeking employment. The questions in this section focused on the job search process, including: whether/how long they were seeking employment, what kind of employment they were seeking, whether they perceived barriers in that search, their beliefs around their own capabilities and qualifications, their access to and need for assistive technology, whether a lack of assistive technology had factored into their job search, what their job search strategies were, whether they felt they had been treated unfairly by potential employers, the relationship between disability benefits and job-search motivation, and descriptions about job search experiences.

Section D consists of twelve closed-ended questions based on Link's Devaluation-Discrimination Measure (Link, 1987). These questions targeted the extent to which legally blind individuals believed stigma has an impact on their lived experience and draw attention to the inequality LBP face when applying for jobs they are qualified for and capable of doing. In the Devaluation-Discrimination Measure, stigma is quantified based on the participant's responses to questions relating to whether they believe people consider them to be trustworthy, intelligent, capable, skilled and valuable. Each question is answered through a six-point scale ranging from "strongly agree" to "strongly disagree." Although originally formulated to examine the experiences of the mentally ill in relation to stigma, the Devaluation-Discrimination Measure is translatable to stigma resulting from other traits (Mak, W., Poon, C., Pun, L., & Cheung, S., 2007), and is used to capture the degree of perceived stigma among the legal blindness. Because of the reliability and validity (attributed) to the Devaluation-Discrimination Measure, it is possible to quantify the experiences of stigmatization among legally blind

individuals. The measure has earned a strong reputation in evaluating the level of stigma faced by various marginalized groups (Mak, Poon, Pun & Cheung, 2007). For the purpose of this research, the questions were minimally altered to investigate the experiences of legally blind individuals.⁸

For my data analysis, I drew upon data from all four sections of the interview protocol. The demographic data was used only to provide context for the narrative data which was examined in greater detail making up the findings portion of this thesis.

Sampling and Recruitment

Participants were recruited through the use of various sampling techniques, including a list-serve provided by our community partners, and flyers posted at the Community and Social Services office, the Canadian National Institute for the Blind (CNIB), and the “Talking Books” section of the local public library. A 54 person list-serve provided by our community partners acted as the initial sampling frame, since all of the people included in the list-serve qualified to participate in the research. I contacted everyone on the list-serve but only 11 participants were recruited in this manner. Further recruitment was necessary due to low participation, at which point snowball sampling was employed, and a call for participants made at the annual Canadian Federation of the Blind Conference (May 1st – May 3rd, 2009). Snowball sampling was used to leverage contacts for potential participants from individuals who had already agreed to be involved in the project. In addition, on May 1st, 2009 I attended a conference being held by our

⁸ See section D of the Interview Protocol in Appendix B for these questions.

community partners and made a call out for participants. Finally, flyers advertising a request for study participants were distributed to the various agencies in the Greater Victoria Region (including the CFB, the CNIB, the Talking Books Library, and Community Social Services). When I followed up with the CNIB, my contact expressed a reluctance to assist in recruiting participants, particularly after learning about the involvement of our community partners, who have in the past, expressed criticism of the role that the CNIB played in the “charity economy.”⁹ Six additional participants were recruited from snowball sampling from the list serve or conference. Only one participant learned of the study from the “Talking Books” library.

The participants interviewed ranged in age from 20 to 62 years. Of the 18 participants, 11 were female and 7 were male. Five reported being blind since birth, 6 reported becoming blind prior to the age of 18, and 7 reported adult onset blindness. Of the 7 participants who lost their vision during adulthood, 6 were currently unemployed, and the other reported being underemployed¹⁰. The age of onset for legal blindness is of particular importance, because most of the government funded training programs available to the legally blind population are run during elementary and high school, creating an access issue for individuals who experience blindness later in life. Among our participants, there were no significant differences in employment rates or job satisfaction between the sexes, and because we gathered income levels based on ranges, it is difficult to assess whether sex factored into earnings among our participants.

⁹ The economy based around “helping” marginalized populations, including teachers, researchers, medical specialists etc. These professionals are often non-members of the groups they support and have been accused by some of “pathologizing” disability (Kudlick, 2003)

¹⁰ Underemployed refers to the participants who have some level of employment, but are either overqualified for their positions, or working part-time when they would prefer full-time hours.

All of the participants had successfully completed high school, and two-thirds of them had taken some post-secondary education. Eleven of the 18 participants reported that they were not currently in the workforce (including the 3 participants who were studying in a post-secondary education setting). Of these unemployed participants, three were retired, two were starting small businesses, one had elected to stay home and raise children, and one had abandoned the job search. Five of the unemployed participants indicated that they were still interested in obtaining some kind of full or part-time paid employment. All but one of the employed participants reported high levels of job satisfaction although two indicated a desire for full-time hours rather than the part-time hours they currently worked (these two could be considered underemployed). The only employed participant that indicated a level of dissatisfaction in her current role was also one of six participants who had discontinued formal education upon graduation from high school.

In Benoit et al. (2012), the national mean income listed for non-disabled Canadians was \$37,994 compared to \$29,303 for other working age adults with disabilities, and \$15,680 for legally blind Canadians. In other words, legally blind Canadians made 41% of the average income of an able-bodied Canadian. Among the participants, mean income was \$23,750 (63% of the average for able-bodied Canadians). Thus the participants earned considerably more than their blind counterparts across Canada, despite a nonetheless significant income disparity. The low income level reported by participants factors into to an inability to afford assistive technology, training, and devices they may require in order to perform efficiently in the workplace, creating a

significant barrier to obtaining employment and limiting opportunity to improve their personal circumstances.

Following contact, interview arrangements were made with participants based on their availability and interest in contributing to the research project. All participants for this study were working-age (15-65 years old), legally blind, identified male and female residents of the Greater Victoria Region. Each participant received an honorarium of \$25 for contributing to this research. Ethical approval was granted by the University of Victoria for this project prior to the commencement of participant interviews. All interview data were collected as part of the parent project. ¹¹

Data Collection and Analysis

I conducted 18 structured face-to-face interviews in May 2009 at the participants' homes, places of employment or at the University of Victoria library. Prior to each interview, the participant was required to sign an informed consent form.¹² This document advised them that their information would also be accessed by a professional transcriptionist who was bound by a confidentiality agreement as well as the research team. Due to accessibility limitations, the form was read aloud to the participants. Interviews ranged in length from 25 minutes to 2.5 hours. While the interview protocol was adhered to, several of the questions were expanded upon through probing when the participant expressed a particularly salient experience. Field notes were taken during the interviews in order to record data in the event of technical failure, as well as to record emerging ideas and themes which assisted in probing during the interview. In addition, I

¹¹ Appendix C

¹² See Appendix D

documented sentiments, mannerisms and conversations that were not captured in the recordings of the interviews as soon as practical following each interview. Field notes are of particular importance in qualitative research because they permit the preliminary identification of first-order themes during the interview without disrupting the interview process (Miles and Huberman, 1994).

All interviews were recorded and transcribed verbatim. Because of the generous funding provided by the Disability Health Research Network (DHRN) and Mitacs, we were able to hire a professional to transcribe the interviews verbatim. The assistance of a professional transcriptionist was sought in an effort to expedite the data analysis, and improve the accuracy of transcription. Unfortunately, the transcriptionist was unable to discern the poor audio recording in many of the interviews, resulting in incomplete transcriptions. I completed the transcriptions using the audio recordings and my field notes to fill in missing information; in the end, I was satisfied with the quality of the transcripts and after considerable review believed that the transcriptions used were complete and accurate. Because of the complicated and sometimes painful nature of the participants' lived experiences, I often felt emotionally drained following the interviews. Having to later relive these interviews through the transcription process contributed to an unfortunate feeling of exhaustion with the subject matter. However, there was a significant benefit to transcribing my own interviews in the resultant increased familiarity with the content, which provided assistance in the coding process.

The process of data analysis followed the principles of grounded theory, including the constant comparison method and inductive thematic analysis (Charmaz and Mitchell, 2001; Glaser and Strauss, 1967). The analysis diverged from grounded theory in that the

recruitment of participants was not iterative nor was there any attempt to reach theoretical saturation, which typically occurs with a sample size of 30 participants or more (Charmaz and Mitchell, 2001; Glaser and Strauss, 1967). Such a large sample size exceeds the requirements of a Master's thesis. In conjunction with constant comparison, thematic analysis of this data followed an inductive process (Charmaz and Mitchell, 2001). In inductive thematic analysis, the themes that were identified are closely tied to the data collected and the coding process takes a "ground up" approach (Boyatzis, 1998). This means that themes are shaped by the data, rather than by preconceived, theoretical expectations of the researcher (Boyatzis, 1998; Braun, 2006), and informing a process of constant comparison wherein data is analyzed during the collection process as it became available. An example of this relates to my findings on resilience; in analyzing the data, I noted that a population of participants who reported previous negative labour market experiences, responded by starting their own businesses. The self-employed group of participants expressed the highest level of job satisfaction among the sample population, even though their mean annual income was lower than the remainder of the employed participants, and their job security was often tenuous. This finding began to emerge during data collection and was later established by examining codes around job satisfaction, responses to negative labour market experiences, income, and job security. These four codes recurred throughout the interviews and established a theme I referred to as resilience at the individual level which applies to a sub-group of participants who responded to their negative experiences in the labour market by taking charge of their own conditions and creating employment for themselves, rather than becoming disenfranchised by their circumstances.

In addition to the data analysis that took place concurrent and immediately following collection, formal data analysis followed four phases. In Phase 1, I listened to the recorded interviews while reviewing the completed transcriptions. This process also allowed me to gain familiarity with the transcriptions. In Phase 2, I reviewed the transcripts a second time in detail to identify emergent codes. Finally, in Phase 3, I conducted a third review of the transcripts, aimed at verifying existing codes while seeking out new codes. In Phase 4, I reviewed the transcriptions a fourth time, with an aim at organizing the codes into overarching themes that best categorized the results of the data collection. A spreadsheet was used to organize the key themes that emerged in the interviews; this allowed for a quantitative tally to be kept of the number of times each theme was touched on during the participants' responses. Phase 4 produced emergent theoretical propositions about the labour experiences of participants. For example, one theoretical proposition is that some participants encounter more negative interactions at work because of a *perception* of stigmatization which framed each of their interactions through a lens of anticipated negative feelings. However, such negative interactions were also more commonly reported by participants with lower education working in roles that involved unskilled labour or factory work. Thus, participants' negative experiences in the work place may result from a combination of anticipatory stigmatization, lower education and a workplace culture that is less tolerant of people with disability. In reviewing all of the interview data, I assessed the validity of these emergent theoretical propositions through constant comparison.

Issues of Validity

In qualitative research, the researcher is the instrument and the position of the researcher in relation to the population being studied is a central component in the process of qualitative data collection (Dwyer and Buckle, 2009). As Maher and Tetreault (2001) state, “knowledge [is] valid when it takes into account the knower’s specific position in any context, a position always defined by gender, race, class and other socially significant dimensions” (p. 22). In the interest of transparency (Finlay, 2002), the impact of my personal experiences on the research process merits reflection. Exercising reflexivity provides an opportunity for me to account for the ways in which my personal circumstances and assumptions influence how I engaged with the methodology, research participants, and the findings. I will also address the ways in which engaging with this research sensitized me to issues confronting marginalized populations.

My status as a sighted, able-bodied, university-educated woman could have significantly impacted the process of recruiting participants. However, for the most part, the people I spoke to were excited at the prospect of participating in the research project. One exception was Dr. Jones¹³ who was confrontational and accused me of disrespecting him by failing to refer to him as “Dr. Jones” during the initial recruitment phone call. I apologized and advised him that I was unaware of his status as an academic from the limited information I was given. He informed me about his many challenges to obtain a PhD as a blind person, and that the fact that I failed to acknowledge his credentials spoke volumes about my ignorance as a sighted person. He was very upset with me for failing

¹³ Name changed.

to “do my research” prior to contacting him, but begrudgingly agreed to participate in the study. I arranged to meet him at a location that was minimally disruptive to him but he failed to attend the meeting, as well as a second meeting I arranged with him several days later. After the second attempt failed, I concluded that he was trying to avoid participating in my research.

Insider/outsider status can impact the nature of the data collected during the interview process. Specifically, being perceived as an outsider by a research participant can impact the interview rapport and thus the quality of the answers provided therein (Couture et al., 2012). Several of the participants I interviewed asked about my interests in the subject matter, establishing me as an outsider early into the interview. I would respond to these questions with information about my personal beliefs around equality, and that my interest in this research traced to my relationship with two close friends who were legally blind, well-educated, and struggling with securing employment in their field. This disclosure seemed to build some level of rapport with participants. In addition, I also belong to the LGBTQ2IA (Lesbian, Gay, Bisexual, Transgender, Queer, Questioning, 2-Spirited, Intersexed, Asexual) community. I have faced considerable discrimination based on my membership in this community, including being denied housing on two separate occasions, and being disowned by my family of origin. As a result of these experiences, I have developed a degree of sensitivity to issues around marginalization, discrimination, and stigma. Of course, I am aware that my experiences as a member of a marginalized group varies dramatically with the experiences of individuals from other marginalized groups; however my own personal history has sensitized me to the barriers created by stigma and discrimination. Although I was aware

of the impact that my stigmatizing status had on my research experiences, I did not share my status with the participants in this study. My decision to withhold my status as a member of a marginalized group was twofold: I was concerned that some participants would feel less comfortable during the interview process if they had homophobic beliefs; and as a sighted researcher, I was concerned that disclosing personal details about my life would derail the conversation and focus attention on me rather than on the participant.

Validity of findings was enhanced through a variety of practices. These included establishing strong rapport with the participants which is substantiated by the length and depth of interviews, combined with the absence of issues arising from my positionality as a researcher. As I completed more interviews, I found my confidence in the interview questions as well as a familiarity with some of the typical responses, diminished my feeling of being an outsider with the participants. During the process of data collection, I carried out some of the data analysis in a systematic and comprehensive manner, using constant comparison method (Maykut and Morehouse, 1994). To this end, I believe I was able to identify potential points of interest between/?? and during later interviews, I spend more time probing issues that appeared to represent common experiences. I believed I also faced less resistance than I might have interviewing members of other marginalized populations because issues around the morality of stigma did not factor into the equation, unlike some other marginalized populations like sex workers (Benoit, McCarthy & Jansson, forthcoming), LBP are rarely blamed by society for the source of their disability (Menec & Perry, 1998) and may be less inhibited in disclosing information about their marginalizing conditions. Throughout the course of interviewing participants, several shared that they were grateful some research was being done on their

community because they felt as though it could give them a voice. Their sentiments reflected Ewick and Sibley's assertion that the two virtues of narrative scholarship were to present the voice of the subject and to unsettle power (2003).

Finally, validity was further established by developing interpretations that are well-supported by the data, as well as by selecting the constructs of perceived, felt, and enacted stigma which fit closely with the data. It should be noted, that the sample used in this study was made up of legally blind individuals residing in and around Victoria, British Columbia, which is the provincial capital and home to both a public college and a university. As such, the participants have access to a significant infrastructure of public transit and other important resources aimed at supporting individuals with disabilities. Because the quality of public transit and disability support services vary between jurisdictions, some of the experiential data obtained in this study will be of limited use in articulating the experiences of legally blind people across Canada (particularly in more remote areas). Most of the participants in this research were drawn from a socially isolated group (indicating that their friends were also LBP), and associated with a community organization that had a strained relationship with the support programs in place for legally blind people in the region. As such, the findings obtained from this population may not necessarily represent the overall experiences of the legally blind population. For example, the prevalence of felt stigma might be higher among this group because of their shared beliefs around disability politics and the disempowering nature of disability support.

Summary

This chapter provides information about the methodological considerations of the research, including details about the parent study, a review of the research questions, information about sampling and recruitment, data analysis and collection, as well as issues around positionality and transferability. In the latter case, consideration is given to researcher reflexivity and the impact that her life experiences may have had when engaging with the topic, participants, and during the analysis of the interview transcripts.

Chapter Four: Perceived and Enacted Stigma Experiences in the Workforce

This chapter examines participants' accounts of their employment experiences and the impact of employment barriers they faced. Of the 18 participants in this study, only one entirely disengaged from participating in the labour market. In addition, the participants' work experiences will be explored, specifically in relation to the concepts of perceived and enacted stigma, and the impact these forms of stigma had on their motivation to seek employment and remain in the workforce. As defined earlier, perceived stigma refers to "erroneous and negative social attitudes toward a distinguishing physical or behavioural characteristic of a person or group" (Pyne et al., 2004, p.278; Goffman, 1963). This kind of stigma is not necessarily ill-intentioned, and may relate to a lack of exposure and education leading to a level of ignorance on the part of the stigmatizer. As also noted, another common term for this kind of stigmatization is "microaggression," which describes experiences of marginalization through subtle and commonplace exchanges or indignities (both conscious and unconscious) that convey demeaning messages to the marginalized person (Constantine & Dorazio, 2008). Microaggressions are usually perceived by perpetrators as harmless and inoffensive, but can cause psychological distress and spiritual drain for those that experience them (Constantine & Dorazio, 2008).

Enacted stigma refers to episodes of actual discrimination which are enacted upon a marginalized group (Scambler & Hopkins, 1986; Scambler, 1990; Jacoby, 1994). These

instances of enacted stigma are relatively uncommon compared to other kinds of stigma (Scambler & Hopkins, 1990), but are both deliberate and concrete in their impact.

Perceived Stigma in the Workplace

All participants in the interviews reported having been stigmatized because of their blindness at some point in their employment. A common sentiment among participants was that the majority of discrimination and other barriers they experienced were rooted in a lack of awareness and sensitivity, rather than ill-intentions and/or overt discrimination. One of the self-employed participants shared his experiences taking courses in order to maintain his credentials:

I've never had anything provided in Braille or in any [accessible] form. I mean, maybe someone could do it online now but they don't tend to do that. You tend to show up and the course material is there, and I'm always at a disadvantage on that, right? So it kind of puts you off.

This lack of consideration to special accommodations was echoed by a number of participants, one of whom worked in a hospital where large pieces of furniture were being rearranged on a regular basis, preventing her from memorizing the layout of the area:

The environment was always changing... I wasn't comfortable in using my white cane... and I didn't feel comfortable in mobility in the way of going down to you know, down the hall or the different rooms where I needed to pass messages to the nurses.

The lack of appreciation for her particular needs posed such a significant challenge for her at work that she decided to retire early. Although there is no indication this participant's coworkers were trying to challenge or harass her, their inability to consider her needs reflects a kind of willful ignorance about the issues she faced.

Another common form of perceived stigma took the form of comments or reactions from co-workers or managers that drew attention to the participants' disability and made them feel uncomfortable. The following quote illustrates the nature of this stigma:

[My work experiences] have been pretty positive. Again it's very rare, but the odd time I'll meet up with someone who's like rude in their reaction. They're sort of negative. [L]ike they'll see me working, because I look quite close to the screen, and I sort of have my head down when I write, and they'll walk by and say, "Oh, I don't know how you can do that, oh I couldn't stand that, I don't know how you can do that." It's just sort of a negative. It's not like they're really interacting with me; just sort of commenting, I get one every six months.

Many participants expressed frustration over the assumptions made about their capabilities which they believed were based in a lack of public education around blindness:

People will tell me how 'amazing' it is that I can do regular things like get around, I know they mean well, but it isn't actually amazing at all, that's just what I need to do, so I do it.

Another participant shared their biggest complaint about their current work environment:

Having to always educate people, like coworkers and employers, about my abilities, so always feeling on edge, that I have to kind of continuously do not just do well but really, really, really, really, well on the job to prove myself.

Participants also felt that their disability resulted in a lack of trust on the part of the coworkers and managers. This subtle form of discrimination is illustrated by this comment:

I know what I am able to do and what I am not able to do. [I have a problem with] people making decisions for me without asking me about whether I can do things; ...with the co-op job I just had... I kept thinking,

when are we going to move on to the next part of this project?... as it was described to me, and then I find out later that they passed on the work to a student to do because they just assumed I couldn't do it and they didn't discuss it with me. I find that really problematic, people making decisions, like people feeling too awkward to approach the person and talk about... how it can be done.

This lack of trust in the participant's capabilities expressed by sighted coworkers could contribute to feelings of anxiety and isolation in the workplace. Nearly all participants reported dealing with coworkers who were doubtful of the participants' ability to competently assume work duties. Such doubts can be considered a form of microaggression which acts to marginalize LBP by casting doubt upon their abilities in a professional setting. In response, many of the participants took on the responsibility of educating colleagues about their capabilities in formal and informal ways in order to increase trust and reduce stigma. Participant responses to this expectation ranged from resentment over the amount of time and energy it took, to gratitude that interest was being shown in their abilities. One participant said: "My least favourite part of the job search is having to educate potential employers because there's a lot of misunderstanding about what blind people are capable of doing." Yet, many participants also felt this approach typically resulted in a positive outcome, as noted by this participant:

It seems to me, that what we have to do is shift attitudes. My own experience has been that when... people have seen me working, then the response is sometimes amazement and they marvel at what I do and they realize I can do it and, but the barrier is always getting through the door.

Another participant, who reported a high level of job satisfaction in her career as an IT professional, commented about her coworkers, "I wasn't sure how they'd react, but they were great, they're kind of, especially IT guys, are quirky already, so they don't judge me for [being blind]." Still another participant expressed appreciation for the approaches

used by coworkers in learning more about her capabilities; “they usually just question how I’ll do things like when I’m dealing with clients or presentations, it is more from a point of view of being helpful than challenging you.”

Enacted Stigma in the Workplace

As mentioned earlier, enacted stigma pertains to relatively uncommon episodes of actual discrimination which are enacted upon a marginalized group (Scambler & Hopkins, 1986; Scambler, 1990; Jacoby, 1994). An example of blatant enacted stigma reported by one participant involved him referring an equally-qualified, legally blind friend to apply for a job at his place of work. When the employer learned the new applicant was also legally blind, he refused to hire him, explaining: “We already have one blind person working here.”

Most often, enacted stigma took the form of subtle but nonetheless purposeful discrimination as indicated by this participant’s comment:

I’m satisfied with my job, but I find coworkers, they’re hard to get along with sometimes, like when you try to talk to them and they don’t want it, they make fun of your vision and I just don’t care much for that... they’re hostile towards me... they even make comments underneath their breath that “oh that blind person’s doing this, she’s going to burn herself.

The same participant shared similar concerns about her manager:

I have one manager; he’s not really friendly with me right at the moment. He’s not talking to me. He’s not nice to me. Anyways, every time I say good morning to him, he will say “Yup” and like not say good morning... I don’t know how to make him feel friendly towards me.

Another participant reported having to deal with a similar type of incident:

There's actually a manager I was going to work with on a client site, he came by just to meet me and had that reaction right away and walked off, and then we ended up deciding not to work together, but it's a big enough company it's not an issue.

Two participants shared experiences that reflected deliberate discrimination after having been hired; according to one:

I did have a job at one clinic in Vancouver, I was there for three months and I left. Every day I was there... a woman there in charge of the office who was older and not very enlightened... told me and other people there that it was not the right job for me, I'd be better off in some other clinic. So, and that was like every day I was there, honestly every single day. So I mean you know ... I've been told pretty flat out that I don't belong.

This participant reported that she transferred from the position shortly after starting because she was unable to tolerate the negative work environment. In response to the discrimination she had faced from her employer, she filed a human rights complaint and was later awarded compensation: "I think they were pretty careful after that to like, not try to push me around." The second participant reported a toxic work environment where co-workers were "imitating me and my voice, and when you go to the toilet, they imitate it... they make hissing sounds like when I'm going, that's disgusting." She expressed reluctance to report the workplace harassment because she was fearful that she would lose her job. This participant also expressed feeling trapped in this unwelcoming work environment, "this is the only kind of job that I can do, and there's no other job that I am really qualified for." As a result, she reported being very reluctant about pursuing other job opportunities or legal support to ensure that her human rights would be honoured.

As some of the participants revealed, discriminatory work environments had some very real psychological and emotional consequences:

[Some of my coworkers] don't treat people with respect, they don't like people with disabilities too much... I know I am lucky I have a job, because there are lots

of blind people that don't, but sometimes I just don't want to go to work, you know, on account of the harassment, I just get exhausted.

Many participants also recounted feeling as though they were being "shooed out" of job interviews as indicated by this comment: "I have just simply been told you know, you won't like the job, it's just too much paperwork, it's too much for you, you'd be better off somewhere else."

Similar experiences were shared by other participants:

Before I had my [college] diploma... [when applying for] entry level positions, I ran into this a lot, arriving at an interview and the person interviewing me like saw me, and said, "I don't want to interview you", or "I don't think you qualify" just from seeing me.

These discriminatory screening practices significantly reduce the opportunities available to legally blind workers, preventing them from even being considered as candidates.

Participants spoke of the added burden of convincing potential employers that their application merits consideration:

When you go to an interview, you know, they're going to see that I'm blind, you know, and make a judgment of some kind, so you're always, I'm always having to... [address the] fact that I would need equipment, expensive equipment, to do the job, so I feel like I'm at a disadvantage both because there's a stigma about blindness and also because in reality I do need equipment, whereas, you know, another person wouldn't have those two things to deal with so I feel like I start at a disadvantage.

Not surprisingly, the participants who indicated lower levels of perceived stigma also tended to have well-paying jobs or government jobs they were proud of having secured, as indicated here: "I enjoy it and it is fun and – I wouldn't even call it a job really unless somebody forces me to, but that's why I keep doing it."

Enacted Stigma and Work Accommodation

Most participants with later-onset blindness reported facing considerably more discrimination in the workplace than individuals with congenital or earlier-onset blindness. This form of enacted stigma manifested itself in several ways, including resentment among colleagues over having to accommodate the conditions and adjust the way they worked, as well as the lag time between onset of blindness and proficiency with adaptive technologies in the newly blind worker.

Several participants singled out the lack of support in their workplace for retraining or the purchase of such technologies. This is captured in this comment:

When I became blind, I faced an aspect of stigma... for example when I applied for vocational rehabilitation [through work] I had twenty-five years [experience in my role], but I could no longer do my old job... they refused the training for me, and turned a blind eye to me, and transferred me to another department.

This participant ended up relinquishing the employment he had cherished for so many years after management put pressure on him to apply for long-term disability benefits through their private insurance company. Similar stories were reported by the participants with later-onset blindness.

Some of participants also mentioned ongoing challenges with assistive technologies creating a barrier for their job performance:

When I was doing transcription for the [a government agency], my Braille Note broke down, and the motherboard went on it and... it was completely unusable. Unfortunately, it took a month to replace it and that Braille Note was being used during that job quite heavily, so I was cut back drastically in my employment.

As an independent contract worker, this participant experienced significant financial hardship as a result of her lack of access to the technology she required for her work.

Several participants mentioned the process of qualifying for disability pension as a form of institutionalized discrimination; an unthinking adherence to organizational norms which acts to exploit or oppress one group by another in the distribution of rewards (Scott & Marshall, 2009). Specifically, they mentioned the reduction of pension payments for individuals with part-time or short-term jobs, which is common among LBP. Participants referred to this policy as “being penalized for working,” as suggested by these testimonies:

[A]s soon as you bought anything and have assets, you know, greater than a few thousand bucks, the disability benefits prohibits that, and you know you’re sort of disqualified from having... disability benefits.

[It is] no wonder blind people, a lot of blind people don’t work because as soon as you get a job you lose all the benefits and all the pathetic qualifications [for government programs].”

Another issue was the need to acknowledge being permanently unemployable due to blindness in order to qualify for the pension. This is an admission many were unwilling to make. Other participants also reported encountering difficulty in claiming they were “unemployable due to their disability” because they had been employed in the past and were thus rejected from collecting benefits when they became unemployed:

I applied for disability when I got laid off, and they said I couldn’t get it because I worked before, so it was like a catch-22, I proved that I could work which is great... but I couldn’t get any benefits because of that.

Many participants felt ambivalent about qualifying for disability support, and spoke of the impact that negotiating this system has had on their self-concept. This is illustrated by the following comment:

I just think that there needs to be less of a sort of charity kind of model in terms of disability in general like for instance, for myself, I don't feel that I should have to be on a governmental subsidy every month I, I don't think I should be receiving money every month because of my blindness... I don't view my blindness as a disability, but I have to lie to the government and play up the problem, and basically say, 'oh well, I'm blind, you know I have no prospects for employment, give me more money.'" I have to basically use my disability as a pity party.

Overall, the bureaucratic rules surrounding the disability pension were seen as disincentives to seeking employment (especially short term work) because LBP could not be assured return to the stability of a disability income if their employment was terminated. As a result, many of the participants simply refused to apply for a government disability pension.

Finally, several participants felt that the fundraising activities of blindness support agencies like the CNIB reinforce stereotypes of helplessness and disability and thus contributed to discrimination and enacted stigma. This comment from one of the participants underlines this point:

I'm totally against things like the CNIB Golf Tournament raising money for CNIB and all this nonsense. I disagree with it because it just portrays us as being pathetic again, and we don't benefit, they benefit... the CNIB is useless.

These participants felt that these charity events focused on eliciting public pity in order to draw in more donations. Tying into Scott's work (1965), the participants believed that many, if not all, support agencies had a financial interest in disempowering the blind population as part of the charity economy within which they operated. A common sentiment among participants was that any financial gains acquired through fundraising campaigns were overshadowed by the damaging stereotypes they perpetuated about LBP.

Discrimination related to level of education was rarely mentioned by participants as a source of discrimination, despite the importance it is given in much of the research

(Shaw, Gold & Wolffe, 2009). A few participants commented on the importance of seeking an education that complimented one's abilities and provided an opportunity to work with people who had an open mind as illustrated by this comment:

When you're applying for higher level jobs you're being interviewed and hired by people with more education and awareness too, so I think I see more of a correlation there now that I've been in school for a while and met a lot more, you know, educated people... I think the more kind of straightforward, blue-collar types of employment are more problematic. I mean, it's strictly productivity and they're all answerable to their bosses for productivity stuff and that's where I can't compete, or you know I'm limited somewhat.

It should be noted, however, that the participants in this study had comparatively high education levels, which may have contributed to the lack of issue they encountered with that particular barrier.

Another element that appears to be a source of enacted stigma is the intersectionality of marginalized traits. Intersectionality teaches us that membership in one social group can only be fully understood when considered in conjunction with membership in other social groups, and that these memberships inform social power dynamics (Krolokke, 2009). Of the four participants who identified as racial minorities, one was underemployed, one was unemployed, one was a full-time student, and the other was very dissatisfied in her current role. The employment circumstances described by this group of racialized participants were markedly poorer when compared to other participants in the study. Although none of the racialized participants acknowledged their ethnicity as a barrier to employment during the interview, it appears as though the intersection of race and disability may have some impact on the labour market experiences of this group. Likewise, two of the participants indicated secondary disabilities, both related to hearing loss. Of these participants, one had completely

resigned from seeking employment at the suggestion of her doctor, and the other was retired. Although this is a very small sample, having a secondary disability seems likely to increase the impact of blindness as a barrier to employment.

Compounding Effects of Enacted Stigma

During the course of the interviews, many participants shared experiences around discriminatory behavior they had endured outside the labour market but which could be construed as compounding the stigma they experienced in the work place. One of the participants recounted a negative interaction he had with a security guard while conducting research for a book he was writing. He was originally denied access to the research archives because the security guard did not understand how he could benefit from being there when he couldn't see, it was only after contacting a manager he was granted access, however the security guard continued to treat him poorly:

I think generally there is still the perception of some degree of disrespect about blind people being a burden to society rather than you know not we're not considered people of value and that's the kind of approach you get when you go to these places it's awful treatment. [Y]ou know, I write letters 'cause I want to change things and need to leave an impression, 'cause I think that's much better than just having a big do with somebody, you know I try to keep it as calm as I can.

Other participants acknowledged difficulty convincing the parents of their children's friends that they were capable of managing the children without assistance:

I know I am capable of looking after children. The majority of blind people are capable of looking after children. There are some people who aren't, and I think for the few that aren't, it's a terrible assumption to say that blind people are not able.

Another participant described becoming blind later in life, after being involved in a car accident caused by his reckless and impaired driving. The experiences he shared in the interview were consistent with those of a person who had some degree of responsibility in the origin of his stigmatized characteristic. He indicated that he was subjected to more negativity and hostility around his blindness when the people he was interacting with learned of the role he played in his becoming blind (Jones et al., 1984). He described the social exclusion that followed his car accident, specifically the way in which his friends blamed him for his circumstances, and expressed that they no longer knew how to interact with him or wanted to include him in events because of what they referred to as “accessibility concerns:”

I had tons of friends growing up in high school as well as college. I could pretty much just count on one hand now [my friends], and two of those are just my folks. It is really hard; people use that ‘I don’t know how to react around them now’.

As previously reported, this kind of social rejection contributes to participants limiting their social network, compounding the effects of stigmatization.

Summary

This chapter examined the participants’ experiences of work-related stigmatization they faced as a result of their blindness. A recurrent theme in the data was the barrier created by limited access to assistive technology and devices. This finding related to the pre-employment and job retention stages of labour market experiences. Consistent with the literature, incidents of enacted stigma were relatively rare in comparison to experiences with perceived stigma. In discussing pre and post-employment experiences, one of the most relevant themes was that participants felt as

though they shouldered the burden of educating coworkers and employers of their capabilities. This responsibility resulted in feelings of insecurity and irritation, and reflects the significant impact of perceived stigma on the labour market experiences of the legally blind population.

Chapter Five: Responding to Stigma

This chapter explores the participants' employment experiences in relation to the concept of felt stigma and resilience to perceived and enacted stigma. Felt stigma refers to the internalization of perceived and enacted stigma, or the shame that is rooted in a fear of experiencing enacted stigma or discrimination, even when enacted stigma is absent from the experience (Goffman, 1963; Scambler & Hopkins, 1986; Link, 2001; Link et. al, 2004; Benoit et. al, 2012). Felt stigma often results in the subject limiting their social experiences due to fear of rejection (Alonso et al., 2009). Felt stigma results in the internalization of feelings of inadequacy, however not all members of marginalized groups experience this internalization. In many cases, participants expressed resistance to the negative stereotypes and social interactions they faced, displaying resilience to the stigmatization. Narratives of resilience will also be presented in this chapter. Resilience to stigma refers to how individuals resisting perceived and enacted stigma. Schoon (2006) defines resilience as the process by which individuals adapt to adversity, which in this study pertains to blindness but also to the social responses to blindness and the barriers associated with this disability. In spite of the barriers presented by perceived and enacted stigma, discrimination, ignorance, and a lack of access to assistive technology, many participants were able to overcome these issues, resist felt stigma, and enjoy successful careers, and pursue new endeavors.

The Experience of Felt Stigma

One consequence for legally blind people experiencing felt stigma is that they may decrease their engagement in the job search in order to avoid feelings of rejection

and shame from unsuccessful attempts. Another consequence of felt stigma is that they may find themselves with a limited social network to tap into when seeking employment because of this self-imposed isolation. In order to compensate for the felt stigma experienced in their daily lives, they may also seek out a social network that is largely made up of other blind people (an already under-employed group) with limited connections in the labour market (Alonso et al., 2009).

The impact of felt stigma on the social group of legally blind people has significant negative consequences on their social network, creating an important barrier to accessing the labour market. Felt stigma can be of such intensity that the stigmatized entirely bar themselves from certain situations in order to minimize the negative emotions resulting from their anticipation of discrimination (Scambler & Hopkins, 1986). An example of this was found in one respondent who had completely disengaged from the labour market on the advice of her doctor. After several failed job interviews, her anticipation of being rejected was weighing on her emotional wellbeing "...there are so many things involved with my health, that... I can't overstress because it can cause me to lose what little vision I still have." In this case, the consequences of felt stigma had become so serious there was a risk of permanent physical damage.

Several participants reported experiencing strong felt stigma that impacted how they perceived themselves as competent employees and their ability to pursue employment matching their abilities. For these participants, the impact of felt stigma manifested in all areas of labour market participation. As an individual with intersecting forms of marginalization (race, multiple disabilities, gender), one participant discontinued her job search at the suggestion of her doctor who advised her that the stress could cause

more damage to her vision. Another participant expressed a lack of self-confidence in job searching:

[I will be applying for a] volunteer position 'cause I, I don't feel – how could I put this? I, I don't really feel that I'm confident. I'm not comfortable enough to just jump into employment. I'm much more comfortable say doing a volunteer position for say a year and then maybe applying for a job... at the volunteer place.

This internalized lack of confidence stemmed from a consistent pattern of rejection from previous employment interviews and how this had “worn him down” over time. The result had been a self-imposed limitation to apply for volunteer positions instead of paid positions to avoid facing further rejection, which had a significant financial impact.

A young participant with recent-onset blindness was discouraged about the prospect of finding employment due to the anticipated rejection in the labour market: “I think I would be discouraged at finding a new job, I don't know, by the fact that I can't read anymore, so maybe I'd be an undesirable employee.” She was starting to come to terms with her condition and was not ready to face any kind of rejection at that point; thus she decided not to search for employment despite being in a financially compromised position. Her decision originated from previous negative interactions concerning her blindness. She recounted an incident where she sought help from the CNIB shortly after becoming blind, and was discouraged by a support worker from continuing in her computer science program at university because the worker did not think she was capable of succeeding in the program. She felt reluctant to access the CNIB again because of the worker's discouraging comments and criticisms, which limited access to important employment resources through that organization.

Another participant spoke of the consequences of her numerous failed job searches on her self-image:

It makes it so that in your head the rejections become your fault, right? It was [discouraging], yeah. I hated looking for job – I hated it, I was the most honestly optimistic person I know... I feel weird saying negative things, and I want to be a really optimistic person, that's why it feels weird to talk like this but I, I found looking for jobs really hard and really difficult and hard on your self-image.

This participant subsequently abandoned seeking employment in order to avoid further damage to her self-image.

One participant decided to limit her job applications only to employers with equity hiring practices. This strategy was motivated by a desire to avoid rejection or having to struggle against preconceived ideas about her capabilities. It also significantly limited the job opportunities available to her:

I was always having to deal with that little bit of an issue when I was having an interview, and then the fact that I would need equipment, expensive equipment, to do the job [is brought up]. I feel like I'm at a disadvantage both because there's a stigma about blindness and also because in the reality, I do need equipment whereas you know another person wouldn't have those two things to deal with so I feel there is a real disadvantage... I don't bother anymore if I know I am going to have to answer questions like that because I just can't compete.

Participants also reported the impact of felt stigma as an aspect of their employment. Even among the participants who expressed the highest level of job satisfaction, felt stigma could be observed in their reluctance to apply for promotional opportunities:

Well some of the barriers were trying to get promotions trying to get ahead because I couldn't see... I didn't really push myself you know, it's funny because you want to push yourself to a point and you get that feeling of satisfaction... but then there is the whole fear of being turned down and them not thinking you're good enough.

This participant recalled with some regrets how he held the same job for twenty years and had failed to pursue career advancement because he did not believe his managers would consider him capable of increased responsibilities.

Another happily employed participant expressed struggling with making phone calls, a significant part of his job role, "I have to make a lot of phone calls. Just my confidence levels are a little low." He tied this loss of confidence to a diminished ability to relate socially to new people following the onset of his blindness. He described this insecurity stemming from feeling like individuals whom he contacted would think less of him if they knew he was blind.

Another participant described his experiences with his employer when he was new to the job:

You sort of got the feeling that they were a little more worried about how they were going to, you know, set up the environment for you, that they maybe would not have been as worried about setting up the environment for just any other, you know, university student coming into their workplace.

This experience sparked feelings of insecurity and left him feeling as though he had to continuously prove his worth and abilities.

Both of the participants who went on private, long-term disability benefits through work said they did so in order to avoid facing anticipated discrimination from their employers over their disability. One participant shared:

...I sort of felt my job was threatened because – they were reducing hours like they were sort of rearranging everything budget-wise so my hours were sort of reduced. I was having trouble [getting accommodations] and we just sort of figured with all the factors I'd be better off to sort of quickly get onto pension...

Several participants suggested that LBP's jobs were more vulnerable during periods of economic recession because of the significant cost of accommodations, this belief provided context for the above participant's decision to leave her job before she would have preferred.

Another participant with late onset blindness complained that his managers "ignored" him following his diagnosis; this perceived slight resulted in him feeling as though his job was not secure:

I think because of those factors that you face on a daily basis the long term disability decision did come out that way. You know, and sometimes I look back in a very negative manner... just because of frustration, you know? ... I'm still new to being blind and still a little angry.

Both of these participants regretted leaving their jobs, but felt they had no other choice. In both cases, they expressed a loss of self-confidence and self-esteem, as well as a diminished social network after leaving work. While neither of them recounted experiencing outright, enacted stigma, their decision to leave work was nonetheless based on anticipated discrimination or rejection—a decision which speaks volume about the impact of felt stigma in the context of employment.

It is important to recognize that not all participant experiences fit clearly into categories of felt stigma or overt enacted stigma. For example, one of the participants provided an example of stigma as an aspect of her interactions at work: she worked on an assembly line in a factory and felt rejected and isolated when her supervisor moved her workstation into a small closet, an action she interpreted as discrimination. He told her she was being moved for safety reasons because of her history of bumping into her co-workers on the assembly line. She saw this decision as a form of workplace harassment intended to alienate her from her co-workers. While she acknowledged that there might have been some risks to keeping her on the line, she ultimately believed safety was not the true motive behind removing her from the line. She lost her morale and felt her co-workers were “making fun of her.” While her manager might have made the decision out of concern for her safety and that of her co-workers, the end result was that she developed feelings of shame and low self-worth.

During the interviews many participants acknowledged observing behaviour in other LBPs that were consistent with experiences of felt stigma. One participant commented that she had no issues meeting new people or making friends, but that:

Some blind people have been so damaged and hurt from the constant feeling of rejection, of not feeling good enough, that they just stop trying, they just turn inward and only spend time alone, or with other blind people, or on the internet where they might not have to make the disclosure about being different.

Another participant believed that her former co-workers (who had other kinds of disabilities) resigned from their positions because they saw that she was being treated poorly and had concerns that “they would be next.”

Resilience to Stigma

In reviewing participants' responses to how they dealt with perceived and enacted stigma, the theme of resilience clearly emerged. Schoon (2006) defines resilience as the process by which individuals adapt to adversity, which in this study pertains to blindness but also to the social responses to blindness and the barriers associated with this disability. In spite of the barriers presented by stigma, many participants were able to overcome these issues, enjoy successful careers, and pursue new endeavours. This participant's comment echoes this narrative of resilience, "I am unwilling to be judged on someone else's poor performance." In some cases, ongoing experiences of stigmatization resulted in an increased motivation to resist oppression. These participants were aware that they were being treated unfairly, and asserted themselves in fighting back. For example, two of the participants were involved in successful human rights trials: one pertained to the use of a Seeing Eye dog and the other was a workplace harassment case.

Several participants displayed resilience by strategically adapting to their disability. For example, one participant spoke of how she retrained for employment in a way that was more adapted to the loss of sight:

I found myself in a position where I just couldn't do the job I loved anymore, I was a jeweler, and you know, you need to see to be able to do that well... [It] took some time, but I decided I needed to go back to school, I will be starting at UVIC in the fall. I am taking political science and hoping I can get in with the government when I am done, I just, you know, feel like they are more likely to be able to accommodate me better.

However, retraining may not be an option for all participants due to cost factors and/or the challenge of returning to school late in life. Thus, other participants spoke of relying on their social networks to find suitable employment:

Yeah, it's like individual people who go "hey this job could be really good for you"... I apply for these jobs and find out yes that this is a really good job for me, these are jobs that I that I'm alerted to by people who recognize my capabilities and alert me to jobs that I could possibly get.

These informal networks are very important because, as one participant indicated, many job search websites are inaccessible to blind people, "the screen-reading software couldn't get into the websites, so it meant I had to get into talking to other people to see what I could come up with." Many participants face challenges in their job search due to their inability to read the job postings, which is compounded by their often limited access to a social network.

A number of participants who had become frustrated in their quest of adequate employment decided to start their own small businesses. This group of entrepreneurs reported the highest levels of job satisfaction among participants. One of the participants who started a small business with his mother, described his job as "a real true gift, you get a real sense of accomplishment." Similar sentiments were expressed by all participants identifying as self-employed.

Others participants spoke of proactively educating their coworkers about human rights in the workplace and about educating their colleagues about their disability.¹⁴ The importance of implementing human rights education in the work place was highlighted by findings reported by Benoit et al. (2012) that 67% of participants believed that most employers would not hire a LBP even if he or she was capable for the job and that 83% of participants believed that most employers would pass over the application of a blind

¹⁴Since this research was conducted, Ontario has passed legislation mandating the formal education and training of employees, employers, and educators about issues around discrimination, stigma, and accessibility for individuals considered "disabled." This legislation will be discussed in the following chapter.

person in favour of a sighted applicant. In addition, participants spoke about the need for employers to address concerns around the capabilities of LBPs, rather than relying on the LBP to educate their co-workers about their abilities. In addition, employers must take on the responsibility of ensuring LBPs feel comfortable working with their colleagues. For example, one participant talked about being grateful for working in a large company that accommodated her desire to avoid working with colleagues who were disrespectful or inappropriately concerned about her disability. She felt this accommodation reduced the impact of negative interactions with colleagues in a way that is not possible in smaller and less flexible companies.

Other participants spoke of resorting to hiding their blindness by not using their assistive devices (e.g., white canes) during the initial phases of an interview process. This strategy is described as follows by this participant:

I think I am fortunate that I had sight as a kid, I can get away with a lot of stuff now that gets me into the sighted world, because I look and act the same, I think that gets me into places. I am a great “passer.”

Another participant shared an incident where she was denied entry into an academic program due to her blindness because the instructor informed her that the last blind person to take the course had been unsuccessful. Showing a great deal of resilience, the participant returned to take the program two years later:

I didn't have my cane, I purposely didn't take my cane in there and I went and people think I can see, right? I could see a bit better back then too actually, and I actually met [that instructor], and chatted with her and she was saying, 'Oh, you are going to love the program.'... [a few days later] she agreed to meet with me and when... she recognized me, she was blubbering and stammering... I don't like doing that to people, but I also don't like being pushed around... Even at the graduation thing she was very apologetic...

These strategies speak to the sacrifices some blind people are willing to make in terms of mobility and safety to gain acceptance in the workforce and to conform to societal norms. The use of such strategies, however, was not supported by all participants—several argued that addressing the issue up front in the interview, including their limitations, was more likely to improve job prospects and reduce stigma, which is a strategy that is promoted in government training programs. A number of participants mentioned the benefits of government programs that prepared them well in resume building and interview techniques with real, concrete skills. As one participant indicated, “that was the place I best learned how to handle talking about my disability with an employer.”

Finally, experiences in co-operative learning or internship opportunities were mentioned by several respondents as an effective way to get their “foot in the door” to employment and enhance acceptance of LBP. Not only do internship programs allow inexperienced workers to obtain valuable, relevant employment skills, but they also provide a venue for the worker to prove their capabilities to a potential employer while they build a professional network. These partnerships are relatively low-risk to employers (they are generally unpaid), and allow for an opportunity to overcome stigma in the workplace.

Not surprisingly, employees who developed blindness while employed in the public sector reported less perceived and enacted stigma than their counterparts in the private sector. Because public sector work often emphasizes the value of equity in the workplace, these participants reported higher morale, and a more successful transition in their accommodations. For example, one participant spoke about how his loss of vision was accommodated through promotion to a managerial position:

I love my job, I'm satisfied and every minute is challenging... You're not only using the skills you've been trained in...[the employer] does provide training in various social aspects as well... The employer is very supportive that way... and the management is supportive of paying for that.

This comment suggests that positive discrimination policies might be critical in facilitating the adaptation of blind employees in the workplace, particularly for employees with later onset blindness, and in diffusing any stigma that could emerge as a result of such transition.

However, other participants expressed ambivalence over such policies, which they characterized as tokenism. Several of the currently unemployed participants expressed a belief that they had been selected for their previous positions based solely on tokenistic equity hiring:

Oh it is total tokenism; I actually had to really consider whether to continue with the job because I saw through it before I got qualified to go out in the field. The reason why I decided to do it was that I believed I could make a personal difference to the individuals in their attitude.

Even after being hired in the line of work they were interested in, these participants believed that they had been given their position to fulfill some kind of quota, rather than because their employer believed in their skills.

One of the more concrete barriers to labour market success identified by participants was the financial inaccessibility of assistive devices, "I think you know there are costs of blindness... equipment, and all sorts of things." Many employers are reluctant to make the significant monetary investment associated with assistive technology, effectively discriminating against blind workers and shutting them out of the labour market. Yet, these devices improve the efficiency of the worker which will in turn

improve their acceptance and morale within the workforce. Several participants empathized with employers who may not want to shoulder the costs of assistive technologies in a competitive job market, while others interpreted this as discrimination.

These participants offered several suggestions to improve access to costly assistive technology. This included providing a monthly stipend to blind individuals (regardless of employment status) and a cost sharing program between the employee, the employer, and government. Indeed, a number of Canadian provinces have programs which reimburse individuals with disabilities for the assistive technology they purchase, however each province differs in the percentage of cost that is covered, and all provinces provide insufficient funding considering the needs of this population (Gordon, 2006). No such program was available in British Columbia when this research was conducted; as a result, legally blind workers continue to have to cover the cost of their own assistive devices. This stands in contrast to the support available in other countries. In Australia, for example, blind workers receive a bi-weekly allowance that covers the cost of assistive devices at home and in the workplace; this allowance is available for employed and unemployed Australians who qualify as disabled (Australian Government, 2013). This program allows blind workers to afford assistive devices while actively participating in the labour market, as opposed to Canadian policies which largely provide financial support to blind people who have been determined unemployable due to their condition and are receiving a disability pension. By providing a more satisfactory support system, the government could mitigate one of the more significant barriers to employment for the legally blind population.

Summary

In this chapter, findings around felt stigma and resilience to stigma were presented. Felt stigma impacts participants at each stage of the employment process and throughout their day-to-day lives and had a negative effect on self-esteem, self-confidence, and mental health. Even the most resilient participants disclosed personal experiences and behaviours that were influenced by felt stigma.

The chapter also examines the ways in which participants responded to stigma, and how they managed their marginalizing experiences within the workplace. Many participants acknowledged the difficulty some legally-blind people face in the labour market, stressing the value of formal education, a strong network, and social/familial support in their success. Although all participants experienced stigmatization and discrimination, their responses showed a great deal of variation. Resilient participants were able to overcome the obstacles they faced, often enjoying rewarding and successful careers as legally blind labour market participants; the disenfranchised group on the other hand, were more likely to struggle with the oppressions they faced, and either resigned themselves to surviving on a disability pension or remained in an unsatisfying job. Many participants denounced the lack of awareness in the general public and on the part of employers when it came to understanding the capabilities of the legally blind population. The role of the charity economy in perpetuating the stereotype of blind people as needy and helpless was denounced by a number of participants. Finally, strategies for mitigating the impact of employment barriers were discussed, including improving access to assistive technology and managing one's identity.

Chapter Six: Discussion

This research project examined the experiences of LBP as they navigated the Canadian labour market and faced a variety of societal, personal, and financial barriers to success. The central aim was to understand the causes of employment and economic disparity in the legally blind population when compared to the general population in Canada. The participants' narratives offer valuable information on strategies to overcome some of the current barriers LBP face in the labour market. Moreover, the participants' experiences of enacted, perceived and felt stigma provide insights that relate but also contribute to previous literature on blindness, stigma, and employment barriers. The following section relates the study's findings with current research in the area.

The Cycle of Stigma

Figure 1 serves to illustrate key findings from this study with a focus on the common responses to stigmatization and the ways in which they affected the behaviour of the study's participants. My findings are informed by some of the theoretical insights presented below, but also contribute to the layout of the figure.

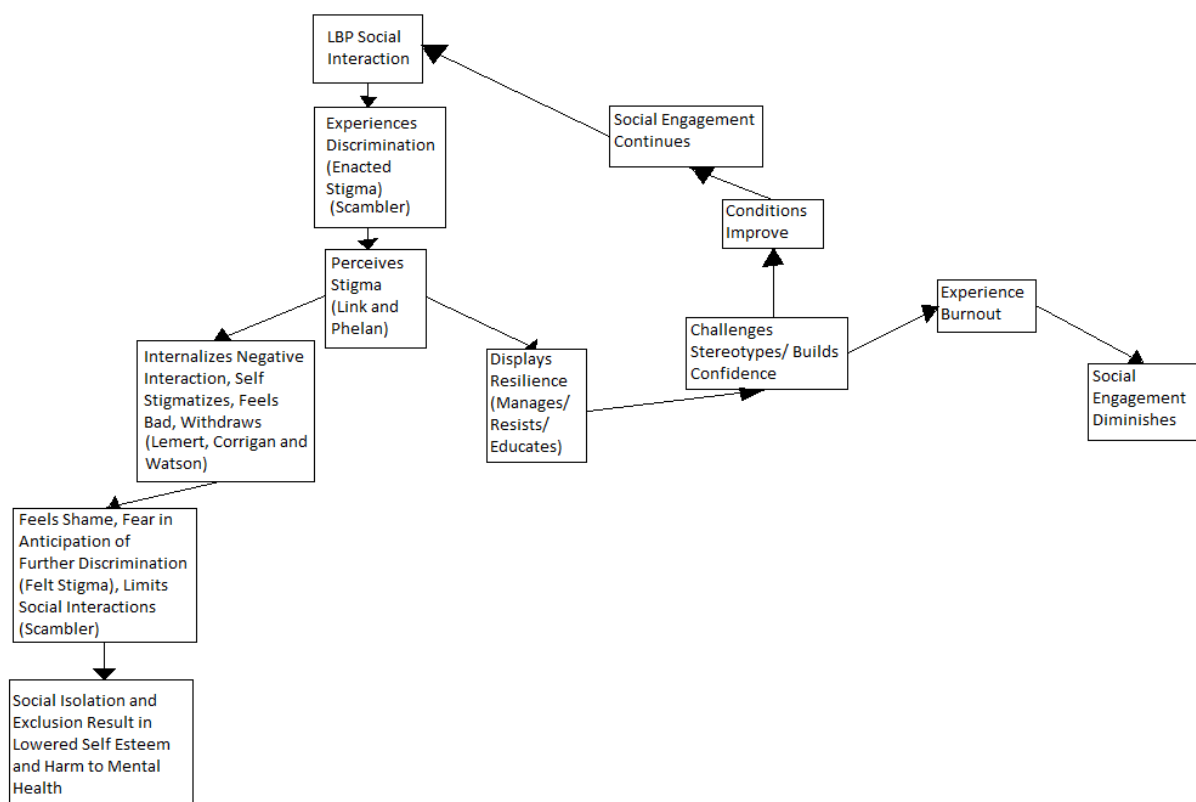


Figure 1 Responses to Stigma and Discrimination

Informed by Blumer's (1969, 1973) symbolic interactionist perspective, this figure draws attention to how the participants' accounts of their stigmatizing experiences in the work place reflect the impact of social interactions on their identities of LBPs. While this impact is often negative, several participants displayed resiliency and resisted or overcame the stigmatizing and discriminatory actions they faced. These participants showed a great deal of strength in countering the barriers created by misconceptions around their capabilities as well as more subtle forms of discrimination which Link and

Phelan (2014) refer to as microaggressions. These subtle forms of stigmatizations reflect the complex power dynamics created by stigmatizers and the "...hidden, misrecognized cultural circumstances that make stigma processes effective" (p. 24). The participants provided numerous examples of microaggressions, including instances when they needed to educate co-workers about their skills and capabilities which created feelings of insecurity, irritation, and alienation in the workplace. Although these incidents were not deliberately discriminatory, their consequences remained powerful and destructive. Link and Phelan (2014) suggest that these subtle forms of discrimination are particularly effective in oppressing marginalized groups because they are often difficult to identify or articulate and do not appear hostile.

Resistance and resilience

Resistance and resilience played heavily into the narratives of our participants. Many of the people I spoke with expressed a deep satisfaction with their personal circumstances and careers in spite of having faced discrimination and stigmatization in their lives. This dissatisfaction extended to the current model of disability promoted by support agencies like the CNIB.¹⁵ Many participants reported feeling as though their personal agency was removed when adhering to this model, expressed feeling disempowered by the support workers from CNIB, and felt frustrated at having to navigate a system that they believed was built around creating dependence rather than self-sufficiency. Participants suggested that CNIB support workers had narrow

¹⁵ CNIB is a registered charity, and receives significant government funding. They provide the majority of disability support to blind Canadians nationwide (CNIB, 2014)

conceptions about the capabilities of LBPs which are often projected on to them through support interactions. Despite the current labour market having expanded because of new accommodation technology, our participants believed that the culture within the CNIB and other accommodation-based agencies continues to lag behind in recognizing the capabilities of LBP.

This form of resistance reflects Scott's (1967) characterization of support agencies as being either accommodative or rehabilitative. Accommodative support agencies operate on the principle that blind people are different and basically unable to function in the world of the sighted. These agencies construct a separate reality for blind people, providing training that is only useful in that world and forcing them to rely on the sighted population in order to participate in general society. Accommodative agencies have a vested interest in sustaining the dependency of LBP on their services, as they have built a charity economy around that very premise. In contrast, rehabilitative agencies build their support around providing training aimed at self-sufficiency. They stress training in skills that are used in navigating everyday life in a society built around the needs of the sighted.

Another strategy of resistance employed by several participants was trying to "pass" as sighted. In most cases, this meant refraining from the use of accommodation devices (for example, the white cane), to lower their visibility as a LBP. Although some participants reported satisfaction with this strategy, it does diminish the mobility of the LBP, and places some limitations on their level of efficiency.

Most of the participants in this study acknowledged the value of a solid education; however all of the participants that spoke to education emphasized the importance of other factors like networking, social skills, and work experience in strengthening the candidacy of LBP for jobs.

Limitations of this Study

As with all social research, there are some limitations to the findings of this study. These limitations include: representativeness of our sample population, and limitations in the interview protocol. Although the interviews generated rich narrative data, participant demographics and affiliations may have shaped the nature of their responses. Most of the participants were associated in some way to a community agency highly critical of the current model of disability support in general, and the CNIB in specific. This is an important context to the narratives provided by participants, as their experiences may be might have been shaped by their membership into this agency. Moreover, the participants lived in an affluent city boasting a strong public transportation system which may not be the case for many LBP across Canada. Transportation and physical accessibility have a significant impact on the lived experience of LBP, and those in more rural locations may have notably different experiences.

Another limitation to this research is the absence of questions related to social/familial support in the interview protocol. The socio-economic status of the LBP's family of origin could have impact on their ability to afford accommodation devices, specialized education, and overcome other social barriers to employment. Having access

to financial resources could improve LBP's opportunities and mitigate some of the effects of discrimination and stigmatization. Although some participants spoke to the socio-economic status of their family of origin in the interview, during data analysis it became clear that more information in this area would have improved the richness of the findings.

Despite the limitations mentioned, this research provided valuable narratives reflecting the lived experiences of stigmatization and discrimination of participants.

Summary

This chapter has considered the findings presented in chapters four and five in relation to previous research in the area. Figure 1 illustrates the cycle of stigma in a schematic way by showing the various ways in which LBP respond to discrimination and stigmatization. The chapter also presents findings on how participants overcame and resisted discrimination in the labour market and larger society. The charity economy is also discussed as it relates to the current popular model of disability support for the LBP population. Finally, some of the limitations of this study were outlined, including issues related to the sample population as well as the interview protocol that was used for the collection of data. In the concluding chapter, I will provide recommendations around policy and practice to assist government and employers in creating equity within the labour market for LBP.

Chapter Seven: Conclusion

The insights and suggestions provided by participants in this research project have valuable implications for future policy development around supporting the legally blind population. For conditions to improve, strategies for countering stigmatization and discrimination must be addressed not only at the individual but also at the collective level, starting with education as well as socio-structural changes in the conditions of employment for LBP.

Policy and program recommendations

First, the implementation of a formalized education process for labour market participants combined with the provision of improved financial support for accommodation devices could mitigate and remove some of the current barriers faced by LBP attempting to participate in the labour market. A common sentiment among participants was a need to implement a formal education program in the workplace to raise awareness about the needs of workers with differing abilities. One example of this type of initiative is the Accessibility for Ontarians with Disabilities Act (AODA). The act mandates structured training programs for places of employment and educational institutions rather than relying on individual members of marginalized groups to provide education about their capabilities and accommodation devices. The AODA came into effect in 2011 and...

...Recognize[s] the history of discrimination against persons with disabilities in Ontario, the purpose of this Act is to benefit Ontarians by,

- a) developing, implementing and enforcing accessibility standards in order to achieve accessibility for Ontarians with disabilities with respect goods, services, facilities, accommodation, employment, buildings, structures and premises on or before January 1, 2025; and
- b) providing for the involvement of persons with disabilities, of the Government of Ontario and of representatives of the industries and of various sectors of the economy in the development of accessibility standards.

(Accessibility for Ontarians with disabilities Act, 2014)

The AODA includes standardized, mandatory education and training for all employees in Ontario, including informing applicants during the recruitment and hiring process that modifications will be made to accommodate disabilities; accessibility needs of employees built into human resource practices; written processes for developing and documenting individual accommodation plans as needed; and individualized safety response plans provided for disabled workers in order to ensure safe relocation in cases of emergency (Ministry of Economic Development, Trade and Employment, 2014). Employers are required to implement additional training programs and accessibility measures incrementally over the course of several years or face extensive fines if these thresholds are not met. Another concern addressed in the AODA legislation is the financial burden incurred by employers who are often expected to assume the cost of accommodation equipment.¹⁶ Under this legislation, Ontario now subsidizes the purchase of accommodation devices, providing a degree of equity by mitigating the costs of accommodating people living with disabilities who require accommodation in the work place.

¹⁶ The percentage of which varies between provinces.

Although this legislation is unique to Ontario, several other provinces are considering implementing similar programs (Ministry of Economic Development, Trade and Employment, 2014). AODA legislation has widespread implications in Ontario, and considers both institutional and educational barriers to employment and social participation for LBP; however the significant cost of implementation may be prohibitive for some provinces. As an alternative to AODA legislation, these provinces might consider the Australian model of disability support, which provides a guaranteed accommodation allowance regardless of employment status or income. This monthly allowance is intended to supplement the cost of accommodation equipment regardless of disability pension status and could mitigate some of the structural barriers to equity and acceptance within the workplace.

Future Directions for Research in the Area

The Mental Health Commission of Canada is currently evaluating the effectiveness of 68 anti-stigma projects across Canada in order to develop a plan to combat stigma around mental health (MHCC, 2014). The findings from this research could contribute to the development and study of similar strategies in combating stigma for LBP as well as other disability populations.

Study participants criticized the current popular model of support provided by the CNIB. Building on Scott's criticisms of the accommodative (rather than rehabilitative) model implemented by the CNIB, several participants felt there was a disconnect between the sighted CNIB employees and the LBP they are employed to support. Future

research on the engagement of LBP receiving training from legally blind peers instead of sighted persons could be of significant value in changing the nature of support currently offered to LBP.

Another area for future research is looking at the effectiveness of current AODA training in Ontario. As the implementation of this legislation is relatively new, the impact of these accessibility standards may not be observable for several years, however they provide clear expectations aimed at mitigating the discrimination and stigmatization faced by individuals living with disabilities.

Concluding Remarks

Improving the current labour market conditions for LBP has significant financial benefits for all Canadian citizens. Reconfiguring institutional expectations around workplace equity through the implementation of formal disability training and the provision of financial assistance to cover accommodation devices could lead to considerable improvements in the employment rate and lived experience of LBP. It is my hope that the generosity of the participants in sharing their stories for this research project is acknowledged through policy changes at a governmental level.

Bibliography

- Akyeampong, E. (2007). Canada's unemployment mosaic, 2000 to 2006. *Statistics Canada* 8(1).
- Alonso, J., A. Buron, S. Rojas-Farreras, R. deGraaf, J. Haro, G. de Girolamo, R. Bruffaerts, V. Kovess, H. Matschinger, & G. Vilagut. (2009). Perceived stigma among individuals with common mental disorders. *Journal of Affective Disorders*, 118(1-3), 180-186.
- Amato, S. (2002). Standards for competence in Braille literacy skills in teacher preparation programs. *Journal of Visual Impairment & Blindness*, 96(3), 143-153.
- AODA. May 25, 2014. *Accessibility for Ontarians with Disabilities Act (AODA) S.O. 2005 Chapter 11*. <http://www.aoda.ca/the-act/> (retrieved May 25, 2014).
- Benoit, C., McCarthy, B. & Jansson, M. In press. Stigma, service work, and substance use: A two-city, two-country comparative analysis. *Sociology of Health & Illness*.
- Benoit, C., Jansson, M., Jansenberger, M. & Phillips, R. (2012) Disability stigmatization as a barrier to employment equity for legally-blind Canadians. *Disability & Society*, 28(2), 1-14.
- Bickenbach, J., Chatterji, S., Badley, E., & Ustun, T. (1999). Models of disablement, universalism and the international classification of impairments, disabilities and handicaps. *Social Science & Medicine*, 48(9), 1173-1187.
- Blatt, B. (1981). How to destroy lives by telling stories. *Journal of Psychiatric Treatment and Evaluation*, (3), 183-191.
- Blaxter, M. (1976). *The Meaning of Disability: a sociological study of impairment*. London: Heinemann.
- Blumer, H. (1969). *Symbolic Interactionism: Perspective and Method*. Englewood Cliffs, NJ: Prentice-Hall.
- Blumer, H. (1973). A note on symbolic interactionism. *American Sociological Review*, 38(6).
- Boorse, C. (1975). On the distinction between disease and illness. *Philosophy and Public*, 5(49).
- Boorse, C. (1977). Health as a theoretical concept. *Philosophy of Science*, 44(4), 542-573.
- Boyatzis, R. (1998). *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks, CA: Sage.
- Braun, V. (2006). Using thematic analysis in psychology. *Qualitative research*, 3(2), 77-101.
- Canadian Charter of Rights and Freedoms. 1982. Part 1 of the Constitution Act, 1982.

- Charmaz, K., & Mitchell, R. G. (2001). Grounded theory in ethnography. Pp. 128-153 In Atkinson, P., Coffey, A., & Delamont, S. (Eds.), *Handbook of ethnography*. London: Sage.
- CNIB. May 25, 2014. *CNIB: About Us*. <http://www.cnib.ca/en/about/Pages/default.aspx>. Retrieved May 25, 2014.
- Constantine, M & Dorazio, C. (2008). Racial Microaggressions. *Encyclopedia of Counseling* Ed. Frederick, T., L. Leong, E. Altmaier & B. Johnson. Vol. 3: Cross-Cultural Counseling. Thousand Oaks, CA: Sage.
- Corbett, J. (1996). *Bad Mouthing: The Language of Special Needs*. London: Falmer Press.
- Corbin, J., & Strauss, A. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (3rd ed.). Los Angeles, London, New Delhi & Singapore: Sage.
- Corker, M. & French, S. (1999). *Disability Discourse*. United Kingdom: Open University Press.
- Corrigan, P., Watson, A. (2002). Understanding the impact of stigma on people with mental illness. *World Psychiatry*. 1(1), 16-20.
- Couture, A., A. Zaidi, E. Maticka-Tyndale. (2012). Reflexive accounts: an intersectional approach to exploring the fluidity of insider/outsider status and the researcher's impact on culturally sensitive post-positivist qualitative research. *Qualitative Sociology Review*. 8(1), 73-91.
- Creswell, J. (2009). *Research Design*. (3rd Ed.). Los Angeles: Sage.
- Crocker, J., Major, B., & Steele, C. (1998). Social stigma. Pp 504-553 in Gilbert, D. T., & Fiske, S. T. (Eds.), *The Handbook of Social Psychology*. Boston: McGraw-Hill.
- de Feyter, M., Smulders, P. & de Vroome, E. (2001). De inzetbaarheid van mannelijke en vrouwelijke werknemers. *Kenmerken van invloed, Tijdschrift voor Arbeidsvraagstukken*, 17(1), 47-59.
- Dwyer S. & Buckle, J. (2009). The Space Between: on being an insider-outsider in qualitative research. *International Journal of Qualitative Methods*, 8(1), 54-63.
- Ewick, P. & S. Silbey. (2003). Narrating social structure: stories of resistance to law. *American Journal of Sociology*. 108(6), 1328-1372.
- Finlay, L. (2002). "Outing" the Researcher: The Provenance, Process and Practice of Reflexivity. *Health Policy & Services*, 12(4), 531-545.
- Fitzgerald, J. 1998. Geneticizing disability: The human genome project and the commodification of self. *Issues in Law & Medicine*, 14(2), 147-157.

- Forrier, A. & Sels, L. (2003). The Concept of Employability: a complex mosaic. *International Journal of Human Resources Development and Management*, 3(2), 102-122.
- Foucault, M. (1977). Nietzsche, genealogy, history. Pp. 139-164 in Bouchard, D.F. (Ed), *Language, Counter-memory, Practice..* New York: Cornell University Press.
- Foucault, M. (1979). Cuvier's Position in the History of Biology. *Critique of Anthropology*, (4), 125-130.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine de Gruyter.
- Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, NJ: Prentice Hall.
- Gordon, P. (2006). A Federal Disability Act: Opportunities and Challenges. *Council of Canadians Living with Disabilities. ARCH Disability Law Centre*.
- Higgins, P. C. (1992). *Making Disability: Exploring the Social Transformations of Human Variation*. Springfield, IL: Charles C Thomas.
- Heidegger, M. (1927). *Being and Time*. (J. MacQuarrie and E. Robinson Trans.). New York: Harper Press.
- Heider, F. (1958). *The Psychology of Interpersonal Relations*. Lawrence Erlbaum Associates, Hillsdale, NJ: LEA.
- Hoppe, E. (1992). Evaluating the Laws Defining Blindness. *Journal of the American Ophthalmological Association*, 63(6), 390-394.
- Husserl, E. (1936). *The Crisis of European Sciences and Transcendental Philosophy*. (D. Carr Trans). Evanston: Northwestern University Press.
- Jacoby, A. (1994). Felt versus enacted stigma: A concept revisited. *Social Science & Medicine*, 38(2), 269-274.
- Jones, E., Farina, A., Hastorf, A., Markus, H., Miller, D. T., & Scott, R. (1984). *Social Stigma: The Psychology of Marked Relationships*. New York: Freeman.
- Krolokke, C. (2009). Look and Feel those Chubby Cheeks. Pp. 123-144 in Oleksy, E. & Golanska, D. (Eds.) *Teaching Visual Culture in an Interdisciplinary Classroom*. . Zuidam Uithof Drukkerijen: Utrecht.
- Kudlick, C. (2003). Disability history: Why we need another 'other'. *The American Historical Review*, 108(3), 763-793.

- Kutner, N. (2007). The sociology of disability. Pp. 98-106 in Bryant, C., & Peck, D. (Eds.) *21st century sociology*. Thousand Oaks: SAGE Publications.
- Lalonde, E. (2002). Back to Blind. *The Blind Canadian*, 1:1.
- Lee, E. (2013). Elite Colleges and Socioeconomic Status. *Sociology Compass*, 7(9), 786.
- Link, B. & Phelan, J. (2014) Stigma power *Social Science & Medicine*, 103, 24–32.
- Link, B., Phelan, J. C., & Dovidio, J. (2008). Stigma and prejudice: One animal or two? *Social Science & Medicine*, 67(3), 358-367.
- Link, B. & Phelan, J. C. (2001). Conceptualizing Stigma. *Annual Review of Sociology*, 27, 363-385.
- Link, B., Struening, E., Neese-Todd, S., Asmussen, S., & Phelan, J.C. (2001). Stigma as a Barrier to Recovery: The Consequences of Stigma for the Self-Esteem of People with Mental Illnesses. *Psychiatric Services*, 52:12.
- Link, B. & Phelan, J.C. (1999). Labeling and stigma. Pp 481-494. In Aneshensel, C.S. & Phelan, J.C. *The Handbook of the Sociology of Mental Health*. New York: Plenum.
- Link, B., Struening, E. L., Rahav, M., Phelan, J. C. & Nuttbrock, L. (1997). On stigma and its consequences: evidence from a longitudinal study of men with dual diagnoses of mental illness and substance abuse. *Journal of Health and Social Behavior*, 38,177–90.
- Link, B., Cullen, F. T., Struening, E., ShROUT, P. & Dohrenwend, B. P. (1989). A modified labeling theory approach in the area of mental disorders: an empirical assessment. *American Sociological Review*, 54,100–123.
- Link, B. (1987). Understanding Labelling Effects in the Area of Mental Disorders: An Assessment of the Effects of Expectations of Rejection. *American Sociological Review*, 52(1), 96-112.
- Littlejohn, S. & Foss, K. (2009). *Encyclopedia of Communication Theory*. New York: Sage.
- Mak, W., Poon, C., Pun, L. & Cheung, S. (2007). Meta-analysis of stigma and mental health. *Social Science & Medicine*, 65, 245-261.
- Maher, F. A. & Tetreault, M. K. T. (2001). *The feminist classroom: Dynamics of gender, race, and privilege* (Expanded Ed.). New York: Rowman & Littlefield.
- Maykut, P. & Morehouse, R. (1994). *Beginning Qualitative Research: A Philosophic and Practical Guide*, London: Sage.

- McCarty, C., Burgess, M. & Keeffe, J. (1999). Unemployment and under-employment in adults with vision impairment: The RVIC Employment Survey. *Australian and New Zealand Journal of Ophthalmology*, 27(3-4), 190-193.
- Menec, V. H., & Perry, R. P. (1998). Reactions to stigmas among Canadian students: Testing attribution-affect-help judgment model. *Journal of Social Psychology* (138) 443–453.
- Mental Health Commission of Canada. May 25, 2014. *Issue: STIGMA*.
<http://www.mentalhealthcommission.ca/English/issues/stigma> (retrieved May 25, 2014).
- Ministry of Economic Development, Trade and Employment. (2014). *Making Ontario Accessible*. <http://www.mcass.gov.on.ca/en/mcass/programs/accessibility/>
- Miles, M. & Huberman, M. (1994). *Qualitative Data Analysis*. (2nd Ed.). New York: Sage.
- Noe, R. A. & Barber, A. E. (1993) Willingness to accept mobility opportunities: destination makes a difference. *Journal of Organizational Behavior*, 14(2), 159–175.
- O'Day, B. (1999). Employment Barriers for People with Visual Impairments. *Journal of Visual Impairment & Blindness*, 93(10), 627.
- Oliver, M. (1996). *Understanding Disability: From Theory to Practice*. Basingstoke, UK: Macmillan.
- Pyne, J., Kuc, E., Schroeder, P., Fortney, J., Edlund, M. & Sullivan, G. (2004). Relationship Between Perceived Stigma and Depression Severity. *The Journal of Nervous and Mental Disease*, 192(4), 278-283.
- Samsel, M. (2013). The impact of media representation of disabilities on teachers' perceptions. *Support for Learning*, 28(4), 138-145.
- Scambler, G. & Hopkins, A. (1986). Being epileptic, coming to terms with stigma. *Sociology of Health and Illness*, (8), 26-43.
- Scambler, G. (1990). Social Factors and Quality of Life and Quality of Care in Epilepsy. In Chadwick, D. (Ed.), *Quality of Life and Quality of Care in Epilepsy*. London: Royal Society of Medicine.
- Scambler, G. (2009). Health-related stigma. *Sociology of Health and Illness*. (31) 441-455.
- Schafer, M. & Ferraro, K. (2011). Does Perceived Weight Discrimination Affect Identity and Physical Health? *Social Psychology Quarterly*, (74), 76-97.
- Schoon, I. (2006). *Risk and Resilience: Adaptations in Changing Times*. Cambridge University Press.

- Scott, J. & Marshall, G. (2009). *A Dictionary of Sociology (3rd Ed.)*. Oxford University Press.
- Scott, R. (1969). *The Making of Blind Men: a study of adult socialization*. New York: Russell Sage Foundation.
- Sharp, L. (2000). The Commodification of the Body and its Parts. *Annual Review of Anthropology*, 29(1), 287-328.
- Shaw, A., Gold, D. & Wolffe, K. (2007). Employment-related experiences of youths who are visually impaired: how are these youths faring? *Journal of Visual Impairment & Blindness*, 101(1), 7-21.
- Statistics Canada. August 5, 2011. *Labour Force Survey*. <http://www.statcan.gc.ca/daily-quotidien/110909/dq110909a-eng.htm> (retrieved August 5, 2011).
- Tremain, S. (2005). *Foucault and the Government of Disability*. University of Michigan Press. Michigan.
- van Dam, K. (1999). Employability orientation: an investigation of personal and work-related antecedents. *Conference Human Resource Management: 'Confronting Theory and Reality'*. Presented at Erasmus University, Rotterdam.
- van der Velde, M. E. G. & van den Berg, P. T. (1999). Willingness and ability as two dimensions of employability: antecedents and work outcomes. *Conference Human Resource Management: Confronting Theory and Reality*. Presented at Erasmus University, Rotterdam.
- Wendell, S. (1996). *The Rejected Body: Feminist Philosophical Reflections on Disability*. New York: Routledge.
- World Health Organization. (2009). *Causes of Blindness and Visual Impairment*. World Health Organization, Retrieved 19 February 2009. <http://www.who.int/blindness/causes/en/>.

Appendix A: Link's Devaluation/Discrimination Measure

- 1) Most people would willingly accept a former psychiatric patient as a close friend
- 2) Most people believe that a person who has been in a psychiatric hospital is just as intelligent as the average person
- 3) Most people believe that a former psychiatric patient is just as trustworthy as the average citizen
- 4) Most people would accept a fully recovered former psychiatric patient as a teacher of young children in a public school
- 5) Most people feel that entering a psychiatric hospital is a sign of personal failure
- 6) Most people would not hire a former psychiatric patient to take care of their children even if he or she had been well for some time
- 7) Most people think less of a person who has been in a psychiatric hospital
- 8) Most employers will hire a former psychiatric patient if he or she is qualified for the job
- 9) Most employers will pass over the application of a former psychiatric patient in favour of another applicant
- 10) Most people in my community would treat a former psychiatric patient just as they would treat anyone
- 11) Most young people would be reluctant to date someone who has been hospitalized for a serious psychiatric disorder
- 12) Once they know a person was in a psychiatric hospital, most people will take his or her opinions less seriously

All questions are rated on a 6-point scale: “Strongly agree,” “Agree,” “Agree slightly,” “Slightly Disagree,” “Disagree,” “Strongly disagree” (Link, 1987)

Appendix B: Interview Protocol

**Valuing the Blind:
The Impact of Stigma on Attaining Employment and Achieving Quality of Work
Life**

Thank you for participating in this study. If you are interested in receiving a copy of the material that is produced from this research, please provide an email address:

A: Background and Demographic information:

- 1) What Month _____ and year _____ were you born?
- 2) What is your marital status?
- Married
 - Divorced
 - Single (Never married)
 - Co-habiting
 - Common-law
 - Widow/Widower
 - Other (specify)
-
- 3) What level of education or training have you achieved so far?
- Some high school
 - Completed high school
 - Some college or university
 - Completed college degree
 - Completed undergraduate degree
 - Completed graduate degree
 - Completed doctorate
 - Some vocational training
 - Completed vocational training
 - Other (please specify)
-
- 4) Do you identify as an ethnic or racial group, other than Caucasian?
- Yes
 - No
- 5) If Yes, please name the group with which you identify _____
- 6) What is your approximate personal (after tax) income for the past year?
- \$0-9,999
 - \$10,000-24,999
 - \$25,000-39,999
 - \$40,000-54,999
 - \$55,000-69,999

\$70,000-84,999

\$85000+

7) What is your approximate household (after tax) income for the past year?

\$0-9,999

\$10,000-24,999

\$25,000-39,999

\$40,000-54,999

\$55,000-69,999

\$70,000-84,999

\$85000+

8) Have you been legally blind since birth?

Yes

No (6a)

9) If not, at what age did you become legally blind? _____

10) Are you currently collecting any kind of disability benefits?

Yes

No

11) If yes, are you receiving long term, or short term disability benefits from the provincial government?

long-term _____

short-term _____

12) Are you currently receiving any other insurance or pension benefits?

Yes

No

13) Do you use a white cane?

Always

Sometimes

Never

14) Do you use a guide dog?

Always

Never

15) Do you consider yourself literate in reading Braille?

Yes

No

16) Do you consider yourself literate in writing Braille?

Yes

No

B: Employment Information:

17) Have you ever worked for a wage or salary?

Yes

No (go to section C)

18) What strategies did you use to gain employment?

Networking

Referral

Government Services (please specify which ones)

Other

19) Have you used assistive technology at your place of employment?

Yes

No

20) What types of assistive technology have you used?

Computer screen reader

Braille note taker

Braille printer

Braille translator

Refreshable Braille technology

Recording devices

Perkins Braille

Slate and stylus

Talking Note Taker

Large print devices

Other (please

specify)

21) Who provided this equipment?

Government agency

Employer

Yourself

Other (please specify)

22) Are you currently receiving a wage or salary for work?

Yes

No

23) If yes, are you currently employed:

- Full-time (>37.5 hours/week)
 Part-time (<37.5 hours/week)
 Co-op/temporary employment
 Contract

24) How long have you worked at your current place of employment?

25) What kind of paid work do you do?

26) Do you feel your salary or wage is reflective of you training and skills?

- Yes
 No

27) Are you paid at the same level as your equally skilled co-workers?

- Yes
 No

28) How do you find the *quality* of your current employment? For example, is it meaningful to you? Is it challenging to you? Are you satisfied with your job?

29) What aspects of your current job do you enjoy the most? _____

30) What aspects of your current job do you enjoy the least? _____

31) In which employment sector do you work?

- Self-employed
 Private
 Public
 Non-profit
 Other (Please specify) _____

32) If you are NOT currently working for a wage or a salary, what kind of work have you done in the past?

Type

1: _____

Type

2: _____

Type

3: _____

Type

4: _____

33) Do you believe you face any barriers in maintaining employment?

Yes

No

34) If yes, please tell me about the barriers you face?

35) To what extent do you believe your legal blindness has been a barrier to maintaining employment?

Strongly agree

Agree

Neither agree nor disagree

Disagree

Strongly disagree

36) To what extent do you believe you have been treated unfairly by an employer due to your legal blindness?

Strongly agree

Agree

Neither agree nor disagree

Disagree

Strongly disagree

37) How often do you believe you were treated unfairly by a co-worker due to your legal blindness?

Always

Relatively often

Sometimes

Hardly ever

Never

C: Experiences seeking employment:

38) Are you currently seeking employment?

Yes
 No

39) How long have you been seeking employment?

40) Do you believe you face any barriers in attaining employment?

Yes
 No

41) If yes, what are they? _____

42) What type of employment are you seeking?

43) Do you believe you are qualified for this kind of work?

Yes
 No

44) Do you believe you are capable of doing this kind of work well?

Yes
 No

45) Do you require special equipment to undertake this type of employment?

Yes
 No (go to 9)

46) Is this equipment available to you?

Yes
 No

47) If yes, how do you access it? _____

48) If no, why isn't it available? _____

49) Has a lack of assistive technology ever impacted your ability to attain employment?

Yes
 No

50) What strategies have you used in seeking employment?

Networking

Referral
 Government Services (If so, which ones)

Other (Please specify)

51) To what extent do you agree that your legal blindness has been a barrier to securing employment?

Strongly agree
 Agree
 Neither agree nor disagree
 Disagree
 Strongly disagree

52) To what extent do you agree that you have been treated unfairly by a potential employer due to your legal blindness?

Strongly agree
 Agree
 Neither agree nor disagree
 Disagree
 Strongly disagree

53) To what extent do you believe you have been passed over for employment you were qualified for due to your legal blindness?

Strongly agree
 Agree
 Neither agree nor disagree
 Disagree
 Strongly disagree

54) If you are not hired for a job, what is the reason most often given?

55) Do you believe that your ability to secure employment been affected by being on disability benefits?

Yes
 No

56) What employment strategies and services did you find most helpful, and why?

57) Describe the experience of seeking employment, has it been generally positive or negative? _____

58) Describe your experiences with managers or bosses at your place of employment: _____

59) Describe your experiences with co-workers at your place of employment: _____

60) If you are not currently collecting disability benefits, have you ever collected disability benefits?

Yes

No

61) Why did you stop collecting disability benefits?

D: Link's Devaluation/Discrimination Scale:

62. Most people would willingly accept a blind or legally blind person as a close friend:

Strongly agree

Agree

Agree somewhat

Disagree somewhat

Disagree

Strongly disagree

62. Most people believe that a person who has been diagnosed as blind or legally blind is just as intelligent as the average person:

Strongly agree

Agree

Agree somewhat

Disagree somewhat

Disagree

Strongly disagree

64. Most people believe that a blind or legally blind person is just as trustworthy as the average citizen:

Strongly agree

Agree

Agree somewhat

Disagree somewhat

Disagree

Strongly disagree

65. Most people would accept a blind or legally blind person as a teacher of young children in a public school:

- Strongly agree
- Agree
- Agree somewhat
- Disagree somewhat
- Disagree
- Strongly disagree

66. Most people feel that being blind or legally blind is a sign of personal failure:

- Strongly disagree
- Disagree
- Disagree somewhat
- Agree somewhat
- Agree
- Strongly agree

67. Most people would not hire a blind or legally blind person to take care of their children, even if he or she had children of their own:

- Strongly disagree
- Disagree
- Disagree somewhat
- Agree somewhat
- Agree
- Strongly agree

68. Most people think less of a person who is blind or legally blind:

- Strongly disagree
- Disagree
- Disagree somewhat
- Agree somewhat
- Agree
- Strongly agree

69. Most employers will hire a blind or legally blind person if he or she is qualified for the job:

- Strongly disagree
- Disagree
- Disagree somewhat
- Agree somewhat
- Agree
- Strongly agree

70. Most employers will pass over the application of a blind or legally blind person in favor of another applicant:

- Strongly disagree

- Disagree
- Disagree somewhat
- Agree somewhat
- Agree
- Strongly agree

71. Most people in my community would treat a blind or legally blind person just as they would treat anyone:

- Strongly disagree
- Disagree
- Disagree somewhat
- Agree somewhat
- Agree
- Strongly agree

72. Most young people would be reluctant to date a blind or legally blind individual:

- Strongly disagree
- Disagree
- Disagree somewhat
- Agree somewhat
- Agree
- Strongly agree

73. Once they know a person is blind or legally blind, most people will take their opinions less seriously:

- Strongly disagree
- Disagree
- Disagree somewhat
- Agree somewhat
- Agree
- Strongly agree

Thank you for participating in this study, do you have anything else you would like to say, that may not have been addressed in these questions?

Appendix C: Ethics Approval

-----Original Message-----

From: Emily Little

Sent: Wednesday, November 19, 2008 8:59 AM

To: 'Martha Jansenberger'

Cc: Cecilia M. Benoit; Zoe Lu; Kathy, Graduate Admissions and Records Secretary

Subject: Approval of Ethics Review Application

Dear Martha Jansenberger:

Please be advised that your Application for Ethics Approval entitled 'Examining the Barriers to Meaningful Employment of Blind Adults in the Victoria, BC Census Metropolitan Area' has been approved and assigned Protocol Number 08-329.

Beginning January 2, 2008, as per federal regulations, ethics protocols will be approved for a one-year period. All Principal Investigators are required to submit a Request for Annual Renewal form prior to the Certificate Expiry Date to maintain ethics approval. You will be contacted via email with details of Renewal submission approximately six weeks prior to the expiry date on your Certificate of Approval.

You may begin your research and will receive a Certificate of Approval via regular mail.

Good luck with your Study.

Emily Little | Human Research Ethics | University of Victoria | Technology Enterprise Facility,
Room 218 | Victoria, BC | Canada | Tel: 250-472-4545 | FAX: 250-721-7836 |
<http://www.research.uvic.ca> | E-mail: ethics@uvic.ca

Appendix D: Informed Consent

University of Victoria
Department of Sociology
PO Box 3050 STN CSC
Victoria BC V8W 3P5 Canada
Tel (250) 721-7572, Fax (250) 721-6217

Examining the Barriers to Meaningful Employment of Blind Canadians

Community-Academic Research Project

Cecilia Benoit, Ph.D.

Professor
Department of Sociology
Office phone: (250) 721-7578
Email: cbenoit@uvic.ca

Hassan Chawdhury,

M.A. Student Intern
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Martha Jansenberger,

M.A. Student Intern
Department of Sociology
Phone: (250) 886-9157
Email: jansenbergerm@hotmail.com

Elizabeth Lalonde,

President
Canadian Federation of the Blind
Phone: (250) 598-7154
Email: info@cfb.ca

Consent Form

Purpose of the Study

We are conducting a study about the barriers to meaningful employment among blind people of working age (15-65 years old) in the Greater Victoria Area. This study is being undertaken to provide blindness-specific statistics regarding unemployment and underemployment among blind people of working age in Canada, with follow-up in-person interviews with a sample of legally blind adults in the Victoria area. The goal of the study is to provide a final report that outlines the experiences of blind Canadians seeking employment, the barriers to employment, and recommendations for removing these barriers and increasing the employment outcomes for this vulnerable population.

Participation

You have been invited to participate in this study because you are legally blind, are of working age (15-65 years old) and live in the Greater Victoria Area. If you are willing to participate, one of our graduate student interns would like to interview you about your experiences seeking and maintaining employment. We anticipate the interview will last between 30-45 minutes. It will cover such topics as your personal background, your experience of seeking and maintaining employment, and your experiences of accessing employment assistance services. A summary of the findings will be available to you upon your request. Because the graduate student will be using the interviews as the basis for one part of the final report, she/he will ask permission to tape record your interview. However, this is optional and, if you prefer, the graduate student can instead take written notes.

Confidentiality

All information that you provide will be kept confidential. Only the graduate student interns (Hassan Chawdhury and Martha Jansenberger) and the graduate intern supervisor (Dr. Cecilia Benoit) will have access to your interview. No information will be used that might personally identify you or your family members. We are able to provide you with a modest honorarium (\$25) for your participation, and we also believe the blind community will benefit from your participation by reading the final report we will produce based on your own and other respondents' answers to our questions. All digital files and transcripts of the interviews will be stored in a locked filing cabinet or on a password-protected computer and transcripts will not contain respondents' identifying information. Instead, all documents associated with your interview will be identified only by code number. The key to these numbers will be kept only by the graduate intern supervisor and the graduate student interns and will not be publicly released under any circumstances. You will never be identified by name in any reports

derived from the completed study. Only pseudonyms will be used in the final research report. All digital recordings will be deleted from all file locations and transcripts will be shredded upon completion of the research project.

Remuneration

Your participation in this interview is totally voluntary. We are providing a modest honorarium of \$25. The full honorarium will be given even if you decide for any reason to withdraw before the interview is completed.

Your rights

We do not believe there are any risks to you associated with your participation in this study. However, your participation is entirely voluntary and you are free to refuse to answer any questions or the interview at any time. If you have any questions or want further information about the study, please contact Martha Jansenberger at (250) 886-9157 or email her at jansenbergerm@hotmail.com. Or you may contact Dr. Cecilia Benoit at (250) 721-7578 or email her at cbenoit@uvic.ca. You may verify the ethical approval of this study, or raise any concerns you might have about your treatment or rights by contacting the Associate Vice-President, Research at (250) 472-4545 or ovprhe@uvic.ca

Consent

Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time without jeopardy to you. If you choose to withdraw from the study after being interviewed, all information collected in the interview will be destroyed. Your signature below indicates that you consent to participate in this study and that you have received a copy of the consent form for your own records.

I do ___/do not ___ agree to my interview being tape recorded

Signature.....

Date.....

Printed Name:.....

Researcher's Name:.....

University of Victoria
Department of Sociology
PO Box 3050 STN CSC
Victoria BC V8W 3P5 Canada
Tel (250) 721-7572, Fax (250) 721-6217
Consent

Letter of Information for Implied

Examining the Barriers to Meaningful Employment of Blind Canadians

Community-Academic Research Project

Cecilia Benoit, Ph.D.

Professor
Department of Sociology
Office phone: (250) 721-7578
Email: cbenoit@uvic.ca

Hassan Chawdhury,

M.A. Student Intern
Department of Sociology
Phone: (250) 385-8005
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Martha Jansenberger,

M.A. Student Intern
Department of Sociology
Phone: (250) 886-9157
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Elizabeth Lalonde,

President
Canadian Federation of the Blind
Phone: (250)
Email: elalonde@shaw.ca

You are invited to participate in a study entitled Examining the Barriers to Meaningful Employment of Blind Canadians that is being conducted by Martha Jansenberger and Hassan Chawdhury, and Dr. Cecilia Benoit.

Martha Jansenberger and Hassan Chawdhury are M.A. students in the department of Sociology at the University of Victoria and interns to this research grant under the supervision of Dr. Cecilia Benoit. If you have any further questions you may contact Martha by email: jansenbergerm@hotmail.com or by phone: (250) 886-9157; or Hassan by email: hassan@uvic.ca or by phone: (250)

385-8005; or contact Dr. Benoit by email: cbenoit@uvic.ca or by phone (250) 721-7578

The research is being funded by the MITACS Accelerate BC Internship Program and the Disability Health Research Network of BC.

Purpose and Objectives

We are conducting a study about the barriers to meaningful employment among blind people of working age (15-65 years old) in the Greater Victoria Area. This study is being undertaken to provide blindness-specific information regarding unemployment and underemployment among blind people of working age in Victoria. The goal of the study is to provide a final report that outlines the experiences of blind Canadians seeking employment, the barriers to employment and recommendations for removing these barriers and increasing the employment outcomes for blind people.

Participants Selection

You are being asked to participate in this study because you are legally blind, of working age (15-65 years old) and living in the Greater Victoria Area.

What is Involved

If you agree to voluntarily participate in this research, your participation will include participation in a 30-45 minute face-to-face interview in a location of your choice. The Canadian Federation of the Blind will be helping us find eligible respondents. Please note that 1) your participation in the study is voluntary, and 2) declining to participate or to withdraw will not affect current or future services from the CBF. The interview will be audio recorded, with your permission.

Inconvenience

Participation in this study may cause some inconvenience to you, including 30-45 minutes of your time. We will arrange interview around your schedule to the best of our ability.

Risks

There are no known or anticipated risks to you by participating in this research.

Benefits

The potential benefits of your participation in this research may include a contribution to better understanding of the barriers to employment among blind people in Victoria so that this information can be incorporated into a report that will be used by the Canadian Federation of the Blind to try and improve the employment outcomes and experiences for blind people in the Greater Victoria Area.

The potential benefits to society from this research may include a better understanding of this segment of the population and the dispelling of myths and stereotypes about the abilities and employment outcomes of blind people in the Greater Victoria Area.

The potential benefits to the state of knowledge from research may include accurate blindness-specific unemployment and underemployment statistics and possible barriers to employment for people of working age (15-65 years old) in the Greater Victoria Area, as well as qualitative narratives of their experiences seeking and maintaining employment.

Voluntary Participation

Your participation in this research must be completely voluntary. If you decide to participate in an in-person interview, you have the right to withdraw at any point during the interview. We will use the data upon your withdrawing from the project if you agree to it. If this is the case, we will draft a consent form based on the use of data as negotiated.

Researcher's Relationship with Participants

The researchers do not have a relationship to the potential participants.

Anonymity

In terms of protecting your anonymity, no identifying information will be collected with the interview and there are no questions included in the interview schedule that will compromise anonymity based on certain participant characteristics.

Confidentiality

We will do our best to keep your confidentiality and the confidentiality of the data will be protected at all times. I will use pseudonyms for dissemination as well as on code sheets and transcripts. We will change any information such as place of employment interview, place of work, etc. that may identify you or your employer(s). However, because the CFB will be helping us find eligible respondents for interview, confidentiality may be limited.

Dissemination of Results

It is anticipated that the results of this study will be shared with others in the following ways: A final project report will be submitted to the MITACS Accelerate BC Internship in order to complete the internship requirements; a final report will also be submitted to the Disability Network of BC for distribution to their membership, and a final report will be submitted to the Canadian Federation of the Blind for their records and advocacy work.

Disposal of Data

Data from this study will be disposed of two (2) years after completion of the project through deletion of all related electronic files. Any paper copies of data will be shredded.

Contacts

Individuals that may be contacted regarding this study include Martha Jansenberger, email: jansenbergerm@hotmail.com; or Hassan Chawdhury (hassan@uvic.ca), email: hassan@uvic.ca; or Dr. Cecilia Benoit, email: cbenoit@uvic.ca

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca)

By completing the electronic survey, **YOUR FREE AND INFORMED CONSENT IS IMPLIED** and indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researchers.

Please retain a copy of this letter for your reference.