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Disability Rights in an Ableist Health Care Environment:

**How do Women with Disabilities Understand and Address Systemic Barriers to
Preventative Community Health Services?**

By

Cynthia Brown

A Thesis

Submitted to the Faculty of Graduate Studies

through the Faculty of Law

in Partial Fulfillment of the Requirements for

the Degree of Master of Laws

at the University of Windsor

Windsor, Ontario, Canada

2019

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Disability Rights in an Ableist Health Care Environment:

**How do Women with Disabilities Understand and Address Systemic Barriers to
Preventative Community Health Services?**

by

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30 July 2019

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ABSTRACT

This thesis explores how women with disabilities understand and address their rights to preventative health care within a context of systemic barriers.

As the investigator of an empirical study consisting of interviews of five women with disabilities (WWDs) who participated in a barrier-free cancer screening clinic day, I began by exploring the context within which WWDs must operate as they strive to obtain preventative health services to which they are entitled.

To this end, a literature review revealed numerous barriers to health care services for WWDs across jurisdictions. In addition, human rights and accessibility legislation, primarily within the Canadian jurisdiction was explored, along with key cases related to health care access for persons with disabilities (PWDs) and WWDs.

The interview data was analyzed according to grounded theory methodology, using a feminist theoretical framework and a critique of the literature related to ableism, identity development and rights consciousness. The data, supported by the literature, confirms the existence of multiple barriers to health care for WWDs, and the existence of health care ableism.

Most significantly, the data suggests that health care access for WWDs centers around their relationship with their rights to access versus their relationship with the access barriers. I propose a model of rights consciousness, composed of three stages of identity: Imposed Identity, Formative Identity and Integrated Identity. Based on this model, the stages of identity development influence WWDs' recognition of exclusion and rights infringement related to health care, as well as their decision and degree of support required to act upon it.

DEDICATION

This thesis is dedicated to all the people with disabilities that I have come to know throughout my career as an occupational therapist (OT). My experiences with every one of them over the past thirty-five years has shaped me both personally and professionally.

ACKNOWLEDGEMENTS

I wish to thank my advisor, Professor Laverne Jacobs. Your quiet patience and support throughout this challenging project were invaluable to me, and I am most grateful. Thank you for helping me to find my passion! I would also like to thank Professor Tess Sheldon, my internal department reader, and Dr. Nathania Liem, my external department reader. Both of you have been very supportive of my research project.

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I would be remiss if I did not mention the team with whom I collaborated in order to conduct my empirical research: Dr. Nathania Liem and her medical students Abbey Nicoletti and Kawmadi Abeytunge, Marla Jackson, Dr. Jennifer Voth and Rachel Gough, of the Department of Research and Evaluation Services at Hôtel-Dieu Grace Hospital, Gayle Iannicello and Ben Parent of the Erie St. Clair Regional Cancer Program, and Dr. Milrod. I could not have found a more supportive group with whom to negotiate access to study subjects!

I wish to thank my family and friends who encouraged me every step of the way. Thank you to my son Dan and daughter Erin and my special friends Carol and Marcie for encouraging me to take the next right step. A special thank you to Professor G.E. Lasker, who gave me the initial inspiration to pursue higher studies, and who has offered unfailing support throughout.

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LIST OF ABBREVIATIONS

ADA	<i>Americans with Disabilities Act of 1990 (as amended by ADA Amendments Act of 2008)</i>
AMA	<i>Accessibility for Manitobans Act</i>
AODA	<i>Accessibility for Ontarians with Disabilities Act</i>
CBPR	Community Based Participatory Research
CRPD	<i>Convention on the Rights of Persons with Disabilities (UN)</i>
EHIS	European Health Interview Survey
GP	General Practitioner
GPPS	General Practice Patient Survey
HDGH	Hôtel Dieu-Grace Healthcare
HRTO	Human Rights Tribunal of Ontario
NHS	National Health Service (U.K.)
NPHS	National Population Health Survey
NSAA	<i>Accessibility Act (NS)</i>
OBSP	Ontario Breast Screening Program
ODA	<i>Ontarians with Disabilities Act</i>
OT	Occupational Therapist
PWD	Person with disabilities
SCI	Spinal Cord Injury
WWD	Woman with disabilities
WHO	World Health Organization

CHAPTER 1
INTRODUCTION

1.1 Statement of the Problem

Societal understanding of the rights of persons with disabilities continues to evolve, with rights-based disability legislation emerging in several jurisdictions through the latter half of the twentieth century. The pivotal United Nations *Convention on the Rights of Persons with Disabilities*, which was adopted in 2006 and entered into force in 2008, provided an international guide-post for the drafting and/or revision of rights-based legislation in many countries, as well as their respective states, provinces and territories. The goals of the legislation are lofty, but the impact on the ground appears to be lacking. People with disabilities (PWDs), and, specifically the subject of this thesis, women with disabilities (WWDs), have not fully realized the benefits that were expected from these laws. WWDs appear to have borne the intersectional brunt of both gender discrimination and disability discrimination, as they seek preventative health care services within their community.

Why is this the case? What are the barriers to health care and why do they continue to exist, despite the existence of laws? How do WWDs view these barriers, and how do they choose to deal with them? How do women understand their rights with respect to health care access, and how do they recognize, and seek remedy for any infringement on those rights? When and why do they seek remedy, and when and why do they choose not to? Are they aware of pertinent legislation related to their rights to health care? How does this knowledge, or lack of it, impact their choice to act?

That these barriers exist is indeed a problem; but the greater problem lies in the fact that these health care barriers faced by women continue to be perpetuated despite the existence of legislation intended to counteract them. It is the goal of this thesis to begin to uncover the reasons for this apparent discrepancy between intent of the law and the lived experience of WWDs. This will be done through an exploration of the barriers, an exploration of the law and complaints processes, and most importantly, in my view, an exploration of the lived experience of women with disabilities as related to health care access.

1.2 Outline

This thesis is organized into seven chapters. Following this introductory chapter, Chapter Two provides a literature review of the barriers which are experienced by PWDs and, specifically, WWDs. Chapter Three undertakes a review of the human rights laws which protect the rights of persons with disabilities. Key cases are presented to illustrate the implementation and application of these laws. Chapter Four details the methodology and design of the empirical research, which was conducted in the form of interviews with women with disabilities selected for a barrier-free cancer screening clinic day. Analysis of the interview results is conducted in Chapter Five. Following from the grounded theory approach, Chapter Six further analyzes the data by engaging with applicable theoretical frames of reference and other key areas of academic thought. Chapter Seven serves as a conclusion to the thesis, providing suggestions for further discussion and research.

CHAPTER 2

BARRIERS TO HEALTH CARE

2.1 Background

Despite the assurance by human rights legislation that all individuals are protected from discrimination, evidence shows that PWDs, and specifically, WWDs, encounter the discriminatory impact of barriers to health care access. Studies have been conducted in various jurisdictions related to these health care access barriers. The focus of these studies ranges from a medical perspective, to a health policy/population studies perspective, and finally to a disability studies viewpoint. In order to provide a structured presentation which is reflective of the broad avenues of research in the field, the following literature review is presented according to study methodology.

The methodologies include quantitative data analysis, comparative quantitative analysis (those with and without disabilities), health policy/population studies, and qualitative studies consisting of surveys, interviews, and focus groups using a grounded theory approach. Within each of these methodologies, a variety of viewpoints and perspectives is presented. Studies specific to WWDs will be presented separately.

2.2 Literature Review

2.2.1 Quantitative Studies

Beginning with a quantitative study, from a medical perspective, Mudrick et al¹ conducted an analysis using existing data obtained from on-site reviews of doctors' offices in the state of California. They requested access to the data that is routinely required by state health plans. They analyzed a 55-item instrument that assessed parking, exterior

¹ Nancy R. Mudrick et al, "Physical accessibility in primary health care settings: Results from California on-site reviews" (2012) Disability Health J 5 159 at 159.

access, building entrance, interior public spaces, doctor’s office interior, and the presence of accessible exam equipment.² From their analysis, the researchers found “that although the parking arrangements and exterior entrances of most medical buildings are accessible to a patient with a disability, significant barriers continue to exist inside their physician’s office. Only 34.3% of provider offices met all of the interior office access criteria appropriate for their setting.”³ The authors described how the provider offices fell short, stating that “[a]n accessible weight scale was present in 3.6% and a height adjustable examination table in 8.4% of the sites. Other high prevalence areas for access barriers were bathrooms and examination rooms.”⁴ The authors noted that the majority of the architectural elements which were used as access criteria were from the 1991 *ADA Standards for Accessible Design (ADAAG Guidelines)*.⁵ It appears from this study that legislated guidelines are not consistently translated into reality in the jurisdiction of California. Legislative instruments and their application will be discussed further in the next chapter.

Another medically-based quantitative study focused on preventative care. Stillman et al⁶ conducted a cross-sectional, observational study on individuals with spinal cord

² *Ibid* at 161-162. A breakdown of specific items reviewed on the instrument include exterior ramps, stairs, and walkways; building entrance (including signs and door hardware); interior circulation (including hallways, ramps, and stairs); elevator characteristics (where an elevator is present); entrance to the doctor’s office (door weight and hardware); waiting area; restrooms (stall size and layout, grab bars, door hardware, and sink access); examination room (size, door weight and hardware); and medical examination equipment (examination table and weight scale). See also 55 item assessment tool at online: www.dhcs.ca.gov/provgovpart/Documents/Waiver%20Renewal/FEB24/ADA%20Tool_IEHP_LACare_HealthNet_Molina.pdf.

³ *Ibid* at 165.

⁴ *Ibid* at 159.

⁵ *Ibid* at 161. The *ADA* refers to the *Americans With Disabilities Act of 1990*, 1990, Pub. L. No. 101-336, 104 Stat. 328 (1990), [*ADA*]. Note that 41 of the 53 architectural elements are from the *ADAAG* (*Americans with Disabilities Act Accessibility Guidelines*). See also *ADAAG* online: www.ada.gov/regs2010/2010ADAStandards/2010ADAstandards.htm.

⁶ Michael D. Stillman et al, “Health Care Utilization and Barriers Experienced by Individuals with Spinal Cord Injury” (2014) 95 *Arch Phys Med Rehabil* 1114.

injury (SCI) in the U.S., using an internet-based survey. They studied adults with SCI who use a wheelchair as their primary means of mobility. The objective of their study was “[t]o identify from whom individuals with spinal cord injury (SCI) seek health care, the percentage who receive preventative care screenings, and the frequency and types of barriers they encounter when accessing primary and specialty care services; and to examine how sociodemographic factors affect access to care and receipt of preventative screenings.”⁷ In their discussion, the authors noted that people with SCI seek and obtain medical attention, but they were troubled by “respondents’ reports of not being weighed, being examined while fully clothed and seated in their wheelchair, and not receiving routine and preventive interventions.”⁸ In addition, the authors commented that screenings for colorectal, cervical, and breast cancers were lacking for this subject group.

On a related note to this subgroup of individuals with SCI, and indeed to many other disability subgroups, a pertinent financial barrier exists related to fair and equitable access to medical supplies. According to Spinal Cord Injury Ontario (SCIO), “[i]ntermittent catheterization is a recommended bladder management method for people with urinary retention due to spinal cord injury or other conditions such as prostate enlargement. In Ontario, approximately 38,000 people use ICs and monthly supply costs can be up to \$2,500 for specialized single-use ICs.”⁹ SCIO and its partners are advocating for a province-wide comprehensive medical supply coverage program for people with disabilities, across all sub-groups.

⁷ *Ibid.*

⁸ *Ibid* at 1118.

⁹ “Access to Medical Supplies”, online: *Spinal Cord Injury Ontario* <sciontario.org/advocacy/advocacy-scio/advocacy-campaign-portal/access-to-medical-supplies/>.

2.2.2 Quantitative Comparison Studies

The studies reviewed in the next section are all quantitative studies, with the common feature of viewing the experiences of individuals with and without a disability from a comparative perspective (ie those with and without disabilities).

The goal of a study conducted in England by Popplewell et al,¹⁰ was to compare patient-reported access to English primary care for adults with and without physical disability. They conducted a secondary analysis of the 2010/11 General Practice Patient Survey (GPPS) using logistic regression.¹¹ The GPPS consisted of a nationwide, cross-sectional survey, “sampling from adults registered with an English NHS [National Health Service] GP [General Practitioner].”¹² Their analysis led them to conclude that:

[a]dults in England with physical disability experience worse physical access into primary care buildings than those without. Physical disability is also associated with increased unmet healthcare need due to difficulty getting to GP premises, compared with the experience of adults without physical disability. Increasing age further exacerbates these problems.¹³

In light of this final comment related to age, it is important for those of us who believe that we are immune to the challenges experienced by PWDs to take note. According to Statistics Canada, the prevalence of disability increases with age, “from 13% for those aged 15 to 24 years to 47% for those aged 75 years and over.”¹⁴ According to the World Health Organization (WHO), “[a]lmost everyone will be temporarily or permanently impaired at some point in life, and those who survive to old age will experience increasing difficulties

¹⁰ Nicola T. A. Popplewell, Boika P. D. Rechel & Gary A. Abel “How do Adults with physical disability experience primary care? A nationwide cross-sectional survey of access among patients in England” (2014) 4:8 e004714 *BMJ Open* 1 DOI: <10.1136/bmjopen-2013-004714>.

¹¹ *Ibid* at 1.

¹² *Ibid* at 2.

¹³ *Ibid* at 1.

¹⁴ Stuart Morris et al, *Statistics Canada: Disability in Canada: A demographic, employment and income profile of Canadians with disabilities aged 15 years and over, 2017*, November 28, 2018, Catalogue no. 89-654-X2018002, ISBN 978-0-660-28689-1, 1 at 4.

in functioning.”¹⁵ It appears that we must embrace the fact that disability is part of the human condition.

Sakellariou and Rotarou¹⁶ conducted a study in the UK, in which they looked at access to health care for both men and women with disabilities. The aim of the study was to investigate differences in access to health care between people with and without disabilities. The investigators performed a secondary analysis, using logistic regressions, of de-identified cross-sectional data from the European Health Interview Survey (EHIS, Wave 2). The original EHIS face-to-face and telephone survey method obtained data from a sample of 12,840 community-dwelling people over the age of 16. Of this sample, 5,236 individuals had a disability. The authors of the study concluded that people with disabilities experienced decreased access to health care as compared to the rest of the population, with transportation, cost and long waiting lists being the main barriers.

In their 2015 U.S. study, Mahmoudi and Meade¹⁷ examined national trends related to disparities in access to health care. They sought to identify the impact of physical disability and the personal factors that are associated with unmet health care needs, defined as the self-reported ability to get medical care, dental care or prescription medications. They conducted a logistic regression analysis of a sample of working age adults within the United States, aged 25-64, with and without physical disabilities, using pooled data. They found that having physical disabilities increases the odds of unmet health care needs,

¹⁵ “World Report on Disability” (2019) at 3, online (pdf): World Health Organization <https://www.who.int/disabilities/world_report/2011/en/>.

¹⁶ Dikaos Sakellariou & Elena S. Rotarou, “Access to healthcare for men and women with disabilities in the UK: secondary analysis of cross-sectional data” (2017) 7:8 *BMJ Open* 1 at 1 DOI: <10.1136/bmjopen-2017-016614>.

¹⁷ Elham Mahmoudi & Michelle A. Meade, “Disparities in access to health care among adults with physical disabilities: Analysis of a representative national sample for a ten-year period” (2015) 8 *Disabil Health J* 182 at 188.

especially among females, those living at or near the poverty level, and those who lack health insurance.

2.2.3 Health Policy/Population Studies

Health policy studies speak from the perspective of legislation, regulations, commissioned reports, program directives or guidelines which may have “either direct or indirect implications for policy governing access to health services.”¹⁸ These studies typically utilize a population perspective, analyzing health issues of society at large, or of vulnerable subgroups such as PWDs.

In their 2010 Canadian study, McColl, Jarzynowska and Shortt¹⁹ expanded on the policy-based definition of access to specialized health care services. They stated that the usual health policy definitions of access include such indicators as “wait times, human resource shortages or geographical distribution of providers.”²⁰ They pointed out that the access issues experienced by people with disabilities are unique, in that they include factors such as the physical configuration of the practice, attitudes of providers and staff to disability, expertise regarding issues related to disability and systemic factors such as funding models or regulatory programs.²¹

The authors also discussed four junctures in which individuals with disabilities may experience health care barriers: “Along with members of the general population, they may experience difficulties finding a doctor or getting an appointment. Because of their disability, however, they may also experience difficulties entering the premises, using its

¹⁸ Mary Ann McColl, “Structural Determinants of Access to Health Care for People with Disabilities” in Mary Ann McColl and Lyn Jongbloed, eds, *Disability and Social Policy in Canada*, 2nd ed (Concord, ON: Captus Press, Inc., 2006) 293 at 299-300.

¹⁹ Mary Ann McColl, Anna Jarzynowska & S.E.D. Shortt, “Unmet health care needs of people with disabilities: population level evidence” (2010) 25:2 *Disabil Soc* 205 DOI: <10.1080/09687590903537406>.

²⁰ *Ibid* at 205.

²¹ *Ibid* at 205-206.

facilities and receiving a reasonable standard of care.”²² The term “standard of care” takes on different meanings in different contexts. In the context of this study, and in an earlier research paper conducted by McColl et al,²³ “[e]xpertise-related barriers have their primary impact on the standard of care delivered.”²⁴ The authors further explained that the lack of physician expertise relates to the ability to accurately diagnose disabling conditions and to anticipate further disabling consequences.

In a legal context, “standard of care” refers to issues of negligence and malpractice in tort cases. The Canadian Encyclopedic Digest states that “[e]very health professional could bring to his or her task a reasonable degree of skill and knowledge and must exercise a reasonable degree of care. He or she is bound to exercise that degree of care and skill which could reasonably be expected of a normal, prudent practitioner of the same experience and standing.”²⁵ While the meaning differs somewhat between the two different contexts, I propose that people with disabilities are entitled to the same standard of care as any other individual, and that health care providers are bound both professionally and legally to provide such a standard of care. Sadly, this does not appear to happen consistently.

The research from the study conducted by McColl et al indicated that “those with the greatest need are also the least likely to have those needs met by the healthcare system,” and the authors pointedly stated that “[o]ne can only conclude that the system appears to be geared to best serve those who are the easiest to serve.”²⁶ The truth of this statement

²² *Ibid* at 206.

²³ Mary Ann McColl et al, “Physician Experiences Providing Primary Care to People with Disabilities” (2008) 4:1 *Healthcare Policy* e129 at e144.

²⁴ *Ibid*.

²⁵ CED 4th (online) *Hospitals and Health Care* “Health Law Proceedings: Negligence Actions Against Health Professionals and Facilities: Negligence of Doctors: General” (V.1.(e).(i)) at §357.

²⁶ McColl (2010), *supra* note 19 at 206.

will be borne out in section 6.2.1 of this thesis, as I discuss the empirical results of my study, which point to the issue of health care ableism.

Following from their definition of access, McColl et al conducted a cross-sectional study to examine the relationship between disability and unmet health needs in a Canadian sample. They utilized a secondary analysis of a population-based survey:

The sample was drawn from the National Population Health Survey (NPHS) (Statistics Canada 1998–1999). The NPHS is based on the Canadian Labour Force Survey sampling frame and uses a cluster sampling approach. For the NPHS one member of each household was interviewed about his or her specific health experiences. Information was collected on health status, utilization of health services and determinants of health, as well as demographic and economic information.²⁷

The results of the study “revealed that disabled adults (aged 20–64) reported more than three times as many unmet healthcare needs as their non-disabled counterparts.”²⁸

McColl et al reported on a second important finding: “The greatest deterrent to receiving needed services among individuals with disabilities was cost. Unlike their non-disabled contemporaries, disabled respondents identified economic issues, not time constraints, as the main factor limiting their access to needed care.”²⁹ The authors concluded that Canada, despite having universal health care, and presumably offering access to all, “fails to meet the needs of some of its most vulnerable constituents – those with disabilities...”³⁰

In their 2015 U.S. population studies-based discussion paper, Gloria L. Krahn, Deborah Klein Walker and Rosaly Correa-De-Araujo stated that:

[d]espite passage of the ADA more than 20 years ago, health facilities and services often are not fully accessible. National data are not available, but a

²⁷ *Ibid* at 207.

²⁸ *Ibid* at 212.

²⁹ *Ibid* at 213.

³⁰ *Ibid* at 217.

recent survey of almost 2400 primary care facilities serving Medicaid patients in California noted that fewer than half of facilities were fully architecturally accessible; only 8.4% had accessible examination tables, and less than 4% had accessible weight scales. Furthermore, there are few resources to help people with disabilities know which medical facilities will accommodate their limitations. As a result, many people with disabilities do not receive complete medical examinations because equipment such as weight scales, examining tables, and mammography equipment do not accommodate their disability.³¹

The authors referenced the ADA, or *Americans with Disabilities Act*,³² in their article. This statute will be discussed in context with other legislative instruments in section 3.1.5.

2.2.4 Qualitative Studies (Interviews/Focus Groups)

A study by McClintock et al³³ consisted of focus groups, utilizing grounded theory methodology. They included persons with disabilities (PWD), persons without disabilities (PWOD) and health care providers, using a purposive sampling technique. The objective of their U.S. study was “to explore recommendations of PWD and PWOD as well as health care providers for improving access to and quality of health care for PWD.”³⁴ Common themes emerged from discussion with all three sub-groups: “Core categories [of recommendations] identified by PWD, PWOD and health care providers were addressing assumptions, increasing awareness and knowledge, improving communication, promoting advocacy as well as modifying and creating policy.”³⁵ In reflecting on the results of their study, the authors recognized a paradigm shift towards empowerment.³⁶ They noted that “[m]any study participants discussed political empowerment and engagement as central to

³¹ Gloria L. Krahn, Deborah Klein Walker & Rosaly Correa-De-Araujo, “Persons With Disabilities as an Unrecognized Health Disparity Population” (2015) 105:S2 Am J Public Health S198 at S198 DOI: <<https://doi.org/10.2105/AJPH.2014.302182> >.

³² *Americans With Disabilities Act of 1990*, 1990, Pub. L. No. 101-336, 104 Stat. 328 (1990), [ADA].

³³ Heather F. McClintock et al, “Health care access and quality for persons with disability: Patient and provider recommendations” (2018) 11 Disabil Health J 382 at 382.

³⁴ *Ibid* at 383.

³⁵ *Ibid* at 385.

³⁶ *Ibid* at 388.

health care reform.”³⁷ The issue of bringing personal experience into the political sphere will be discussed in the context of feminist theory in section 6.1.

In the U.S., Neri and Kroll conducted a qualitative study which took a slightly different perspective on the issue of health care access barriers for adults with disabilities.³⁸ One of the purposes of their study was to gain a better understanding of “the scope and nature of consequences that adults with disabilities perceive as the result of denied or delayed access to health care services...”³⁹ regardless of the type of barrier experienced. They provided the following description of their methodology:

Qualitative, semi-structured, in-depth interviews were administered over the telephone to 30 participants with spinal cord injury, cerebral palsy, or multiple sclerosis. The interviews were transcribed and coded for analysis, and consequences were grouped into one of five categories: social, psychological, physical, economic and independence issues.⁴⁰

Some examples of the perceived social consequences of denied or delayed access to health care services included strained relationships with others and limited social participation.⁴¹ Psychological consequences included “depression, frustration, stress and devaluation.”⁴² Physical consequences, perhaps the most commonly considered, were summarized as “a general deterioration in health. This included the increased risk for secondary conditions, as well as limitations in completing household chores and maintaining personal hygiene.”⁴³ Economic consequences included issues such as missed work due to declining health as a result of inadequate access to services, as well as increased health service expenditures

³⁷ *Ibid* at 388.

³⁸ M. T. Neri & T. Kroll, “Understanding the consequences of access barriers to health care: experiences of adults with disabilities” (2003) 25:2 *Disabil Rehabil*, 85 at 85 DOI: <10.1080/0963828021000007941>.

³⁹ *Ibid* at 85.

⁴⁰ *Ibid*.

⁴¹ *Ibid* at 88.

⁴² *Ibid* at 89.

⁴³ *Ibid* at 90.

such as the need for additional physical therapy which was not covered by the person's health plan.⁴⁴ The last category, independence consequences, entailed the perceived dependency on others as a result of not receiving the needed health care services that would have facilitated the individuals' ability to do things for themselves.⁴⁵ The authors discussed the influence of multiple consequences, noting that "[t]here was substantial overlap among consequence categories. For most respondents, negative consequences were not limited to just one area - frequently, one consequence triggered others."⁴⁶

Mari-Lynn Drainoni et al⁴⁷ conducted a U.S. study using a focus group methodology. The goal of their study was to analyze and better understand "the barriers to health-care access that confront consumers with disabilities, particularly in light of their functional abilities."⁴⁸ The individuals who participated were predominantly health care consumers with disabilities but also included some proxies, such as parents, caregivers, and advocates. Data from the focus groups were analyzed using the standard qualitative analytic techniques of grounded theory. Grounded theory will be discussed further in section 4.3.1 of this thesis.

Drainoni et al's qualitative analysis revealed patterns in the types of barriers experienced by the focus group participants when they accessed, or attempted to access, health-care services. The investigators developed a comprehensive list of barriers to health care access in their study: Structural barriers included health insurance, policies, transportation, physical environment, communication with providers, time constraints and

⁴⁴ *Ibid* at 90-91.

⁴⁵ *Ibid* at 91.

⁴⁶ *Ibid* at 85.

⁴⁷ Mari-Lynn Drainoni et al, "Cross-Disability Experiences of Barriers to Health-Care Access: Consumer Perspectives" (2006) 17:2 *J Disabil Policy Stud* 101 at 106.

⁴⁸ *Ibid* at 103.

continuity of care. Financial barriers included providers and services, medications, equipment, repairs and supplies. The final category included personal/cultural barriers, such as insufficient knowledge, misconceptions about people with disabilities, insensitivity and disrespect, failure to take caregivers seriously, and reluctance/unwillingness to provide care. I believe that these personal/cultural barriers may well be the locus of ableism within the health care environment.

The investigators emphasized the vulnerability of PWDs, concluding that “[w]ith regard to health care, people with disabilities as a group are among the nation’s most vulnerable populations, given their special health-care needs as well as their lower financial status.”⁴⁹ They commented on the American health-care system, stating that it “has in many respects failed to address the particular needs of this key group of stakeholders.”⁵⁰

Story, Schwier, and Kailes⁵¹ also utilized a focus group methodology in their U.S. study:

Participants of eight focus groups discussed medical equipment accessibility and safety issues experienced when using or attempting to access four specific categories of medical devices: examination tables, imaging equipment, medical chairs, and weight scales. Content of the transcript of each focus group was categorized according to five major themes: safety issues, equipment issues, health care provider issues, patient issues, and environmental issues. The results were then aggregated.⁵²

The focus group participants reported on various problems related to the equipment which resulted in inconvenience, difficulty and discomfort during the process of moving on and

⁴⁹ *Ibid* at 113.

⁵⁰ *Ibid*.

⁵¹ Molly Follette Story, Erin Schwier & June Isaacson Kailes, “Perspectives of patients with disabilities on the accessibility of medical equipment: Examination tables, imaging equipment, medical chairs, and weight scales” (2009) 2 *Disabil Health J* 169.

⁵² *Ibid* at 169.

off the equipment and maintaining their posture while on the equipment. They added that accessible weigh scales were rarely available.⁵³

While this focus group study included males, the issues that were specific to females with disabilities were quite remarkable. Female focus group participants who commented on these gender-specific issues noted that they could not adequately transfer onto the examination table for a pelvic exam, and the stirrups were not accessible due to spasticity or paralysis of the lower extremities. They also commented that mammography machines were inaccessible, if they were unable to stand up to access the machines in the “conventional” manner. The barriers presented are such that it deters patients, and especially female patients with disabilities from seeking preventative medical care.

The authors of this study, Story, Schwier and Kailes, who have a background in rehabilitation engineering, occupational therapy and social work, respectively, concluded their paper by providing concrete recommendations for physical access/design improvements.⁵⁴ At the end of their paper, the authors touched briefly on the human issues that must be addressed such as institutional barriers and misperceptions and stereotypes related to disability.⁵⁵

This study is best summarized by a quote from one of the participants:

I’m going to be honest: I have avoided GYN exams. I’m a 31 year-old woman [and] I have not had a pelvic exam - I know it’s shocking - ever, because of all these different complications, and fears, for multiple reasons.... You know, it’s hard to express that to my OB/GYN, because I have met with her. I had talked with her about what we would do when we do have the exam, and I always put it off because I’m just thinking of all of the planning and all

⁵³ *Ibid.*

⁵⁴ *Ibid* at 178. Some of the suggested recommendations: height-adjustable exam tables and chairs with adequate weight capacity, handles/railings and smooth-glide surfaces on examination tables, pillows or straps to assist the patient to hold position, and provision of whole-leg supports instead of stirrups for women with disabilities. Visual contrast was also recommended to assist those patients with visual impairments.

⁵⁵ *Ibid* at 179.

the assistance that I'm going to need. And here I am, a woman who's a researcher in sociology of health, and you know, I claim to be a real health advocate for others and myself, and this is my, like, secret shame. - 31-year-old power wheelchair user.⁵⁶

This poignant quotation illustrates the common challenges that many women with disabilities (WWDs) face, regardless of their education or socioeconomic status, and it is an appropriate springboard for a more specific review of health care access barriers for WWDs. In this thesis, novel qualitative data based on interviews of WWDs will be summarized and explored within the context of relevant theoretical frameworks.

2.3 Literature Review - Women with Disabilities

The literature which has been reviewed to this point has included studies on both men and women with disabilities. It is evident from this literature that WWDs present as a unique group. The following studies pertain specifically to WWDs and will demonstrate the gendered issues that they face, related to access to health care. The studies are divided into three categories of methodologies; literature reviews, quantitative (questionnaire) and qualitative (interviews/focus groups).

2.3.1 Literature Review Studies

In an Australian study, Ramjan et al⁵⁷ conducted an integrative literature review to investigate the fact that, when compared to the rest of the community, women with disability were less likely to use preventive health screening services. Multiple databases were systematically searched for literature published between 2001 and 2013. The authors took a systemic approach in formulating the conclusion that “barriers to access to primary health care and preventive services by women with disabilities needed to be considered in

⁵⁶ *Ibid* at 177.

⁵⁷ Lucie Ramjan et al, “Barriers to breast and cervical cancer screening for women with physical disability: A review” (2016) 56:2 *Women & Health* 141.

relation to not only access to adequate health insurance, but also to the broader system level inequities in such areas as education, literacy, employment, and health insurance, as well as the societal attitudes, misconceptions, homogenization, and stereotyping of women with disabilities.”⁵⁸

In their U.S.-based literature review, Todd and Stuijbergen sought to provide an overview of the existing evidence of the barriers to breast cancer screening experienced by women with physical disabilities.⁵⁹ The authors arrived at 5 barriers: financial, environmental, those barriers related to physical attributes, barriers generated by health carers and psychosocial barriers. With respect to financial barriers, they found that women with disabilities were financially disadvantaged, stating that “41% of women with disabilities live at or below the national poverty level.”⁶⁰ Environmental barriers appear to be the most common theme arising from this literature review. Examples include unreliable and limited public transportation, which prevents the patient from even getting to the screening site. The authors added that, the “frustrations continue” for the prospective patients once they enter the examination centers. Many facilities are not equipped with mammogram machines which will accommodate for women who use wheelchairs and are unable to stand for the conventional machine.⁶¹ With respect to barriers related to physical attributes, the authors referred to the work of Joann M. Thierry,⁶² which they summarized by stating that “women, 65 years or older, with three or more physical functional limitations were less likely to have had mammograms in the previous 2 years than those

⁵⁸ *Ibid* at 154.

⁵⁹ Ana Todd & Alexa Stuijbergen, “Breast Cancer Screening Barriers and Disability” (2012) *Rehabil Nurs.* 37:2 74 at 74 DOI:<[10.1002/RNJ.00013](https://doi.org/10.1002/RNJ.00013)>.

⁶⁰ *Ibid* at 75.

⁶¹ *Ibid* at 75-76.

⁶² Joann M. Thierry, “Increasing Breast and Cervical Cancer Screening among Women with Disabilities” (2000) 9:1 *J Womens Health Gend Based Med* 9 at 10 DOI: <[10.1089/152460900318894](https://doi.org/10.1089/152460900318894)>.

with no functional limitations or younger women with less limitations.”⁶³ Essentially, the higher the number of “functional limitations,” the less likely it is that women with disabilities will obtain preventative breast screening.

The authors provided a rationale for their terminology earlier in their article, and stated that “[f]or the purpose of this article...the terms disabilities and functional limitations, will be used somewhat interchangeably for the sake of consistency and to provide accurate representation of the language commonly used in the research literature used for this overview.”⁶⁴ The fact that the term “functional limitations” is used so commonly and casually amongst health care professionals is further suggestive of health care ableism. The term suggests that function is measured by an ideal “able-bodied” standard, against which people with disabilities consistently fall short. Further to this, the authors summarized that health care providers demonstrate “lack of knowledge, ineffective communication, and inappropriate stereotyping.”⁶⁵

Finally, psychosocial barriers are typified by issues such as clinical depression. The authors indicated that according to the U.S. Department of Health and Human Services, “[i]t is estimated that 30% of women with disabilities have clinical depression compared to an estimated 8% of women with no disabilities.” They commented on the health consequences of this finding, stating that “[w]omen who are clinically depressed are less likely to get screening mammograms.”⁶⁶ They concluded that, when combined, disability

⁶³ Todd & Stuijbergen, *supra* note 59 at 76.

⁶⁴ *Ibid* at 74.

⁶⁵ *Ibid* at 76.

⁶⁶ *Ibid*.

and depression can even further reduce the likelihood that women will seek preventative breast cancer screening.⁶⁷

2.3.2 Quantitative Studies

The objective of a U.S. comparative quantitative study by Nosek and Howland was to “examine rates of screening for breast and cervical cancer and factors associated with regular screening in a large sample of women with a variety of physical disabilities and a comparison group of women without disabilities.”⁶⁸ Following the administration of a written questionnaire, and subsequent analysis, the authors found that “[w]omen with physical disabilities are at a higher risk for delayed diagnosis of breast and cervical cancer, primarily for reasons of environmental, attitudinal, and informational barriers.”⁶⁹ The authors detailed numerous reasons for decreased compliance with breast and cervical screening, including low income, low educational level, lack of a regular health provider, seeing a male physician, and lack of health insurance coverage.

Floud et al conducted a prospective breast and bowel cancer screening study of women in England, whose purpose was to gain “information about participation in organised population-wide screening programmes by people with disabilities.”⁷⁰ Their quantitative method involved the administration of “a questionnaire on socio-demographic, lifestyle, and reproductive factors...” Re-survey questionnaires were sent to the participants by mail at 3–5 yearly intervals.⁷¹ Disability categories used in their study

⁶⁷ *Ibid.*

⁶⁸ Margaret A. Nosek & Carol A. Howland, “Breast and Cervical Cancer Screening Among Women with Disabilities” (1997) 78 *Arch Phys Med Rehabil* S-39 at S-39.

⁶⁹ *Ibid.*

⁷⁰ S. Floud et al, “Disability and participation in breast and bowel cancer screening in England: a large prospective study” (2017) *BJC* 1711 at 1711 DOI: < <https://doi.org/10.1038/bjc.2017.331> >.

⁷¹ *Ibid.*

included: hearing, memory, mobility, vision and self-care. Following analysis, they concluded that “women in England with disabilities, especially in domains of self-care, vision, and mobility, are considerably less likely than other women to accept invitations to participate in routine screening for breast or bowel cancer.”⁷² This study did not categorize barriers encountered by the subjects of the study; however, the authors noted that women with multiple disabilities and those with no access to a car were less likely to access cancer screening procedures.

In their 2014 Ontario study, Lofters et al “linked provincial survey and administrative data in a retrospective cohort study to determine the association between appropriate cervical cancer screening and levels of disability and multimorbidity among women eligible for screening in Ontario.”⁷³ The authors defined multimorbidity based on their literature review, as “the co-existence of at least 2 chronic conditions⁷⁴ in 1 patient.”⁷⁵ The results of their study indicated that “women with disability, particularly those with multiple chronic conditions, are not consistently receiving appropriate cervical cancer screening in Ontario, despite having more contact with the health care system and with their primary care providers than their peers.”⁷⁶ The authors proposed some possible reasons for these findings:

Time constraints because of competing demands during primary care visits may play a major role, namely a focus on acute medical management of the patient’s chronic conditions or disabilities. Physical limitations, both in getting to physicians’ offices and within physicians’ offices, such as getting

⁷² *Ibid* at 1713.

⁷³ Aisha Lofters et al, “Screening for cervical cancer in women with disability and multimorbidity: a retrospective cohort study in Ontario, Canada” (2014) 2:4 CMAJ Open E240 at E240 DOI: <10.9778/cmajo.20140003>.

⁷⁴ *Ibid* at E241. The authors refer to the following self-reported diagnoses of chronic conditions included in the Canadian Community Health Survey: arthritis, hypertension, chronic obstructive pulmonary disorder, diabetes, heart disease, cancer, stroke, dementia and mood/anxiety disorder.

⁷⁵ *Ibid*.

⁷⁶ *Ibid* at E245.

on the examination table, have also been identified as potentially influencing screening practices for women with disabilities. Physicians' "self-identified lack of confidence" (in appropriately treating patients with disabilities) has been noted in the literature. Physician recommendation is known to be an important predictor of cervical cancer screening.⁷⁷

In exploring demographic factors, the authors found that "women with disability had lower income, less education and fewer marital or common-law supports than women without disability."⁷⁸

2.3.3 Qualitative Studies

Iezzoni et al conducted a study in the United States, in order "[t]o explore the perceptions of patients with breast cancer with mobility impairments of the physical accessibility of healthcare facilities and equipment."⁷⁹ The study consisted of audiotaped interviews of a duration of one to two hours.⁸⁰ Following qualitative analysis of the interview transcripts, the investigators found that:

[t]he 20 participants identified issues with inaccessible equipment, including mammography machines, examining tables, and weight scales. The patients sometimes needed to insist on being transferred to an examining table when physicians preferred to examine them seated in their wheelchairs. When staff would transfer them, patients feared injury or felt badly when clinical personnel were injured during transfers. Other issues included difficulties with positioning and handling patients' uncontrollable movements. Even when clinical sites had accessible equipment, this equipment was sometimes unavailable for the appointment.⁸¹

These findings further highlight the multiple barriers that women with mobility impairments face as they seek treatment for breast cancer. This study is also unique, in that the participants were women with disabilities who had already received a diagnosis of

⁷⁷ *Ibid.*

⁷⁸ *Ibid* at E244.

⁷⁹ Lisa I. Iezzoni, Kerry Kilbridge & Elyse R. Park, "Physical Access Barriers to Care for Diagnosis and Treatment of Breast Cancer Among Women with Mobility Impairments" (2010) 37:6 *Oncol Nurs Forum* 711 at 711.

⁸⁰ *Ibid*

⁸¹ *Ibid*

breast cancer. It leads the reader to question: if these women had access to more accessible and timely screening services, could their breast cancer diagnosis have been averted, or at least detected sooner?

A 2003 study was conducted by the British Columbia Centre for Women's Health, utilizing surveys, and a focus group.⁸² The report which was generated detailed the results of surveys conducted with women with disabilities, their primary care providers, and community agencies, related to their experiences with gynecologic and breast health screening. The investigators found that WWDs in their "limited convenience sample received regular cervical and breast cancer screening less frequently than the general population (ranging from 52 – 70%) in their region."⁸³

The authors summarized the multiple challenges and barriers reported by the study subjects, stating that "[f]or women in this study, the ideal of universal access to care was compromised by physical and psychosocial obstacles that demand resolution if the population of women with disabilities is to receive adequate care."⁸⁴ The physical obstacles noted were consistent with those already raised by other studies, such as lack of an accessible examination table, and inability of present screening technology to accommodate women in wheelchairs.⁸⁵ Some psycho-social challenges included "a lack of awareness on the part of women that screening exams were important, respondents' physicians telling them it wasn't necessary, and respondents' own assumptions that such exams were impossible due to the disability."⁸⁶

⁸² Lenore Riddell et al, *We're Women, Too: Identifying Barriers to Gynecologic and Breast Health Care for Women with Disabilities* (Vancouver, B.C: British Columbia Centre of Excellence for Women's Health, 2003).

⁸³ *Ibid* at 19.

⁸⁴ *Ibid* at 20.

⁸⁵ *Ibid*.

⁸⁶ *Ibid* at 21.

An issue arose from this study that has not been mentioned in the literature review to this point: “There is a high rate of physical and sexual abuse among women who are disabled.”⁸⁷ Thus, for those WWDs who have experienced sexual trauma, “[w]hen a sense of safety is not forthcoming, the consequences involve avoidance of care. This contributes to the underrepresentation of the needs of survivors of sexual abuse in gynecological and breast health care.”⁸⁸

Gibson and Mykitiuk conducted a Canadian study of WWDs utilizing a focus group design. Their stated purpose was to examine whether the rights within the United Nations *Convention on the Rights of Persons with Disabilities*⁸⁹ and other international human rights conventions were being upheld in Canada for women with disabilities.⁹⁰ After coding and analysis of the data, the investigators arrived at three themes which the participants expressed as impeding access to health care: “1) [l]abyrinthine health service ‘systems,’ 2) assumptions, attitudes, and discriminatory practices, and 3) inadequate sexual health or reproductive services and supports.”⁹¹ Their conclusion was sobering: “Canada, one of the wealthiest and most progressive nations in the world, falls significantly short of guaranteeing disabled women’s human rights to access health care supports and

⁸⁷ *Ibid* at 21-22. For further information related to issues of physical and sexual abuse of women with disabilities, see generally Sara-Beth Plummer and Patricia A. Findley, “Women with Disabilities’ Experience with Physical and Sexual Abuse: Review of the Literature and Implications for the Field” (2012) 13:1 Trauma, Violence, & Abuse 15.

⁸⁸ *Ibid* at 22.

⁸⁹United Nations *Convention on the Rights of Persons with Disabilities*, 30 March 2007, 44910 UNTS 2515 (entered into force 3 May 2008), [CRPD].

⁹⁰ Barbara E. Gibson & Roxanne Mykitiuk, “Health Care Access and Support for Disabled Women in Canada: Falling Short of the UN Convention on the Rights of Persons with Disabilities: A Qualitative Study” (2012) 22:1 Women’s Health Issues e111 at e111.

⁹¹ *Ibid* at e113-e114.

services.”⁹² This suggests a dissonance between the rights contained within legal instruments and the lived experience of those who are the intended beneficiaries.

An interactive 2012 study by Angus et al is perhaps a fitting way to conclude this chapter review of relevant studies related to health care barriers for PWDs and WWDs.⁹³ Using a Community Based Participatory Research Method (CBPR), the researchers reached out to over 44 community organizations in the Toronto area. They conducted five focus groups with 24 women with mobility disabilities.⁹⁴ Focus group discussion questions included inquiries about barriers to accessing mammograms, cervical screening and colorectal screening, as well as suggested accommodations to improve access. The final focus group question was phrased as follows: “What are some strategies the healthcare system could use in order to reach more women with disabilities?”⁹⁵ The results were enlightening.

Aside from issues related to physical access barriers, the focus groups shed light on some deeper issues related to access to health care for WWDs: “Access to cancer screening involved three areas of complex work: (1) arranging and attending health-related appointments, (2) confronting assumptions about women's bodies and (3) seeking reliable health care and information.”⁹⁶ With respect to arranging appointments, the common concern of transportation arose, but along with this, focus group participants shared frustration related to obtaining an order for screening from their primary care physician. Often, other issues took precedence during an appointment, and the issue of preventative

⁹² *Ibid* at e117.

⁹³ Jan Angus et al, “Access to Cancer Screening for Women with Mobility Disabilities” (2012) 27:1 J Canc Educ 75 DOI: <10.1007/s13187-011-0273-4>.

⁹⁴ *Ibid* at 76.

⁹⁵ *Ibid* at 77.

⁹⁶ *Ibid*.

screening was low on the priority list. Additionally, health care providers appeared to be hesitant to perform certain procedures on patients with disabilities:

[O]ne woman was refused a colonoscopy because of her history of respiratory illness: “I requested a colonoscopy and I had a doctor that I wasn’t impressed with to say the least. He basically said, ‘I don’t want to do this because of your disorder and I’ll have to sedate you and you may not come out of this alive’ But I’m really proactive about my respiratory health and I go to sleep studies every other year but that was never asked.”⁹⁷

The authors summarized the planning and preparatory expectations expressed by the focus group participants:

Ultimately, participants were responsible for the coordination of services required to prepare for and attend screening appointments. This coordination had to be responsive to the sometimes-conflicting operating principles of different institutions. This could involve initial contact with primary providers for referral; multiple telephone contacts to arrange appointments for screening, transportation and attendant care services; envisioning, organizing and following up with any required bodily preparation; and then communicating required accommodations to providers. This additional work could deter women from uptake of cancer screening.⁹⁸

From this description, it is not surprising that many WWDs are deterred from pursuing screening procedures, as it appears to be exhausting to plan and execute and is often fraught with complications.

With respect to confronting assumptions about women’s bodies, the focus group participants described another physically and emotionally exhausting process, related to “embarrassments, vulnerabilities and bodily predicaments.”⁹⁹ The participants spoke of issues that they experienced related to “normative assumptions about the function and form of the female body.”¹⁰⁰ These assumptions were related to typical expectations and

⁹⁷ *Ibid* at 78.

⁹⁸ *Ibid*.

⁹⁹ *Ibid* at 79.

¹⁰⁰ *Ibid*.

arrangements encountered within the health system, such as “referral, intake and appointment scheduling; the type and placement of furniture within waiting rooms; expectations and knowledge of providers; and design and use of equipment for screening.”¹⁰¹

Participants described the fact that the screening machines often placed them in embarrassing positions. The authors provided a perceptive summary of this indignity: “Inscribed within this machinery was the expectation that all women's bodies conform to certain dimensions of height, flexibility and balance.”¹⁰² Additionally, the participants reported that health care providers could be dismissive of participants’ knowledge of their own bodies, and some even expressed a sense of pity and dismay about the participant’s disability.

Finally, as related to securing reliable health care and information, the participants stated that, although they sometimes received adequate health information from their health practitioners, much of it is obtained through trial and error, exploration of a variety of information sources, and contact with peers.¹⁰³ The authors stated that “[p]articipants expressed surprise and disappointment that the professionals whom they most expected to understand the issues of disability seemed complicit in social relations of marginalization.”¹⁰⁴ This issue will be discussed later in section 6.2.1, and expanded upon through the topic of health care ableism.

¹⁰¹ *Ibid.*

¹⁰² *Ibid.*

¹⁰³ *Ibid* at 80.

¹⁰⁴ *Ibid* at 79.

2.4 Summary of Literature Review

Several common themes emerge from this review of the literature on access barriers to health care: the common access barriers to all individuals with disabilities, the issue of PWDs and WWDs as populations who experience health care disparities, the gendered health care experiences that come in to play for WWDs, the sense that the health-care system in more than one jurisdiction has failed its constituents with disabilities, and the attitudinal undertone of policy makers and health care professionals that is suggestive of systemic ableism.

These themes will be explored in greater detail in subsequent chapters of this thesis. The laws which were designed to protect the rights of PWDs will be discussed next in Chapter Three.

CHAPTER 3

APPLICABLE HUMAN RIGHTS LAWS AND KEY CASES

It is evident from the previous chapter that numerous health care barriers exist for all people with disabilities, but women with disabilities encounter specific gendered barriers. This chapter explores the legal instruments that are in place on an international, national and provincial level, and which are intended to uphold and protect the rights of PWDs, some of which contain special provisions for WWDs. These legal tools address a diverse array of topics as related to disability rights, including accessibility to the physical environment, to transportation, to information and communications, and to other facilities and services open or provided to the public,¹ including the focus of this thesis: health care services.

3.1 Human Rights Legislation and Key Cases

3.1.1 UN *Convention on the Rights of Persons with Disabilities*

An array of conventions, charters and legislative tools address the rights of individuals with disabilities. The first to be considered is the over-arching United Nations *Convention on the Rights of Persons with Disabilities*, which will be referred to, henceforth, as the CRPD.²

Article 1 of the CRPD outlines the purpose of this international human rights instrument, and provides a definition of disability:

The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. Persons with disabilities include those who have long-term physical, mental,

¹ United Nations *Convention on the Rights of Persons with Disabilities*, 30 March 2007, 44910 UNTS 2515 (entered into force 3 May 2008), [CRPD] at Art.9.

² *Ibid.* See Generally.

intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.³

Article 6 of the CRPD refers to women with disabilities (WWDs) as a specific group unto itself:

1. States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.
2. States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.⁴

Article 9 of the CRPD, addresses accessibility, as follows:

To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:

- a) Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;
- b) Information, communications and other services, including electronic services and emergency services.⁵

In addition to the above, Article 9 stresses that States Parties must ensure that there are minimum standards for accessibility for PWDs, along with training for stakeholders. Examples of accessibility provisions include public signage in Braille, easy to read forms, as well as guides, readers and professional sign language interpreters. Finally, access to

³ *Ibid*, art 1.

⁴ *Ibid*, art 6.

⁵ *Ibid*, art 9.

communication technologies, including the internet, is stressed as a critical component of inclusion and participation for those with disabilities⁶.

The first point of Article 20, Personal Mobility, is pertinent to this discussion. It proposes that:

States Parties shall take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities, including by:
a) Facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost...⁷

From the discussion in the previous chapter, it is apparent that this provision is not adequately fulfilled by those jurisdictions to which the CRPD is applicable,⁸ as many WWDs report that limited, inconvenient, expensive and unreliable transportation is one of the major barriers to access to preventative health services.

The most pertinent to this thesis, Article 25, pertains to health:

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

- a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
- b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- c) Provide these health services as close as possible to people's own communities, including in rural areas;
- d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity,

⁶ *Ibid.*

⁷ *Ibid.*, art 20.

⁸ Unlike Canada, the U.K. and Australia, the United States has not ratified the CRPD.

autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.⁹

Article 25 provides a comprehensive overview of health rights which are pertinent to the focus of this thesis. The importance of providing gender-sensitive health services is mentioned, and this is emphasized in item a), with respect to equitable sexual and reproductive health services. Of note is item d), which stresses that health professionals must provide care of equal quality. Based on the literature reviews in Chapter 2, this concept of health care of equal quality for PWDs and WWDs does not appear to be consistently respected.

The CRPD has been a pivotal piece of international human rights legislation. In her 2016 work, Theresia Degener stated that the CRPD:

...has had profound impact on disability law and human rights law globally. With 162 State Parties the Convention has reached more than 80% universal ratification for its 10th anniversary. Most State Parties have reviewed and revised domestic disability law and have established National Monitoring Mechanisms as prescribed by the Convention.¹⁰

Canada ratified the CRPD on March 11, 2010 and it entered into force for Canada on April 12, 2010. Canada acceded to the *Optional Protocol to the Convention on the Rights of Persons with Disabilities* on December 3, 2018.¹¹ This gives Canadians recourse to file a complaint, should they find that their rights under the CRPD have been violated. At the

⁹ *Ibid*, art 25.

¹⁰ Theresia Degener, "Disability in a Human Rights Context" (2016) 5:35 *Laws* 1 at DOI: <10.3390/laws5030035>.

¹¹ UN General Assembly, *Optional Protocol to the Convention on the Rights of Persons with Disabilities*, 13 December 2006, A/RES/61/106, Annex II.

time of this writing, there have been no Canadian cases brought forward to the United Nations under the above-noted *Optional Protocol*.

3.1.2 Canadian Federal Human Rights Legislation

The First Report of Canada on the CRPD was submitted in 2014.¹² Within this report, reference was made to Canadian human rights legislation, including the *Canadian Bill of Rights*¹³ and the *Canadian Charter of Rights and Freedoms*,¹⁴ “which applies to all government action and guarantees all individuals fundamental freedoms and rights, including an explicit equality rights guarantee for persons with disabilities.”¹⁵ The section of the *Charter* on equality rights is important for the focus of this thesis:

15.(1) Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.¹⁶

This concise but powerful statement is significant, in that it outlines the rights of WWDs, the subjects of this study, to equal protection on at least two grounds; gender and disability. For many WWDs there are additional protected grounds contained within section 15.(1) which may apply to them.

Of the federal legislative tools pertaining to human rights, the *Charter* is unique, in that:

[b]y virtue of the *Constitution Act, 1982*, human rights and fundamental freedoms were given an enhanced legal status through the *Canadian Charter of Rights and Freedoms*, which, as a part of the Constitution, entrenched these rights within the supreme law of the country. Section 52(1) of the *Constitution*

¹² *Convention on the Rights of Persons with Disabilities: First Report of Canada*, Her Majesty the Queen in Right of Canada, represented by the Minister of Canadian Heritage and Official Languages, 2014 Catalogue No. CH37-4/19-2013E-PDF ISBN 978-1-100-21419-1.

¹³ *Canadian Bill of Rights*, SC 1960, c44, s 2.

¹⁴ *Canadian Charter of Rights and Freedoms*, Part 1 of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982 (UK)*, 1982, c 11 [Charter].

¹⁵ *Convention*, first report, *supra* note 12 at para 11.

¹⁶ *The Charter*, *supra* note 14 at Art. 15.

Act, 1982 expressly states that "The Constitution of Canada is the supreme law of Canada, and any law that is inconsistent with the provisions of the Constitution is, to the extent of the inconsistency, of no force or effect."¹⁷

Indeed, as the *Charter* is entrenched in the Constitution¹⁸, it supersedes other laws.

Of the few Canadian *Charter* claims related to access to health care by persons with disabilities, one of the most pivotal has been *Eldridge v. British Columbia (Attorney General)*.¹⁹ This case is significant for this thesis study, as it demonstrates the inherent right of individuals with disabilities to receive the same health care services as all other individuals, and to receive the accommodations necessary to ensure the equitable provision of these services.

The appellants in this case, Robin Susan Eldridge, John Henry Warren and Linda Jane Warren were born deaf. Their preferred means of communication was sign language. Factual background in the case was provided by La Forest J. of the Supreme Court of Canada:

Until 1990, the Western Institute for the Deaf and Hard of Hearing, a private, non-profit agency, provided free medical interpreting services for deaf persons in the Lower Mainland of British Columbia. This program was funded entirely from private sources without any contribution from the provincial government. In September 1990, the Institute discontinued the service because it no longer had sufficient funds to pay for it.²⁰

The British Columbia Ministry of Health denied a funding request from the above institute, citing a lack of resources and desire to avoid an undesirable precedent "for the funding of similar services for the non-English speaking immigrant community."²¹

¹⁷ Nancy Holmes, "Human Rights Legislation and the Charter: A Comparative Guide *MR-102E*" (13 October 1992 Revised 18 September 1997), online: *Parliamentary Research Branch* < <http://publications.gc.ca/collections/Collection-R/LoPBdP/MR/mr102-e.htm> >.

¹⁸ *Constitution Act*, 1982, being Schedule B to the *Canada Act 1982 (UK)*, 1982, c 11.

¹⁹ *Eldridge v. British Columbia (Attorney General)*, [1997] 3 S.C.R. 624 [*Eldridge*].

²⁰ *Ibid* at para 3.

²¹ *Ibid* at para 4.

One of the appellants, Robin Eldridge, had numerous medical conditions, including diabetes, which necessitated regular attendance at medical appointments. She had used the free services from the Western Institute for the Deaf and Hard of Hearing up until its discontinuation. She stated that she was unable to afford to pay privately for these services on a regular basis. She testified that she could not communicate adequately with her doctors without a sign language interpreter. Her medical specialist supported this, stating that he could not be sure of the accuracy of his communication with Ms. Eldridge, and that, in the absence of an interpreter, communication “was inhibited and frustrating.”²²

The other appellants, John and Linda Warren also reported having frequent medical appointments. They stated that they had hoped to have an interpreter for the birth of their twin daughters, but they did not have the opportunity due to the premature birth of the twins. Linda Warren testified that, without an interpreter, “the birth process was difficult to understand and frightening.”²³ Ms. Warren’s physician testified that the method of communication which was resorted to at the time — writing notes — was not effective. The physician added that if adequate communication is established with the patient, “complications are less likely to occur, and the patient is less apt to have a traumatic birth.”²⁴ The Warrens testified that they too could not afford to pay privately for a sign language interpreter.²⁵

The respondents, the Attorney General of British Columbia and the Medical Services Commission, argued that some health services are funded only in part, or not at all, under the Provincial Medical Services Plan. In addition, it was explained that hospitals

²² *Ibid* at para 5.

²³ *Ibid* at para 6.

²⁴ *Ibid* at para 7.

²⁵ *Ibid*.

in British Columbia are provided with lump sum payments, which they allocate as they see fit. They are rarely ordered by the government to provide specific services.²⁶

An application was filed by the appellants in the Supreme Court of British Columbia, seeking “a declaration that the failure to provide sign language interpreters as an insured benefit under the Medical Services Plan violates s. 15(1) of the *Charter*.”²⁷ The trial judge dismissed that application, reasoning that, while a government should distribute an existing benefit equally, it is not obligated to provide the benefit in the first place.²⁸

On appeal to the British Columbia Court of Appeal, it was determined that lack of interpretation services in hospitals does not constitute discrimination “because the *Hospital Insurance Act*²⁹ does not provide any ‘benefit of the law’ within the meaning of s. 15(1) of the *Charter*.”³⁰ In addition the B.C. Court of Appeal determined that s. 15(1) of the *Charter* was not violated by the *Medical and Health Care Services Act*³¹ because there was no distinction created between the deaf and hearing populations.³²

Lambert J.A. held, in a dissenting view, that the legislation was in fact in violation of s.15(1), as the plaintiffs were denied effective communication between practitioner and patient. He qualified that this infringement was justified, however, stating that, in the allocation of scarce financial resources, “governments must make choices about spending priorities.”³³ I find it disappointing that Lambert J.A. asserted the notion that financial priorities of governments can trump the rights of individuals under the *Charter*.

²⁶ *Ibid* at paras 9 - 10.

²⁷ *Ibid* at para 11.

²⁸ *Ibid* at para 12.

²⁹ *Hospital Insurance Act*, R.S.B.C. 1979, c. 180 (now R.S.B.C. 1996, c. 204).

³⁰ *Supra* note 19 at para 13.

³¹ *Medical and Health Care Services Act*, S.B.C. 1992, c. 76 (now the *Medicare Protection Act*, R.S.B.C. 1996, c. 286).

³² *Supra* note 19 at para 14.

³³ *Ibid* at paras 15 - 16.

At the highest level of appeal in the Supreme Court of Canada, La Forest J. determined that hospitals, while technically considered to be private institutions, act as agents of the government in providing specific health services.³⁴ What is most pertinent to this thesis is the content of La Forest J.'s discussion of s. 15(1) of the *Charter* and its relevance to the underlying issues of the case. In recounting the unfortunate history of exclusion and marginalization experienced by people with disabilities in Canada, he opined that the “the notion that disability is an abnormality or flaw,” resulted in a lack of the equal concern, respect and consideration demanded by s. 15(1) of the *Charter*.³⁵

He commented on the prevalence of paternalism towards PWDs, stating that persons with disabilities “have been subjected to paternalistic attitudes of pity and charity, and their entrance into the social mainstream has been conditional upon their emulation of able-bodied norms.”³⁶ La Forest J. added that the plaintiffs in the case are disadvantaged by a world that is organized around the notion that everyone can hear, resulting in barriers in communication which have been largely created by the hearing population.³⁷

This astute and compassionate assessment of the status of persons with disabilities, rendered by La Forest J. more than 20 years ago, contained within it an implicit indictment of systemic ableism. This case is also pivotal, in that it supports the premise that all individuals with physical disabilities (in this case, hearing impairment) are entitled to necessary accommodations which would permit them to access and derive benefit from available health care services in the same manner as any other recipient.

³⁴ *Ibid* at paras 50, 51.

³⁵ *Ibid* at para 56.

³⁶ *Ibid*.

³⁷ *Ibid* at para 57.

Justice La Forest pointed out the relevance of adverse discrimination in the case of disability. As opposed to direct discrimination in which disabled persons may be directly singled out due to their disability, adverse discrimination occurs when they are negatively affected by institutional or organizational policies, procedures or regulations. In explaining adverse discrimination, Justice La Forest stated that disabled persons are rarely singled out for discriminatory treatment, adding that what is “[m]ore common are laws of general application that have a disparate impact on the disabled.”³⁸ He made a pointed statement regarding the reticence of governments to accommodate PWD:

To argue that governments should be entitled to provide benefits to the general population without ensuring that disadvantaged members of society have the resources to take full advantage of those benefits bespeaks a thin and impoverished vision of s. 15(1).³⁹

La Forest J. concluded that the failure to provide sign language interpreters where they are necessary for equitable delivery of health care “constitutes a denial of s. 15(1) of the *Charter* and is not a reasonable limit under s. 1.”⁴⁰ His remedy was to grant a declaration that this failure was unconstitutional and to direct the government of British Columbia to rectify the system of delivery of medical services.⁴¹ In short, this case was a victory for the appellants in this case.

As a result of La Forest J.’s declaration, American Sign Language (ASL) interpreters are now provided at no direct cost to clients or health care providers for services that fall under the *Medicare Act* and the *Hospital Insurance Act* in British Columbia. The web page for the Provincial Health Services Authority of British Columbia indicates that

³⁸ *Ibid* at para 64.

³⁹ *Ibid*, summary.

⁴⁰ *Ibid* at para 95.

⁴¹ *Ibid* at paras 95-96.

“[t]his service is provided following a 1997 Supreme Court of Canada ruling that sign language interpretation must be provided to Deaf patients in BC to comply with the *Canadian Charter of Rights and Freedoms*.”⁴² This therefore demonstrates a victory not only for the appellants in this case, but also for deaf, deaf-blind and hard of hearing patients in the province of British Columbia, and indeed throughout Canada. Unfortunately, the impact of this victory does not appear to have been applied across Canada, due to provincial discretion in implementation. The province of Ontario, for example, offers only a subsidy for sign language interpretation services, in certain circumstances.⁴³

David Lepofsky summarized concerns related to *Charter* challenges by PWDs:

Having to separately fight accessibility barriers, one at a time, by individual human rights/*Charter* challenges, imposes tremendous unfair hardships on individuals with disabilities. Most don't bother. Well-resourced organizations, like the Federal Government, can deploy teams of lawyers to mount a vigorous defence. An unsuccessful *Charter* claimant can be ordered to pay the respondent's legal costs; few individuals with disabilities will risk such financial exposure. Canadians with disabilities are disproportionately unemployed, impoverished, and can lack full access to effective legal services.⁴⁴

The frustration and hardship encountered by individuals with disabilities in Canada who seek remedies for discrimination and/or lack of accommodation under human rights legislation is expanded upon by other scholars. For example, Laverne Jacobs referred to the system of piecemeal, individual human rights challenges discussed above and the

⁴² Provincial Health Services Authority, “Sign Language Interpreting” (2019), online: *Provincial Health Services Authority* < <http://www.phsa.ca/health-professionals/professional-resources/sign-language-interpreting>>.

⁴³ Canadian Hearing Society, “CHS Interpreting Services Terms and Conditions of Service” (2019), online: *The Canadian Hearing Society (CHS)* < <http://www.chs.ca/interpreting-services-terms-and-conditions#19.%20INTERPRETING%20RATES%20-%20ONSITE%20SERVICES>>.

⁴⁴ David Lepofsky, “What Should Canada’s Promised New National Accessibility Law Include? A Discussion Paper” (2018) 38:1 NJCL 169 at 173-174.

respective statutory human rights bodies that address them, as reactive regulation.⁴⁵ Jacobs notes that reactive regulatory bodies are “triggered only in response to a complaint by an aggrieved party.”⁴⁶ These administrative actors are not forward looking beyond the parties in dispute. Reactive regulation “provide(s) remedies only in discrete situations, as opposed to setting blanket standards.”⁴⁷ Jacobs went on to describe proactive regulation, in which accessibility standards are set in advance in order to create a more inclusive society, and, theoretically, reduce the instances of discrimination claims which are brought to human rights agencies and the courts.⁴⁸ The concept of proactive legislation will be expanded upon in Section 7.2.2 of this thesis, in the context of recommendations for future research.

3.1.3 Provincial Human Rights Legislation

A key Canadian *Charter* case dealing with disability and health care has been discussed. Disability rights cases can also be addressed through provincial human rights legislation to address those issues under provincial jurisdiction. The empirical research which was conducted and summarized for this thesis took place in the province of Ontario. Thus, the *Human Rights Code*⁴⁹ is the applicable legislation.

Few cases related to health care access barriers have been brought to the Human Rights Tribunal of Ontario (HRTO)⁵⁰ by persons with disabilities. One relevant case is *Quesnel v. London Educational Health Centre (1995)*.⁵¹ This case was in fact brought to

⁴⁵ Laverne Jacobs, “‘Humanizing’ Disability Law: Citizen Participation in the Development of Accessibility Regulations in Canada” (May 31, 2016) 2016 *Revue Internationale des Gouvernements Ouverts* 93 at 94 (Available at SSRN: <https://ssrn.com/abstract=2787422>).

⁴⁶ *Ibid.*

⁴⁷ *Ibid* at 95.

⁴⁸ *Ibid* at 96.

⁴⁹ *Human Rights Code*, RSO 1990, c H-19.

⁵⁰ See generally <http://www.sjto.gov.on.ca/hrto/>.

⁵¹ *Quesnel v. London Educational Health Centre (1995)*, 28 C.H.R.R.D/474, 1995 CarswellOnt 4201 (Ont. Bd. Of Inquiry) < https://archive.org/stream/boi95_012/boi95_012_djvu.txt>.

the Ontario Board of Inquiry, a mechanism which was in place prior to the implementation of the HRTO. In this case, the complainant, Tanys Quesnel, had a condition called Spinal Muscular Atrophy. She used a wheelchair as her primary means of mobility. She attended an appointment at a chiropractic clinic operated by the respondent, only to find that she was “unable to gain access to the building as there was no ramp, lift or elevator which could accommodate her wheelchair.”⁵² She went home. In a later telephone conversation, the owner of the facility and the chiropractor offered to either carry Ms. Quesnel up the stairs or make a home visit. The complainant declined both offers.

During the hearing, the owner of the facility stated that another chiropractor in the community with wheelchair accessible premises was prepared to make his services available to the complainant. Both the complainant and the Ontario Human Rights Commission proposed that the appropriate remedy was for the owner of the facility to build a wheelchair accessible ramp to the first floor of the premises, arguing that permitting the owner to rely on the services of a chiropractor elsewhere in the community would defeat the purpose of the *Human Rights Code*. The owner of the premises responded that this would create undue hardship.⁵³ The chair of the Board of Inquiry determined that the respondents were “responsible for a breach of Ms. Quesnel’s right to equal treatment as protected by Section 1 of the *Code*.”⁵⁴ In addressing duty to accommodate, five options were discussed: “1. Lifting 2. Off-site Services 3. Construction of an Elevator 4. Construction of a Wheelchair Lift 5. Construction of a ramp.”⁵⁵ The option of lifting was dismissed for reasons related to the inherent assault to the complainant’s dignity in being

⁵² *Ibid* at para 1.

⁵³ *Ibid*.

⁵⁴ *Ibid* at para 6.

⁵⁵ *Ibid* at para 10.

physically hefted up the stairs. The two forms of off-site services: home service and attendance at an alternate, wheelchair-accessible chiropractic clinic within the community were also dismissed. It was determined that these options restrict choices for PWDs “in ways that do not exist for others.”⁵⁶ Of the three options for physical modifications to the premises, construction of a ramp was deemed to be the most cost-effective.

While the respondent argued that such construction would create undue hardship, this assertion was ultimately dismissed following an analysis of the options by the chair of the Board, as the respondent had “not been able to prove on a balance of probabilities, that such an accommodation would constitute undue hardship as defined in Section 17 [of the *Human Rights Code*].”⁵⁷ The final order from the Board stated that the respondents, the London Educational Health Centre and owner, Robert Brent Eidt, were jointly and severally liable. They were ordered to pay \$500.00 in damages to the complainant due to the infringement of her rights. They were also ordered to take immediate steps to provide wheelchair access by ramp to the premises in question.⁵⁸

This classic case of an access barrier to a health facility took place over twenty years ago. If such scenarios have occurred and likely continue to occur within communities throughout Ontario, we must give pause and consider why there is a paucity of similar cases on record.

David Lepofsky has provided some answers to this question, referring to the cost and the hardship involved for PWD to launch such cases.⁵⁹ Laverne Jacobs also stated some reasons in her work. She confirmed that the issue of cost is a factor for PWDs, citing the

⁵⁶ *Ibid* at para 10-11.

⁵⁷ *Ibid* at paras 12-30.

⁵⁸ *Ibid* at para 4 (Order).

⁵⁹ Lepofsky, *supra* note 44 at 173-174.

fact that: “In some instances, human rights statutes do not allow for the complainants to be awarded the costs of their litigation.”⁶⁰ She added that many PWDs live below the poverty line and therefore the cost of litigation can be prohibitive.⁶¹ An additional interesting reason provided by Jacobs is the fact that many cases addressed through the reactive human rights process are settled through methods such as mediation, in which case the files are typically sealed and “cannot be used as precedent in later similar cases.”⁶²

Some informative parallel cases by other identified vulnerable groups have been brought to the Ontario Human Rights Tribunal. Examples include cases put forward by individuals who felt that they were discriminated against due to perceived mental health disabilities or substance abuse issues, respectively. In the case of *Marshall v. Durham (Region) Police Services*, the applicant alleged that she experienced discrimination in the provision of goods and services based on her disability or perceived disability. In addition, the applicant pleaded that this differential treatment was related to her ancestry, colour, ethnic origin, family status, marital status, place or origin, race, record of offences, and sex.”⁶³ The applicant sought remedies for “how hospital staff deal with people who they think are ‘mental patients’.”⁶⁴ It was determined by the Human Rights Tribunal of Ontario that the applicant did not provide sufficient evidence to substantiate her allegations, and the application was dismissed.⁶⁵

In the second example, *Cantwell v. Toronto East General Hospital*, the applicant alleged “discrimination with respect to goods, services or facilities because of disability

⁶⁰ Jacobs (2016), *supra* note 45 at 95.

⁶¹ *Ibid.*

⁶² *Ibid.*

⁶³ *Marshall v. Durham (Region) Police Services*, [2013] O.H.R.T.D. No. 2239, 2013 HRTO 2029 at para 3.

⁶⁴ *Ibid* at para 41.

⁶⁵ *Ibid* at paras 8, 47.

contrary to the *Human Rights Code*.”⁶⁶ The applicant had previously suffered a left knee injury that resulted in chronic pain which had been managed with narcotics prescribed by the applicant’s family doctor. For reasons detailed in the case, the applicant no longer had access to a physician for his narcotics prescription. He thus presented at the emergency room of Toronto East General Hospital, requesting a renewal of his narcotics prescription. The physician on duty declined to do so, and the applicant, in recounting the events, stated that the physician referred to him as “another junky.”⁶⁷ The physician denied making this statement.⁶⁸ The situation escalated, and the applicant was escorted from the emergency room by security. The applicant maintained that the physician’s refusal to renew his narcotics and subsequent request to remove him from the premises amounted to discrimination due to his disability under the *Code*.⁶⁹ The adjudicator determined that the applicant did not produce evidence to show that the medical care received was influenced by discrimination on the basis of the applicant’s disability. This application was also dismissed.⁷⁰ The literature reveals that it is not uncommon for human rights tribunal cases dealing with disability to be dismissed at the preliminary level.⁷¹

While this is a sample of only two tribunal cases, it is significant that, in both instances, the applicants demonstrated escalated behaviour during the incidents under

⁶⁶ *Cantwell v. Toronto East General Hospital*, [2017] O.H.R.T.D. No. 877, 2017 HRTO 872 at para 4.

⁶⁷ *Ibid* at para 40.

⁶⁸ *Ibid*.

⁶⁹ *Ibid* at para 77.

⁷⁰ *Ibid* at paras 84, 88.

⁷¹ Laverne Jacobs, "The Universality of the Human Condition: Theorizing Transportation Inequality Claims by Persons with Disabilities in Canada, 1976-2016" (2018) 7:1 *Canadian Journal of Human Rights* 35 at 52. In her work related to transportation claims by PWDs, Jacobs stated that “[a]pproximately a third of the cases of transportation conflict were dismissed at the preliminary stage, and almost two thirds of those dismissed were dismissed for being deemed to have no prospect of success.”

review, and in both cases, their applications were dismissed. Could ableism have been at play in the decisions made by the adjudicators?

3.1.4 Accessibility Legislation

In her analysis of the administrative governance functions of legislation that provides accessibility standards, Laverne Jacobs noted that there are practical differences between human rights laws and accessibility laws, and that there is a “need for more clarity about how these two laws interact.”⁷² Human rights legislation at both the federal and provincial levels of jurisdiction has been reviewed to this point in sections 3.1.2 and 3.1.3, respectively. The focus of the discussion will now turn to accessibility legislation.

At the time of this writing, Canada has recently passed a federal accessibility law; *An Act to ensure a barrier-free Canada*, or the *Accessible Canada Act*.⁷³ The law received Royal assent on June 21, 2019 and was proclaimed in force on July 11, 2019. The Act is summarized as legislation which “would add to the existing rights and protections for people with disabilities, including the *Canadian Charter of Rights and Freedoms*, the *Canadian Human Rights Act* and Canada’s approval of the *United Nations Convention on the Rights of Persons with Disabilities*.”⁷⁴ Included within the purpose of the *Accessible Canada Act* are the identification and removal of barriers, and the prevention of new barriers related to areas under federal jurisdiction, such as employment, the built

⁷² Laverne Jacobs, “The Interplay between Human Rights and Accessibility Laws: Lessons Learned and Considerations for the Planned Federal Accessibility Legislation.” (2018) 1 at 2 (Available at SSRN: <https://ssrn.com/abstract=3180846> or <http://dx.doi.org/10.2139/ssrn.3180846>).

⁷³ Bill C-81, *An Act to ensure a barrier-free Canada*, 1st Sess, 42nd Parl, (assented to 21 June 2019), SSC 2019, c 10 [Accessible Canada Act].

⁷⁴ Government of Canada: Employment and Social Development Canada, “Proposed Accessible Canada Act – Summary of the Bill” (last modified 11 Dec a footnote here for thec. 2018), online: *Government of Canada* <https://www.canada.ca/en/employment-social-development/programs/accessible-people-disabilities/act-summary.html>. See also *Canadian Human Rights Act*, RSC 1985, c H-6.

environment, information and communication technologies and transportation.⁷⁵ In Canada, the provision of health care comes within the jurisdiction of the provinces, through provisions of the *Constitution Act, 1867*.⁷⁶ The *Canada Health Act*⁷⁷ stipulates certain criteria by which each province receives federal funding for health care. These criteria are: 1) public administration; 2) comprehensiveness, 3) universality, 4) portability; and 5) accessibility.⁷⁸

Despite the federal government of Canada's efforts to engage citizens, including those with disabilities, the legislation has been criticized and described as weak by groups such as the AODA Alliance.⁷⁹ The Standing Senate Committee on Social Affairs, Science and Technology proposed changes to the bill in its thirty-fourth report, and these amendments were reflected in the final bill.⁸⁰ Among the amendments are inclusion of sign language as officially recognized communication, recognition of intersecting forms of marginalization, and a timeline of January 1, 2040 for the full implementation of the bill.⁸¹

Ongoing concerns have been voiced by disability advocacy groups regarding the strength of this new law, however I believe that the passage of federal accessibility legislation is an admirable achievement. Although the *Accessible Canada Act* does not

⁷⁵ *Supra* note 73 at para 5.

⁷⁶ *Constitution Act, 1867*, 30 & 31 Victoria, c. 3. (U.K.), s 92(7) and s 92(13). Section 92(7) establishes jurisdiction over hospitals, while section 92(13) refers to property and civil rights.

⁷⁷ *Canada Health Act*, R.S.C., 1985, c. C-6.

⁷⁸ Peter W. Hogg, *Constitutional Law of Canada: Fifth Edition Supplemented* Volume 1 (Toronto: Thomson Reuters, 2007, 2018) at 32-4.1.

⁷⁹ AODA Alliance, "Canada's Parliament Has Now Passed Bill C-81, the Accessible Canada Act -Here Are Seven Preliminary Reflections" (June 3, 2019) online: www.aodaalliance.org < <https://www.aodaalliance.org/whats-new/canadas-parliament-has-now-passed-bill-c-81-the-accessible-canada-act-here-are-seven-preliminary-reflections/>>.

⁸⁰ Canada, Parliament, Senate, Standing Committee on Social Affairs, Science and Technology Proceedings, 42nd Parl, 1st Sess, Thirty-Fourth Report (7 May 2019) as amended by the Senate on 8 May 2019.

⁸¹ *Ibid.* See numbers 3, 5 and 6.

have direct impact on provincially governed health matters, its impact on the lives of Canadians with disabilities will undoubtedly be followed closely by all stakeholders.

Three Canadian provinces have current accessibility legislation; Ontario, Manitoba and Nova Scotia. The respective statutes are: The *Accessibility for Ontarians with Disabilities Act*,⁸² the *Accessibility for Manitobans Act*,⁸³ and most recently, the *Accessibility Act* in Nova Scotia.⁸⁴ The *Ontarians with Disabilities Act, 2001* (ODA)⁸⁵ is the precursor to the *Accessibility for Ontarians with Disabilities Act*, hereafter referred to as the AODA.⁸⁶

The AODA has a laudable purpose:

1. Recognizing the history of discrimination against persons with disabilities in Ontario, the purpose of this Act is to benefit all Ontarians by,
 - (a) developing, implementing and enforcing accessibility standards in order to achieve accessibility for Ontarians with disabilities with respect to goods, services, facilities, accommodation, employment, buildings, structures and premises on or before January 1, 2025; and
 - (b) providing for the involvement of persons with disabilities, of the Government of Ontario and of representatives of industries and of various sectors of the economy in the development of the accessibility standards. 2005, c. 11, s. 1.⁸⁷

The AODA also contains a useful description of the term ‘barrier’:

“[B]arrier” means anything that prevents a person with a disability from fully participating in all aspects of society because of his or her disability, including a physical barrier, an architectural barrier, an information or communications barrier, an attitudinal barrier, a technological barrier, a policy or a practice.⁸⁸

⁸² *Accessibility for Ontarians with Disabilities Act*, 2005, S.O. 2005, c. 11 [AODA].

⁸³ *Accessibility for Manitobans Act*, SM 2013 c 40, CCSM c A1.7 [AMA].

⁸⁴ *Accessibility Act*, SNS 2017 c 2 [NSAA].

⁸⁵ *Ontarians with Disabilities Act, 2001*, S.O. 2001, c. 32 [ODA].

⁸⁶ See Laverne Jacobs (2016), *supra* note 45 at 93. In her work on citizen participation in the development of accessibility laws, Jacobs referred to the discontent related to the enforcement potential of the ODA, which has now largely been repealed. This led to the development of the *Accessibility for Ontarians with Disabilities Act*.

⁸⁷ See AODA, *supra* note 82 at para 1.

⁸⁸ *Ibid* at § 2 (“barrier”).

Specific health care standards have not yet been developed under the AODA at the time of this writing, however a committee has been established in order to develop health care standards as required by section 9 of the AODA.⁸⁹ Currently, providers of health care are aligned with the *Integrated Accessibility Standards*.⁹⁰ Standards related to the built environment are governed by the Ontario *Building Code Act*.⁹¹

Enforcement of the AODA, as well as a mechanism for the public to lodge individual complaints has unfortunately been lacking. David Lepofsky elaborated on this issue, stating that “Ontario has only appointed a tiny number of officials to conduct AODA inspections and audits: and has only imposed monetary penalties on a minuscule percentage of known AODA violators.”⁹² In addition, he added that the AODA does not have a strong mechanism for members of the public to lodge complaints and seek enforcement. While a toll-free number is available to report AODA violations, this number is not well publicized, and “there is no public indication that the Ontario Government has used any specific complaints to initiate AODA enforcement.”⁹³

Jacobs, Cino and DeCosta reviewed the *Accessibility for Manitobans Act* (AMA) in light of some of the enforcement issues that have arisen with the ground breaking AODA.⁹⁴ They discussed the fact that enforcement of standards can depend on government priorities, and stated that “[o]ne lesson that should be learned from Ontario’s experience with

⁸⁹ “Scope and timelines for the development of health care standards” Accessibility: legislative reviews, committees and councils (Updated March 20, 2019) Government of Ontario, online: < <https://www.ontario.ca/page/accessibility-legislative-reviews-committees-and-councils>>.

⁹⁰ *Integrated Accessibility Standards*, O. Reg. 191/11, s. 1 [IASR].

⁹¹ *Building Code Act*, R.S.O. 1990, c. B.13.

⁹² Lepofsky, *supra* note 44 at 190.

⁹³ *Ibid* at 191-192.

⁹⁴ Laverne Jacobs, Victoria Cino & Britney DeCosta, “The Accessibility for Manitobans Act: Ambitions and Achievements in Antidiscrimination and Citizen Participation” (2016) 5:4 Canadian Journal of Disability Studies 1 (Available at SSRN: <https://ssrn.com/abstract=2753855> or <http://dx.doi.org/10.2139/ssrn.2753855>).

the AODA is that lack of political will to enforce accessibility standards can effectively obstruct the philosophical and social goals of an accessibility standards statute.”⁹⁵

Jacobs, Cino and DeCosta commended the AMA for its inclusion of a set of guiding principles within the primary statute: access, equality, universal design, and systemic responsibility.⁹⁶ These principles align with the social model of disability. It was also noted by Jacobs that the AMA further reinforces the social model by adopting use of the term “persons disabled by barriers” versus the more standard “persons with disabilities” adopted by legislators in the provinces and territories across Canada.⁹⁷

Silvers discussed the connection between the social model and politics, stating that “the social model understands disability as a political problem calling for corrective action by citizen activists who alter other people’s attitudes and reform the practices of the state.”⁹⁸ The social model locates disability within society as opposed to within the individual. In contrast, the medical model views disability as a problem which is “both the prerogative and the responsibility of medical professionals to fix.”⁹⁹ In addition, the medical model views disability as situated within the individual, rather than within the imposed and sometimes oppressive structures and conventions of society.

Jacobs, Cino and DeCosta stated that the AMA is subject to some typical criticisms of the social model, with respect to “insufficient recognition of the role of impairment in the lives of persons with disabilities, and a weak portrayal of the connection between disability

⁹⁵ *Ibid* at 15.

⁹⁶ AMA, *supra* note 83 at s 2(2).

⁹⁷ Jacobs, Cino & DeCosta, *supra* note 94 at 4.

⁹⁸ Anita Silvers, “An Essay on Modeling: The Social Model of Disability” in D. Christopher Ralston and Justin Ho, eds, *Philosophical Reflections on Disability*, (Houston: Springer, 2009) 19 at 19.

⁹⁹ *Ibid*.

discrimination and intersectional difference.”¹⁰⁰ They continued their discussion of the influences on standards compliance by stating that:

[i]t is only when government officials entrusted with that discretion are most invested in ensuring compliance with the standards that one can be sure of rigorous enforcement of the statute. Examples from Ontario demonstrate that accessibility legislation enforcement can be extremely malleable – with an expansion and contraction of protection for people with disabilities that depends on the priorities of the government of the day.¹⁰¹

Inconsistency of enforcement is a significant concern for WWDs as they encounter barriers to health care. This issue will be discussed further under recommendations in section 7.2.2.

3.1.5 U.S. Legislation

The major legislative tool for disability rights in the U.S. is the *Americans with Disabilities Act, 1990*, or the ADA.¹⁰² The purpose of the ADA is excerpted as follows:

- (1) to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities;
- (2) to provide clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities;
- (3) to ensure that the Federal Government plays a central role in enforcing the standards established in this chapter on behalf of individuals with disabilities; and
- (4) to invoke the sweep of congressional authority, including the power to enforce the fourteenth amendment and to regulate commerce, in order to address the major areas of discrimination faced day-to-day by people with disabilities.¹⁰³

ADA complaints may be filed online, by mail, or by facsimile. Persons with visual impairments or those unable to write or type may have their complaint scribed over the phone. People who communicate via American Sign Language may communicate their

¹⁰⁰ Jacobs, Cino & DeCosta, *supra* note 94 at 7.

¹⁰¹ *Ibid.*

¹⁰² *Americans With Disabilities Act of 1990*, 1990, Pub. L. No. 101-336, 104 Stat. 328 (1990), [ADA].

¹⁰³ *Ibid* at Sec. 12101 b).

complaint via videophone.¹⁰⁴ These mechanisms for filing a complaint appear to be more straightforward and transparent as compared to processes in Canada, if such processes exist at all.

The following is an example of the application of the ADA: The United States Attorney's Office in Rhode Island issued a press release in February 2019, as to the results of its investigations into seven Landmark Medical Centre offices in Woonsocket, Rhode Island. The deficiencies were discovered as a result of a citizen complaint. Landmark Medical Center reportedly cooperated in a prompt fashion, and "now has designated accessible parking spaces and accessible medical equipment, including an accessible scale and adjustable-height exam tables and transfer boards at all of its medical offices..."¹⁰⁵ In this same press release, favourable responses were reported from similar investigations which had taken place over the previous year at two other Rhode Island medical offices. Examples of voluntary corrective measures that were taken include voluntary modification of the facility entrance, and the purchase of accessible examination room equipment, as well as the provision of adequate parking access.¹⁰⁶ ADA enforcement cases from 2006 to the present are available for review on the ADA.gov website.

Cases pertinent to health care access are listed under the Title III category.¹⁰⁷ This mechanism of public access is commendable in its transparency and availability to the

¹⁰⁴ "Information and Technical Assistance on the Americans with Disabilities Act: How to File an Americans with Disabilities Act Complaint with the U.S. Department of Justice" online: *ADA.gov United States Department of Justice Civil Rights Division* <www.ada.gov/filing_complaint.htm>.

¹⁰⁵ "American with Disabilities Act Investigations Ensure Accessibility at Three Medical Providers" (February 21, 2019), online: *United States Department of Justice: The United States Attorney's Office District of Rhode Island* <www.justice.gov/usao-ri/pr/american-disabilities-act-investigations-ensure-accessibility-three-medical-providers>.

¹⁰⁶ *Ibid.*

¹⁰⁷ "Information and Technical Assistance on the Americans with Disabilities Act: ADA Enforcement Cases 2006 - Present" online: *ADA.gov United States Department of Justice Civil Rights Division* <www.ada.gov/enforce_current.htm>.

general public. In addition, while not without criticism, the ADA has generally been praised, at least by the media and general population, as comprehensive and overarching.¹⁰⁸

It must be pointed out, however, that the ADA and Canadian accessibility legislation such as the *Accessible Canada Act* cannot be viewed in the same context. In her discussion of accessibility standards development, Laverne Jacobs points out that the ADA is an example of a “reactive regulatory antidiscrimination regime.”¹⁰⁹ Thus, standard-setting is not its primary function, as opposed to the Canadian accessibility legislation discussed above.

3.1.6 International Legislation

While a detailed discussion is beyond the scope of this thesis, mention should be made of international disability rights instruments, such as the *Equality Act* in the United Kingdom,¹¹⁰ the *European Social Charter (Revised)* in the European Union¹¹¹ and the *Disability Discrimination Act, 1992* in Australia, to name only a few.¹¹²

In this chapter, various legislative tools which are applicable to WWDs have been described. Subsequent chapters of this thesis will address the perceptions of WWDs as they strive to access health care services in their community. Their understanding of the legislation that is in place, their rights consciousness, and their desire to address existing health care barriers through formal legal claims will also be explored.

¹⁰⁸ “It’s past time for our own Disabilities Act: We continue to treat the inclusion of people with disabilities as a privilege rather than a right” Picard, Andre. *The Globe and Mail* (1936-Current); Toronto, Ont. [Toronto, Ont.] 11 Aug 2015: A11. (ProQuest Historical Newspapers: The Globe and Mail).

¹⁰⁹ Jacobs (2018), *supra* note 72 at 14.

¹¹⁰ *Equality Act 2010* (UK).

¹¹¹ *European Social Charter (Revised)*, 3 May 1996, entry into force: 1 July 1999, E.T.S. 163.

¹¹² *Disability Discrimination Act 1992*, (Austl).

CHAPTER 4

METHODOLOGY

4.1 Research Question

From the literature, we know that persons with disabilities face barriers to health care, and that women with disabilities face their own unique challenges as a marginalized group. What has not been fully elucidated in the literature to date, is the impact that these barriers have on the lives of women with disabilities, in terms of their own lived experience. Additionally, we do not know how women with disabilities understand their health care rights, nor do we know their choices and methods of seeking legal remedies if indicated.

Research Question: *How do Women with Disabilities Understand and Address Systemic Barriers to Preventative Community Health Services?*

4.2 Author's Standpoint

Prior to any discussion of my research approach, design, data collection and data analysis, it is important for me, as the author of this thesis, to state my personal standpoint with respect to disability. My first degree is a Bachelor of Medical Rehabilitation (Occupational Therapy) which I achieved in 1984. I have been practicing full time as an occupational therapist (OT) for 35 years. I presently do not identify as having a disability; however, I consider myself to be an ally and friend to people with disabilities. Despite my years of professional experience working with people with disabilities, I consider myself to be an outsider to the disability movement. Until such time as I experience a disability myself, I cannot claim to be an insider.¹ I also view myself as an advocate for people with

¹ See Michael J. Prince, *Absent Citizens: Disability Politics and Policy in Canada*, (Toronto: University of Toronto Press, 2009) at x (Preface). Prince refers to his 'insider' and 'outsider' roles within the Canadian disability community.

disabilities, but only with the permission and full participation of those with lived experience of disability.

4.3 Research Method

In order to explore the lived experience of WWDs seeking access to preventative health care, I selected a qualitative empirical research approach. While the doctrinal method of researching applicable human rights and accessibility statutes was a useful strategy in the development of the previous chapter, the efficacy and impact of these statutes on society and the individuals within it can best be explored by direct methods, such as interviews of individuals with lived experience. The word ‘empirical’ denotes evidence about the “real world.”² This evidence, or data, can be either numerical (quantitative) or nonnumerical (qualitative).³ Within this study, most of the data obtained is qualitative in nature.

4.3.1 Grounded Theory Approach

I have chosen to delay any discussion of theoretical frameworks until later in this thesis, after the data has been analysed. This follows from the perspective of the grounded theory approach. Charmaz explained the iterative nature of grounded theory, stating that “grounded theory methods consist of a set of inductive strategies for analyzing data.”⁴ Ideally, additional data is collected based on emerging ideas and themes.⁵

She also discussed the fact that the method is generative, and pointed out that: “[t]he hallmark of grounded theory studies consist of the researcher deriving his or her analytic

² Felicity Bell, “Empirical research in law” (2016) 25:2 Griffith Law Rev 262 at 264.

³ Lee Epstein & Gary King. “The Rules of Inference” (2007) 69:1 Univ Chicago Law Rev 1 at 2-3.

⁴ Kathy Charmaz, “Grounded Theory” in Robert M. Emerson, *Contemporary Field Research: Perspectives and Formulations*, 2nd ed. (Prospect Heights, Ill.: Waveland Press, 2001) 335 at 335.

⁵ *Ibid* at 336.

categories directly from the data, not from pre-conceived concepts or hypotheses.”⁶ While I, as the researcher, began my interviews with a certain perspective, world view and expectations, I used these pre-conceived concepts as points of departure to listen to the interviewees and analyse the data.⁷ To this end, I sought to obtain rich, detailed “thick” data,⁸ from which I could extract meaning from the interviewee, beyond the structure and function of the question being asked. I did find that, as I interviewed the participants, I engaged in data analysis concurrently with data collection, and that this analysis drove my subsequent data collection, via the prompts that I used within the semi-structured interview technique.⁹ The ultimate goal, according to Charmaz, is the generation of theory.¹⁰

Given the short time frame available during this study, the gathering of additional data was limited to asking the interviewees one additional question following the completion of the initial interview: “How long have you identified as a woman with a disability?” I pursued this additional question, as I suspected that length of time identifying as having a disability may be correlated with the emergence of personal identity, as supported by the literature:

Michilin and Juarez-Marazzo discussed the implications of length of time identifying with disability, and noted that: “[w]hen the disability happens at a young age, much of its effects on the child’s personality development and the child’s coping ability is dependent on the response of the family and the community.”¹¹ There is a sense of

⁶ *Ibid* at 336 - 337.

⁷ *Ibid* at 337.

⁸ *Ibid* at 338.

⁹ *Ibid*.

¹⁰ *Ibid*.

¹¹ P. Minou Michilin & Silvia Juarez-Marazzo, “Ableism: Social Work Practice with Physically Disabled Individuals” in George A. Appleby, Edgar Colon & Julia Hamilton, eds, *Diversity, Oppression, and Social Functioning: Person-in-Environment Assessment and Intervention*, 3rd ed (Boston: Pearson/Allyn and Bacon, 2011) 186 at 194.

empowerment if the individual, family and community respond to the disability as a challenge, whereas if the response is to view the disability as a loss, the disabled individual's self-esteem is affected.¹² This empowerment persists as persons with a disability attain adulthood. When the disability occurs later in life, there are different implications for the individual, in that there has been the past experience of life without a disability. The response of the individual and support system/family will be influenced by their perception of this change in life circumstances.¹³

This perspective from Michilin and Juarez-Marazzo will be expanded upon, as concepts of personal identity and rights consciousness are explored and developed further in section 6.3. At that time, the views of other authors from fields such as rehabilitation psychology and law will be incorporated.

4.4 Research Design

4.4.1 Participants: My research proposal was cleared by the Research Ethics Board (REB) at the University of Windsor.¹⁴ The sample consisted of female participants with a mobility disability selected for a pilot project barrier-free cancer screening clinic day planned by Dr. Nathania Liem and associates of Hôtel Dieu-Grace Healthcare (HDGH), in Windsor, Ontario, Canada. "Hôtel-Dieu Grace Healthcare is a unique community hospital offering services in Mental Health & Addictions; Rehabilitative Care; Complex Medical and Palliative Care; and Children and Youth Mental Health..."¹⁵

¹² *Ibid* at 193 - 194.

¹³ *Ibid* at 196.

¹⁴ The research proposal was reviewed by the Research Ethics Board of the University of Windsor and approved on February 16, 2019: Principle Investigator: Ms. Cynthia Brown; REB Number: 35654; Research Project Title: REB# 19-019: "Disability Rights in an Ableist Health Care Environment: How do Women with Disabilities Understand & Address Systemic Barriers to Preventative Community Health Services" Clearance Date: February 16, 2019; Project End Date: March 31, 2020.

¹⁵ "Hôtel-Dieu Grace Healthcare: About Us" (2018), online: *Hôtel-Dieu Grace Healthcare* <<https://www.hdgh.org/aboutus>>.

The clinic took place in collaboration with members of the Erie St. Clair Regional Cancer Program, on March 29, 2019. Participants were recruited by physiatrist Dr. Nathania Liem and her associates through the Beyond Disability Network.¹⁶ In addition, Dr. Liem asked her physiatrist colleagues to inform their patients of the upcoming clinic day. Physiatrists are doctors who specialize in physical medicine and rehabilitation.¹⁷ The women who were contacted self-selected, after which time they were determined by Dr. Liem and associates to be eligible according to cancer screening criteria.¹⁸

The clinic consisted of two screening tests: cervical screening (PAP test) which took place at the HDGH site, and breast screening (mammogram).¹⁹ The mammogram screening was offered at three different Ontario Breast Screening Program (OBSP) sites across the City of Windsor. Thirteen women took part in the screening. Three women only required the mammogram testing, and thus were not required to attend the HDGH site. Ten women attended the HDGH location for cervical screening. Transportation was offered by clinic organizers to those women who required it, in the form of an accessible van.

¹⁶ Beyond Disability Network is a virtual collaborative community dedicated to enhancing the lives of adults living with a chronic disability by providing a comprehensive guide to services, resources, and information regarding social/recreational events and activities in the Windsor and surrounding community. This virtual network, collaborating with various community organizations, provides an aggregated, intersectional source of information that "crosses disabilities", bringing persons with disabilities together in real space and time. The network's primary objective is to integrate persons with disabilities into the greater community by serving as a gateway to information and access to community services. See *Beyond Disability Network*, online: *Facebook* <www.facebook.com/Beyond-Disability-Rehabilitation-Network-233905587102357/>.

¹⁷ Physiatrist noun Definition of physiatrist (2019) online: Merriam-Webster.com <<https://www.merriam-webster.com/dictionary/physiatrist>>.

¹⁸ For cancer screening guidelines, see "Ontario Cervical Screening Guidelines Summary" (2016), online: *Cancer Care Ontario* <https://www.cancercareontario.ca/en/system/files_force/derivative/OCSPScreeningGuidelines.pdf> and "Ontario Breast Screening Program (OBSP) Guidelines Summary" (2015) online: *Cancer Care Ontario* (<https://www.cancercareontario.ca/sites/ccocancercare/files/assets/OBSPGuidelinesSummary.pdf>).

¹⁹ *Ibid.*

At the HDGH location, assistance for transfers was made available if needed, in the washroom, and on and off the exam table. This assistance was provided by a female rehabilitation nurse and/or a male rehabilitation assistant. A mechanical lift was also available for those who required it. Amenities, including lunch and a gift bag, were also provided by the organizers.

4.4.2 Recruitment

Negotiation of access to the research sample took place via a series of four meetings with Dr. Liem and her associates, after which time I removed myself from the clinic planning process to ensure impartiality. My thesis faculty advisor attended the initial meetings. Following the Research Ethics Board approval, a letter of no objection was obtained from HDGH (see Appendix I).

I attended the screening clinic at the HDGH screening site on March 29, 2019. I handed out information flyers to attendees as they waited in the waiting area for their procedure, or during their lunch break. A total of ten participants received the printed recruitment materials.²⁰ Of the ten individuals who received the materials, five agreed to, and completed an interview, representing a 50% response rate.

Consent to participate in research (see Appendix II) and to audiotaping if applicable (see Appendix III), was obtained from the interviewees immediately prior to conducting the interviews.

Four of the five interviewees used a wheelchair as a primary means of mobility. One interviewee used a cane. I did not specifically ask the interviewees about their diagnosis, as I felt that this direct request for medical information was not necessary in

²⁰ Per request, one individual asked that the materials be emailed to her.

answering the research question, nor in the context of research ethics, as the question would have required unnecessary disclosure of medical information. In addition, the preferred focus of this study is a social rights approach, therefore medically-directed questions which are reflective of a medical model view, were avoided. Some interviewees did, however, volunteer this information within the context of the interview.

4.4.3 Data Collection

The selected method of data collection was an in-person interview, situated in a private room at Hotel Dieu-Grace Healthcare. Alternatively, if transportation was a barrier for the participant, a private and confidential Skype interview or telephone interview was offered. See Appendix IV for the interview schedule.

Accommodations were offered to facilitate the interview process, as three of the five individuals who agreed to the interview utilized an alternative means of communication. Two of the three used a communication device and/or typed on a keyboard, and the third used single words, gestures and drawing.²¹ In total, two interviews took place in person, one took place via Skype, and two via email exchanges to accommodate expressive communication needs of the participants.

I found it significant that three out of the five individuals who expressed interest in an interview were unable to communicate via what society would consider “conventional means;” that is, verbally. In light of the data collected, I interpret this interest to arise from

²¹ These three individuals were accommodated via their preferred means of communication: two individuals responded to the interview questions via email. The third individual attended for an in-person interview, and utilized single words, gestures and drawing to respond to the interview questions.

a sense of agency and a need to be heard.²² I trust that my data analysis and results will honour and address this need.

The three participants who were interviewed in person or via Skype, agreed to audio-recording of the interview. The audio recordings were then transcribed. The two remaining participants typed out their answers and submitted them by email. Any requested clarifications required of the email participants were conducted via email exchange. The email interviews had some inherent limitations, as the back and forth exchange and the time lag interfered with my ability to conduct a true, iterative, semi-structured interview. The format took on more of a survey approach; thus, the information gleaned was not as rich or “thick” as the in-person or Skype interviews. Nevertheless, the five transcripts were coded manually for themes and trends, according to grounded theory methodology.

4.5 Limitations of the Study

Due to the sample size of five, the group of individuals in this research study may not be representative of the general population of WWDs. The general population of WWDs would be diverse with respect to gender identity, sexual orientation, age, race, ethnicity, socio-economic status, education and degree of connectedness with community resources such as regular attendance for primary medical care.

It must be noted that the five women who came forward to be interviewed for my study had already taken the initiative to self-select for the opportunity to participate in a barrier-free clinic day. Some of these participants had well established self-advocacy skills

²² Agency, in this context is referred to as “...an individual's capacity to determine and make meaning from their environment through purposive consciousness and reflective and creative action”. See Cameron Parsell, Elizabeth Eggins & Greg Marston, "Human Agency and Social Work Research: A Systematic Search and Synthesis of Social Work Literature" (2017) 47:1 BJSW 238 at 239 DOI: < <https://doi.org/10.1093/bjsw/bcv145>>.

and awareness of the importance of access to, and participation in screening procedures. This sampling would not have captured those women with disabilities in the community who perhaps do not have a family doctor, or who do not attend medical appointments regularly. In addition, two of the individuals reported that they had been involved in citizen participation with the AODA, and therefore may have had a greater understanding of their rights, and of legislative instruments as compared to other WWDs. It is therefore important to conduct further research which would capture a sampling of women with disabilities who may not have had contact with the health care system or the above-noted advocacy opportunities. It would also be beneficial for a future researcher to inquire about whether participants self-identify as racialized or newcomers. The responses to the interview questions from a more generalized sample could yield different, and even more illuminating results.

Regardless of these limitations, the rich information provided by the semi-structured interview format offered insights into the experience of WWDs as they seek access to health care.

CHAPTER 5

ANALYSIS OF EMPIRICAL DATA

Rich data was obtained from all five interviewees. The information obtained will be presented below, beginning with demographic information, and moving generally through the order of questions within the interview schedule. Some responses to questions will be grouped together according to topic.

Following this, the results of manual coding, analysis and derivation of key themes which are most responsive to my research question will complete this chapter.

5.1 Demographics

Level of Education: The only specific demographic question which was included in the interview schedule pertained to the interviewees' level of education. This question was selected in order to determine if level of education influenced perception of, and action upon, perceived barriers to health care. It was also considered as a possible factor in the development of identity.

A wide range of educational levels was noted. One individual has 3 university degrees. Another has a bachelor's degree, another a college diploma, another achieved Grade 12, with some supplementary university courses and college courses, and another achieved some high school but did not attain a diploma. This wide range of educational levels did not appear to have an impact on the level of understanding and insight regarding barriers, rights, legislation and the willingness/ability to seek remedy.

Length of time identifying as a WWD: As previously stated in Chapter Four, a follow-up question was asked of each of the interviewees, regarding the length of time that she had identified as a WWD. One individual identified as such for her entire life, while another identified as such since her teenage years i.e. most of her adult life. The remaining

three women came to identify as having a disability more recently, in their adult lives, with the onset ranging from 2004 to 2011. This question was asked due to a suspected correlation regarding identity development and rights consciousness.¹ A correlation was not identified in this study; however, this presents an interesting avenue to develop for future research. Additional interview questions would need to be added in order to flesh out the development of personal identity over the interviewees' life span.

5.2 Interview Results

The interview schedule (see Appendix IV) was generally divided into two parts: the first part addressed the interviewees' experience and understanding of preventative health care, including a discussion of the common barriers to access that they encountered, and how they felt about it. Their perception of the accessible screening clinic day was also addressed, as a comparator to past experiences. Sections of part one lent themselves to a degree of quantitative analysis, with the generation of tables and a graph (see Tables 1 and 2, and Figures 1 and 2).

The second part addressed the interviewees' understanding of possible underlying causes of the barriers, human rights and accessibility laws, their own perception of their rights, and their decision whether to seek remedy. Results are summarized according to the specific questions, or groups of questions, generally in the order in which they were asked. Individual interviewees are referred to by alias initials, in order to protect their identity.

¹ Michilin and Juarez-Marazzo, *supra* Chapter 4, note 11.

5.2.1 Past Cancer Screening – Perceptions and Experience

Initially, the interviewees were asked if they felt it was important for WWDs to have cancer screening tests done regularly. They unanimously agreed that it is important for WWDs to be screened. The general view of the interviewees was that, if a condition is caught early, it can be addressed, and a life can potentially be saved.

The interviewees were each asked how frequently, if at all, they had undergone pap tests or mammograms. The results are listed in Table 1 and Figure 1 below:

Frequency of Screening

PARTICIPANT	FREQUENCY OF PAP TEST	FREQUENCY OF MAMMOGRAM
1	Past 5 years	Past year
2	Past 15 years	Past 10 years
3	Past 10 years	Past year
4	Past 3 – 4 years	Once before
5	Never	Never

Table 1

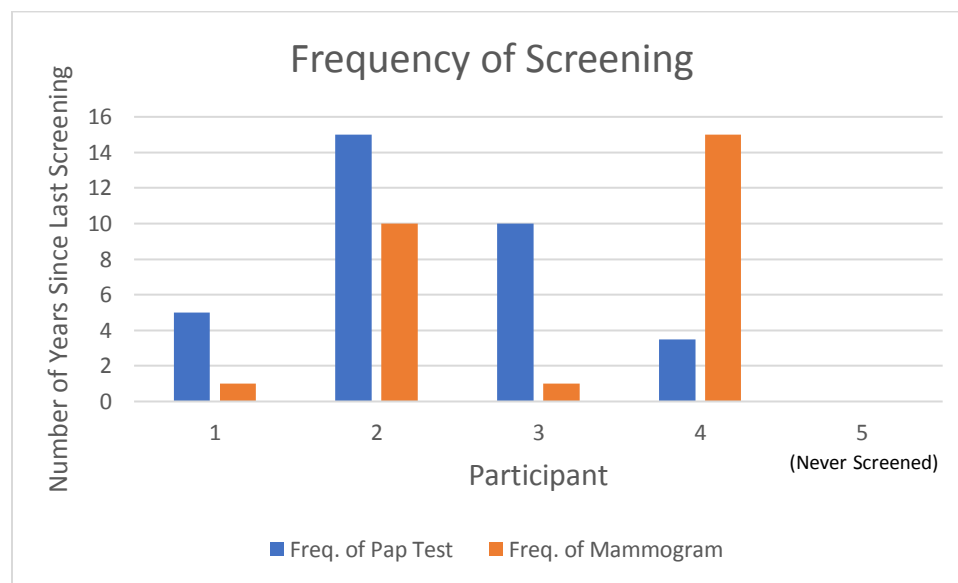


Figure 1

It appears from analysis of Table 1 and Figure 1 that the interviewees were more likely to have had recent mammograms, as opposed to Pap tests. Two of the interviewees stated that they had had mammograms within the past year. It could be theorized that the accessibility barriers for obtaining a Pap test as related to transferring onto an examining table may be greater than the positioning barriers for obtaining a mammogram. In addition, most interviewees had the mammogram screening in a hospital environment or a mammography clinic; these environments, according to the interviewees' accounts, are more likely to be physically accessible than physicians' offices.

The interviewees who only infrequently attended for screening, or not all, were asked to provide reasons. Two interviewees cited decreased physical accessibility as the primary reason. One interviewee stated that the examining tables were too high. IJ stated: "I had appointments to go [to]. Everywhere they sent me was not accessible to get in, and then the one place that was; they didn't have lifts; or 'they didn't deal with that', they said. So, I never got sent to an accessible place."² She called ahead before trying to attend another facility. Apparently, the building was accessible, but the staff informed her that they weren't equipped once she got inside, so she didn't attend.

CD stated that her family doctor did not provide her with a reminder for her mammogram screening. The importance of referral by primary care physicians for preventative screening has already been noted in the literature review.³

EF cited the stresses of dealing with a new diagnosis as a deterrent to routine screening tests: "I had bigger issues to conquer with my health...getting properly

² Interview with IJ (9 May 2019) in Windsor, Ontario (notes on file with author).

³ Aisha Lofters et al, *supra* Chapter 2, note 73 at E245: "Physician recommendation is known to be an important predictor of cervical cancer screening."

diagnosed from so many specialists and [I] didn't want to think of cancer. It was too much to handle with my neurological disorder.”⁴

The interviewees were asked to describe what their previous screening experiences were like, prior to attending the accessible clinic day. EF stated that she last went for a mammogram within the past year. While the hospital itself was accessible, she stated that she did not have a wheelchair accessible vehicle. She purchased a power portable chair that her spouse put in the trunk. She added that some technicians were helpful, but others expected her spouse to assist with dressing and undressing and to support her while standing. She added that this created some stress for herself and her spouse. If her husband were not available to assist, she stated that she would need to hire a personal support worker to meet her at the hospital.

This scenario illustrates the financial burden imposed upon WWDs in the form of privately purchased medical equipment or support services. In addition, potential relationship stresses occur when a spouse or someone close to the individual is relied upon for assistance, versus having it offered as a part of the service at the health facility. GH's statement summarizes this issue: “I have to bring a male friend to actually lift me onto the exam table. Who wants that?”⁵

5.2.2 Identified Barriers

All five of the interviewees freely provided information related to access barriers to health care, and some of the quotes noted above already allude to these barriers. The barriers will be categorized as physical access barriers, transportation barriers, financial barriers, communication barriers, health system barriers, and society's attitudinal barriers.

⁴ Interview with EF (10 May 2019) in Windsor, Ontario (notes on file with author).

⁵ Interview with GH (10 May 2019) in Windsor, Ontario (notes on file with author).

Interviewee AB used the term “hidden barriers”⁶ to describe such issues as the multitude of steps and the inordinate amount of planning required by a WWD in order to set up a medical appointment or series of appointments. This planning includes the scheduling of the personal support worker to get ready for the day, arranging transportation, scheduling of multiple appointments on the same day to economize on time and resources, and calling ahead to each medical facility to see if they are accessible and if they have personal assistance available. This issue, related to the burden of planning for appointments was raised in the literature review.⁷

The reported barriers will be reviewed below and are summarized in Figure 2 (In the figure, all the physical access barriers are grouped under the heading “Physical”).

1. Physical Access Barriers

All the interviewees referred to problems with poor physical access and/or inadequate physical space, as they sought to access medical care in the community. In discussing the use of her wheelchair for medical appointments, AB referred to the need for a ramp to exit her home. In addition, she stated that even though the medical building may be accessible, the individual offices inside of the building may not be able to accommodate a standard wheelchair. She stated: “you have to have a second wheelchair. You have to purchase a collapsible one; a small transport chair.”⁸

This further illustrates the need for WWDs to assume personal financial burdens through the purchase of additional medical equipment in an ironic effort to “accommodate”

⁶ Interview with AB (5 April 2019) in Windsor, Ontario (notes on file with author).

⁷ Angus et al, *supra* Chapter 2, note 93 at 78.

⁸ AB, *supra* note 6.

inaccessible spaces in the health care arena. The WWD assumes responsibility for the accommodation, versus the onus being rightly placed on the health care system.

CD mentioned lack of curb cuts near medical facilities and commented on inadequate physical space in her family doctor's office. She added that she occasionally encounters inaccessible washrooms in health care facilities. CD drives a vehicle independently and commented that she cannot always find an accessible parking space.

EF commented that: "[t]he medical clinic closest to my condo has no accessibility to the building so I have to wait for someone to open the door to enter and exit. The window is too high, so the receptionist has to come around to get my information. It's a little embarrassing." She added that "[i]t's frustrating when doctors and dentists' offices don't have access to the front door. People are willing to help but it's the lack of independence that's hard for me." She stated that an ideal scenario would include a: "modern facility with a walk in clinic close to home to travel to in my chair during nice weather. I like the independence."⁹

IJ has already been quoted as saying that she was sent to a screening appointment only to discover that the building had stairs to get in with "no back way."¹⁰ One facility that IJ investigated admitted that they had no mechanical lift, and no staff qualified to assist a PWD.

The issue of the "back way" is a common concern that I have heard personally in my professional work with PWDs and WWDs. They state that they are often relegated to a back entrance or to a freight elevator. This discriminatory practice suggests that those

⁹ EF, *supra* note 4.

¹⁰ IJ, *supra* note 2.

with disabilities are viewed as less worthy than other citizens who seek access to health care and other services.

2. Transportation Barriers

AB aptly embedded transportation barriers amidst a list of other barriers:

If you are living in your own home, which is the motto that you're supposed to 'age in place', so then the first barrier is you have a ramp, and then you need access to vans... there's different companies. You see the vans all over. And they can get you to a doctor's appointment, but you have to have a doctor that's accessible. And then once you get in the building you need to find a doctor that has an accessible office.¹¹

She added that hired transportation is an option for those who do not own their own van, however there is no definite pick up time or drop off time. This creates a hardship for the individual, who may need to wait in the facility for pick up for an inordinate amount of time. AB ultimately purchased her own accessible van at her own expense.

IJ discussed the challenges of taking the city bus for appointments, but she, like EF, added that she enjoys the independence of going somewhere on her own in her power wheelchair in nice weather. She added that there is an expense for stretcher service, should she require emergency transportation to and from the hospital. This expense has unfortunately prevented her from seeking medical care, at times.¹²

3. Financial Barriers

Financial barriers have already been touched upon in the discussion of transportation barriers and the need to purchase additional space-saving mobility equipment. AB discussed financial barriers within the context of planning and securing a

¹¹ AB, *supra* note 6.

¹² Laverne Jacobs, *supra* Chapter 3, note 71 at 37. In her article on transportation inequality claims, Jacobs discussed the issue of transportation as a known barrier for people with disabilities across Canada.

personal attendant. She stated that a family member may not always be available, and it is expensive to hire someone:

You can call... [an] agency, but they are \$30 an hour or so, and you have to block certain amounts of time; you can't just book them. You have to call a week or two ahead; they have to see if there's staffing available; there's many, many hidden barriers.¹³

AB also mentioned the drain on the family finances and its effect on the family unit and on family and personal relationships. This financial strain was echoed by the other interviewees as they discussed the need to seek out both transportation and personal support services.

Financial barriers presented as a common theme throughout the literature review in Chapter Two. From the literature review, McColl, Jarzynowska & Shortt were among many authors who noted that cost was one of the greatest deterrents to receiving needed services among PWDs.¹⁴

4. Communication barriers

Two individuals commented on communication barriers. One interviewee expressed communication frustrations due to difficulties with expressive speech. She stated that most problems have occurred at retail stores and in the community. She stated that she has had generally good experiences with medical personnel and her family doctor. She added that, due to her communication difficulties, she relies on her sister to be her advocate to set up and organize health care appointments.

¹³ AB, *supra* note 6.

¹⁴ McColl, Jarzynowska & Short, *supra* Chapter 2, note 19 at 213.

GH stated:

Because of my speech impairment, some people assume I'm not as intelligent as I am. This can be a barrier when dealing with doctors who are unfamiliar with me. I have to say, though this doesn't happen as often as it once did.¹⁵

This interviewee suggested from her other interview responses that she has maintained a group of health professionals who have come to know her and her communication system, thus minimizing potential frustrations.

5. Health System Barriers

Health system barriers consist of issues such as lack of staffed personal attendant services during medical appointments, waiting lists, and costs related to service provision and retrofitting of accessible equipment.

AB commented on the lack of available assistance during medical appointments. She discussed the process of setting up and attending a mammogram appointment at the local hospital. She indicated that she was told that there would be assistance available, but this was not the case:

...well let's say we did half of the test and I said, 'I'm sorry I'm leaving'. I have high tolerance for pain, but I said 'you're just bruising me. I am leaving'. I understood there was assistance, but obviously there was miscommunication. There was just the technician, and I left.¹⁶

Another interviewee inquired about the availability of physical assistance, only to be told directly that such assistance was not available as part of the screening service.

AB discussed the problem of waiting lists, and the impact on the quality of life and daily functioning of WWDs: "...you deteriorate; your medical condition deteriorates as you are waiting."¹⁷ In addition, she commented pragmatically on what she viewed as an

¹⁵ GH, *supra* note 5.

¹⁶ AB, *supra* note 6.

¹⁷ *Ibid.*

exorbitant cost to the system, should physician's offices be expected to be retrofitted to remove barriers: "...and how could they afford the staff? Or the equipment? I just don't see it."¹⁸

6. Attitudinal Barriers

The category of comments and concerns related to societal attitude covers issues such as lack of awareness and understanding of the needs of WWDs, and condescending/patronizing attitudes.

a. Lack of awareness and understanding of the Needs of WWDs

One interviewee elaborated on an Emergency Room experience in which she was left alone in an exam room for a long time without being turned. She was unable to reposition herself due to her disability. This caused extreme pain which resulted in her crying and calling out. She stated that she was told by the hospital staff person: "You need to calm down; you're scaring the other patients." The staff person then walked away without offering assistance.¹⁹

CD expressed that the public does not understand or know how to anticipate the communication and physical needs of those with disabilities and stated that it "makes her mad."²⁰ She added, however, that medical personnel have generally been more aware and understanding as compared to the general public.

¹⁸ *Ibid.*

¹⁹ II, *supra* note 2.

²⁰ Interview with CD (9 April 2019) in Windsor, Ontario (notes on file with author).

b. Condescending/Patronizing Attitude

In discussing communication barriers, one interviewee stated that she was disappointed by: “[d]octors/nurses not knowing how intelligent I am and talking down to me.”²¹

IJ stated that:

I deal with that when I’m in the hospital where they treat you like a mental disability; like I’m a mental disability, where I’m fully aware of what’s going on around me and I can hear you whispering over there. They treat everyone the same; we’re all balled in. If you’re in a wheelchair, it can be humiliating. Even when you try to put your foot down, they go: ‘It’s OK dear.’ You just want to... I usually just end up leaving. They don’t see me. They just see the chair.²²

When asked what groups of people tend to have this attitude, IJ stated that it is mostly the nurses and assistants.

IJ discussed using an advocate for support when meeting with health professionals who may have these condescending attitudes. In one challenging situation during a doctor’s appointment, the advocate stated, according to IJ, “Treat her like a human or we’re leaving.”²³ IJ stated that this eased the situation, but she won’t go back to that health care professional. She added: “I really...I was taken aback. I thought ‘you can’t talk to me like that’. But if [the advocate] wasn’t there, I’m not sure what I would have done. I needed that appointment. I think people don’t like talking about it. Or they just figure ‘OK that’s the way doctors are.’ That’s not the way I want to be treated.”²⁴

²¹ GH, *supra* note 5.

²² IJ, *supra* note 2.

²³ *Ibid.*

²⁴ *Ibid.*

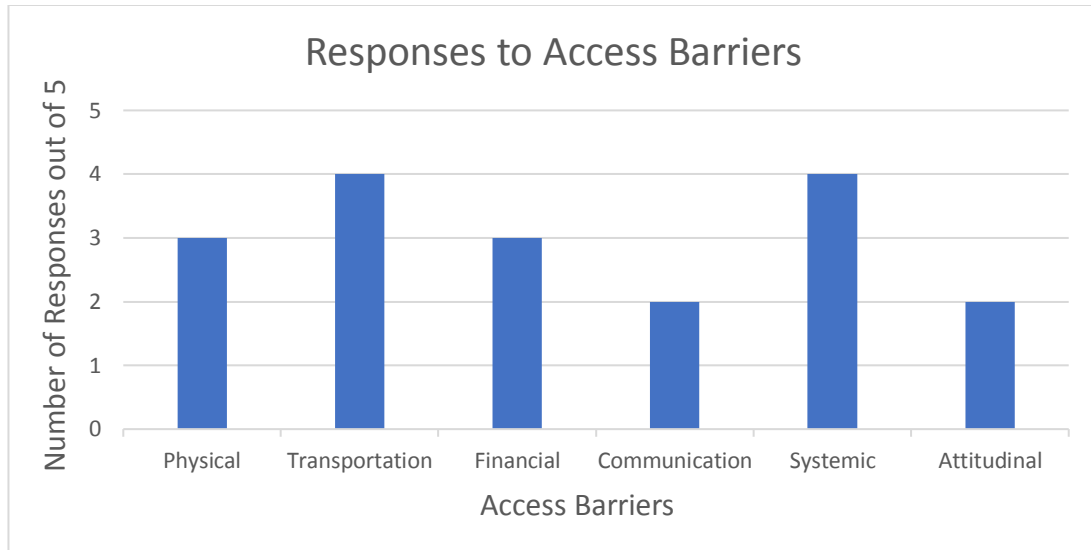


Figure 2

5.2.3 Perception of an Accessible Health Care Experience

Given the discussion of the above barriers, it should not be surprising that the interviewees' experience with the accessible screening clinic was unanimously positive. Two individuals specifically mentioned the accessible screening clinic day as the best example of a positive experience within the health care system.

In general, the interviewees appreciated the atmosphere, the availability of personal assistance, the banter at lunch time, the gift bag and photo. AB stated: "...there is a vacuum; there is nothing else like this."²⁵ EF added that "...the support and transportation is so helpful. Otherwise obstacles faced are too disruptive to our lives."²⁶ This accessible experience appears to have made an otherwise challenging and invasive experience a pleasant one.

²⁵ AB, *supra* note 6.

²⁶ EF, *supra* note 4.

When asked of any possible downsides to their experience with the accessible clinic, two interviewees commented that, due to the time of the appointment, they needed to make special arrangements with their personal support workers to help them to get ready. Another stated that the clinic location was far from her area of the city and added that she would appreciate if the next clinic were in a more central location.

Lastly, one interviewee commented that the only difficulty during the clinic day was having a man assist her with physical transfers. She added that this discomfort extends to some male doctors as well, depending upon the privacy and intimacy of the medical procedure being conducted. While beyond the scope of this thesis, further research and exploration of the perceptions and experiences of WWDs with male health care providers is warranted.

IJ summarized the clinic day by stating: “They treat you like you’re their family, and you know they want to make you as comfortable as possible. It’s also breaking a barrier right there; for a lot of people.”²⁷

5.2.4 “The Problem”

The interviewees were asked to explore the possible underlying reasons for the existing barriers to health care for WWDs.

Two interviewees provided practical responses, citing such underlying concerns as lack of transportation, lack of availability of a caregiver, decreased accessibility to equipment and not having proper assistance. The remaining three interviewees spoke of societal attitudes and values.

²⁷ IJ, *supra* note 2.

AB stated that:

...it's a value of life issue. Living a meaningful life...oh yes you run into that very often. As soon as you become part of the world of disability it's a whole different; that's a parallel universe. You get all kinds of comments made; you know. 'Oh, I couldn't live like that.'²⁸

She concluded: "You get comments like that; there's all kinds of judgement on value of life."²⁹ When asked where these comments come from, AB stated that "[i]t's sprinkled through society."³⁰

CD succinctly stated that it has to do with "legislation."³¹

IJ stated: "Just the attitude of society: "Women are less, right? 'Strong Men.' We're just fragile women."³²

5.2.5 "The Solution"

The interviewees were asked: "What do you think should be done to make health care access better and more available for women with disabilities?"

Three interviewees provided practical suggestions, such as: more accessible doctor's equipment, wider examining room doorways, more room to manoeuvre a wheelchair, and access to affordable transportation. One interviewee stated: "Why can't doctors have one examining table that is lower? Lower tables would allow some people to transfer onto the table."³³

As with the discussion of the underlying problems, some of the interviewees took a more systemic approach to the possible solutions. AB referred to the need for having

²⁸ AB, *supra* note 6.

²⁹ *Ibid.*

³⁰ *Ibid.*

³¹ CD, *supra* note 20.

³² IJ, *supra* note 2.

³³ GH, *supra* note 5.

attendant services as part of the health care service provision plan. She also stated that it is important to:

... have equal consideration for female; just generally female patients; there's all types, but such a sub-group like people with mobility issues; not just female...It's a whole community; people with mobility issues - not necessarily just female, but I guess you could target that group there - may be especially marginalized.³⁴

She concluded that it is important "to encourage that the laws that we have in Canada and Ontario for accessibility are enforced for the good of everyone, male and female, and there's the subgroups."³⁵

IJ stated that it is important to have more accessible clinics like the one that she recently had the chance to experience. She added:

I don't know; to be more understanding maybe, when you become a nurse, and even a secretary; you should maybe do a little...couple of days on training on how to treat people. Not everybody's the same. That's got to be an important lesson.³⁶

5.2.6 Putting Forth a Complaint

The interviewees were asked if they ever wanted to put forth a complaint about health care barriers. This question is perhaps the most direct in addressing my research question, regarding the way in which WWDs address barriers to health care. All five of the interviewees expressed that they had wanted to complain but did not. Two of the five did complain regarding public access in the community, but the complaint was not specific to health care access. The interviewees were asked why they did not complain about a health care issue.

³⁴ AB, *supra* note 6.

³⁵ *Ibid.*

³⁶ IJ, *supra* note 2.

AB stated: “The question is always “report to whom?” She added: “It’s knowing where to report.”³⁷

EF put her reply in context through the description of an experience: “I had very poor balance and had to access my doctor’s heavy glass door by pushing backwards with my rollator [walker]. Someone opened the door and I fell backwards but I was too embarrassed to complain.” She added that she did not complain because: “I wasn’t sure of the process and worried about my diagnosis and I wasn’t injured by the fall. It was an uphill battle for me.”³⁸

GH wanted to complain but did not, because it was “[t]oo much hassle and [I] wasn’t sure who’s responsible for height of examining tables.”³⁹

IJ prefaced her response to the question of lodging a complaint, by stating that she recently has begun to stand up for herself. She qualified this, however by stating: “When you complain about someone that you have to see continuously; that’s going to come back and bite you.”⁴⁰ She later stated: “It’s fear – my life is in their hands!”⁴¹ She concluded later in the interview: “Some people just can’t handle confrontation. I’m one of those people but I’m learning I’m not going to get anywhere in life if I just shut up.”⁴²

5.2.7 Understanding of Rights

The interviewees were asked: “What is your understanding regarding your rights?”

AB stated:

I guess what I’ve observed; most people; their understanding of the rights of the disabled involve only making a door to the building with a button that lets

³⁷ AB, *supra* note 6.

³⁸ EF, *supra* note 4.

³⁹ GH, *supra* note 5.

⁴⁰ IJ, *supra* note 2.

⁴¹ *Ibid.*

⁴² *Ibid.*

you in and that's where the knowledge of rights, maybe on both sides, from the individual and the other side; the owner of the building; the occupant of the building; maybe that's where the rights sort of...what's the right word... the knowledge stops. Just having a door with a button; yes, technically, you are now an accessible building. It's what happens inside the building; what about the washrooms; what about the drinking fountain? What about let's say a dentist's office; like there's no accommodation once you can get in. That's where it stops.⁴³

Regarding WWDs having regular preventative tests, AB added: "Isn't it unfortunate but I'm thinking it's nice to have but I don't know that we can assume that it's a right."⁴⁴ When asked to elaborate, AB stated:

Well it's just that the equipment doesn't exist. They just cannot accommodate certain women with certain conditions; there is no...I don't know which doctor's office could accommodate or which hospital could accommodate certain conditions. I think it would be based on which condition you had. I would think that some conditions could just not be accommodated.⁴⁵

One interviewee defined rights as equivalent to the term "access."⁴⁶ Another stated: "I know I have the same rights to health care as able-bodied people."⁴⁷

One interviewee admitted: "I know very little about rights to access health care. I think it's important that I learn about my rights."⁴⁸

IJ stated that she "[n]ever really thought about it. I never ran into the barrier where I couldn't get health care; just a lot of barriers getting there. It's all barriers pretty much." She added "I think I should know my rights..."⁴⁹

While this question was presented with the assurance that there would be no judgement related to the knowledge of rights or lack thereof, some interviewees expressed

⁴³ AB, *supra* note 6.

⁴⁴ *Ibid.*

⁴⁵ *Ibid.*

⁴⁶ CD, *supra* note 20.

⁴⁷ GH, *supra* note 5.

⁴⁸ EF, *supra* note 4.

⁴⁹ IJ, *supra* note 2.

an apologetic tone, and others were noted to become self-reflective as the interview proceeded.

5.2.8 Experience with Legislation

The interviewees were asked about their familiarity with human rights laws. Examples provided were the *Charter*, the AODA, and the CRPD, and the interviewees were invited to mention any other applicable laws with which they were familiar. All five of the women who were interviewed had heard of at least one of these pieces of legislation. Four out of the five had heard of at least two.

Two of the interviewees stated that they had been involved in committee work related to the AODA, and another referenced the AODA. Another expressed an understanding of the premise of the AODA “that every place has to be accessible now.”⁵⁰

Three interviewees stated that knowledge of applicable legislation may not have led to a formal complaint, but it did help them to take steps regarding health care barriers or other issues encountered in the community related to their disability. One interviewee indicated that her knowledge of legislation and related committee work did help her, stating “I can be assertive when needed.”⁵¹

5.2.9 Desire for further information

When asked if they would like to learn more about their rights and related legislation, four out of the five interviewees stated that they would like to learn more. All interviewees were referred to a link on the Law, Disability and Social Change website at

⁵⁰ *Ibid.*

⁵¹ GH, *supra* note 5.

the University of Windsor, which was created in conjunction with this thesis study. It provides information on legislation and advocacy resources for people with disabilities.⁵²

5.3 Coding and Development of Themes

Following from the grounded theory approach, manual coding of the above data was conducted. The five printed transcripts were reviewed for common themes. Some of these themes were common across all five interviews, and some were coded and developed within a single interview. The common statements were noted in the left margin of the transcripts, and broader categories/themes were analyzed and noted in the right margin. Five main themes/categories were then derived from the coded data, as follows.

5.3.1 Health Care Ableism

All of the interviews were consistent with at least one of the following coded sub-themes which will be grouped under the category of health care ableism. Items 1. and 2. have already been detailed in the description of attitudinal barriers in section 5.2.2. They warrant additional attention below, in the context of this over-arching theme.

1. Pre-judgment, Stereotyping and Condescending Attitudes

Interviewees reported that health care professionals frequently called their competency into question, when they saw that the interviewees had a disability. Two interviewees pointed out that WWDs are often viewed as a homogeneous group. Similarly, those interviewees with communication barriers commented that they were judged by health professionals to be of lesser competence, simply due to their alternative communication methods.

⁵² “Legislation and Advocacy Resources for People with Disabilities” (March 1, 2019), online: *Law, Disability & Social Change* <<https://lawdisabilitysocialchange.com/2019/03/13/legislation-and-advocacy-resources-for-people-with-disabilities/>>.

2. Lack of Understanding of the Needs of WWDs

Interviewees discussed the lack of understanding on the part of health care professionals of the physical comfort, physical access and communication needs of WWDs. This broadly covers many issues which were touched upon by all interviewees, from the discomfort experienced during a mammogram, to the multitude of physical barriers, to the negation of personhood because of a non-conventional communication method.

3. Decreased Value of Life of WWDs

Some interviewees stated that they felt less valued by health care professionals due to their status as a WWD.

4. Sub-standard Health Care Scenarios

Several interviewees commented on the expectation from health care providers that they settle for less than standard care, such as having a seated examination instead of accessing the examining table and receiving incomplete examinations with makeshift equipment or positioning. These scenarios suggest that the health care providers felt that the services provided and/or offered were “good enough.” In describing this situation, Silvia Yee stated that “[t]he fear of injury and indignity experienced by people with disabilities in the face of these so-called “alternatives” deeply discourages the scheduling of regular provider visits and preventive exams”.⁵³

⁵³ Silvia Yee, “Disability Discrimination in Health Care” (paper delivered at the Jacobus tenBroek Disability Law Symposium held at the Jernigan Institute, Baltimore, MD, 1 April 2012), online: *Disability Rights Education & Defense Fund* <<https://dredf.org/public-policy/health-access-to-care-old/disability-discrimination-in-health-care/>>.

5.3.2 Rights Consciousness

One of the most striking observations from my empirical research was the change in the focus of the interview as some of the interviewees began to explore the issue of rights, legislation, and the decision-making process surrounding the lodging of complaints. This series of questions in the interview schedule was noted to spark a self-reflective response on the part of some of the interviewees, leading to an iterative approach in my line of questioning in order to learn more. Some interviewees, when initially asked about their knowledge of their rights and applicable legislation, appeared apologetic, stating that they really didn't know much about it, but they later began to open up and reflect.

Through direct questioning, or spontaneously, all the interviewees provided input related to their knowledge of disability laws and rights, as well as their decisions to act upon injustices, or not. They spoke of their knowledge of legislative tools, and some reported that they had been involved in committee work for the AODA. A reflection on the concept of rights was noted to be a common thread in the conversation among many of the interviewees, but the expression of this understanding appeared to range from a level of emerging awareness to more integrated awareness.

One interviewee did comment that she has begun to speak up for herself and assert her rights. She returned to the issue of rights during the interview, and actively sought information on the steps involved. Two interviewees stated that they were not familiar with applicable legislation, but later in the interview, stated that they would like to find out more. One interviewee expressed a more solid understanding of her rights, stating: "I should be

able to get the same health care as any other woman, despite my disability. ‘Rights’ in this sense mean I’m entitled to health care.”⁵⁴

Interestingly, the responses from the interviewees were unanimous in expressing a lack of knowledge regarding recourse to injustices encountered while seeking health care. Many indicated that they wanted to put forth a health access complaint but did not due to unfamiliarity with the process. This is remarkable, given the depth of understanding expressed by all five of the interviewees, and the actual experience and input that two of them had with the consultation process for the AODA legislation. This suggests that there may be a lack of a clear and easy mechanism for WWDs to pursue legal remedies in the area of health care access barriers.

The consensus amongst the interviewees, as well, was that it is just too much trouble to formally complain. None of the interviewees articulated why it is too much trouble. This issue was not developed fully in the iterative process; however, it warrants further research.

5.3.3 Gender Marginalization

Two of the interviewees brought up the issue of being marginalized due to being female. AB expressed the need for equal consideration for female patients in general; not just WWDs, and IJ commented that women are viewed as being lesser and weaker than males, regardless of the issue of disability.

AB and IJ both stressed the intersectional marginalizing experience of being a woman and having a disability. IJ went further by suggesting that women with disabilities are valued less, and that their intellect is questioned.

⁵⁴ GH, *supra* note 5.

5.3.4 Power Imbalance

IJ explicitly spoke of the fear of speaking up against injustices perpetrated by those in a position of power over her, stating: "...my life is in their hands!"⁵⁵ The literature also reports that WWDs often don't wish to complain against their doctors' offices regarding access barriers, for fear of damaging their relationship with their care provider. Yee stated that a PWD "might hesitate before suing the provider that he already has a relationship with, or the specialist from whom he needs urgent ongoing treatment."⁵⁶

5.3.5 Consequences Faced by WWDs

1. Pain and discomfort

In experiencing a mammogram at the hospital last year, one interviewee stated that she was required to assume uncomfortable and awkward postures which resulted in pain and bruising. Another relayed an experience of pain in the emergency room as her positioning needs were ignored.

2. Loss of privacy

AB discussed the lack of privacy that results from makeshift accessibility arrangements:

One step further is you have to get from the waiting room with a small chair into their individualized small offices, so you have some confidentiality, to actually have what 'normal' people would have, where you could get in the office and shut the door to have a discussion with the caregiver...Some of them end up leaving the door open, because the chairs don't fit.⁵⁷

⁵⁵ IJ, *supra* note 2.

⁵⁶ Yee, *supra* note 53.

⁵⁷ AB, *supra* note 6.

3. Financial Burden

The interviewees frequently mentioned the financial burden involved related to transportation to health care appointments, as well as the cost of hiring an attendant to accompany them, if necessary.

4. Impact on Personal/Family Relationships

Two of the interviewees discussed the stress on their marital relationship related to the spouse's role in providing attendant care during medical appointments. One interviewee discussed the impact of the financial burdens on the whole family unit. Another discussed the embarrassment of having a male friend step in as her personal attendant for transferring onto the exam table.

5.4. Key Themes

Of the five categories detailed above, two specific categories, or themes, appear to align most closely to the research question; that of health care ableism, and rights consciousness. Health care ableism addresses the societal context within which WWDs must attempt to access their health care needs. Ableism is defined as a network of beliefs, processes and practices that produce a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability, then, is cast as a diminished state of being human.⁵⁸

In his judgment on a case involving the alleged discrimination against an identifiable class (disabled children of unmarried parents),⁵⁹ Justice A.W.J. Sullivan defined ableism as follows: “When law privileges the non-disabled, and further

⁵⁸ Fiona A.K. Campbell.,” Inciting legal fictions: Disability’s date with ontology and the ableist body of the law” (2001) 10 Griffith L Rev 42 at 44, footnote 5.

⁵⁹ *Coates v. Watson*, 2017 ONCJ 454 at para 43.

disadvantages people with disabilities, this is ableism -- discrimination on the basis of disability.”⁶⁰

In the context of this thesis, rights consciousness addresses the emerging awareness and understanding of WWDs regarding their rights to access health care and it appears to have an impact on their decision to act against injustice. In the next chapter, I will discuss and explore these two themes through additional literature critique and analysis.

⁶⁰ *Ibid* at para 110.

CHAPTER 6

ANALYSIS OF KEY THEMES

Grounded theory methodology provides the impetus for critique of the literature based on the two key themes which were derived from the empirical results in Chapter Five.¹ The data obtained through the interviews of the five WWDs brought the concept of health care ableism to light, prompting further research and analysis into the environment within which WWDs must operate in order to access the health care services to which they are entitled, and to exercise their rights if these entitlements are denied. I propose that the challenges of dealing with an ableist health care milieu can be formative with respect to the development of identity and rights consciousness.

The second, and primary theme, rights consciousness of WWDs, arose from the iterative process inherent in the interviews. As many of the interviewees spoke of their understanding of their rights and responded to questions that arose from their own responses, they demonstrated what appeared to be an increased interest and awareness in learning more about their rights, and indirectly, about themselves and their own identity. The formation of identity will be incorporated into the development of the theme of rights consciousness; the culmination of my analysis.

Prior to a deeper discussion of both above themes, an overview of feminist theoretical frameworks is warranted, given that all the interviewees have encountered the health care system through the lens of both gender and disability.

¹ See Kathy Charmaz *supra* Chapter 4, note 4.

6.1 Feminist Theory

Feminists across many disciplines regularly ask about the gender implications of rules and practices which might otherwise appear to be neutral or objective.² The topic of feminist theory naturally arises from the empirical study within this thesis, given that the primary subjects are women with disabilities who accessed screening services which are specific to the female body. In addition, it is notable that two of the interviewees from this study raised the issue of being marginalized due to being female.

From her own empirical studies, Carol Thomas found that women with disabilities are engaged in relationships throughout the life course that typify “modern womanhood.”³ Their experience cannot be understood independently of the gendered character of their lives.⁴ Referring to the importance of WWDs finally beginning to tell their stories, Thomas stated: “In the last quarter of the twentieth century the years of silence (or rather, silencing) have been broken and the voices of disabled women are now in the public domain.”⁵ It is significant that the voices of the WWDs in this thesis study are being heard.

In her book *The Rejected Body*, Susan Wendell discussed the feminist view that the world has been designed for the bodies and activities of men.⁶ She noted the implications for WWDs:

Much of the public world is...structured as though everyone were physically strong, as though all bodies were shaped the same, as though everyone could walk, hear, and see well, as though everyone could work and play at a pace that

² Katharine T. Bartlett, “Feminist Legal Methods” (1990) 103:4 Harv L Rev 829 at 837 < <https://www.jstor.org/stable/1341478>>.

³ Carol Thomas, *Female Forms: experiencing and understanding disability*, (Philadelphia: Open University Press, 1999) at 28-29. In reviewing her empirical data from WWDs, Thomas noted that “modern womanhood” was represented at different phases in the life course and was defined through formal and informal social relationships, such as girlfriend, wife, mother, grandmother or carer.

⁴ *Ibid* at 29.

⁵ *Ibid* at 68.

⁶ Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability*, (New York: Routledge, 1996) at 39.

is not compatible with any kind of illness or pain, as though no one were ever dizzy or incontinent or simply needed to sit or lie down....the entire physical and social organization of life tends to assume that we are either strong and healthy and able to do what the average young, non-disabled man can do or that we are completely unable to participate in public life.⁷

Wendell stated that much of the experience of disability and illness go underground because there is no mechanism for society to acknowledge the physical and psychological experience of disability that the five interviewees from this study have so eloquently expressed.

She concluded that the more that disability is dealt with in a private manner, the more disability it creates by failing to make the public sphere accessible to a wide range of people.⁸ One of the purposes of my thesis study is to elucidate the lived experience of WWDs as they access health care, in order to bring their issues and concerns into the broader arena.

Wendell's discussion of the need to move the private experiences of WWDs into the public, and political sphere, elicits the following slogan which originated during the women's movement of the 1960s and 1970s: *The Personal is Political*. In her essay on feminism, Tarrant⁹ stated that this slogan implies that what happens in our private lives reflects the power dynamics of the broader society. The slogan is especially relevant to the WWDs in my study, as "[i]t recognizes that seemingly personal issues point to larger, institutionalized practices and are therefore legitimately political issues."¹⁰ The interviewees provided their own personal experiences of access barriers to health care,

⁷ *Ibid.*

⁸ *Ibid* at 40.

⁹ Shira Tarrant, "Overview and Introductions: This Is What a Feminist Looks Like" in Margaret Hobbs & Carla Rice, eds, *Gender and Women's Studies in Canada: A Critical Terrain* (Toronto, ON: Women's Press, an imprint of Canadian Scholars' Press Inc. 2013) 57 at 60.

¹⁰ *Ibid.*

however these experiences really reflect the power dynamics of the health care system and of the broader society. The personal experiences of WWDs have political implications, especially in the health care arena.

In her essay on the emergence of feminist disability theory, Rosemarie Garland - Thomson proposed that the study of disability “deepens, expands and challenges feminist theory.”¹¹ In turn, the study of feminism can elucidate and acknowledge the marginalizing experiences of disability. Garland -Thomson proposed four domains of feminism which can be constructively impacted by inserting within them a discussion of disability. The domains are: “representation, the body, identity and activism.”¹² These domains will be discussed in the context of my empirical results.

Within the domain of representation, Garland -Thomson discussed the fact that disability is often used to confirm “the form and functioning of female bodies as nonnormative.”¹³ She spoke of the fact that the stereotypical views of the bodies of both women and the disabled are conflated, and consist of labels such as “dependent, incomplete, vulnerable and incompetent.”¹⁴ This nonnormative view is evident in the reports provided by my interviewees regarding the expectations and judgments that they experienced while accessing health care. It is especially reflected in the lack of equipment which is available to accommodate WWDs, such as height adjustable examination tables. Instead of providing a variety of options for a variety of forms, it is “one size fits the normative.”

¹¹ Rosemarie Garland-Thomson, “Integrating Disability, Transforming Feminist Theory” in Kim Q. Hall, ed *Feminist Disability Studies*, (Bloomington: Indiana University Press, 2011) 13 at 15.

¹² *Ibid* at 18.

¹³ *Ibid* at 19.

¹⁴ *Ibid* at 20.

The second domain discussed by Garland -Thomson is related to the unique contribution of feminist theory to the discussion of the body. In discussing imposed medicalization, she drew a comparison between women and the disabled as being viewed as “medically abnormal.”¹⁵ She critiqued the medical model from within this domain, stating that “[t]he ideology of cure directed at disabled people focuses on changing bodies imagined as abnormal and dysfunctional rather than on exclusionary attitudinal, environmental, and economic barriers.”¹⁶ While they provided no direct quotes related to this domain of the body, my interviewees’ comments regarding their experiences in the health care system clearly reflected society’s view that they are to be cured or “fixed” rather than accommodated.

Garland -Thomson’s third domain relates to identity. She stated that no woman is ever “*only* a woman,”¹⁷ as there are many identity categories that she may claim. She added that feminism has moved away from the binary male/female focus, given that there are so many “binary aspects of the category *woman* itself.”¹⁸ An extensive discussion of identity will take place later in this chapter, in section 6.3.1, in the context of the development of rights consciousness of my interviewees.

The final domain discussed by Garland -Thomson is activism. She discussed many areas in which feminist disability activism can be expressed.¹⁹ The form of activism that she discussed which is most pertinent to this thesis is “academic activism.”²⁰ Garland -Thomson described this academic activism as a means by which our communal knowledge

¹⁵ *Ibid* at 22.

¹⁶ *Ibid* at 28.

¹⁷ *Ibid* at 30.

¹⁸ *Ibid*.

¹⁹ *Ibid* at 35-39.

²⁰ *Ibid* at 40.

is shaped throughout the spectrum of the education system “from kindergarten to the university.”²¹ She stated that this shaping of knowledge culminates with a body of identity studies which is interdisciplinary, and which strives to “expose the workings of oppression, examine subject formation, and offer counter-narratives for subjugated groups,”²² including WWDs. This model is very applicable to the academic focus of this thesis. It is interesting and somewhat surprising that Garland -Thomson did not discuss activism in the context of the individual WWD or groups of WWDs. This is an important component, as activism which is led by the academy without including WWDs may inadvertently leave them behind. The topics of activism and allyship will be expanded upon in section 7.2.5.

Feminist theory need not be applied exclusively to the issues of women. Garland -Thomson stressed that “[w]e need to study disability in a feminist context to direct our highly honed critical skills toward the dual scholarly tasks of unmasking and reimagining disability, not only for people with disabilities, but for everyone.”²³ Feminist theory can offer profound insights, methods and perspectives to the study of disability,²⁴ and in turn, the voices of women with disabilities offer unique perspectives to issues that confront women and can help to find meaning in being “gendered female in an ableist and sexist society.”²⁵ Feminist theory is a relational theory that is applicable to other marginalized groups.

Unfortunately, WWDs may find themselves excluded from a movement to which they would appear to naturally belong. Fine and Asch stated that:

²¹ *Ibid.*

²² *Ibid.*

²³ *Ibid* at 16.

²⁴ *Ibid* at 13.

²⁵ Beth A. Ferri & Noël Gregg, “Women with disabilities: missing voices” (1998) 21:4 *Women’s Stud Int Forum* 429 at 430 DOI: <[https://doi.org/10.1016/S0277-5395\(98\)00038-7](https://doi.org/10.1016/S0277-5395(98)00038-7)>.

[w]omen with disabilities traditionally have been ignored not only by those concerned about disability but also by those examining women's experience. Even the feminist scholars to whom we owe great intellectual and political debts have perpetuated this neglect. The popular view of women with disabilities has been one mixed with repugnance. Perceiving disabled women as childlike, helpless, and victimized, non-disabled feminists have severed them from the sisterhood in an effort to advance more powerful, competent, and appealing female icons.²⁶

This exclusion is illustrative of the concept of intersectionality, which was raised by two of the interviewees concurrently with their statements related to gender. The experience of being female and disabled, and living within a society which devalues both, leads to a discussion of this term.

The phrase was originally introduced by African American feminist scholars to address the overlapping issues of feminism and black civil rights.²⁷ Intersectionality “references the critical insight that race, class, gender, sexuality, ethnicity, nation, ability, and age operate not as unitary, mutually exclusive entities, but as reciprocally constructing phenomena that in turn shape complex social inequalities.”²⁸

Dan Goodley stated that:

[a]s soon as disability emerges as a site of marginality then so too do Other identities. Ethnicity, class, gender, sexuality and pan-national identities converge around the problems of disability as a consequence of attempts to maintain what Campbell (2009)²⁹ terms ableist normativity. Disabled people, women, children, queer people, people of colour and poor people share an Other space to that of the dominant same founded upon ableist,

²⁶ Adrienne Asch and Michelle Fine, “Introduction: Beyond Pedestals” in Michelle Fine and Adrienne Asch, eds, *Women with Disabilities: Essays in Psychology, Culture and Politics*, (Philadelphia, 1988) 1 at 3-4.

²⁷ See generally, Kimberle Crenshaw, “Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color” (1991) 43:6 *Stanford Law Review* 1241 <www.jstor.org/stable/1229039>.

²⁸ Patricia Hill Collins, “Intersectionality’s Definitional Dilemmas” (2015) 41 *Annual Review of Sociology* 1 at 2.

²⁹ Fiona Kumari Campbell, *Contours of Ableism: The Production of Disability and Abledness* (New York, NY: Palgrave Macmillan, 2009) at 10.

heteronormative, adult white European and North American, high income nations' values.³⁰

Intersectionality is not summative; we cannot simply add areas of marginalization such as disability and gender and/or race. Rather, it is exponential. Devlin and Pothier stated that it is not helpful to conceive of intersectionality as an additive concept, “that is, race + disability + gender = discrimination (to the third degree). Rather, there is the sense of a concatenated experience that is more than the sum of its parts.”³¹ WWDs encounter many possible permutations and combinations of marginalizing experiences.

These complex interactions of experiences can be illustrated in the context of the community within which my empirical study was conducted. While no one identified as such in my study, the intersectional factors involved for WWDs who have recently immigrated is very applicable. Interviewee AB raised this issue on her own and reflected on her concerns for new Canadians who are female with a disability. They must deal with the multiple issues of gender, race, language, culture, disability and socio-economic barriers. AB remarked: “[t]hat’s a subgroup of a subgroup of a subgroup.”³² This subgroup would be an excellent focus for future study.

6.2 Ableism/Disablism

Goodley’s discussion of intersectionality includes and leads into the topic of ableism. It is important to explain how WWDs are situated within an environment of ableism as they strive to develop their rights consciousness.

³⁰ Dan Goodley, *Dis/Ability Studies: Theorising disablism and ableism*, (New York: Routledge, 2014) at 22.

³¹ Richard Devlin & Dianne Pothier, “Introduction: Toward a Critical theory of Dis-Citizenship” in Dianne Pothier and Richard Devlin, Eds, *Critical Disability Theory: Essay in Philosophy, Politics, Policy and Law* (Vancouver: UBCPress, 2006) 1 at 14.

³² AB, *supra* Chapter 5, note 6.

I propose that the dual concepts of disablism and ableism derive from the medical model of disability. The medical model, which was described in Chapter Three in the context of accessibility laws, places the locus of the “problem” within the person with the disability.³³ Disablism and ableism perpetuate this view.

It is appropriate at this point to formally define and compare disablism and ableism within the context of disability scholarship. Dan Goodley’s work supports my proposal regarding the medical model. He equated disablism with the discourse of medicalization.³⁴ He defined disablism as “the exclusion of people with sensory, physical or mental impairments from everyday life.”³⁵ He defined ableism as “...practices associated with a contemporary society that promotes the species-typical individual citizen and a whole set of values associated with this idealised individual.”³⁶

Goodley’s work was influenced by that of Fiona K. Campbell, whose definition of ableism referred to the network of values and beliefs as the corporeal standard.³⁷ As noted in Chapter Five, she described the ableist view of disability as a “diminished state of being human.”³⁸ She indicated that the two terms, disablism, and ableism, “render quite radically different understandings of the status of disability to the norm.”³⁹ She explored the ableist viewpoint, indicating that a chief feature “is a belief that impairment or disability (irrespective of ‘type’) is inherently negative and should the opportunity present itself, be ameliorated, cured or indeed eliminated.”⁴⁰ Goodley refined Campbell’s distinction

³³ Silvers *supra* Chapter 3, note 98 at 19.

³⁴ Goodley, *supra* note 30 at 5.

³⁵ *Ibid* at xiv.

³⁶ *Ibid*.

³⁷ Campbell (2001), *supra* Chapter 5, note 58.

³⁸ *Ibid*.

³⁹ Campbell (2009), *supra* note 29 at 5.

⁴⁰ *Ibid*.

between the two terms, stating that “[h]er work shifts attention away from the problems of disablism (the marginalized Other) to the problems of ableism (the same or the dominant).⁴¹ Following from these definitions of disablism and ableism, a more specific discussion of ableism in the health care system is warranted.

6.2.1 Ableism in Health Care

I have alluded to ableist attitudes within the health care system throughout this thesis, and empirical evidence of this phenomenon has emerged in the interviews of the five WWDs (“They treat everyone the same...They don’t see me. They just see the chair” – IJ).⁴² The critique of the literature also offers support for the existence of health care ableism. The sub-codes which were derived in Chapter Five within the theme of health care ableism were: pre-judgment and condescending attitude, lack of understanding of the needs of WWDs, decreased value of life of WWDs and sub-standard health care scenarios. I will structure the discussion of health care ableism according to these sub-codes, however many of the scenarios from the literature, as well as my empirical evidence, support the interplay of many of these sub-codes.

The following studies support the existence of ableist attitudes among health care professionals. Geskie and Salasek described the view of health care workers towards PWDs as follows:

The attitudes held by a variety of treatment personnel toward different disability populations vary but are consistently less positive than expected. Education, type and extent of contact, and authoritarian belief systems seem to be variables involved with these findings.⁴³

⁴¹ Goodley, *supra* note 30 at 22.

⁴² IJ, *supra* Chapter 5, note 2.

⁴³ Mary Anne Geskie & James L. Salasek, “Attitudes of Health Care Personnel Toward Persons with Disabilities” in Harold E. Yuker, ed, *Attitudes Toward Persons with Disabilities*, (New York: Springer Publishing Company, Inc.,1988) 187 at 193.

They also referred to a study by Bell,⁴⁴ who found that the attitudes of rehabilitation staff working with patients did not differ significantly from the general hospital staff. Bell attributed this somewhat surprising finding to the fact that equal-status contact is required for positive attitude formation and surmised that the rehabilitation setting does not lend itself to such a relationship.⁴⁵ This is a sad testament to the nature of the rehabilitation environment.

The interviewees from my study commented on a condescending, paternalistic attitude among society at large, and especially among health professionals. Hahn summarized the issue of paternalism towards disabled individuals:

Paternalism enables the dominant elements of a society to express profound and sincere sympathy for the members of a minority group while, at the same time, keeping them in a position of social and economic subordination. It has allowed the nondisabled to act as the protectors, guides, leaders, role models, and intermediates for disabled individuals who, like children, are often assumed to be helpless, dependent, asexual, economically unproductive, physically limited, emotionally immature, and acceptable only when they are unobtrusive.⁴⁶

David L. Hosking expanded on the topic of paternalism using the metaphor of the voice: “When the disabled voice says what the able-bodied perspective wants to hear, it is heard; when it says something the able-bodied perspective does not want to hear, it can simply be dismissed as the inappropriate response of a person who has developed an unhealthy response to the impairment.”⁴⁷ This speaks to IJ’s experience, in which she

⁴⁴ A. Howard Bell, “Attitudes of Selected Rehabilitation Workers and other Hospital Employees Toward the Physically Disabled” (1962) 10 *Psychological Reports* 183-186.

⁴⁵ Geskie & Salasek *supra* note 43 at 192.

⁴⁶ Harlan Hahn, “Public support for rehabilitation programmes: The analysis of U.S. disability policy” (1986) 1:2 *Disability, Handicap & Society* 121 at 130.

⁴⁷ David L. Hosking, “Critical Disability Theory” (2008) 1 at 1, online (pdf): *CeDR Disability Studies Conferences Archive*.

expressed her dissatisfaction with the manner in which she was being treated by a health care professional, only to be told, in a condescending manner: “It’s O.K. dear.”⁴⁸

On the topic of stereotyping, Frazee et al reported on the results of a focus group on sexuality, reproduction and family, which “highlighted stereotypical assumptions about the needs and desires of women with disabilities that pervade the assessments of health-care providers and structures their interactions.”⁴⁹ The critical disability studies literature has documented some of these assumptions, including the commonly held, but erroneous notion that WWDs are asexual.⁵⁰

Carol Thomas’ work supported evidence of negative attitudes and stereotypes held by health and social care professionals and workers towards people with disabilities, and she stated that the impact of such attitudes could have “...profoundly exclusionary consequences by working on their sense of personhood and self-esteem.”⁵¹

The stereotypical views of WWDs espoused by health care professionals, and the lack of understanding of the needs of WWDs, are illustrated in a study of physicians’ perceptions of access barriers to reproductive health promotion for WWDs.⁵² Joseph,

⁴⁸ IJ, *supra* Chapter 5, note 2.

⁴⁹ Catherine Frazee, Joan Gilmour & Roxanne Mykitiuk, “Now You See Her, Now You Don’t: How Law Shapes Disabled Women’s Experience of Exposure, Surveillance, and Assessment in the Clinical Encounter” in Dianne Pothier & Richard Devlin, eds, *Critical Disability Theory*, (Vancouver, BC: UBC Press, 2006) 223 at 229.

⁵⁰ Meera Joseph, Sujen Saravanabavan & Jeff Nisker, “Physicians’ Perceptions of Barriers to Equal Access to Reproductive Health Promotion for Women with Mobility Impairment” (2018) 7:1 CJDS 62 at 64. The authors noted that the critical disability studies literature has also identified physicians’ attitudinal barriers, including the presumption among many physicians that disabled women are asexual (Basson, 1998; Becker et al., 1997; Gibson & Mykitiuk, 2012; Kroll et al., 2006; Nosek et al., 1995; Whelner, 1997), those who are single are celibate (Basson, 1998; Kallianes & Rubenfeld, 1997; Shakespeare, 2000), and disabled women cannot be mothers (Basson, 1998; Kallianes & Rubenfeld, 1997; Nosek et al., 1995), even though it is extremely rare for a disability to hinder a woman’s reproductive development or diminish her feelings of sexuality (Basson, 1998; Gibson & Mykitiuk, 2012).

⁵¹ Thomas, *supra* note 3 at 47-48.

⁵² Joseph, Saravanabavan & Nisker, *supra* note 50 at 62.

Saravanabavan and Nisker identified barriers to equal access to reproductive health promotion and sought:

[t]o interview physicians to investigate their perceptions as to why these barriers still exist, how these barriers can be dissolved, and what physicians are doing to ensure accommodation for women with mobility impairment to receive equal access to reproductive health promotion.⁵³

I will highlight several illuminating quotes from some of the physicians who were interviewed. These quotes exemplify the concerns expressed by some of my interviewees surrounding a lack of understanding of the needs of WWDs, in addition to stereotypical attitudes.

In discussing the additional time required when meeting with a female patient with a mobility impairment, one physician stated: “I think they should feel fortunate that there are people out there willing to spend more time ... They should consider themselves lucky, I think. And fortunate...”⁵⁴ The researchers later used this, and similar quotes as examples of the way in which “research participants in this study were unaware of their legal duty to provide women with mobility impairment the same high quality of reproductive care as they provide their other patients so as their care would be non-discriminatory under human rights codes.”⁵⁵ I would extend this hypothesis to suggest that, beyond a lack of awareness of the rights of WWDs, the physicians did not view the WWDs as deserving of the same standard of care as a woman without a disability. This aligns with the sub-code from my empirical data related to sub-standard health care scenarios.

Some of the physicians interviewed by Joseph, Saravanabavan and Nisker spoke of insufficient remuneration for additional time spent with more “difficult” patients. The term

⁵³ *Ibid* at 64.

⁵⁴ *Ibid* at 70.

⁵⁵ *Ibid* at 82.

“difficult” provides insight into the attitude that some of the physicians held towards WWDs. The connotation is that WWDs require additional work with no added benefit or return. The physicians indicated that they spent the time out of a sense of “duty,” or out of the “goodness of their hearts.” One physician elaborated on this issue, stating: “you’re spending so much time but then there’s no compensation. ...there’s nothing to encourage or to pay you for the efforts you have done, except your own conscience that you’ve done something good. You’ve done your duty...”⁵⁶

A solution promoted by some of the physicians who were interviewed in Joseph, Saravanabavan and Nisker’s study, was the implementation of increased remuneration for seeing patients with “mobility impairment.”⁵⁷ It seems that the medical system in Ontario, where this study was conducted, is set up to reward physicians for seeing patients who are quick to serve, and not “difficult,” as labeled by the physicians. We can refer back to a study by McColl, Jarzynowska and Shortt from the literature review in Chapter Two, in which they stated: “[o]ne can only conclude that the system appears to be geared to best serve those who are the easiest to serve.”⁵⁸

While we may be inclined to judge the physician interviewees in the above study for what appear to be ableist attitudes, it is important to note that their comments are situated within the training (or lack thereof) that they received regarding the needs of WWDs, and a within a systemic reimbursement environment that can severely limit the time and resources available to health care professionals.

⁵⁶ *Ibid.*

⁵⁷ *Ibid* at 79.

⁵⁸ McColl, Jarzynowska & Shortt, *supra* Chapter 2, note 19 at 206.

Further to this point, one physician reflected on some of the same concerns expressed by the WWDs interviewed in my study, citing the lack of support personnel to assist with clothing changes, and with lifting on and off of the examination table.⁵⁹ The physicians did also acknowledge their own lack of training regarding the needs of WWDs,⁶⁰ and suggested the establishment of specialized clinics, such as the one described in this thesis, at HDGH.⁶¹ These comments from the literature are supported by data from my study: interviewee IJ also suggested increasing the prevalence of accessible clinics, as well as educating health care professionals on the needs of WWDs.

My discipline of occupational therapy has also been critiqued in relation to health care ableism. In his 1995 article, Paul Abberley concluded that “OT, despite what may be the best of intentions on the part of its practitioners, serves to perpetuate the process of disablement of impaired people.”⁶² He commented on the dynamics of the relationship between the OT and PWDs, and suggested that “to justify the occupation’s continued existence, a counterbalancing rhetoric of expertise, which serves to ensure the separation of practitioner and client is required.”⁶³ The occupational therapy academy responded to this argument in 2005, a decade later. In his guest editorial for a special issue on disability studies in the American Journal of Occupational Therapy, Gary Kielhofner acknowledged the criticism directed at occupational therapy and discussed two unintended consequences of the medically based rehabilitation approach: negative impact on disability identity and

⁵⁹ Joseph, Saravanabavan & Nisker, *supra* note 50 at 71.

⁶⁰ *Ibid* at 80-81.

⁶¹ *Ibid* at 81.

⁶² Paul Abberley, “Disabling Ideology in Health and Welfare - the case of occupational therapy” (1995) 10:2 Disability and Society 221 at 222.

⁶³ *Ibid* at 225.

reinforcement of social oppression.⁶⁴ He suggested as a solution that the field of occupational therapy should incorporate disability studies concepts into theory and practice.⁶⁵

In a discussion of ableism and the value of life, Carol J. Gill outlined the inaccurate and negative attitudes that many health professionals hold toward life with disability, in a thought-provoking discussion of the decision-making power that these professionals can wield in relation to the issue of disability and medical assistance in dying. She commented on the misperceptions held by many in the health field, stating that “health professionals significantly underestimate the quality of life of persons with disabilities compared with the actual assessments made by people with disabilities themselves.”⁶⁶

In fact, the literature reveals that many people with disabilities have found their lives to be satisfying and rewarding, far beyond the expectations of the health and rehabilitation professions.⁶⁷ Adrienne Asch discussed the commonalities in the human condition between PWDs and non-disabled people, stating: “[w]hen people with disabilities report unhappiness or dissatisfaction (a minority in every study), the sources resemble sources of unhappiness in the lives of nondisabled people - inadequacies in financial security, work, or social and personal relationships.”⁶⁸

Further related to the issue of the value of life, interviewee IJ from my study described the experience of attending the emergency room and being expected to sit for

⁶⁴ Gary Kielhofner, “Rethinking Disability and What to Do About It: Disability Studies and Its Implications for Occupational Therapy” (2005) 59:5 AJOT 487 at 489-491.

⁶⁵ *Ibid* at 494.

⁶⁶ Carol J Gill, “Health Professionals, Disability, and Assisted Suicide: An Examination of Relevant Empirical Evidence and Reply to Batavia (2000)” (2000) 6:2 Psychology, Public Policy, and Law 526 at 530.

⁶⁷ Adrienne Asch, “Disability, Bioethics, and Human Rights” in Albrecht, Seelman & Bury, eds, *Handbook of Disability Studies*, (Thousand Oaks, CA: Sage Publications, Inc., 2001) 297 at 301.

⁶⁸ *Ibid*.

many hours waiting to be seen. She stated that she felt that she was valued less in this context because she is a WWD and was thus considered a lower priority. AB's comment that becoming part of the world of disability is a "parallel universe,"⁶⁹ speaks of the "otherness" of being a WWD. Susan Wendell spoke of this "otherness:"

When we make people "other," we group them together as the objects of our experience instead of regarding them as fellow subjects of experience with whom we might identify. If you are "other" to me, I see you primarily as symbolic of something else-usually, but not always, something I reject and fear and that I project onto you. We can all do this to each other, but very often the process is not symmetrical, because one group of people may have more power to call itself the paradigm of humanity and to make the world suit its own needs and validate its own experiences.⁷⁰

We can equate AB's term, "parallel universe"⁷¹ as being outside of the paradigm of humanity, to which Wendell referred. AB's reference to other peoples' comments such as "I couldn't live like that"⁷² speaks to the fear that non-disabled people experience when they are faced with the fact that they too, will likely experience disability at some point in their lives. Exploring the unifying experience of aging, Wendell stated: "Aging is disabling. Recognizing this helps us to see that disabled people are not 'other,' that they are really 'us.' Unless we die suddenly, we are all disabled eventually."⁷³

The concept of "us," rather than "other," as a means of affirming the dignity and value of all individuals is reflected in the work of other scholars. Garland - Thomson described disability as "...perhaps the most universal of human experiences."⁷⁴ Yet, the view that a life with a disability is a life not worth living prevails within our society, and

⁶⁹ AB, *supra* Chapter 5, note 6.

⁷⁰ Susan Wendell, "Toward a feminist theory of disability" (1989) 4:2 *Hypatia: A Journal of Feminist Philosophy* 104 at 116 <www.jstor.org/stable/3809809>.

⁷¹ AB, *supra* Chapter 5, note 6.

⁷² *Ibid.*

⁷³ Wendell, *supra* note 70 at 108.

⁷⁴ Rosemarie Garland-Thomson, "Feminist Disability Studies" (2005) 30:2 *Signs: Journal of Women in Culture and Society* 1557 at 1568 <www.jstor.org/stable/10.1086/423352>.

within the fields of medicine and bioethics. Adrienne Asch remarked that scholars and activists in disability are compelled to “...assert that the first right of people with disabilities is a claim to life itself, along with the social recognition of the value and validity of the life of someone with a disability.”⁷⁵

Finally, in a review of health barriers among people with disabilities in developing countries, Judith Baart & Florence Taaka noted that “[s]tigmatization and marginalization are significant barriers in accessing health care services. In particular, these are largely imbedded in negative family and community attitudes towards people with disabilities...”⁷⁶ Ableism appears to be an attitude which is entrenched in society both locally and internationally. It is also clear that ableism is “alive and imbedded” within the health care system. As interviewee AB put it: “It’s sprinkled through society.”⁷⁷

6.2.2 Internalized Ableism

Up to this point, the discussion of ableism has centered around the attitudes, policies and power structures held by societal institutions and the power-wielding individuals operating within those institutions; notably the health care system. Fiona K. Campbell used critical race theory in developing her concept of internalized ableism.⁷⁸ She discussed the consequences of having a self-image influenced by ableism, stating that “[i]nstead of embracing disability at the level of beingness (i.e. as an intrinsic part of the person’s Self), the processes of ableism, like those of racism, induce an internalisation or self-loathing

⁷⁵ Asch, *supra* note 67 at 301.

⁷⁶ Judith Baart & Florence Taaka, “Barriers to Healthcare Services for People with Disabilities in Developing Countries: A Literature Review” (2017) 28:4 Disability, CBR & Inclusive Development 26 at 33 doi:<https://doi.org/10.5463/dcid.v28i4.656>.

⁷⁷ AB, *supra* Chapter 5, note 6.

⁷⁸ See, generally Fiona A. Kumari Campbell, “Exploring internalized ableism using critical race theory” (2008) 23:2 Disabil Soc 151.

which devalues disablement.”⁷⁹ She discussed the pre-conditions for this state of devaluation, adding that “[f]or internalised ableism to occur there needs to be an existing a priori presumption of compulsory ableness.”⁸⁰ This compulsory ableness is very much ingrained in the fabric of our society, and is reflected in the multitude of physical, psychological, social and attitudinal barriers which hinder or block the full participation and inclusion of WWDs. The concept of internalized ableism may have an impact on the development of the WWD’s identity and rights consciousness. This key theme which arose from my empirical research will be discussed next.

6.3 Rights Consciousness

The above discussion related to the ableist health care environment and internalized ableism was instructive in setting the context within which WWDs must seek health care services, deal with encountered barriers, and understand and exercise their rights. As noted, rights consciousness emerged as a culminating theme from my empirical study, noted as a marked spontaneous response by some of the interviewees to the discussion of rights, legislation and lodging of complaints. The discursive process appeared to spark self-reflection on the part of some of the interviewees, indicative of the existence or emergence of rights consciousness. Some scholars use the term legal consciousness. For the purpose of this thesis, I will use the terms rights consciousness and legal consciousness synonymously.

Consciousness of rights, from the view of US civil rights studies, “is defined as the extent to which rights holders understand the law, gain access to lawyers and legal

⁷⁹ Campbell (2009), *supra* note 29 at 20.

⁸⁰ *Ibid* at 25.

institutions, and weigh the costs and benefits of legal action.⁸¹ But, there is a more nuanced definition that we may apply to WWDs:

Individual rights consciousness derives from the intersections of a person's life experience with the particular interpretive frameworks that are available in the social environment. The relevance or irrelevance of rights depends in large part on how individuals come to understand their own identities and on the stories they and others tell to make sense of their lives.⁸²

Thus, by this definition, rights consciousness is context specific, and related to the understanding and development of one's identity.

Ewick and Silbey used the term legal consciousness and defined it as "part of a reciprocal process in which the meanings given by individuals to their world become patterned, stabilized, and objectified. These meanings, once institutionalized, become part of the material and discursive systems that limit and constrain future meaning making."⁸³ In essence, Ewick and Silbey were saying that people's experience and interpretation of the law cannot be separated from their social experience; the law is socially constructed.⁸⁴

The understanding of one's identity is noted to be an important component in the development of rights consciousness. The interplay between identity and rights consciousness will be expanded upon.

6.3.1 Rights Consciousness and Identity Development

Formation of personal identity appears to be a strong factor for WWDs in framing the experience of disability and their sense of rights. Fiona Kumari Campbell described this identity development, stating that "[t]he experience of impairment within an ableist

⁸¹ David M. Engel & Frank W. Munger, *Rights of Inclusion: Law and Identity in the Life Stories of Americans with Disabilities*, (Chicago: The University of Chicago Press, 2003) at 40.

⁸² David M. Engel, "Vertical and Horizontal Perspectives on Rights Consciousness" (2012) 19:2 *Indiana Journal of Global Legal Studies* 423 at 427 < <https://www.jstor.org/stable/10.2979/indjglolegstu.19.2.423>>.

⁸³ Patricia Ewick & Susan S. Silbey, *The Common Place of Law*, (Chicago: The University of Chicago Press, 1998) at 39.

⁸⁴ *Ibid* at 33-38.

context can and *does* [affect] the formation of self – in other words ‘disability is me’, but that ‘me’ does not need to be imbued with a negative sense of self-ness.”⁸⁵ In her work on internalized ableism and critical race theory, Campbell pointed out that: “Unlike other minority groups, disabled people have had fewer opportunities to develop a collective consciousness, identity or culture, let alone interrogate cultures of ableism.”⁸⁶ Campbell spoke of the importance of a collective consciousness or identity, but the development of an individual identity is also critical to WWDs in understanding and addressing their rights within this ableist culture.

A discussion of rights consciousness and identity development will assist in exploring and answering my research question: *How do Women with Disabilities Understand and Address Systemic Barriers to Preventative Community Health Services?*

To begin, some key studies will be critiqued related to the development of identity by individuals with disabilities.

Anjali J. Forber-Pratt and Marianne P. Zape conducted a qualitative study in 2017 with the goal of exploring the disability identity development of college students with disabilities.⁸⁷ They developed a model of identity development which included four statuses through which individuals purportedly transition: Acceptance, Relationship, Adoption and Engagement.⁸⁸ The authors provided some instructive comments to health professionals, noting that “[h]ealthcare community members should pay attention to these developmental statuses to recognize that not every individual with a disability may have

⁸⁵ Campbell (2009), *supra* note 29 at 27.

⁸⁶ Campbell, (2008), *supra* note 78 at 155.

⁸⁷ Anjali J. Forber-Pratt & Marianne P. Zape, “Disability identity development model: Voices from the ADA-generation” (2017) 10 Disability and Health Journal 350 at 350.

⁸⁸ *Ibid.*

come to terms with or accepted their disability.”⁸⁹ The authors’ statement related to “acceptance” and “coming to terms with disability” does not resonate well with the theme of this thesis, in which the ableist notion that disability is a tragedy that demands “acceptance” is actively refuted. Nevertheless, this model of identity development warrants consideration for future research.

In a related study, Anjali J. Forber-Pratt et al conducted a systematic review of the literature in order to synthesize existing empirical research on disability identity development.⁹⁰ They commented on the challenges involved, noting that “[d]isability can occur at any point in one’s life span, thus making it difficult for researchers to establish a consensus model of disability development.”⁹¹ The authors compiled an impressive list of studies and models of disability identity development.⁹²

In his thesis work, Doron Dorfman used qualitative research methods to explore how the perception of self affects claimants’ experiences with the disability determination process in the United States.⁹³ Dorfman developed the “Disability Identity Spectrum” which ranged from identification with the medical & individual models of disability, to identification with the social model. Moving within this range from medical to social, were a series of identity categories: normalization, crusadership, resignation, situational identification, quasi-normalization and affirmation.⁹⁴ The concept of a spectrum of development is intriguing – it reflects the fact that there may be unique differences in

⁸⁹ *Ibid* at 354.

⁹⁰ Anjali J. Forber-Pratt et al, “Disability Identity Development: A Systematic Review of the Literature” (2017) 62:2 *Rehabilitation Psychology* 198 at 198.

⁹¹ *Ibid* at 199.

⁹² *Ibid* at 201 – 203.

⁹³ Doron Dorfman, *Conflicts Between Private and State Disability Identities – Bay Area Subjects’ Procedural Justice Perceptions of the Disability Determination Process* (Master of the Science of Law Thesis, Stanford University, 2014) [unpublished].

⁹⁴ *Ibid*.

identity development both within individuals and among groups of PWDs. In a later published work, Dorfman elaborated on his initial findings,⁹⁵ and he noted that research in the area of identity development for PWD has implications for creation of better policies, and for better communication between the state and marginalized groups.⁹⁶

David M. Engel and Frank W. Munger took yet another approach to identity development in their research on the life stories of individuals with disabilities.⁹⁷ Their findings illuminated the development of legal, or rights consciousness, in the context of the individuals' environment (personal, social and legal), their personal supports, and their own perception of themselves as persons with a disability.

In their study, they chose to frame legal consciousness through the life stories of their interviewees. Based in the United States, their goal was to chronicle the impact of the ADA⁹⁸, and to find out “what rights actually did and how they mattered, or did not matter, to their intended beneficiaries.”⁹⁹ They developed an ethnographic study, in which they conducted lengthy, in-depth interviews and follow-up interviews with sixty interviewees. They selected eight of the sixty interviewees for a repeat interview, six of which they completed and included in their book.¹⁰⁰ Their focus was to explore the relationship between identity and employment rights. While the employment context deviates from the focus of this thesis; access to health care, the results of their study were illustrative, and applicable across categories of human endeavour.

⁹⁵ Doran Dorfman, “Re-Claiming Disability: Identity, Procedural Justice, and the Disability Determination Process” (2017) 42:1 Law & Social Inquiry 195 at 195.

⁹⁶ *Ibid.*

⁹⁷ See generally, Engel & Munger, *supra* note 81.

⁹⁸ See ADA, *supra* Chapter 2, note 102.

⁹⁹ Engel & Munger, *supra* note 81 at ix.

¹⁰⁰ *Ibid* at 7-9.

Engel and Munger asserted a profound statement regarding the relationship between identity and rights:

The issue of who one is and where one belongs precedes the issue of the rights one might choose to assert. Viewed from this perspective, law is often of secondary importance to those it is supposed to help and is at times an irrelevancy. The more fundamental question is how and when individuals view themselves as inappropriately situated in the social framework, as excluded from activities in which they should take part, as unfairly separated from mainstream settings by barriers that have been improperly constructed or placed. The perception of boundaries wrongly marked is inseparable from the sense of self. The perception that exclusion is appropriate or inappropriate, indeed the *awareness* that exclusion has occurred, hinges on the way in which individuals and those around them define their identity.¹⁰¹

To summarize, the authors were stating that a PWD must first establish identity before the experience of exclusion and infringement of rights can even be recognized. They framed identity development from a socio-legal versus a medical perspective. Interestingly, Engel and Munger did not refer to a “disability identity.” While they acknowledged that the experience of disability is important in identity development, they simply used the term “identity,” when discussing PWDs. This approach to identity more closely aligns with the focus of this thesis.

Engel and Munger discussed the importance for PWDs to narrate a forward-looking life story in order to differentiate their disability from their sense of self. Those individuals that they interviewed who were able to achieve this, developed a concept that “...*the disability was not the self*, although it was a part of their life experience that sometimes had great importance.”¹⁰² Further, they stated that “the capacity to distinguish disability from self can be a key to opening a space in which rights might become active.”¹⁰³

¹⁰¹ *Ibid* at 40.

¹⁰² *Ibid* at 46.

¹⁰³ *Ibid*.

I will illustrate, using a hypothetical scenario from my study within the health care context: If a WWD perceives her core identity to be that of a disabled person, she may be less likely to view any barriers to health care access as unfair treatment; rather, they may be viewed to simply be a part of the experience of being disabled. On the other hand, if the WWD has a self-image which incorporates many abilities and traits; with disability being just one of them, she may be more likely to view exclusion as unfair, and to see that a rights boundary has been breached. She may then decide to take steps to remedy the injustice.

Engel and Munger explained the implications for PWDs who recognize social boundaries that are exclusionary, stating that “[i]dentity connects directly to a sense of justice, for the unfairness of exclusion is apparent only to the person who assumes that inclusion is her natural and expected status.”¹⁰⁴ It is important, however, not to view the status of a WWD’s self-identity at any point in time through a lens of judgment. Many factors may contribute towards or negate the development of identity. They include the influence of family, religion, community, education, class, race and gender. Engel and Munger stated that all these factors contribute to “the stories of the self in which rights play a more or less prominent role.”¹⁰⁵

Malhotra and Rowe built upon the work of Engel and Munger by interviewing twelve Canadian post-secondary students with mobility impairments, using grounded theory methodology.¹⁰⁶ Through their exploration and analysis of the narratives obtained through these interviews, they arrived at a theme of advocacy identity, and “illustrate[d]

¹⁰⁴ *Ibid* at 68-69.

¹⁰⁵ *Ibid* at 142 and 177-178.

¹⁰⁶ Ravi Malhotra & Morgan Rowe, *Exploring Disability Identity and Disability Rights Through Narratives: Finding a Voice of Their Own* (New York, NY: Routledge, 2013) at 33.

the systemic barriers in education, employment and transportation that remain prevalent in Canadian Society.”¹⁰⁷

The type of identity work conducted by Engel and Munger, and Malhotra and Rowe has been especially instructive for the analysis of the empirical results from my own study, given the reflective nature of the interview process involved in their studies, the socio-legal lens, and the implications for rights consciousness. In the next section, I will propose a concept of identity based on the themes from my data that were outlined in Chapter Five.

6.3.2 Rights Consciousness - Stages of Identity

The five interviewees in my study appear to have been at different stages on their own journey of understanding as to who they are and how they assert their rights within societal institutions.

How might we characterize “identity” in the context of the WWDs seeking health care who were interviewed in my study? My research design was not structured to gather detailed “stories of the self” from the five interviewees, however the rich data derived from the iterative process surrounding discussion of legislation and rights yielded useful information to begin to generate a theory of identity formation as related to rights consciousness.

I propose three stages, based on what has been discussed thus far in the literature, and considering the empirical data provided from the five interviewees in this study. The first would be termed an imposed identity, the second, an emerging, or formative identity, and the third, an integrated identity.

¹⁰⁷ *Ibid* at 182.

1. Imposed Identity

I use the term “imposed” for this stage of identity, based on the sometimes unavoidable and externally imposed influence that societal ableism appears to have on the identity development of WWDs. While they did not speak directly to the impact of ableism on their identity, the interviewees discussed how barriers and ableist attitudes made them feel (anger, embarrassment, humiliation). Ableism clearly impacts the identity of WWDs in a negative manner.

Individuals at this stage of identity development would equate themselves with an externally imposed identity consisting of the ableist societal implications and expectations that are placed upon them by virtue of their disability. A WWD with an imposed identity would likely not recognize that she has been inappropriately excluded from mainstream settings by barriers that have been improperly constructed or placed.¹⁰⁸ There would likely be no awareness that exclusion has occurred, or, if the awareness exists, it would be accepted by the WWD as part of the experience of being disabled, as it is externally defined. None of the interviewees from my study appeared to be located at this stage.

2. Formative Identity

Most of the interviewees in my study appeared to be working from within what I define as a formative identity. At this stage, individuals are questioning, and self-reflective of their identity. At this stage, they may or may not identify completely with their disability, however disability is only one component of their formative identity. Other components of identity that they may consider would include relationships, educational or vocational status, and other life roles.

¹⁰⁸ Engel & Munger, *supra* note 81 at 40.

At this stage, WWDs may demonstrate increasing interest in, or awareness of their rights, and of the legal instruments, and resources available to them within their community. The theme of acceptance of barriers expressed by some interviewees as noted in my data may be reflective of the fact that there is not yet full awareness that boundaries have been wrongly marked, and that an infringement of rights has occurred.¹⁰⁹ They may not be fully aware of being inappropriately placed or excluded from their social framework, but specific circumstances with strong emotional or other consequences may lead them to reflect more fully and thus recognize that their rights have been breached. A WWD at this stage may or may not invoke a formal legal claim. If she chooses to do so, she may be ambivalent due to the fluidity of her identity at this stage, and she may require the support of a family member, friend, or ally.

3. Integrated Identity

It could be suggested that an integrated identity is something to which every human being aspires. For the purpose of this thesis as related to WWDs, an integrated identity would involve the cohesive inclusion of disability among many other variables, creating a base from which one can assess objectively whether or not one has been inappropriately excluded from the mainstream. As noted earlier, Engel and Munger discussed the importance of the ability to differentiate disability from the sense of self, and in so doing, to create a space in which rights become active.¹¹⁰ Within this model of identity development, I do not ascribe to their view that disability must be differentiated from the self. One interviewee from my study who appeared to express the strongest awareness of her rights and her identity, also appeared comfortable in defining herself, at least in part,

¹⁰⁹ *Ibid.*

¹¹⁰ *Ibid* at 46.

through the lens of her disability. Thus, the term “integrated” is well-suited to this stage of identity development. The different parts of the WWD’s identity, including her disability, are not aggregated, but integrated, permitting the “forward-looking life story.”¹¹¹ A WWD at this stage of identity development would be most likely to recognize that she has been inappropriately excluded from a social setting or service to which she is legally entitled, and would require less support than WWDs in other stages, however she still may choose not to invoke a formal legal claim. Reasons for this will be discussed in the summary of this chapter.

The model is presented below, in Table 2.

MODEL OF RIGHTS CONSCIOUSNESS – STAGES OF IDENTITY	
IMPOSED IDENTITY	<ul style="list-style-type: none"> • Externally defined • Influence of ableism • No recognition of exclusion • Unlikely to lodge formal legal claim
FORMATIVE IDENTITY	<ul style="list-style-type: none"> • Questioning • Self-reflective • Increased interest in and awareness of rights • Variable recognition of exclusion • May or may not lodge formal legal claim, if so, with support
INTEGRATED IDENTITY	<ul style="list-style-type: none"> • Cohesive inclusion of disability into multi-faceted identity • Able to recognize exclusion • May or may not lodge formal legal claim, if so, less likely to need support

Table 2

WWDs may transition through each stage and back again, depending on circumstances and events in their life. Some may never enter into one or more of the particular stages. For some, this model may not be applicable.

¹¹¹ *Ibid.*

This model of identity development for WWDs is based on the results of grounded theory, informed by literature review and the empirical data from this study. In developing the model, I did use inference to develop some areas, such as required level of support to lodge a complaint and recognition of exclusion. While preliminary, this model provides a fascinating forum for further research using a larger representative sample. It would be important to explore the multitude of factors affecting identity development as it relates to rights consciousness, creating possibilities for expanded categories and stages of development.

6.4 Summary

In this chapter, an overview of the feminist theoretical framework was presented in order to set the background regarding the gendered experience within which my interviewees are situated. In addition, the proposed phenomenon of health care ableism was explored, and its existence confirmed via literature review and empirical data. The influence of health care ableism is an important factor in the development of identity of WWDs as they seek to deal with health care barriers.

As a culmination of my analysis, rights consciousness was explored and identified as a major determining factor in the way in which a WWD interacts within the health care environment. A preliminary model of the stages of identity development of WWDs was proposed. Based on this framework, it appears that the stage of identity development as related to rights consciousness has a direct bearing on WWDs' recognition of exclusion and rights infringement, as well as their decision and degree of support required to act upon it.

In concluding their work, Engel and Munger discussed the fact that “rights do not typically have a direct, legally empowering effect on their intended beneficiaries.”¹¹² Following from this statement, I admit that my initial reaction to the realization that none of the five interviewees from my study had sought recourse to address blatant health care barriers, was one of dismay. I interpreted this to mean that, in some way, the legal system and the web of human rights and accessibility laws are too obtuse, too difficult to navigate, and out of reach for most WWDs. While my assumption may have some merit, Engel and Munger add a very different perspective. Remarkably, all sixty of their interviewees had experienced discrimination, but none of them went forward with a formal legal complaint. Engel and Munger explained this by rejecting the assumption that the only way that rights become active is when they are invoked in formal legal proceedings.¹¹³ They stated that the formal qualities of rights, the “doctrinal features that occupy the attention of most judges and academic writers,” made little difference to the subjects that they interviewed in their study.

To summarize in the context of this study, WWDs may choose not to formally invoke their rights, but the factors related to their decision to do so or not, are reflected in the proposed model of identity development and rights consciousness.

At the beginning of this chapter, I indicated that the culminating theme of rights consciousness would assist in answering my research question:

How do Women with Disabilities Understand and Address Systemic Barriers to Preventative Community Health Services?

¹¹² *Ibid* at 79.

¹¹³ *Ibid* at 90.

Based on analysis of the empirical data and exploration of additional literature sources, I must propose a revision to the above research question:

How do Women with Disabilities Understand and Address their Rights to Health Care within an Ableist Context of Systemic Barriers to Access?

In formulating my research topic, I assumed that the task of WWDs is to address the barriers that they face in seeking health care. While exploration of barriers during the interview process was fascinating and enlightening, it became apparent that the issue at stake for WWDs in their negotiation of access to health care lies in their concept of rights consciousness. It is their relationship to their rights that is at issue, not their relationship to the barriers.

Through my proposed model of identity development, we may now better understand how WWDs may perceive exclusion, or denial of rights, if at all, how they may act upon it, and with how much external support. Further research in this area is warranted, as a greater understanding of rights consciousness and identity development of WWDs will assist in understanding how WWDs might become empowered to attain the health care services to which they are entitled by law.

CHAPTER 7

SUMMARY AND RECOMMENDATIONS

7.1 Summary

In this thesis, I outlined through a review of the literature, a multitude of barriers that WWDs face as they attempt to access preventative health care services. I also reviewed the applicable human rights and accessibility legislation in Canada and provided some comparative legislation from other jurisdictions. Despite a paucity of applicable Ontario and Canadian cases related to health care access, a few key cases were outlined. This overview set the legal landscape within which women with disabilities must exercise their rights to health care.

I provided a description of my empirical research project, in which five women with disabilities were interviewed following a barrier-free cancer screening clinic day at HDGH. The data from the interviews was coded and categorized according to themes, per the grounded theory method. The barriers noted in the literature review were supported by my empirical data.

To situate the data analysis, a feminist theoretical framework was presented and explored as a means to locate my interviewees' gendered encounter within the health care system. Among several themes which arose from the data, it was determined that the themes of health care ableism and rights consciousness of WWDs were most responsive to my research question. I conducted a review of these key themes.

The title of this thesis implies an ableist health care environment. Through the analysis of ableist themes brought forward by my interviewees, and through the exploration of emerging literature, the existence of ableism among health care providers has been

clearly demonstrated. This revelation has been reached with chagrin on my part, given my lengthy career as an occupational therapist.

Rights consciousness of WWDs emerged as a culmination of my analysis, suggesting that it is the relationship between WWDs and their rights consciousness and identity development that is paramount in their interaction with the health care system. Identity development of WWDs was discussed as an integral component of rights consciousness, and a model consisting of three stages of identity development/expression was outlined: Imposed Identity, Formative Identity and Integrated Identity.

Did the results of this thesis project respond to, and satisfy the research question?

As noted in Chapter Six, it was necessary for me to adjust the lens through which I viewed and understood my research question, to reflect that fact that it is the interplay of WWDs with their rights that is key, not the interplay with the barriers that they encounter.

It is clear that rights consciousness is in play for WWDs, even if they choose not to lodge a formal legal complaint. Engel and Munger's assertion of the constitutive influence of law "even when its formal institutions and procedures are not set in motion,"¹ provides me with a very different lens through which to view the impact of law and rights legislation on the lives of WWDs – one of hope.

7.2 Recommendations

While hope is an important tool in our arsenal as we battle serious systemic issues and concerns, hope alone cannot solve the problem of persistent barriers to health care for WWDs. These barriers, aside from being demoralizing and "soul-crushing,"² can result in

¹ Engel & Munger, *supra* Chapter 6, note 81 at 93.

² See generally, The Honourable David C. Onley, *Listening to Ontarians with Disabilities: Report of the Third Review of the Accessibility for Ontarians with Disabilities Act, 2005*, January 2019, 1, online: *Queen's Printer Ontario, 2012-19* < www.ontario.ca/page/2019-legislative-review-accessibility-ontarians-

delayed diagnosis and additional hardship and health consequences for WWDs. These barriers continue to exist in Ontario, despite the passage of the AODA in 2005.

I propose the following areas to which future dialogue and research can be directed, in order to work towards the goal of elimination of barriers, prevention of new ones, and inclusion of PWDs and WWDs fully into our society. The following areas will be discussed: cross-disability research, a pro-active approach to legislation for persons with disabilities, active involvement of WWDs in policy and program development and community initiatives, integrated education of health care professionals regarding the specific needs and issues of WWDs, and finally, allyship with the diverse community of PWDs/WWDs.

7.2.1 Cross-Disability Research

While my study was specifically focused on the important needs of women with physical disabilities, it would be beneficial to extend future research studies to other categories of disabilities, and to the broader population. Indeed, Drainoni et al, whose research was reviewed in Chapter Two, explored health care barriers from a cross-disability perspective.³ The authors noted that consumers spoke of similar barriers regardless of disability type, and they concluded that it is important to take a broad perspective when making policy decisions.⁴ Other authors have also stressed the importance of exploring

[disabilities-act-2005](#). The Hon. David C. Onley gave a scathing critique of the progress of the AODA legislation to date, and stated that, for PWDs, “Ontario is not a place of opportunity but one of countless, dispiriting, soul-crushing barriers.”

³ Drainoni et al, *supra* Chapter 2, note 47. Along with people with physical disabilities, the authors’ study included individuals with autism, developmental disabilities, psychiatric disabilities and those who were HIV-positive.

⁴ *Ibid* at 101.

both visible and invisible disabilities, and of the development of a cross-disability consciousness inclusive of psychiatric disabilities.⁵

As discussed in study limitations in section 4.5, it is also important to conduct future research with a view to capture study samples which are representative of the broader population. It is especially important to include those individuals who may not have experience with self-advocacy, or connection with services or community resources.

7.2.2 Proactive Approach to Legislation

As discussed in Chapter Three, legislation and the vulnerable groups that it was designed to protect have a tenuous relationship. In discussing reactive legislation, Vera Chouinard, as quoted by Jennifer Murphy (2016), “argues that the powers granted to quasi-judicial bodies like human rights commissions are a reflection of the inequities in gaining access to justice for marginalized groups within an ableist dominant culture.”⁶ Chouinard used the term “shadow citizenship” to describe the manner in which rights are given to PWDs in order to empower them to overcome barriers through enabling legislation. Despite the institution of these rights, PWDs are denied opportunities to participate fully in society.⁷

⁵ Engel & Munger, *supra* Chapter 6, note 81 at 8. In their study, Engel and Munger interviewed people with two different types of disabilities: those with learning disabilities and those with physical disabilities requiring the use of a wheelchair. They noted a contrast between the experiences of the two groups. In addition, see generally, Sykes et al, “Reflections on an Effort to Develop a Cross-Disability Consciousness Inclusive of People with Psychiatric Disabilities” (2007) 27:4 Disability Studies Quarterly <<http://dsq-sds.org/article/view/49/49>>.

⁶ Vera Chouinard, “Legal Peripheries: Struggles over DisAbled Canadians’ Places in Law, Society, and Space” in Tanya Titchkosky & Rod Michalko, eds, *Rethinking Normalcy: A Disability Studies Reader*, (Toronto: Canadian Scholars Press, 2009) 217 at 221. See also citing source: Jennifer Murphy, “Human Rights, Disability and the Law in Canada” in Jeannette Robertson & Grant Larson, Eds, *Disability and Social Change: A Progressive Canadian Approach*, (Blackpoint, Nova Scotia: Fernwood Publishing, 2016) 80 at 89.

⁷ *Ibid.*

There is a place for human rights laws and the tribunal process, but the way in which WWDs must fight for each entitlement on a case by case basis does little to promote systemic change. Laverne Jacobs’ work related to reactive and proactive legislation, which was introduced in Chapter Three, warrants further discussion.⁸ As noted, Jacobs described the human rights/tribunal process as reactive regulation. This process is established by the statutes enabling human rights bodies in Canada, and it provides remedies only in discrete situations.⁹ In this reactive scenario, the administrative actor is not required to correct any causative or underlying wrongs, and the process is not forward-looking beyond the involved parties.¹⁰ In addition, the costs involved for legal representation for this method of dispute resolution can be prohibitive for WWDs, who are known to experience financial barriers. Jacobs described a contrasting approach via the development of accessibility regulations. She referred to this approach as *proactive legislation*.¹¹ The idea of this type of legislation is to break down or prevent the barriers before they occur, thus helping WWDs to avoid the necessity for at least some human rights claims. As described in Chapter Three, the AODA is the applicable accessibility legislation for the Province of Ontario. Jacobs noted a history of concerns with the AODA surrounding the enforcement of the obligations under the standards that have been created.¹² Clearly, without strong enforcement, the legislation is of little value to the people for whom it was created to protect. According to the World Report on Disability, “[t]he reporting guidelines for the CRPD obliges States Parties to report on progress in achieving Article 9 (Accessibility).¹³

⁸ Jacobs, *supra* Chapter 3 note 45 at 94-95.

⁹ *Ibid* at 95.

¹⁰ *Ibid* at 94.

¹¹ *Ibid* at 96.

¹² *Ibid* at 105.

¹³ “World Report on Disability” (2019), *supra* Chapter 2 note 15 at 175.

The report suggested three practices which can lead to better enforcement: laws with mandatory access standards, good design reviews and inspections, and accessibility audits.¹⁴

With the new federal accessibility legislation, the *Accessible Canada Act*,¹⁵ recently coming into force at the time of this writing, I assert that it has never been more important to refine, implement and enforce both provincial and federal accessibility legislation. This will serve to ensure proactive legislation with “teeth,” in a forward-looking society which is imbued with a responsibility towards universal design and universal access. Nested within and flowing from this proactive approach, there emerges a truly preventative health care paradigm which permits WWDs to receive their cancer screening without barriers, and thus bypass the sequelae of delayed diagnoses.

7.2.3 Active Involvement of WWDs

The next area to address is the promotion of active involvement of WWDs in policy and program development, and community initiatives related to their unique needs. This follows from the above discussion regarding the development of accessibility legislation. Laverne Jacobs discussed the opportunities for persons with disabilities to engage in consultation related to the development of the AODA and Manitoba’s AMA, in her work on citizen participation in the development of accessibility regulations in Canada.¹⁶ Within the AODA, each standard must be developed by a standard development committee, consisting of PWDs.¹⁷ Two interviewees from my study alluded to having participated in such processes, and their feeling about their involvement was generally good. These

¹⁴ *Ibid.*

¹⁵ *Accessible Canada Act*, *supra* Chapter 3, note 73.

¹⁶ Jacobs, *supra* Chapter 3 note 45 at 106.

¹⁷ *Ibid.*

opportunities for consultation must be in the forefront, and the voices of WWDs must be heard. As noted in Chapter Three, at the time of this writing, a health care standards development committee for the AODA has been established, but the work of the committee is currently under suspension by the Ontario Government.¹⁸ It is critical that political agendas do not impede this very important work.

Another means of including WWDs in program development and service delivery is through community-based initiatives which fully involve all stakeholders. One such strategy is Community Based Rehabilitation (CBR). A joint position paper regarding CBR was issued in 2004 by the International Labour Office, the United Nations Educational, Scientific and Cultural Organization, and the World Health Organization. The paper defined CBR as:

...a strategy within general community development for the rehabilitation, equalization of opportunities and social inclusion of all people with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families, organizations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services.¹⁹

The major objectives of CBR are to ensure that persons with disabilities maximize their abilities, have access to opportunities and become contributors to their community and to society at large. In addition, the intent is to encourage communities “to promote and protect the human rights of people with disabilities through changes within the community, for

¹⁸ Greg Thomson, “Breaking News! The Accessibility Directorate of Ontario Tells the AODA Alliance that One Standards Development Committee is Going Back to Work After a 119-Day Freeze? And News on the Federal Accessibility Front” (19 October 2018), online: *Accessibility for Ontarians with Disabilities Act* <<https://aoda.ca/breaking-news-the-accessibility-directorate-of-ontario-tells-the-aoda-alliance-that-one-standards-development-committee-is-going-back-to-work-after-a-119-day-freeze-%C2%96-and-news-on-the-federal/>>.

¹⁹ “CBR: A Strategy for Rehabilitation, Equalization of Opportunities, Poverty Reduction and Social Inclusion of People with Disabilities Joint Position Paper 2004” (1996-2019) at 2, online (pdf): *International Labour Organization* <www.ilo.org/skills/pubs/WCMS_107938/lang--en/index.htm>.

example, by removing barriers to participation.”²⁰ The initial implementation focus of CBR was in developing countries and/or rural communities, however I see this approach as beneficial and applicable to developed countries as well.

Raymond Lang outlined the history of CBR and comments on the CBR guidelines²¹ which were developed after the publication of the joint position paper (2004).²² Lang described CBR as being synonymous with “inclusive development” and with “participatory approaches to disability policy and practice.”²³ He added, however, that the implementation of CBR strategies has faced a number of challenges.²⁴ One challenge is related to the role of the professional in health service provision. This will be discussed further in the next section, related to the integrated education of health professionals.

Another opportunity for WWDs to be more fully involved, is in the area of community initiatives. In their work from 2017, Lord and Hutchison discussed their “New Story” initiatives, which represent innovative ways of supporting Canadians with disabilities or other vulnerabilities to be participants in, and contributors to, their communities.²⁵ They described the potential opportunities to be creative, stating that “[i]n all parts of Canada, there are pockets of innovation that challenge the conventional wisdom about how to provide support in the community.”²⁶ The authors discussed the need for the beneficiaries of such initiatives to have direct involvement, indicating that “people who

²⁰ *Ibid* at 2-3.

²¹ “Community-based rehabilitation guidelines” (2019), online (pdf): *World Health Organization* < <https://www.who.int/disabilities/cbr/guidelines/en/>>.

²² See Generally, Raymond Lang, “Community-based rehabilitation and health professional practice: developmental opportunities and challenges in the global North and South” (2011) 33:2 *Disability & Rehabilitation* 165-173.

²³ *Ibid* at 169.

²⁴ *Ibid* at 169 – 171.

²⁵ John Lord & Peggy Hutchison, *Pathways to Inclusion: Building a New Story with People and Communities*, 3rd ed (Concord, ON: Captus Press, 2017) at xi-xii.

²⁶ *Ibid* at 5-6.

require support should have power and control over those supports as part of their rights as citizens.”²⁷ An example of a New Story initiative which was developed and established in Windsor-Essex, the location of this thesis study, is the Windsor-Essex Brokerage for Personal Supports. This is a model which permits persons with physical disabilities to access individualized funding for attendant services.²⁸ This is an example of an initiative which was centered around the needs of persons with disabilities. I envision such possibilities for unique initiatives to support WWDs in their communities as they seek to access preventative health care, especially pertaining to the issues surrounding transportation and attendant care that is essential for WWDs to attend medical appointments.

Certainly, the barrier-free cancer screening clinic day, through which I negotiated access to my interview subjects, is another example of an innovative strategy. This unique approach provided the needed supports to permit a marginalized group to receive equitable access to health care. While such initiatives may be resource-intensive, the societal benefits to the health, self-esteem and well-being of WWDs more than offset the costs involved.

Further discussion of possible initiatives is beyond the scope of this thesis; the prospects are intriguing, and further research in this area is warranted.

7.2.4 Integrated Education of Health Care Professionals

The next critical area of need is related to the integrated education of health care professionals regarding the specific needs and issues of PWDs and WWDs.

²⁷ *Ibid.*

²⁸ *Ibid* at 170-175.

In summarizing his paper on Community Based Rehabilitation, Lang stated that “[a] crucial point in understanding the relationship between disabled people and those working in the medical and paramedical [professions] is to examine how the latter are trained. The majority of doctors, physiotherapists and occupational therapists undergo long periods of training which emphasises, by and large, a purely ‘clinical’ approach to the cure and/or amelioration of physical and psychological ‘deficiencies’.”²⁹ This training approach was touched upon during the discussion of health care ableism.

Lang added that many health professionals are making efforts to embrace the legitimate issues of persons with disabilities, and are aligning with the tenets of the social model of disability.³⁰ Physical therapists, Roush and Sharby, explained the unknowing bias that service providers may have towards those with disability, and proposed a model for physical therapists to follow in order to address this in their practice.³¹ They suggested the use of the biopsychosocial model, which they describe as incorporating the concepts of the World Health Organization’s International Classification of Function, Disability and Health (ICF).³²

Canadian Occupational Therapists have incorporated a client-centred model for the past three decades.³³ My subjective experience as a current occupational therapy

²⁹ Lang, *supra* note 22 at 171.

³⁰ *Ibid.*

³¹ SE Roush & N Sharby, “Disability reconsidered: the paradox of physical therapy” (2011) 91:12 Phys. Ther. 1715 at 1718.

³² *Ibid* at 1719. See also generally, “International Classification of Impairments, Disabilities, and Handicaps: A Manual of Classification Relating to the Consequences of Disease” (Geneva, Switzerland: WHO, 1980), online (pdf):

< apps.who.int/iris/bitstream/handle/10665/41003/9241541261_eng.pdf?sequence=1>.

³³ See generally Elizabeth Townsend, *Enabling occupation: an occupational therapy perspective*, (Ottawa, ON: Canadian Association of Occupational Therapists, 1997) and Elizabeth A. Townsend & Helene J. Polatajko, *Enabling occupation II: advancing an occupational therapy vision for health, well-being & justice through occupation*, (Ottawa, ON: Canadian Association of Occupational Therapists, 2007).

practitioner suggests that the use of these theoretical approaches by physical therapists and occupational therapists is not enough. Kielhofner recommended the integration of disability studies themes into occupational therapy education in order to contribute toward increased awareness and reflexivity among future practitioners.³⁴ This is a good start, but the integration of disability studies must go beyond the integration of themes via individual units of study or courses. Disability studies and the current evolution of the social model of disability must be interwoven into the fabric of every health care professional training program. It requires that the health care student internalize a culture of dignity for those with disabilities rather than obtaining a cerebral understanding. I suspect that it will require some persuasion for the academy to make such sweeping changes to curricula.

7.2.5 Allyship with the Diverse Community of PWDs/WWDs

The final recommendation for further dialogue and research, is the concept of allyship. I distinguish between the terms allyship and advocacy. Advocacy suggests action. The verb “advocate” means “:to support or argue for (a cause, policy, etc.): to plead in favor of.”³⁵ “Ally,” however, is defined as “: one that is associated with another as a helper : a person or group that provides assistance and support in an ongoing effort, activity, or struggle” or “— often now used specifically of a person who is not a member of a marginalized or mistreated group but who expresses or gives support to that group.”³⁶

E. Davis Martin, Jr. discussed the importance of advocacy in democratic change, stating that:

³⁴ Kielhofner, *supra* Chapter 6 note 64 at 494.

³⁵ Advocate verb Definition of advocate (Entry 2 of 2) (2019) online: Merriam-Webster.com <<https://www.merriam-webster.com/dictionary/advocate>>.

³⁶ Ally noun Definition of ally (Entry 2 of 3) (2019) online: Merriam-Webster.com <<https://www.merriam-webster.com/dictionary/ally>>.

[t]o facilitate change and to empower persons with significant disabilities, we – persons with disabilities, family members, loved ones and professionals – must become effective advocates...Change in a democracy comes about through the actions of an enlightened citizenry. Advocacy is the first step in bringing about change...³⁷

He emphasized that the advocacy efforts must be sustained locally, regionally and federally in order to ensure the full integration of PWDs into the mainstream.³⁸

I do not fully agree with Martin Jr.'s statement, as I believe that such a blanket statement regarding advocacy poses a risk. The risk of declaring oneself an advocate for persons with disabilities, is that such a statement is very often made without the consent of the intended beneficiaries. Well-intentioned members without a disability, health care professionals, and even other PWDs can fall into the trap of stepping in when their direct intervention is not welcome.

Instead, I propose that declaration of allyship is the first step. In being an ally, we are placing ourselves on a level playing field with the person and/or group that we are supporting, and we do not take any action without their express involvement and consent. Advocacy work may arise from this, but formation of the alliance must come first. In addition, self-advocacy by PWDs with the support of their allies should be the goal. Rights consciousness is a primary theme of this thesis. By supporting PWDs and WWDs in developing their rights consciousness, they can then be empowered to take action of their own accord.

³⁷ E. Davis Martin, Jr., *Significant Disability: Issues Affecting People with Significant Disabilities from a Historical, Policy, Leadership, and Systems Perspective*, (Springfield, IL: Charles C Thomas Publisher, Ltd, 2001) at 205.

³⁸ *Ibid.*

How can such an allyship be facilitated? To promote this within the general population, the slow, steady work of raising awareness of, and eliminating ableist attitudes is the primary means. For health care professionals, the onus is greater.

An appropriate way to conclude this thesis is to reflect on the words of Bonnie Sherr Klein, feminist filmmaker, author and disability rights activist. In her keynote address presented at the annual Canadian Association of Occupational Therapists Conference in Edmonton Alberta, May 1995, she exhorted the audience of OT's to become allies with PWDs.³⁹ She spoke of the way in which OT's address the disabilities of individuals, but often fall short on those that are imposed by society:

We need you to act as our ally and help us to adapt society to us, to remove the barriers. It is important that you see this as your role. If you want to help people become independent and to accept their disability and live a full life, you have to be part of the process of making a place for us. You are ideally equipped to help us in this battle. You are one of our strongest allies.⁴⁰

Sherr Klein concluded by providing concrete suggestions for becoming an ally:

You can be our ally in all of this. Encourage people to state their needs and expect - demand even – that they be met. Actively recruit qualified people with many different kinds of disabilities into your profession. Ensure accessibility in your places of education and employment. Include us in your decision making groups so that we can speak for ourselves and pay us for our expertise. Learn about the disability rights movement and advocate for our issues, as individuals and professional organizations, to support our needs for dignity and inclusion. And get to know us as individuals not just as clients.⁴¹

These words were spoken over twenty years ago, and the change that Sherr Klein invoked at that time has been slow. Her recommendations were directed specifically to OT's but could apply to other health professionals, and indeed, to all members of society.

³⁹ Bonnie Sherr Klein, "Reflections on/Réflexions sur: An ally as well as a partner in practice" (1995) 62:4 CJOT 283.

⁴⁰ *Ibid* at 285.

⁴¹ *Ibid*.

7.3 Conclusion

This study has provided a fascinating window into the experiences of WWDs as they seek preventative health care through the lens of rights consciousness, and several suggested avenues for future research have been generated. We must strive to pursue these future research avenues in the context of community based research, with the full participation of WWDs. As seen from the insights derived from my empirical data, WWDs have much to offer as full partners within the research community. The benefits of truly collaborative research, both in the local context and within the broader society, will be realized beyond what we may imagine.

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APPENDIX I: LETTER OF NO OBJECTION



HÔTEL - DIEU GRACE HEALTHCARE

ESTÉ 1888

January 23, 2019

HDGH No Objection Letter RE: "Disability Rights in an Ableist Health Care Environment: How do Women with Disabilities Understand & Address Systemic Barriers to Preventative Community Health Services?"

Dear Ms. Brown and Dr. Jacobs,

I am pleased to inform you that the information and material to support your proposed research project, "Disability rights in an ableist health care environment: How do women with disabilities understand & address systemic barriers to preventative community health services" to be conducted at Hôtel-Dieu Grace Healthcare (HDGH) and with the inclusion of HDGH patient recruitment, has been fully reviewed and we have no objection to the proposed study. I would remind you of the necessity to comply with the *Personal Health Information Privacy Act*, the *Guideline for Good Clinical Practice*, and the *Food and Drug Regulations*, where applicable.

Please note that compliance with the approving Research Ethics Board, where required, is mandatory and that any significant changes to study related documents must be communicated to HDGH. All reports of adverse events and/or study status reports must also be submitted to HDGH.

Hôtel-Dieu Grace Healthcare reserves the right to request further documentation or relinquish permission to conduct the above mentioned study at any time, particularly in situations requiring the protection of the best interests of the organization or the patients we serve. Should you have any further questions concerning this letter, please contact Ms. Marla Jackson, Manager, Research and Evaluation Services.

Sincerely,

Joe Karb, Vice President
Restorative Care

CHANGING LIVES TOGETHER

1453 Prince Rd, Windsor ON, N9C 3Z4 | T:519.257.5111 | www.HDGH.org



APPENDIX II: CONSENT FORM



CONSENT TO PARTICIPATE IN RESEARCH

Title of Study: **Disability Rights in an Ableist Health Care Environment: How do Women with Disabilities Understand & Address Systemic Barriers to Preventative Community Health Services?**

You are asked to participate in a research study conducted by **Cynthia Brown, Masters (LLM) Student**, from the **Faculty of Law** at the University of Windsor. **The results of the project will be included in Cynthia's Master's Thesis and related papers and presentations.**

Your decision to participate in the research and your answers to the research questions will not have any influence on your treatment today or any treatment or services that you might seek in the future from Hôtel Dieu-Grace Health Care (HDGH).

If you have any questions or concerns about the research, please feel to contact **Cynthia Brown at _____, or her Supervisor, Dr. Laverne Jacobs at _____.**

PURPOSE OF THE STUDY

The main goal of this project is to explore the extent to which women with disabilities identify and address experienced and perceived health care barriers within a human rights framework and to obtain an appreciation of their own lived experience.

PROCEDURES

Participate in an interview following your involvement in an accessible health-care screening day. This interview is expected to take approximately 45 minutes. The interview will take place at a mutually agreed-upon date and time, in a private room at Hotel Dieu Grace Healthcare. If transportation is a barrier, we can conduct the interview by Skype, or by phone.

POTENTIAL RISKS AND DISCOMFORTS

It is possible that some questions may make you feel uncomfortable. If so, you will not be required to answer them. Any risks to your privacy will be minimized by conducting the interview in a quiet and private location/environment. All of your information will be kept confidential, and any information which may reveal your identity will be eliminated via use of alias initials rather than your name. Personal quotes from your interview may be used in the write-ups. Identifying details will be eliminated in analysis and write-ups.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

As a result of your participation, you could gain useful knowledge about yourself and about disability rights instruments. In addition, the information would be useful to the larger disability community and particularly to women with disabilities, along with disability advocates and peer supports. In addition, health service providers and policy makers would benefit from the information gained to assist with policy revision and/or development of future policies and practices. The study will also help us to gain knowledge on women in Windsor-Essex who have disabilities and are accessing health care. Finally, the research communities which focus on law, disability rights and access to justice, among others, would benefit from informed research on the more general topic of access of marginalized groups to public services and institution

COMPENSATION FOR PARTICIPATION

You will be provided with a \$5 gift card as an expression of appreciation for your time and participation.

CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission.

Interview information will be attached to alias initials, and not to your name. It will be kept in a secure and locked location. It will be retained only as long as required to analyse the data and use it for thesis write-up and subsequent papers/presentations, after which time it will be shredded/destroyed. The audio recordings will be erased after transcription and verification.

PARTICIPATION AND WITHDRAWAL

The investigator may withdraw you from this research if circumstances arise which warrant doing so. You have the option of withdrawing from the study and withdrawing any interview data which may have been obtained up until completion of the interview. Data obtained from the interview (written and audio) cannot be withdrawn after the completion of the interview. If you withdraw after the interview has been completed, you will be entitled to keep the \$5 gift card.

FEEDBACK OF THE RESULTS OF THIS STUDY TO THE PARTICIPANTS

A summary of the research findings will be made available at:

Web address: <https://scholar.uwindsor.ca/research-result-summaries/>

Date when results are available: by August 30, 2019.

SUBSEQUENT USE OF DATA

These data may be used in subsequent studies, in publications and in presentations.

RIGHTS OF RESEARCH PARTICIPANTS

If you have questions regarding your rights as a research participant, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario, N9B 3P4; Telephone: _____; e-mail: _____

SIGNATURE OF RESEARCH PARTICIPANT/LEGAL REPRESENTATIVE

I understand the information provided for the study **Disability Rights in an Ableist Health Care Environment: How do Women with Disabilities Understand & Address Systemic Barriers to Preventative Community Health Services?** as described herein. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

Name of Participant

Signature of Participant/Legal Representative

Date

SIGNATURE OF INVESTIGATOR

These are the terms under which I will conduct research.

Signature of Investigator

Date

APPENDIX III: AUDIO CONSENT FORM



CONSENT FOR AUDIO TAPING

Research Participant Name:

Title of the Project: **Disability Rights in an Ableist Health Care Environment: How do Women with Disabilities Understand & Address Systemic Barriers to Preventative Community Health Services?**

I consent to the audio-taping of interviews.

I understand these are voluntary procedures and that I am free to withdraw at any time by requesting that the taping be stopped. I also understand that my name will not be revealed to anyone and that taping will be kept confidential. Recordings are filed by alias initials only and stored in a locked cabinet.

The destruction of the audio recordings will be completed after transcription and verification.

I understand that confidentiality will be respected and that the audio recording will be for professional use only.

This research has been cleared by the University of Windsor Research Ethics Board.

(Signature of Research Participant)

(Date)

APPENDIX IV: INTERVIEW SCHEDULE

Interview Schedule

Introduction

My name is Cynthia Brown. I am a Master of Laws Student at the University of Windsor. I am doing a study which is focused on access to health care services for women with disabilities. I have found in my literature review that barriers to health care exist for women with disabilities. In speaking with you today, I would like to find out about your personal experience with accessing health care, any problems which may have come up, and how you might have dealt with them.

Your information will be very valuable, as it will give a “snapshot” of issues which may be prevalent in our local area. I will then compare this information with information that I have researched, to see how such issues in Windsor/Essex may compare with those of the disability community in the rest of Canada and beyond.

There is also a gap in knowledge that I would like to fill through my study – I would like to know:

- 1) how women with disabilities address barriers to health care,
- 2) what women with disabilities understand about disability rights and corresponding legislation as related to health care.

My goal through this study is to validate and document the concerns that you and other women with disabilities may have about access barriers to health and to explore awareness of disability rights, disability legislation and advocacy. You will be given

information on how to access the study results and will be provided with a link to resources.

All responses will be kept confidential, and your identity will remain confidential.

Personal quotes from your interview may be used in the write-ups. Identifying details will be eliminated in analysis and write-ups.

Your decision to participate in the research and your answers to the research questions will not have any influence on any treatment or services that you might seek in the future from HDGH.

Questions for discussion

1. You recently attended a cancer screening clinic. How did you find out about it?
2. Do you think it's important for women with disabilities (WWD) to have these types of cancer screening tests done regularly? If so, why? If not, why not?
3. Do you think this type of cancer screening clinic should continue? If so, why? If not, why not?
4. How often have you gone for cancer screening in the past (select one)?
 - a. In the past 5 years
 - b. In the past 10 years
 - c. In the past 15 years
 - d. Greater than 15 years
 - e. Never

5. If you have never gone in the past, or have received screening more than 5 years ago, what are some possible reasons for this?
6. If you did go for screening in the past, where did you go? How would you describe that experience?
7. What are the main barriers or obstacles, if any, that you have experienced in the past when you have tried to access health care services?? (e.g. transportation; access to medical equipment in the doctor's office; physical accessibility to the building, attitudes of service providers, etc.)
8. Does your experience with the screening clinic differ from past experiences in which you tried to get health care services? In what ways was it better; In what ways might it have been more difficult?
9. Describe a disappointing experience that you had, if any, while accessing health services in your community.
10. Describe a good experience that you had, if any, while accessing health services in your community.
11. What do you think is the underlying problem or problems that causes barriers to health care for women with disabilities?
12. What do you think should be done to make health care access better and more available for women with disabilities?
13. If you have experienced barriers or obstacles in the past, have you ever wanted to put forth a complaint? Yes No
 - a. Did you do so? Yes No

- b. Why did you put forth the complaint(s)?
- c. If you did complain, how did you go about it? (explain for each instance, if there are multiple complaints)
14. If you decided not to complain, what were the main reasons (e.g. didn't know the process, too much hassle, no funds to pay for legal counsel, etc.) Remember that it is OK if you decided not to complain. There are no right or wrong answers.
15. What is your understanding regarding your rights as related to accessing health care services in your community? Can you describe what you understand about these rights? What do rights mean to you?
16. Are you familiar with the titles of any of the human rights instruments that protect the rights of persons with disabilities to access health care services?
- | | | |
|---|------------------------------|-----------------------------|
| Canadian Charter of Rights and Freedoms | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Accessibility for Ontarians with Disabilities Act | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Convention on the Rights of Persons with Disabilities | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Other: _____ | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
17. If you've heard of any of these titles, please tell me what you know about these pieces of human rights legislation.
18. If you are familiar with this legislation, has this information helped you to decide what actions to take related to barriers to health care or other problems you may have encountered related to your disability?

19. If you're not sure of your rights, or haven't heard of the legislation, would you like to know more? If so why? If not, why not?
20. Please tell me your highest level of education (Eg. Elementary School, High School, College, University, Graduate School)
21. Please provide any additional thoughts on your experience as a woman with a disability accessing health care services.

VITA AUCTORIS

NAME: Cynthia Brown

PLACE OF BIRTH: Shoal Lake, Manitoba

YEAR OF BIRTH: 1961

EDUCATION: University of Manitoba, Winnipeg, Manitoba
1981-1984 BMR (OT)