THE SOCIAL GEOGRAPHIES OF ADULT IMMIGRANTS WITH DISABILITIES IN CANADA

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A Thesis Submitted to the School of Graduate Studies in Partial Fulfillment of the Requirements for the Degree Doctor of Philosophy

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McMaster University DOCTOR OF PHILOSOPHY (2019) Hamilton, Ontario

TITLE: The Social Geographies of Immigrants with Disabilities in Canada

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PAGES: 200

Lay Abstract

Limited research has been done on adult immigrants with disabilities in Canada. Adopting a mixed-methodology, the thesis explores the intersection of immigrant status and disability from both a quantitative and qualitative perspective. Quantitative methods examine and compare the receipt and need of support services between immigrants and the Canadian born population with disabilities. Building on the quantitative findings, the qualitative research adopts a feminist disability theory and an intersectional framework to explore the lived experience of immigrants with physical disabilities from the Middle East and South Asia, living in Canada. The qualitative chapter examines how different categories, for example disability, gender culture, religion, and immigrant status can intersect to create unique lived experiences that changes over time and place. The quantitative and qualitative findings were evaluated to further the knowledge of immigrants with disabilities and future research directions are suggested.

Abstract

Limited research has been done on adult immigrants with disabilities in Canada. Adopting a mixed-methodology, the thesis explores the intersection of immigrant status and disability from both a quantitative and qualitative perspective. Previous research on immigrants with disabilities has primarily focused on parents with disabled children. Little is therefore known about the lived experiences of adult immigrant with disabilities and how these experiences are negotiated and can change across time and place. The quantitative section of the thesis utilized the Participation and Activity Limitation Survey (PALS) from 2006 to examine the receipt of and need for services based on gender, immigrant status, income, education, and age. Quantitative results identified that immigrant women as receiving the least amount of services compared to any group, potentially resulting in them being more vulnerable compared to any other group. The qualitative part of the research consisted of two studies. First, community leaders and disability activists from Middle Eastern and South Asian communities were interviewed to examine the understandings of disability within their communities. Building on key informant findings, the second part explored the lived experiences of physically disabled adult immigrants from the Middle East and South Asia through in-depth interviews. Drawing on both quantitative and qualitative results it was identified that place, gender, culture, and policy significantly influence the lived experiences of immigrants with disabilities. Overall, the research highlighted the need for further research on larger service organizations and their provision of services to immigrants. The findings also identified the need for a greater understanding and provision of culturally appropriate services.

Acknowledgements

An old African proverb has famously said that it takes a village to raise a child, writing a thesis is no different. While I am the one who has written the thesis and the one who will ultimately be awarded a degree, I could not have done it without my village. First off, I would like to thank my supervisors Dr. Robert Wilton and Dr. Bruce Newbold. Without your support, guidance, knowledge, and patience I would not have been able to finish my thesis. I truly benefitted from having you both as supervisors and being able to draw on your different expertise to help me produce the best thesis that I could. I appreciate the quick turn arounds of drafts, the time you devoted to make changes along the way, and most of all, your optimism. I also wish to thank my committee members, Dr. Olive Wahoush and Dr. Vera Chouinard, for their support, guidance, and ideas.

A special thank you goes out to Waad Khogali who was my cultural informant and office mate. Without Waad the research would not have been completed and I can't thank him enough for helping me when it looked like it was never going to happen. Your friendship and eternal optimism will never be forgotten and I know that I wouldn't be defending this thesis if it wasn't for you. To my other office mates, thank you for your endless support over the years and for lending an ear when I needed talk. I really appreciate the way that we have been able to be there for each other to support, guide, and give a hug when needed.

I also want to thank my friend Michelle for her eternal support and belief in my abilities in terms of what I can accomplish. Without you, I still wouldn't believe that I would ever get a job after the PhD. Thank you for seeing my potential and helping me reach it. I also wish to thank my thesis boot camp and writing group friends. The majority of my thesis was written at boot camp and your friendship helped make those hard writing days better.

Most importantly I need to thank my family, the most significant members of my village. To Julie, thank you for being supportive of this journey and being willing to listen to all my grad school complaints over the last 6+ years. Thank you for being a great mom to our son and taking extra "parenting shifts" when I needed to write. To Anders, thank you for being a great son who has helped me understand the meaning of work - life balance. You put a smile on my face every day and your hugs are the best. To my mom and dad, thank you for supporting me through this journey and coming to visit when I could not make it home to see you. To Louise and company, thank you for bringing a smile to my face and making vacations full of fun! To Mo and Rod, thank you for listening to all my complaining over the years and supporting me, as well as coming to help us out when we needed it.

I could not have done this without my village, and I will forever by grateful for all of their support!

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List of Abbreviations

CMA: Census Metropolitan Area

GTHA: Greater Toronto and Hamilton Area

PALS: Participant Activity Limitation Survey

WHO: World Health Organization

UPIAS: Union of the Physically Impaired Against Segregation

NGO: Non-Governmental Organization

UK: United Kingdom

CSD: Canadian Survey on Disability

ADL: Activities of Daily Living

CILT: Center for Independent Living Toronto

SAS: Student Accessibility Services

ODSP: Ontario Disability Support Program

CNIB: Canadian National Institute for the Blind

CAM-D: Canadian Association of Muslims with Disabilities

UCIP: United Cerebral Palsy

UAE: United Arab Emirates

AODA: Accessibility for Ontarian with Disabilities Act

YWCA: Young Women's Christian Association

YMCA: Young Men's Christian Association

ISIS: Islamic State of Iraq

Declaration of Academic Achievement

I, Stine Hansen, declare this thesis to be my own work. Chapter 4 is based on a paper that was co-authored by my supervisors Dr. Bruce Newbold and Dr. Robert Wilton, I was the primary researcher and author of the paper. I collected the data and wrote the paper. I am the sole author of all other chapters in this thesis. The thesis was completed under supervision of Dr. Robert Wilton and Dr. Bruce Newbold and with the help of my supervisory committee Dr. Olive Wahoush and Dr. Vera Chouinard.

Chapter One

Introduction

1.1 Background

Persons with disabilities are some of the most marginalized and vulnerable populations globally. Fifteen percent of the world's population is believed to have a disability, making it the largest minority in the world. This number is expected to increase as the world's population ages and ageing being associated with higher risk of disability (World Health Organization, 2011). Persons in lower income countries are considered more vulnerable to disability and it is estimated that 80% of all persons with disabilities currently live in developing countries (World Health Organization, 2011). Globally, persons with poor wealth, women, and older people have a higher prevalence of disability. People with a lower educational attainment, low income, as well as people who are out of work are also at a higher risk of disability (World Health Organization, 2011). Persons with disabilities in developing countries are found to be especially vulnerable due to lack of access to adequate healthcare and rehabilitation (World Health Organization, 2011).

Persons with disabilities and households with a disabled member, in both developed and developing, countries are more likely to live in poverty, where they face food insecurity, poor housing, and lack of access to safe water and sanitation, compared to non-disabled individuals. Persons with disabilities are often caught in a 'poverty trap' as they have less access to education, overall lower educational attainments, and difficulty obtaining employment (Filmer, 2008; Stapleton, O'Day, Livermore, & Imparato, 2006; United Nations, 2007; World Health Organization, 2011). The World Health Organization (2011) World Report on Disability revealed that children with disabilities are significantly less likely to attend school compared to children without disabilities and those who are in school had lower rates of staying in school. This was found to be true for both low and high-income countries.

As mentioned, persons with disabilities are more likely to be unemployed. Data from the Organization for Economic Co-operation and Development (OECD) has found that working age persons with disabilities faced labour market disadvantages and worse labour market outcomes compared to their non-disabled counterparts (World Health Organization, 2011). The average employment rate for persons with a disability was 44%, whereas it was 75% for persons without a disability (World Health Organization, 2011). An American study found that the employment rate for adults with a disability in the United States was 22.6% compared to 71.9% for adults without a disability (Turner, Unkefer, Cichy, Peper, & Juang, 2011). Globally, employment rates for persons with a disability also depend on gender with males (53%) more likely to be employed compared to females who have a disability (20%). Common barriers to employment have been identified as discrimination, stereotypes towards persons with disabilities, ignorance, and misconceptions of ability (Benoit, Jansson, Jansenberger, & Phillips, 2013; González, 2009; Wilson-Kovacs, Ryan, Haslam, & Rabinovich, 2008).

From a Canadian perspective, the 2012 Canadian Survey on Disability (CSD) found that 14% (3.8 million) of the adult Canadian population[1] reported having a disability that limited their daily activities (Arim, 2017). Prevalence of disability also varies by province and territory with Nunavut reporting the lowest prevalence of

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[1] Persons aged 15 years or older

disability in Canada at 6.9% and Nova Scotia reporting the highest at 18.8%. The prevalence for Ontario in 2012 was 15.4% (Arim, 2017). As seen worldwide, the Canadian disability prevalence increases with age where 10.1% of working age Canadians[2] have a disability compared to 33.2% of those aged 65 and older (Arim, 2017). Overall, women (14.9 %) report a higher prevalence of disability compared to men (12.5 %) (Arim, 2017). Similarly to the global data, results from the CSD shows that Canadians with a disability are less likely to be employed, have a lower income, and less likely to have a university degree, compared to the non-disabled Canadians (Arim, 2017).

From an immigration perspective, immigrants make up approximately 22% (7.5 million) of the Canadian population (Statistics Canada, 2017b). Of those 7.5 million immigrants, 1.2 million are recent immigrants who have arrived in Canada between 2011 to 2016 (Statistics Canada, 2017a). Historically, Canada is known as a land of many immigrants that has relied on immigration for population growth due to its decreasing total fertility rate, which is currently 1.6 (Citizenship and Immigration Canada, 2011; Statistics Canada, 2018a). Currently, Canada admits the largest number of immigrants per capita compared to other G8 countries with 271,845 permanent residents admitted in 2015, the majority being economic immigrants (Canada, 2016). The top 10 countries of birth of recent immigrants from 2011 to 2016 were: Philippines, India, China, Iran, Pakistan, United States, Syria, United Kingdom, France, and South Korea (Statistics Canada, 2017a).

On a smaller scale, 29.1% of all immigrants in Canada reside in Ontario, which is the largest percentage of any province (Ontario Ministry of Finance, 2017). Of the recent

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[2] Age 15-64)

immigrants that arrived in Canada between 2011- 2016, 39% (472,170) of the 1.2 million newcomers settled in Ontario. The majority of recent immigrants (68.8%) settling in Ontario are from Asia, including the Middle East, and 75.6% of these newcomers settle in the Toronto Census Metropolitan Area (CMA) (Ontario Ministry of Finance, 2017). The Toronto CMA currently has the highest percentage of immigrants compared to any other CMA in Canada, with 46.1% of the population being foreign-born. The Hamilton CMA has the fifth highest foreign-born population at 24.1% (Ontario Ministry of Finance, 2017). As demonstrated, disability and immigration are both important aspects of Canadian society, however, our knowledge of the intersection of disability and immigrant status in Canada is currently very limited.

1.2 Study Focus

The overall focus of this study is to explore the lived experiences of immigrants from South Asia and the Middle East with disabilities in the Greater Toronto and Hamilton Area (GTHA). Lived experiences refers to how the experiences of immigrants with disabilities are shaped by factors such as gender, religion, disability, immigrant status, and culture and how these factors influence how people live their daily lives. By focusing on lived experiences this research is able to explore understandings of why some experiences are privileged over others (Given, 2008).

While several policies are in place to prevent immigrants with disabilities from immigrating to Canada and causing an excessive burden on the Canadian health and social systems (El-Lahib, 2015; El-Lahib & Wehbi, 2012; Wilton, Hansen, & Hall, 2017) immigrants with disabilities are present in Canada either after immigrating with a disability, becoming disabled while living in Canada, or developing disabilities as a result of ageing. Using a mixed methods approach this thesis explores the lived experiences of immigrants with disabilities, focusing particular attention on questions of disability meaning and identity, community support, and service utilization to better our understanding of how these topics are instrumental in shaping the daily lives of immigrants with disabilities.

The empirical research is organized into three related sections. Employing quantitative methods, the first section of the thesis uses Statistics Canada's Participation and Activity Limitation Survey (PALS) from 2006 and descriptive statistics to provide sample characteristics of immigrants and the Canadian born population with disabilities focusing on severity, age, gender distribution, education, income, and who provides them with support. Employing a multivariate analysis the section also explores and compares service utilization between immigrants and the Canadian born population to assess their use, need, and access focusing on four types of support: meal support, housework support, errand support, and personal support. These types of supports were chosen as they are common everyday supports that people are likely to receive regardless of age, gender, and marital status.

While the first section raises interesting questions about differences in access to, and use of services, the second section uses qualitative data to unpack the everyday lived experiences by exploring themes such as family, employment, transportation, religion, and service needs of immigrants with disabilities from the South Asia and the Middle East communities. Initially, I draw from key informants with and without disabilities from these communities to examine the meanings of disability in relation to culture and religion. By recruiting religious leaders as key informants (without disabilities), disability is explored from an Islamic perspective to help achieve a better understanding of the perceptions of and attitudes toward disability within the Qur'an, and Islamic communities. The perspective of key informants with disabilities, explores some of the issues that immigrants with disabilities face in Canada in relation to acquiring services, knowledge of services, appropriateness of services, as well as what is needed from a service perspective to assist immigrants with disabilities living in Canada.

In the third and final section, I turn to explore lived experiences of immigrants with disabilities and how these experiences can change over time and place. Drawing from interviews with a small sample (n=8) of immigrants with physical disabilities from South Asia and the Middle East, this section focuses its attention on the ways in which the social, cultural, economic, political, and built environments confronted by immigrants with disabilities before, during, and after immigration work to shape their experiences of disability.

The thesis discusses the implications of their experiences of employment, the built environment, cultural understandings of disability, and services before providing recommendations for future research that can help expand the knowledge of immigrants with disabilities living in Canada.

1.3 Study Themes and Aims

The main themes explored in respect to the lived experiences of immigrants with disabilities are: is support service utilization different for immigrants with disabilities compared to the Canadian born population with disabilities, how does gender, culture, and religion, influence support and lived experiences, and what are the weaknesses of the current service system.

A related aim is to understand how place influences these lived experiences of disability both negatively and positively. For example, policy is explored to further our understanding how policy and place impact the lives of persons with disabilities. Furthermore, the thesis explores the gendered experiences of disability and how it can impact services utilization, relationships, and acceptance.

To date, very little research, either quantitative or qualitative, has engaged with immigrants' experiences of disability in Canada (see chapter 2) and even less research has been done concerning adult immigrants with physical disabilities from specific regions. Quantitatively, studies of disability have neglected to include immigrants in their analyses, leaving a knowledge gap on a macro scale with respect to the overall well-being of immigrants with disabilities in Canada. From a qualitative perspective, the little social science research that exists, has focused heavily on the experiences of immigrant parents with a disabled child (Daudji et al., 2011; Lindsay, Desmarais, Tetrault, King, & Pierart, 2014; Lindsay, King, Klassen, Esses, & Stachel, 2012) rather than the perspective of the immigrants with disabilities themselves. Further, there has been a lack of research into access and the cultural appropriateness of care provided to immigrants in Canada. With more and more immigrants arriving in Canada, from non-Western countries, with different cultural and religious views of disability, it becomes increasingly important to expand our understandings of how these views can impact and influence the lives of immigrants with disabilities in Canada. Without research on the intersections of disability, immigrant status, and gender, fully informed decisions cannot be made in regards to the needs of services and care of these immigrants. This thesis addresses these knowledge gaps through the following objectives/aims:

- add to the limited knowledge and provide a better understanding of the lived experiences of adult immigrants with physical disabilities living in Canada.
- to examine how gender impacts the lived experiences of disability in regard to the receipt of support services, acceptance in society, and relationships.
- contribute to the geographic and social science literature on the experiences of disability using mixed methods to explore disability from a feminist geographical and intersectional perspective.
- to recommend further research avenues that can advance our knowledge of immigrants with disabilities to improve their experiences of living with a disability in Canada. As well as providing suggestions for more inclusive policies and the development of culturally appropriate programs and services for immigrants with disabilities.

The background for these aims is found in the following chapter, where the literature review engages with the current knowledge that exists on immigrants with disabilities and gaps in that knowledge.

1.4 Thesis Structure

The overall thesis is organized into seven chapters, including the introduction. Chapter two reviews the current literature from diverse disciplines such as geography, religious studies, and rehabilitation sciences. The literature review explores immigrant health as well as disability from a macro and micro level including global perceptions, understandings, and experiences. Lastly, the literature review explores the existing knowledge of disability in the regions that are focused on in this study, the Middle East and South Asia. Overall, the literature review introduces themes of culture, religion, prevalence, and understandings of disability.

Chapter three focuses on the methods and techniques used in the thesis and the justification of why these methods were chosen. Chapter four[3] works at a macro scale using the PALS 2006 data set to capture differences between immigrants and non-immigrants with disabilities, and to explore differences in their access to, and use of, supports. Using the PALS data set, the chapter explores support service utilization in relation to age, gender, income status, education, and severity. Chapter five draws on the results of 10 key informants with knowledge of culture, religion and disability in Middle Eastern and South Asian communities. Six key informants were non-disabled religious leaders or active members in their mosque. The remaining key informants had a physical disability and were well known in their communities for their activism and knowledge of disability services for immigrants. The chapter explores how culture and religion in the Middle East and South Asia influences the experiences and understandings of disability, the services that are available to immigrants with disabilities from these regions, as well as revealing the lack of current service organization in relation to providing services for immigrants with disabilities. Chapter 6 draws on interview data from eight immigrants from the Middle East and South Asia who all had a physical disability and lived in the GTHA. This chapter focuses on their experiences before, during, and after migration to Canada in relation to topics such as the built environment, employment, medical

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[3] Chapter 4 is an edited version of a paper submitted to the Canadian Journal of Disability Studies, which was published in November 2018. Hansen. S, Newbold, K. B., Wilton, R. (2018). Disability and the Use of Support by Immigrants and Canadian Born Population in Canada. *Canadian Journal of Disability Studies*, 7(3), 31-51.

inadmissibility, culture and disability, and services. Using feminist disability theory and an intersectional framework, the chapter explores the concept of being a “misfit” and how the fluidity of certain categories, for example immigrant status and disability status, changes the lived experiences of disability depending on time and place.

Chapter seven provides a discussion of the significant findings from chapter four, five, and six by drawing on the various results to show a more complete perspective of the lived experiences of immigrants with disabilities in Canada. Further, chapter seven discusses the contributions of the research as well as future avenues for research needed to expand on our knowledge of immigrants with disabilities living in Canada.

Chapter Two

Literature Review

2.1 Introduction

This chapter reviews the literature that informs the research undertaken and considers how this research will contribute to our understandings of the lived experiences of immigrants with disabilities and the unique challenges that they face. The chapter is organized in three main sections; the first section introduces literature on immigrant health and immigrants' access to health services in Canada. While this section does not pertain specifically to disability it acts as an introduction to immigrant health and unique challenges that immigrants often face when accessing healthcare. The second section explores literatures on disability, focusing on definitions, the impact of disability on a global scale, and the relationship between disability and space to further understand how space and the built environment can influence every day experiences of persons with disabilities. The third section examines disability in relation to culture, religion, and immigration by examining literature that explores both global perceptions and understandings of disability as well as the prevalence and understandings of disability in the Middle East and South Asia Religion. Culture and global understandings are reviewed to allow for an exploration of how these cultural and religious ideas of disability can influence the lives of persons with disabilities in the Middle East and South Asia as well as for immigrants with disabilities from these regions living in Canada.

2.2 Immigrant health

Until the middle of the 20th century, the immigrant health literature, and broader public opinion, was influenced by the 'sick immigrant' paradigm. This paradigm promoted the idea that the public should be protected from sick immigrants, with the view influenced by the fact that immigrants from Europe had been responsible for bringing diseases such as smallpox, cholera and measles to North America in the 16th and 17th centuries (Beiser, 2005). While the sick immigrant paradigm is not prevalent in the current literature it still informs Canadian immigration policies, which state that: “a foreign national is inadmissible on health grounds if their health condition is likely to be a danger to public health” (Immigration and Refugee Protection Act, 2001/2015). The Immigration and Refugee Protection Act also states that a foreign national who “might reasonably be expected to cause excessive demand on health or social services” can be denied permanent residency in Canada. Healthy immigrants are therefore more likely to immigrate to Canada as a direct result of the medical screening processes creating what is known as the *healthy immigrant effect*. The healthy immigrant effect captures the fact that immigrants are healthier than the Canadian born population upon arrival in Canada. This is illustrated by their lower likelihood of reporting chronic conditions or disabilities compared to the Canadian born population. However, this health advantage is eventually lost over time depending on length of stay in Canada (Chen, Wilkins, & Ng, 1996; De Maio, 2010; De Maio & Kemp, 2010; Newbold, 2005). Overall, healthy immigrants are more likely to migrate because they are better able to complete the journey (De Maio & Kemp, 2010; Vang, Sigouin, Flenon, & Gagnon, 2015). While immigration policies have made it less likely for ‘unhealthy’ individuals or those with significant disabilities to enter Canada (El-Lahib, 2015; Hanes, 2009; Wilton et al., 2017), medical screenings pertaining to “excessive demand on health and social services” do not pertain to individuals who apply under the family class, or as refugee or protected persons (Immigration and Refugee Protection Act, 2001/2015). Although immigrants are healthier upon arrival in

Canada, they face several barriers to accessing health care in Canada. These are explored in the next section.

2.2.1 Health services and culture

Immigrants face significant barriers to accessing health and social services in Canada. Common barriers include, but are not limited to, language, transportation, cost, knowledge of services, stigma, and lack of access to a family doctor (Asanin & Wilson, 2008; McKeary & Newbold, 2010; McKenzie, Hansson, Tuck, & Lurie, 2009; Newbold, Cho, & McKeary, 2013; Wang & Kwak, 2015). Language has been identified as one of the most significant barriers to accessing care as a result of the fact that the majority of immigrants arriving in Canada are from non-English speaking countries, resulting in them accessing care in Canada with a limited language capability (Newbold et al., 2013). Lack of interpretation services has also been identified as creating a persistent barrier for immigrants when accessing primary health care, oral health, and mental health services. Interpretation services have to be booked in advance and are often costly, making it difficult for many immigrants to access services in their own language (Newbold et al., 2013). Service providers, for example rehabilitation professionals and occupational therapists, report that they are unable to meet the needs of immigrants because they have not received training in culturally appropriate care and lack the language abilities to communicate with patients (Lindsay, Desmarais, et al., 2014). Canadian service providers have acknowledged that conventional social policies have failed to support the needs of immigrants, and due to these barriers, immigrants often find themselves relying on friends and family to help them access services. (Simich, Beiser, Stewart, & Mwakarimba, 2005).

Not all immigrants who land in Canada share the Western views of medicine which inform the Canadian health care system (Gushulak, Pottie, Roberts, Torres, & DesMeules, 2011). These immigrants often have culturally specific health beliefs that influence their approach to care and how they understand and explain symptoms. Chinese medicine is an example of this, with the prioritization of 'Chi' (Qi), the idea that vital energy flows through the whole body to maintain good health, and the concept of hot and cold (Ying/Yang) feelings within the body as part of understanding one's health and treatment (Wang, Rosenberg, & Lo, 2008). Some immigrants find that Canada relies on testing rather than treatment, which keeps them from accessing health care because they do not understand this approach (Wang & Kwak, 2015). Others rely heavily on their faith, citing worship, prayer, medication, and spiritual readings as an important part of their treatment and wellbeing (Chaze, Thomson, George, & Guruge, 2015). Traditional medicine and knowledge from home countries also influence how immigrants access care and seek treatment once they are in Canada, with many using traditional medicine in concert with 'Western' treatment or using herbs and prescription drugs from their home country to assist with treatment in Canada (Barimah & Van Teijlingen, 2008; Lightfoot, Blevins, Lum, & Dube, 2016; Wang et al., 2008). From a preventative health care point of view, stigma and misconceptions have been found to influence some immigrants' likelihood of accessing preventative screenings for conditions such as cervical and breast cancer in North America (Echeverria & Carrasquillo, 2006; Johnson, Mues, Mayne, & Kiblawi, 2008; Lofters et al., 2017). For example, research shows that Asian communities' misconceptions around cervical cancer exist in that it only affects Americans, married women, and was a product of karma, which led to lower participation in preventative screening (Johnson et al., 2008). Similarly, a Toronto study found that immigrants from Muslim majority countries were significantly more likely to be overdue for a pap smear compared to immigrants from non-Muslim majority countries, regardless of region (Lofters et al., 2017).

Moving from a focus on overall immigrant health, the next section centers on disability with a focus on definitions as well as the social and medical models of disability.

2.3.1 Disability

There is not one universal definition of disability nor is there one word used to describe it. Words like impairment and handicap are often used to describe disability, depending on culture and the prevailing model of disability. The World Health Organization (WHO) defines disability as an “umbrella term” that includes impairments, activity limitation, and participation restrictions (World Health Organization, n.d.). While the WHO definition of disability states; “any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being” it also distinguishes between impairment and disability and argues that disability is a complex issue that reflects the interaction between the features of the person’s body and the society in which he or she lives (World Health Organization, 2001). The WHO definition is widely used and has been the foundation for post-census surveys such as the Canadian Participation and Activity Limitation Survey (PALS) and the Canadian Survey on Disability.

While widely used, the WHO definition is not without its critics and problems. For example, while it recognizes that “disability is… not just a health problem”, its definition remain overly reliant on the medical model of disability in which disability is ultimately sourced in the problems and limitations of the individual's body (Oliver, 2009). Further, in its positivistic approach the medical model regards the disability as a condition that needs to be 'fixed' with the disabled person regarded as deficient in relation to a non-disabled norm (Gilson & Depoy, 2000; Shakespeare, 2006).

Other more critical conceptions of disability exist. In particular, the social model that emerged in the 1970s from the work/ideas of the Union of the Physically Impaired Against Segregation (UPIAS) in the United Kingdom, with Michael Oliver later coining the term "social model" in the 1980s (Oliver, 2009). The social model adopts a more contextual approach to disability, arguing that it is constructed through society's material organization. The social model makes a clear distinction between impairment and disability, arguing that impairment is "lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments" (Oliver, 2009, p. 22). Disablement therefore actively excludes people with impairments from fully participating in society and thereby subjects them to social oppression (Oliver, 2009). The social model has itself faced many criticisms, particularly because of its neglect of individual embodied experiences of impairment and its inability to distinguish the impacts of the impairment from the impacts of social barriers (Shakespeare, 2006). While these criticisms are valid, the purpose of the social model was never to be a theory or an all-encompassing framework for everything that happens to people with disabilities, but instead to serve as a theoretical and political tool to demonstrate that disability is not only located within the self but within the larger society (Oliver, 2013). The next section explores how geography has engaged and contributed to the study of disability.

2.3.2 Geographies of disability and the built environment

Disability studies has its roots in the emergence of the political activism of the 1960s and 1970s, which saw the organization of movements such as anti-war, environment, and the feminist movement (Johnston & Sidaway, 2004). Such movements influenced people with disabilities in demanding that their human rights were recognized, which inspired the formation of several disability rights movements and organizations such as the Independent Living Movement in the United States and UPIAS in the United Kingdom (Imrie & Edwards, 2007; Park, Radford, & Vickers, 1998). Disability geography has its roots in the 1980s but gained momentum in the 1990s when Reginald Golledge (1992, 1993) introduced pioneering work on disability in human geography with his introduction of disability as a socio-spatial issue (Gleeson, 1996; Imrie & Edwards, 2007). Golledge's work was, however, heavily criticized by geographers engaging with the social model; these scholars argued that his reliance on the medical model meant that he was more concerned with technological ways to 'fix' disability, rather than examining disability in a socio-spatial context of oppression (Gleeson, 1996; Imrie & Edwards, 2007; Park et al., 1998), it also thrust disability into the broader geographical discussion. The second "wave" of geography of disability was introduced by Brendan Gleeson in the early 1990s, with a shift from Golledge's positivistic approach to a social model perspective on disability (Chouinard, Hall, & Wilton, 2010). Using a historical materialist perspective, Gleeson focused on the importance of space in the creation of disability. He examined how industrialization had resulted in the "creation" of disability by separating work and home (Gleeson, 1999; Park et al., 1998). Whereas in feudal societies, prior to industrialization, it is assumed by Gleeson (1999) that people with impairments/disabilities were able to contribute to their families and the society by working in their home and at their own pace, however, this form of contribution was later lost with the industrial city and the emergence of a capitalist society. Industrial cities created a shift that resulted in people migrating from the country side to cities for work. This move from rural to urban, resulted in people with impairments no longer being able to contribute because they were unable perform and live up to the expectations of work in factories (Gleeson, 1999). Factory work saw the rise of mechanized forms of production, which included productivity standards and ideas around the “normal” worker (male and non-impaired).The standards around speed, discipline, and time-keeping in factory work therefore ended up disqualified most individuals with impairments (Gleeson, 1999). Gleeson’s work was one of the catalysts for the development of critical geographies of disabilities, which began to explore how social relations and the organization of social space have contributed to the disablement of those experiencing impairments and illness (Chouinard, 2009; Parr & Butler, 1999). Later contributions to geographies of disability have focused on mind and body spaces, embodiment, and identity. This newer research focus has encouraged a move away from the social model of disability to a focus on the embodied experiences of people with disabilities (Parr & Butler, 1999). Spatial interpretations of disability have also expanded to include other bodies that are different from the societal “norm” including obese people, older people, people with intellectual impairments, and chronic illnesses (Chouinard et al., 2010).

An important focus of the geography of disability has been the ways in which the built environment can hinder people with disabilities' mobility and restrict their access to places (Golledge, 1993; Imrie & Kumar, 1998). Inaccessible built environments remain common and are often encountered by people with disabilities in everyday life in places such as inaccessible homes, sidewalks, public transit, and lack of access to buildings. The built environment has been argued to be an oppressive space for people with disabilities often coming across as hostile, as seen when buildings, streets, and places are impossible to access, and exclusive when inaccessible (Imrie, 1999). Inaccessible built environments embody and reproduce the dominant values of an able bodied society that is designed for the "normal body" (Imrie, 1999; Imrie & Edwards, 2007).

A later development in geography, which moved beyond the social model, came from Valentine (2007) who encouraged feminist and critical geographers to explore intersectionality. Further, she argued that it is important that geography moves beyond the theorization of intersectionality and explores the experiences of intersectionality by understanding how categories, such as disability, race, gender, and immigrant statues, exist and are experienced in specific spatial and temporal moments in everyday life. Valentine (2007) also argues that spaces are power-laden and that the ability to enact certain identities and realities depends on the dominant groups that organize these spaces.

Connecting immigrants and disability, the next section explores the current literature that exists on immigrants with physical disabilities in Canada to help identify the current gaps in the literature.

2.3.4 Disability and immigrants in Canada

An estimated 13.7% of the Canadian population are identified as having a disability and the prevalence of disability rises with age, with 10.1% of working age Canadians (15-64) reporting a disability compared to 33.2% of those aged 65 and older (Statistics Canada, 2013a). Newly arrived immigrants (those who have been in Canada 10 years or less) are significantly less likely to report having a disability as compared to longer-term residents (Newbold & Simone, 2015). That recent immigrants are less likely to report a disability is not surprising considering the immigration policies that Canada has in place around medical screenings before entry and rejecting applicants who are considered to place an excessive demand on the Canadian health and social service system (El-Lahib, 2015; Hanes, 2009; Wilton et al., 2017). With age, however, the differences in rates of disability disappear, with research suggesting that immigrant women have some of the highest age-specific disability rates and that immigrant males report some of the lowest age-specific disability rates, particularly for mobility, agility, and vision disabilities (Newbold & Simone, 2015).

Beyond prevalence and difficulties immigrating with a disability, there is limited literature on the experience of immigrants with a disability living in Canada. The majority of literature produced about immigrants and disability has been from a rehabilitation/social work perspective and focuses on the perspective of immigrant mothers with a disabled child. For example, one study of South Asian mothers with disabled children living in Canada found that mothers had multiple perceptions of disability influenced by “traditional” beliefs about disability such as it being an act of God, and more “Western beliefs” around medical treatments. Further, the study found that while the women faced less stigma in Canada than in their home country, they still faced a great deal of stigma from their cultural communities, for example being blamed for their child's condition or facing discrimination because they had kept the child against advice (Daudji et al., 2011). From a service provider perspective, research has shown that social workers and occupational therapists acknowledge that there is a growing need for culturally sensitive care when dealing with immigrants with disabilities. However, providers also recognize that there is substantial lack of knowledge and training on the topic, making it more difficult to address issues such as the language barrier, different cultural views of disability, gender power dynamics, and the importance of building rapport (Lindsay, Desmarais, et al., 2014; Lindsay et al., 2012; Lindsay, Tétrault, Desmaris, King, & Piérart, 2014). Immigrants are often not aware of what services and financial help is available to them, resulting in medical professionals having to help them advocate for service and financial help (Lindsay et al., 2012; Lindsay, Tétrault, et al., 2014).

Hansen et al. (2017) explored the experiences of adult immigrant women with visual impairments living in Canada and found that these women used a mix of biomedical, cultural and religious interpretations to understand their visual impairments. These views were influenced by their experiences in their country of origin and by more recent experiences in Canada. Some of the women concealed their impairment to avoid stigma from their cultural community. Stigma was found to shape their social geographies, for example not being able to attend their cultural community center due to negative attitudes or not being able to have company during the day when it was bright out and the disability could not be concealed/hidden (Hansen et al., 2017). In addition, many of the women found it difficult to access employment due to employers' perceptions of their impairments and abilities, hindering both their economic well-being and social participation (Hansen et al., 2017). Similarly, Dossa's (2009) work explored the difficulty of being a racialized disabled female immigrant in Canada and how the intersection of these different categories exposes women to multiple forms of oppression at once. Participants found that because of their disability they were labeled as undeserving immigrants because of their lack of participation in the workforce despite trying to gain access to employment (p.126). Dossa (2009) also argues that racialized disabled women often are viewed and treated as lesser beings and are subjected to racism in everyday life because of this status.

Given the focus of this thesis on disability and immigration, the following section moves from a Canadian perspective on health and disability to a more global focus on disability, with particular attention to experiences of disability in the developing world, to understand how different global understandings of disability can influence the lives of people with disabilities.

2.4. Disability, culture, and religion in the Developing World

While knowledge of adult immigrants living in Canada with a physical disability is limited, several studies outside Canada have focused on disability in other countries and cultures. The purpose of the following section is to explore these understandings and experiences of disability. The section will begin by examining the current knowledge of disability on a global scale from both a cultural, religious, and immigration perspective. The second part of this section brings attention to disability in the two regions that are the focus of this thesis; the Middle East and South Asia.

2.4.1 Access to services

Disability research has been criticized for primarily focusing on the global north despite the fact that 80% of the world's disabled people live in developing countries (Chouinard, 2014). The limited research that is available on the lived experiences of persons with disabilities in developing countries paints a dramatically different picture compared to that of the global north. For example, people with physical disabilities in developing countries have extremely limited access to mobility aids to assist them in everyday life and governments provide little to no social assistance. Countries often rely on non-governmental organizations (NGOs) and foreign aid agencies to provide aid and support for people with disabilities (Bayat, 2014; Chouinard, 2014). Relying on foreign aid and NGOs is problematic given that these organizations are often understaffed and often do not stay for longer periods of time in the same place (Bayat, 2014). NGOs are also problematic in the sense that organizations do not always have the ability to follow the individual who receives aid, so when the assistive device breaks they are left without a way to fix it (Chouinard, 2014). Similar to the global north, people with disabilities in developing countries find themselves living in poverty with very little chance of moving out of it, characterized by periodic employment (at best), discrimination, and lower pay (Chouinard, 2014). Disabled individuals living in rural areas where communities rely on farming find themselves disadvantaged of they are not able to help in the field due to their impairments. In such contexts, they can be positioned as a burden to their families, and as an extra mouth to feed (Don, Salami, & Ghajarieh, 2015).

2.4.2 Global understandings of disability

It is important to acknowledge that the word 'disability' is a Western social concept when examining people's experiences in other countries and cultures (Oliver & Barnes, 2012).

‘Disability’ when used in the West, especially the United Kingdom and the United States, is often linked to civil rights and independent living movements (Imrie & Edwards, 2007; Thomas, 2014). However, “disability” is not a globally agreed upon word or concept. In fact, not all cultures have a word for disability and Western meanings of disabilities do not necessarily fit the experience of people in other countries (Devlieger, 1995; Thomas, 2014). Thomas (2014) found that in Cape Verde, disability was found to be associated with a permanent state of ‘being with no hope’ as opposed to a Western notion of independence and civil rights. For the Songye of Zaire, words such as ‘faulty’ (kilema) and ‘bad’ (malwa) are used to describe children with disabilities, where bad children are considered inferior to other members of society and supernatural and are given only basic care as they are expected to die (Devlieger, 1995).

When people with different views and perceptions of disability immigrate to other countries, they may bring these views with them. Research from the United Kingdom (UK) found that Pakistani and Bangladeshi parents of disabled children living in the UK used both biomedical and traditional/theological explanations in their understanding of disability (Bywaters, Ali, Fazil, Wallace, & Singh, 2003; Croot, Grant, Cooper, & Mathers, 2008). Parents were more likely to use theological explanations of disability when they did not have a clear understanding of the medical diagnosis of the impairment. However, when parents were faced with shame, stigma, and negative attitudes from their cultural community, they drew on biomedical explanations of disability as a way to defend their child’s condition (Bywaters et al., 2003). In Belgium, Albrecht et al. (2009) explored the lives of disabled Iranian immigrants. Participants expressed feeling more free in Belgian society as it was not dominated by religion, which had negatively impacted their basic human rights in Iran (Albrecht et al., 2009). Despite feelings of freedom, participants were highly marginalized in Belgian society, where they experienced social isolation, prejudice, and discrimination as a result of their immigrant and disability status. While many participants had been employed in Iran, they found it difficult to gain employment in Belgium and faced a 'double-disadvantage' in Belgian society as they were both disabled and an immigrant (Albrecht et al., 2009).

2.4.3 Disability and Religion

The next section focuses on disability in South Asia and the Middle East and includes introductions to disability in Hinduism and Islam. It is important to note that the discussion of disability in relation to religion is not limited to these two religions. Religions such as Christianity and Judaism also have a complex relationship with disability. Treatment of people with disabilities has long been problematic, for example, in ancient Greece, both Plato and Aristotle encouraged infanticide of children with a disability (Belser, 2011; Gracer, 2003). In Christianity, sickness and disability are linked to sin and the first step in the healing process is to recognize one's own guilt (Mackelprang & Salsgiver, 1996; Schumm & Stoltzfus, 2007). For example, in relation to healing, Jesus healed a paralytic and told him "See, you are well! Sin no more, that nothing worse befall you" (Schumm & Stoltzfus, 2007). Churches are often viewed as a haven for everyone; however, people with disabilities have often not been welcomed in churches due to the negative views of disability in Judeo-Christian theology (Rose, 1997).

In Judaism, the Hebrew Bible commands that one should not insult the deaf or place a stumbling block in front of the blind but instead show compassion for and bless people with disabilities instead of killing them as Plato and Aristotle encouraged (Belser, 2011; Gracer, 2003). However, disability is viewed more problematically when it comes to the idealized body of priesthood. Because priests represent holiness it is important that there are no physical distractions from his form and it goes on to say that a priest who has a defect will not be qualified to offer God's gift (Belser, 2011). In Judaism, individuals who are born with a disability are considered to be a creature of God, however, if a person becomes disabled later in life it is seen as a judgement from God (Gracer, 2003).

2.4.4 Disability in South Asia and Middle East

We know that poverty and disability are connected and that the majority of people with a disability live in the developing world. However, exact prevalence rates are difficult to come by and South Asia and the Middle East are no exception. Not all countries in South Asia and the Middle East administer a census or survey to count disability and those who do often have very different outcomes. One of the problems with measuring the prevalence of disability in South Asia and the Middle East and comparing prevalence rates with countries in the West is that the definitions of disability vary greatly depending on the country in question. For example, the definition used in the Canadian Disability Survey (CDS) from 2012 produced by Statistics Canada is based on the WHO International Classification of Functioning and includes ideas from the social model where *disability as the relationship between body function and structure, daily activities, and social participation, while recognizing the role of environmental factors* (Arim, 2017; World Health Organization, 2001). The CDS estimates that 14% of the Canadian population aged 15 and older has a disability.

On the other hand, Nepal has defined disability as purely relating to function where *people who are mentally or physically unable or incompetent to lead a normal life*

(Mol, Van Brakel, & Schreurs, 2014). Given the more narrow definition of disability, the Central Bureau for Statistics in Nepal estimates that only 1.94% of the population in Nepal have a disability, which according to the WHO is a gross underestimation based on lack of evidence (Lamichhane, 2015; Mol et al., 2014). The same evidence is found in Pakistan where the 1998 census identified 2.5% of the population as having a disability. Much like Nepal, Pakistan relies on a medical and rigid definition of disability, with severe underreporting due to cultural stigma surrounding disability (Singal, Bhatti, & Malik, 2011). By contrast Singal et al. (2011) study on prevalence rates found that one in five Pakistanis have a disability. Similar findings have been observed in India where the 2011 Census of India identified roughly 1.8% (22 million) of the population as having a disability. However, unofficial estimates suggest that 6% (~70 million) of the population are diagnosed with a disability (Anees, 2014). The discrepancy in numbers is linked to India not having adopted the WHO definition of disability but instead, as seen with Nepal and Pakistan, relying on a narrower and more medical definition (Anees, 2014).

While some data on the prevalence of disability exist in South Asia, disability prevalence rates in the Middle East are even more difficult to find. One example is Lebanon, which has not had a census since 1932 (Zeki Al Hazzouri, Mehio Sibai, Chaaya, Mahfoud, & Yount, 2011). Many countries in the Middle East have been impacted by war and conflict, which has contributed to higher rates of disability. Much like South Asia, the definition of disability greatly impacts prevalence rates but also measurement of disability prevalence is a factor. For example, in Jordan, disability is measured by asking “do you have a disability? Yes/No?”, which is drastically different from the United States and Canada where an activity based measurement is used (Mont, 2007). In Iraq, the WHO estimates that 2 million people have a disability, which is roughly 5% of the population, whereas the Iraqi Ministry of Health estimates that there are only one million people living in Iraq with a disability (Rutherford & Hinton, 2015; UNAMI & OHCHR, 2016). Similarly to many other South Asian and Middle Eastern countries, there is a lack of unified definition of disability in Iraq and no reliable statistics to estimate prevalence (UNAMI & OHCHR, 2016). A study from Saudi Arabia found differences in estimations of prevalence based on who conducted the research; it was estimated by the authors that 3.73% of the population had a functional disability, however, a countrywide survey estimated that just 0.8% of the population had a disability (Al-Jadid, 2013). In Iran, the 2011 census found that the prevalence of disability was 0.13% for all disabilities and 0.8% for physical disabilities. Prevalence of disability was found to be higher among men (Soltani, Khosravi, & Salehiniya, 2015), which is different from what is seen in Canada where men report lower rates of disability than women. Similarly, prevalence estimates from Lebanon estimate that men (1.8%) have higher prevalence of disability than women (1.1%). This significant underreporting likely reflects, in part, the stigma that is associated with disability in South Asia and the Middle East.

2.4.4.1 Culture, karma and disability in South Asia

Religion has significantly impacted the experiences and perceptions of disability in South Asia, where the three main religions are Hinduism, Islam, and Buddhism (Central Intelligence Agency, 2016). A large number of Muslims live in South Asia, however, for the purpose of organization, this section covers only Hinduism and Buddhism and the section on Islam and disability has been added to the Middle East part of this chapter.

In countries like India, Nepal, and Sri Lanka; views of disability have been strongly influenced by the notions of Karma and Dharma. Karma is the idea that one's actions bring about the consequences one earns, whether good or bad, whereas Dharma refers to one's religious duties and righteousness towards family, society, and the world (Anees, 2014; Das, 2010; Lamichhane, 2013). In relation to Karma, disability is often viewed as punishment for prior misdeeds of parents with a disabled child or a punishment for behaviour in a previous life by the disabled person because there is a strong belief in reincarnation (Anees, 2014; Lamichhane, 2013). The law of Karma works independently from God's will and is believed to determine one's appearance, bodily stature, health, and the surroundings of one's birth and life (Das, 2010). The belief in Karma is so strong that it transcends the rural-urban divide and all social classes (Anees, 2014; Lamichhane, 2013). As a result of Karma, disability has been heavily stigmatized in South Asia and is broadly associated with bad luck and a belief that persons with disabilities are ominous and therefore their presence should be avoided (Anees, 2014).

These negative and exclusionary social constructs of disability have a lasting impact on the lives of people with disabilities in South Asia, where disability is more likely to be treated as a charity issue, in relation to Dharma, than a human rights issue. The social model that we know from the West exists only on paper and despite being the most marginalized group in India, people with disabilities are not seen as a distinct group but are instead included in a broader category of destitutes, widows, the diseased and the aged (Das, 2010). The lack of human rights has impacted access to education where people with disabilities in South Asia are less likely to have an education as they face many barriers to accessing education such as physical barriers in the built environment, lack of access to special schools and education as well as stigma (Hammad & Singal, 2015; Lamichhane, 2013; Singal et al., 2011).

Women with disabilities, in this region, are more vulnerable than men. The patriarchal nature of most South Asian societies has resulted in disabled females being extremely vulnerable to neglect and interpersonal violence as they are the least powerful in the familial hierarchy. Research has shown that females with a disability are less likely to be fed if the food supply is scarce as they are considered the least valuable to the family and infanticide is higher in female infants with disabilities than male infants with disabilities (Das, 2010). Females with disabilities are often kept out of sight and excluded from community participation due to the taboo and stigma that surrounds disability, which then results in feelings of isolation, depression, and low self-esteem. Females with disabilities have historically been portrayed as less than men, where scriptures have shown that men with disabilities can still hold power, influence, and wealth. On the other hand, women are portrayed as ugly, manipulative, evil, and spiritually deficient (Anees, 2014).

Marriage is extremely important in South Asian societies as it is seen as an important marker of adulthood. However, females with a disability are less likely to marry as they are often not considered "able enough" to fulfill the requirements of the traditional woman (Das, 2010; Singal et al., 2011). Many South Asian societies have arranged marriage systems where women are often judged on their appearance. Women are considered to exist to support the male and the disabled female is not considered able to perform the task of a wife, which includes giving birth to children, taking care of children, the household and the husband (Anees, 2014). Research found that in India, men with disabilities are more likely to get married (40% do not get married) than women with disabilities (60% of whom do not get married) (Das, 2010). Similarly, a Canadian study (Savage & McConnell, 2016) found that women with a disability living in Canada were significantly less likely to be married compared to women who had no disability.

2.4.5.1 Culture, Islam and disability in the Middle East

Like South Asia, religion plays an important part in everyday life in the Middle East, where the main religion for the majority of countries is Islam. The Qur'an is the central religious text of Islam and is considered to be God's direct and personal address to mankind delivered by his last prophet, Muhammed (Bazna & Hatab, 2005). Muslims are commanded by the Qur'an and must follow the five pillars of Islam 1) Shahada; there is only one God, 2) Salat; prayers, 3) Sawm; fasting during Ramadan, 4) Zakat; annual 2.5% tax, and 5) Hajj; the pilgrimage to Mecca during their lifetime (Al-Aoufi, Al-Zyoud, & Shahminan, 2012; Hasnain, Shaikh, & Shanawani, 2008). Muslims are expected to follow these pillars of faith but only to the extent that they are able. For example a person who is living in poverty is not expected to pay Zakat (Hasnain et al., 2008).

The word disability, as it is known in the West, does not exist in the Qur'an. However, there are mentions of people with what would be considered as disabilities. In the Qur'an, disability is considered a morally neutral term, meaning that it is neither a punishment nor a blessing but simply a part of the human condition (Bazna & Hatab, 2005; Hasnain et al., 2008). A human's worth is not related to their physical or material attributes but rather to their heart and spiritual development (Hasnain et al., 2008). The Qur'an calls for the removal of barriers or stigma so that people with disabilities can have full inclusion, while emphasizing the rights of people with disabilities and society's duty to care (Al-Aoufi et al., 2012; Bazna & Hatab, 2005). The Qur'an focuses on the 'disadvantaged', which is a broad category of people determined to lack the necessary social, economic, or physical attributes that people value. The Qur'an places the responsibility of correcting this inequality on the shoulders of the larger community (Bazna & Hatab, 2005; Hasnain et al., 2008). People with disabilities are often considered to be part of the disadvantaged and are therefore considered to be rightful recipients of Zakat and charity as a way to rectify their 'disadvantage' (Al-Aoufi et al., 2012). Receiving Zakat and meeting other needs of disabled people is not always done out of pity but also as a way of seeking goodwill from God (Al-Aoufi et al., 2012). Much like Hinduism, Islam believes in the concept of reward and punishment which means that each individual is responsible for his or her actions, behaviour, intentions, and motives. The belief is that violating Allah's law will bring punishment either in this life or later on in the Day of Judgement (Al-Aoufi et al., 2012).

However, while disability is considered neither a punishment or a blessing in Islam, the belief in 'Qadar' - preordination; the idea that "what is meant to be will be, and what is not meant to happen can never occur", results in people thinking that disability is an act of God and therefore a punishment from Allah (Al-Aoufi et al., 2012). Similarly, South Asian parents of disabled children have expressed beliefs that their disabled child is a punishment and sometimes even see it as a family curse. Because of these religious beliefs, some parents may refuse medical treatment for their child with a disability because they believe that the disability is a punishment from Allah and that they deserve this punishment (Al-Aoufi et al., 2012). Research has shown that people who believed deeply in destiny and qadar were less likely to comply with instructions around care or to be satisfied with medical care that was received (Hasnain et al., 2008). Having a disabled child often brings shame and blame to families and especially to the mother. Stigma and negative attitudes towards people with disabilities have resulted in their isolation from society, especially for women with disabilities (Al-Aoufi et al., 2012; Al-Jadid, 2013; Turmusani, 2001). People with disabilities are therefore kept from participating in social activities and some parents keep their children from attending mosques to avoid feelings of embarrassment, stigma, and to protect themselves (Al-Aoufi et al., 2012; Wehbi & Lakkis, 2010).

Marriage is also an important part of growing up in the Middle East, however, people with disabilities are less likely to get married and to find companionships, or long term relationships (Hasnain et al., 2008; Turmusani, 2001). Women in Middle Eastern societies are less likely to get married compared to males with disabilities. Not getting married is especially hard for women in the Middle East as the life of an unmarried woman is often considered not worth living, this being a result of both patriarchal culture and Islamic traditions. Women with disabilities were also found to be two times more likely to experience divorce/separation and are the victims of more violence against them than able-bodied women. (Turmusani, 2001). Islam states that men are superior to women and that women are created for the man, including being less spiritual, these perceptions and attitudes towards women influences the gendered inequalities and oppression that women experience in the Middle East (Turmusani, 2001).

Overall, as is seen with respect to other religions such as Christianity, the line between culture and religion has been blurred when it comes to disability. Islam has certain beliefs and principles that it expects its followers to abide by, however, these beliefs and principles are up for interpretation and Islam is often shaped by the cultural influences of the society that the Muslim population inhabits whether that be in the Middle East or Western countries, for example the United States (Hasnain et al., 2008).

2.5 Conclusion

The preceding review of the current literature confirms the need for additional research into the lived experiences of immigrants with disabilities in Canada and how these experiences impact utilization of services and social and economic participation in Canadian society. While the literature shows that there has been some exploration of immigrants with disabilities in Canada, it is clear that we know very little about the lived experiences of immigrants with disabilities in Canada and even less about immigrants with disabilities from the Middle East and South Asia. Furthermore, the literature explores immigrant health, employment, and disability but there has been little research done on how immigrant status and disability might intersect to create unique experiences for immigrants with disabilities. The research in this study will build on this existing literature by exploring this intersection, while also investigating informal services, and utilization of services by immigrants with disabilities to give a more complete picture of the lives of adult immigrants with disabilities in Canada. By narrowing the study region to the Middle East and South Asia, the research allows for an exploration of how culture, religion, and political climate influence every day lived experiences of employment, accessibility, and social relationships. The following chapter focuses on the methodology used in this study for each of the three stages.

Chapter Three
Research Methods & Techniques

3.1 Introduction

A review of the current literature has shown that there is limited knowledge of the experiences of adult immigrants living with disabilities in Canada. This study employed a mixed methods approach where quantitative methods in the form of descriptive and multivariate analysis were used to examine need for, and access to, support services by Canadian born and immigrant populations living with a disability. The main purpose of the quantitative analysis was to gain an overall understanding of the use of support services by Canadian born and immigrant adults with disabilities, and to explore any difference between the two. The analysis also further explored gender differences within and between the two groups. By necessity, the quantitative analysis included all immigrants regardless of country of origin.

As Chapter 4 will show, quantitative methods are able to provide us with an overall idea of prevalence of disability and service utilization but they convey little about the perceptions and lived experiences of people with disabilities. Qualitative methods were therefore used to further explore perceptions and understandings of disability, access to services, and lived experiences in greater depth within Middle Eastern and South Asian communities. To accomplish this, two separate qualitative phases were carried out: 1) Interviews with key informants in these communities (religious leaders and ethnic service providers) and 2) in depth interviews with immigrants from the Middle East and South Asia living in the GTHA who have a physical disability.

3.2 Quantitative methods

The purpose of the quantitative analysis was to evaluate the type and level of support services used by adults living with disabilities in Canada, and whether immigrants and non-immigrants differ in their need for, and use of, support services. Three questions guided this stage of the project. First, is there a difference in the utilization of support services for adult immigrants with disabilities compared to the disabled Canadian born population? Second, do immigrants with disabilities express a higher need for support services than the Canadian born population? Third, what is the importance of socio-demographic and socio-economic factors such as age, gender, immigrant status, education, severity of disability, and income on the use of and need for support services in the immigrant population living with a disability? It is important to address these questions to try and understand any differences that may exist in the service utilization and needs, as well as to examine the reasons for any possible variations.

The quantitative analysis used Statistics Canada's 2006 Participation and Activity Limitation Survey (PALS) dataset. The PALS adopts the World Health Organizations (World Health Organization, 2001, p. 20) definition of disability as "any restriction or lack of ability (resulting from an impairment) to perform an activity in the manner or within the range considered normal for a human being". The PALS is a post-census survey, and its population consists of person who answered "yes" to either of the 2006 Census questions on activity limitation ("Do you have any difficulty hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing any similar activities?" and "Does a physical condition or mental condition or health problem reduce the amount or the kind of activity you can do a) at home?; b) at work or at school?, or; c) in other activities, for example, transportation or leisure?"). The same filter questions were repeated during the PALS interview. Further questions within the PALS determined the type of disability (i.e. mobility, agility, hearing, speaking, and vision) and whether the disability was corrected (i.e. via hearing aids or glasses) or uncorrected. The PALS data includes individuals with physical disabilities, for example mobility, sensory, or hearing, as well as developmental, and mental disabilities.

While the WHO definition provides a benchmark for this research, it is important to note that the conceptual framing of disability within the PALS is problematic when read through a lens of critical disability theory. While the WHO definition recognizes that "disability is… not just a health problem"[4], the definition remains overly reliant on a medical model in which disability is ultimately sourced in the problems and limitations of the individual's body or mind (Oliver, 2009). Despite the problematic definition of disability used in the PALS, quantitative data of this nature are still useful in providing a window into disabled people's experiences.[5] Similarly, the PALS survey uses the word 'caregiver' to identify persons who provide support for disabled people. This term is used throughout the thesis to describe and interpret the data produced by Statistics Canada, but it should be acknowledged that 'care' is a problematic word to use when describing the supports required by people with disabilities (Shakespeare, 2000; Wood, 1991). Wood (1991) argues that disabled people have never asked or demanded care but instead advocate for independent living. From a critical perspective, the use of the terms 'care' and 'caregiver' risks implying that persons with disabilities are necessarily dependent on

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[4] See http://www.who.int/topics/disabilities/en/ [35]

[5] Goodley (Goodley, 2016) makes a similar argument with respect to the data contained in WHO's World Report on Disability when he states: "Like it or loathe it, the World Report has put disability on the geopolitical map"

others. Throughout this work, a modified social model is used to approach and interpret the insights that emerge from the PALS data. From this perspective, I focus attention on the ways in which the organization of society, and specifically the extent to which people have access to different forms of formal and informal support may hold implications for their ability to participate in economic and social activities (Oliver & Barnes, 2012).

The population covered by PALS includes individuals living in private and some collective households (i.e., senior citizen residences) across Canada, including the three northern territories. The sample includes approximately 39,000 adults aged 15 years and over, representing a weighted population of 2.4 million people in Canada with a disability. For this study, the sample was restricted to individuals aged 40 and over, capturing the ages at which rates of disabilities, and therefore need for support services, start to increase. Age was also restricted to 40+ due to low samples sizes in the lower age categories, which resulted in low cell counts that could not be released, meaning that the number did not fulfill the minimum number for Statistics Canada to release the information. Low cell numbers can lead to breach of confidentiality and are therefore not disclosed. All responses in the PALS are self-reported, and all respondents reported that they had difficulties with activities of daily living (ADL), such as preparing meals, everyday housework, heavy chores, and personal care. The PALS also includes variables from the 2006 Census, such as immigration status, socio-economic and sociodemographic information, which is linked at the individual level. As seen with disability, immigrant status is self-identified, and includes all individuals who are not Canadian citizens by birth (i.e., born outside Canada) and eligible to reside in Canada permanently. Regrettably the PALS file does not allow further distinction by immigrant status, particularly distinctions between immigrants and refugees where differences in disability and use of support services may be different given different needs. Throughout the analysis, weights developed by Statistics Canada for use in analyzing the PALS were incorporated. Reporting standards were congruent to the standards enforced by Statistics Canada.

The quantitative analysis employed both descriptive and multivariate analysis to examine the use of support services. The descriptive analysis was used to provide a picture of the sources of people's care and support, identified as family, friends and others. 'Family' includes immediate family such as spouse/partner, parents, children and siblings. 'Friends' include family members such as grandparents, in-laws, and friends. 'Other' includes paid employees, organizations, and government services. The multivariate logistic regression explores the covariates associated with the need for care, receipt of care, and type of care. The receipt of care/support services variable identifies if a person received care regardless of the type of care/support service. The 'need' for care was identified if the individual believed that they needed help in addition to the help that they already received. For type of care/support service, four different dependent variables were used to identify the type of care/support service that the person with a disability received: Meals, housework, errands, and personal care.

Independent variables were used in the models, these included a mix of sociodemographic and socioeconomic factors. Sociodemographic variables included age (10-year age cohorts, 40-49, 50-59, 60-69, 70-79 and 80+), gender, immigrant status (immigrant and non-immigrant), and severity of the disability.[6] Socioeconomic variables

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[6] Severity is classified as mild, moderate, severe, and very severe by statistics Canada and should be interpreted as "very severe" having a more severe disability compared to "severe", and "severe" having a more severe disability than "moderate" and so on (Statistics Canada, 2007).

included education (less than high school, high school, college and trade, bachelor or better) and income (<$19,999, $20,000-$49,999, $50,000-$79,999, $80,000-$99,999 and >$100,000). In addition to the direct effects, a number of interaction terms between immigrant status and selected effects were evaluated to gain a better understanding of the differences between immigrants and Canadian born individuals with disabilities in terms of service utilization.

3.3 Qualitative methods

Qualitative methods are used to further understand how the lived experiences and perception of immigrants with disabilities are shaped by subjective factors such as gender, religion, culture, and immigrant status. The qualitative work focuses on two specific world regions; the Middle East (including Sudan)[7] and South Asia. The choice to focus on these two regions was based on previous research by Daudji et al (2011) and Hansen et al. (2017) which indicated that these regions have different views about disability from those seen in the West and western medicine, and that these views are still prevalent within immigrant communities in Canada. As noted in Chapter 1, Ontario, and especially the GTHA is home to many immigrants, with the majority now arriving from regions such as the Middle East and South Asia (Statistics Canada, 2016). It is important to learn more about the meanings and experiences of disability within these immigrant communities to ensure that disabled people are understood and that appropriate services are provided.

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[7] Sudan was knowingly chosen to be included in the definition of the Middle East despite being located in North Africa as Sudanese people consider themselves more part of the Middle East due to culture and Islam being the majority religion of Sudan (Ahmad, 2011) .

Qualitative research methodology was adopted for this part of the research because of its ability to examine subjective experiences and situational meaning (Liamputtong, 2010). Qualitative methods are especially useful in situations where little is known about a subject, as seen in Canada with immigrants with disabilities from the Middle East and South Asia. While qualitative methods are often criticized for not having the same rigor and transferability as seen with quantitative research, they allow for participants to tell their ‘stories’ and capture their lived experiences from their own personal perspective (Corti & Thompson, 2006; Liamputtong, 2010). A related strength of qualitative research methods is their ability to gather the voices of the ‘silenced, othered, and marginalized in a dominant social order (Liamputtong, 2010). A more in-depth description of the different stages of the qualitative research is presented below, but first I outline the decision to utilize a cultural broker for the qualitative research. It is important to discuss the cultural broker first, to understand the role that he played in recruitment as well as the shaping of the research.

3.3.1 The cultural broker

The term cultural broker stems from anthropology where anthropologists observed that certain people in the community acted as middlemen between the colonial power and peasant societies (Jezewski, 1990; Jezewski, Sotnik, & Stone, 2005). Today, cultural brokering is defined as:

> The act of bridging, linking, or mediating between groups or persons of different cultural backgrounds for the purpose of reducing conflict and producing change (Jezewski, 1990; Jezewski et al., 2005, p. 37).

Cultural brokers are known to be problem solvers who negotiate, advocate, and or network between researchers and the community. Cultural brokers also function as interpreters who can translate behaviours and meanings of local people to help avoid social errors and foster a good relationship (Liamputtong, 2010). For this research, a cultural broker was used to negotiate/ mediate and network within the Middle Eastern community. The decision to utilize a cultural broker was made early on in the study to help facilitate recruitment for the qualitative part of the research. Specifically, I anticipated that as a Caucasian, presumably Christian, woman I would face challenges recruiting in a male dominated Arab culture. Some of these issues included language barriers, as well as an ability to get "in the door" to talk to people, and ask them to participate. The cultural broker for this project was a male PhD student who belongs to the Arab community, is Arab speaking, and familiar with the Muslim community, culture, and behaviours. All of these characteristics were essential in gaining access to the Mosques and participants. The cultural broker assisted me in both qualitative stages to facilitate initial contact with potential participants.

3.3.2 Religious Leaders and Ethnic Service Providers (Advocates)

The primary goal for the initial phase of the qualitative research was to gain a better understanding of the processes that immigrants with disabilities go through to find and gain access to services when arriving in Canada. Sample criteria for this stage were: knowledge of immigrants and refugees, knowledge of immigrants and refugees with physical disabilities, and knowledge of services. Initially, recruitment was going to focus on organizations that provide services to newcomers such as the YWCA, YMCA, COSTI immigrant services, Center for Independent Living Toronto (CILT), and the Immigrant Working Center. However, once the research started the cultural broker suggested that I should also interview Imams and leaders of mosques because of their extensive community involvement and knowledge of services in the community. Imams are particularly important because they are community leaders and are responsible for prayer, information sharing with members, and can provide spiritual guidance. Several organizations involved with providing services to immigrants and newcomers were contacted for interviews but declined to participate or did not respond. This increased the focus on religious leaders with their connections in the community.

Purposeful sampling was initially employed but changed throughout the research, when participants were able to put the researcher in contact with important members of the community that she would not otherwise have access to. That ultimately led the study to rely mainly on snowball sampling, where participants are asked to suggest additional people for interviewing (Babbie & Benaquisto, 2009). Imams/religious leaders were recruited through the cultural broker, who would enter the mosque and ask to speak to an Imam or leader of the mosque. He would then explain the research and if they agreed to participate, the researcher would be invited in to interview the participant. Imams provided contacts in the community, which allowed the researcher to further recruit participants using the snowball sampling method. The sample size for this stage of the study was ten, including five Imams/religious leaders, one doctor, and four ethnic disability service providers/activists. Only religious leaders from the Islamic faith were recruited. Despite attempts at contacting several temples in the GTHA about the study, no-one responded to the request.

Participants were asked to participate in a semi-structured interview. The interviews ranged anywhere from 15 minutes to 1.5 hours in length and focused on their position in the community, their knowledge of services, knowledge of immigrants with disabilities, and their knowledge of religion and disability. Interviews either took place at the participants' place of worship, work, or home. Participants chose the location where they wanted the interview to take place to ensure that they were comfortable. Prior to starting the interview, participants were presented with a letter of information and consent form (Appendix A) outlining their rights as participants including the right to withdrawal, anonymity/confidentiality, and their right to refuse to answer questions. All participants were asked questions using the same interview guide (Appendix B). The interviews were semi-structured to give participants the chance to share their views and what they perceived as important, in response to the questions. The interview guide was divided into four sections. First, the participants were asked to introduce themselves and their position in the community. Second, they were asked about their organization, and its role in the community. Third, the interview focused on the cultural meanings of disability. Fourth, the interview focused on access, knowledge, and provision of services for people with disabilities.

Interviews took place from July 2016 to November 2016. With the permission of participants, all interviews were audio recorded and detailed notes were taken. The interviews were all transcribed verbatim by the researcher and coded using NVivo 12. Coding was done using a thematic analysis where nodes were derived deductively from the research objective, for example services provided or cultural understanding of disability, and inductively from the interview data as these themes arose, for example charity model (See list of nodes in appendix C). Coding and nodes were used to support the analysis of the interviews. To ensure validity, transcribed interview transcripts were externally checked by one of the researcher's supervisors to ensure that data was appropriately analyzed.

3.3.3 Middle Eastern and South Asian immigrants living with a disability

The purpose of the second qualitative stage of the study was to interview adult immigrants from the Middle East and South Asia with physical disabilities living in the GTHA in order to gain a better understanding of their lived experiences. Through in-depth individual semi-structured interviews, the aim was to explore how disability, culture, gender, and immigrant status intersect to influence and shape the experiences of service use and everyday life of immigrants living with a disability in the GTHA. In order to take part, individuals had to meet the following criteria: immigrant/refugee from South Asia or Middle East including Sudan, lived experience of physical impairment, aged 18-65, English speaking, and living in the GTHA. Despite the study focusing on adult immigrants an age range of 18-65 was implemented to focus on people who were in their working years. This was a conscious decision to avoid participants who had become impaired due to ageing. These individuals were excluded because they have often left the labour market and face different challenges from individuals who experience impairment during their younger and working years. While not done in this research, it is important to note that there is still a need to address the experience of older immigrants in the literature. English speaking was specified since there was no access to a translator due to a lack of funding and connections. Some participants were recruited using snowball sampling through contacts from the previous qualitative stage. Snowball sampling proved especially valuable for recruiting immigrants with disabilities as it allowed the researcher to be known to others through positive recommendations who could also to vouch for cultural competency (Liamputtong, 2010). Snowball sampling is especially valuable in trying to access hard to reach and vulnerable populations and people who are suspicious of the research process. However, a known limitation of snowball sampling is that it often leads to participants who resemble each other and can limit diversity of participants (Liamputtong, 2010). The cultural broker was utilized to gain access to people in the community through his networks and connections. The cultural broker made the initial contact and then relayed the contact information to the researcher. Facebook was also used to try and recruit in this part of the study. Another member of the Arab cultural community posted posters on several different specialty groups on Facebook as a way to reach more people. Unfortunately, these attempts at recruiting were unsuccessful. Posters were also posted on the McMaster campus, including at the Student Accessibility Services (SAS) center. Additionally, the study was advertised in the SAS newsletter which is sent to all students accessing SAS services. The sample size for this stage of the study was eight.

Interviews ranged from one to three hours depending on how much the participant had to share. Interviews took place at either the participants' home, place of work, or over Skype depending on what they preferred. Participants were informed of their rights as participants prior to participating either by email or phone. The letter of information and consent (Appendix D) was outlined in detail before start of the interview. All the interviews used the same interview guide (Appendix E) as a reference, focusing on the following topics: introducing the individual, socio-spatial and cultural experiences of disability pre, during, and post migration, and knowledge and utilization of services. Questions allowed for the exploration of how different aspects of their identity such as disability, immigrant status, and gender intersected in place prior to coming to Canada. This was followed by an exploration of how different aspects of identity were negotiated after arriving in Canada, allowing for an in-depth understanding of subjective experiences pre and post migration. Comparing and contrasting these experiences provides insight into how meanings and lived experience may shift over spaces and time.

Interviews took place from May 2017 to November 2017. With the permission of the participant, in person interviews were audio recorded and Skype interviews were recorded using ECAMM Skype recording software. Detailed handwritten notes were also taken, with the signed or oral permission of all participants, during all interviews whether they were in person or conducted over Skype. Interviews were transcribed and analysed thematically as in the previous qualitative stage. Transcripts were externally checked by project supervisors to ensure the validity and appropriate interpretation and analysis of the data.

3.3.4 Cultural sensitivity in cross-cultural research

It was evident in the literature review that there is a need for cultural sensitivity training and a provision of culturally sensitive services in the Canadian health care system. To identify what these culturally sensitive services are and how they should be implemented it is essential to do cross-cultural research. Due to the sensitive nature of the cross-cultural research, it is critical for researchers to be respectful of participants' culture and ensure that the research does not harm the community but has the potential to benefit them (Liamputtong, 2010). Cultural sensitivity is defined as (Sieber, 1992, p. 20):

> 'the understanding and approaches that enable one to gain access to individuals in a given culture and learn about their actual lifestyles (beliefs, habits, needs, fears and risks)'

To perform appropriate cross-cultural research, it is important to gain extensive knowledge of the group involved in the research, meaning that the researcher needs to have an understanding of all aspects of the culture including religious, historical and familial factors. (Liamputtong, 2010). Laverack and Brown (2003) argue that it is important for cross-cultural researchers to have skills that allow for 'tolerance for ambiguity, patience, adaptiveness, capacity for learning, and courtesy'. These skills are especially important in cross-cultural research as the researcher engages with cultures outside their own who potentially do not have the same customs and expectations as the researcher such as shaking hands and following through on promises made.

It was especially important for me, as a white, presumably Christian, female accessing Middle Eastern and South Asian communities, to develop extensive knowledge of cultural norms during this project to ensure that members of these communities were approached and interacted with in a culturally appropriate manner. One way that cultural sensitivity was applied in the research process was through the conscious decision to access mosques prior to interviewing individuals with disabilities. The reason for this decision was for the researcher to gain a better understanding of the cultural and religious context prior to asking more vulnerable participants about their own experiences within this context. Prior to accessing the mosque, the cultural broker also briefed the researcher on the appropriate way to act in the mosque. I, the female researcher, entered the mosques through the designated entrances for women, where applicable. I also wore a head scarf, where it was requested, to respect religious customs and needs. I was also aware not to shake hands with Muslim males and instead greeted them by placing a hand to the chest. When any questions or issues arose, I made sure to consult with the cultural broker to ensure that situations were handled in the most appropriate manner. Not all participants belonged to the Islamic religion, therefore it was also important for the researcher to educate herself on overall issues of the Middle East including wars and post-war transitions, the Sri Lankan Civil War, and relevant socio-political issues such as women's rights, the Arab spring, The Islamic State of Iraq and Syria (ISIS), and economic issues facing the region. Knowledge of these issues was important to understand the factors shaping participants' lived experiences.

3.3.5 Ethics

Ethics is an important part of research as it protects participants from potential harm. In cross-cultural work, this requires explicit attention to cultural sensitivity in order to ensure that participants are protected and respected during the research process. One of the main principles of ethics is to 'do no harm' when conducting research but ethical principles also encourage researchers to maximize the potential benefits of research for those involved (Liamputtong, 2010). Ethics was taken into consideration throughout the whole research project, from proposal building, to recruitment, to data collection, during analysis, and dissemination. Part of the originally proposed research, focusing on the perceptions and understandings of non-disabled participants, was scrapped early on in the research process because it was deemed that the research could not be done without harming the community by potentially portraying them and their cultural values as 'backwards' or 'wrong'. These types of considerations are especially important when working with vulnerable populations. One ethical consideration that arose during the recruitment process was prompted by the mosque shooting in Montreal on January 26th, 2017. After this incident it became much more difficult to contact mosques. Given the traumatic nature of the shooting it was decided that it was not appropriate to contact more mosques during the research process.

Because of the sensitive nature of the topic of disability many ethical considerations were taken into account during the recruitment and especially in the interview process itself. To protect anonymity, participants were given a pseudonym. Easily identifiable data including disability diagnosis, exact age, city of residence in Canada were excluded from the results and analysis as this had the potential to cause harm to the participants. Participants were informed of their rights to anonymity and confidentiality throughout the project and any concerns around privacy were handled on an individual basis.

Recruitment efforts at mosques required the researcher adapt the ethics protocol in order to make an initial contact with potential participants in a different cultural context. While mosques were initially contacted by email to explain the study and ask about participation, email recruitment proved unsuccessful. Similarly, setting up interview times by phone proved to be unsuccessful. Instead, a more direct approach of contacting Imams while waiting nearby often yielded the response of ‘come now’. That they wanted to meet right away was both a representation of how busy Imams are as well culture. The cultural broker explained that it is common that people from the Middle East want to meet right away when setting up an appointment. He explained that if a later appointment was set up, they would likely forget about the appointment. This is very different from how we are often instructed to make contact according to ethics protocols. Imams and mosque leaders are extremely busy, and it was found that they were mostly available immediately. While this recruitment strategy was more direct and resembled cold-calling, participants’ rights were still made very clear and the voluntary nature of the process was ensured. Indeed, several mosque leaders declined to participate either because they felt that they could not speak on the subject, were not interested, or did not have time. Interviewing within the Muslim community also required the researcher to take into account prayer times as they dictate when the Imam and some participants would be available.

3.3.6 Conceptual Framework

This study draws on feminist disability theory and intersectionality to conceptualize and understand the lives of immigrants with disabilities. Feminist disability theory aims to unsettle dominant notions and stereotypes that surround people with disabilities (Garland-Thomson, 2005). Similarly to the social model of disability (see chapter 2), feminist disability theory argues that disability is culturally constructed narrative of the body and not a natural state, while providing a framework to explore how culture has shaped these stereotypes and perceptions surrounding disability (Garland-Thomson, 2002). Examining disability from a social perspective rather than a medical one allows us to explore how disability has been produced by a system of exclusion and stigmatization (Garland-Thomson, 2005). Feminist disability theory scrutinizes the way that disabled bodies have been culturally labeled as dependent, incomplete, vulnerable, incompetent, and as a failure of normalcy (Garland-Thomson, 2002, 2017). Disability has come to mean “disadvantage” and disabled bodies have been devalued because of their inability to conform to the able standards of normalcy (Garland-Thomson, 2002). Feminist disability theory allows for an expansion of how we understand the lived experiences of disability, for example, through examining how the way that the world has been built shows and enforces discrimination against person with disabilities (Garland-Thomson, 2017).

Garland-Thomson (2011) argues that disability is inherently linked to spatiality and temporality meaning that disability – as an experience of 'misfitting' - can vary both spatially and temporarily, allowing for persons with disabilities to exercise agency. Garland-Thomson (2011) uses the word "misfits" to describe an incompatible relationship between a person with a disability and the material environment. She argues that one can only fit when the environment is suitable and when one fits, they are able exist anonymously in the space (Garland-Thomson, 2011). Because bodies are situated, it is possible for a body to fit today and be a misfit tomorrow as well as changing one's spatial context can shift the fit/misfit of a body depending on the environment in the space (Garland-Thomson, 2011). Similarly to the social model, feminist disability theory argues that access to the environment should be achieved by changing the space and not the bodies that use the space.

An important part of feminist theory is recognizing that no woman is only ever a woman and feminist disability theory builds on this notion by highlighting the intersections of other identity-based critical perspective, for example ethnic and queer studies (Garland-Thomson, 2002). This approach insists on the adoption of an intersectional framework, which is discussed in further detail below.

Intersectionality allows for an exploration of the multiple positions that an individual with disabilities occupies at any given time. It draws attention to the ways that social identities at the micro level such as gender, immigrant statues, disability, intersect with macro level structures such as sexism and culture (Bowleg, 2012). Intersectionality emphasizes that individuals do not belong to one static category, be it gender or 'race', but instead these categories are fluid, meaning that they have the potential to change over time and space (Hankivsky, 2014; Valentine, 2007). Further, intersectionality allows for an exploration of how geographical location has the ability to change the relationship and power dynamics of categories including gender, immigrant status and socio-economic status. Hankivsky et. al. (2010) argues that when focusing on one category, such as gender, in analysis and interpretation, one runs the risk of treating all women the same. Many things outside of gender, for example, ability, socio-economic status, ‘race’, and sexuality influence lived experiences and create unique individual women. The same logic can be applied when examining disability. From a policy perspective, persons with a disability are often treated as a homogenous group yet many different categories intersect to create varied experiences of disability over time and space. An example of this is seen in Valentine (2007) where she explains that identity, in the Deaf community, can shift when acquiring sign language from being deaf to Deaf. While I argue that from an analytical perspective it is possible to examine disability using an intersectional perspective that does not mean that disability as a category is the same as, for example, race and gender. Shakespeare (1996) argues that race and gender categories are different from the experiences of disability because persons with a disability are likely to grow up in a family where they are the only ones with a disability. Disability as a category is therefore more like sexuality, in the sense that there can be a sense of isolation, particularly within families.

While the theoretical approach to intersectionality has been heavily discussed, there is less literature addressing how to carry out intersectional research empirically. Among the literature that has engaged with how to apply intersectional research methods, there is a consensus that this is not an easy thing to do (Christensen & Jensen, 2012;

Windsong, 2018). Christensen and Jensen (2012) applied qualitative methods to explore life stories and examine the complex processes of identity and positioning that occur in the creation of social relations in neighbourhoods. Through the life stories of participants they were able to conduct an empirical intersectional analysis of the data to explore how gender, class, and ethnicity facilitated the construction of belonging and roots in given neighbourhoods. On the other hand, Windsong (2018) chose to ask participants intersectional questions in her interviews, instead of incorporating intersectionality as an emergent theme. In her case, theory guided the construction of her research questions. Interestingly, she found that when she asked direct intersectional questions, her participants had a harder time understanding and answering the questions as compared to other in-depth research questions that did not address intersectionality directly (Windsong, 2018). In this study, both the key informant chapter and the immigrants with disabilities chapter, both methods are utilized, meaning that theory guided the research questions in the interview guides while also leaving the questions open ended enough to allow the participants to contribute what they found important in their life stories and intersectional themes were then derived from that. An example of a direct intersectional question is seen in the interview guide for immigrants with disabilities (Appendix E). The question asks: what are the meanings and beliefs associated with disability in your cultural community? This direct intersectional question allows for an exploration of the possible intersection of disability and culture. An example of open ended questions that allow for participants to share their experiences and where intersectional themes could be derived during the analysis was seen in question 1: can you tell me a bit about yourself? This question allows the participant to share what they feel is important to who they are.

They are in control of telling the stories of their life and which part of their identity is the most important to them.

Using a feminist disability theory lens in this study allows for an exploration of how different categories namely gender, disability, race and immigrant status shape the lived experiences of people with disabilities before and after immigrating to Canada. An important part of feminist geographical methodology is the notion of reflexivity, which is discussed further in the next section.

3.3.7 Positionality and reflexivity.

As previously mentioned, I am an outsider to the community that I was studying. Being an outsider can affect the research in both positive and negative ways. One danger of being an 'external outsider', someone who is socialized within a community that differs from the community where he or she is conducting the research, is that the external outsider only has a partial understanding and appreciation of the values and knowledges of the community (Liamputtong, 2010). From a positive perspective, being an outsider allows the researcher to observe issues that may not be apparent to the community being researched but more importantly when doing cross cultural research, being an outsider has the potential to allow participants to open up to the researcher in a way that they would not if the person belonged to their community. In this sense, the external outsider can be seen as a neutral party with no community ties (Liamputtong, 2010).

I was a clear external outsider (Caucasian, able bodied, and having grown up in western culture) to the community I studied for the qualitative part of the research. I did not share the same region of origin, ethnicity, religion, and cultural values. This required me to continuously reflect on my position in relation to the people that I was researching.

For example, I quickly realized that I had not fully appreciated the importance of mosques as a place of gathering and the influence of Islam in these cultural communities. Using a cultural broker helped me navigate these issues by having him explain the importance of the mosque, the hierarchy within the mosque, and giving insights into the community in regards to customs such as how to greet people. Being an external outsider negatively affected the study in the way that I was not able to gain access to the community myself and establish trust. This resulted in the need for a cultural broker to make these connections. Being an outsider also affected some of the interviews and one particular interview was an unpleasant experience because of my outsider status and gender. Instead of being viewed as a neutral observer, I was treated as an intruder by the interviewee and other members of the mosque. In this mosque I was not allowed, as a woman, to speak to the leader, he was given a copy of the interview guide and answered the questions as he read them. It was clear, that my status as a woman, despite the cultural broker explaining that I was his senior, was an issue for this participant and the interview was subsequently influenced by my own feelings of being mistrusted and unsafe. These feelings were magnified by the interview taking place in a very small space, where the interviewee sat and blocked the door while the interview took place. The participant, repeatedly, made negative comments about the interview questions, alluding to the questions being irrelevant and insignificant. During the debrief, with the cultural broker after the interview, I found that he had been uncomfortable as well and that he had tried to find a way to end the interview so that we could leave. In other interviews with religious leaders, where the cultural broker attended, I was at times ignored during the interview and the leader would speak in Arabic to the cultural broker. When the leader spoke

Arabic to the cultural broker, it was not relating to the study but instead about personal matters between the two. I would wait patiently, sometimes several minutes, for the conversation to end and try direct attention back to the interview questions. The cultural broker tried to navigate these interruptions by bringing the attention back to the interview and me as a researcher, however, since he could not disrespect the senior/elder/ leader who was being interviewed, returning the focus to the interview was not always easy. I believe that these interactions were influenced by my gender as much by me not being part of the cultural community, an outsider. These interactions made me increasingly conscious of my lack of fit based on gender and ultimately resulted in a lack of self-confidence heading into other interviews as I was not sure of my position and if I would be accepted or respected. Feelings of being an outsider were present throughout the study, making me question whether or not I had the right to do the research in the first place as I was not part of the community. However, participants with disabilities made me feel like I had a right to do the research as most were encouraging and extremely supportive of the study and my involvement.

From a positive perspective, I believe that participants with disabilities confided things to me that they would not have confided to someone who was a member of their cultural community. For example, participants recounted experiences of discrimination within their own cultural community, and issues of physical and emotional abuse. They also articulated criticisms of places of worship and the services they provided to persons with disabilities. Speaking to an outsider also allowed participants with disabilities to control the narrative and ‘educate’ the researcher on their lived experiences. Because the researcher was not part of the cultural or religious community their knowledge provided them with the power to educate the researcher through their personal stories. As a researcher, it was important for me that the participants knew that their stories were the foundation of the research and acknowledge the importance of these stories.

When researching vulnerable populations, such as immigrants with disabilities, it is important to be mindful of the power imbalance that may occur during the research process. Reciprocity is an important part of dealing with power imbalance (Liamputtong, 2010) and this was applied during the research process. In the context of interviews, this was done was through the researcher sharing personal information for example being an immigrant herself, thoughts and experiences of parenthood, and other shared experiences. Sharing these experiences helped participants feel more at ease but also helped reduce the power imbalance by for example speaking woman to woman, mother to mother, or immigrant to immigrant. In one instance, a participant expressed an interest in and need for counseling. I shared positive aspects of my own counselling experience and provided the participant with contacts for subsidized counselling in their area. I checked in on this participant several times after the interview to ensure their wellbeing and to thank them for all their help with the research project. Most interviews with immigrants with disabilities took place at their homes as a way to decrease the feeling of a power imbalance by them feeling more comfortable and having greater confidence because of the home environment. It was a conscious decision to give participants the option of meeting in their home rather than a more formal interview setting, for example an office with a desk separating the two, to make the interview process seem more open and comfortable. It is also important to financially compensate participants for their time to show that the researcher has a genuine interest in their lived experiences and wellbeing

(Liamputtong, 2010). Immigrants with disabilities were financially compensated by being given a $20 honorarium as a thank you for their participation. Participants were also given the option to sign up to receive a copy of the report once it was done to inform them of the results of the research, with all participants expressing great interest in this option. Giving something back to participants in form of research results and insights to the study can help to reduce the power imbalance (Liamputtong, 2010).

Being aware of being an outsider is also important for the accuracy of the writing of results and analysis. Positionality was repeatedly checked during these stages to check bias against my own situated knowledge by making sure that my interpretation and analysis was grounded in the knowledge and the experiences that participants shared. One way this was done was through meetings with supervisors to discuss and critically reflect on my interpretation of the data. Despite being aware of how my own knowledge is situated and partial while trying to neutralize the power imbalance, the power imbalance can never fully disappear as I am a white, middle class, and able-bodied graduate student. Some of the ways that the power imbalance was negotiated was through sharing of personal experiences such as immigration. Being a first-generation immigrant myself, we were able to share experiences of the immigration process including processing times, medical requirements and examinations, as well as settling in Canada. While this was a shared experience, being a Caucasian European immigrant, I could not relate to the immigrants' experiences of racism and islamophobia. Being an able-bodied researcher, researching people with disabilities, can never be fully overcome. One way that this was negotiated was through participants having the opportunity to teach me about disability and their experiences. It was important for me that participants knew that they were the ones with the knowledge and expertise and that they were in control of the stories they wanted to share.

3.4 Issues in the recruitment process

The recruitment process faced several challenges throughout the research. Recruitment of key informants (chapter 5) produced a small sample of religious leaders and ethnic service providers who shared similar characteristics, with an overrepresentation of Islamic leaders and no representatives from temples. Many other avenues of recruitment were explored but people either declined to participate, did not return phone calls or emails, or agreed to participate and then ignored further contact. Some organizations that were contacted for a possible interview expressed that they did not want to participate because of the topic of disability. For some, they declined because they did not believe that they knew enough about disability to participate, while others did not provide reasoning, perhaps indicating the stigma that is associated with disability.

The recruitment of immigrants with disabilities also faced several difficulties. The cultural broker contacted approximately twenty people but only two agreed to participate. After debriefing with the cultural broker at the end of the study it became apparent that stigma heavily influenced the narrative around disability. Some family members/caregivers for people with disability would not allow the cultural broker to talk to the person with a disability because they did not want to bring them more pain. The cultural broker explained one scenario:

> *I asked her [caregiver] if she [her daughter] could participate in research pertaining to disability and her initial words to me was "I don't want my… I don't want my family member to ever be subjugated to this research [research on disability] or whatever it is". To some degree she was confusing me as a telemarketer, I kept telling her, no it is not, it's research that will help and has some benefits and she said something very interesting and in referral to her dependent [her daughter] in a very interesting way,*

> *she says… she [the mother] told me specifically "society does not care about her [the daughter]" and what shocked me is, she says this "they treat her like human residue, society treats my daughter like human residue". Very powerful statement showing neglect of that specific, of her family dependent and I tried to reason and explain, try to get an explanation, why did she feel that way specifically. Everything was mostly concerning, "I don't want to bring pain… we don't want to bring pain to her anymore. We don't want her to feel or to remind her that she is disabled"*

Others did not find participation in the research project beneficial, as they believed that it would not change anything in their lives and they therefore failed to see the value in participating. Another possible participant expressed the feeling of being over researched. Overall, the cultural broker was surprised by the stigma he encountered when approaching people and peoples' unwillingness to participate in the study. Several people who were approached to participate did not understand the purpose of the research and how they could possibly contribute to the research. It should be noted that many of the people contacted originate from war torn countries where governments cannot be trusted and where they have faced severe discrimination and sometimes violence and abuse because of their disability. A lack of knowledge about research and suspicions about sharing information with others may have kept some possible participants from agreeing to participate in the study.

Ultimately eight immigrants with disabilities (chapter 6) were recruited, relying mostly on snowball sampling. This resulted in many of the participants sharing similar characteristics for example activists, extremely independent, and strong willed. Other avenues of contacting participants were explored but were ultimately all unsuccessful. It was also difficult, in the recruitment process, to navigate the fine line between encouraging and pressuring people to participate. The cultural broker explained throughout the recruitment process that Arab culture is a "pushy" culture where you have to push and be more insistent when trying to get people to talk to you. As previously mentioned, cultural norms of being insistent on participation made people more likely to participate but there is a fine line regarding how much you want to encourage people to participate when dealing with disability or any vulnerable population. This negotiation was done subjectively of each situation, meaning that we analysed each individual situation by interpreting body language and words spoken to us, to decide if “pushing” for participation would cause any harm or help encourage participation.

3.5 Conclusion

This chapter has outlined the methodology, methods, and conceptual framework used for the recruitment, collection of data, and recruitment. To summarize, the main purpose of the first stage of the research was to examine the utilization and need for support services amongst immigrants with disabilities in Canada using quantitative methods. The results of the quantitative analysis are outlined and discussed in chapter 4. The second and third stage both employed qualitative methodology to examine services available to immigrants with disabilities, cultural community understandings and perceptions of disability, as well as the lived experiences of immigrants with disabilities living in the GTHA. Building on chapter 4, chapter 5 explores services and cultural understandings of disability from a key informant perspective. Chapter 6 is an in-depth exploration and analysis of the lived experiences immigrants with disabilities from the Middle East and South Asia based on qualitative interviews.

Chapter Four

Quantitative Analysis exploring differences in support service utilization

4.1 Introduction

This chapter adopts a quantitative methodology to explore the need for, and use of, support services by immigrants with disabilities in Canada. Using the 2006 PALS data set, the chapter uses descriptive and multivariate statistics to explore the differences in use of support services between the Canadian born population and immigrants with disabilities. The chapter also explores other variables that may impact the use of support services including gender, income and education. First, the chapter outlines the background for the research, followed by results, and lastly the discussion of the results and how this help inform the subsequent research stages in this study.

4.2 Background

Approximately 14% of the Canadian population (aged 15+) reported a disability in 2012, with women more likely to report a disability (14.9%) than men (12.5%) (Statistics Canada, 2013b). Disability rates tend to increase with age, reaching 42.5% amongst those aged 75 and over (Statistics Canada, 2013b), with pain, flexibility and mobility the most prevalent types of disability (Galarneau & Radulescu, 2009; Statistics Canada, 2013b). Oftentimes, people with disabilities experience lower rates of labour force participation (Galarneau & Radulescu, 2009) and social marginalization (Albrecht et al., 2009). Immigrants with disabilities may also face significantly greater challenges in integrating into Canadian society as compared to non-immigrants with disabilities, a process that is made more difficult by language barriers, lower incomes, and employment issues such as lack of recognition of professional and education credentials (Bauder, 2003). Discrimination in workplaces, health care settings or social environments (Edge &

Newbold, 2013) based on immigrant status, skin colour, and/or disability itself may also occur, but the literature dealing with this is limited.

This complex intersection of immigrant status, disability, and gender also raises important questions about people's need for, and access to, supports. For those with disabilities, support with activities of daily living (ADLs) may be a significant determinant of their social and economic integration into society. For instance, a 2010 Statistics Canada report based on PALS data (Fournier-Savard, Mongeon, & Crompton, 2010) revealed significant (self-assessed) unmet need for support, with 30% of those with a disability indicating that they would like more help than they receive, or were not receiving support at all, even though they needed help with activities of daily living. Not surprisingly, the amount and type of support received depended on the type of disability, and the amount of support received increases with age and severity of disability, but sufficient support was also increasingly hard to get as need for support increased.

It is also likely that problems accessing supports may be exacerbated within immigrant communities: immigrants may have less knowledge of services available and/or comparably fewer resources (monetary, family, friends) and options to ensure adequate help with activities of daily living given their level of need for support (Chen et al., 1996; McKeary & Newbold, 2010). Differences in the type and source of support between immigrants and the Canadian born may also exist. Given observed differences in income along with access to health and social services (including use of preventative health services) between immigrants and Canadian born people, it could be hypothesized that immigrants may be less able to pay for formal supports (such as a personal support worker) and are more reliant on family and/or friends (McKeary & Newbold, 2010).

While there has been some analysis of need, type, and source of support (Fournier-Savard et al., 2010) for people with disabilities, the literature has typically not differentiated between immigrants and non-immigrants. Yet, immigrants with disabilities may have different support needs than Canadian born people. They may also confront different institutional barriers, with the consequence that needs may go unmet. At the same time, immigrant groups may have different cultural expectations about how support needs will be met. For example, a study of caregivers in Hong Kong showed that caregiving was a 'natural' and expected role for family members, with no expectation that care should be the responsibility of the government (Mok, Chan, Chan, & Yeung, 2003). Research from the United States and Canada has also noted the importance of informal caregiving within the Vietnamese immigrant community, with the expectation that immigrants will depend on family members for health needs unless the family has exhausted all of its resource (Donovan & Williams, 2015; Purnell, 2008).

From a policy and programming perspective, it is vital to understand whether immigrants with disabilities are more (or less) disadvantaged than non-immigrants with disabilities in terms of receiving support (or if there are cases of unmet need), the type of assistance that is used, and who is providing support (including but not limited to, family, friends, paid help). Insight into the sources and types of support will enable greater understanding of the different constraints and opportunities that immigrants and non-immigrants with disabilities face in the course of their everyday lives.

4.3 Results

Table 4.1 reports on the sample characteristics. Immigrants represent 25.2% of the sample, slightly larger than the proportional size of the immigrant population within

Canada. Recalling that all individuals included in the PALS have a disability, it is interesting to note that a greater proportion (44%) of immigrants report a severe disability as compared to the Canadian born (40.1%). Otherwise, the immigrant sample tends to be somewhat older, more female, better educated, and reports a higher earned income than the Canadian born non-immigrant group with disabilities.

Table 4.1. Sample characteristics (%), Immigrants and Canadian born, aged 40+

		Canadian born	Immigrant
Immigrant status		74.8	25.2
Severity	Severe	40.1	44.0
Age cohort	40-49	20.2	11.1
	50-59	23.5	19.0
	60-69	19.5	24.5
	70-79	20.8	23.8
	80+	16.0	21.5
Gender	Female	54.7	57.7
Education	Less than High School	36.8	33.4
	High School	22.7	20.5
	College and Trades	31.3	32.5
	University	9.3	13.7
Income	$0 - $19,999	19.4	14.6
	$20,000 - $49,999	37.2	33.4
	$50,000 - $79,999	21.8	26.0
	$80,000 - $99,999	8.5	9.0
	$100,000+	13.1	16.9
N (Weighted)		2,687,179	907,027

Table 4.2 reports on the proportion of immigrants and non-immigrants aged 40 and over who receive support for a disability, with results indicating that females are much more likely than males to report use of support, regardless of immigrant status and severity of disability. Despite potential differences in the source of support and ability to pay for

support, there is comparatively little difference in the proportion of immigrants and non-immigrants reporting use of supports. For instance, 68.3% of immigrant women reported use of support, and 69.3% of Canadian born women reported use, with a similarly small difference between Canadian born and immigrant men (47.4% and 49.1%, respectively). However, women reported greater use of support than their male counterparts.

Turning to the severity[8] of a disability and immigrant status, greater use of support was, not unexpectedly, associated with greater severity regardless of immigrant status. However, immigrants reporting mild/moderate disabilities were slightly more likely to report use of support (46.8% versus 45.0% for immigrants and Canadian born, respectively). Conversely, immigrants reporting a severe disability are less likely to report use of support (77.2%), compared to 80.8% of Canadian born people. Finally, although 80.8% of immigrant women with severe disabilities reported receiving support, 85.7% of their Canadian born counterparts reported use of support services, a difference of 4.9 percentage points. In comparison, there was just a 2.8 percentage point difference between immigrant and non-immigrant males reporting a severe disability, suggesting that immigrant females with a severe disability were at a slightly greater risk of not receiving support.

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[8] Statistics Canada created an index measuring the severity of the disability based on the self-rated answers to the survey questions. Points were given according to the intensity and the frequency of the activity limitations reported by the respondent. A single score was computed for each type of disability and each score was then standardized to have a value between 0 and 1. The final score is the average of the scores for each type of disability.

Table 4.2 Receipt of support (%) by immigrant status, severity, and gender, aged 40+

	Canadian born			Immigrant		
	Male	Female	Total	Male	Female	Total
Mild/Moderate	31.7	57.1	45.0	34.9	56.9	46.8
Severe	74.0	85.7	80.8	71.2	80.8	77.2
Total	47.4	69.3	59.3	49.1	68.3	60.2

Table 4.3 extends this analysis by considering type of caregiver (family, friends, other), age cohort, gender, and immigrant status, from which four broad observations can be made. First, immediate family members such as a spouse, partner, child, or parents were the most likely to be the care provider for any disabled individual regardless of gender, immigrant status, or age cohort. Second, family members were more likely to provide support for immigrants as compared to non-immigrants, again regardless of age cohort or gender. Third, while family members were the primary source of support in each case, support from friends was more important amongst non-immigrants. That is, friends represented a greater share of providers amongst non-immigrants as compared to immigrants. Similarly, non-immigrants were generally more likely to have a caregiver that was either paid, from a NGO or the government (i.e., 'other' providers) compared to immigrants. Amongst immigrants, women were typically less likely to use these 'other' providers as compared to men. Fourth, the use of 'other' caregivers tended to increase with increasing age, reflecting increasing use of formal supports external to the immediate circle of family or friends, while the use of both family and friends tended to decline with age. One of the possible reasons for the decline in the use of family and friends with age, is that as people age so do their friends, and if they have been taken care of by their parents, their parents age as well or pass away, leaving them to rely on other

sources for support for example service provided by the government and/or charitable organizations.

Table 4.3 Caregiver type (%) by immigrant status, gender, and age cohort.

			Caregiver		
Age Cohort	Gender	Immigrant Status	Family	Friends	Other
40-49*	Male	Immigrant	---	---	---
50-59	Male	Immigrant	82.9	6.6	10.5
60-69	Male	Immigrant	78.6	15.9	5.5
70-79	Male	Immigrant	73.2	15.4	11.4
80+	Male	Immigrant	62.8	11.0	26.2
40-49	Male	Non-immigrant	69.7	17.3	13.0
50-59	Male	Non-immigrant	66.4	18.2	15.4
60-69	Male	Non-immigrant	61.1	21.0	17.9
70-79	Male	Non-immigrant	58.8	17.7	23.6
80+	Male	Non-immigrant	53.2	15.5	31.3
40-49	Female	Immigrant	76.3	11.0	12.8
50-59	Female	Immigrant	82.4	8.7	8.9
60-69	Female	Immigrant	80.3	14.3	5.4
70-79	Female	Immigrant	58.7	27.6	13.7
80+	Female	Immigrant	57.1	24.7	18.2
40-49	Female	Non-immigrant	72.3	15.2	11.5
50-59	Female	Non-immigrant	69.1	15.4	15.5
60-69	Female	Non-immigrant	62.8	18.9	18.3
70-79	Female	Non-immigrant	56.4	15.7	27.9
80+	Female	Non-immigrant	45.6	20.7	33.8

* Values suppressed given small sample size.

Multivariate results, which are presented in Table 4, further explore the covariates associated with receipt of support (regardless of the provider type), type of support received (support for meals, housework, errands, and personal care) and additional need for support. First, considering the overall receipt of care and the type of care provided, the results suggest that immigrants are more likely to receive support, including support for meals, housework, errands and personal care. Second, females are more likely to receive support than males, confirming the descriptive results. Additionally, individuals with a severe disability were also more likely to receive support, in line with expectations. Although increasing age is typically associated with greater use of support regardless of the type of support required, other sociodemographic and socioeconomic factors demonstrate inconsistent results with respect to the use of support. Although it might be expected that higher income groups are more likely to report the use of supports, there is no clear pattern associated with income, suggesting that the use of support is relatively equitable with respect to income. Results associated with educational attainment are, however, less intuitive, with higher levels of education (high school and higher) associated with less use of supports than individuals with less than a high school education.

The addition of a series of interaction effects between immigrant status and other correlates of use extends the analysis. From the results shown in Table 4, it is clear that some sub-groups within the immigrant population are less likely to report use of supports, suggesting greater inequalities between immigrants and non-immigrants than the direct results reveal. For instance, despite females generally having greater use of support than males, the interaction between immigrants and females reveals that female immigrants are less likely to receive support for a disability, an outcome that is only visible after controlling for other covariates. Immigrants reporting a severe disability are also typically less likely to receive support. In several cases, including overall support, housework, errands, and personal care, lower income immigrants are also less likely to use support services, as are immigrants with a high school or better educational attainment. Conversely, some of the older immigrant cohorts are more likely to use support.

The final columns in Table 4 report on the need for additional support, essentially allowing the respondent to consider whether there is a need for further support. Results suggest that immigrants are neither more nor less likely to report additional need for support as compared to their Canadian born counterparts. However, individuals with a severe disability, as well as females, are more likely to report additional need, as are individuals with more than a high school education, suggesting that there may be greater awareness of either their need for support or the availability of support. Individuals with a low income (<$20,000) report less need for additional support. The inclusion of interaction effects reveal that low income immigrants (<$20,000) are less likely to report additional need for support, as are immigrants aged 50-59. However, immigrants aged 70-79 are more likely to report need for additional support.

Table 4.4 Logistic regression: Use and Need of support by disabled adults, age 40+

	Receives Care		Meal Support		Housework Support	
	OR	*p*	OR	*P*	OR	*p*
Immigrant	1.884	<0.0001	2.091	<0.0001	1.453	0.0004
Severe	5.620	<0.0001	7.105	<0.0001	5.149	<0.0001
Female	2.367	<0.0001	1.562	<0.0001	2.004	<0.0001
Age (Reference = Aged 40-49)						
Age 50-59	1.072	0.1448	0.812	0.0003	0.889	0.0133
Age 60-69	1.028	0.5465	0.695	<0.0001	0.915	0.1109
Age 70-79	1.267	<0.0001	0.681	<0.0001	1.103	0.0738
Age 80+	2.051	<0.0001	1.210	0.0006	2.443	<0.0001
Education (Reference = Less than High School)						
High School	1.018	0.7038	0.863	0.0025	1.152	0.0040
College	1.107	0.0186	0.896	0.0307	1.225	<0.0001
University	0.878	0.0431	0.749	0.0003	1.111	0.1298
Income (Reference = >$100,000)						
< $20,000	0.771	<0.0001	0.436	<0.0001	0.664	<0.0001
$20,000 - $49,999	0.868	0.0068	0.682	<0.0001	0.828	0.0006
$50,000 - $79,999	0.997	0.9552	0.874	0.0232	1.004	0.9425

$80,000 - $99,999	0.971	0.6402	0.878	0.0861	0.939	0.3608
Interactions						
Imm*Severe	0.758	0.0004	0.753	0.0008	0.874	0.0707
Imm*Female	0.869	0.0557	0.616	<0.0001	0.732	<0.0001
Imm*<$20	0.757	0.0091			1.161	0.0587
Imm*$20 - $49	0.869	0.0873				
Imm*High School	0.672	0.0001			0.735	0.0024
Imm*College	0.414	<0.0001	0.832	0.0429	0.652	<0.0001
Imm*University	0.461	<0.0001	0.623	0.0007	0.475	<0.0001
Imm*Age 50-59	0.592	<0.0001	0.771	0.0290		
Imm*Age 60-69			1.520	0.0002	1.235	0.0300
Imm*Age 70-79	1.351	0.0018	1.302	0.0193	1.388	0.0006
Imm*Age 80+	1.430	0.0015				
N (sample)		22,513		22,513		22,513
Likelihood Ratio		4452.06		3378.66		3820.60
Rho-squared		0.146		0.148		0.138
% Concordant		74.2		76.1		74.8

Table 4.4 (Continued)

	Errand Support		Personal Support		Needs Support	
	OR	*p*	OR	*P*	OR	*p*
Immigrant	1.664	<0.0001	1.836	<0.0001	0.999	0.9812
Severe	5.912	<0.0001	9.731	<0.0001	4.213	<0.0001
Female	2.025	<0.0001	1.017	0.7561	1.637	<0.0001
Age (Reference = Age 40-49)						
Age 50-59	0.742	<0.0001	0.783	0.0034	0.872	0.0062
Age 60-69	0.807	0.0002	0.968	0.6713	0.814	<0.0001
Age 70-79	1.057	0.3122	1.451	<0.0001	0.793	<0.0001
Age 80+	2.521	<0.0001	2.397	<0.0001	0.838	0.0005
Education (Reference = Less than High School)						
High School	0.784	<0.0001	0.735	<0.0001	1.073	0.1029
College	0.690	<0.0001	0.783	<0.0001	1.244	<0.0001
University	0.608	<0.0001	0.503	<0.0001	1.283	<0.0001
Income (Reference = >$ 100,000)						
< $20,000	1.043	0.4965	0.793	0.0119	1.479	<0.0001
$20,000 - $49,999	0.843	0.0012	0.807	0.0053	1.113	0.0389
$50,000 - $79,999	0.883	0.0254	0.973	0.7382	0.885	0.0266
$80,000 - $99,999	1.003	0.9629	1.226	0.0410	1.084	0.2346
Interactions						
Imm*Severe	0.830	0.0129				
Imm*Female			0.682	0.0003		
Imm*<$20	0.636	<0.0001	0.711	0.0206	0.746	0.0029
Imm*$20 - $49						
Imm*High School	0.814	0.0417				

Imm*College	0.760	0.0027				
Imm*University	0.493	<0.0001				
Imm*Age 50-59			0.648	0.0083	0.729	0.0020
Imm*Age 60-69	1.266	0.0158				
Imm*Age 70-79	1.347	0.0018			1.757	<0.0001
Imm*Age 80+			0.737	0.0106		
N (sample)		22,513		22,513		22,513
Likelihood Ratio		4954.46		2691.30		2680.43
Rho-squared		0.175		0.175		0.100
% Concordant		76.8		80.8		69.7

4.4 Discussion

Immigrants and persons with disabilities both constitute important groups within the Canadian population, but relatively little is known about how immigrant status, disability, and gender intersect. This chapter provides one attempt to explore the nature of this intersection, comparing access to, and needs for, formal and informal supports amongst immigrant and non-immigrants with disabilities. Initial results suggest that there is broad parity in terms of the use of support, with immigrants and Canadian-born nearly equally likely to use supports. Unsurprisingly, the use of supports was greater amongst people who reported having a more severe disability. When examining income, individuals at the lower end of the income spectrum were not found to be disadvantaged relative to their higher income counterparts, suggesting a broad equity in the use of support services. When examining who provided the support/care, descriptive results suggested that immigrants with disabilities were more reliant on family members as support providers as compared to either friends or other sources, including paid service providers, which could reflect cultural norms and expectations of family caring for family members with health issues. While immigrants overall were neither more nor less likely to report additional need for support as compared to the Canadian born population, closer analysis revealed that particular sub-groups of immigrants – in particular women, those with severe disabilities, and some age, income and educational groups – were less likely to access supports after controlling for other correlates. Consequently, the data suggest that some members of the immigrant community may be more vulnerable when it comes to receiving support compared to the Canadian born population.

While these results are valuable, it is important to note that they do not allow us to explore the reasons for these differences in access to, and use of, supports. For example, we are not able to determine based on these numbers why immigrant women are less likely to report access to support compared to any other group. The data provide a useful starting point for qualitative work that can provide an in-depth examination of the underlying causes behind these numbers. Such work can usefully adopt an intersectional approach to understand the complex interrelationships between immigrant status, gender, culture, disability and people's use of formal and informal supports. Importantly, literature on the provision of care rarely focuses on those people receiving the support (Parr, 2003) but instead foregrounds those individuals who provide formal and informal care. This literature clearly indicates that caregiving is gendered, with women more likely to be formal and informal caregivers (Adams, 2010; England, 2010). With neoliberalism, care has seen a shift from formal care provided through the welfare state to a growing reliance on informal care provided by local voluntary organizations and/or family, friends and private care providers. This shift has disproportionally affected women as providers of support (England, 2010; Milligan, Atkinson, Skinner, & Wiles, 2007). But how might these changes to the nature of supports impact women (and men) as recipients? One study (Milligan et al., 2007) that examined the intersection of gender, care, and disability among elderly people with disabilities in the US found that women were much less likely to receive informal care compared to men and this was especially true for married disabled women (Katz, Kabeto, & Langa, 2000). The analysis of the PALS data provides further evidence of gendered differences with respect to the receipt of support, but it also suggests that there are important differences *among* women that reflect the intersection of disability with immigrant status and other socio-cultural factors. The qualitative analysis that follows in Chapters 5 & 6 work will help to shed light on the impact of these factors.

As suggested in Chapter 3, it is important to adopt an intersectional approach to examine immigrants' experiences with disability support services to be able to not only explore how gender impacts the use of support services but also the importance that culture has in terms of informing decisions about care and support. We know from previous studies that disabled immigrants and immigrant mothers with disabled children report facing significant stigma from their cultural communities, which has the potential to impact attitudes towards the utilization of support services (Daudji et al., 2011; Hansen et al., 2017). Cultural values such as taking care of one's parents and elders also have the potential to impact care and needs to be explored further in data sets such as the PALS survey. The expectation of certain Asian cultures, for example Korean, Chinese, and Vietnamese, for the family to provide informal care to elders has the potential to be challenged by the assimilation of younger immigrants to Canadian cultural norms such as education and greater autonomy, impacting the care of older immigrants (Donovan & Williams, 2015). Without culturally appropriate care provided by the government, older people from more traditional societies may choose to not receive the care that they need. For example, Chang and Hirdes (2015) found that Korean Canadians had higher incidence of major chronic diseases and impairments, yet they were less likely to receive personal supports and home nursing.

The following chapters in the thesis use qualitative methods to address some of concerns raised in this chapter. Through narrowing down the region to the Middle East and South Asia, chapters 5 and 6 go beyond the numbers and examine the meanings and understandings that are associated with disability, disability services, and service provision. The following chapters focus on two regions, the Middle East and South Asia, which allows for an exploration of how culture and religion influences the lives of people with disabilities. In chapter 5, disability is explored from the perspective of key informants, who were both disabled and non-disabled. The chapter focuses on understandings of disability as well as services provided and needed in Middle Eastern and South Asian communities living in the GTHA. By focusing on services, the chapter provides some examples of why immigrants may or may not use services in Canada. Chapter 6 builds on these findings by focusing on the lived experiences of immigrants with disabilities from the Middle East and South Asia. These experiences include but are not limited to access to services, social relationships, employment, and navigating the built environment both pre and post migration to Canada. Chapter 6 uses feminist disability theory and an intersectional framework to explore the intersections of gender, culture, race, disability, services, and immigrant status to address some of the concerns of chapter 4. Due to the data being pre and post migration, it allows for a deeper analysis of the understandings and influences of culture on the lived experience of disability and how this can shift both through time and space.

Chapter Five

Key informants

5.1 Introduction

The previous chapter showed the differences between the Canadian born population and immigrants with disabilities in their use of support services based on age, gender, income, education, and severity. This chapter switches the focus from individuals with disabilities' perspectives to a community focus, which allows for a more careful exploration of people's experiences in their cultural communities and Canada. By focusing on the cultural communities from the Middle East and South Asia, this chapter examines disability and service use from the perspective of key informants. First, the chapter focuses on non-disabled key informants from mosques, followed by the voices of activist key informants, all of whom had a disability. The chapter ends with an examination of where services stand for immigrants with disabilities and how the key informant interviews inform the next research stage involving immigrants with disabilities.

Both purposeful and snowball sampling methods were used to recruit participants for this stage. In total, 10 participants were recruited, including 6 non-disabled key informants and 4 key informants with disabilities (see table 5.1). Before diving into the results of the key informant interviews, a further introduction to the participants is needed. Of the six non-disabled key informants, five were either Imams or had some form of leadership position at the mosque. Four were men and one was a head sister, meaning she was the wife of the Imam. The sixth key informant was a family doctor with strong ties to the Islamic community through his mosque and patients. All four key informants with disabilities were activist/advocates for immigrants with disabilities and had been part of forming organizations to help immigrants with disabilities. All key informants were first generation immigrants to Canada.

As mentioned in the methodology chapter (chapter 3), the original purpose of this chapter was to interview larger national service organizations. However, when those plans fell through; religious centers were contacted based on the recommendation of the cultural broker. Through visiting religious centers in the respective communities, access was gained to smaller organizations and activist individuals with extensive knowledge of disability within the Middle East and South Asia communities in the GTHA. The shift to a narrower focus on key informants actively engaged in these communities allows for a more in-depth examination of perceptions of services and disability within those communities.

Table 5.1 Key Informant Characteristics

Key Informant Number	Role/Position	Gender	Disability Y/N
1	Mosque leader	M	N
2	Imam	M	N
3	Imam	M	N
4	Top sister/ wife of Imam	F	N
5	Imam	M	N
6	Disability Advocate/Activist	F	Y
7	Disability Advocate/Activist	F	Y
8	Disability Advocate/Activist	M	Y
9	Disability Advocate/Activist	M	Y
10	Family Doctor	M	N

5.2 Voices of religious leaders and providers

The following section presents the voices of Imams, religious leaders, and one Muslim family physician who were involved in the community and providing some form of services to people with disability. The first section focuses on the importance of helping others in Islam, including the idea of zakat and charity. Secondly, descriptions and understandings of disability in the context of Islam are explored. Lastly, the section explores understandings and provisions of services provided by Mosques.

5.2.1 The importance of helping others in Islam

The Muslim community is a relatively young community in Canada, which can be linked to the change in immigration policies in Canada and the change in countries from which people emigrate. The participants were all first-generation immigrants and so were many of the members of their mosques; for many new immigrants, religious institutions serve as important places of information and community, and throughout interviews with mosque leaders and members it became clear that mosques wear many hats and that they are important places to gather in the community and not simply a place for prayer, but also serve as venues for social events such as Saturday dinner and Eid celebrations. Additionally, some Mosques have their own schools, provide funeral services, and serve as food banks for their members, amongst other services. The interviews also highlighted that mosques are often important places of first contact for many new immigrants and refugees when they come to Canada. They are sites where they can receive help with finding housing, employment, transportation, welcome dinners, workshops and seminars on how things are done in Canada, along with translation services from other members. Participants explained that helping others is central to the Muslim faith and that it is a duty/ obligation that has been bestowed upon Muslims by the prophet Muhammed. Key informant 5 explained:

> *This is our Islamic duty. To help all kinds of human beings who needs our assistance… Any human being, doesn't matter if they are Muslim, he belongs any religion, he is our brother, we are product of Adam and the product of Eve, they are our fathers, we have to help each of them in good faith. Because the Qur'an says, the Qur'an says [Arabic] help each other in goodness and don't help each other in the evils.*

The quote gives an insight into how imbedded it is in Muslim culture/religion to help others and not only people of their own faith. Muslims are not only required to help, but have also been ordered by Muhammad to pay Zakat, a form of "tax", to the mosque every year, to help those in need and those who are poor. The amount that people are required to pay is usually 2.5% of their household income, but in some of the mosques visited for this study, Zakat was as high as 6.25%. Key informant 5 explained:

> *… as five-time prayer is necessary, there is one thing that is a big part is the obligation to charity. Every Muslim who is wealthy, he has to pay every year 2.5% of his value because in addition to his own needs. So, whatever he has to pay 2.5% of that. Because in our land we call zakat, the obligatory charity…*

Zakat is only expected of people who are financially able to pay and is part of the fulfillment of the five pillars of faith that Muslims must abide by to be a true Muslim. The money that is collected from Zakat is used for charity including food banks, feeding the homeless, disaster relief, and helping members who are in financial trouble. Participant one explained that Islam is not only about prayers and fasting during Ramadan but so much more, especially providing services. Services and charity are extremely important for Muslims because it is believed that helping others will elevate a Muslim in their paradise ranking.

The next section explores participants' understandings of disability with attention to how the complex intersection of faith, culture, and services shapes perceptions of disability.

5.2.2 Understandings of disability

When asked about how they understood disability, the majority of participants referred to physical disabilities in relation to mobility restrictions such as getting around the mosque, sitting down to pray, and wheelchair use. One participant, the family physician, mentioned developmental and mental disabilities, referencing cases that he was familiar with from his own mosque and his job as a physician

All non-disabled participants expressed positive views of people with disability, noting that they had disabled members at their mosques and that these members did not face stigma or barriers when attending the mosque. However, it should be noted that while participants spoke positively of members with disabilities, most of the key informants mentioned that they only had 1-3 members with disabilities who attended their mosque regularly. The largest mosque said that they had over 500 families where someone had a disability. Despite the positive views of participants, different perceptions of disability were uncovered in their interviews. One way in which disability was characterized came through the idea of the normal vs abnormal. Key informant 5 made the distinction between normal and abnormal several times as seen in the following two quotes:

> *Prophet Muhammad said, the prophet ordered us to help each other. Doesn't matter that he is disabled or normal.*
>
> *...he insists of us, he said they are your brothers, they are like you. They are, if they are losing something [have a disability], it is an exam, because in Islam we say, life by itself is a trial. Life by itself is a trial. You are normal, or you are abnormal.*

The two quotes show the participant's clear distinction between being disabled and being normal. He further goes on to explain how they try to help people with disabilities at his mosque to get back on their feet, so that they can stand like normal people. Several participants mentioned the idea of healing people with disabilities and getting them back to normal. The belief that everything can be cured except death is stated by key informant 3 below:

> *…this is a prayer where we are taught these prayers by our Prophet Mohammed, he has taught us prayer for different ailments and for different diseases and he has taught us also that everything can be cured except death.*

In addition to (ab)normality, people with disabilities were also repeatedly characterized as disadvantaged, needy people, poor people, and people in need of charity. The following three quotes show this grouping:

> *More important than even prayers and fasting and so on, is to look at people who are disabled, people who are poor, people who are disadvantaged… (participant 1)*
>
> *They would share anything with the people who are not… And this is why there is also a high reward, high reward in Muslim faith for helping any person who is disabled. (Participant 1)*
>
> *We offer them prayer, other than that we have a system and office within the community who takes care of the needy people. You might have heard the name of humanity first, humanity first is a partner organization which helps all kind of disabled, homeless people, (Participant 3)*

Because people with disabilities are positioned as less than "normal" by being categorized as needy, they become objects of charity and viewed as dependent on others. The second quote above by key informant 1 shows the connection between charity and disability. By saying that there is a high reward for helping a person with a disability it becomes more about the person who is performing the charitable act and not the person with the disability. Focusing on the importance of the act itself may result in an overall lack of understanding of the needs and wants of the person with the disability. The link between charity and paradise is furthered by key informant 1 in the following quote:

> *We believe in the hereafter and so on. And one of the things he says is that people who help people, who actually live their life to serve people who are at disadvantage, who are disabled…*

While categorizing people with disabilities as needy and objects of charity was common among non-disabled participants, the family physician had a different view of disability. Significantly, he explained that culture had greatly influenced how Muslim people view disability and that these cultural views of disability were brought with them to Canada. He explained:

> *…the minute you know somebody is disabled it seems like we right away compare it to… judge that they are incapable and less capable for example physically, they are going to be of course poor because they are unable to offer or get or gain an employment bring a good income… it was a like any disability will carry some sort of an imaginary lower level or level class people. Although it's against the religion to think this way but still culture is different.*

Interestingly, he argued that the negative view that many of the other participants held of disability goes against the Muslim faith. Moving beyond understandings of disability and back to services, the next section focuses on services provided by mosques as well as the work that mosques do to inform members of services and their view of services provided by the government.

5.2.3 Understandings of Services.

As part of the research, participants were asked about the specific kinds of services they provided to members with disabilities. The answers varied greatly, with the large mosques/centers not unexpectedly mentioning more services than smaller places. For example, larger mosques provided sign language interpreters for their highly attended Friday prayers, while smaller mosques/centers mentioned that they provided accessible space but that they did not provide specific disability services because these services are provided by the government. Reflecting the earlier discussion, the majority of participants, when asked about disability services, brought up their services for "needy people" such as the foodbank and financial support through their charity box as seen in the quotes below:

> *Interviewer: … do you provide any services or assistance to people with disabilities?*
> *Key informant 4: No, we try to help out with financials. That's about… and the food bank… They come to us and if we can't help them, we try to put them to the region, the Peel region. So, we put them on to that, like services. We have brochures that we will give.*

> *Interviewer: Do you provide any specific services [disability services]?:*
> *Key informant 5: We have many kinds of services for them [people with disabilities]. At least we can help them to take them to hospital, or visit the hospital. If they need financial help, we have, we can provide them through our charity box. If they need, if they require it, they can get help from the organization.*

Some participants also mentioned that they provided prayer for people with disability as a service. By linking services such as a foodbank, financial support, and prayer, participants make the assumption that people with disabilities are "needy" and require their help, where this might not be the case.

One of the newer ways that members are informed about services was through social media, with several mosques using different social media platforms such as twitter and Facebook to inform members of services and events at the mosque. Online newsletters and server lists were another way that information was shared. One of the larger mosques had a designated office where people could go to get information about government and community services. Another of the larger mosques used phone calls as the main way of informing about services. Key informant 3 explained:

> *We have divided up our memberships into groups, sub groups, for example, if you are a member, I'll ask you to [tell them that] these are the ten homes you are responsible for them. To just convey them the message, so what we do if there is anything we need to communicate I will be just calling him and calling the homes. So, if we have one hundred*

> *houses there are 10 people we have appointed and all we need is to just make ten calls and before the day is over these hundred people will have the message. So, the system of communication is very effective.*

As mentioned by key informant 3, this mode of communication had been very effective for their mosque. Another powerful way that people are informed about services is through word of mouth among members and community members. For many mosques, word of mouth was still the most effective way of communicating information. The highly attended Friday prayer was another way that people were informed about services and charities.

In addition to providing services, the majority of the participants mentioned that they did everything possible to direct members with disabilities to the appropriate government service to make sure that they were aware of them. Mosques have also taken it upon themselves to inform members of services provided not only by themselves but also by the government. Participants explained that they had noticed that members often did not know about services, and this was especially true for older members. To address this, mosque leaders and Imams now meet with city officials to learn about services, which they then relay to their members. Key informant 4 explained:

> *Through my husband's knowledge of it, he would be told that there is a special seminar going on, educational services, whatever services are available, the Peel board will let him know to set a representative. That is how we would know. So, we would send a couple of the volunteers to go, to attend the session.*

The relationship between mosques and government agencies was seen as extremely important to ensure that members were informed of available services.

Overall, participants had a very positive view of government provided services. One smaller mosque explained that they did not feel the need to provide a lot of disability services to their members because they are so well taken care of by the government through services such as Ontario Disability Support Program (ODSP) and accessible transportation. Key informant 3 explained that it often takes new immigrants a couple of years to learn of the services that are available to them but once they do learn, they are happy with the system..

5.3 Voices of key informants with physical disabilities

The following section explores the perceptions of key informant activists/advocates who had a physical disability. While the first section's key informants were all Muslim, key informants in this section represented several religions such as Islam, Hinduism, and Christianity but were all from the Middle East and South Asia and had extensive experience in living with a disability and advocacy/activism.

5.3.1 Charity and Zakat

The previous section showed how people with disabilities are often categorized as being needy, poor, and in need of charity. While this was the predominant view of non-disabled key informants, this view did not align with the views of key informants with physical disabilities from these cultural communities. For example, Zakat was not mentioned by any of the key informants who had a disability, and those who mentioned charity at all referred to it negatively. Key informant 8 argued that when you attend a mosque or a temple that adopts a charity approach to disability, this results in a feeling of not being included or equal to other members. Similar to the physician in the previous section, key informant 6 mentioned the intersection of religion, culture, and disability. She argued that nowhere in the Qur'an does it say that people with disabilities should be treated like objects of charity, she explained:

> *…their [imams] understanding [of disability] is very limited. And we have done a lot of work around their… by the way, but it's surprising that their understanding is still very limited. And again, you know, the charity model is again the cultural influence. There is nothing in the doctrine that says, charity toward disabled people. It's again, overarching people who are less fortunate. It is not specific to disability, it's people who are socially on the margins. So, it's not the label of disability per se. it's more tied to financial capacity and all that kind of stuff. (Key informant 6)*

In the above quote, the participant is referring to Imams and the broader community with which she has experience. She argues that the categorization of people with disabilities as being needy, poor, or less fortunate is a cultural construct because the Qur'an does not say this. In reference to the religion the Qur'an says that charity should go to those who are socially on the margins, however, the notion that people with disabilities necessarily belong to this group is a product of cultural influences. She further explained that many of these negative views of disability in Islam and her cultural community reflect the negative views of disability that persists in South Asia, where the idea of Karma and reincarnation has contributed to these views. She explained:

> *Which may not be something that Muslims necessarily believe in, we don't believe in reincarnation, but we sort of inherit that value around disability that, you know, it's a curse, as... it's a punishment, it's a curse. So those kinds of taboos are often conflicting for many Muslim families with their cultural values although their faith actually does not discern disability in any way. It is just a fact. God creates it, God creates us as he wishes, and God does not create imperfection. God creates perfection.*

In this quote, it becomes clear that the respondent believes that the intersection of two different religious beliefs, Islam and Hinduism, creates a unique situation for Muslim families in South Asia who adopt the idea of disability being a curse or taboo from Hinduism despite it being against their own faith.

At the same time, the participant also argues that disability is neither a test nor a gift from God but instead is merely a 'fact'. She says that God does not create imperfection, therefore someone with a disability is not imperfect or abnormal, which is different than some of the perceptions displayed by able bodied participants.

None of the key informants with disabilities accessed services in their mosque, church, or temple as none of the services provided fit their needs. At the same time, they identified several barriers and restrictions when it came to accessing services outside their respective religious institution, which will be discussed further in the next section.

5.3.2 Services – barriers, needs, and the way forward

Several barriers to accessing appropriate services at larger charitable organizations were mentioned by key informants, but one of the most significant ones was that services did not fit their needs. Key informant 7, who had polio, explained that when she came to Canada in the 1990s she had gone searching for services and had been put in contact with March of Dimes. However, she explained that because Canada had experienced polio in the 1940s, the support group to which she was assigned was made up of older people who were at a very different stage in their life in regard to their illness, age, marriage, family, and needs. She did not feel that she fit in because she was in her twenties and about to get married herself. So, while a service existed for polio survivors, as a new immigrant she had very little in common with these people, which influenced the appropriateness of the service. Another participant explained that although much progress has been made in service provision for immigrants, especially in physical and mental health services, but that services for immigrants with disabilities were still lacking. Key informant 6 explained:

> *Certain sectors have done better [at providing services], health is doing better around it. Mental health is doing better around it, but disability services isn't necessarily. And that's why you find different cultural groups and organizations coming forward to serve their respective communities, so you know you have networks, you have a network within*

> *the Tamil community for example, you have some specific projects within the Chinese community to support their community members for example.*

As seen in the above quote, because services are lacking or do not necessarily fit the needs of immigrants, immigrants with disabilities are forming their own networks and service organizations to address these needs that are not fulfilled by government services or organizations like the Canadian National Institute for the Blind (CNIB) and March of Dimes. Key informant 7 explained that public services and disability organizations are still based on white culture and that this is not going to change unless you make them, she explained:

> *So, the system is still like white based culture, I mean culture not skin and you have to break in and you have to make yourself noticeable to break in. and they are not going to… why would they want to reach out to you? System is working, why would they want to do change?*

In this context, immigrants often find that they cannot bring up their needs because there is a lack of cultural competency among case managers. Key informant 6 believes that the lack of cultural competency and diversity strategies is because of the lack of funding for such projects and if they are done it is on a project basis and not more permanently. Key informant 6 explained their culture of care and family needs often differ from those seen in North America. She explained that the conventional group homes for people with developmental disabilities, which are common in North America, do not fit the needs of Muslim families for whom it is the norm to take care of their loved ones at home. They are therefore not seeking residential care but are instead looking for in-home supports, which can help their family members to maintain their lifestyle. Further, she explained that other programs will often put on events that are not appropriate for their communities such as Halloween and Valentine’s Day parties, which results in them not using the service.

Given dissatisfaction with the charity model in their cultural communities and the absence of immigrant-focused disability services, some key informants had started their own organization in the 1990s to address this need in the immigrant community. They found themselves becoming activists, fighting for the rights of immigrants with disabilities and hoping to improve people’s access to and knowledge of services. The organization was run by a small number of volunteers who made it their mission to create an organization that catered to immigrant needs and where immigrants with disabilities could go to receive knowledge of available services provided by other organizations. They wanted the organization to be the liaison/missing link between newcomers with disabilities and the system, while also advocating for more inclusive services. Unfortunately, due to the fact that this organization was led by few individuals who had their own lives and careers, the organization failed to become what they had hoped for; an organization that could complement existing organizations by providing immigrants with disabilities with information and guidance. While the organization still exists today, the majority of the key informants moved on to form other organizations because they saw a need for organizations that could provide information and services for their specific cultural and religious community and immigrants with disabilities.

Forming the organization had not been easy or without barriers; one of the barriers that they faced was the perception that they were duplicating services that were already provided in Canada. Key informant 9 explained:

> *…okay, so we tried, we started right [referring to start of the organization]. We agreed on a lot of things and those individuals had the same things in common at that time*

> *[immigrants with disabilities from Middle East and South Asia]. But the lack of funding, even the lack of acceptance [by other organizations and funding agencies] of such an organization at that time I heard few questions saying, "why this duplication", "why do you need an organization like this [catering to immigrants with disabilities] when we have other organizations that assist people with disabilities?" Where [name of organization] wasn't to have an individualized organization, it was to complement whatever available simply because their [immigrants with disabilities] needs are different.*

Because of the challenges and struggles with support from society and the government, as well as the issues with regulations, key informant 9 decided to no longer be part of the organization. Further, they explained that many of the issues they tried to eliminate within the organization are still present today and public service providers simply do not have the time or training to tailor programs to immigrants with disabilities. Due to lack of assistance by the government and the failure of several disability organizations, knowledge of services still relies mostly on word of mouth. Despite the missed potential of their ethno-cultural organization, community disability organizations were still found to be important for notifying people of services. These organizations are especially important in providing information about services to people who have languages barriers and/or are socially isolated without access to information about services.

Participants had several ideas and wants about what they would like services to look like for immigrants with disabilities. Key informant 8 believed that the ideal solution would be a one-stop-shop where people with extensive knowledge, like the key informants, can provide help and assistance with finding services but also with applications and appeals. He believed that having a one stop shop would allow for a more holistic approach to the provision of services to immigrants with disabilities, which would focus on advocacy, training, and independent living. It was noted that for a place like this to exist there would need to be substantial funding since training people on these issues and staying on top of them is extremely time consuming.

While key informant 8 hoped for a one stop shop, key informant 6 had ideas of how things could change within her own community. For change to happen she believed that the larger community needed to understand that charity and building mosques will not change anything. Instead, there is a need for people to understand the importance of developing programs that support people with disabilities. She explained:

> *We need people [the members of the mosque] to understand that they need to give [zakat/donate money] to local programs and services to meet community needs [such as disability programs] rather than just put all their resources into building a mosque or building a school or sending relief dollars to feed people in somewhere.*

It was her belief that if some of the charity dollars that people in her community donate was used for services, real change could happen. Overall, money was a common factor in why organizations had a hard time doing what they set out to do and why more established and heavily government funded organizations like the CNIB and March of Dimes do not provide appropriate and extensive enough cultural care and outreach.

5.4 Discussion

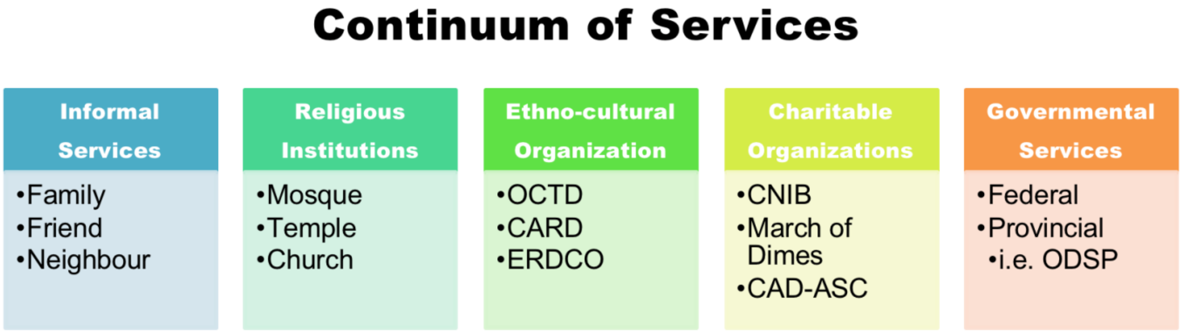
By examining the views of both non-disabled and disabled key informants, this chapter sheds light on the intersection of religion and culture in regards to disability, and how these influenced understandings of disability as well as the approach to service provision. Findings from the key informant interviews showed the importance of charity and helping those in need in the Muslim faith and that people with disabilities often were viewed as being the recipients of such charity. However, further examination of this type of charity revealed that individuals with disabilities did not want charity but instead they wanted appropriate services to live independently and to be treated as equals in the community. For some participants, the charitable approach to disability was a result of the intersection of religion and culture where cultural views of disability as weakness and neediness had influenced religious views, assigning people with disabilities to a broader category of those in need. Participants with disabilities explained that the Qur'an did not categorize people with disabilities as needy.

The idea that people with disabilities are objects of charity is certainly not limited to Muslims and people from the Middle East and South Asia. Similar cultural ideas persist in North America and Europe where people with disabilities have long been portrayed as objects of charity in the media (Barnes, Mercer, & Shakespeare, 2000, p. 182; Riddell & Watson, 2014, p. 44). Portraying persons with disabilities as objects of charity then reinforces negative stereotypes while also becoming another form of victim blaming (Barnes & Mercer, 2001). To some extent, this charity model has been challenged in European and North American contexts through disability rights movements, which have advocated for inclusion and accommodation instead of pity and charity. Middle Eastern and South Asian countries have not experienced the same degree of activism and advocacy for disability rights compared to many Western countries, for example Canada, the United States, and the United Kingdom, and for this reason it might be harder for Muslim communities to move beyond the charity model as it is so engrained in culture and religion.

The results showed that most non-disabled key informants indicated that they had less than a handful of people with disabilities attend their mosque, it is possible that attendance is so low due to people not feeling welcome or accepted for who they are at their place of worship due to the dominant views and categorization as objects of charity and pity. This proposition is supported by a 2007 report prepared by the Canadian Association of Muslims with Disabilities (CAM-D), a national organization aimed at increasing awareness, inclusion and access for people with disabilities. Their report found that Muslims with disabilities often faced negative attitudes, feelings of pity, as well as stigma in their mosques. These experiences influenced their engagement with mosques and some had stopped going altogether or felt a need to hide their disability (Khedr, 2007).

It is important to note that this chapter does not argue that charity is negative or that it should be abandoned by the Muslim faith or other religious communities. Instead, the argument articulated by disabled participants was that they would rather have a focus on more inclusive services that furthered their participation in society as compared to charity that kept them vulnerable and dependent. Given the importance of charity in Islamic tradition, mosques have the potential to become an important ally in providing services for immigrants with disabilities. However, it is important that these services are designed by and for people with disabilities to ensure that they are inclusive and appropriate.

Importantly, key informants who had disabilities explained that they are currently caught between a charity-based model of services within their cultural communities and the mainstream disability services provided by organizations such as the CNIB, March of Dimes, and group homes. The charity model categorized people with disabilities as being dependent and in need of charity whereas the mainstream services were found to be culturally inappropriate and/or inaccessible for immigrants. Because of this gap in services, some key informants had formed their own service organization in an attempt to address this need within the immigrant population and the cultural communities. The goal of the organization was to be part of the continuum of services (see fig 5.1) and to create a connection between immigrants and other service providers, as well as educating people about the needs of immigrants with disabilities.



Continuum of Services

Informal Services	Religious Institutions	Ethno-cultural Organization	Charitable Organizations	Governmental Services
•Family •Friend •Neighbour	•Mosque •Temple •Church	•OCTD •CARD •ERDCO	•CNIB •March of Dimes •CAD-ASC	•Federal •Provincial •i.e. ODSP

OCTD: Organization of Canadian Tamil's with Disabilities, CARD: Canadian Alliance on Race and Disability, ERDCO: Ethno-Racial People with Disabilities Coalition of Ontario, CNIB: Canadian National Institute for the BLIND, CAD-ASC: Canadian Association of the Deaf

Figure 5. 1

It is not uncommon for people to create disability organizations when they identify a need that is not fulfilled by other organizations. An example of this is United Cerebral Palsy (UCP), which was created by parents of children with cerebral palsy seeking other parents who were in the same situation and wanted to make physicians aware of the lack of services (Fleischer & Zames, 2001). Participants were "forced" to become activists as a way to provide the services that they knew were needed. The identified lack of ethno-cultural disability services resonates with the current literature, which identified that, for example, occupational therapists lack training in providing culturally sensitive services (Lindsay, Desmarais, et al., 2014; Lindsay, Tétrault, et al., 2014). Similar results were seen in a CNIB study that showed that staff felt that they were unable to provide services to members of ethnic groups because they lacked cultural sensitivity training and awareness (Shaw & Gold, 2009).

The descriptive results from chapter 4 (see table 4.3) showed that immigrants were more likely to be cared for by a close family member as compared to friends, neighbours, or organizations. Linking this to the results discussed in this chapter, the reason for this lower use of “other” forms of care could be because of the barriers that they face in the knowledge of services available as well as the appropriateness of these services. Results in this chapter showed that group homes are considered inappropriate for Muslim families, who put a great emphasis on family taking care of their own. This is supported by the current literature, where Hasnain et al. (2008) explain that the Qur’an states that it is the duty of children to take care of their parents in old age and that this applies to the weak and disabled as well. Further, they explain that these values of family care are often brought with them and magnified when they immigrate and find themselves in foreign environments where they have less access to community supports and often share a distrust in regards to health and social providers (Hasnain et al., 2008).

The next chapter moves beyond the views of key informants and focuses on the lived experiences of immigrants with disabilities from the Middle East and South Asia, living in the GTHA. Using semi-structured interviews topics of services utilization, understandings of disability, and barriers faced in everyday living are explored to build on findings from chapters 4 and 5.

Chapter Six

Immigrants with Physical Disabilities from the Middle East and South Asia

6.1 Introduction

Building on chapters 4 and 5 this chapter goes beyond the statistics and key informant views to explore the experiences of immigrants with physical disabilities from the Middle East and South Asia living in the GTHA (see table 6.1). First, the chapter explores the pre-migration lived experiences and barriers that participants faced in their countries of origin before moving on to their experiences of migration. Lastly, the chapter explores the post-migration lived experiences of participants in Canada. While the chapter is organized around experiences before, during and after immigration, it is important to note that the lived experiences of participants are more complicated than that. There are both tensions and continuities that are experienced over time and place that both distinguish and connect the different stages and places of people's lives[9]. The concluding discussion of this chapter explores these experiences as a whole.

Table 6.1 Participant Characteristics

Number	Name	Gender	Age
1	Daisa	Female	45-55
2	Erajh	Male	45-55
3	Idris	Male	45-55
4	Faheem	Male	45-55
5	Nazeer	Male	20-30
6	Milana	Female	30-40
7	Farah	Female	45-55
8	Azar	Female	20-30

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[9] I recognize that there are important differences between countries within these regions, however, to preserve the confidentiality of participants in the research some information has been generalized or deliberately minimized.

6.2 Pre-migration experiences

6.2.1 The built environment and assistive devices

Participants faced numerous challenges in their countries of origin, which made it difficult to live there with a disability. Many of these challenges were centered around accessibility in relation to the built environment, education, employment, and services. The built environment was primarily a concern for participants who used wheelchairs to get around. Inaccessible built environments manifested themselves in different ways, including sidewalks with no curb cuts, no sidewalks at all, inaccessible buildings, and lack of elevators. Idris and Farah had to rely on family members to transfer them from their apartments to the street or a car because of stairs and inaccessible roads. Daisa lived in a small town situated in a mountainous region with few sidewalks. Instead of using a wheelchair, she used crutches so that she could stay mobile and get around independently. When she came to Canada, she was forced to use a wheelchair as her body could no longer handle the pressure of the crutches.

The built environment did not only keep participants from leaving their houses without help, but it also limited their access to education. Many schools were inaccessible due to a lack of ramps. While some classes were moved to accommodate some participants with disabilities, Farah decided to quit school as she did not want to rely on her brothers to carry her every day, she explained:

> *…the principal she told my mom, [name of participant] can come back to school if she wants to, we will remove her class… to the first floor, you have to go maybe around 12 stairs to the court, to the play, whatever, the playground or whatever and from there you have to take another maybe 12 stairs to go to the first floor. I said to my mom, I am not going back to school, I don't want to put pressure to my brothers to take me up and down the stairs to go to school and in the winter time, I am not going to.*

After quitting school, she got a job and decided to take French classes at a private language school to improve her French.

Daisa faced problems when trying to access university; she was not able to go to university in the capital because of war but went to a university in her province instead, which had little awareness of accommodation issues:

> *I have a disability and they don't have accessibility, they don't even… they can't spell accessibility. So, it's very, very difficult to move around to do things…*

Because she was using crutches and not a wheelchair at the time she was able to attend university, however, it was still a challenge to do so. Milana explained that in United Arab Emirates (UAE), public special needs schools were only available to citizens of the UAE forcing non-citizen parents with children who have disabilities to pay for private special schools or have no access to schools at all.

6.2.2 Employment

Barriers were also faced when trying to access employment. Milana was denied a job at a hospital because managers feared she would need accommodations given her use of a power wheelchair. However, when she visited the hospital, she found that it was a fully accessible building. She believed that it was the perception of her disability that was the real reason for her being denied employment and not accessibility, as she explained:

> *…they say that it is accessibility. But I assume that they were afraid that I won't be able to do it perfectly, I would be asking for more sick leave.*

Faheem experienced that he was not able to succeed in employment in his home country because of the lack of access to assistive devices. He said:

> *…they are not having these assistive devices, assistive devices actually they have a role in bridging this gap for people with disability. We don't have this in [home country] so they try to accommodate and respect but when it comes to the practical things because of the*

> *lack of assistive devices, people with disability cannot make it to the leadership and some places [and] also some jobs and things like that.*

Not having access to assistive devices, for example computers and magnifiers, meant he was unable to perform at the same level as his peers and therefore he was, in his opinion, not able to advance his career.

All participants who were employed prior to moving to Canada spoke to the difficulty of finding employment and especially meaningful employment. Milana explained how her boss had to fight for her to be hired as a translator and how her boss was faced with negative attitudes around Milana's possible employment. Milana argued that concerns about her ability to perform her employment duties were misguided. She explained:

> *...I remember telling my boss later on; do they want me to dance or to be a translator? If they wanted me to dance, I cannot. That's true! But if they wanted me as a translator I can do a good job.*

The visibility of her disability meant she was unfavourably judged and her ability to work was questioned despite being able to do the job well since it did not require someone who could walk or was fully mobile.

Farah who had had a job working with and advocating for people with disabilities in her home country found that there was limited job security when it came to her own employment situation because her employer was a non-government organization with precarious funding. More generally, she found that jobs for people with disabilities in her home country were hard to find and those available offered low wages that did not provide the financial basis for a reasonable life. She further explained that she eventually left her country for Canada because of the accommodations that she could receive in everyday life, despite having a job in her home country.

Lack of access to assistive devices, barriers to employment, and inaccessible built environments reflect broader societal and cultural values surrounding disability. To examine this further, disability and culture is evaluated in the next section.

6.2.3 Culture and Disability

Many different themes were found in relation to culture, with major themes centered on shame/stigma, weakness, and marriage/relationships.

Several participants mentioned either hiding their own disability from others or seeing how other people with disabilities were hidden in their communities. Idris explained a situation that he had observed prior to becoming disabled himself:

> *When I was able bodied, our neighbor, that I know them for years… I was on the roof and we have a second town house, but there was a backyard, a shared backyard, one time I was there, and I looked at the back yard and I see a disabled child, she was, well CP, that is on the back yard. So, I ran to my mother downstairs and said, "I just saw a person, who was weird", those were the words I used I think. And she said, yeah, they have a disabled child. I said "wow, I've never seen her" she was maybe eight years old, you know, a girl. So, speaking of hiding, feeling ashamed that they had a disabled child, yes, that is the way it is there*

Idris' observation demonstrates the pressure parents face to hide their children from the community by keeping them at home and out of school because of the shame and stigma surrounding disability. Daisa, who was disabled as a child, commented that there were no other children with disabilities at school:

> *… Nobody with a disability was in the school, maybe one guy. So, I thought there was no disability in the town, people with disabilities. I didn't think there was*

> *anybody, right. But then I realized later on in life that their parents did not let them go to school.*

Indeed, Daisa's own parents had kept her out of school early on because of her disability. She explained that her parents were scared for her and her mom had therefore home schooled her until later when they let her go to school. Erajh also talked about his parents' reluctance with respect to schooling. His parents did not want him to attend blind school because they were ashamed of his visual impairment and did not want him to use a cane. Some participants with disabilities who had attended school recounted experiences of discrimination and bullying from teachers, principals, and other students. Faheem commented that discrimination against people with disabilities was so ingrained in the culture that it was rooted in folklore, the school curriculum, and poetry. Azar observed that parents would hide their children's assistive devices as soon as they left the classroom. She explained:

> *So, those parents didn't want their children… they didn't want other people to know that their children had a hearing impairment and even their close family didn't know, so when they were at dinner parties and things like that their aunts and uncles didn't know, nobody knew.*

That families went to great lengths to hide disability is not surprising considering some of the experiences that participants recounted. Idris explained that it was common for people in Iraq, including family members, to not come to the house to visit if there was a disabled child because the child was considered a curse from God that might be passed on. Parents also hid their children as a way of protection, yet Daisa argued that this protection really amounted to a form of imprisonment. Being from smaller towns and rural areas also greatly limited the exposure that people had to people with disabilities.

Further, Daisa explained that it was not uncommon that a person with a disability was hidden for their whole life and when they passed away no one, except for the family, had ever known them. Parents' shame and their efforts to hide children with disabilities were observed by participants 30 years ago as well as in recent years.

Participants suggested that the pressure to conceal disability was linked to perfectionism and the idea of the Middle Eastern ego. Idris, who uses a wheelchair, explained that physical appearance is so important in Middle Eastern cultures that having a disability challenges the desired physical appearance as seen in the following quote:

> *... having invisible disability may be a blessing as it is not very obvious. Even the physical appearance, in that culture, appearance is important to that culture. So, think about two physical disabilities, one like me, my body is the same, my face, my smile, my this and yet another person with let's say CP or another disability where the body or the face will be disfigured. So, I am blessed to have that vs another person who [pause] so, that person will be seen as even worse*

The quote demonstrates that Idris believed that it would have been a blessing if he had had a less visible disability but that he was also lucky because he did not have any visible disfigurements. The idea of weakness and striving for perfection was mentioned by many participants as one of the root causes of negative cultural perceptions of disabilities in their countries. As several participants explained; Middle Eastern culture valued people based on their performance, ability, and contribution while also being closed off and narrow-minded in their understandings of the abilities of persons with disabilities. Ego, particularly the male ego was mentioned by participants as a reason behind many of the negative perceptions of disability in their culture. However, the ego is not only related to disability with any form of 'weakness' being heavily stigmatized and feminized. As Idris explained:

> *...in general, [Middle Eastern country] have very high ego, yes. And it can work against them when they are asked, for example by a medical professional will say:" are you in pain?" and the answer will be, even if I am in pain I will not say "I am in pain" because I am a man, I am not supposed to be in pain.*

Idris explained that the male ego in his culture had contributed to him being ashamed of his disability and conditioned him to not show or express pain as this was seen as weakness. When he became disabled, he became dependent on other people for his care and movement, which was extremely difficult for him. Azar had experienced similar notions around how ego and weakness has impacted stigma around disability, she said:

> *I think there is definitely a stigma in [Middle Eastern country] when it comes to disability, it's a country where we drive ourselves to be perfect we can't be seen as weak.*

A general lack of sensitivity towards disability or anything that could be interpreted as weakness was observed by participants in their own cultures. Weakness, not being limited to disability, included gender i.e. being a woman, or being of a different race or ethnicity. Faheem explained:

> *It's is not only towards disability, towards weakness in everyone. They could harass women for example for their status in the society, they could harass [people] with disabilities, they could harass strangers for being, for example, different in their race or ethnicity or things like that. So, it is part of the superiority and inferiority of how they consider people superior or inferior. So, it is kind of discrimination, kind of oppression, things like that, so, it is there in the culture.*

At the same time, Faheem explained that it was possible for a disabled person in his country to be considered superior if you "overcame" your disability:

> *...when you have disability and you achieve people's consideration for that change, drastically change [performing above what they expect you to be able to], [they go] from discriminating against you and considering you as inferior to considering you as superior because you overcome this kind of disability... but you have first to prove it [that you could still perform as non-disabled person]. You have to prove yourself first, so this [being viewed as superior] sort happen.*

One of the ways that people could “overcome” their disability was through education. Instead of people with disabilities being accepted and respected for who they are, they had to prove themselves first and earn respect from their culture. Considering that being female was also viewed as a weakness, being able to “overcome” ones disability is likely limited to males since women and people of other races and ethnicities would still be disadvantaged.

Two participants mentioned that perceptions of disability had changed over time in their home countries one example of this change was due to war. Because many soldiers became disabled in the war it was no longer thought of as karma or an act of God, which helped soldiers with disabilities be accepted into society.

Negative perceptions of disability not only limited access to education and employment, and the visibility of disabled people in the community but also impacted social relationships and marriage. Not all participants were married but most talked about the relationship between disability and marriage whether it was based on their own experiences or those of other people in their community. There was agreement among participants that someone with a disability was less likely to marry compared to someone who was able bodied. Idris explained that marriage is extremely important in Iraqi culture, however, when people have a disability the expectation of marriage goes away. Idris said:

> *I: So, would you say that marriage is very important in Iraqi culture? Getting married?*
> *P: Yes, but when you become disabled it is okay if you don’t get married, people will view it, you cannot get married, you cannot have kids, how you can perform, how you do your duties as a husband, as a father*

Not all participants mentioned gender and marriage together but those who did, believed that males with a disability would be more likely to marry than women who had a disability. As long as the man could provide for the family, it mattered less if he was disabled compared to a woman. Milana commented:

> *An adult with disability, no one thinks… without saying it explicitly, you can feel it that you cannot… you won't go into a relationship. You won't get pregnant. I mean there are cases, of course, where they were married, and they had kids but these are very, very, very, limited cases, a very small number. I mean while any man, mostly, any man in a wheelchair would make proposal to women and it happens but us, we never get proposals. Let's say we rarely get proposals.*

For women, the theme of pregnancy and children was prevalent throughout the interviews. Several women explained that it was often assumed that they could not become pregnant as disabled women, which meant that there was no reason to marry. Even if a person really wanted to marry you, they would not be supported by their family or the community because of the stigma of disability. From a male perspective, if a male with a disability could not provide for his wife and children he would be considered useless and not marriage material. Idris felt strongly that he had missed out on the opportunity to get married because he internalized these negative stereotypes of disability expressed within his home country.

While the likelihood of marriage was low, one participant explained that many who did end up getting married had to settle when it came to their partner instead of marrying the partner they wanted. Daisa, who was married, had felt that her family's view of disability and marriage had been hurtful. Her brother believed that she should not get married and that she should instead live with him. Her parents could not decide if it was a good idea for her to get married or not, although they never discussed the issue with the participant herself. While her friends started looking for possible spouses and preparing for marriage, she did not. It was not only her family who displayed negative attitudes towards getting married but also the overall community. She explained:

> *...so, people treated my friends differently especially when it comes to marriage and there were a lot of these expressions that they used on these occasions something like you go to a wedding they tell you usually they wish you hopefully you are next or we hope you are next to be married. To me, they used to tell my friends, they will tell you, we wish you are next, which is a good wish, me they will tell me we wish your brothers next.*

There was an assumption that she would not or could not get married because of her disability. Daisa found this difficult because her culture and faith had taught her from a young age that women needed someone to take care of them and she was not given that opportunity. She later married when she came to Canada.

Another dominant theme throughout the interviews was the importance of family and most critically the presence or absence of supportive parents who were willing to advocate for their children. Participants who had supportive parents emphasized the importance of this support and how it had helped them feel part of the community and gain access to education. Such parents played a significant role in making sure that children were included and did not feel left out or hidden. For Milana, it was not until later that she realized the courage her parents had had when including her in everything, she said:

> *...I realized that my parents… they were so much encouraging so, they put a lot of stress on education, they always took us out, introduced us to people, asked us to speak, they always, we were never hidden ... So, they were literally dealing with two kids and limited supportive community.*

Milana's mother had also challenged the principal at her school when she had requested that Milana changed schools because the one that she attended was not accessible. Her mother had refused this request and challenged the principal who later complied. The progressiveness and educational level of parents also impacted the lengths that they would go to advocate for their children. However, sometimes the culture the parents had grown up in limited how supportive they could be. As an example of this Daisa said:

> *...my mom used to help me build that wall [referring to a wall you build within yourself to be strong so that you can face anything] but to a point because she is a daughter of her culture, she wanted me to please. She wanted to please, she was born to please and she made me the same. Me, I want to please you but without sacrificing myself.*

Daisa's mother supported and wanted to build a strong daughter but could only help her so far because she was influenced by her own cultural norms. However, not all parents advocated for their children, which often influenced the experiences that the children had. Milana explained:

> *I found that so many of them [parents of children with disabilities] were not strong, strong advocates for their kids. So many of them could not see or maybe they were frustrated by the lack of services, the lack of education, the lack of awareness but certainly, many of them were not doing so well.*

Recognizing that many parents were not strong advocates for their children by for example advocating for services, accommodation, and access to schools had led her to understand and appreciate how encouraging and inclusive her parents had been when she was growing up. Further, she explained that many parents were frustrated with lack of services, education, and awareness of available services but that this frustration did not necessarily result in them advocating for their children.

6.2.4 Services

A common theme across the different interviews was the lack of services in participants' countries of origin. As is explained below, lack of services was one of the reasons that people chose to immigrate to Canada. An overall lack of state support in their country of origin meant they were often forced to rely on not for profit organizations such as the Red

Cross and smaller disability organizations. However, participants found that these organizations were chronically underfunded, influencing the level of service that they could provide. In some of the countries basic medical care was also not covered by the government and was only accessible if you had money or insurance, providing a barrier to healthcare and services for participants.

In this context, religious institutions and often mosques had taken it upon themselves to give to people with disabilities. This "giving" was often seen in the form of a charity model (see chapter 5) where money, food, shelter and other necessities were given to people with disabilities because they were considered needy. This charity often came in the form of favours and sympathy, however, as Azar explains, this is not necessarily a good thing:

> *…but they don't look at the other aspect where we are asked to start new good things, where we are asked to grant people the status that they deserve, it is not a favour from the community.*

Idris further explained that this model of sympathy was degrading because it reinforces the notion that people with disabilities are weak and are in "need" of help from others ultimately positioning them as second class citizens. Relating back to chapter 5, we see that these views of people with disabilities as needy and in need of charity carry over into cultural communities within Canada.

6.3 Immigration: Motivations and Experiences

Participants had different immigration experiences and stories but shared the common goal of seeking a better life and opportunities. Some immigrated with their families when they were children while others immigrated later in life, either alone or with family members. Family reunification, political unrest/war, and the status of people with disabilities in Canada were the primary reasons for immigrating. The majority of participants already had family members living in Canada when they came as visitors or started the immigration process.

The perceived status of people with disabilities in Canada as respected and protected by disability rights was one of the reasons for immigrating. For Milana, her aunt had been in Canada for over 20 years and encouraged her to immigrate because of the visibility of disability and the opportunities that people with disabilities had. Visibility was observed by her aunt in everyday experiences, for examples seeing persons with disabilities take public transit and walking down the street. Opportunities she had observed included using public transit, going to the mall, and using accessible public washrooms.

Idris initially came to Canada in search of advanced medical treatment and was hoping to find a way to walk again. However, when war broke out in his home country he applied for refugee status instead of returning home as it was unsafe for him to do so. He already had siblings in Canada who were able to assist with legal advice and how to apply to stay as a refugee. Nazeer immigrated with his family as a baby when political unrest broke out in their country and it was no longer safe to stay. Despite not having any family in Canada they chose Canada as the place to start a new life. Similarly, Faheem also left his country due to political unrest; however, he did not choose Canada but was assigned to Canada when he applied to become a refugee.

When Azar came as a young child with her parents, the decision to immigrate to Canada was not based on political unrest, economic opportunity, or war; instead her parents made the decision to immigrate when they found out that their daughter had a disability. They did not believe that their current country of origin had the resources to support their daughter. Azar explained:

> *"…basically, back then, when I was young the education system didn't really have resources for people with disabilities. I hear it is getting better now but they didn't have that and my parents didn't want me to fall behind in school so they applied to come to Canada pretty much right away, as soon as they found out. But obviously it took quite a few years for us to finally get here. But yeah, that was the main reason why we came here."*

Some participants had difficulty immigrating to Canada and were denied permanent resident status due to medical inadmissibility. Daisa's brothers had immigrated to Canada and wanted her and their mom to join them. However, because of her disability she was denied permanent residency:

> *"…my mom came supposedly for a visit. But when she came they [her brothers] told her, stay here and we will sponsor everybody. Because we were still young. So, they started bringing one at a time… And because of my disability Canada won't accept me. So, it was very hard, they refused me three times. So, I stayed in [home country] five years without my mom… So anyhow, it took them four times, they got it right. They got the sponsorship, they got everything, what the government need to fulfill the requirement. That they are responsible for me for three years, that I won't go to social services... That I'm not a burden to the system, blah blah blah. Then I came."*

Daisa described the years without her mother as being "horrible years" because of her disability and inability to go to the fields and help but still had to prepare food for the winter. Daisa wanted to immigrate to Canada because of the lack of opportunities for her in her home country. She wanted to be independent, have a house, become pregnant, and have a job, and she had come to the realization that these goals were not achievable in her home country. For example, when she tried to become a teacher, she was faced with the reality that the country's law stipulated that people with a disability could not hold a government job.

Farah also experienced rejection due to medical inadmissibility. Her brothers tried to sponsor her, but her application was denied. Instead, she came to Canada as a visitor to see her brother and parents who her brothers had successfully sponsored. Her brothers wanted to sponsor her to come live in Canada as well, both for her personal safety and because their parents would not be alive to take care of her for ever back home. She explained:

> *"I came in here as a visitor and at the same time my brother was working with the immigration to see if I can stay here. He said; "you know what, you get injured in [home country] and it's not easy for you to live in there, my parents they won't live forever for you to have that support"*

However, she was initially rejected after the medical examination. At this point, the family brought the application to human rights and argued for family reunification. Her application was later accepted based on humanitarian grounds because she had lived with and been dependent on her parents in her home country and her parents had immigrated to Canada. Thus, in order to be able to immigrate to Canada, she was forced to adopt a position of dependency.

Milana applied as a skilled worker but had little hope of admission after the medical examination. She convinced herself that she would not gain permanent residency but was overcome with joy when her lawyer called a couple months later to let her know that she had been granted permanent residency. She said:

> *Coming here is a miracle and it is the most magnificent thing that happened to my life. Why it is a miracle? Because as a person with disability it is almost unbelievable to be granted an immigrant status.*

Significantly, Milana explained that had she known about the medical requirement and the previous cases against the government regarding medical inadmissibility prior to applying, it would likely have discouraged her from applying in the first place. She also expressed a broader hope that more people with disabilities would be given the opportunity to immigrate to Canada. She explained:

> *why are we always stereotyped as being a burden? Yeah, I mean, to be fair we need some accommodations. My theory was always that I am not a complete burden and paralyzed people and at the same time I am not superhero, I played the superhero role for quite some time and then I thought that was unrealistic and I need to face reality, reality is to accept your abilities and your limitations. So, we just need to be seen like anybody else, I have weaknesses and I have strengths.*

Overall, family was the main reason behind immigrating to Canada for most of the participants in this study. It should be noted that while many participants immigrated to Canada because they had family members here and wanted to join them, many of these family members had originally left their country because of war and political unrest.

6.4 Post-migration experiences in Canada

Knowing something of lives participants had prior to coming to Canada and their reasons for immigrating, this section considers their lived experiences post migration from accessing services, employment, political rights, and views and experiences of disability within their cultural community and in the broader Canadian context.

6.4.1 Services

Participants in this study accessed a wide variety of services to assist them with their daily living. The most common services were financial services i.e. ODSP or financial subsidies used to help subsidize assistive devices. Transportation was another common service utilized by participants. Many participants were from the Toronto area and accessed Wheel-Trans for their transportation needs. Some participants supplemented

Wheel-Trans with other private transportation options such as Uber and taxis. A couple of participants had access to their own accessible vans for transportation. The third most common service accessed was attendant care services. Several participants had significant disabilities that required daily attendant care services.

To access services, one must first know about services that are available and the services that one qualifies for. All the participants, except for younger participants who had primarily grown up in Canada, had learned of the most important services through word of mouth from friends, friends of friends, or people they had been introduced to by family members. However, some people had lived in Canada for years before they learned about services to assist with their daily living. As Daisa explained:

> *…. I cannot do the housework so then I applied, and I had a friend [name of friend] was my good friend she helped me… I did not know, [name of friend] did. So, [name of friend] guided me to get homecare first. Imagine, homecare gave me one hour per week, but she said don't worry about it, accept it. We can build on it, she coached me, that's how it is. And then after that I kept looking into another organization and I got another organization who gave me three hours a week.*

Daisa was struggling with taking care of her children, housework, and working and saw that she needed help, however, she did not know where or how to access this help. With the guidance of her friend she was able to apply and gain access to services. Despite not thinking that the help she was offered was enough, with the assistance of her friend, she accepted the help and later built on it so that she could receive more assistance.

Some of the participants had been involved in creating community organizations that assist immigrants with disabilities to gain access to services. Erajh explained:

> *How people find out? Through mainly word of mouth or through this community organization we formed… regular organizations they don't provide a service they just send you to disability organization and the disability organizations are not equipped to deal with additional issues, people with additional issues like immigrants.*

Participants had also used the Internet to access information on services available, however they noted that with the Internet there were often language barriers that kept new immigrants from accessing services. Government websites were also described as being difficult to navigate, making it hard to figure out which services one was eligible for. Not only knowledge of services but also filling out the applications themselves was identified as a barrier to gaining access to services. Idris explained:

> *…there are services for anybody who lives in Canada who is eligible but yet, there are a lot of people that don't know about, they don't know how to access it, they don't know it is in existence, they don't know how to fill out a form to be eligible and that is very sad. I personally helped quite a few people to access to those service that they are eligible for but that they didn't know about it and hearing about it is not enough sometimes, they actually don't know how to apply. They need somebody, either it is a language barrier, shy or they are… or they don't want to admit that they need it, or they are also down and they need somebody to do it for them. So, having the services is one thing, having workers filling out and assisting and following up is another thing.*

While no participant said that they had been denied services, many recalled friends or acquaintances who had been denied services because they were not able to correctly fill out the paperwork required to gain access. Participants had assisted friends with access going as far as to appear in court. Idris explained:

> *So, if it wasn't for me he wouldn't apply or appeal, he was eligible from day one, he didn't fill out the application properly, not knowing English, the English language barrier and the person who assist him didn't maybe she just filled out to the best of her knowledge and he wouldn't be able to go find a lawyer and apply and get a certificate of approval, it's a lot of work. Even in the interview, I was a translator, and the question, I really had to break it down to him because he had also some developmental limitations but he did pass. I feel very proud*

As the quotes from Idris suggests, it is not always a question of being eligible for a service but more importantly, it is about being able to fill out the application correctly in order to access services. Many participants said that there is no place where they can go and receive help filling out applications often leading to having to go to court, as seen in the example above.

For younger participants who had mostly grown up in Canada access to services had been secured through medical professionals or schools. Azar expressed frustration trying to identify accessibility services available at Canadian universities. She explained that not all services are created equally and that it was almost impossible to identify all services available before entering university. She considered herself “lucky” that she had found a university with significant accommodations.

While appreciative of the services they were receiving, participants also had several criticisms of some services and sometimes lack thereof. One of the main things that participants identified as missing was assistance in the form of a knowledgeable helping hand. People are required to rely on friends and people who have gone through the experiences of applying or using services to gain access to these services. Participants identified a need for a “center of excellence” or “one stop shop” where they could get professional assistance to learn about and apply for available services. Erajh explained how living in an information age is hurting more than it is benefitting immigrants with disabilities.

> *Even though we are living in an age [of information], information overload, but on the other hand we still, if it’s too much information, [and it is not] not reaching the right people…ideally, we should have like a place, center of excellence or something who [the persons working there] can really know all the system... we need more people who can really look at the higher level, the holistic issues also things on different perspective, even now we need enormous amounts of energy to fight to get anything [services provided] done for us.*

For a person with a disability, finding the right information and advocating for yourself or others requires an enormous amount of resources and energy. Because of the difficulties participants had faced while living with a disability many had found themselves becoming advocates not only for themselves but also for others living with disabilities. The theme of advocating was seen both pre and post migration. Nazeer explained the necessity of becoming an advocate for oneself:

> *…when living as an individual with a disability in Canada, people aren't going to come to you, you have to come, you are going to have to advocate for yourself…, there are resources available, you have to scope them out, and if you don't communicate with the; "I need help", you are not going to be able to access it. You got to advocate, you got advocate for yourself for your needs… that's unfortunately the nature of the disability, the fortunate side is that there is actually resources available to you… it is a full-time job in the sense, I spend a lot of time in my life dealing with logistics of certain things, transportation arranging this and that, I have to be one step ahead of everything I do.*

While advocacy is important, Erajh explained that self-advocacy is not necessarily easy for immigrants especially when there are cultural and language barriers. For example, in Canada, disability advocates push for independent living, but what does 'independence' mean? For some immigrants, independence means that they should not use Wheel-trans, they should not have volunteers assisting them, and they should not ask for help. Erajh explained that in a Canadian context, this is not what independence refers to but for many immigrants the idea of independent living becomes complex and confusing and there is a need for newcomers to be introduced to what is meant by independence in Canada. In relation to his argument for a one stop shop, Erajh also argued that there is a need to educate immigrants about the philosophy of independent living and what it means to get assistance and support from the government and other sources.

Several participants had dual disabilities, which resulted in them having to navigate different organizations because the system is not necessarily set up to deal with dual disabilities. Erajh explained:

> *we only talk about one disability but multiple disability, dual disability is complicated maybe intersectionality you want to maybe add… those things is why we really need a center of excellence to deal with these things and not just simple CNIB or March of Dimes or agencies or regular church can't handle it [needs of immigrants with disabilities from non-Western countries].*

As mentioned previously in this chapter, four participants received attendant care services and we saw that Daisa had to advocate and utilize several organizations to get the services that she needed. Idris found that attendant care services were not appropriate to serve his cultural needs. When he needed a new attendant he was offered a female attendant but he had grown up in a culture where he should not expose himself to someone who is not his wife or a family member. Having a female care attendant made him extremely uncomfortable, but when he asked for a male attendant, the manager told him "on this job, all are women". He found this to be frustrating because first of all, it was not true, but he also felt that the care should be sensitive to and respect his culture. Milana's experience of caregiving allows us to explore how place can shape the experiences of caregiving and service. In the UAE, Milana had been able to hire a live-in caregiver as this was an affordable option there, however, due to policy and cost, she was not able to do the same in Canada, she explained:

> *I need constant assistance. In the UAE, the good thing is that it wasn't very, a financial burden to afford having a live-in caregiver… And I was very lucky, I had amazing live-in caregivers, that gave me a lot of freedom. Because I didn't have to ask my family for much in regard to my self-care. It gave me a lot of freedom because this person was giving me a service and I was giving her a salary, so it some kind… you are on an equal status, you know. She is not doing you a favour and you are not doing her a favour.*
>
> *I like the idea that in the UAE you can afford a live-in care giver while here you cannot do so. And it's not only the money, it's also as I said, the logistics of training, certificates, and these kinds of things. (Milana)*

After moving to Canada, Milana had access to a personal support worker only one hour per day, making her more dependent on her mother for help. This impacted her relationship with her mother and her ability to live independently. She wanted to bring her live-in caregiver from the UAE to Canada but due to lack of language proficiency and Canadian training of the caregiver, she was unable to do so.

6.4.2 Employment

Four out of eight participants were currently in fulltime employment, while one participant was a fulltime student, and three were part-time/contractually employed. While half of the participants had fulltime employment, they noted that finding fulltime work as an immigrant with a disability was often the exception rather than the norm. Daisa considered her employment situation as a senior manager at a technology company to be a dream come true but also recognized that she had been lucky in getting the jobs that she had. Overall, participants talked about the difficulty of finding employment in Canada but even more so fulltime employment. There was a common sentiment that there are fewer jobs available for people with disabilities. For example, Daisa explained:

> *Getting employment is very hard to get, there are fewer jobs and like especially for people with disabilities. We are not good to sit there and sell retail, we are not there, we are not attractive to sell retail, that option is not… and that's big in Canada.*

In this quote, Daisa is speaking to the unattractiveness of having someone with a disability working in retail. Not being able to enter the labour market at the retail level makes it increasingly difficult for people with disabilities to gain access to employment. Faheem further explained:

> *I couldn't work anywhere according to my disability, people work when they come, work as cash registers, or work cab drivers, pizza, drivers, things like cook and I couldn't work.*

Because of his disability Faheem was not able to enter the labour market the same way that many immigrants do when they come to Canada. Not being able to enter the labour market in an entry level position was a significant barrier to gaining access to Canadian experience, which many jobs require. Farah, who had volunteered for years, was surprised that volunteering often did not count towards Canadian experience. She finally gained Canadian experience when a fellow immigrant hired her part-time because she herself knew the importance of Canadian experience and had struggled to achieve it herself. Several other participants had also gained access to employment as a result of volunteering. Milana was volunteering when her boss asked her if she wanted to accompany her to an ability expo; she was happy to do so and subsequently met contacts at the expo who were able to set her up with career services and eventually a part-time job. While she would prefer a fulltime job, Milana was grateful to be doing any work.

Another theme that emerged from interviews was the issue of part-time/contractual employment. All three participants who had part-time/contractual jobs were interested in finding fulltime employment but had great difficulty doing so. Feheem had tried finding employment in academia but found that only sessionals were being hired and that he lacked Canadian experience. Instead, his primary source of income was ODSP while he worked as a freelance translator, whenever jobs became available. Milana had immigrated to Canada as a translator under the skilled worker program, but had faced many barriers to working as a translator once in Canada. In particular, she found that the majority of translating jobs were booked last minute, and this was a problem because she could not get Wheel-trans to take her to appointments with short notice. Accessibility was also an issue as many of the places that she needed to go to provide translation were not accessible for someone using a wheelchair. Through talking with coworkers in her current part-time employment, she found that while Ontario has the Accessibility for Ontarians with Disabilities Act (AODA), on a deeper level you might be rejected for a job position for any reason that people can come up with arguing that discrimination against people with disabilities is still prevalent, she explained:

> *So, this kind of discrimination cannot always be observed or seen because no one will say I don't want you because you are so on… the issue is still there, it is obviously still there.*

Idris was stuck in a similar situation where he was unable to find fulltime permanent employment. In his current contractual position as a disability expert, he experienced first-hand how the work that he did was more about money than about him, as a person with a disability, doing the job. This was seen when the project neared its deadline and the company hired an able bodied coop student who could do the job faster so that it would get done in time. He explained:

> *…when we were on a deadline, they hired a co-op student to do the same because it is an app and she doesn't have to enter the data and all that but there are things that I can see that she cannot see but for the speed purposes and all that, they hired… and she did a lot too. Which is okay… so, companies they are after the expenses, they look how much money they are going to make, they are in the business of making it.*

Despite knowing that he was more qualified for the job based on his life living with a disability, the company was more focused on meeting the deadline and saving money. However, while Idris understood why they hired an non-disabled person to complete the project, he also believed that there were things that he could see that she would not because of his experiences of living with a disability.

Lastly, money was another predominant theme in the interviews when it came to discussing employment. For many participants, having a job was not financially beneficial because it resulted in them losing their benefits, rent subsidies and/or ODSP. Idris explained:

> *When I worked, I was earning money, my rent went up 5 times, my benefits got cut off, this job doesn't have benefits because it's a contract, so actually I would pay for supplies and repairs and all that so when you… at the end of the month, if I calculate the financial incentive of working, it is not that much from sitting at home and not working.*

Because the position was contractual, he was "punished" for being employed to the point where it was no longer worth being employed versus staying at home and being unemployed. This was not only observed in part-time/contractual work but also among participants with fulltime jobs and benefits, who felt the burden of being financially responsible for all their costs, related to their disability, because of their employment. Participants explained that having a fulltime job meant that most expenses had to be paid out of one's own pocket as most subsidies do not apply to people who are working. They were also entitled to fewer services because of their employment status and the expectation from the government that they would pay their own way. While working was not financially beneficial for most participants, they all said they would rather work than be unemployed. For example, Azar preferred to work because she did not want to depend on anyone, including the government.

6.4.3 Disability and culture in Canada

As part of the research, participants were asked about their experiences of disability within their own cultural community in Canada. Participants described varying experiences, shaped in part by their length of time in Canada and by the nature/visibility of their disability. The main themes concerned lack of awareness of persons with disability and charitable responses to disability, as well as changing understandings of disability over time.

The Middle Eastern and South Asian communities in Canada are still relatively young communities with many first-generation immigrants. Due to these communities being so young it is perhaps not surprising that five participants found that many of the understandings and perceptions of disability that they had experienced in their countries of origin were also present in Canada within those cultural communities. One of the ways that cultural meanings of disability have been transferred to Canada is through the hiding of children or family members who have a disability. Daisa explained:

> *My community is so behind, they are still behind closed doors, so protected, like me, what I came from. They are behind doors. They think "oh, we will take care of them", eventually their parents will leave their house for them and some inheritance, they think this is life.*

Daisa had on several occasions' encountered families who were hiding members with disabilities while living in Canada. She explained that parents hide their children because they feel ashamed and fear that people will judge their child. She believed that this behaviour was not likely to change within her community unless parents' approaches to disability changed:

> *Whoever screams louder gets heard. And nobody is screaming for the disabled because their parents do not want to scream, because their parents are ashamed, and they just want to hide.*

Idris explained how he, himself, had brought negative views of disability with him to Canada and that it had been hard to move past these negative views and learn to accept and embrace the disability. He explained that every time he met someone from his own cultural community he was reminded of these negative views, he argued that culture is so embedded in people that it is difficult to change and therefore they bring their “baggage” (cultural views) with them to Canada as seen in the quote below:

> *...you are coming here with baggage. Until you, liberate from those baggages, we have been brainwashed and traumatized. It takes a while to get that negativity to fade for people to excel. And it’s not actually somebody’s fault. The other day I tried to see [thought about] “okay, is this culture right? this and that culture right? nor this culture wrong or that culture wrong” it is not about right or wrong. In Iraq, this is the way they view things [disability], so it is right to them. Here they see things [disability] differently and it’s right to them. (Idris)*

The quote shows the complexity of culture and the ways that shared meanings move across time and place. As suggested in chapter 5, responses to disability were often framed by a model of charity/sympathy, which focuses on helping people and providing them charity as opposed to respect and support. A similar model of charity/sympathy was experienced by participants with disabilities, Daisa explained:

> *They think… and you know the community, because they are not educated… they are not educated, they don’t even know what support means. They can’t spell support, this is support, not give me food or anything, support is look at me, see what I need to cook, if I can cook, which meal that I can cook and give me ideas and things that I need and basic things that help me cook. It’s not doing it for me, that don’t help. It helps in the short term and help make you feel better… I give you a piece of cake and you are so happy but to teach you how to make the cake…That’s a lot of work and a lot of commitment, right?*

The above example illustrates the tension between help and support. Daisa believed that her community had not been educated in how to support and approach people with disabilities. Because of the existing culture within the community, they want to help and think they are doing the right thing by “giv[ing] you a piece of cake” instead of “showing you how to make it”. Idris echoed this sentiment, explaining that the idea of sympathy and “we will help you” is degrading because he does not want help and often already has the ability to do it. Similarly, for Erajh it was important to find a prayer center that was inclusive and accommodating as opposed to one informed by a charity/sympathy model.

While it took time for him to find the right prayer center, which he eventually did, it was especially important for him to find an inclusive prayer center because he did not feel included or equal to other people in a prayer center when faced with the charity/sympathy model.

However, not everyone felt the notion of the sympathy/charity model in Canada. Nazeer distinctively mentioned feeling respected within his community. He explained that when he attends the mosque there are always people ready to help him if he needs it, for which he is grateful. Milana, who was a more recent immigrant to Canada, had also found a prayer center that was inclusive and accommodating. For this reason, she therefore did not feel the sympathy/charity model had been imposed on her. In her life in Canada she found explicitly that she was free of the sympathy model that she had experienced in the Middle East. She said:

The good thing is that you don't feel sympathy [in Canada], you do there [country of origin].

Isolating and negative views of disability were not only felt in the broader community but also in relation to family members. Erajh said that his wife and children were deeply ashamed of his disability and that measures were taken to hide his disability when out in public. One example of this was him not being able to bring his white cane because it was viewed as being an embarrassment by his family.

I can't keep my white cane at the door, it should be hidden, even now, my family and children they don't want me to use the cane because everybody look at them, people stare at them, so they don't want that, so they say… You don't need the cane, and sometimes they forget to tell me the steps so… I hit people and they mad, all these things happen.

He was also encouraged by his family members to not disclose his disability to others when in a public setting because it was felt that it would disadvantage the family. Idris' grandmother, who also lived in Canada, had signed up to use Wheel-Trans when she started experiencing mobility issues. After using the services only once, she refused to use it again because there had been people with cerebral palsy on the bus, which in their country was associated with being 'crazy'. Idris had also met an older man in his cultural community who could no longer walk, but when it was suggested that he should start using a wheelchair, the man refused because a wheelchair is taboo where he comes from and considered a bad omen for those around him.

Idris also thought that people in his community treated him differently because of his disability. They assumed that he would not know answers to questions because he was in a wheelchair and he found that he constantly had to prove himself and try to earn their respect,. When his community put on events, there was no thought to having those events in accessible spaces and little consideration of whether or not he could attend as a person with a disability. While he found this to be a minor thing, it was hurtful none the less:

> *…there will be a party for my community and they will hold it in a non-accessible place. I will love to be part of that party. But no one has thought to make it accessible. Because "it's only [name of participant] who cannot come". That kind of thing. It's may be small, but I will take it personally. Because I have been told here that I am a human being, I am an equal, I should have the right to participate yet my culture doesn't see it, that acceptance, so I am in a constant dilemma; who is right? I know this is right, the Canadian right but okay, my culture has been for generations this is the way they think so in their mind they are right.*

Earlier in this chapter, five participants explained how they came from countries where people with disabilities are often hidden, where there are few disability organizations, and no disability rights legislation. After migration, participants found themselves living in Canada, more specifically in Ontario and protected under the AODA and the Human

Rights legislation. Interviews revealed that just knowing of this legislation had positively influenced the lives of several participants.

For Daisa, living in Canada had changed her own perceptions of her disability and what she had a right to ask for. When she initially came to Canada she felt that she was "troubling people" when she asked for things but that this had changed over time:

> *In the beginning I used to be so scared to even, I didn't want people to think that I am trouble or that I bring trouble. Right now, I changed the way I think about it. No, it's not trouble, it's accommodation, that you really have to have for seniors, for people with disabilities, for anybody who needs it.*

The quote above is related to her wanting to access a fitness facility in her neighbourhood. She explained how her perception of her rights and being "trouble" had changed and that she now believed that it is her right to be able to use the facility to the same extent as abled bodied individuals. She further explained how she had come to believe in the 'Canadian system':

> *I believe in how Canada does inclusivity, opportunity, freedom of opportunity for everybody, right? That's what I think is one of the highlights of Canada. If you are a human being and you want to get somewhere in life, you are here, that's your land.*

Living in Canada where she had rights as a person with a disability had taught Daisa that she is a human being, that she is equal, and that she has the right to opportunity just like anyone else living in Canada regardless of being disabled or not.

Milana had been in Canada less than a year at the time of the interview but an awareness of disability rights had already had an impact on her beliefs and sense of belonging. Comparing life before and after immigration, she said:

> *I can speak with more courage, I will complain why this station is not more accessible or why this button is not working. Because I feel that the law grants me that right. I can do that more with confidence I will say here.*

Because of the disability laws that Canada and Ontario has in place, she felt that she had the right to speak up and can do so with courage.

While participants' sense of themselves as disabled persons could change through recourse to a disability rights framework, similar shifts were also observed within their cultural community. Despite expressing frustration about negative attitudes and practices towards disability in their cultural communities, four participants thought that these attitudes could change. Some of the ways that perceptions were changed was through disability legislation and visibility of disability in everyday life.

Faheem explained how he had seen a change within his community in Canada as a result of the visibility of disability and disability legislation:

> *…they adopt these ideas about the equality, these things. Especially for disability because they see the… they see that people with disabilities are respected here and they are helped and there is not a lot of discrimination against… there is discrimination but not the way it is in [his country] or other countries*

Faheem further explained that the AODA had required his prayer center to follow the law and become accessible, which was now the norm. They had adapted and now accommodated people with disabilities both inside and outside the prayer center.

For Milana, the visibility of people with disabilities is what changes people's perceptions whether it is within her cultural community or the broader Canadian society. She said:

> *…when you and I get used to people on scooters and wheelchairs and white canes, it has an effect also because [they] are not rare cases anymore.*

The visibility of people with disabilities as well as education and information were mentioned as key factors that could change cultural beliefs. Participants expressed that there is still a long way to go in terms of disability rights and acceptance both within their cultural communities and Canadian society. They believed that these changes needed to come from people in positions of authority (i.e. politicians and policymakers) and through the education of children. Idris wished that the government would make teaching about disability mandatory in schools so that children were exposed to acceptance and knowledge of disability early on. Idris did not believe that there was much hope teaching the parents because the culture is so engrained in them but had hope that children could change the future of people with disabilities. Similarly, Daisa hoped that the next generations would be able to change the level of acceptance of people with disabilities within her cultural community. She believed that changing the minds of the older people controlling the prayer centers would be hard to change but had high hopes for the second 2nd generation:

> *...I'm hoping second generation will do much better job because they are open. They grew up in this culture, they know how to deal with that [disability]...*

While participants were critical of their cultural communities, they also had critiques of the broader Ontario/Canadian society. These critiques mostly centered on the lack of accountability attached to the AODA, which was interpreted as the province of Ontario not prioritizing or respecting people with disabilities. Everyone spoke highly of the AODA and most agreed that Canada was moving in the right direction with respect to disability rights. However, progress was being made too slowly. The positives and negatives of the AODA as well as the built environment and accessibility are discussed further in the next section.

6.4.4. The built environment and accessibility

Before coming to Canada, participants, especially those with mobility impairments, had been faced with inaccessible built environments, inaccessible housing, lack of accommodation for education and/or employment, and lack of accessible transportation. Post-migration participants had access to some if not all of these accommodations. Many of these accommodations were understood by participants to be a result of the AODA. For Idris, seeing the disability movements and the accessible transportation that was available in Canada made him realize that with the right accommodations, people with disabilities can be part of society. Accessibility and accommodations in Canada had made it possible for all the participants to live more independent lives. Accessible built environments (i.e. sidewalks and subway stations, housing, and transit) had positively influenced their daily lives. Accommodation in the work place and sites of education had also had positive impacts, notwithstanding the barriers people faced to obtaining paid work. Access to provincial benefits such as ODSP had contributed to people's social participation and financial subsistence. Despite these positive views of accessibility and accommodation, seven of the eight participants felt that there was still work to be done to improve the lives of people with disabilities.

Inaccessible built environments are still an issue in Ontario despite the AODA having been in effect since 2005. While the extent of the inaccessibility in the built environment does not compare to their countries of origin, it is something that greatly impacts their daily living. One of the most mentioned examples of inaccessibility by participants was the Toronto subway system. While participants praised the overall subway system, they found it frustrating that many subway stations do not have elevators, resulting in the subway being inaccessible to them. While they agreed that the city of

Toronto was making an effort to make the subway accessible, they also believed that it was happening at a slow pace. Buildings were another site of inaccessibility that influenced daily living. Not all restaurants and bars are accessible making it difficult if not impossible to access them, other businesses had made an “effort” to be accessible but had failed due to certain design errors. Idris had an example of this:

> *...pizza pizza, big company, very reputable, they have automatic doors, they have a sign on the door that says automatic, they have a push button on the side but they have a big step in the front, so I go there, I can’t reach that button, if I reach it the door will open but I cannot go up that big step so whoever designed this didn’t see it from the purpose of having it accessible. Accessible door is for a person like me, so they saw the door and the button but not the step.*

For Idris the frustration was rooted in the fact that they made accommodations that followed policy, but they did not make accommodations that actually accommodate someone with a mobility restriction. While this form of inaccessible design is not only frustrating it can also be hurtful to the people who encounter it. Nazeer explained:

> *…And I find it very disheartening particularly those places that… they don’t… there isn’t any attention to people with disabilities and you get the feeling, okay, does that mean I’m not… you don’t want me there, you know what I mean?*

Idris explained that this type of inaccessibility leads people with disabilities to feel like they are an afterthought in the planning and design process so that urban environments continue to reflect the views of the non-disabled designers and developers. He commented:

> *…in 2008, the international day of people with disabilities slogan or theme was “nothing about us without us”, meaning if you want to design something for people with disabilities you better have us or our say, because we are the experts in that field… I say “do not design something for me, if I don’t have a say with this”. Because you may view things different than my needs, if you don’t understand my needs, you are designing something that is useless for me.*

Inaccessible built environments were also a factor in the workplace. Idris' place of employment was in a heritage building, which was exempt from being accessible under the AODA. Due to the heritage designation of the building, he was not able to enter the building and his company relocated him to a different building that was accessible. While this might sound like a reasonable solution this was hard on Idris as he was not able to be a part of the office environment, take part in daily meetings and communications, or associate with colleagues, which led him to feel isolated and not part of the company. Even though he was relocated to an accessible building the accommodations were far from perfect, as he explained:

> *I go through the parking lot and then accessing the [building] through the garage and then take the elevator up but the doors, two sets of doors, there is no automatic [button] so they actually installed automatic because I used to call a colleague can you help me to exit because I just cannot exit by myself so I was going back and forward and then eventually they installed it, the washroom wasn't accessible, no push door, I would wait for someone to pass by to say "excuse me can you open the door" so they eventually they did that after three months, so they were accommodating in one way but I still had that different office.*

Several participants who used a wheelchair made mention of not having access to a washroom in their place of employment. For one participant a button was installed to make the washroom accessible, where Farah had experienced the inaccessibility prior to the AODA and had been forced to limit her work hours because she could not access a washroom in her place of employment.

In relation to housing, all participants with mobility restrictions lived in accessible housing. Some owned their residence and had spent significant amounts of money retrofitting their house/apartment to be accessible to their needs. Others lived in rental apartments that had been made accessible to varying degrees by landlords and building owners.

6.5. Discussion

The experiences discussed by participants in this chapter gives some insight into how place can influence the lived experiences of people with disabilities. By examining participants' experiences before, during, and after migration, it is possible to explore how barriers and lived experiences change based on time and place.

Prior to immigrating to Canada, participants faced several barriers the most common ones being environmental, attitudinal/cultural, and organizational. Environmental barriers were experienced in the form of inaccessible built environments, which constrained opportunities to attend school and university. In regard to employment, participants were faced with attitudinal/cultural barriers preventing them from gaining meaningful employment or access to assistive devices to aid them in their employment as employers did not respect them or expect them to be able to perform the job because of their disability. The fact that many participants experienced disabling built environments, is perhaps not surprising considering that many of the countries represented in this study, for example Syria, Iran, Iraq, and Lebanon have all experienced ongoing conflicts for many years, making it hard for these countries to maintain their domestic infrastructure. At the same time, these disabling built environments may represent a broader reflection of the dominant values of society and the idea of the performance of the 'normal' body (Garland-Thomson, 2011; Imrie, 1999; Imrie & Edwards, 2007)

The views and experiences shared by participants revealed the complex influence of culture in regards to disability, gender, and place in the Middle East and South Asia.

One of the ways that culture was seen as influencing disability, in relation to place, was through the act of hiding people with disabilities from the general population, as was done by parents and family members. People with disabilities were hidden because of the inherent association of disability with stigma, shame, and religious ideologies such as karma in these local cultures. These findings are supported by existing literature (Al-Aoufi et al., 2012; Al-Jadid, 2013), which suggests that people with disabilities in the Middle East and South Asia are often isolated because of the negatives attitudes and stigma. While the literature suggests that isolation is more common for women with disabilities than males in these regions, this was not definitively supported by the interviews, although most examples given by participants involving isolation referred to females (Al-Aoufi et al., 2012; Al-Jadid, 2013; Turmusani, 2001).

Another example of the influence of culture on the lived experience of disability in the Middle East and South Asia was seen through the intersection of disability and gender. Here, culture was observed as intersecting with gender and disability in the narratives regarding weakness, ego, and the strive for perfectionism. Participants explained how cultures in their home countries valued people based on their performance and the importance of the male ego. Disability was associated with weakness and therefore seen as a challenge to perfectionism, the ego, and valued forms of masculinity. Idris, who became disabled as an adult, explained how he became ashamed of his disability because he was no longer able to live up to the culturally valued norms of masculinity. Masculinity being challenged by disability is not limited to the Middle East and has been widely researched and observed within Western contexts as well (Gerschick & Miller, 1995; Valentine, 1999). Gender further played a role for women with disabilities who were often considered second or third-class citizens since being a woman was considered a weakness in itself. The intersection of disability oppression with patriarchy then resulted in an even lower status than that of non-disabled woman.

Culture, disability, and gender also intersected in participants' narratives on marriage and relationships. Echoing literature on marriage and relationships in South Asia and the Middle East (Hasnain et al., 2008; Turmusani, 2001) participants explained the importance of marriage within their culture and shared the belief that males with a disability were more likely to get married than females who had a disability. Milana specifically noted that having a disability meant that all expectations of you getting married would disappear. It was the dominant belief within the culture that if you had a disability you would not be able to get pregnant and there was therefore no reason to marry the person, further disadvantaging women with disabilities.

The interviews highlighted the importance of supportive parents and there was a link between the presence of supportive parents and a greater likelihood of participants accepting their disability and participating socially. Some parents found themselves becoming "accidental activists" when they had to advocate for their children to make sure that they had access to education. In line with current literature from North America (Panitch, 2012) it was mothers who often found themselves to be activists for their children. In her book Disability, Mothers, and Organization, Panitch (2012) explains how historically mothers of children with disabilities have gotten together to advocate for their children and formed organizations when no one else was advocating for them. Participants' mothers worked to fight the stigma and ignorance surrounding their children's disabilities to make sure that they had access to education and were accepted in the community.

Focusing on migration, peoples' decisions to move are based on a mix of economic, political, environmental, and social factors. The interviews showed that there were often several reasons why participants emigrated from their country of origin and that these reasons often overlapped with one another. Overall, social and political migration, were the most commonly observed reasons for migrating, however, in-depth exploration of the data shows that environmental and economic migrations were also reasons for emigrating from their origin country. Examples of social migration were; to reunite with family and better quality of life in terms of accessibility and acceptance of disability. An example of political migration was escaping war/political unrest. Environmental migration applied to participants in this study who experienced hostile built environments in their countries of origin, which constituted environmental barriers to full social and economic participation in society. For participants with mobility impairments inaccessible built environments were a reason for immigrating to Canada because of the more accessible built environments in Canada. Milana explicitly immigrated to Canada as an economic immigrant, however, she also listed social and environmental reasons for her migration such as better life in terms of disability rights and accessibility. While others did not immigrate to Canada as economic immigrants the hope of better education and employment opportunities were included in their reasons for migrating.

Three participants were initially denied permanent residency in Canada, which further supports the existing literature on medical inadmissibility and excessive burden, where people with disabilities are denied because of the excessive cost of their disability on the social system (El-Lahib, 2015; Wilton et al., 2017). The notion of medical inadmissibility further reinforces the notion of the "perfect immigrant" and findings in this study broaden our knowledge of how it feels to be classified a burden and the stress of trying to go through the immigration process to be reunited with family.

When exploring the experiences of participants post migration, it is possible to contrast the pre and post migration experiences to examine how these experiences of living with a disability can change over time and space. Prior to immigrating to Canada, participants had very few services available to them but now most accessed ODSP, transportation services such as Wheel-Trans, and other resources. The research highlighted how participants were reliant on the knowledge of other immigrants with disabilities when gaining access to services. Word of mouth and assistance from people who were already accessing services, and people who knew how to apply, were the predominant ways that participants were able to gain access to services. The findings with regard barriers to services and how participants gained access are supported by current literature, which states that immigrants often face numerous barriers when trying to gain access to services i.e. language, knowledge of services, and transportation to mention a few (McKeary & Newbold, 2010; Newbold et al., 2013). Another barrier to service can be observed by the experiences of participant 6 who found that she had better personal care in the UAE compared to Canada. Here, policy was a barrier to gaining access to the type of care she was used to and desperately needed to remain independent. By comparing Canada and the UAE, it is evident that several factors intersect to shape the experiences of immigrants with disabilities and that it is not simply a here vs there or an argument that Canada is better than the UAE or other countries.

From an accessibility perspective, participants were relatively positive about the built environment compared to their country of origin. The accessible built environment in Canada had been a pull factor for many participants, however, they did find that inaccessible spaces still exist whether that be a lack of curb cuts, access to buildings, or to subway stations.

The pre and post migration experience of the built environment allows for an examination of how policy and place changed the personal experiences of disability. Before migration participants faced hostile built environments, feelings of not being supported, accommodated, and even accepted by society. Post migration, participants experienced accommodation, services, and feelings of relative acceptance and respect of disability from the Canadian population. Importantly, having rights within the AODA and the Canada charter of Human Rights allowed participants to feel more accepted and equal in society. Because of their new found rights in Canadian society, participants felt that it was their right to ask for accommodations and services from the government and society overall.

While exploring perceptions and understandings of disability within their cultural communities, results showed that negative perceptions of disability were still present in Canada but also that these perceptions could change. One of the ways that participants saw perceptions changed was through public policy. The very existence of the AODA and Canadian Charter of Human Rights symbolically signalled that people with disabilities should be respected, included, and accommodated in society. Participants explained that ideas of equality and respect could trickle down to help change perceptions of people with disabilities in their cultural community. Current literature in psychology has shown that individuals' perceived norms and understandings can change. Individuals' subjective perceptions of disability, are based on their unique local experiences, however, institutional signals can potentially change these norms (Tankard & Paluck, 2016). When an institution, for example the Canadian government, makes decisions and innovations, these can signal that some behaviours or opinions are common or desirable within a group (Tankard & Paluck, 2016). An example of this was seen in the United States when the power of law and policy was found to change perceptions that had previously been observed relating to acceptance of same sex marriage. Tankard and Paluck (2017) found that the 2015 Supreme Court ruling in favour of same sex marriage was associated with an increase in perceived support of same sex marriage. Relating the current literature from psychology to this study's findings, it is possible that because disability rights and acceptance are promoted by both federal and provincial governments in Canada, immigrants with different cultural views of disability will see the Canadian views as common or desirable because they are shared by the larger group and influenced by the institution, which can potentially result in a change in perception of disability. For example, Faheem believed that accessibility laws pertaining to access to mosques had made people in the mosques more accepting and willing to assist when someone entered using either a walker or a wheelchair.

Employment is an important part of feeling included in society and being able to financially support one self. The findings around employment, pre and post migration were somewhat contradictory in this study. Four participants were employed in their place of origin but emigrated to have better opportunities and quality of life. However, they were unable to find fulltime employment in Canada. Despite not being able to find fulltime employment three participants preferred to be in Canada. One might think that not being able to find employment would negatively affect quality of life, however, it appears that having disability rights, acceptance, and access to financial support during the job search helps negate some of these negative effects. Based on current literature on disability and employment and immigrants and employment in Canada, it is not unexpected that participants in this study faced barriers to fulltime employment or any employment at all. The current employment rate for working age[10] people with disabilities in Canada is 49% compared to 79% of Canadians without disabilities (Turcotte, 2014). Similarly, employment rates for recent immigrants[11] age 25-54 is 69% compared to the Canadian born employment rate of 84% (Statistics Canada, 2018b). It is possible that the intersection of disability and immigrant status creates a "double disadvantage", preventing participants from gaining access to employment. While Canada has policies in place to prevent discrimination based on disability and immigrant status, it is clear that discrimination and/or negative attitudes towards disability still exist within the Canadian population and in North America in general (Lindsay, 2011; McMahon et al., 2008; Shier, Graham, & Jones, 2009).

Having explored the lived experiences by immigrants with disabilities pre, during, and post migration in this chapter, the following concluding chapter draws on the findings of chapters 4, 5, and 6 to examine the overall meanings and implications of the research

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[10] Age 25-64 https://www150.statcan.gc.ca/n1/en/pub/75-006-x/2014001/article/14115-eng.pdf?st=yjQYxnqD

[11] Immigrants landed 5 or less years earlier

as well as exploring contributions, limitations within the research and avenues for future research.

Chapter Seven

Discussion and Conclusion

7.1 Introduction

The goal of this doctoral research was to expand on the limited knowledge that currently exists in Canada of adult immigrants with disabilities. The first part of the thesis explored disability at a quantitative and macro level using the PALS data set from Statistics Canada to examine the service and support behavior of immigrants and Canadian-born population with daily activity limitations in Canada. Due to the sample size of immigrants in the PALS it was not possible to look at differences in service and support behaviours amongst immigrants from different regions of the world. While the PALS did not allow for an examination of specific regions, the qualitative portion of the research narrowed the regions examined to the Middle East and South Asia to address the knowledge gap that exists with regard to the lived experiences of adults with physical disabilities from these regions.

Initially, chapter five focused on the perspectives of key informants who either provided and/or had knowledge of services for immigrants with disabilities from the Middle East and South Asia. Using qualitative methods, the research explored knowledge of services, services provided, understandings of disability, and insights into religion were explored through conversations with key informants. Chapter six offered an in-depth analysis of the lived experiences of immigrants with disabilities from the Middle East and South Asia. Using semi-structured in-depth interviews, immigrants with disabilities were asked questions about their lived experiences pre, during, and after migration in regards to use of supports, challenges faced in everyday life from a Canadian and cultural community context, as well as their understandings of disability.

This concluding chapter returns to the three research questions that were posed in the introductory chapter (chapter 1): Is support service utilization different for immigrants with disabilities compared to the Canadian-born population with disabilities? How does gender, culture, and religion influence support and lived experiences? What are the weaknesses of the current service system? It considers how these questions were approached and answered. First, I summarize the main findings of the analysis. This summary is then followed by a section on the contributions that the research contributes to the current literature, how it could guide policy, what the results and methodology mean for further research on immigrants with disability, how it contributes conceptually, methodologically, empirically, as well as how it contributes to the discipline of geography. This is followed by a discussion of limitations of the research including ideas of how these limitations can be mitigated in future research on the topic of immigrants with disabilities.

7.2 Significant findings

The most significant findings of the thesis are discussed in the following sections.

7.2.1 Intersectional framework and feminist disability theory perspective

Researchers have called for increased adoption of an intersectional framework in health research to explore how the fluidity of different categories influences health and lived experiences of people (Hankivsky, 2012). A mixed methods approach to intersectional research has been considered by some to be the most appropriate way to conduct intersectional research because of its ability to gather data on both a micro and macro level (Hankivsky & Christoffersen, 2008). The quantitative analysis in Chapter 4 engaged with intersectionality through using several interaction terms to explore how activity limitations and service needs are shaped simultaneously by income, educational level, immigrant status, age, and gender. These results showed that women were more likely to receive care compared to men. However, when comparing difference based on gender and immigrant status, it became apparent that immigrant women were less likely to report receiving support in regards to meals, housework, and personal support. If analysis had been limited to the differences between genders, the results would have showed that women were more likely to receive support. However, when including immigrant status results show that immigrant women are disproportionately less likely to receive certain types of support, potentially leaving them in a more vulnerable position.

While the quantitative analysis allows for analysis on a macro scale, the data is taken at one point in time and does not allow for an exploration of the “why” behind the numbers and how these categories can change. Chapter 5 and chapter 6 offer further insight into the “why”/ and reasons behind the numbers, albeit at a micro scale. In an intersectional approach, categories, such as gender, ability, and sexuality, are fluid and flexible, meaning that they can change at any given time (Hankivsky, 2012; Valentine, 2007). Further, intersectionality allows for a way to simultaneously examine how a person can experience the effects of privilege and penalty. An example of this was seen in chapter 6, where participants experienced both privilege and penalty in regards to their (dis)ability while living in Canada. Before moving to Canada, participants were faced with stigma, negative cultural attitudes towards disability, and hostile built environments that limited their access to employment, education, and freedom to move freely.

Migration to Canada shifted the issues surrounding access that they had experienced in their countries of origin where in Canada they benefited from a framework of human rights and accessibility, which they had not experienced to the same extent in their countries of origin. However, this newfound privilege was accompanied by a penalty in the form of difficulty accessing the Canadian labour market. Immigrants entering the labour market in Canada often do so in low skilled jobs (Bauder, 2003) such as taxi drivers, delivering food, or working in stores. Because of their disability, participants in chapter 6 were excluded from labour force and some were forced to rely on ODSP for financial support. So, while they had newfound rights and mobilities, they had great difficulty entering the labour market likely due to their immigrant status and disability.

It is important, from an intersectional perspective, to acknowledge that factors/categories, for example gender, are not always at play in the research and that one should not assume that they are when forming the research questions or during the analysis (Hankivsky, 2012). At the same time, it is important to not assume that a factor is always either positive or negative. Previous research has shown that immigrants' health after arriving in Canada is often impacted by isolation, loss of identity and culture, and an overall decline in health over longer periods of time, known as the healthy immigrant effect (Hankivsky, 2012; Newbold, 2006). However, when looking at the results in chapter 6, participants felt that they have mostly benefitted from moving to Canada in relation to their health and cultural acceptance. While they still faced issues in gaining access to services and negative perceptions in their cultural community in Canada, they also had an improved quality of life because of disability rights, access to supports, positive perceptions of disability, and some access to the built environment. Examining the role of (dis)ability in this manner allows for a move beyond the overgeneralized macro level data and instead provides access to what Valentine (2007) refers to as the lived experience of intersectionality. While many participants in chapter 6 had similar experiences, the interview data also supported the fact that there is no one common experience of disability. Participants' lives are shaped by different factors over time and through space, and it is therefore important that research and especially policy reflects these differences and moves beyond the assumed norm of the heterosexual, white, middle-class man or woman (Hankivsky & Christoffersen, 2008).

Intersectionality and feminist disability theory both suggest that categories are fluid and can change over time and space (Garland-Thomson, 2011; Hankivsky, 2012). Garland-Thomson's (2011) paper on "Misfits" presents the idea of how a person with a disability at one point can fit but when the spatial and temporal context shifts so does the fit. Most participants in chapter 6 felt like misfits in their countries of origin before migrating to Canada because of the inaccessible built environments and cultural ideas and attitudes surrounding disability. The temporal and spatial move to Canada did not result in a complete 'fit' but the availability of accommodations and the more positive perceptions of disability in Canadian society did contribute to a greater degree of fit in cultural terms. At the same time, this did not mean that there were not times that they were still misfits in Canada, particularly in relation to the labour market where disability and immigrant status worked to exacerbate their exclusion.

Idris, for example, was a fit when he was hired as a disability consultant for a company. However, he became a misfit when the office building was not accessible to him and he was forced to work away from other employees in another building. Later, he also encountered being a misfit when the project neared its deadline and the company hired a non-disabled co-op student to do the work in an attempt to speed up the process and finish the project on time. Misfitting in Canada was also experienced by participants in gaining access to social services, inaccessible subway stations, incompatible policies around booking accessible transportation, and gaining access to restaurants to name a few. Another example of participants misfitting in Canada was seen through the efforts to find a prayer center (mosque, temple, or church) that accepted them and treated them as equals in Canada. In Canada, participants had agency to be able to find another prayer center that respected them and treated them equally. Agency was also observed in the interviews with key informants who had a disability. Having identified a gap in the services provided to immigrants with disabilities, they decided to form their own organization to try and address this need. While all participants eventually left the organization they continued to be activists within their communities trying to better the lives of other immigrants with disabilities who faced the same struggles that they had. Having the right and ability to act was a common theme throughout chapters 5 and 6.

7.2.3 The role of gender

Moving beyond place, the interviews revealed a complex relationship between gender and disability. In chapter 4, it was evident that immigrant females were less likely to receive support for certain tasks such as housework and personal care. Chapter 4 also showed the relationship between gender and receiving support. Males, regardless of immigrant status, were less likely to report receiving or needing support. Chapter 6 revealed how ego was an important part of Middle Eastern culture and that this could impact the experiences of disability. For both males and females, the ego and the stigma of ‘weakness’ had a profound impact on meanings associated with disability. Disability was considered to be "weakness" because it challenged the idea of perfection. Considering the importance of "ego", especially for males, in Middle Eastern cultures, it is possible that low numbers in receipt of services for males as seen in chapter 4 is partly due to ego and the importance of not appearing weak to others.

Other studies have shown that males are also less likely to report having a disability compared to females, when asked using subjective measures (Grönvik, 2009), while other studies have found that immigrant males generally report the lowest rates of disability compared immigrant females, who report some of the highest rates of disability (Newbold & Simone, 2015). That immigrant women report the highest prevalence of disability (Newbold & Simone, 2015) and chapter 4 revealing that they are less likely to receive certain supports, exposes a possible disconnect between prevalence and receipt of support for immigrant women. The analytical chapters in this thesis do not provide a definitive answer to why this discrepancy exists, but it is possible that it is a result of the gendered nature of care. It is well documented that care-giving, both formal and informal care, is gendered and considered the responsibility of women (Da Roit, Hoogenboom, & Weicht, 2015; 2016; Navaie-Waliser et al., 2002). Previous research found that women were more likely to provide care for a disabled husband, whereas children were the main providers of care for disabled women (Katz et al., 2000). Similarly, it has also been documented that men are much less likely to provide personal care compared to women (Family Caregiver Alliance, 2016). Katz et al. (2000) also found that married women with disabilities overall receive much less homecare as opposed to married disabled men. Taking the findings of the current literature and the results from this thesis it is plausible that a combination of factors such as being treated as third class citizens, language barriers, gender, and the gendering of caregiving, all play a role in the low receipt of support for immigrant women with a disability living in Canada. Not having access to culturally appropriate support is another possible reason for the lower use of supports. Kulwicki, Miller, and Schim (2000) found that Arab women in the United States preferred seeing a female physician and when this was not possible, care was deemed culturally inappropriate.

7.3 Contributions

The overall thesis makes several contributions to the current literature and can inform future policy and practice. The contributions are discussed below in three different sections: empirical contributions, methodological and theoretical contributions, as well as contributions to policy and practice.

7.3.1 Empirical Contributions

Empirically, the thesis makes contributions to several literatures including but not limited to health geography, social and cultural geography, and public health. As mentioned previously, very little is currently known about adult immigrants living with a disability in Canada. Previous research has primarily focused on immigrant parents with disabled children and the challenges that they face in Canada in regards to services, perceptions of disability, and rehabilitation (Daudji et al., 2011; Jennings, Khanlou, & Su, 2014; Lai & Ishiyama, 2004; Lindsay et al., 2012; Lindsay, Tétrault, et al., 2014). Very little literature was found on the prevalence and experiences of disability amongst immigrants with disabilities living in Canada (Dossa, 2009; Hansen et al., 2017; Newbold & Simone, 2015). The majority of research found on adult immigrants with disabilities were reports published by charitable organizations, and ethnic disability organizations (Gold & Simson, 2005; Khedr, 2007). Statistics Canada produces the Canadian Survey on Disability, which includes questions about immigrant status, however, their published results and reports do not include any analysis or information on immigrants with disabilities. Indeed, the Newbold and Simone (2015) paper, comparing prevalence between immigrants and the Canadian born population, was the only quantitative paper found that specifically addressed immigrant status in its analysis. Some policy research has focused on the inadmissibility of immigrants with disabilities and how Canadian policies display inherent ableism in their criteria for acceptable immigrants, however, this research does not expand on the lives of immigrant adults with disabilities once admitted to Canada (El-Lahib, 2015; El-Lahib & Wehbi, 2012; Wilton et al., 2017).

This thesis therefore adds to the current knowledge by exploring both quantitative and qualitative data about immigrants with disabilities. First, the quantitative analysis of chapter 4, which explored the differences in receipt of support between immigrants and non-immigrants, showed that immigrants overall were more likely to receive support but that immigrant women and immigrants with severe disabilities were less likely to receive support and they are therefore potentially the most vulnerable populations in regards to receiving support for their disabilities. While chapter 4 did not provide answers to why these differences occur, chapter 5 and 6 showed that the experiences of disability are highly gendered and that women may confront particular problems at the intersection of disability oppression and patriarchy. Another possible explanation is that services for severe disabilities do not fit the cultural needs of immigrant populations. While the discovery that families are expected to take care of elders and sick members of the family is not a new finding (Donovan & Williams, 2015) the idea that support services for immigrants with disabilities may be culturally inappropriate has not been observed in the Canadian literature on immigrants with disabilities.

As mentioned earlier, previous literature has explored Canadian immigration policies and their criteria surrounding medically admissible immigrants (El-Lahib, 2015; El-Lahib & Wehbi, 2012; Wilton et al., 2017). While this literature offers analysis and critiques of the ableist polices presented by the government in regards to medical inadmissibility, they have not engaged with the actual lived experience of going through the process of applying and facing medical inadmissibility demands. Chapter 6 gave insights into the stress that participants felt when trying to apply to be reunited with their families and the feelings of not being wanted by Canada because of their disability. Similarly, interview data showed that the Canadian medical inadmissibility policy had the potential to deter people with disabilities from applying because it appeared, based on the policy, that they would automatically be rejected.

From a health geography and geography of disability perspective, the research adds to the literature on the importance of place on the lived experiences of disability. Previous literature has extensively dealt with the built environment and how it can appear hostile to people with disabilities when it is inaccessible (Butler & Bowlby, 1997; Imrie, 1997, 2000; Imrie & Kumar, 1998). The current research echoed these findings, while adding in the issue of immigration and the shifting contexts in which disability is experienced. Chapter 6 showed that one reason for immigrating to Canada was due to inaccessible built environments in their country of origin. Before Canada, many participants were faced with complete dependence on others for help due to inaccessible built environments. The more accessible built environments in Canada allowed them to regain/obtain a greater degree of independence. While participants still faced inaccessible built environments in the GTHA, conditions were a significant improvement from their previous experiences in their country of origin.

Previous health geography research has examined how socio-economic inequalities, inequities, and poverty are related to place and how this influences health, well-being and disease. Overall, place played an important part in understanding participants lived experiences in relation to their disability. Moving from the Middle East/South Asian region to Canada significantly improved the quality of life for participants through access to services, policies and rights for persons with a disabilities as well as a feeling of general acceptance of disability in Canada. In relation to place, results showed the impact of culture on the experience of disability. Canadian disability culture and policy was found to positively impact participants' experience in Canada and they argued that more positive attitudes towards people with disabilities had a positive effect on their lives. However, results also showed that participants still faced attitudinal barriers in their cultural communities and sometimes from family members. While the move to Canada improved lives, the results also showed that cultural values and ideals surrounding disability have the ability to travel across space and impact people from the Middle East and South Asia even after settling in Canada.

7.3.2 Methodological Contributions

The research also adds to the current literature and knowledge on qualitative methodology as well as adding to the literature on the application of intersectional research.

From a methodological perspective the study faced several challenges due to its cross-cultural focus. Recruitment for chapter 5 and 6 were among the most significant issues faced in this research. In chapter 5, larger organizations such as CILT, COSTI, and YWCA were originally contacted but no connections were made, despite repeated attempts to connect with them. When it was suggested that I contact mosques instead, to gain understanding from that perspective, the research had to be adapted. Instead of solely focusing on services and service provision, it became an education in Islam, Middle Eastern and South Asian culture, as well as an insight to the important role that the mosque has for Muslims and newcomers in Canada. However, gaining access to the mosques was a challenge in itself as I was an outsider to the community.

To help overcome my outsider identification, a cultural broker was used to help facilitate interviews. The research showed the important role that a cultural broker can have in making cross-cultural research successful. Through the efforts and persistence of the cultural broker, I was able to get in the door at mosques to ask questions and make connections to other potential key informants. Most key informants were initially skeptical of the research and did not see how they could assist. With the help of the cultural broker we were able to convince them to sit down with us and explain how their knowledge would be helpful to the research. Without the cultural broker, it would have been extremely difficult for me to gain any access to the mosques as many initially spoke Arabic and I was considered an outsider to the community as well as being female.

Recruitment of individuals with a disability was no easier and I also faced several challenges. Despite the efforts of the cultural broker, I was only able to recruit 8 participants. Debriefing with the cultural broker provided insight into how hard it can be to recruit despite having connections to the community. Difficulties recruiting provided a very real example of the disability stigma that exists in cultural communities. It was the hope for this research that I would be able to recruit some of the more “hidden” people who do not attend a mosque, and who do not receive adequate services. Despite using a cultural broker and snowball sampling to recruit from other participants, these people were not recruited. Some felt over researched, others expressed that there was no point to the research as nothing would ever change, and some were skeptical and suspicious of the research process and simply refused to have any contact with me as a researcher.

From an ethical perspective, it was important that only people who wanted to participate, did so. Anyone who expressed an unwillingness to participate were not contacted further or pressed for participation. These challenges faced in the recruitment process show us how difficult recruitment can be, and that despite my best efforts to create a comfortable and safe environment, it may not be perceived this way by potential participants. Throughout the thesis, I have shown how deeply ingrained the perceptions of disability are in the culture and religion and that these perceptions and understandings are brought to Canada with immigrants. If someone has faced great stigma in their country of origin, it is not surprising that they would want to protect themselves in Canada. Many of the people that the cultural broker and I tried to recruit were from countries plagued by war and poor governments such as Sudan, Iraq, Syria, and Lebanon. It is possible that people from these countries are inherently skeptical of researchers as they may think that I was from the government or that their information would somehow be shared.

When we prepare ethics protocols at universities in North America, the ethics process, to some extent, expects participants to respond similarly to our recruitment efforts. Certain guidelines have to be followed in the recruitment and interview process and these exist for a good reason: to protect the participants. However, the thesis research showed that not all cultures are the same and this was seen in the recruitments as well. The preferred method of recruitment is to contact a person either by phone or email to explain your research to them and try and get them to agree to participate. This approach was initially attempted but not one individual responded to my emails or phone calls. This prompted me to sit down with my cultural broker and ask him why I was not getting any responses as I had expected. He explained that Imams and leaders of mosques are extremely busy and rarely respond to email and phone calls. In the methodology section (chapter 3), we saw that the cultural broker mentioned that Arab culture was a “pushy” culture and that it was important for us to be more insistent on their participation while also leaving them a choice to whether or not they wanted to participate. The cultural broker suggested that we should be in the neighbourhood when we contacted participants because it was likely that they wanted to meet right away if they had the time. So instead of sitting in an office and calling, recruitment efforts were modified so that we sat in nearby parking lots and called possible participants and/or the cultural broker walked in the door to explain what the research was about and if someone could talk to us about it. We found that many did not answer their phones and that the best way to recruit was for the cultural broker to enter the mosque, explain the research and the importance of their participation. These recruitment challenges show the importance of being adaptable to the culture that is researched as well as the importance of a cultural broker to be able to get in the door to talk to potential participants. The cultural broker not only helped with recruitment but also provided me with information on how to interact with Arab males and females, what was appropriate and what to avoid such as shaking hands with males and instead putting a hand to the chest, and how to properly greet people in Arabic. All of these insights assisted me in making sure that participants knew that I respected and had some knowledge of their culture.

7.3.3 Theoretical contributions

The research employed both feminist disability theory and an intersectional framework in its analysis of qualitative data. While the research has not advanced feminist disability theory or the intersectional framework, it has added to knowledge of the application of these two frameworks. In her paper 'Theorizing and Researching Intersectionality: A Challenge for Feminist Geography' Valentine (2007) calls for feminist geographers to engage with intersectionality and to focus on the lived experiences to *understand the intimate connections between the production of space and the systematic production of power (Valentine, 2007, p. 19)*. The analysis presented here speaks to this relationship, highlighting how and to what extent immigrants with disabilities fit or do not fit in certain spaces, for example countries of origin, prayer centers, and places of work.

Further, the research responds to Hankivsky's (2012) call for more attention to the agency, resiliency and resistance to domination, including the domination of able-bodied norms and expectations. She argues that too much attention has been focused on the lived experiences of vulnerable populations instead of the agency described above. While the research is grounded in the lived experiences of immigrants with disabilities it has also noted that agency and resistance exists. Agency and resistance were seen in some participant's efforts to leave their countries of origin to seek out life in Canada where they would have better opportunities, disability rights, and quality of life. Resistance and agency was noted in their choice of prayer center and the unwillingness to attend a prayer center that did not respect them because of their disability. Participants had the agency to resist these hostile environments and find a suitable place, where they felt respected.

Hankivsky (2012) has also argued for the need to explore intersectionality from a mixed methods approach to be able expand the intersectional analysis. This research adopted a mixed methods design in an attempt to explore both the macro and micro level of intersectional analysis through the analysis of how different variables/categories can intersect to shape receipt of support and experiences of disability. While this research was not completely successful in this application of mixed methods due to the inability to recruit service providers for chapters 5, the mixed methods approach did allow for an examination of how gender, place, and culture can potentially impact service utilization for immigrants with disabilities. The thesis demonstrated that lives of immigrants with disabilities cannot be understood purely from a disability perspective; instead it is important to examine other categories such as immigrant status, culture, religion, gender, employment status, and place to truly understand the complexities of their lived experiences. Further, through applying the intersectional framework along with feminist disability theory, in the form of Garland-Thomson's (2011) concept of "misfits", the research was able to reveal the uniqueness of each participant's experience, demonstrating that there is not one singular experience of disability.

7.3.4 Policy and Practice

The present research did not engage in policy evaluation nor was it meant to be a policy analysis paper. The findings in this research will likely not impact future policy, none the less; the results do give some insight into the importance and power of policy. Results in chapter 6 revealed that Canadian disability policy was viewed, by participants, as a positive catalyst for changing the acceptance of disability within certain cultural communities. Disability policies also made participants feel like they had rights and agency to stand up for themselves and resist forms of discrimination that they faced because these rights were there to protect them and include them in society. Despite this favourable view of policy, results also indicated that there is need for policy to reflect the diversity that exists in Canada in order to better address the needs of groups such as immigrants with disabilities. Results from this thesis have shown the complexities of the lives of immigrants with disabilities, whether that is perceptions of (dis)ability in their own community, access to culturally appropriate services, or gaining access to meaning full employment, as well as the challenges that they face in accessing services. While the literature often calls for culturally sensitive training for medical professionals and service providers, there is also a need for culturally sensitive services. For example, in the form of day programs, which can be alternatives to group homes that respect the participants' cultural needs and/or a guarantee that an assigned caregiver is the preferred gender and fulfills the cultural norms of the person receiving the services.

Results also highlighted the difficulties that exist when trying to access services, suggesting that some of these difficulties could be mitigated with either a one-stop-shop where immigrants could get qualified help and information or the wider availability of trained personnel who are aware of issues that immigrants face. The fact that immigrants with disabilities, who qualify for services, are not able to obtain these services because they cannot fill out the paperwork properly is a major downfall in the system that has the potential to leave immigrants with disabilities in a more vulnerable position compared to non-immigrants with disabilities. Several participants expressed frustrations with regard to finding information on disability both prior to coming to Canada and after they arrived. The fact that several key informants had started their own organization to address these needs of immigrants is further evidence of significant gaps in the service system. These key informants formed this ethno cultural organization on their own time and eventually could not keep up either because of obligations in regards to employment, family, or both. It should not be the responsibility of immigrants with disabilities to form their own organization to receive the care and information that they need, this should be readily available to all and not rely on the volunteer time of a few people who have recognized this need. It is important that the government, both on a federal and provincial level, address this lack of information and service to ensure that immigrants with disabilities do not fall through the cracks when trying to access services and information. Since data sets like the PALS, used in chapter 4, inform policy it is important that future data sets include a larger sample size of immigrants from all regions to allow for a more in-depth analysis of cultural differences in the utilization of care within Canada. Currently, the PALS dataset sample size is too small to draw conclusions on different regions causing results to be over generalized. Greater samples sizes combined with qualitative data analysis will provide a better understanding of the complex intersections of care, culture, gender, and place.

7.4 Limitations

There were several limitations to this research, the majority being linked to issues of recruitment and sample sizes. I have already touched on some of the issues surrounding recruitment both related to recruiting organizations and recruitment through the cultural broker. Due to these difficulties participants in the qualitative stages of the research shared similar characteristics and some of the more “hidden” immigrants with disabilities were not recruited. The stigma surrounding disability acted as a limitation in recruitment for both participants in key informant interviews and immigrants with disabilities.

Sample size was another limitation in both the quantitative and qualitative chapters. In chapter 4, sample sizes of immigrants were small and especially lacked representation of immigrants in the younger age categories, resulting in low numbers that could not be released. The small sample sizes of immigrants in the PALS dataset also made it impossible to examine support service utilization based on country or region of origin. The PALS data presented in this research is therefore overgeneralized to all immigrants and not representative of the Middle East and South Asian populations discussed in chapter 5 and 6. The sample size of 8 immigrants with disabilities was lower than what I had hoped to recruit but because of previously mentioned recruitment issues it was not possible to recruit more people. While the sample size was small, saturation was still achieved on several topics, including knowledge of services, marriage and relationships, and support services.

Other limitations included time constraints, lack of previous literature to compare results to, and language. Due to the time restraints of the doctoral research, it was not possible to keep up efforts of recruitment beyond the 10 months that was devoted to the process. Had this been a longitudinal project, it may have been possible to spend a significant amount of time in the respective communities to make connections with possible participants; however, this was not possible for this research. As mentioned previously in the thesis, there is limited literature that has explored adult immigrants with physical disabilities and comparisons to other literatures were therefore limited. One of the recruitment criteria was that participants had to speak English. Due to lack of funding, it was not possible to pay a translator to participate in interviews. Having English language criteria may have excluded some participants from participating in the research. If they did not speak English or did not feel comfortable speaking English they may have chosen to not participate, or where not aware of opportunities given that the recruitment material was also in English.

Another possible limitation was the use of face-to-face interviews to gather data. Since disability is highly stigmatized, it is possible that participants did not want to meet with a researcher face-to-face. It is possible that surveys would have resulted in more participants being recruited. However, surveys would not have resulted in the same in depth data as was gathered in this research as well as not allowing for probing or follow up questions.

7.5 Future Research

The research in this thesis is a starting point for future research and adds to the limited literature on immigrants with disabilities from the Middle East and South Asia. Through conducting and analyzing the current research several ideas for future avenues of research have emerged. Many of these build from the highlighted limitations and others are related to the theoretical framework.

From a statistical perspective there is a need for datasets with larger sample sizes of immigrant populations from all regions and ages. The current small sample sizes of the PALS dataset and the Canadian Survey on Disability, do not allow researchers to examine differences between regions that might be more vulnerable in regards to prevalence of disability and receipt and need of support. Larger surveys focused on specific regions, for example the Middle East, South East Asia, Sub-Saharan Africa or specific countries, would allow for an in-depth analysis of differences between regions including comparisons between Canada and these regions.

The current study only had access to one cultural broker. It would be advantageous for future research to utilize several cultural brokers representing different; genders, religions, cultures, and language abilities. Having diverse cultural brokers could potentially ease the recruitment process and create trust between researchers and participants to address the issues of the researcher being an outsider. On the other hand, future research conducted by a researcher who is a member of the researched community is a possible advantage both in relation to trust and knowledge of the community. However, using a researcher who is member of the community could also have a negative effect if there is a high level of stigma situated in regards to disability in the community and if participants would feel exposed or unhidden by being interviewed by a member of their cultural community.

It is important for future research to explore the experiences of immigrants with disabilities from other regions. While this research focused on the Middle East and South Asia, Canada also has large numbers of immigrants from East Asia and we know little about adults with disabilities from this region as well. Since all of these regions are large, it would also be advantageous for future research to explore disability in immigrants from specific countries as the experiences in Lebanon may not be comparative to experiences in India. There is also a need for future research to explore the lived experiences of immigrants with disabilities in different provinces. Ontario has a large immigrant population and significant ethnic diversity but there is little to no knowledge of how immigrants with disabilities are doing in other provinces and smaller cities. This research showed that "place" plays an important role in the experiences of immigrants with disabilities but what happens when someone lives in a smaller town in Canada? How does this experience change? Does living in a smaller town or province automatically make an immigrant with a disability more vulnerable or do they experience the same advantages because of policy as was seen in this research? Doing a policy analysis of disability rights in the different provinces in Canada would be important to see if any provinces or territories have specifically included immigrants in their policies or provide specific services catering to immigrants. Overall, there is a need to expand the literature on immigrants with disabilities to ensure that they are provided with culturally appropriate supports. It is also imperative that future research focuses on the perspective of service providers. While government services and charitable organizations have been critiqued by participants, it is important to acknowledge that many of these services lack the funding to accommodate immigrants with disabilities. It is therefore important for future research to explore what the needs of services organizations are and recommend ways that these needs can be addressed by federal, provincial, and municipal governments.

7.6 Conclusion

This thesis has shown the importance of exploring disability amongst immigrants from other cultures and religions living in Canada and has provided several insights into the lived experiences of immigrants with disabilities from the Middle East and South Asia living in the GTHA. Through quantitative and qualitative methods the importance of place, gender, culture, and policy were revealed to all significantly impact these lived experiences of disability. Further, several methodological observations were made in regards to researching other cultures. This was particularly observed in regards to adapting recruitments efforts of key informants.

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Appendix A

LETTER OF INFORMATION / CONSENT

A Study about experiences of disability in Canada's Middle Eastern and South Asian communities

Principal Investigator:	**Supervisor**
Stine Hansen	Dr. Robert Wilton
School of Geography and Earth Sciences	School of Geography and Earth Sciences
McMaster University	McMaster University
Hamilton, Ontario, Canada	Hamilton, Ontario, Canada
hanses2@mcmaster.ca	*wiltonr@mcmaster.ca*
	(905) 525-9140 ext. 24536

What am I trying to discover?

I am conducting this study to better our understanding of the unique experiences and lives of disabled immigrants living in Canada.

I am interested in learning about (1) understandings and perception of disability in Middle Eastern and South Asian Communities in the Greater Toronto and Hamilton Area (GTHA), (2) the services and supports available to disabled people from these communities, and (3) the unique challenges that this population may face compared to other people with disabilities.

You have been asked to participate because as an executive director/member/owner/leader of such an organization, you have an in-depth understanding of these issues and your input would be very valuable to this project.

What will happen during the study?

I am asking you to take part in a face-to-face interview to tell me about your organization, knowledge and experience of disabled people from Middle Eastern and/or South Asian communities. The interview will last about 30-60 minutes and can be conducted at a time and location of your choosing.

I will ask you a range of questions about your organization and experiences. These questions will cover a variety of topics including services and supports available to disabled people, challenges and barriers that disabled people may face as well as a few questions about you i.e. your position within the organization, how long you have worked/been a member/leader there etc. Last, I will ask if you and your organization would consider participating in a second stage of the research project. This stage would involve participant recruitment.

The interview will be audio-recorded and handwritten notes will be taken.

Please be advised that you cannot disclose any confidential information about your clients to me.

Are there any risks to doing the study?

The risks involved in participating in this study are minimal. You may feel embarrassed if there are questions that you cannot answer or upset if you feel that you are not able to help. You may also feel a loss of privacy if you identify yourself to others after having done the interview. Please keep your confidentiality in mind.

You do not need to answer questions that you do not want to answer or questions that make you feel uncomfortable. You can also withdraw from the research at any time. I have taken several steps to ensure your privacy and confidentiality to minimize the risks of your participation in this study, please see below.

Who will know what I said in the study?

Every effort will be made to protect your confidentiality and privacy. I will not use your name or the name of your organization in any written reports or publications. Only members of the research team (me, my supervisors and cultural broker) will know that you participated in the research project.

However, there are a limited number of organizations that have contact with disabled immigrants and other people in your field may be able to identify you based on your answers. Please keep this in mind when deciding what to tell me in the interview.

The audio-recording of the interview will be kept on a password-protected computer in my research office. Transcripts of the interview will be kept in a locked drawer in the same office. Both audio-files and transcripts will be assigned a code number and will have identifying information removed. Only members of the research team will have access to this data. Once the study has been defended in the fall of 2018 the interviews and transcripts will be destroyed.

Please be advised that Waad Khogali, is assisting me with this research and may take part in interviews and recruitment. He is subject to confidentiality and will not discuss this research with anyone outside of this study.

Are there any benefits to doing this study?

The research will not benefit you directly. However, I hope to learn more about the unique experiences that disabled immigrants from the Middle East and South Asia have and how it impacts and challenges their everyday lives. This will help raise awareness around the experiences of disabled immigrants and add to our knowledge on immigrants with disabilities, which is very limited. Whenever possible, findings will be shared with policy makers and disability organizations.

What if I change my mind about being in the study?

Your participation in this study is voluntary. If you decide to be part of the study, you can decide to stop at any time, even after signing the consent form or part-way through the study. If you don't want to answer some questions you do not have to, but you can still be in the study.

If you decide to withdraw, there will be no consequences to you. If you choose to withdraw, any data you have provided will be destroyed~~.~~ However, once the research is complete and the results of the study made public (i.e. thesis or publication), you will not be able to withdraw. The results may be made public as early as January 2018, so you will be able to withdraw until December 2017. Please be advised that while this stage of the research will be completed approximate December 2017, I will keep your data until the thesis has been defended in Fall 2018 and papers have been published.

Information about the Study Results

I expect the overall (including subsequent stages) research to be complete by approximately July 2018. If you would like a brief report summarizing the results, please let me know how you would like it sent to you.

Questions about the Study:
If you have questions or need more information about the study itself, please contact me at:

Stine Hansen
hanses2@mcmaster.ca
or my supervisor
Robert Wilton
wiltonr@mcmaster.ca, 905-525-9140 ext. 24536

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat
Telephone: (905) 525-9140 ext. 23142
C/o Research Office for Administrative Development and Support
E-mail: ethicsoffice@mcmaster.ca

Consent

- I have read the information presented in the information letter about a study being conducted by Stine Hansen of McMaster University.
- I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.
- I understand that if I agree to participate in this study, I may withdraw from the study at any time or up until approximately December 2017
- I have been given a copy of this form.
- I agree to participate in the study.

1. I agree that the interview can be audio recorded.
… Yes.
… No.

2. …Yes, I would like to receive a summary of the study's results.
Please send them to me at this email address ___________________________________
Or to this mailing address: ____
____
____

… No, I do not want to receive a summary of the study's results.

3. I agree to be contacted about follow-up recruitment for stage two, and understand that I can always decline the request.
... Yes. Please contact me at: ____
... No.

Signature: ____

Name of Participant (Printed) _____________________________________

Date: _________________________

Appendix B

Interview guide for key informants

Intro:

1. Can you tell me about your role at [name of organization]?
2. How long have you been part of/working for this organization?
3. Can you tell me about the membership of/population served by your organization (who are they, demographics, etc.)?
4. Based on your own experience, to what extent is disability (particularly physical disability) something the members/population of your organization are dealing with?

Your organization

5. To what extent is your organization involved in providing services or assistance to people with disabilities?
6. Can you describe the different kinds of assistance/service provision that you offer?
7. Generally, how would people find out about/access these services?
8. Are there any differences in the services available to men and women?

Cultural meanings of disability

9. What are the meanings/beliefs associated with 'disability' in your cultural community?
10. What factors influence these meanings/beliefs? (prompt: religion, cultural norms, familial structures, gender)
11. Are there differences between how disability is viewed in your cultural community and in Canada at large?
12. Can you explain what those are?
13. How do members of your community negotiate these differences?
14. Is the experience of being disabled different for men and women in your community? If yes, how so?

Access to service

15. Based on your experience, are disabled members of your cultural community hesitant to access services?
    a. If yes, why do you think that is?
    b. Are men or women more hesitant to access services?
16. Based on your experience, do disabled members of your community face barriers to service?
    a. If yes, what are these barriers?

    b. Are these barriers a result of…

17. What do you think could be done to help disabled people within your community to access needed services??
    a. If yes, can you expand on what this might be? Cultural changes, policy changes or other?

18. Do you want to add something that is not just about ‘access to service’ but is more broadly about how /to what extent disabled members of the community face problems participating in social and community life?

19. Is there anything else you would like to add, that you believe might be of importance to the study

Appendix C Nodes

Nodes

Chapter 5 Nodes – Key Informants

Accessibility Services
Accommodation
Activism
Amount of People with disabilities
Assistive Devices
Attitude
Barriers to Services
Charity Model
Creating Awareness
Cultural Sensitivity
Culture
Culture and Religion
Disability and Faith
Duty to Help
Faith
Faith and Services
Government
Government Services
Hiding Disability
Islamophobia
Knowledge of services
Male Ego
Marriage
Perception and Understanding
Policy
Political Climate
Services
Stigma
The lack in the System
Needs
Zakat

Appendix C
Nodes

Chapter 6 Nodes – Participants with Physical Disabilities

- **Accessibility**
    - Accommodation
    - Assistive Devises
    - Barriers
    - Challenges
    - Experts
    - Housing
    - Isolation
    - Language
    - Life in Country of Origin
    - Sport
    - Technology
    - Transportation
- **Culture**
    - Abuse
    - Attitudes
    - Awareness
    - Burden
    - Canadian Culture
    - Charity Model
    - Cultural Community
    - Cultural Sensitivity
    - Curiosity
    - Discrimination
    - Educating/Informing Others
    - Ego
    - Gender
    - Hiding Disability
    - Lack of Awareness
    - Marriage
    - North American Culture vs Their Culture
    - Perceptions of Disability
    - Shame
    - Stigma
- **Employment - Work**
    - Achievement
    - Canadian Experience
    - Education
    - Empowerment
    - Opportunities
    - Pay it Forward
    - Volunteer Work
- **Family**
    - Advocate
    - Friends
    - Parents
    - Protection
    - Spouse
- **Feelings**
    - Confidence
    - Dreams
    - Equality
    - Feeling of Belonging
    - Freedom
    - Happiness
    - Identity
    - Independence
    - Sadness
- **Health**
    - Cure
    - Depression
    - Disability Condition
    - Health Care
    - Health Professionals
    - Pain
    - Pregnancy
- **Immigration**
- **Money**
    - Financial Assistance

  - Poverty
  - Quality of Life
- **Politics**
  - Change of perceptions
  - Human Rights
  - ODSP
  - Policy
- **Religion**
  - Curse
  - Karma
  - Islam
  - Religion vs Culture
- **Services**
  - Decrease in services
  - Help/Assistance
  - Ineligibility
  - Knowledge of Services
  - Personal Care
  - Support
  - Needs

Appendix D

LETTER OF INFORMATION / CONSENT

A Study about experiences of disability in Canada's Middle Eastern and South Asian communities

Principal Investigator:	**Supervisor:**	**Supervisor:**
Stine Hansen School of Geography and Earth Sciences McMaster University Hamilton, Ontario, Canada Hanses2@mcmaster.ca	Dr. Robert Wilton School of Geography and Earth Sciences McMaster University Hamilton, Ontario, Canada wiltonr@mcmaster.ca (905) 525-9140 ext. 24536	Dr. Bruce Newbold School of Geography and Earth Sciences McMaster University Hamilton, Ontario, Canada Newbold@mcmaster.ca (905) 525-9140 ext. 27948

What am I trying to discover?
I am conducting this study to better our understanding of the unique experiences and lives of disabled immigrants living in Canada.

I am interested in learning about (1) understandings and perception of disability in Middle Eastern and South Asian Communities in the Greater Toronto and Hamilton Area (GTHA), (2) the services and supports available to disabled people from these communities, and (3) the unique challenges that this population may face compared to other people with disabilities.

You have been asked to participate because you are someone who has immigrated to Canada from the Middle East or South Asia and you also have experience of living with a disability. Your in-depth understanding of these issues would be very valuable to this project.

What will happen during the study?
I am asking you to take part in a face-to-face interview to tell me about yourself, your knowledge and experience of being a person with a disability coming from a Middle Easter or South Asian community. The interview will last about 60-90 minutes and can be conducted at a time and location of your choosing.

I will ask you a range of questions about you, your daily life, cultural community and experience of living with a disability as an immigrant in Canada. These questions will cover a variety of topics including services and supports available to disabled people, challenges and barriers that you may face as well as a few questions about what you think could be done to improve lives for immigrants with disabilities.

The interview will be audio-recorded and handwritten notes will be taken.

You will receive $20 as a thank you for participating in the study. You do not have to return this money if you choose to withdraw from the study during or after the interview.

Are there any risks to doing the study?
The risks involved in participating in this study are minimal, however there are some risks. Some of the questions may make you feel uncomfortable, embarrassed, worried or upset.

You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. You can withdraw (stop taking part) from the interview at any time. I have taken several steps to ensure your privacy and confidentiality to minimize the risks of your participation in this study, please see below.

Who will know what I said in the study?
Every effort will be made to protect your confidentiality and privacy. I will not use your name in any written reports or publications. Only members of the research team (my supervisors and I) will know that you participated in the research project unless you wish to tell him or her. However, keep in mind that others may be able to identify you on the basis of references that you make. You will be given a pseudonym in the study so that your real name will not be disclosed at any point during the research. General characteristics may be used in the final study but no identifiable characteristics, which could identify you, would be used.

If you choose to have the interview in a public place, please note, that anyone who saw us together would potentially know that you participated.

The audio-recording of the interview will be kept on a password-protected computer in my research office. Transcripts of the interview will be kept in a locked drawer in the same office. Both audio-files and transcripts will be assigned a code number and will have identifying information removed. Only members of the research team will have access to this data. Once the study has been defended in the fall of 2018 and papers have been accepted for publication the interviews and transcripts will be destroyed.

Are there any benefits to doing this study?
The research will not benefit you directly. However, I hope to learn more about the unique experiences that disabled immigrants from the Middle East and South Asia have and how it impacts and challenges their everyday lives. This will help raise awareness around the experiences of disabled immigrants and add to our knowledge on immigrants with disabilities, which is very limited. Whenever possible, findings will be shared with policy makers and disability organizations.

What if I change my mind about being in the study?
Your participation in this study is voluntary. If you decide to be part of the study, you can decide to stop at any time, even after signing the consent form or part-way through the study. If you do not want to answer some questions you do not have to, but you can still be in the study.

If you decide to withdraw, there will be no consequences to you. If you choose to withdraw, any data you have provided will be destroyed~~,~~ however, once the research is complete and the results of the study made public (i.e. thesis or publication), you will not be able to withdraw. The results may be made public as early as March 2018, so you will be able to withdraw until January 2018. Please be advised that while this stage of the research will be completed approximate January 2018, I will keep your data until the thesis has been defended in Fall 2018 and until the papers have been accepted for publication.

Information about the Study Results
I expect the overall (including subsequent stages) research to be complete by approximately July 2018. If you would like a brief report summarizing the results, please let me know how you would like it sent to you.

Questions about the Study:
If you have questions or need more information about the study itself, please contact me at:

Principal Investigator
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or my supervisor
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wiltonr@mcmaster.ca, 905-525-9140 ext. 24536
or my supervisor
Bruce Newbold
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C/o Research Office for Administrative Development and Support
E-mail: ethicsoffice@mcmaster.ca

Consent

- I have read the information presented in the information letter about a study being conducted by Stine Hansen of McMaster University.
- I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.
- I understand that if I agree to participate in this study, I may withdraw from the study at any time or up until approximately January 2018
- I have been given a copy of this form.
- I agree to participate in the study.

1. I agree that the interview can be audio recorded.
… Yes.
… No.

2. …Yes, I would like to receive a summary of the study's results.
Please send them to me at this email address ___________________________________
Or to this mailing address: ____
____
____

… No, I do not want to receive a summary of the study's results.

Signature: ____

Name of Participant (Printed) _____________________________________

Date: _________________________

Appendix E

Interview guide for Immigrants

Intro:

1. Can you tell me a bit about yourself?

   Prompts for question #1:
   - How long have you been in Canada?
   - How old were you when you arrived in Canada?
   - What country did you emigrate from?
   - Are you married?
   - Are you employed?
2. Can you tell me about your disability?

   Prompts for question #2:
   - Have you been disabled/impaired since birth?
   - Has your disability changed? (more or less severe)
   - Can you tell me about a time your disability caused you to experience a challenge?

Social and cultural experiences of disability

3. What are the meanings and beliefs associated with disability in your cultural community?
4. What factors influence these meanings and beliefs? (prompt: religion, culture, family structure, gender, etc.)
5. Are there differences in how disability is viewed based on gender?
6. Do you feel that you face any barriers because of your disability?
7. How do people in your cultural community feel about your disability?
   a. Do you feel hesitant to access community centers and places of worship?
8. Do you feel welcome in your cultural community?
9. Do you see any differences in how disability is treated/viewed/understood in Canada compared to your country of origin/ or other countries you have lived in?
   a. Can you explain what those are?
10. What do you think could be done to help disabled people within your community?
11. Do you receive any services or help for your disability?
    - What kind of help do you get/receive?
    - How did you find out about these services?
    - Do you receive any services from your place of worship (mosque, church, temple)

12. Is there anything else, ideas suggestions that you would like to add?

Generic prompts:
Can expand on that?
What do you mean by that?
How did that make you feel?
Can you explain/give me an example of this?
Tell me about a time when…

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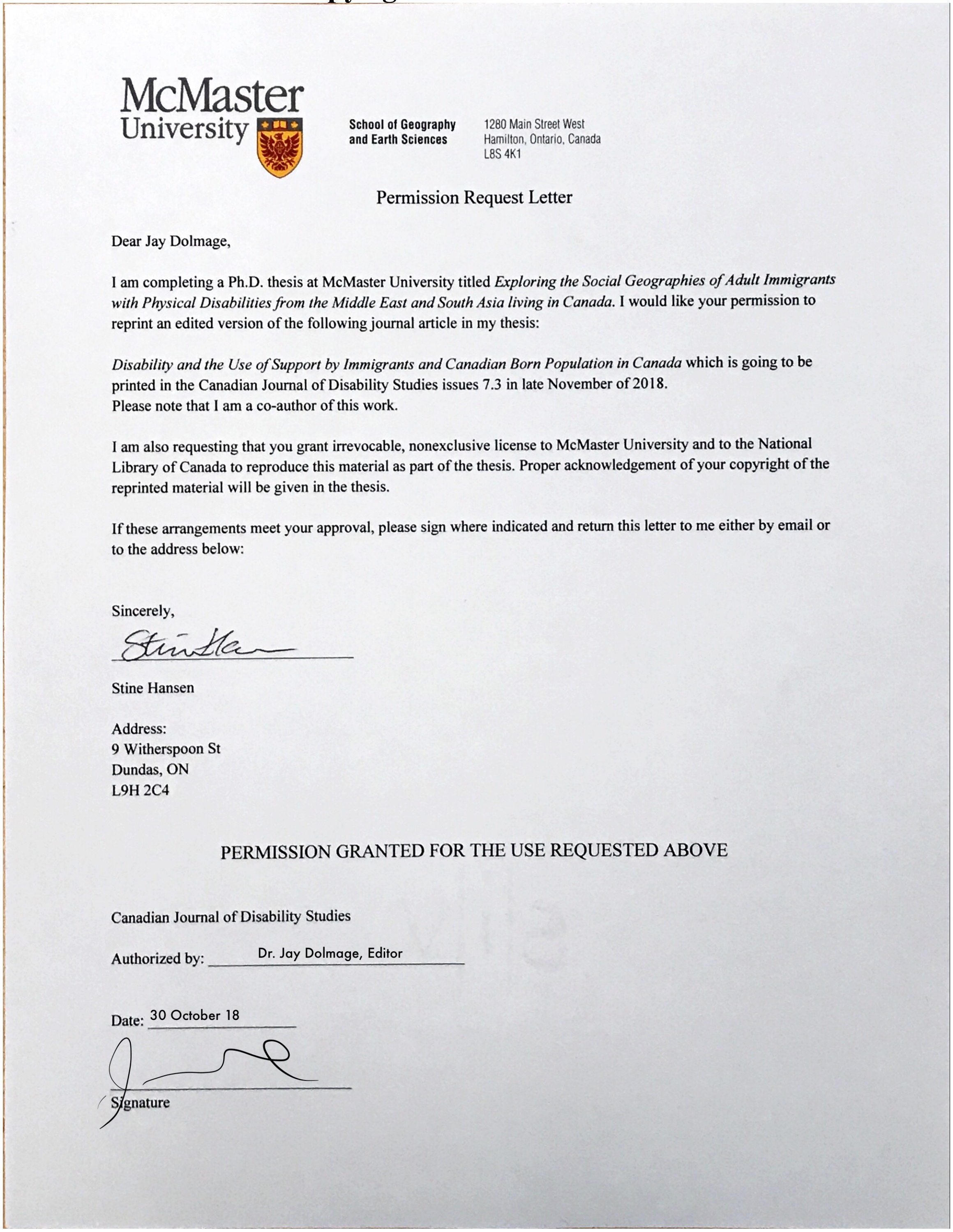

McMaster
University

School of Geography
and Earth Sciences

1280 Main Street West
Hamilton, Ontario, Canada
L8S 4K1

Permission Request Letter

Dear Jay Dolmage,

I am completing a Ph.D. thesis at McMaster University titled *Exploring the Social Geographies of Adult Immigrants with Physical Disabilities from the Middle East and South Asia living in Canada.* I would like your permission to reprint an edited version of the following journal article in my thesis:

Disability and the Use of Support by Immigrants and Canadian Born Population in Canada which is going to be printed in the Canadian Journal of Disability Studies issues 7.3 in late November of 2018.
Please note that I am a co-author of this work.

I am also requesting that you grant irrevocable, nonexclusive license to McMaster University and to the National Library of Canada to reproduce this material as part of the thesis. Proper acknowledgement of your copyright of the reprinted material will be given in the thesis.

If these arrangements meet your approval, please sign where indicated and return this letter to me either by email or to the address below:

Sincerely,

Stine Hansen

Address:
9 Witherspoon St
Dundas, ON
L9H 2C4

PERMISSION GRANTED FOR THE USE REQUESTED ABOVE

Canadian Journal of Disability Studies

Authorized by: Dr. Jay Dolmage, Editor

Date: 30 October 18

Signature