Claiming Our Space:

Embedding Intersectionality in Research with Diverse Women with Disabilities

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Abstract

This document details research I conducted in partial fulfillment of the Master of Arts in Women and Gender Studies program, jointly provided by Saint Mary's University and Mount Saint Vincent University in Halifax, Nova Scotia. I applied a theoretical lens consisting of the social constructionist approach to disability, feminist intersectionality and theory of misfitting, to reveal that an intersectional exploration of the experiences of women with disabilities is often absent in academic literature. I developed this research question in response: What tools and practices are necessary to ensure that diverse women with disabilities can fully participate in, and benefit from, research? I employed intersectionality to analyze the themes that emerged from focus group and demographic data to develop three recommendations aimed at supporting researchers wishing to include and reflect diverse women with disabilities in all phases of research — from planning to dissemination of findings.

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Chapter One: Introduction

This thesis, and the research it documents, is but one step in my journey as a woman who identifies as having disabilities[1] and who has engaged with research in a variety of roles. As a young child, I was diagnosed with a rare congenital eye condition and was visually impaired (Acker-Verney, 2016). At around age nine, I became aware of being an object of research when I heard my ophthalmologist tell my parents that he had written an article about my eye condition. That was the first time I began wondering - what would anyone know about me? I rode my bike, I ran, I played with other kids, I did needlework, and I learned to knit. What does an eye condition have to do with me, I wondered? That was the first time that I felt what I now understand to be, objectified. Years later when I began coordinating and conducting research, I reflected on the experience with the ophthalmologist and realized I did not want to objectify others in the same way. I did not want to reduce people to their disability. I did not know until many years later that asking what I considered to be important questions and providing opportunities for other people to answer them would be a central focus of my life. I write this now in my 56th year and am grateful to be able to provide people with disabilities

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[1] I use the term "disability" to mean a socially constructed identity category that is, as Linton (1998) writes, a "social, political and cultural phenomenon" (Loc 146). Disability is generally associated with deficiency, abnormality and deformity (Baynton, 2013; Ben-Moshe, 2013; Garland-Thomson, 2002). "Disabilities" is the plural form of "disability" and is most commonly used to indicate the presence of more than one "impairment" (concepts that are explored thoroughly in the literature review).

opportunities to speak their minds, and to hear and witness the power of their thoughts and opinions, whether spoken, written, or signed.[2]

This thesis explores the following question: What tools and practices are necessary to ensure that diverse women with disabilities are able to fully participate in, and benefit from, research? I have employed a feminist intersectional lens, which I have learned requires intentional application to be evident in the results. I began approaching research with a gender lens in 2000 when I was taking courses for a graduate degree in Women and Gender Studies. I did not complete that degree, but I did well in the classes, believed in the need to incorporate a gender lens in my work, and assumed that thenceforth, gender would be a central tool of analysis in any research I conducted. In 2004, after I left that degree program, I became the lead researcher of a provincial research project.[3] In 2014, I conducted a review of the three documents produced as a result of that project as part of my course work for this master's degree. To my surprise and disappointment, I realized that none of those three documents evidenced my intentional inclusion[4] of diverse[5] men and women with disabilities in all phases of the research. Though the team had been intentionally inclusive with the participants and the roles they could play in the research, the questions we asked, the methods we provided to

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[2] I use "sign" to mostly refer to American Sign Language, but it also includes English Sign Language or any type of tactile sign language such as that used by people who are Deaf and blind.

[3] I have written more extensively about this research project elsewhere; see Acker-Verney (2016) for more information.

[4] I use the term "inclusion" here to refer to the recruitment of individuals with disabilities who were subsequently supported to participate in the research project.

[5] I acknowledge the important criticisms of the prevalent use, and institutional-specific definitions, of terms associated with diversity, including that commonly used terms like "diverse" can mask uninterrupted social injustices and institutional inequalities (see Ahmed, 2007). I use the term "diverse" with social justice in mind; I use it to refer to variations in identity markers, (e.g., gender, disability, age), social locations, employment status, income levels, relationship status) and combinations thereof.

receive responses, and the intentionality of diversity were invisible in the final reports. The gender lens, in particular, was missing in the final analysis. Even more striking to me was the silence of the women who participated in various roles, including members of the project advisory committee. Why did I not notice this silence while preparing the presentation of research results? I quickly realized I wanted to turn that haunting question into a guiding principle for my work thereafter. Featuring women's voices became the primary goal of my thesis research.

An academic literature review, completed in 2014/2015, revealed that women with disabilities and Deaf[6] women were, relative to "persons with disabilities," rarely discussed, though there were feminists within social science disciplines whose work was invigorating (Garland-Thomson, 2011; Kelly, 2013; Lunn & Munford, 2007; Malacrida, 2009; Silvers, 1998; Stienstra, 2002; Stienstra et al., 2004). The arrival of significant numbers of refugees to Nova Scotia in 2015 prompted me to wonder how my thesis might include and support women with disabilities from the Global South.[7] A stroke of incredible good fortune resulted in my joining Dr. Deborah Stienstra and others on the research project, *(Re)Building Inclusive Societies: Critical Reflections on Disability and Global Development.*[8] My thesis-related goals began to include learning how to support women with disabilities from countries and cultures other than my own to participate in,

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[6] Thanks to teachings from leaders in the Nova Scotia Deaf community, I understand people who are Deaf to be members of a culturally distinct community rather than members of the mainstream disability community by virtue of being Deaf. People who are Deaf may identify as having disability either because they are Deaf or for other reasons. I assume cultural affiliation but respect the claims of identity individuals make.

[7] "Global South" and "Global North" are linked to post-colonial and global disability studies. Global North is used to refer to developed countries while Global South refers to developing countries. This is explored more thoroughly in the literature review in particular.

[8] For more information on this project, please see the special issue of *Third World Thematics*, volume 1, issue 3 (2016).

and benefit from, research. This thesis details the path I took in my attempt to connect with diverse women with disabilities. It begins with a description of the theoretical frame I chose to use. I weaved together the social constructionist approach to understanding disability (Baynton, 2013; Davis, 2013; Oliver, 1990), feminist intersectionality (Hankivsky, 2014; McCall, 2005), and Rosemarie Garland-Thomson's (2011) theory of "fit" and "misfit" to guide my literature review which, in turn, informed the development of my research question. I have positioned the research question before the literature review for the purposes of this document.

The literature review in Chapter 2 consists of three main sections. The first section traces the development of the social construction of disability and the development of ideology surrounding the "abnormal" body (Davis, 2013). Here, I detail the dominant moral, medical, and social narratives used to explain disability in the Western world (Vehmas, Kristinsen, & Shakespeare, 2009). The second section is dedicated to the development of the social model of disability and emancipatory approach to research with the disability community (Barnes, 1996, 2002; Oliver, 1990, 1992). This section also presents challenges and limitations of the social model and emancipatory research from a variety of vantage points, including those of feminist disability (Garland-Thomson, 2002, 2005, 2011; Hall, 2015; Morris, 1991) and global disability scholars (Berghs, 2015; Connell, 2014; Grech & Soldatic, 2015; Mucina, 2010; Stienstra & Ashcroft, 2010). The third section discusses inclusive research (Walmsley & Johnson, 2003; Nind, 2014) and inclusion research such as that which is carried out by the Ontario Women's Health Network (2009). The chapter concludes with a discussion of gaps in the literature.

The methodological approach I took and the methods I used to conduct my research are described in Chapter 3. The centrality of feminist principles (e.g., reciprocity and reflexivity) in my research and their importance to me as a researcher are described here. Preparing to invite and support women with disabilities from cultures other than mine and countries other than Canada led me to consider the history of researchers appropriating participants' voices (Prakash, 1994) and the creation of the subaltern (Mohanty, 1988, 2003).

I conducted this research by inviting women with disabilities to participate in small group discussions and provide some demographic information. I attempted to recruit women from three distinct communities to participate in an initial community-specific focus group. The three communities were the Deaf community,[9] the newcomer community,[10] and the mainstream disability community.[11] My plan was to then invite women from each of the first three focus groups to attend a final small group discussion where we would explore themes emerging from the first-round discussions. This chapter details the recruitment strategies I used in what would ultimately be a revised methodology. I held a total of three focus groups, including the final thematic discussion, with women of the mainstream disability community in response to the absence of participants from either the Deaf or newcomer communities. Chapter 3 also includes the

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[9] "Deaf community" refers to a culturally distinct community within which individuals may claim an identity that includes disability.

[10] "Newcomer community" refers to individuals who hail from countries other than Canada and are currently living in Nova Scotia.

[11] I use the term "mainstream disability community" or "wider disability community" to refer to any community other than Deaf or newcomer communities, recognizing that these are not mutually distinct categories.

practices and processes I designed to work with and interpret the data gathered through research.

Chapter 4 details the findings of my research and includes a discussion of those findings. A thematic analysis guided by my theoretical framework was used to analyze participants' demographic information and the data from the three focus groups. The following six themes emerged from the first round of two focus groups and were further explored by the women who attended the final focus group:

- Theme 1: There is benefit in defining ourselves.
- Theme 2: Participation in research is influenced by gender and disability as an extension of community participation.
- Theme 3: Women want research to reflect what is important to them and for their participation to make a difference.
- Theme 4: Researchers should not attribute expert status or community-wide representation to individual women with disabilities.
- Theme 5: All research and researchers wield power.
- Theme 6: Women experience tension between identifying as having disabilities while understanding the value in our differences.

Further analysis of the entire body of focus group data led me to settle on the following four themes to frame my presentation of research findings:

- Participation in research can be rewarding for participants.
- Challenges and barriers to research participation exist
- Research participation is embedded in complicated daily lives.
- Women have complicated relationships with research.

The Discussion of Findings section details my use of feminist intersectionality and Garland-Thomson's (2011) critical concept of misfit to reflect on my research findings. The result is a discussion of the complexities associated with the participation of women with disabilities in research. I also explore participant interactions during all three focus groups. My data analysis in this regard reveals what I believe are valuable aspects of peer support realized by participants in my study.

The fifth and final chapter includes my recommendations to assist researchers to support the participation of women with disabilities in research:

- Academic and other research should be interrogated to reveal the silences and absences of women with disabilities.
- Researchers need to intentionally attend to the inclusion and reflection of women with disabilities, building a body of literature focusing on the critical exploration of research methodologies, methods, analytical tools, and results.
- The relationship between research and women with disabilities can be recalibrated and transformed through a research praxis that is guided by greater emphasis on reciprocity.

The chapter and this document come to a close with my thoughts on potential areas of focus for future research.

1.1. My Positionality

This thesis is part of a very challenging but interesting and rewarding piece of my journey as a woman. My experiences and understanding of the world (and my place in it) have always been from within a body labelled by many as “disabled.” I was visually impaired as a child, became blind by the age of 40, and hard of hearing at 54. In fact, becoming blind-hard of hearing[12] began around the time I started this degree and worsened during the completion of my thesis research. While my hearing loss is considered moderate by audiologists, not hearing well has impacted my life and work — including this thesis — significantly. While I cannot say exactly how, I know in my bones that this thesis and the research it reflects has been greatly influenced by the life changes I have undergone while completing it. I could not have asked for a better way to experience, understand, or reflect upon the many complexities involved with attempting to design and conduct research that is inclusive[13] to women with disabilities.

While I embody disadvantage, I also embody privilege. I come to this research as a Western, white, and cis-gendered woman, and I claim an identity that includes disability. My visible disabilities are, at least to some degree, socially accepted, although rarely understood with any accuracy by members of the general public. It is even rarer to talk with someone who shares my love and appreciation of blindness,[14] for example, as a full immersion in what seems a parallel universe to that of the sighted world. At the time of this writing, I do not have the same affection for experiences that reflect my new reality as a woman who is blind-hard of hearing, but I feel the day approaching when I

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[12] I use the notation of a hyphen between “blind” and “hard of hearing” to symbolize the holistic nature of experiencing the new reality of being blind and hard of hearing.

[13] I use the term “inclusive” to refer to research that is flexible to the needs and preferences of participants; reflects their expertise; intends to affect positive social change; and, employs an intersectional analysis to reflect and respond to complexities experienced by participants (adapted from Acker-Verney, 2016, p. 3).

[14] I refer to myself as being blind. Someone else with the same eye condition and/or visual acuity may use another term. I gather very little information about my surroundings through a sliver of a visual field in either eye. My “sight” consists of light and dark fog depending on the contrast between what is light and what is dark.

will. Regardless of how I currently feel about entering this new reality, I (continue to) soundly reject the notion of “disability” as deficiency or inability, favouring instead the idea of variation in human strengths. I take a strength-based approach[15] to understanding the diverse ways that “disability” is manifested in society, while understanding this stance is problematic and contestable. Still, I consciously write from this vantage point. I understand there is great diversity in how human variation is experienced, but I insist that there is much to gain from challenging the normative (ableist) understanding of our corporealities.

I feel restricted by the language of disability while also feeling hypocritical about using it to get what I need. This is complicated by my struggle to find another language to describe this community to which I claim a sense of belonging. At any rate, I am an insider to the disability community and feel a sense of sisterhood with other women with disabilities, whether I share their disability-specific experience or not. The voices and perspectives of women with disabilities are so rarely heard that I feel like I have cracked open a locked treasure chest.

I come to this data with the understanding that it is socially produced (Braun & Clark, 2006). The questions I asked, participants’ responses, and my interactions with data and datum are influenced by relationships to social systems that include sexism and ableism (Braun & Clark, 2006). In addition, I recognize that I am particularly interested in exploring the effects of how identity and relationships to power are intrinsic to, for

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[15] A “strengths-based approach” assumes the presence of valuable skills, abilities and knowledge (Conder, Milner, & Mirfin-Veitch, 2011) that can be unrecognized within an ableist society. There are many examples of this in my own life, including the prevailing understanding of blindness as the inability to see rather than focusing on the (learned) ability to navigate my environment without light.

example, participants’ interpretations of lived experience. My epistemological space is infused with understanding that comes from my embodiment, which is as nebulous and fluid as my experiences within the sighted-hearing world.

1.2. Notes about My Writing Style and Document Layout

This document is written to be accessible to people who use electronic screen readers and who may or may not be blind. The engagement of audible readers challenges the author to realize that visual qualities of the text are not always knowable. Specifically, most punctuation marks, including quotation marks, italics and otherwise highlighted text, section breaks, and text headings/subheadings can be rendered invisible by the inability of screen reading software to identify them. As a result, I write to present the text with this in mind. For example, a sentence such as, “Inclusive practice requires intention” (Acker-Verney, 2018, p. 4) may instead be written as follows: As Acker-Verney writes, “Inclusive practice requires intention” (2018, p. 4). I suggest configuring screen reading software to announce all punctuation where possible. Writing and presenting text to be accessible is a skill I intend to build and hone over the rest of my academic career. It is becoming a hallmark of my writing style, and I hope, one of the contributions I will make through my research to my discipline.

1.3. Theoretical Perspectives

The theoretical approach guiding my research weaves together elements of the social constructionist approach to disability studies, feminist intersectionality, and feminist disability studies. I believe that the combination of these three theoretical strands is well-suited to illuminating the challenges and solutions related to the full participation of women with disabilities in research.

1.3.1. The Social Constructionist Approach to Disability

A fundamental premise of my research rests on the belief that “disability” is socially produced, and that experiences of women who claim disability as part of their identities are co-constituted by boundaries of social identities within social structures and systems in which disability is one mechanism of “establishing social hierarchies that justify the denial of legitimacy and certain rights to individuals or groups” (Baynton, 2013, p. 17). In the ground- breaking *The Politics of Disablement*, Mike Oliver writes:

> All disabled people experience disability as social restriction whether those restrictions occur as a consequence of inaccessible built environments, questionable notions of intelligence and social competence, the inability of the general population to use sign language, the lack of reading material in Braille or hostile public attitudes to people with non-visible disabilities. (1990, p. xiv)

As a social construct, disability is one piece of a larger ideology. The concepts “average” and “normal” are historically rooted in the development of the science of statistics and the eugenics movement (Baynton, 2013; Davis, 2013) and are closely tied to industrialization (Baynton, 2013; Davis, 2013; Oliver, 1990). Disability has been constructed in opposition to dominant perceptions of “The Ideal” (Davis, 2013). Baynton notes that “normality is a complex concept, with an ideology that includes the rise of the social sciences, the science of statistics and industrialization with its need for interchangeable parts and interchangeable workers” (2013, p. 17). The experiences of persons with disabilities remain shaped by systemic and societal understandings of disability as something to be fixed and “avoided at most costs” (Emens, 2013, p. 41). Explaining the social experience and consequences of disability through a generic social constructivist lens is useful to a point, but a more nuanced analysis is required for this research.

A mainstream approach to explaining disability fails to uncover the particular and diverse social and personal experiences of women who claim disability as part of their identities. In contrast, intersectionality is a theoretical and analytical tool that encourages an open and fluid approach to understanding the social participation of women with disabilities in research and is integral to the framing of my research.

1.3.2. Intersectional Feminism

Kimberlé Crenshaw coined the term “intersectionality” in the late 1980s,[16] but it has a long history in the work of feminists of colour, critical race theorists, and

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[16] With respect to Black feminisms and Black feminist thought in particular, it seems particularly important to recognize the critical voices and otherwise invisible experiences uncovered by intersectionality in this moment of outrage at systemic racism, evident in the Black Lives Matter movement. “Intersectionality is conceptually rooted in Black feminisms and was originally a call to understanding the ways in which Black women lived at the intersection of these two social locations, such that they disappeared within women (white) and within Blackness (male).” (Michele Byers, personal communication, August 2020).

Indigenous world views (FemNorthNet, 2015; Hankivsky, 2014; McCall, 2005). Intersectionality, as Hankivsky writes, “[pays] attention to context, relationships, interdependence, and [entails] a commitment to social justice” (2014, p. 252). An intersectional analysis refuses primacy, constancy, or simple addition of identity categories, viewing them as fluid and changing in proximity to systems and institutions of power (Bê, 2012; FemNorthNet, 2015; Sprague, 2016). Intersectionality recognizes identity categories such as gender, disability, and ethnicity as layered, relational, and intersecting axes. As Stienstra explains, “multiple and intersecting identities result in multiple and intersecting oppressions” (2012, p. 381). Women’s intersecting identities and the way they are played out through personal and collective experience are socially constituted through structural mechanisms that include social and public policy (Bê, 2012; McCall, 2005). I contend that research that excludes or silences women with disabilities, and/or research that results in a conflation of the identity categories of gender and disability, are also examples of such a mechanism. My research employs an intersectional lens to uncover structural mechanisms that can be challenged and then leveraged to support accessible and inclusive research for diverse women with disabilities.

Attention to intersectionality prompts me to critically examine the inclusion or exclusion of women with disabilities who engage in social structures and relationships of power as they participate in research, whether as investigators or participants. For instance, several women in my study reported participating in medical research but their experiences and decisions around prolonged participation varied for different reasons.

One woman rejected the researchers' assumption of the certain progression of illness, while another woman reported feeling overwhelmed by the research-related obligations in addition to her other daily obligations.

Intersectionality helps me explore the tangle of complexities inherent in women's experiences and perspectives as they are shaped by inclusion and access needs. The women who participated in my study had varying access-related needs, including wheelchair access, designated accessible parking spots close to building entrances, large print, public transportation and attendant care. Each woman's needs and preferences were specific to them, multiple in number, and integral to their ability to participate in research. Employing intersectionality encourages me to ask whose voices are missing, silenced, or misrepresented within dominant discourses relating to disability research. For instance, discussions among women in my study revealed the influence of traditional gender roles, such as caregiving, on women's decision to participate in research. Intersectionality supports an analysis that, for instance, highlights the ways and means through which fluid and shifting "anchor points of identity" (Bê, 2012, p. 372) influence women's experiences within the various structures underlying research, and the dynamic dimensions of relationships within and among researchers.

1.3.3. Feminist Disability Studies

Feminist disability studies provides ways to conceptualize the material-corporeal relationship that influences women's experience of disability and incorporates fundamental aspects of feminist analysis which allow me to privilege and contextualize the voices of women with disabilities. Feminist disability scholars, including Rosemarie Garland-Thomson and Jenny Morris, were pioneers in challenging feminism to include disability as an analytical category.

> Feminist discussions seldom include disability in their taxonomy of difference. Although ethnicity, race, and sexuality are frequently knitted into current feminist analysis, the logical leap toward seeing disability as a stigmatized social identity and the reading of the body remains largely untaken. (Garland-Thomson, 1994, p. 585)

A focus on including disability as a dimension of identity contributed to gendered (women-centric) readings and understandings of, for example, cultural representations of disability (Garland-Thomson, 1997), dependency (Fineman, 2004), and physical ideals (Garland-Thomson, 2002, 2005).

Rosemarie Garland-Thomson has been instrumental in the development of what she describes as "feminist disability analysis and critique as a major critical subgenre within feminism" (1994, p. 587). The concepts of fitting and misfitting expand the traditional social constructionist approach to disability. In this approach, the focus is on the shifting and dynamic relationship between a body and an environment. The primary point of focus is not on the person who uses a wheelchair, the wheelchair, or the steps/ramp to a building, but the relationship between the body, wheelchair, and physical environment. Garland-Thomson writes, "Misfitting serves to theorize disability as a way of being in an environment as a material arrangement" (2011, p. 593). A good enough fit between a body and the environment causes no disruption for anyone or to anything (Garland-Thomson, 2011). By contrast, "the experience of misfitting can produce subjugated knowledge from which an oppositional and politicized identity might arise" (Garland-Thomson, 2011, p. 597). Misfitting can serve as motivation for many types of political action, including wheelchair users protesting the inaccessibility of buildings (Garland-Thomson, 2011).

Garland-Thomson's theory of misfit is consistent with intersectionality and is particularly useful to my research. Garland-Thomson's theory of fit and misfit provides a useful vantage point from which to think about the dynamic nature of social experiences that women with disabilities have with research. Supporting women with disabilities to participate in research requires researcher flexibility and openness to participants' changing needs and preferences in relation to their participation. Garland-Thomson theorizes that there is no such thing as a "theoretical generic disabled body" (2011, p. 591). In line with an intersectional analysis, she posits that fit and misfit between even a relatively stable environment and body is relational and will vary depending on time, space, function, etc. For example, I move through a space differently depending on whether I am working with my guide dog or mobility cane. My guide dog allows me to move through the centre of a room with relative ease because he will generally take the shortest route from one point to another, making adjustments for obstacles. Working with a cane, I will generally trail walls to find doorways, elevators, etc. This is true for spaces I know as well as spaces with which I am unfamiliar. This is because my orientation cues are different (guide dogs can see and look for objects they know; canes slide over the ground).

Using this theoretical lens, the focus is on supporting individuals' changing needs from one setting to another, even from one day to another in the same setting. For example, researchers cannot assume that a woman who is blind will want or need the same support every time she participates in research and in every research setting. This approach, from disability as a static to a fluid experience, and the focus on fit, is transformative in that it supports individuals to be valued for being themselves rather than for their ability to adapt to an ableist environment. Garland-Thomson writes:

> The concept of misfit clarifies the current feminist critical conversation about the shifting spatial and perpetually temporal relationship and confers agency and value on disabled subjects at risk of social devaluation by highlighting adaptability, resourcefulness and subjugated knowledge as potential effects of misfitting. (2011, p. 2)

1.4. The Research Problem

The word "inclusion"[17] invites multiple levels of interpretation, depending on who and what is involved. Being inclusive takes intentional effort (Grundy, McGinn & Pollon, 2005, p. 457). Results and analysis of an extensive literature review reveal that the emergence of non-traditional, alternative research paradigms have contributed to changes in research processes, practices, and purposes. However, there is a need for further development that includes a more nuanced interrogation of the experience of participating in research from the perspective of women with diverse and intersecting social locations influenced by disability, age, immigration status, socioeconomic status, etc. Applying an intersectional feminist disability lens to the existing body of literature

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[17] Within this document, I use the term "inclusion" to mean the presence for opportunity and the ability of diverse women with disabilities to participate in, and benefit from, research.

highlights the need to raise the voices of diverse women with disabilities, particularly in terms of their involvement in research as participants, researchers, and in other roles. To this end, the following research question was developed: *What tools and practices are necessary to ensure that diverse women with disabilities are able to fully participate in, and benefit from, research?*

A focus on fitting, in terms of individual resourcefulness, knowledge, and agency expresses value for women with disabilities. The idea of fit prompts the researcher to encourage women with disabilities to ask themselves questions such as: "*What do I need to participate fully in this research?*" On a broader scale, women might ask: "*How do I want to influence research I agree to take part in?*" and "*What might indicate that a research project is not one I want to be involved with?*" The next chapter presents the evolution of theoretical and practical approaches to disability-related research. It explores, among other things, activism through scholarship consistent with feminist goals of social justice and transformative social change.

My research question, *"What tools and practices are necessary to ensure that diverse women with disabilities can fully participate in, and benefit from, research?"*, is based on gaps revealed in my literature review and builds on the work of other scholars. It calls for the knowledge and experiences of women with diverse identity markers and social locations to be recognized and validated as legitimate. My question echoes the strengths-based approach to disability (Conder et al., 2011; Martin, 2015), presuming the positive contributions of women with disabilities if practices and processes are in place to support their participation in research. It is aligned with feminist goals of social change in its reference to participants benefitting from research results and reflects the need for research to be intentionally supportive of participants from conceptualization to dissemination of findings.

Chapter Two: Literature Review

The following review divides the literature into three sections. The first provides background information on the idea of accessible and inclusive research by surveying the historical context of the social production of “disability” as an identity category. The second section describes the relationship of persons with disabilities to research, researchers, and the social process of knowledge production. It chronicles the evolution of the social model of disability and the emancipatory approach to research and includes criticisms and challenges leveled at the social model by feminists and global disability scholars. The third section focuses on research labelled by the authors as “inclusive” and “inclusion,” including challenges and benefits to these research approaches, and methodological considerations.

Literature surveyed in-depth for this review was limited to the literature published in English spanning the 1970s to 2018, and almost exclusively related to adults with disabilities. I tried to be aware in each instance of which voices were being amplified by the literature, for example, *women* with disabilities, *men* with disabilities, and *persons* with disabilities. I did not extend my in-depth review to global or international development, inclusive education, or family studies due to limited space and time, but I acknowledge the relevance of scholarly contributions to these fields. Much of the literature originated in the Global North and, consistent with the timeline involved in the evolution of emancipatory and inclusive research approaches, spans the last thirty years. My literature review was limited by the inaccessibility of some of the literature to my text-to-screen reading technology. This limitation became more of an issue in the final stages of the thesis because of institutional misinterpretation of changes made to the Canadian copyright laws.[18]

2.1. Social Processes Shaping Traditional Disability-Related Research

The social context within which research is produced and consumed guides research and has resulted in the alienation and oppression of persons with disabilities (Abberley, 1992; Oliver, 1992; Stone & Priestly, 1996). Disability-related research has been guided by particular philosophies about truth, power, and disability (Davis, 2013; De Bruin, 2015; Goodley, 2013; Grech, 2015; Grech & Soldatic, 2015; Oliver, 1992; Vehmas, Kristiansen & Shakespeare, 2009). Persons with disabilities have been historically categorized as deviant and “unnatural” by philosophy and research in the arts and social science disciplines (Davis, 2013; Vehmas et al., 2009), with a history that includes colonial practices and processes situated in material and geopolitical contexts (Grech, 2015; Grech & Soldatic, 2015; Meekosha, 2011, & Nguyen, 2018). Persons with disabilities have been largely reduced to sources of data by academic researchers (Oliver, 1992) and used as test sites for medical model intervention (Grech, 2015) in relationships structured by dominance and subjugation (Grech, 2015; Oliver, 1992). Mike Oliver writes of the alienating process and results of much of social research, noting that “social research has been alienating, and alienation in all the four forms suggested by [Karl] Marx are

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[18] I was able to buy hard copy books, and between 2014-17, have them broken down by print shops, and scanned by various departments within either Mount Saint Vincent University or Saint Mary’s University. I became aware of a change to this practice in 2018 when I was advised that this was no longer possible because of changes in Canadian copyright laws. As a result, literature reviewed in the latter stages of my program are restricted to those I could access independently and in a timely fashion.

usually present; from the product of research, from the process itself, from other research subjects and, finally, from self" (1992, p. 103).

Writing and thinking about difference, as expressed by the disabled body, has varied throughout history and has been dominated by theorists and researchers of the Global North.[19] Vehmas et al. (2009) note that there have been three general approaches to explaining disability in the Western world: moral, medical, and social. The moral view, rooted in the Western Judeo-Christian view of disability (Clapton & Fitzgerald, 2012), conceptualized disability as punishment for the sins of the parents, if the disability was present at birth, or as punishment of the individual if acquired later in life (Vehmas et al., 2009). Lennard Davis writes that the social construction of disability as a *problem* emerged in the 18th and 19th centuries, resulting from "[a] set of practices and discourses that are linked to late 18th and 19th century notions of nationality, race, gender, criminality, sexual orientation and so on" (2013, p. 1). Davis (2013) credits a French statistician, Adolphe Quetelet, with the conceptualization of "l'homme moyen", or the average man, which combined moral and physical attributes. The statistical formulation of the average and associated creation of the norm divided the population into normal and abnormal. Davis draws a direct connection between early statistical science, eugenics, and the early social construct of disability, noting that "a symbiotic relationship exists between statistical science and eugenic concerns. Both bring into society the concept of a norm, particularly a normal body, and thus in effect create the concept of the disabled body" (2013, p. 3).

The legacy of colonization of the Global South by nations of the Global North[20] has also contributed to the constitution of physical, emotional, and spiritual difference as deficient and

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[19] "Global North" is a term linked to post-colonialism. It, along with "minority world" and "metropole," refer to nations commonly referred to as "developed countries" or "First World" (Goodley, 2011).
[20] "Global South" refers to what is commonly known as "developing countries" (Goodley, 2011).

immoral in the Western world (Grech, 2015; Grech & Soldatic, 2015; Meekosha, 2011). Helen Meekosha writes:

> The idea of racial and gender supremacy of the Northern Hemisphere is very much tied to the production of disability in the Global South and racialized evolutionary hierarchies constructed the colonised as backward, infantile and animal-like. We cannot meaningfully separate the racialized subaltern from the disabled subaltern in the process of colonization. (2011, p. 673)

More recent Western explanations of disability have been dominated by a focus on a scientific and individualized approach (Vehmas et al., 2009), with a continued link to eugenics. Vehmas et al. write: "disability has become, among other phenomena… a paradigm case of medical modelization (a term which refers to a process where people and societies are explained increasingly in medical model terms)" (2009, p. 2). Commonly referred to as the medical model within disability studies literature, this approach is similar to the moral approach in that the location of the "problem" is within the individual. The goal for research guided by the medical model approach is to fix the individual's problem (Barnes, 2012; Crow, 1996; Garland-Thomson, 1997, 2002, 2011; Kafer, 2013; Mertens, Sullivan, & Stace, 2011; Morris 1991, 1992, 1993, 2001; Oliver, 1990; Shakespeare & Watson, 2013; Stone & Priestly, 1996; Vehmas et al., 2009; Watson, 2012). The influence of the medical model of disability is not restricted to inside the bricks and mortar of medical model institutions, including the internal processes, protocols, and personnel. Rather, as Kafer states, "what characterizes the medical model… [is] the positioning of disability as an exclusively medical model problem, and especially the conceptualization of such position as objective fact and common sense" (2013, pp. 5-6).

It is, in large part, individual medical model perspectives on disability, and the emphasis on “value free”, objective, positivist research that continue to shape dominant notions of disability and disability-related research in the Global North. Statistical information, on which much public policy and social service strategies are based, has historically been positivist in nature, guided by medical modelized notions of disability, and not adequately informed by people with disabilities (Abberley, 1992; Oliver, 1992). The social construction of disability and associated dependency (Barnes, 2012; Garland-Thomson, 2002; Linton, 1998; Morris, 1991) permeates both social discourses and cultural representations of disability (Garland-Thomson, 1994, 1997, 2002, 2011; Morris, 1991). In turn, this is the social context in which knowledge is produced and consumed by social institutions, including statistical agencies, higher education, and market economies (Abberley, 1992; Barnes, 2007; Davis, 2013; Goodley, 2011; Petersen, 2011).

The individualized approach to explaining disability in the Western world has been contested since the late 1960s (Vehmas et al., 2009), with the eventual emergence of the social model of disability in the 1970s (Smith, 2009). The social model rests on a materialist-based approach to understanding the social creation of disability and disadvantage (Barnes, 2002; Goodley, 2013; Oliver, 1990, 1992; Shakespeare & Watson, 2013; Wendell, 2013). Theorizing, writing, and research based on the social model of disability began to flourish in the 1980s and 1990s, encouraged by advocates with disabilities in the United Kingdom (Barnes, 2002). Advocates for the social constructionist approach to understanding disability challenged the merits of positivist-based research on disability, calling for greater social-political engagement of persons with disabilities, including a substantive change in the relationship between persons with disabilities and knowledge production (Watson, 2012).

As discussed in the next section, a number of factors, including the widespread acceptance — and criticism — of the social model of disability, the emancipatory approach to research, and the emergence of global disability studies and feminist disability studies, have supported, and continue to encourage, the development of more inclusive approaches to theorizing and researching disability.

2.2. The Social Model of Disability and Emancipatory Research

The social model of disability emerged in the Western world in the latter part of the twentieth century during the civil rights era (Connell, 2011; Danieli & Woodhams, 2005; Shakespeare & Watson, 2013; Watson, 2012). The social model had a massive impact on individual and societal understandings and experiences of disability, an impact that was far-reaching and global. The social model of disability did more than provide an alternative to the dominant approach of focusing on medical model-based causal links between impairment and disability (Oliver & Barnes, 2010); it provided a vehicle for collective action through the politicizing of disability (Oliver, 1992). Oliver writes:

> The late twentieth century has seen a crisis develop in these [social] productions of disability because disabled people have recognized the medical model and individual ideologies underpinning them. What is more, having done so, they are now engaged in a struggle to produce disability as social oppression. (1992, p. 100)

The social production of disability is directly related to research and the social arrangements and structures within which it is created. Oliver (1992) claims that research produced within traditional social relations of research production, whereby the academic researcher is the expert and in control of all aspects of the research, is a source of alienation, misunderstanding, and distortion of the social experience of disability. Oliver called for the development of an emancipatory research paradigm to be, as Len Barton would later write, “transformative, relevant to and significant in the lives of disabled people” (2005, p. 318). The goal for the emancipatory model was to right the wrongs of both positivist and other interpretive, qualitative social research that relied on the subjugated role of research participants. However, the emancipatory model did not result in immediate material changes for participants and focused on the integration of persons with disabilities rather than systemic disablism (Oliver, 1992). It also provided for the positioning of disability as a social experience that could be positively affected through social policy as opposed to an individualistic experience of personal tragedy (Crow, 1996; Morris, 1991; Oliver & Barnes, 2010; Thomas, 2004). In short, emancipatory research was part of a political strategy to counter the social production of the dominant view of disability. Danieli & Woodhams write:

> Under the guise of objectivity and value neutrality, the ontological and epistemological assumptions of previous research on disability perpetuated a dominant understanding of disability which maintained the oppression of disabled people. It is argued that in order to redress this we need to adopt different methodologies and that emancipatory methodology provides a fundamental break with previous methodologies. (2005, pp. 282-283)

Emancipatory research was intended to be democratizing and an important, action-oriented aspect of disabled people’s struggle against oppression. Oliver writes: “Disability research should not be seen as a set of technical objective procedures carried out by experts but part of the struggle by disabled people to challenge the oppression they currently experience in their daily lives" (1992, p. 103). The emancipatory approach called for academic researchers to think critically about the assumptions underlying their work, and to put their skills and resources at the disposal of individuals and organizations of the disability community (Barnes, 2002; Danieli & Woodhams, 2005; Oliver, 1992; Stone & Priestly, 1996; Watson, 2012).

Stone and Priestly (1996) referenced feminist, critical race, and global development thinking in their discussion of the core principles and complexities inherent in emancipatory research. They identified the six core principles of emancipatory research as follows:

1. The social model of disability serves as the basis for the epistemological approach to disability research;
2. Researchers surrender claims of objectivity in favour of supporting the self-emancipation of persons with disabilities;
3. Researchers commit to conducting research that is transformative in either removing social barriers or resulting in other practical benefits for persons with disabilities;
4. Researchers and research are accountable to individuals and organizations within the disability community;
5. Research aims to personalize the political while politicizing the personal experiences of disability and disablement; and
6. Researchers employ a variety of methods to be responsive to individuals' needs. (Stone & Priestly, 1996).

Stone and Priestly's (1996) principles of emancipatory research have been widely accepted within disability studies (Danieli & Woodhams, 2005). Their ideas about personalizing the political and politicizing the personal diverge from the those of scholars such as Colin Barnes who viewed disablement as a collective social experience. For example, Colin Barnes

(2002, 2003) refers to Stone and Priestly's principles of emancipatory research, and while he agrees with the majority, offers an interpretation that privileges the collective understanding and politicization of disability over the individualized experience:

> Experiential research alone has hitherto to yield any meaningful political or social policy outcomes. It is important therefore that within an emancipatory disability research framework, any discussions of disabled people's experiences, narratives and stories are couched firmly within an environmental and cultural setting that highlights the disabling consequences of a society organized around the needs of a mythical, affluent non-disabled majority. (Barnes, 2003, p. 10)

Stone and Priestly (1996) identified several areas of complexity within the emancipatory research framework. They believed that the principle of the researcher working for the disability community could be problematic in light of institutional and funding requirements. There is also the potential for academic researchers to be caught in community and organizational politics while trying to perform research that is beneficial and empowering to an entire community. They identified assumptions embedded within the emancipatory research paradigm, including the presumed similarity of needs within the disability community, socio-political contexts in which research is conducted, and community members' desire to participate as co-researchers. Stone and Priestly (1996) explored the potential for complexity and conflict for researchers when research results are out of alignment with, or contrary to, the theoretical and political views of those in the (Western) disability rights movement. They write:

> Can it ever be the researcher's role (as an individual committed to the politics of disability rights) to politicize the 'unpoliticized' or act as advocate for a Social model of disablement amongst respondents? Consider disability research within a Chinese context: to politicize

> and impose Western conceptualizations would be (rightly) criticized as proselytization. It would also be condemned for irrelevance where disabled people's struggles revolve around daily survival rather than political emancipation. Consider also the relative degrees of politicization amongst disabled people in Britain: should a researcher exploring users [sic] definitions of service quality proselytize amongst those who do not appear 'sufficiently aware' of the wider political nature of their oppression? (Stone & Priestly, 1996, p. 711)

An exploration of power relationships raised by Stone and Priestly, including those between researchers and participants across cultures, are explored later in this chapter. They raise important points about an assumption that social transformation is always required and desired (Watson, 2012).

Humphrey (2000) points to another layer of complexity for the social model and the emancipatory research paradigm when she writes that “both disability politics and disability theory had been dominated by people with particular disability identities” (p. 67). Humphrey points out that individuals who self-identify as persons with disabilities claim membership within the disability community and research. Conversely, not claiming disability as part of one’s identity — as is the case for many members of the Deaf community, for instance — restricts whose experiences are reflected in research results. In other words, only people who self-identify as being persons with disabilities will participate in disability research. This privileges particular voices and experiences in research results.

Danieli and Woodhams (2005) questioned the political priorities of emancipatory research writing:

> If the prerequisite of legitimate research on disability is the adherence to a social model of disability, then the possibilities of producing theories which Oliver (1992)

> argues should be non-dogmatic are much reduced. What we are then left with is the possibility that disability researchers will only produce research findings that support the social model of disability. (p. 287)

The authors postulate that merely substituting the social model for the medical model approach to understanding disability as the starting place for research does not, in itself, produce non-positivist research. Tom Shakespeare and Nick Watson (2013) similarly assert that it is impossible for research done from the starting point of the social model to find that persons with disabilities are anything but oppressed: “The question is not whether disabled people are oppressed in a particular situation but only the extent to which they are oppressed” (p. 211).

Criticisms of the emancipatory research paradigm also include an underlying assumption of the social model that all disability-related research should be emancipatory, and that to do research for other purposes contributes to social oppression of persons with disabilities (Danieli & Woodhhams, 2005). Danieli and Woodhams write: “Not all researchers in the disability field approach their research with the explicit political aim of the emancipation of disabled people nor do they all explicitly link their political position and their methodological approach to research” (2005, p. 283). Danieli & Woodhams (2005) question the degree to which power structures between the academic researcher and individuals with disabilities are truly changed within the emancipatory research paradigm, noting that the privilege bestowed upon the academic researcher as a consequence of being in that role is fraught with difficulty. The additional complexity of power relations within the disability community may result in views that are consistent with prevailing social values and the social model. They write: “Rather than emancipatory research and the social model becoming a means of legitimizing the views of previously silenced disabled people, it can potentially become a means of silencing those whose views do not conform to those of the 'expert' researcher" (Danieli & Woodhams, 2005, p. 288).

Feminist disability scholars have also criticized the social model and emancipatory research paradigm. The absence of gender-based analysis and the invisibility of women with disabilities in theory and research was problematic for scholars who called upon both mainstream disability studies and feminism to account for the distinct experiences of women with disabilities (Bê, 2012; Garland-Thomson, 1994, 2002, 2005, 2011; Kwiotek, 2010; Morris, 1991, 1992, 1993; Vernon, 2016; Wendell, 1989). Rosemarie Garland-Thomson has been instrumental in the development of feminist disability studies. By the early 1990s, she began to argue for both feminism and disability studies to recognize the underlying assumption of homogeneity, and the associated lack of adequate scholarly focus on women with disabilities. She writes of disability studies:

> One of the least explored intersections of multiple identity discourses is feminism and disability studies. Because disability studies is an emerging academic field presently located largely within the disciplines of sociology, medical model anthropology, and medical model rehabilitation, its focus on disability as a primary category of analysis and social identity often obscures gender distinctions, so that feminist concerns within its boundaries tend to be considered as a subfield. Only when gender distinctions are specifically announced… is a fully feminist critique of disability issues undertaken. (Garland-Thomson, 1994, p. 583)

Carving out space to theorize and analyze research with a focus at the intersection of disability and feminism necessitates a reconceptualization of the approach to thinking about women with disabilities. Bê writes:

> The reason [feminists with disabilities] felt it was important to point out both feminism's ableism and disability studies' often gendered character was exactly because, being situated in two social locations as women and disabled persons, they wanted and felt the need to draw from both feminism and disability studies frameworks in original conceptual moves. (2012, p. 364)

Another point of criticism of the social model has been the distinction between "disability" and "impairment", with "disability" belonging to collective social experience and "impairment" being a private matter for the individual. Poststructuralist critics, including those in feminist disability studies, have pointed to the dualistic thinking underpinning the separation of disability from impairment, much like the sort that mainstream feminism had challenged. Bê writes:

> Some disabled feminists began to insist that this strong impairment/disability distinction dismissed the experience of impairment and the body felt altogether. They argued that this division actually mirrored the classic patriarchal split that mainstream feminists had challenged, the split between the public and private where the private becomes a personal arena of no collective significance. (2012, pp. 365-366)

An emphasis on the social construction of disability denies the particular experiences — and potential for identifying points of convergence — among women with disabilities (Blackwell-Stratton, Breslin, Byrone, Mayerson, & Bailey, 1988; Crow, 1996; Hockman, 2010; Morris, 1991, 1992, 1993; Silvers, 2015; Wendell, 2010). Tom Shakespeare and Nick Watson point to the practical difficulty of binary thinking such as this in research: "Any qualitative researcher who does research with disabled people immediately discovers that in everyday life it is very hard to distinguish clearly between the impact of impairment and the impact of social barriers" (2013, p. 211). Feminists with disabilities have employed methods and approaches to theorizing and research that have allowed for convergence, despite difference. Feminist disability scholars, including Diane Driedger (2010), Michelle Fine and Adrienne Asch (1988), and Jenny Morris (1991) have provided platforms for women with disabilities to come together, tell their stories, and be represented in academic literature. Feminist disability scholars have also been leaders in theorizing the continued link between social acceptance of eugenics as manifested through medical model "advancements" in prenatal testing and selective abortions, and the implications of these practices on a future without human variation (Hubbard, 2013; Kafer, 2013; Saxton, 2013). They have also worked to reconcile the tensions between the social and physical dimensions of illness and disability (Kafer, 2013; Stone, 2010; Wendell, 2010, 2013).

Challenges to the underlying assumptions of homogeneity and applicability of the social model of disability and the emancipatory research paradigm are also prominent within global disability studies, a relatively new cluster of theoretical approaches to thinking about the experience of disability and disablement.[21] Critics challenge a variety of aspects, including its materialist-based focus that denies nonmaterial dimensions of the lived experience of disability, such as spirituality (Grech, 2009; Mucina, 2010; Stienstra & Ashcroft, 2010); the assumed homogenous experience of disability devoid of geopolitical and cultural influences (Bayat, 2014; Berghs, 2015; Grech, 2009); and its relative stagnation — while at the same time proliferation

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[21] "Global disability studies" refers to an evolving and much more complex area of scholarship than I can explore in this document. Of particular importance to my research is its post-colonial focus (Goodley, 2011). It recognizes the importance of cultural and geographic context within which disability is constituted and experienced (Davis, 2013). Global disability scholars have created a critical space from which "imperialistic and globalizing practices" (Goodley, 2013, Loc. 921) of theory and research can be explored.

— as a tool for theorizing and researching disability outside the metropole (Bayat, 2014; Berghs, 2015; Connell, 2014).

Stienstra & Ashcroft (2010) point to the absence of spirit and spirituality in dominant conceptualizations of disability. They suggest a broadening of the understanding of the human experience to include disability as more than an individual experience. The authors draw from non-Western and Indigenous cultural philosophies to position "spirit/spirituality as an intersubjective and interdependent aspect of human life" (Stienstra & Ashcroft, 2010, p. 192). Some settler cultures see disability as being experienced both within and by communities. Not all cultures have terms or the same Western understanding of "disability," including the Cree Nations in Manitoba, Canada. Of this, Stienstra and Ashcroft write: "Neither the Dene people nor the Cree in Manitoba have a specific term for persons with disability. Disability is understood as something that contributes to a community by teaching something to the people" (2010, p. 194). Theories of disability that are based on individuals with disabilities "structure out" these other communal, spiritual ideas and beliefs (Stienstra & Ashcroft, 2010, p. 195). Stienstra and Ashcroft (2010) broaden the conversation from the materialist-based understanding of disability to include the metaphysical aspects of the experience.

Consistent with Stienstra and Ashcroft's (2010) exploration of the non-materialist factors that shape the creation and experience of disability, Mucina (2010) offers the African philosophy of Ubuntu as a culturally specific approach to thinking about disability. Ubuntu recognizes the interconnectedness of humans to each other and the whole; individuals do not exist without each other and the whole is dependent on each and all its parts. Mucina explores the complexity involved in internalizing colonization, such that the colonized enforce, and are subsequently confined by, dominant perceptions of what is "normal." He writes: "We become the gatekeepers.

We do a great job of gate keeping in order to secure our own space in the supposedly limited normal culture. Those who seek their freedom by mimicking the oppressors can never gain their freedom" (Mucina, 2010, p. 89). Through the Ubuntu lens, Mucina offers an alternative approach to politicizing disability and democratizing enquiry to affect transformation. He writes:

> Let us regenerate and revive our Ubuntu governance because these are our institutions, which were designed to serve our needs…[A]s these Ubuntu institutions are a reflection of us, we have a duty to make sure that they also reflect our reality and where they fail to do so we should come together and create a solution. This is how you create responsible democratic participation. From this position we cannot point fingers outwardly as the responsibility rests solely on all our shoulders. We, therefore, should be regularly checking if our individual actions are maintaining the status quo and if they are helping to dismantle the status quo we should know how, so we can share the knowledge. (2010, p. 89)

Bayat indicates the global reach of the social model of disability, noting that the social model has influenced the "majority of international efforts on inclusive education" (2014, p. 31). Consistent with Mucina, Bayat suggests that the social model may not be appropriate to understanding or transforming the experience of disability in Africa. For example, divergent views of disability exist between educational professionals and the layperson. Bayat writes: "There are separate views of disability held by the Ivorians: one that is held by the educated and professionals (i.e. the child is diseased), and the other that is held by the general public (i.e. the child is cursed). Both views are in fact intertwined with African cultural beliefs and religious practices" (2014, p. 40). Bayat believes that the imposition of the social model in this context is ill advised, writing: "It may be more useful to explore an alternative approach, which not only promotes the human right of individuals with disabilities, but also is mindful of cultural roots and beliefs about children, their rights, and the role and power of education in general" (2014, p. 41).

Berghs (2015) asserts that new, innovative models for understanding disability are required. She notes that the two main causes of disability throughout the world are war and poverty. Berghs suggests that the development and use of the social model was innovative, but its use should result in continued innovation that includes non-Western voices. Berghs writes:

> The fundamental task at hand… is about understanding disablement and changing the ablest conditions of social oppression. This means not just including or mainstreaming disabled people in policy and practice, but fundamentally and critically letting the local and global political grassroots take the lead to reform societies and thus the models we use. (2015, p. 747)

Disability, according to Berghs, is perpetuated by medical model humanitarianism during times of conflict and disaster and ensures that ableism is replicated. Berghs (2015) describes the complexity involved in being labeled as having disability and being disabled, included and excluded in that social identity, depending on the combined and intertwined contexts of gender, geopolitical, social, cultural and economic factors. Of this, she writes: "A more complex model is needed than just a social model 'rights' approach noting the need for social reforms and understanding of diversity among persons with disabilities" (Berghs, 2015, p. 751). Berghs goes on to say:

> This is about more than ensuring a barrier-free environment or access to individual rights or services, but links a radical social model to other social, indigenous and grassroots movements that are questioning the neoliberal status quo and advocating local and global change. (2015, p. 753)

Connell (2014) offers a Southern theory for understanding the experience of disability in the Global South. Connell's challenge is to develop new ways of thinking and learning within global contexts rather than a prescribed set of propositions. Connell posits that knowledge and theory is exported to the Global South, or periphery, from the metropole, or Global North. Connell writes: "The role of the metropole, as well as producing data, is to collate and process data, producing theory (including methodology) and developing applications which are later exported to the periphery" (2014, p. 211). Connell proposes the promotion of alternative knowledge systems such as those found in Africa or among the Indigenous populations of the world. Connell provides descriptions of various approaches or "knowledge projects;" the fifth she calls "the application of southern theory and postcolonial perspectives" (2014, p. 216), which includes the work of Meekosha (2011) and Meekosha and Soldatic (2011). Connell asserts that the Southern theory should not be seen as a set of prescribed practices because there is no gain in combatting one colonizing means and method of knowledge production with another. Connell writes:

> Thinking at the level of practices helps with a persistent problem about the reception of intellectual work from the south in mainstream northern settings. When talking about these issues in northern universities, I have often been asked, in one way or another, 'What does this add to what we already know?' The assumptions bear thinking about, but these questions relate to real issues about curriculum, citation practices and the like. And it is in practical terms that the issue should be reformulated: 'What does this ask us to do that we are not now doing, as knowledge workers?' (2014, p. 218)

For Connell, Southern theory does not ask what production of knowledge from the Global South contributes to what we think we know but, rather, what it asks us to do differently.

Nguyen (2018) lays out a multi-pronged argument for scholars and global development practitioners to apply southern theory to their critical disability lens. She builds on the work of prominent critical disability and global disability scholars such as Titchkosky and Aubrecht (2015), Ghai (2012), Grech (2012), Meekosha and Soldatic (2011) to explore how this particular theoretical configuration can peel back layers of colonizing processes and practices underpinning, as she writes, "the social productions of disabled bodies through transnational capitalism across the global North and South" (Nguyen, 2018, p. 22). She looks at critical disability studies through lens of southern theory as a way of challenging the universalism and essentialism encapsulated in dominant northern disability theory and the imperialist function of its application. Three components of her argument are:

1. Using southern theory challenges the use of northern epistemologies in the context of the Global South;
2. Southern theory helps reveal how colonial practices of knowledge production in all its forms continues through the dominance of northern theory and results in the invisibility of the experiences of persons with disabilities in the Global South; and,
3. Within the context of global development, southern theory applied to critical disability theory supports the decolonization of northern theory and makes room for indigenous ways of exploring and explaining the experiences of persons with disabilities in the Global South (paraphrased from Nguyen, 2018, p. 3-6).

Nguyen calls for repositioning the focus of critical disability theory to the social, cultural and historical contexts of the social embodiment and engagement experienced in the global South as a project of decolonizing and deconstructing knowledge production practices of the global North.

There is a growing body of literature within global disability studies focusing on many factors influencing the social experiences of women and girls with disabilities in the Global South. Areas of focus are diverse and include forced migration (Pisina & Grech, 2015), education (Nguyen & Mitchell, 2014), and social exclusion (Katsui & Mojtahedi, 2015). Of particular interest to my research is questioning the dominant narrative of the gendered and disabled body as vulnerable (Erevelles & Nguyen, 2016) and foregrounding the voices of women and girls from the global south as participants in research (Nguyen et al., 2016).

In summary, criticisms of the emancipatory research paradigm have included its underlying assumption of homogeneity among persons with disabilities, gendered biases in research and analysis, adherence to the disability-impairment binary, the virtual ignorance of the personal experience of impairment, the potential for silencing views inconsistent with the social model of disability, and the assumed universalism of the Western world’s experience. The social model of disability remains predominant in the Western world, as does the emancipatory research paradigm. Feminist disability scholars have carved out a theoretical and methodological space to raise issues of gender analysis and intersectionality in relation to research and women with disabilities. In addition, global disability studies scholars have begun to ask important questions about the assumptions, processes and practices involved with using a theoretical lens of the Global North to understand experiences of persons with disabilities in the Global South, with a growing body of literature related to women and girls with disabilities. The next and final section of this literature review focuses on self-described inclusive research in terms of practices, challenges, and researchers' reflections.

2.3. Inclusive Research

The term "inclusive research" refers to a host of research approaches, including emancipatory and participatory action research, within academic literature (de Bruin, 2015; Nind, 2014; Petersen, 2011; Walmsley & Johnson, 2003). Melanie Nind (2014) employs "inclusive research" as an umbrella term that refers to a variety of non-traditional approaches to research. Nind states that inclusive research "encompass[es] a range of approaches and methods and these may be variously referred to in the literature as participatory, emancipatory, partnership and user-led research" (2014, Loc. 75). Of the term itself, Walmsley and Johnson (2003) write: "Inclusive research as a term allows for the blurred and shifting boundaries between, for example, feminist, participatory and emancipatory research, and it has the advantage of being less cumbersome and more readily explained to people unfamiliar with the nuances of academic debate" (2003, p. 10).

Some researchers point to the inclusion of persons with disabilities in research as importantly consistent with tenets of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and, in particular, Article 3(c), the "full and effective participation and inclusion in society" (Cumming, Strnadová, Knox, & Parmenter, 2014; Nind, 2014; Ollerton & Horsfall, 2012). Ollerton and Horsfall (2012) describe ableist underpinnings of the traditional human rights paradigm. The assumption of an "abled-bodied rights bearer leads to social inequalities as it fails to include the formulation of rights, the provision of health and social services that many persons with disabilities need to survive" (Ollerton & Horsfall, 2012, p. 618). Ollerton and Horsfall (2012) say these are social and economic rights, and that the Universal Declaration of Human Rights espouses equality, but this does not recognize diversity; i.e., equal treatment is not necessarily equitable treatment. The limitations of the formal equality model are being replaced by the substantive equality model which seeks to better reflect human diversity. The substantive equality model requires that states take steps to eliminate conditions that perpetuate discrimination as a precondition for eliminating discrimination for persons with disabilities (Ollerton & Horsfall 2012).

Researchers also note the role of inclusive research praxis in democratizing research, promoting empathetic understanding, and putting traditionally subjugated voices at the centre of the research (Aldridge, 2014; Lunn & Munford, 2007; Walmsley & Johnson, 2003). In short, inclusive research is positioned as being consistent with "the goal of a more inclusive society" (Conder, Milner & Mirfin-Veitch, 2011, p. 39).

Melanie Nind points out that inclusive research shares the grounding of research in the experiences of individuals with qualitative research more widely, but there is a democratization in the methods and relationships from which knowledge is produced. Inclusive research has its roots in emancipatory research (Nind, 2014; Woelders, Abma, Visser, & Schipper, 2015) and embeds persons with disabilities in the research (Nind, 2014). Nind writes: "Inclusive research can be usefully thought of as research that changes the dynamic between research/researchers and the people who are usually researched" (2014, Loc. 115). Walmsley and Johnson (2003) describe the non-traditional roles occupied by persons with disabilities within the inclusive research approach when they write: "Research involves people who may otherwise be seen as subjects for research as instigators of ideas, research designers, interviewers, data analysts, authors, disseminators and users" (2003, p. 10).

Academic researchers who concentrate on inclusive research with people with learning disabilities point out that the emancipatory research paradigm and its emphasis on empowerment and equitable relationships between researcher and researched, was championed by people with physical disabilities who could advocate for themselves (Woelders et al., 2015). The development of self-advocacy organizations for people with intellectual disabilities in the US and elsewhere came later, in the latter part of the 20th century, post de-institutionalization, and was followed by the emergence of research and writing that included their representation and perspectives (Walmsley, Hart, Davies, Still, & Byrne, 2014; Walmsley & Johnson, 2003). This was in sharp contrast to the previous focus on the perspectives of doctors, researchers, and parents (Walmsley & Johnson, 2003).

Walmsley and Johnson (2003) identify principles and characteristics of inclusive research. They note principles on which to base inclusive research in general (not only that which includes persons with intellectual disabilities) are "that research must address issues which really matter to people with disabilities, and which ultimately leads to improved lives for them; that it must access and represent their views and experiences; that people with learning disabilities need to be treated with respect by the research community" (2003, p. 16). Based on these principles, Walmsley and Johnson identify the following five characteristics of inclusive research, regardless of whether it is participatory or emancipatory in process:

1. The research problem must be one that is owned, not necessarily initiated, by disabled people;

2. It should further the interests of disabled people; non-disabled researchers should be on the side of people with learning disabilities;
3. It should be collaborative - people with learning disabilities should be involved in the process of doing the research;
4. People with learning disabilities should be able to exert some control over process and outcomes; and
5. The research question, process, and reports must be accessible to people with learning disabilities. (2003, p. 63)

Inclusive research in general includes a variety of approaches to research, knowledge production, and social justice. Nind identifies participatory research, emancipatory research, participatory action research, and user-led research as “complementary approaches to achieving meaningful social change through research” (2014, Loc. 250). Nick Watson identifies three main assumptions common to traditional research in general, and emancipatory and participatory research specifically:

1. Traditional research relationships between expert and participant are inequitable;
2. People have a right to be involved and consulted about issues affecting their lives; and
3. The quality and relevance of research is improved when persons with disabilities are closely involved in the process. (2012, p. 96)

Summaries of the descriptions Nind (2014) provides for each of the four approaches are:

- Participatory Research — People being researched participate in the various stages and processes related to the research for the purposes of conducting meaningful research with meaningful results that lead to change. Change can include how knowledge is produced or used. Participatory research is a paradigm rather than a method, with researchers often referring to participatory design rather than participatory methods.

- Emancipatory Research — Nind's (2014) description of emancipatory research is consistent with saying it provides an openness to the in-depth discussion provided elsewhere in this document. In brief, Nind links this to the disability community exclusively. Goals of emancipatory research are said to include political action and empowerment for persons with disabilities involved in the research. Nind (2014) notes the leadership roles performed by persons with disabilities involved in emancipatory research.
- Participatory Action Research — Nind (2014) refers to participatory action research as being like a cousin to both participatory and emancipatory research, with roots in feminist and anti-racist movements; it has a bottom-up approach and an emphasis on the agency of participants. The processes of action and change are "simultaneous and inseparable" (Nind, 2014, Loc. 206-221).
- Partnership, or User-Led Research — As the name suggests, this type of research may be controlled by members of a partnership researching, for example, a service delivery model or research conducted from the perspective of users or consumers of a program. Nind (2014) positions partnership or user led research as closely aligned with emancipatory research in particular; however, there does not appear to be the emphasis on political action and materialist-based oppression.

Community-based researchers in Canada have also developed inclusive research definitions and practices. The Ontario Women's Health Network (OWHN) uses the following definitions of inclusion and inclusion research:

> Inclusion is about belonging and ensuring that everyone has equitable access and opportunity to participate in our society. …OWHN developed a new approach to community-based research that seeks to reach women facing challenges in relation to the determinants of health to ensure their voices inform the development of health policy, programs and research. This is inclusion research. (OWHN, 2009, p. 11)

Tenets of the model used by the Ontario Women's Health Network are:

- Inclusion research includes women from traditionally marginalized groups as Inclusion Researchers (IRs) who are trained and supported to conduct research while they also represent the groups being studied;
- IRs are involved in all aspects of the research, from designing the research to making recommendations, providing knowledge of communities not held by other research investigators;
- Results of research are grounded in "principles of community engagement such as inclusion, transparency, suitability and accountability" (OWHN, 2009, p. 16).

Inclusion research conducted by the Ontario Women's Health Network is said to be based on feminist research principles, participatory action research, and community asset mapping. Feminist research principles highlighted by the Ontario Women's Health Network include:

- challenging gender-based oppression experienced by women;
- valuing women's lived experiences;
- critically analyzing gender and power relationships; and
- participating in researcher reflexivity

Principles of participatory action research identified as important by the Ontario Women's Health Network are:

- Research is conducted by and on behalf of an exploited or oppressed group for the purpose of social transformation;
- Inclusion research rejects the idea that research is objective;
- The starting point for participatory action research is the needs or interests of an oppressed group rather than an idea or hypothesis of academic researchers;
- Members of the oppressed group are involved in every stage of the research;
- Research participants are active subjects in the research;
- "investigation + learning + action" (p. 111); and
- The success of a participatory action research project can be measured by the social change to which it leads. (2009, p. 111)

Benefits of involving persons with disabilities in research are said to include the greater authenticity of the research (Aldridge, 2014; Lunn & Munford, 2007; Nind, 2014), including insider knowledge of their communities (Bigby, Frawley & Ramcharan, 2014b; Kidney & McDonald, 2014; Marshall, Kendall, Catalano & Barnett, 2008; Martin, 2015; Nind, 2014; Walmsley & Johnson, 2003), better research design (Nind, 2014; Walmsley & Johnson, 2003), and more valid findings (Walmsley & Johnson, 2003). Benefits to participants can include a sense of empowerment (Atkinson, 2004; Martin, 2015; Nind, 2014), a sense of agency and control from sharing their knowledge and experience (Aldridge, 2014; Atkinson, 2004; Marshall et al., 2008), and skill development (Conder et al., 2011; Cumming et al., 2014; Martin, 2015). Aldridge writes of inclusive research that "such approaches also emphasize proficiency and potentiality of research participants" (2014, p. 115).

Researchers identify methods and strategies for conducting inclusive research, while acknowledging the importance of context, planning, flexibility, and reflexivity. Ethical and methodological challenges are also identified. Inclusive research can take multiple forms, include a multiplicity of methods, and involve persons with disabilities in any number of roles. Inclusive research can employ either or both qualitative and quantitative methods (Allen, 2000; de Bruin, 2015; Nind, 2014; OWHN, 2009). The Ontario Women's Health Network, for instance, employs methods that include community asset mapping, focus groups, and facilitated discussions.

Choosing methods appropriate and accessible to participants is important (Conder et al., 2011; Duckett & Pratt, 2001; Marshall et al., 2008), with final research design including multiple methods of data collection where appropriate (Duckett & Pratt, 2001). Situating research methods in the cultural context can influence results, as Marshall et al.'s (2008) research with Indigenous women with disabilities in Australia illustrates:

> Well, if you send [a survey] to say, 20 Indigenous women, you would probably get one or two responses back. Personalized approaches were considered to be the only appropriate way to learn from Indigenous women. Meet with them…eye contact is the best contact. A smile is always impressionable. Food is always lovely, Aboriginal people, they like to feed – if you reject food from an Aboriginal person, they get very offended…If you communicate with people, eye-to-eye contact is the best way because then you see their facial expressions and you know if they are telling the truth. You know they can get their neighbour to fill out one of those forms, but it might not be an Indigenous person. (p. 198)

Ethical and methodological challenges are said to include, as Aldridge writes, "broader issues and dynamics, including; 'top down' demands of the academy for 'scientific' rigor, the needs of funders, the need for genuinely innovative methodological approaches, and so on"

(2014, p. 116). Bigby et al. (2014a) point to the advantages of a collaborative and fluid relationship with co-researchers that provides capacity and help to counter the criticism that inclusive research with innovative methods remains at the descriptive level of analysis. They write:

> The emphasis on collaboration in this method brings realism to inclusive research that recognizes the abstract conceptual thought and literacy required for some aspects of research. Sharing tasks between group members enables parts of the work to be done by academic partners, while the emphasis on working as a group ensures the outcomes of such work are shared and built on by group members with intellectual disability. This ensures the research is rigorous, for instance by situating it in the existing body of literature about the subject or moving analysis to a conceptual or theoretical level. In this way, the concerns about inclusive research remaining at a descriptive level, and thus having limited value are avoided. (Bigby et al., 2014a, p. 62)

Other challenges include lead researchers ensuring informed consent in situations where the potential risks associated with participating in research cannot always be predicted (Aldridge, 2014; Morgan, Cuskelly & Moni, 2014). This is particularly problematic in situations where the methods employed (such as photovoice or group interviews) make the private public (Aldridge, 2014; Lunn & Munford, 2007). There can be difficulties when balancing the empowerment and control of participant researchers and confidentiality (Björnsdóttir & Traustadóttir, 2010), particularly when co-researchers must rely on individuals within their personal support systems to access materials (Morgan et al., 2014). Researchers promote a strengths-based approach to persons with disabilities as co-researchers, saying it indicates value for, and an openness to, individuals’ abilities (Conder et al., 2011; Martin, 2015). Role ambiguity can create dilemmas for lead researchers when balancing the need to support the participation of participant researchers with the need to focus on gathering reliable data (Conder et al., 2011); other researchers note the inner conflict they feel as they try to provide co-researchers with support, while respecting their potential (Morgan et al., 2014). Walmsley and Johnson’s (2003) framework is challenged on the grounds that it assumes a group of people who are knowledgeable about the nature of research can express their views about research, and are representative of the larger population of persons with intellectual disabilities (Bigby & Frawley, 2010).

Challenges can also be experienced by academic researchers who find it difficult in the current research and institutional climate to do research that is meaningful to members of the disability community and support their own academic career advancement (Aldridge, 2014), or employ inclusive practices and strategies such as consent forms and other materials written in non-academic languages and formats (Morgan et al., 2014). Other researchers have explored the challenges they experience as outsiders to the communities or groups of participants with whom they are conducting Inclusive Research. Reflecting on her relationship within a group of four researchers where she was the only “neuro typical” person, Martin writes: “There were challenges to me as I am neuro typical and cannot know what it is like to have Asperger’s syndrome in the way that the group does” (2015, p. 212). Martin (2015) identifies two other challenges as:

1. Challenges for people with their unique experiences of Asperger’s syndrome to work together; and

2. A challenge for people with Asperger's syndrome and those without to work together and understand each other.

Researchers with disabilities have (although rarely) identified experiences and challenges associated with their own experiences of disability (Acker-Verney, 2016; Morgan et al., 2014; Tregaskis & Goodley, 2005). Michelle Morgan writes about how her own experience with unpredictable illness, along with existing disability-related factors, influenced her doctoral research participants in her participatory study, as illustrated by the following statement:

> Within the research team, Michelle's deteriorating medical model conditions raised additional ethical issues with regard to disclosure, and additional [self-imposed] demands on the research-partners, together with the impact on the research and the research-partners of the inclusion of a [unfamiliar] disability assistant. (Morgan et al., 2014, p. 1316)

Planning for inclusion in research is vital. Researchers note the benefits of "planning well whilst maintaining flexibility… [are] key to achieving maximum participation" (Conder et al., 2011, p. 39). Producing reports, recruitment, and other materials in non-academic, plain language, and accessible formats is important in order to be accessible to many persons with disabilities (Conder et al., 2011; Duckett & Pratt, 2001; Kidney & McDonald, 2014). Planning for the training and development of disability-related awareness of lead and other researchers also requires attention and has been considered helpful (Duckett & Pratt, 2001; Grundy, McGinn & Pollon, 2005).

Choosing spaces and places for research activities has implications for promoting balance in the relationship between academic researchers, co-researchers, and participants (Duckett & Pratt, 2001; Kidney & McDonald, 2014). This can include making time for informal conversations between members of the research team. The opportunity to build relationships is important in the research context and helps to provide a basis for trust, honesty, and accountability (Kidney & McDonald, 2014). More personal relationships can prove beneficial during delicate times; research that is inclusive of diverse perspectives, including those of persons with disabilities, requires space and time for critical comments which “destabilize authorial voice of the researcher” (Lunn & Munford, 2007, p. 74).

Planning that includes ensuring adequate financial resources to support the disability and other needs of individuals, no matter their level of participation in research, is important (Conder et al., 2011; Duckett & Pratt, 2001). Also required is valuing people external to the research who support the participation of individuals with disabilities and supporting both co-researchers and participants of the research (Conder et al., 2011). Despite a commitment to planning, however, tight time frames for proposal and report writing and conducting research can restrict the time available for co-researchers’ personal and skills development, and for the research team to fully explore emerging solutions to challenges related to participation (Conder et al., 2011).

2.4. Themes Emergent in the Literature

This section serves as a broad summary of the preceding literature review and includes a brief analysis, guided by my theoretical frame, which illuminates specific gaps and silences in the existing literature that my research can help to address.

The history of disability-related theory and research in the Western world is grounded in the social production of the “normal” and “abnormal.” Davis writes of the connection between normalcy and disability: “The problem is not the person with disabilities, the problem is the way normalcy is constructed to create the problem of the disabled person” (2013, p. 1). The social systems and ideologies underlying Western traditions of positivist research have supported research designs and methods that have been alienating to persons with disabilities, separating individuals from their embodied experiences, research as a product and process, and from other research participants (Oliver, 1992). Theorizing disability as a socially constructed identity is relatively new and has been supported by several factors, including the development of work by scholars predominantly of the Global North, focused on other marginalized groups (e.g., feminist and critical race scholars) and the proliferation of social model of disability and the disability rights movement (Barnes, 2012; Barnes & Mercer, 2016). The social model of disability began to gain widespread traction in the Western world in the latter part of the 20th century. This was in opposition to the dominant medical model, which explains disability as being internal to individuals (Oliver & Barnes, 2010). The medical model relies primarily on positivist research and focuses on the goal of cure and prevention (Kafer, 2013).

The social model and emancipatory research paradigm are credited with changing the relationship between people with disabilities and knowledge production in the Western world (Barnes & Mercer, 2016). The intention of this work was to democratize research and provide mechanisms for collective political action (Barnes, 2002; Oliver, 1992). Contributions of the social model and emancipatory research are said to include a redistribution of power among individuals in research relationships and the positioning of persons with disabilities as holders of expertise and leaders in research, capable of directing the efforts of academic and community researchers (Stone & Priestly, 1996). The social model distinguishes between impairment and disability, focusing attention on social barriers to participation as the cause of disablement. It is the common experience of disablement through social and environmental barriers that serves to galvanize members of the disability rights movement, and to politicize disability as a marginalized social location (Barnes, 2003).

The social model has provided a theoretical basis from which to contest the understanding of disability as personal tragedy and loss, dominant in the Global North. Its ungendered analysis, however, continues to be identified as a shortcoming by feminist disability scholars and its assumed universalism a criticism of global disability scholars. Feminists challenge the social model’s dichotomization of impairment and disability, and its focus on the social experience of disability and relative dismissal of the embodied experience of impairment (Bê, 2012). Feminist disability scholars recognize the challenge associated with focusing on the embodiment of illness and impairments as dangerously hugging the ethos of the medical model. At the same time, they insist that there is much to gain from exploring and theorizing the complexity inherent in a false dualism of impairment and disability, since social experiences are holistic (Kafer, 2013).

Global disability scholars point to the assumption of cultural homogeneity, while feminist scholars note the failure of the social model to provide a gender-based analysis of disability. Global disability scholars also note the assumed universalism of the social model as indicated by its use to explain disability in the Global South (Bayat, 2014; Berghs, 2015). Scholars point to non-material factors such as language, philosophy and spirituality that fundamentally shape the social, emotional, and spiritual experience of disability (Mucina, 2010; Stienstra & Ashcroft, 2010). Others identify the opportunity and need for the social model to innovate through its use in the Global South (Berghs, 2015). Scholars note the colonizing effects of exporting the dominant theory of disability in the Global North to the Global South as though there is an essential truth about the experience of disability (Berghs, 2015; Connell, 2014; Nguyen, 2018).

Changing the relationships involved in research and knowledge production is embedded in inclusive research approaches that include emancipatory research. This is commonly presented in the literature as shifting the power imbalance between professional academic researchers and members of the disability community (Walmsley, 2004; Walmsley & Johnson, 2003; Nind, 2014). Despite researchers' efforts and planning, ongoing challenges remain. These include the structural power imbalance inherent in researcher relationships where the "professional" researchers are established and receive financial and other career-related rewards. Disability research has been criticized for not being relevant or transformative to the lives of persons with disabilities (Lunn & Munford, 2007; Marshall et al., 2008).

2.4.1. Positioning my research

With this thesis, I am attempting to address gaps and silences in the literature, namely the dearth of inclusive research beyond education and health; the silence of diverse women with disabilities in research; and the scarcity of self-identified lead researchers with disabilities.

2.4.1.1. Contributing to research beyond education and health.

A search of the inclusive research literature reveals a concentration in the disciplines of education and health. The education-related research seems to be primarily focused on the inclusion of children with disabilities in the classroom and educational systems. Health-related research describes efforts to support the health and well-being of persons with disabilities through participation in community life and finding appropriate methods and approaches to deliver health-related information. A great deal of literature described as inclusive research has focused on persons with intellectual disabilities (Atkinson, 2004; Jackson, 2004; Nind, 2015; Nind & Seal, 2009; Ollerton, 2010; Walmsley, 2001; Walmsley, 2004; Walmsley & Johnson, 2003). I believe my research aligns more closely with that of community-based researchers who have also been involved in developing research methods and approaches that support the inclusion of historically marginalized populations as participants and members of research teams (Ontario Women's Health Network, 2009).

2.4.1.2. Raising the voices of women with disabilities in research.

The literature on inclusive research is dominated by work focusing on the involvement of persons with intellectual disabilities and, as such, receives the most attention in this literature review. With few exceptions, there is a lack of identity-focused discussion and analysis beyond that of intellectual disability. Women with intellectual disabilities are rarely highlighted as being involved, and even rarer is the case where the study or discussion focuses on the inclusion of women with intellectual disabilities as the primary focus of the research. With a few notable exceptions (e.g., the Ontario Women's Health Network), the literature on inclusive research lacks an intersectional analysis that considers the effects of intersecting social locations based on fluid and relational aspects of identity on distribution of power in research and other relationships. There are, for instance, discussions about the challenges and lessons learned associated with supporting persons with intellectual disabilities to participate as co-researchers, but relatively little about specifically involving women with disabilities. By contrast, my study focuses exclusively on the participation of women with disabilities and relies on a feminist intersectional lens to gain a greater understanding of the forces and factors that encourage or discourage their participation in research.

2.4.1.3. Using feminist intersectionality to uncover the complexity of women's lives.

Most of the existing research appears to include people with disabilities based on a specific disability or an additive approach of "disability plus gender," underscoring the need for my research to take an intersectional approach. My research by contrast does not prioritize gender, disability, or any other dimension of identity. Instead, it uses disability as a vantage point. From this perspective, the influence of women's various social locations to their experiences of research is revealed. Research reflecting the involvement of women with diverse and multiple disabilities — as mine is designed to be — is not common, even though it is reasonable to expect that there are many situations in which individuals have more than one disability or impairment. Analyzing the results of the literature review through an intersectional lens also reveals the dearth of research recognizing the myriad of other positionalities of women, including those of newcomers to communities that are culturally and socio-politically different from "home." Most of the literature also fails to acknowledge the positionality of lead researchers. Exceptions include Grundy et al. (2005) and Tregaskis and Goodley (2005) who acknowledge the benefits, promise, and challenges of working as researchers who are persons with disabilities. This provides an opportunity for my voice as a lead academic researcher to add to the small chorus of others who identify as persons with disabilities.

Chapter Three: Methodology

This chapter describes the methodological frame of this research and my chosen research methods. Both the methodological frame and the methods I chose are heavily influenced by the issues and strategies presented in the inclusive research section of Chapter Two. I detail my efforts to recruit participants and the steps I followed to plan for and conduct focus groups consistent with a feminist research praxis that is welcoming of diverse women with disabilities. I explore methodological choices and describe notable ethical considerations. I detail the analytical tool I developed to use with the data and the steps I took to process and analyze the data I collected. Finally, I explore challenges and limitations associated with my choices and actions.

3.1. Methodological Approach and Researcher Positionality

My plan and approach to this research was designed to be consistent with McCall's conceptualization of methodology as "a coherent set of ideas about the philosophy, methods and data that underlie the research process and production of knowledge" (2005, p. 1774). Feminist principles, including reflexivity, reciprocity, and social justice are at the core of my work, calling for research to contribute to social transformation, and that the methodological approach be anchored in feminist philosophy, values, and politics (Ramazanoglu & Holland, 2002; Sprague, 2016). As Sprague points out, a feminist approach to doing research requires, and provides space for, researchers to critically examine all aspects of conducting research:

> Feminism is not just theory, it is a commitment to social justice that entails a political perspective on our work. Feminism calls on researchers to think critically about aspects of research that tend to go unexamined in discussions of methodology: whose questions we are asking and who is benefitting from the answers we discover through our research. (2016, p. 192)

My positionality, while conducting this research, is inextricably entwined with my methodological approach, implementation of the research design, and analysis of the research results. As such, various aspects of my positionality are explored within this section and throughout this chapter.

3.1.1. Reflexivity and Reciprocity

Feminist principles of reflexivity and reciprocity are embedded in my research praxis. Ongoing reflexivity played an important role in assisting me to gain clarity about the choices, assumptions, and interpretations that are reflected in the thesis. Reciprocity, like reflexivity, is rooted in social relationships and comes from the feminist epistemological space that seeks social justice and transformation from research. Reciprocity requires that the benefits of research such as mine extend to the participants and the wider community.

3.1.1.1. Reflexivity

As a feminist researcher, it is important that I be as transparent and self-aware of my positionality as possible, including that of one who is discovering and creating knowledge with others involved in the research (Lincoln, Lynham & Guba 2011; Olesen, 2011). Regardless of the process employed, reflexivity is considered a hallmark of feminist methodology and involves what Ahmed, Hundt and Blackburn refer to as “the process of looking both inward and outward” (2011, p. 468). Feminist understandings of reflexivity incorporate the notion of the researcher as co-creator of research and knowledge within ‘messy’ relationships and contexts that extend to include individual and political layers (Hurd, 1998; Jorgenson, 2011). Research relationships and processes are complex. Feminist reflexivity provides researchers with a mechanism to think about and communicate influencing factors that include researcher biases, systems of power inherent in research processes and practices, and the complexities associated with being an insider or outsider to the community involved in the research (Hurd, 1998; McCabe & Holmes, 2009; Spivak, 2005; Yakushko, Badiee, Mallory, & Wang, 2011). McCabe & Holmes (2009) note that reflexivity is a useful tool of validity and a mechanism to inform the research; reflexivity entails strategies of data collection and analysis to assist in meeting emancipatory goals associated with feminist research.

Feminist researchers who practice reflexivity challenge traditional positivist research assumptions of researcher objectivity, generalization of findings, power asymmetry within research relationships, and methods where, as Hurd writes: “Method and results are conceptualized as separate entities” (1998, p. 196). Reflexivity can be performed after completion of the research or as a continuous critical reflection that informs an evolving research process (Hurd, 1998). Practicing reflexivity throughout research is said to help researchers highlight what Hurd refers to as “the co-constructed nature of all research practices” (1998, p. 202). I am confident that practicing feminist reflexivity helped me identify at least some of the complexities in my research that are shaped by the shifting and layered intersectional experiences involved in conducting, participating in, and reflecting on research.

3.1.1.2. Reciprocity

Reciprocity, as another core value of this research, is entwined with equity and social justice, and is of particular importance to me. It underlies the rallying cry of emancipatory research and the mainstream disability community: “Nothing about us without us!” Reciprocity refers to more than merely making an effort to reach agreement on what will constitute an equal exchange between researchers and individuals with whom they engage (Tuhiwai Smith, 2012). It also includes making the research accountable to the community it represents (Mertens, Sullivan & Stace, 2011); working collaboratively with participants to make research-related decisions (Brydon-Miller, Kral, Maguire, & Sabhlok, 2011); and representation of research participants as agentic knowers (Bell, 2014; Dillard & Okpalaoka, 2011).

Taking steps to achieve reciprocity between researcher and research participants, and the wider community, challenges traditions of objectivity and truth, but does not, in itself, resist the inequalities inherent in research relationships, as Weems illustrates in the following statement: “What is overlooked… is how these positions and relationships [i.e., between the researcher-participants] are complicated by historical, institutional, cultural, and discursive factors“ (2006, p. 1001, bracketed text added). For instance, academic regulations for my degree require that I must be the sole author of record for this research, despite knowledge being discovered, known, and made knowable — as it is contested — within social relationships (Weems, 2006). In other words, the questions I ask, expertise offered by participants, and the lessons learned that constitute research results are not mine alone. I recognize that this is but one example of the tensions raised by the contradictions between my theoretical lens and institutional constraints. As a woman with disabilities, I am sensitive to women of my community feeling exploited and/or dismissed by research projects and the researchers who conduct them. I discussed reciprocity with the women who participated in the focus groups conducted for this project. I fully acknowledged the benefits I will receive as a result of this thesis, specifically my Master of Arts degree. We had wonderful discussions about the rewards they felt they had already experienced and felt were still possible through participation in the research. A more in-depth discussion of the possible rewards (e.g., putting forth ideas about transforming research with women with disabilities) is included in Chapter Four. I also dedicated myself to being mindful and reflexive in my representation of their participation within my thesis. Within the context of my power and privilege, I was determined to challenge traditional colonizing research methods and approaches (Chowdhury, 2009; Kapoor, 2005; Mohanty, 2013).

I understand reciprocity as a moving target of sorts rather than an achievable and static goal. I highlighted two questions raised by Weems that are of interest to me as I prepared for this project and the eventual writing of the thesis:

> How do certain representations of the research process and outcomes position myself and others within relations of power, authority, knowledge, and truth? And how do we take into account the idea that…writing involves negotiating the storied lives of others (linking representation to constructs such as respect and responsibility) without collapsing into a naive fantasy of ethnographic text (in general, and researcher's representations of reciprocity in specific) as a project of redemption, advocacy, or total identification? (2006, p. 1007, parenthetic text in original)

I have not come to a place where I feel I know the answers to these important questions. One of the ways I have tried to honour my commitment to the goals of this research is to write the thesis with disability-related accessibility in mind, as I discussed in Chapter 1.

3.1.2. Post-colonial Intentions

Post-colonial criticism is interdisciplinary and is undertaken by historians, economists, and social theorists across disciplines (Prakash, 1994). It challenges the Eurocentric tradition of universalizing experience and history from the Western perspective and the appropriation of the “Other” as a part of European historical and development narratives (Prakash, 1994). Post-colonial approaches to research, noted in subaltern studies, were important in this study because of my intention to be respectfully inclusive of women with disabilities who are newcomers to Canada, including those from the Global South.

Subaltern studies is a part of post-colonial criticism of knowledge production and social identity construction (Prakash, 1994). To be “the subaltern”, according to Spivak, is “to be removed from all lines of social mobility” (2005, p. 1). Subalternity refers to a space where the “Third World Other” is marginalized and disempowered by dominant Western discourses and institutions (Kapoor, 2004) and a place without identity (Spivak, 2013). “It is not primarily a space of heterogeneity at all” (Spivak, 2013, p. 10). It is where social mobility, self-efficacy, and agency do not exist (Maitra, 2013; Spivak, 2005). Western researchers are called upon to recognize their participation in colonizing practices within neo-liberal systems (Mohanty, 2013) and urged to take a back seat in the process of constructing knowledge as opposed to assuming what Chowdhury refers to as “the benevolent First World feminist position” (2009, p. 52).

Spivak speaks of creating “a space where the intellectual instrumentalises himself or herself in order to go into learning from below; how in fact to think about a polity willing social justice, rather than acting only in self-interest, generation after generation” (2013, p. 10). Spivak and others call on Western scholars to enter into the research relationship and environment such that the subaltern is the teacher and the scholar a student (Spivak, 2013, Mohanty, 2013). My aim was to not merely make room for difference but to do this research with purposeful difference. Doing so included developing a research plan that assumed all women’s agency and expertise such that the results reflected interpretations of data that are shaped by diversity in situated knowledge and cultural understanding.

I envisioned all aspects of this research to be political as it was intended to privilege the voices and experiences of diverse women with disabilities currently residing in Nova Scotia, recognizing that the authentic inclusion of women from the Global South specifically requires that I choose processes and methods that challenge what Mohanty calls, “the scholarly view from above” (2013, p. 967).

3.1.3. Researcher Positionality

All aspects of my thesis research would turn out to be inextricably tied to changes in my personal identity as a woman with disabilities who became hard of hearing over the same time period. The small group discussions originally designed to be in-person affairs proved to be very difficult for me to manage as I struggled to figure out details like where I should sit to make the best use of my residual hearing. My preparation for the three focus groups included questions I had never asked myself before:

- “What do I need to think about when facilitating a group discussion when I may not be able to hear all participants equally?”
- “What back up plans or accommodations do I need that I did not before?”
- “How might my evolving reality shape the experiences of participants?”

My methodological approach to this project was the backdrop for my changing embodiment and associated experiences. It is intersectional, reflecting my belief and embodied experience that social structures and systems create fluid relationships with advantage and disadvantage for, and among, women with disabilities. My own experience of adapting to a new reality that affected every aspect of my life has proven a good illustration for the relationship between situated and relational social location, identity markers (e.g., gender, age and disability) and social systems (e.g., research ethics board processes).

I identify as an insider to the mainstream disability community at the same time as recognizing the diversity and fragmentation it contains. There are disability-specific organizations (e.g., CNIB, Canadian Paraplegic Association, and Brain Injury Association of Nova Scotia); advocacy organizations (e.g., Nova Scotia League for Equal Opportunity and the Disability Partnership); and issue-centered groups (e.g., community-based accessible and supportive housing). I am an outsider to the newcomer and Deaf communities. I will now turn to an exploration of issues associated with these positions, such as recruitment.

There are ongoing debates about the ethics of being insiders or outsiders to the community of study, with a move away from the dichotomization of these as two distinct positions, and good versus bad (Chavez, 2008; Kerstetter, 2012). There are also advantages and challenges associated with being an insider or outsider to the community of study (Chavez, 2008). The role of an objective “outsider” researcher was privileged by positivist disciplines historically, but there is now more recognition that researcher positionality is always at play (Chavez, 2008). Advantages associated with being an insider researcher include a nuanced understanding of community issues and participants' lived experience (Chavez, 2008). Challenges include the often-overlooked dimension of researcher emotional response (Chavez, 2008; Collins & Cooper, 2014). Chavez conceptualizes the social locations of insider and outsider researchers on a continuum, where a fluidity exists in the relationship with the community and participants (e.g., how researchers interact with the information participants share) changes from in-depth knowledge to listening to facts and details. Neither insider nor outsider researchers are guilty or devoid of advantage and bias (Chavez, 2008; Olesen, 2011).

My affiliation with academia is a social location invested with power (Kerstetter, 2012). I acknowledge that historical and current colonial forces continue to shape all aspects of Western scholarship and research, resulting in risk and harm to individuals, communities and cultures of the Global South in particular (Kapoor, 2004; Mohanty, 2013; Prakash, 1994). I developed my research to embed post-colonial criticism and decolonizing processes and practices in an effort to attend to the role of "historical and cultural specificity in understanding [women's] complex agency as situated subjects" (Mohanty, 2013, p. 967, parenthetic text added). Community-specific focus groups were intended to support a sense of belonging for participants and avoid the "tokenism" associated with the absence of similar voices, faces, and lived experience (FemNorthNet & DAWN Canada, 2014). My research was also designed to support participants' greater involvement in data analysis. Women who attended the first round of community-specific focus groups were invited to attend a final discussion to provide feedback on emerging themes.

This section has focused on particularly important aspects that influenced my approach to planning and conducting this research, namely my commitment to practicing reflexivity and reciprocity, to being attentive to post colonial criticisms of research, and being transparent about my researcher positionality as it relates to the communities I wanted to engage in my research. The next section outlines specific methodological choices I made to this end.

3.1.3. Key Methodological Choices

3.1.3.1. Participant Selection

The target population for this research included women who were 16 years old or older, living in Nova Scotia, who self-identify as women with different and multiple disabilities. I designed the research to be broadly inclusive of a woman's basis for claiming an identity that includes disability, whether she adheres to a moral, medical, social constructionist, or other view. I chose the age of 16 and above as an eligibility criteria for two reasons. First, Saint Mary's University Research Ethics Board (SMUREB) policies support the approach that informed consent can be provided by people 16 years and older. Secondly, I recognize that the experiences and perspectives of young women with disabilities, particularly those from the Global South, could quite dramatically vary from those of the Global North.

3.1.3.1.1. Self-identification. I welcomed participants to my research who self-identified as women and as women with disabilities. Potential participants were invited to name and define the support options they deemed appropriate to provide informed consent. No proof of belonging to any social category was necessary. A reliance on self-identification as a member of the disability community results in the exclusion of women who do not claim disability as part of their identity (Humphry, 2000). This creates an unfortunate silence in terms of women who do not claim disability as an identity marker but does recognize women's agency and choices.

3.1.3.1.2. Geographic Boundaries. The research was open to women with disabilities across Nova Scotia. I anticipated that most participants would be from within Halifax Regional Municipality (HRM). Participant diversity is made possible through HRM's rural and urban communities, people with diverse cultural backgrounds, ages, social economic status (SES), etc. As it turns out, providing a teleconference option for attending the small group discussions resulted in more women who live outside HRM than expected expressing an interest in participating.

3.2. Methods and Research Design

My research included practices and processes that are feminist, intersectional, and participatory, with disability-related accessibility and inclusion central to decisions regarding choices and implementation of methods. The research was designed to mitigate factors, including the power structures and colonial traditions, underlying the researcher-participant relationship; the expertise and agency of women who participated in my research; and, acknowledgement that research cannot be separated from the process that produces it (Kapoor, 2004; Letherby, 2003).

The research was multi-phasal and included participants completing the Demographic Information Survey (DIS) and participating in at least one small group discussion, with the option to attend another. I attempted to recruit participants from the newcomer, Deaf and wider disability communities. Women were invited to participate in a first round of community-specific small group discussions and an integrated follow up discussion to provide feedback on themes that emerge from the initial round of focus groups. This layered and iterative approach was intended to support women to feel safe to share their perspectives and experiences and to assume their place as agentic knowers; it also recognizes the historical colonization perpetrated by research and researchers of the Global North.

With respect to the historical colonization through research, I understand this research as an opportunity to deconstruct the researcher-participant relationship and knowledge production as they play out for newcomers from the Global South. At the same time, I recognize my position within Western neoliberal scholarship (Mohanty, 2013; Chowdhury, 2009). As a result, I designed my research to provide multiple opportunities for perspectives and voices with which I am unfamiliar to be agentic in the data gathering stage, influential in data analysis, and evident in the results. I am committed to conducting research that embeds post-colonial criticism and decolonizing processes and practices in an effort to attend to the role of "historical and cultural specificity in understanding (women's) complex agency as situated subjects" (Mohanty, 2013, p. 967, Parenthetic text added). Unfortunately, women from the Global South participate in my study. Nevertheless, I acknowledge my assumptions as the researcher and one who is far too familiar with the advantages afforded me by my privilege (Kapoor, 2004).

3.2.1. Demographic Information Survey (DIS)

I developed the DIS such that it recognized the relationship between experiential knowledge, material surroundings, and sociocultural factors on individuals' interpretations and decision making (Nyumba, Wilson, Derrick, & Mukherjee, 2018). My intersectional analysis of focus group discussions contextualized the interactions among focus group participants. The DIS consisted of 13 questions designed to provide details about women’s lives, including socioeconomic status and cultural background. Six of nine participants submitted the DIS electronically to me before attending their first focus group. I received no other questionnaires.Information gathered by the DIS complemented focus group data.

3.2.2. Focus Groups

Focus groups have been defined as “collective conversations or group interviews” (Kamberelis & Dimitriadis, 2011, p. 545). Focus groups are described as occupying a space between interviews and naturally occurring data (e.g., tape recordings of naturally occurring conversations), with closer proximity to the latter than the former (Perakyla & Ruusuvuori, 2011). Kambereelis and Dimitriadis (2011) note that focus groups have three primary functions - pedagogy, politics, and inquiry - and that the prominence of each function varies and intersects through the use of this particular interpretative research method.

My research consisted of two rounds of focus groups. In the first round, two small groups of women with disabilities identified processes and practices that support the inclusion and participation of diverse women with disabilities in research. In the second round, women explored and provided feedback on the themes that emerged from the first round of discussions. In my research proposal, I had planned three first-round focus groups, but it became evident that a third focus group within the wider disability community was not likely to result in cultural or ethnic diversity.

Gathering data through focus groups was particularly well suited to my research for multiple reasons. Firstly, the multi-functional nature of the method is consistent with my theoretical frame. Focus groups are conducive to participatory research and provide an opportunity for individuals to share and gain in their understanding of their lived experience. They are also useful in democratizing research and can lead to social transformation (Kamberelis & Dimitriadis, 2011; Salmon, 2007; Wilkinson, 1998). The method is said to be democratizing as power is distributed among members of the discussion group (Salmon, 2007; Wilkinson, 1998). The focus group format provides an opportunity for women to share and explore their individual and collective experiences, facilitating a reduction in feelings of social isolation and an increased awareness of the political implications of their social experiences (Salmon, 2007; Wilkinson, 1998). Finally, it was much more practical for me to arrange disability-related accommodations for a group of women than for individual interviews (i.e., more financially viable and time-efficient).

I held three focus groups with a total of nine women over two rounds of discussion. Four women attended the first in-person discussion in August of 2017. Five women participated in the second discussion via teleconference in October of 2017, and six participated in the third and final discussion via teleconference in November 2017. Everyone who participated in the final focus group had attended one of the previously held focus groups. My intention was to recruit four to six women for each focus group. This number is small compared to the numbers suggested by other researchers as most likely to bring a variety of perspectives, but the small number of participants in each of my focus groups helped me to keep track of voices and helped to limit side conversations that often happen in larger groups (Nyumba et al., 2018).

I provided agendas (Appendices A and L) to participants before each focus group in the format and layout of their choice (e.g., hard or electronic copy, large print to their specification). I began each of the discussions by briefly introducing myself and inviting each participant to introduce themselves to the group. I reviewed the reason and goals for my research and invited participants to ask questions. I then presented the concepts of feminist intersectionality, reciprocity, and reflexivity in relation to the research project and their participation; in each focus group, I presented an overview of each of the three concepts in a conversational style and using terminology and examples that I hoped would be easily understood by each woman in the group. I raised the issue of power imbalances inherent in the researcher/researched relationship and introduced the concept of reciprocity and its importance to feminist research (including mine) in each of the first-round discussions. I also elaborated upon it in the final thematic discussion. I encouraged the women to think about and advise me on how my research could benefit them.

I invited focus group participants to discuss any concerns or questions they had as a result of participating. I was aware of the possibility that potential triggers that may occur during focus interactions amongst participants. Wilkinson (1998) has discussed the unintended consequences that can arise from empowering group participants, which is the possibility of contentious behaviour that negatively affects another participant's participation. "Ethical difficulties may arise precisely because of the (relative) lack of control exercised by the researcher over group interactions" (p. 116). Kitzinger (1994) notes the possibility that comments can be "directed to other members of the group and take the form of bullying or intimigation" (p. 118).

Wilkinson suggests that the facilitator prepare for this possibility and think about appropriate interventions prior to conducting a focus group. I invited focus group participants to contact me after their participation in focus groups if they wanted to share feedback on the conversation, my facilitation, or anything else about the focus group. I chose this practice to respond to Lunn and Mumford's (2007) point that providing opportunities for participants to provide constructive and critical feedback to researchers is one way to disrupt power imbalances inherent in research relationships. None of the participants contacted me after any of the focus groups. I also provided them with the names and contact information for help lines and other counseling supports available should any participant feel they wanted someone to talk to as a result of participating in the focus group (see Appendix I).

All three focus groups ran for 1½ to 2 hours. The agenda for the first round of focus groups included the following questions to guide the discussion:

Think about research projects that you have been involved with for these questions:

1. What was asked of you? Were you asked to fill out a questionnaire, attend a focus group, recruit other people for the research, etc.?
2. Why were you asked to participate in the research project(s)? Was it because the project(s) focused on persons with disabilities? Was it because you are a woman? Have there been other reasons?

Think about the times you have enjoyed being a research participant.

1. What was it about those experiences that made them feel good? Did the researcher(s) seem to value what you had to say? Did it feel easy to participate? Did you feel your participation was making a difference? Other reasons?

Now think about times when you did not enjoy participating in research.

1. What was it about those experiences that made them feel bad? Was it difficult to participate in the research for some reason? Other reasons?

Questions within the conversations included:

- What was it about those [research] experiences that made them feel good?
- Did the researcher(s) seem to value what you had to say?

- Did it feel easy to participate?
- Did you feel your participation was making a difference? Other reasons?

In the final discussion, I provided participants with a document itemizing the themes emerging from the first two discussions (see Appendix G), in advance of the focus group. Supporting statements and ideas followed each theme. I included questions to prompt participants on each theme, including: “What can researchers do to make the expenditure of time, energy and other resources worth participating?” and “What steps can researchers take to become better allies to women with disabilities on an ongoing basis?”

3.2.3. Recruitment and Participation

I believed that participant diversity would ultimately reflect my efforts to connect with organizations that are also diverse in terms of the people they support. I attempted to connect with potential participants through my established personal and professional networks, which include program staff and leaders of the following community-based organizations: Independent Living Nova Scotia Association (ILNSA), the Deafness Advocacy Association of Nova Scotia (DAANS), Society for Deaf and Hard of Hearing Nova Scotia, Nova Scotia League for Equal Opportunity (NSLEO), and Immigrant Settlement Association of Nova Scotia (ISANS). I specifically targeted these organizations for recruitment because they are all provincial organizations with contacts across Nova Scotia. They also complement each other in terms of their mandate and work collaboratively to support persons with multiple disabilities and complex realities. The ILNSA is a cross-disability organization with priorities that include providing service to persons with all types of disabilities. NSLEO is a systemic advocacy-focused organization. DAANS is provincial in scope, is individual and systemic advocacy-focused, and specific to the Deaf and hard of hearing community in Nova Scotia. ISANS is the lead organization in resettlement of newcomers to Nova Scotia. I expanded my recruitment efforts beyond these named organizations to include centres for international students at Saint Mary's University, Dalhousie University, and Mount Saint Vincent University campuses. I sent recruitment information to centres for students with disabilities located on Halifax university campuses of Dalhousie University, Saint Mary's University, and Mount Saint Vincent University. I also reached out to friends and colleagues with personal and professional connections to women with disabilities currently residing in Nova Scotia. In the end, I contacted over 20 distinct organizations and individuals to distribute recruitment information. I received emails, Facebook posts, and phone calls from individuals throughout Nova Scotia leading me to believe that the information had been widely distributed.

I began my recruitment efforts in mid-July 2017. Initially, I was attempting to recruit participants from each of the three community groups, simultaneously. I hoped to do the bulk of recruiting in July and hold at least the first round of small group discussions in August 2017, with the thematic discussion to happen by the end of August or within the first week or so of September. As it turned out, I extended this timeline, with the first discussion happening in August and the last in November 2017.

3.2.3.1. Recruiting Within the Deaf Community

I began recruitment efforts by specifically contacting women with whom I had worked on previous research projects. I am not widely known within the Deaf community, so I was hoping to spread the word about my research through personal networks. I sent follow up emails but did not receive responses. I expanded my search for participants by sending emails to organizations, including Society for Deaf and Hard of Hearing Nova Scotians and Deafness Advocacy Association, but I still did not get a response. I continued my efforts until the end of September of 2017. Unfortunately, no one from the Deaf community contacted me in follow up to my recruitment-related emails, resulting in no representation of women who are Deaf. As discussed later in this chapter, I identified a number of possible explanations for the lack of response, including the complexity and language of information about my research, and the legacy of harm stemming from research and research results uninformed by Sign Language cultures.

3.2.3.2. Recruitment Within the Newcomer Community

I had only a small number of experiences with the newcomer community in Nova Scotia prior to this research. I was hopeful that I could leverage my previous connections with those organizations to reach out to women with disabilities. As it turned out, the contacts I had were no longer in the same positions. Once I learned this, I realized I would be starting from scratch in contacting community leaders. Given my short timeline, I decided to focus my attention on contacting the appropriate person at Immigrant Settlement Association of Nova Scotia who works specifically with persons with disabilities who come to Canada and receive support from their agency. I met with the appropriate case worker who agreed to take the recruitment information to her supervisor and, if approved, then distribute it to the small number of women with disabilities currently being supported by that agency. I spent significant time arranging this meeting, and it occurred only after I had exchanged multiple emails, including recruitment information, with a number of people. The supervisor approved the case worker's request to distribute the recruitment information, but no potential participants came forward. As with the Deaf community, I continued recruitment efforts with the newcomer community until the end of September 2017, but I was ultimately unsuccessful in having anyone participate in my research. I explore several possible reasons for the lack of response from the newcomer community later in this chapter. They include the relatively small number of women with disabilities being supported by the Immigrant Settlement Association of Nova Scotia during my data collection period, and Canada's ableist approach to immigration.

3.2.3.3. Recruitment Within the Wider Disability Community

I began recruitment efforts within the wider disability community in mid-July and I very quickly received responses from six women with disabilities. I confirmed five participants by the second week in August and was able to facilitate the first small group discussion in late August of 2017. I was able to widely distribute recruitment information through established networks that included organizational email lists, Facebook groups, and individual women who forwarded the information to friends and family.

I received expressions of interest from women throughout Nova Scotia, with several noting the exclusionary nature of face-to-face discussions. One email, in particular, clearly outlined the exclusionary nature of my chosen methods. The author stated her desire to participate but pointed out that she was unable to travel from her rural community to attend. Some women expressed interest but could not manage the anxiety associated with various aspects of my methods (e.g., driving in an unfamiliar area and speaking within a group setting). I exchanged emails with these women, thanking them for their interest and for pointing out the barriers to inclusion inherent in my methods. I promised to note the points they made in my thesis and endeavour to include options such as Skype or teleconference discussions in future research. The women responded favourably to these emails and asked that I let them know if something changed with the current research so that they could participate using one of these alternatives.

Given the lack of response from the Deaf and newcomer communities, I requested and received approval from Saint Mary’s Research Ethics Board to make an amendment to include the teleconference option and continued to recruit participants within the wider disability community. I reconnected with each of the women who expressed interest in participating if a virtual or teleconference option became available. At least two women participated in my research as a result of adding the teleconference call option.

3.2.3.4. Information Gained Through Initial Contact

I developed and maintained a contact log to guide my conversations with potential participants. I asked all participants the same questions to ensure they fit the eligibility criteria and to gather any disability-related accommodation or other supports necessary to facilitate their participation in my study. I unsuccessfully applied for funding to offset some costs for participants, such as childcare and transportation (see Appendix H for funding request). I had the skills and equipment necessary to provide alternative formatting (e.g., Braille and accessible electronic documents) without additional external funds. I gathered the following information during initial contact with potential participants to screen for eligibility and diversity: name, referral source, over 16 years (yes/no), identify as a woman (yes/no), identify as having one or more disabilities (yes/no), live in Nova Scotia (yes/no), cultural background (e.g., Deaf, Arabic). Once I confirmed their eligibility and interest to participate, I asked for their preferred contact method and the details associated with it. I also made note of their disability or other support needs associated with participating in my research, e.g., “requires large print, aware of energy limitations, works during the daytime.” Some women also advised me of immediate travel plans to assist with advance planning of small group discussions.

3.3. Ethical Protocols of Note

Ethical research practices have long been a linchpin of feminist research (Bell, 2014; Sprague, 2016). Linda Bell (2014) distinguishes between ethics and morality in her discussion of ethical issues in feminist research. Bell defines ethics as “moral principles or rules of conduct…while morality is the identification and practice of what one ought to do” (2014, p. 126). Participation in my research carried minimal risks limited to engaging in a maximum of two focus groups and voluntarily completing the DIS. My project design met the ethical requirements of Saint Mary’s University Ethics Review Board and reflect established expectations of many leaders within the disability community of Nova Scotia. In this way, I am consistent with Bell’s assertion that “what is considered to be ethical research practice in particular circumstances will depend on what is considered to be good moral conduct whether this is founded on social, religious or cultural grounds” (2014, p. 126).

3.3.1. Informed Consent

3.3.1.1. Process of Obtaining Informed Consent

Obtaining informed consent within the disability community requires an individualized approach that attends to factors that include the format a woman uses to access information (e.g., Braille, electronic or hard copy text); how a woman best processes information (audibly, visually or tactilely); and, a woman's cognitive skills and abilities (such as predicting risks associated with her participation). I used a multi-pronged approach to acknowledge and mitigate risks associated with these factors that involves women identifying the preferences, needs, and protocols that ensure their privacy, confidentiality, and anonymity. I discussed information-related preferences and needs with each woman before distributing the consent form, providing the forms for them to complete before they attended their first small group discussion.

3.3.2. Privacy, Confidentiality, and Anonymity

All women who agreed to participate in my research completed a confidentiality agreement as part of the consent form, prior to attending the focus group. In keeping with my commitment to share power and follow inclusive practices, I emphasized that women were in the position to make choices about what they shared about themselves throughout their involvement in the small group discussions. Focus group attendees, including support workers and trusted allies, were reminded of their responsibility to maintain the privacy of other women present by keeping confidential information shared within the focus group.

3.4. Data Analysis

3.4.1. The Politics of My Analysis: Contextualizing Women's Participation

The women detailed the various costs associated with their involvement in my research. These included financial considerations (e.g., transportation costs), time (e.g., choosing to participate in my research meant they would not do other activities), and energy (e.g., participating in my research influenced other activities for that day and week). My commitment to reciprocity spurred me to settle on an approach to data analysis that gave what I believe is the most value to the resulting data, given the goals of this research and the desire for participants to be involved in meeting those goals. I chose what Braun and Clark refer to as a "contextualist" approach (2006, p. 10). This approach "acknowledges the ways individuals make meaning of their experience, and in turn, the ways the broader social context impinges on those meanings, while retaining focus on the material and other limits of reality" (Braun & Clark, 2006, p. 10). Within the contextualized approach, my theoretical lens, experience, and areas of expertise guided me to identify and think about the themes. This is, admittedly, a "top down" (Braun & Clark, 2006, p. 13) approach and sits in tension with my ideals of democratizing all aspects of research.

3.4.2. Developing My Tool: Intersectional Thematic Analysis

3.4.2.1. Thematic Analysis

Braun and Clark define thematic analysis as “a method for identifying, analyzing, and reporting patterns (themes) within data” (2006, p. 7). Thematic analysis is characterized as being a widely used method of data analysis that provides flexibility for use with various data collection instruments and across disciplines through its “theoretical freedom” (Braun & Clark, 2006, p. 6). Asking questions of the data, identifying themes, and otherwise interacting with data, however, depends on the epistemological, theoretical, and as I have pointed out, the embodiment of researchers. As such, it is important that researchers are explicit about the assumptions, biases, and other components of their praxis being applied to thematic analysis (Braun & Clark, 2006).

3.4.2.2. Applying Intersectionality

As I discuss in detail elsewhere in this document, intersectionality is a flexible and critical analytic tool, with several principles that are well suited to guiding the analysis undertaken for this research. Firstly, intersectionality provides the basis for multi-level analysis in which:

> the effects between and across various levels in society including macro (global and national institutions and policies); meso or intermediate (provincial or regional institutions or policies), and micro levels (community level, grassroots institutions and policies) as well as the individual or self. (Hankivsky et al., 2012, p. 3)

Secondly, an intersectionality-infused thematic analysis looks for evidence of diverse knowledges, perspectives, and ways of knowing (Hankivsky et al., 2012). Finally, it recognizes that time and space influence participants’ experiences, perspectives, responses, and interactions with each other without diminishing the value and importance of the present (Hankivsky et al., 2012). Intersectionality honours and illuminates the perspectives of individual women who participated in my research and raises implications for researchers who want to engage diverse women with disabilities generally.

3.4.3. Procedures

3.4.3.1. Demographic Information

Participants electronically submitted their completed Demographic Information Survey (DIS) before attending their first focus group. I replaced participant names with aliases and removed their contact information. I copied and pasted responses from individual surveys to one Excel worksheet, ensuring accuracy of the process by comparing records in the Excel worksheet to individual surveys. I initially analyzed the complete data set to identify:

- the number of surveys that were partially or totally completed;
- the prevalence of common responses;
- the appearance of positive, negative or unknown correlation of responses (e.g., age to educational attainment; income level to educational attainment; and, age to income level to educational attainment); and
- contextual information to situate content of the focus groups and to enhance understanding of the research results.

In the end, I combined the DIS and focus group data to develop participant profiles that inform my intersectional analysis of the research data and findings.

3.4.3.2. Focus Groups

I digitally recorded and transcribed focus groups verbatim. I used various features of Microsoft Word and Excel to code, summarize and check data. My analysis was descriptive and interpretive (Braun & Clark 2006). I reviewed the data for explicit responses to the focus group questions I provided participants in advance of the small group discussion, and those that arose within participants' conversations. I initially analyzed transcriptions of the first two focus groups for broad common themes to serve as the basis of discussion for the final focus group. I did not prioritize the themes based on intensity of dialogue among women or the degree to which consensus was reached. I reviewed the transcripts again to check for missed themes at this initial level, but no additional themes surfaced. I then began my intersectional analysis of the major themes. The questions I asked of the data at this point were both descriptive and transformative (Hanksvky et al., 2012). I developed a document containing the themes and supporting participant quotes and points of conversation and provided this document to the women who participated in the final focus group.

After the final small group discussion, I analyzed the transcript to ascertain the degree to which the themes identified in the first two focus groups were confirmed. I later refined these themes and condensed them into four which are discussed at length within the findings chapter. Finally, I conducted a targeted review of the three discussions, focusing on the interactions among women to explore what else might be revealed about their experiences with research in general, and my research in particular.

3.4.3.3. Targeted Analysis of Participants' Interactions

I took a focused approach to isolating and analyzing the interactions among women who participated in my research. I reviewed the transcripts and digital recordings to identify a quote or segment of discussion that was particularly interesting to me. I performed an intersectional analysis on this content, using questions I developed to help me hear at least some of the complexity of their perspectives:

- What evidence is there of diverse knowledges, perspectives, and assumptions among participants?
- What evidence is there of different and fluid relationships to power among and between participants, and how is this evidence revealed, identified, etc.?
- In what ways do participants infer the individual and common experiences to engagement with macro level issues (e.g., systemic gender and disability bias and discrimination)?
- What implications are made for positive change and transformation across and between the various structural levels (macro, meso and micro)?

I analyzed the conversations among participants to get a sense of how their individual experiences resonated with those of other group members. I listened for a range of responses that included women affirming or gently challenging each other or working together to further explore ideas that surfaced during the discussion.

3.5. Living the Principles of Feminist Research

3.5.1 Recruitment

I designed a participant recruitment strategy intended to result in the engagement of women with disabilities representing three broad groups: women who are Deaf, newcomers to Nova Scotia, and the wider disability community. Unfortunately, I was unable to engage with women who are Deaf, despite multiple attempts. I can only speculate as to an explanation, but I offer the following for consideration. First, research has been historically harmful to people who are Deaf (Harris, Holmes & Mertens, 2009; Singleton, Martin & Morgan 2015). Researchers were traditionally outsiders to the Sign Language community and would employ culturally inappropriate processes (e.g., long complicated consent forms not available in participants' sign languages) and uninformed data analysis that resulted in what Harris, Holmes and Mertens term "research that can today be considered ethically abusive" (2009, p. 4). As a result, people in the Deaf community are wary of researchers. Moreover, as a leader in the local Deaf community advised me, many Deaf people are very reluctant to engage with research because of their experiences of subjugation while at residential schools.

Furthermore, unfortunately, and in retrospect, I realized that the information I prepared to explain my research was long and complicated, and only provided in English. I suspect this made the information inaccessible to the women I targeted, which could have hindered distribution within the Deaf community. I also did not make clear in my recruitment information that I understand the Deaf community as a distinct cultural community versus a subpopulation of the wider disability community. Finally, I began my recruitment efforts during peak time for summer vacations. I think this is relevant because I used organizational email addresses when reaching out to the community.

I was also unsuccessful in attracting participants who were newcomers to Canada. I am once again speculating, but I believe reasons may include the timing of my recruitment efforts, and Canadian immigration policies that have generally excluded individuals with disabilities from relocating to Canada. I also suspect summer vacations affected recruitment efforts within the newcomer community, as it did with the Deaf community. It took me some time to connect with the correct person at ISANS to provide information on my research and arrange a follow up meeting to discuss it in detail. Momentum was further negatively affected when the vacations of the ISANS case worker and her supervisor fell on alternating weeks. The caseworker, who was supporting my recruitment efforts, shared with me in the beginning that there were very few women with disabilities on their case list during the recruitment period, and that the majority of persons with disabilities who were receiving support at that particular time were men.

A review of academic literature reveals that little has been written about the experiences of women immigrants with disabilities, in general, which may indicate the infrequency with which it is known to happen. Scholars describe long-standing systemic discrimination against potential immigrants based on factors including disability (Weber, 2015; Wong, 2012). Canada's immigration policy has been called to task for underlying racist, sexist and ableist subtexts (Hanes, 2009; Li, 2001; Wong, 2012). Immigration efforts are said to be closely linked to economic growth and labour force productivity, with persons with disabilities understood to be non-contributors to these efforts (Wong, 2012). In addition, Canadian policy is concerned with the potential demands on already strained healthcare budgets (Wong, 2012). Wong refers to, "ableist foundations of the Canadian nation state" (2012, p. 2) in Canada's immigration policies. Eligibility criteria and the point system by which potential immigrants are evaluated are built upon what Wong terms, "the procurement of disposable migrant workers" (2012, p. 9).

My unsuccessful recruitment efforts within the newcomer community is not surprising given the historical exclusion of persons with disabilities from Canadian immigration efforts. My social network was also insufficient to support my efforts to recruit research participants.
Over the course of this project, after reflecting on my own thought processes and decisions, I grew in my awareness of the role research can play in revealing, challenging, and perpetuating colonization through research activities conducted with individuals from the Global South. I especially came to recognize at least some of the many complexities involved in building relationships and reaching and connecting with women who may be interested in participating in research. I continue to believe that research such as mine can play a role in deconstructing the researcher-participant relationship and knowledge production as they play out for newcomers from the Global South. At the same time, I have a greater awareness of the ease with which I rest in my position within Western neoliberal scholarship (Chowdhury, 2009; Mohanty, 2013). I did not anticipate the impact of historical factors on my research such as the relationship between members of the Deaf community and research, or the structural impediments to persons with disabilities becoming newcomers to Canada.

Finally, women were not included from all regions of the province. As a result, the questions and answers associated with my research reflect less diversity than I had hoped.

3.5.2. Member Checking

The iterative process developed for my research provided for important member checking of preliminary research findings. Participants who attended the final focus group were provided feedback on the themes that emerged from the first two small group discussions. They confirmed the relevance of each theme in relation to the research question, elaborating on several (e.g., the assignment of expert status to individuals), and discussed additional issues such as how researchers can show value for participants.

3.6 Conclusion

My research relied primarily on data gathered through small group discussions with four to six women to answer the research question: What tools and practices are necessary to ensure that diverse women with disabilities are able to fully participate in, and benefit from, research? Despite my failure to recruit newcomer or Deaf women with disabilities, I adhered to the tenets of my methodological approach insofar as they could enhance the experience for women with disabilities who were members of the wider disability community.

Chapter Four: Findings

This chapter begins with an introduction to participants and then moves on to present the four themes that emerged from my analysis of focus group data:

- Theme 1: Benefits to participating in research;
- Theme 2: Barriers to participating in research;
- Theme 3: Participation in research is embedded in complicated daily lives, and;
- Theme 4: The relationships between individual women and research is complicated.

I incorporate a broad analysis of interactions among participants in this section and elaborate upon it within the Discussion of Findings.

4.1. An Introduction to Participants

Nine women participated in the first round of two focus groups, and six of the nine participated in the final thematic discussion. The following participant profiles are based on the women's responses to the DIS and information they provided during focus group discussions. Six of the nine women completed the DIS. I provide the following information, anonymized as discussed in Chapter 3, to resist "static representations of people's identities and social locations" and the "aggregation of the women into bounded categories such as 'women', 'poor women', 'marginalized women'…without proper attention and investigation of within-group diversity" (Hankivsky, 2014, p. 256).

April[22] is a single woman, between 60 and 69 years old, who lives in Halifax. She identifies as heterosexual and non-racialized. She has completed some post-secondary education, is retired, and participates in her community as a volunteer with a variety of organizations, primarily in the non-profit and public sectors. She discloses multiple disabilities, including chronic pain and vision and mobility impairments. She has participated in community consultation processes involving focus groups and surveys.

Arial is a single, retired woman who lives in a town outside Halifax. She also identifies as having multiple disabilities and is hard-of-hearing and has cognitive disabilities. She participated in academic research while attending university.

Noella is between 50 and 59 years of age and lives with her partner in a rural community. She has completed multiple postsecondary programs and is currently employed full time. She lives with chronic pain and has mobility-related and other physical impairments. She has participated in many focus groups and community consultations.

Subratta is between 50 and 59 years old and lives with her partner in rural Nova Scotia. She identifies as heterosexual and non-racialized. Currently employed full-time, she has mental health and physical disabilities. Her previous participation in research has primarily involved completing surveys.

Ophelia, a single mother aged between 40 and 49, lives in Halifax. Currently a university student, she is employed full-time and volunteers in her community. Her previous research experience includes participation in medical research.

Sawyer, who resides in a small town, is between 40 and 49 years old, is married and has children. Employed full-time, she also volunteers in her community and is currently completing

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[22] All names are pseudonyms.

one of several postsecondary programs. She identifies as heterosexual and non-racialized and has a learning disability. Her previous research-related experience includes participating in community-academic research and facilitating focus groups.

Mandy is married and between 30 and 39 years old. She is employed full-time and a university student. She has mental health, physical, and learning disabilities. Her previous research experience includes participation in medical studies.

Lavinia is single, between 20 and 29 years old and lives in a suburb of Halifax. She has chronic pain, and mobility and learning disabilities. Currently unemployed, she is an active volunteer and a university student. She has participated in research through interviews and surveys.

Maxine, a single woman between 20 and 29 years old, lives in Halifax. She completed a postsecondary program and is employed part-time. She has mobility and learning-related disabilities.

All participants identified as "woman" and disclosed as having one or more disabilities. At the time of participation, they all resided in Nova Scotia and none identified as being racialized or immigrants to Canada. Their diversity emerges with respect to the number and types of disabilities they experience, and their age, presence of children, educational attainment, employment status, area of residence, and relationship status. These and other factors converge "to produce a social location that is different than just the sum of its parts" (Hankivsky, 2014, p. 255). Each woman occupies intersecting axes of identity that inform their experiences with research, including mine. With this in mind, I offer my interpretations of their stories, and my thoughts about supporting women with disabilities to participate in and benefit from research throughout the remainder of this chapter.

4.2. Themes

4.2.1. Participation in Research Can Be Rewarding for Participants

4.2.1.1. Seizing the Opportunity To Define Oneself

The participants' comments during each of the three focus groups point to the value they placed on being able to define themselves and their identities as women with disabilities. Their self-introductions included descriptions of their embodiment in ways that affirmed their knowledge and experience as women with disabilities and validated their involvement and participation in my research. The women shared details of their disabilities that included, but often went beyond, commonly used phrases like "visually impaired" or "wheelchair user." The experiences they described were intersectional in nature. April's self-introduction illustrates this point:

> My name is April. I will be one year older shortly. I just had surgery three months ago. I've been diabetic for many years and there are side effects. I am legally blind, I have multiple disabilities, and complications associated with diabetes. I'm always in some form of pain. I've recently been diagnosed with a condition that will mean I eventually will be using a wheelchair. I am retired from a job that I really enjoyed. I am very involved with numerous [community] groups. On one community board, I am the only person with disclosed disability among a group... I think I've opened a few eyes there.

Other women were at first quite brief in their self-definitions, with a couple providing greater detail as the group discussion went on. The following excerpt provides an example of this pattern. Noella began by stating very briefly:

> My name is Noella. I am a person who lives with several disabilities. I am a social worker. I began working 30 years or more ago in the field of disability. I hold a leadership position in a non-profit organization, and I think that's all I need to say.

Later, after everyone else had introduced themselves, she asked if she could elaborate:

> I said I have multiple disabilities, I should explain. About 25 years ago, I had a fall that did some damage to one of my joints which turned into bursitis. I functioned with that for awhile and then started to have some mobility issues. It turned into more than just the initial problem. After some tests, I was told I had spinal stenosis which is essentially when the column that holds the spinal cord starts to squeeze the spinal cord and that affects your nerve tissues. I use a walker for walking short distances and a scooter for longer distances. It's hard to get transportation with a scooter because it's longer so I can't take Access-A-Bus. Yeah, so mobility, that's kind of my issue. I also live with chronic pain.

Several participants explained to the group the steps they were taking to meet their disability-related needs in their unique situations. Some embedded this information in their self-introduction, while others explained their disability-related access activities after the initial self-introductions. These disclosures indicate a willingness of participants to engage in rapport building with each other (Wong, 2008). For example, Arial briefly described herself as being hard-of-hearing with some cognitive difficulties during the round of self introductions. After everyone else had introduced themselves and before we moved to the next part of the discussion, she explained that she was jotting down notes and described their purpose and the nature of their contents: “I’m taking a few notes to help me remember names and discussion points so I can participate in the conversation, but there’s nothing I’m going to write about anybody. You can all look at it anytime and Julianne will look at it later. I don’t want anyone to feel like I’m being sneaky.”

4.2.1.2. Peer Support and Community Building

All participants engaged with each other on topics beyond those immediately related to my research question. The women in each focus group moved quickly from their initial self-introductions to joking with each other and sharing stories of systemic discrimination and experiences situated within their unique set of social circumstances and identity markers. Many women who participated in the three discussions freely shared details of their disabilities and experiences as women with disabilities. I encouraged the women to share only what they felt comfortable revealing. To help reduce participants’ sense of pressure or expectations about disclosing details, I introduced myself briefly in the beginning of each discussion, offering more detail after all other women had introduced themselves. Some women in each focus group were strangers to each other. Nevertheless, women in each focus group disclosed detailed information, such as their age, age of onset of their disability/disabilities, year of onset, and descriptors (such as ‘mild,’ ‘totally,’ ‘partially’). Participants sometimes shared further information, such as relationship status, sexual preference, and romantic relationship history later in the conversations. Some women offered others possible solutions to problems in daily life that emerged during their conversation (e.g., explaining how they did their grocery shopping or managed chronic pain). They also shared stories of encountering disability-related stigma and misconceptions while performing tasks of everyday living. For instance, the women told stories about times when they had felt reduced to their disabilities, discriminated against, stereotyped, dismissed, and/or underestimated. The following interaction between April and Lavinia provides one example:

> April: I spoke one time at a gathering, and I said I struggled to identify myself as a person with a disability, that's not how I see me. Sometimes I do when it's convenient, but I don't see me as a person with a disability. I'm just as capable as anyone else. It's like when you say, I've had so many people say oh I saw this on TV, did you see that? And then they'll say, oh I'm sorry, I'm sorry. I say, what for? Don't worry about the vernacular, but people see the disability first. It's a fact, people see the disability first no matter what you do.
>
> Lavinia: Only if it's visible though [April agrees]. I'm lucky enough I have all the disabilities. I have a physical disability which is seen and a cognitive disability which is not, I have a learning disorder and then I have depression and anxiety. Those things aren't seen. [Noella agrees and says, "and you're dismissed"]. So, I feel bad for people who have the ones that can't be seen. So, a teacher might say, you're really smart, why didn't you write the article? Well, because that's my disability, I don't remember to write the article.
>
> April: And people don't believe you.
>
> Lavinia: No, they don't. I've been called lazy, I had a teacher tell me I wouldn't amount to anything, I was thought to be lazy.

Later, Lavinia's anecdote about a trip to the grocery store and the subsequent conversation among women provided another example:

> Lavinia: "I went to the grocery store to buy strawberries and when the clerk took them off the shelf for me I said, 'thank you very much' and she said, 'You're so brave' and I was like 'I bought produce.' What about that made me brave?"
>
> Noella: Well it was strawberries!
>
> Arial: Must have thought they were dangerous [light laugh]
>
> Noella: Her intention probably was to give you a compliment.
>
> Lavinia: Yeah, well that's no compliment!

Lavinia's concluding comment implies her rejection of the dominant narrative of disability as tragedy (Garland-Thomson, 2007; Cole, 2009). Another exchange among several of the same women highlights other aspects of the dominant narrative of disability and their resistance to same:

> April: I'm a senior with a disability and I have to stick up for myself. I'm single, and I have to stick up for me, I have to stick up for me and people put labels on me because I do that. You know what I'm trying to say? They'll say, oh you're in a bad mood… or they'll say, why?
>
> Noella: Or they go the other extreme and hero worship.
>
> *[General murmuring of agreement and frustration]*
>
> Lavinia: I get so much hero worship it's not funny.
>
> Noella: That's more insulting than anything.

The women used the term "hero worship" to describe instances when people cast them as heroes, (e.g., Lavinia's story) just for going about their daily lives. The women rejected the narrative of disability as tragedy (Garland-Thomson, 2007), neither did they claim, "identities as… the heroic individual struggle(ing) against adversarial forces" (Garland-Thomson, 2007, p. 118). Instead, the women shared details of their lives that exemplified their role as agents of change and community leaders, such that they "inhabit a marginalized space that is not a site of domination but a place of resistance" (Fine, 1994, p. 70).

4.2.2. Challenges and Barriers to Research Participation Exist

4.2.2.1. Rejection of Research-Related Labels

Some participants described their decision to not participate in research as an action of rejecting research-related understanding of their embodiment and lived experience. For instance, Ophelia noted:

> I found the research to be a very negative experience and why I kind of took my health into my own hands a little bit more was because they made it, um, very doom and gloom I guess is the only way to put it. They just made it seem like you know they really dwelled on the illness and you know, it will never get better, it will only get worse [sounds weighed down] and it was always that kind of stuff that just wasn't me. I was more the, as we say [with a chuckle], the stubborn one. [Other women join in laughter]. When they called me after that to do some of the research studies at other times, I turned them down after the first two that I agreed to do because I thought maybe I could be beneficial in the study but [inhales] that's that.

Ophelia's rejection of opportunities to participate in research seemed to be based on a disconnect between her embodiment and what Garland-Thomson refers to as the, "story of despair, catastrophe, loss, excess, suffering, and relentless cure-seeking" (2007, p.114) consistent with the medical model of disability.

4.2.2.2. Disability-Related Awareness and Accommodations are Often Lacking

The women talked about participation in research as being a complicated endeavour that requires time and energy in addition to daily life. Researchers' ability or willingness to be flexible with timelines and methods of participation has determined the participation of women in my study. Subratta felt that participation rates in research generally would be better "if deadlines for participation can be extended or if [researchers] can understand that women may have disabilities they don't even know about so cannot ask for accommodations ahead of time." The participants in the final discussion all agreed that researchers would experience increased interest in, and participation rates for, research if they provided multiple methods of participation. They also spoke to the importance of researchers' ability and willingness to be flexible and supportive of their disability-related needs. For instance, Subratta described the challenges she experienced being a new mother while participating in one research project:

> The research material was overwhelming, in itself, but for a new mother with a child with health issues, it was too much. If there had been additional support, with the researchers appreciating what was going on with the circumstances, that would have been very helpful.

Maxine spoke about balancing effort and energy in addition to the difference that sufficient time and other supports can make: "It's [about the] time to prepare and brainstorm ideas and it's helpful for me to always have a support person and more time and I also get way too tired way too fast. It's like everything for me takes energy so even talking takes energy for me.” Similarly, Lavinia described an experience when her ability to participate in a research project had been made possible due to researcher flexibility. She was supported to participate in one research project when the researcher came to her house and “sat with me and asked me the survey questions.”

Participants noted that the tools and instruments often employed by researchers do not support the engagement of a diverse group of women with disabilities, resulting in the absence of their perspectives. Sawyer noted, “Tools are not effective for so many people and [researchers] are missing their perspective as a result of their non-participation.” In addition, participants spoke of not engaging in research because, as the following comment from Noella illustrates, their disability-related needs were not taken into consideration in the planning stages.

> Research-related events are often very difficult to get to and are set up for the general public with no real consideration of the barriers anybody with a disability would be dealing with to get there, such as parking, and that kind of thing. I found myself often not participating for those reasons, even though I would have liked to have gone, because I found it interesting it’s just not possible because of the barriers.

Some of the women acknowledged that all research has boundaries, and Subratta, in particular, spoke of researchers’ limitations in conducting their research: “Researchers must accept the limitations they will have to impose to meet time lines and schedules, but being open and acknowledging that more can be done is a good step.”

4.2.3 Research Participation is Embedded in Complicated Daily Lives

Several participants noted the ongoing constraints that traditional gender roles have in the lives of women. Noella, a woman in her 50s, said about the traditional gender roles of women: “We are the ones who have been the caregivers and caretakers of the babies and of the elderly and of anyone who is sick and it just seems to be that women are [still] in that place.” Sawyer similarly offered her perspective as a mother:

> Until my child was self-sufficient, that curtailed a lot of the things that I felt I could do [including] how I could participate in initiatives and research. I had a very supportive [romantic partner] but it was, ok, I’m a mom, I have to tuck her into bed.

April shared her thoughts about the historical implications of gender:

> In earlier years, fathers who had a daughter… well, the only good thing about a daughter was that maybe she could marry into money. The son-in-law would help the family out. So the role of daughters were to get married and have kids. So this is the way it went. So now we’re trying to change that but I think that no matter how much we say that women are independent, I think there continue to be real barriers.

Lavinia’s comment on ideas of gender role expectations, such as those expressed above, points to a generational shift. She said with a sense of certainty, “I’m happy to report that in my generation, that doesn’t seem to be the case in my circle of friends. We don’t do that.” Lavinia also compared her schooling experiences to that of some of her older friends: I went to an integrated school. Lots of women born before me didn’t even go to school. I have a friend in her 50s who has a second-grade education. Some women with disabilities, they don’t know how to do things because they were never taught. They grew up in a time when, ‘you’re disabled, you’re meaningless.’

Several participants shared that their decision to participate in research (and other) activities, particularly during evenings and outside the home, is influenced by their need for safety as women. For instance, Noella noted, “I think fear of harm is a piece that can impact participation in research or town meetings, or anything that happens in the evening.” She continued:

> Fear is a big barrier, fear of being raped, fear of being mugged, fear of having your place broken into, it amazes me. I watch men sometimes, just get out of their vehicle in the dark and walk wherever they want to walk, they don’t have to use a cane and they don’t have to have anything to support themselves.

Access to individual and community resources and supports, and the ability of researchers to be flexible in accommodating individual preferences for participation, also influenced the women’s ability to participate in research. For example, Arial, who lives outside Halifax, noted, “I see a big difference in the resources available for people in general, and people with disabilities and women with disabilities who live in rural areas outside the city.” The lack of transportation options was of particular concern. Subratta, who works full-time and lives in a rural Nova Scotia community, noted that having to travel from her community to a focus group in another community can negatively impact her decision to participate: “If I had to drive two hours there and then participate for two hours and then drive home, I would just, I would just write it off.” Lavinia’s requirement for accessible transportation revealed another challenge: “Unless you can book the [accessible] bus, and not a lot of people can, or you can get one of the five accessible cabs in the entire city, you’re screwed.”

4.2.4. Women Have Complicated Relationships With Research

Many of the women expressed their frustration that research often seems to solely focus on, or give primacy to, disability rather than the person's overall experience. Noella, for instance, commented:

> I'd like to see research that has nothing to do with disability, so that you're going there as a person. If you go there as a person with disability and you're accommodated, then you get to speak from your experience as a person rather than as a disability. It drives me crazy when research is just about, always about disability.

She went on to explain her interest in my research: "The reason I was interested in this is because it's about gender and the impact of disability on research. That, to me, takes it beyond disability."

Participants felt that many researchers were more concerned with checking off boxes associated with the participation of marginalized communities than in gaining an in-depth understanding of diverse experiences. The women drew connections between this approach and research that does not lead to transformative change. Noella commented, in this regard: "It just lets those people who need to have (that perspective)… check it off and say, 'we did it.' There's no constructive suggestions for change, nothing comes to pass."

4.2.4.1. Women Want Their Participation To Be Transformative On Issues Important To Them

Maxine's decisions to participate in research depends, in part, on a thoughtful review of survey questions as referenced in her comment, "Most surveys and research about disability, I find they’re not generic enough to offer me an opportunity to say what’s important to me so that’s why I don’t usually bother participating in research.” She later offered, “I don’t participate if I don’t think my answers will make any difference in issues that the research is about.”

4.2.4.2. Researchers Should Not Attribute Expert Status And Community-Wide Representation To Individual Women With Disabilities

Women who participated in the first round of focus groups shared their frustration with, and attempts to challenge, others’ perceptions of them as representative of all people with the same or even other disability/ies. This theme received quite a bit of attention during the final discussion. Noella referred to it as “the most powerful” and Subratta described this theme as “the one that really stuck out for me.” April, for instance, noted: “I always say to people, you know, I’m only an expert in me. The province is full of thousands and thousands of experts, everybody who lives with a disability.” Noella echoed this point, stating: “I dislike a person with a disability in a room being treated like the spokesperson for all people with disabilities. That makes me crazy because we’re people, we’re all individuals.” When I asked the women to what lengths they felt researchers should go to ensure diverse perspectives, Noella responded, “I don’t know if I would say that [researchers should] look for disagreement so much as other views, like other perspectives, like not from the same, uh, place.“

At the same time, the women acknowledged research-related constraints that may make it difficult to incorporate a broad diversity of participants’ experiences and knowledge. Subratta, for instance, commented that researchers “do the most good they can with what they have” (i.e., accessing a broad representation of members of the disability community), and this assertion was validated by the other women. Nonetheless, they expressed a desire for greater transparency on this point. There was also discussion regarding whether researchers should specifically note the limitations of their research by stating the diversity of disabilities represented by their research participants. Lavinia suggested that community-wide representation is more often attributed to people with disabilities, while other participants felt that this phenomenon occurs in all marginalized communities.

4.3. Discussion

I employ feminist intersectionality and Garland-Thomson’s critical concept of misfit to reflect on my research findings in this section. The result is a discussion of the complexities associated with the participation of women with disabilities in research. After that, I elaborate on what I believe are key aspects of the interaction among participants in my study.

4.3.1. Recruitment and Participation

Participating in my research provided women with opportunities to frame and explore research-related issues and experiences of importance to them. Kitzinger describes moments when participants can take some ownership of the discussion as an exciting possibility: “When group dynamics [work] well the co-participants [act] as coresearchers taking the research into new and often unexpected directions” (1994, p. 107). For instance, the participants’ discussion about the attribution of community-wide representation of individuals with disabilities deepened to reveal their thoughts about the power of social institutions. For example, Noella’s comments link media, the attribution of expertise to select members of the disability community, and research recruitment and methods. Her observations and opinions on this are no doubt reflective of her long-term involvement in the disability community and her keen awareness of social justice issues that include gender roles, ableism, and fat shaming. Noella’s comments also point to the tendency of media to broadcast interviews with people with disabilities whose bodies and overall appearance “fit” the expert role:

> Able-bodied people often look for someone with a disability they can relate to, someone who is not too obviously disabled, uh, their speech is [easy to understand], they’re articulate, they’re decently dressed, they maybe use a wheelchair that’s not too intrusive, maybe a manual chair, and, you know, they’re not, they’re not someone who is uh, too overweight or too, too, struggle too much with their [appearance] because they [appear] to be comfortable with what they know, and the media knows that and that seems to be their attraction, looking for someone they can go to and be comfortable with to speak to about disabilities.

She went on to suggest that the media and researchers need to use different methods for gaining insight into the lives of people with disabilities:

> In my opinion, [researchers and media] are going to have to find other ways to reach people and to make it easy [to participate], whether it be phone or online or, not just small focus groups that people with transportation or people with self-confidence will go to.

Reflection on my own recruitment process reveals tensions identified by the participants of my study. Although not my intention, the opinions and voices of the women who participated in my research could be attributed expert status in the sense that theirs are the only voices being heard. The participants very clearly rejected this as an approach to be taken by researchers.

Rather, they wanted to be understood, as I have tried to present them, as experts on their own lives and experiences. Still, and as discussed previously, my recruitment efforts in communities unfamiliar to me were unsuccessful and depended on my contacts with a small number of people in both the Deaf and newcomer communities. In effect, I was relying on a very small group of people to either direct me to a diversity of voices or lend their voices to my research. Either way, the effect could have been a lack of diversity in opinions and experiences. The women in my study pointed out that diversity of opinion is necessary among participants, not just between participants and researchers.

4.3.2. Communication

Opportunities to learn about and participate in research are often dependant on access to computers or personal computerized devices and internet connection. Recruitment posters and other information about opportunities to participate in research are circulated primarily, and sometimes exclusively, by e-mail and social media posts. An intersectional lens reveals the disadvantages women can experience when location of residence entwines with fluidity of embodiment. The women in my study all reported having access to multiple methods of communication, but equitable quality of cellular or internet coverage among Canadian communities is lacking. The same is true for cell phone and data plans (Raja, 2016; Stienstra & Troschuk, 2005). Cell phone and internet coverage differ across Nova Scotia and in the communities where participants in my study live and work. In addition, the frequency with which women can check text or email messages is influenced by their need for access support, such as sighted or other personal assistance. Once again, I reflect on the idea of fit and misfit and it becomes clear that communication access can be available or unavailable depending on a myriad of factors that include fluid embodiment and appropriately matched disability-related support.

The women in my study did not discuss forms of online discrimination but they were all users of the technology, as evidenced by their ability to read materials related to my research and their references to online shopping and checking transit schedules. Web accessibility, as a means of social inclusion for persons with disabilities, has steadily improved over the past number of years (Skjerve, Giannoumis, & Naseem, 2016). I often learn about research opportunities through social media and email communication, and I relied on these media to recruit participants. My heightened awareness of intersectionality reveals that web accessibility, for some, provides access to research-related information. However, online discrimination rooted in racism, sexism, ableism and other identity markers can impede potential participants from receiving or acting upon it (Skjerve, Giannoumis, & Naseem, 2016).

4.3.3. Systemic Discrimination and Social Institutions

Participants discussed the conflict between person-first language, commonly suggested for use in referring to persons with disabilities, and their perceptions of disability-first attitudes of researchers and others. They noted that researchers often seem to lack an intersectional approach to engaging with participants. Noella offered, “Someone may use a wheelchair but that doesn’t reflect the complexities involved with having other disabilities or living in rural areas of this province.” Sawyer similarly commented, “How can there possibly be one spokesperson when the combination of disabilities, gender, socioeconomic status and other factors change everything for people?” When asked if researchers should seek individuals who offer conflicting views to better reflect the diversity that exists among women with disabilities, the participants responded in the negative. Noella, for instance, stated, “Disagreement isn’t required but ensuring they hear different perspectives is, for sure.”

The participants’ comments point to their awareness that researchers’ attitudes and actions toward women with disabilities are rooted in systemic discrimination and power imbalances. April described an experience of marginalization as an example: “I went to an event and I was escorted to a table and then I was left alone. Behind me, there was a room full of people. They were all chatting, and I felt, I felt like I didn’t exist.” At this point, one of the other participants commented, “I bet you didn’t want to be there,” and April replied, “I didn’t want to be there, exactly.” April’s story implies that there was a material fit between her body and the environment. She was guided to a table and, presumably, able to sit at the table without physical discomfort. She felt excluded because she was seated alone instead of with other people, where she could have engaged in conversation; the person who guided her to her seat made the fit solely between her *body and her environment*, instead of guiding her to a place where she could fit environmentally *and* participate.

4.3.4. Participants’ Rejection of the Disability Label Can Result in Self-Exclusion

Several participants talked about the dissonance between their claimed identity versus the one often ascribed to them. Ophelia, for instance, said of herself: “I always say I have nothing wrong even though blood work and everything else shows that I do.” April said of her long relationship with diabetes in particular: “I’m a diabetic now for many years but I’ve never considered it specifically to be a disability." Subratta similarly spoke about screening herself out of opportunities to engage with research: "I don't really think of myself as having a disability so I tend to not speak up about issues relating to people with disabilities." Ophelia's and Subratta's comments reveal that people with disabilities sometimes choose NOT to claim their identity. One of the implications for research is around participation; women who do not identify as having disabilities are unlikely to participate in research with a disability focus.

4.3.5. Participant Interaction

Participants in each of the three focus groups valued and took advantage of built-in opportunities for peer support. Focus groups can provide participants with "an empowering, consciousness-raising function" (Hollander, 2004, p. 608). One advantage of using focus groups in research is said to be that "they mirror the kinds of conversations participants might have in their daily lives" (Hollander, 2004, p. 607), thereby increasing the validity of data. This is said to be particularly possible if friendship groups of participants make up focus groups (Kitzinger, 1994). Despite this not being the case in my research, women in my study implicitly shared and explored their intersectional experiences and positionalities throughout the three small group discussions.

Some participants, described their experiences of evolving embodiment related to changes in disability, age, and gender, often giving details of the shifting realities of one or more disabilities over time.[23] Both Noella's and April's self-introductions provide evidence of the "fluidity of positionalities" (Yoshida, Hanass-Hancock, Nixon, & Bond, 2014). They talked

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[23] I am choosing to not provide participant comments and quotations for this point because of the very specific details included that could unintentionally identify individual women.

about having acute phases during which the symptoms of one or more of their disabilities first appeared and then lessened over time. Sometimes the lessening was due to improvements in their symptoms. Other times, women's situations improved as they adapted to their new realities.

Through a closer look at the women's stories, I identified three factors involved in participants' fluidity of positionality. Medical, behavioural and emotional interventions emerged from the data. Medical interventions included medications or surgery. Behavioural changes included changes to diet, moving to an accessible residence, or using mobility aids. Emotional interventions involved changing how they understood their bodies, accepting new learning processes, or expressing agency in their relationship to social institutions such as government support programs and educational institutional processes.

Participants in my study worked together to create feelings of safety within the small group discussions. I did not attempt to gather sensitive information from participants but focus groups have been broadly accepted as an effective way to gather information on sensitive subjects (Wong, 2008). Perhaps the participants identified strongly with each other as women with disabilities, since they came together under that premise and, as a result, "were able to express more in-group solidarity… recognize disability discrimination, both personally and against the group" (Nario-Redmond & Oleson 2016, p. 213). Whatever the cause, women in all three discussions shared stories about past and current relationships, details of their sexual preference, and other personal details.

4.4. Conclusion

This chapter began with an intersectional introduction to the nine women who participated in my study. I detailed the major themes that emerged from my analysis of the focus group data within the Findings section, focusing them around four main themes. I used my theoretical lens, including feminist intersectionality and Garland-Thomson’s theory of fitting and misfitting, to further explore these results within the Discussion of findings. Finally, I broadly examined key themes evident in the interactions among participants. The next chapter concludes my thesis. I draw from my research to make three recommendations for supporting the inclusion of women with disabilities in research and I point to my ideas for future study.

Chapter Five: Conclusion

This final chapter offers a summary of the research I conducted for my Master of Arts Graduate Degree in Women and Gender Studies. I reflect on the Findings detailed in Chapter Four as a basis for recommendations aimed at assisting researchers to support the participation of women with disabilities. Finally, I present my ideas for relevant and important future research that have become apparent to me through this process.

5.1. A Summary of My Research

My research question emerged from a review of literature to uncover the extent to which the participation of women with diverse disabilities was evident in academic research: "*What tools and practices are necessary to ensure that diverse women with disabilities are able to participate in, and benefit from, research?"*

My theoretical frame weaved together feminist intersectionality, Rosemarie Garland-Thomson's theory of fitting and misfitting, and the social construction of disability. I employed qualitative research methods to conduct this study, primarily relying on data collected from three small group discussions with a total of nine women with disabilities. My data analysis process was inductive, allowing themes to emerge from multiple reviews of the data (Hash & Cramer, 2003).

I listened intently, and learned from, the words and stories shared by women and their interactions I refined my data analysis of focus groups from six preliminary themes to four themes. I presented and discussed the four themes in Chapter Four. I also explored a broad analysis of the interactions among participant in the discussion of findings section of Chapter Four. My analysis made clear that women with disabilities who participated in my study took advantage of opportunities for peer support and community building.

Qualitative methodology was appropriate for this study as it “can be especially empowering for members of oppressed groups and marginalized populations” (Hash & Cramer, 2003, p. 50). The focus group setting allowed participants to explore ideas as they came to light (Hollander, 2004). Member checking of data was limited to participants of the third and final focus group reviewing preliminary themes accompanied by supporting notes and possible questions for further exploration (see Appendix G).

5.1.1. Methodological Challenges

I encountered one major challenge to completing my research – participant recruitment. I planned to recruit participants from the Deaf and newcomer communities in addition to the mainstream disability community, but I was unable to garner any interest from either of these communities. I met this challenge by amending my recruitment plan and methods. I relied on my recruitment efforts within the mainstream disability community for participants, ultimately securing nine participants. I also included the option for participants to attend focus groups via teleconference and in-person. I have previously discussed the historical and systemic barriers to research experienced by women of these communities. I will take these lessons into account when planning future research.

5.1.2. Research Limitations

My research is based on the participation of nine women with diverse disabilities who reside in communities throughout Nova Scotia. As mentioned in Chapter Three, I made no attempt to gain representation from all regions or communities in Nova Scotia. I developed my recruitment strategy and participant criteria to match my limited resources in terms of time, finances, and organizational capacity. My intersectional data analysis helps reveal participant diversity, but successful recruitment within the newcomer and Deaf communities would have resulted in greater diversity.

5.2. Supporting the Participation of Women with Disabilities in Research

5.2.1. Recommendation 1

Academic and other research should be interrogated to reveal the silences and absences of women with disabilities. Findings from my research show that women's silence is created by research design and practices that reinforce established systems of power, creating a chasm in which the voices of women with disabilities disappear. All women involved in my research reported being recruited for, and participating in, research previous to mine. I do not know the extent to which their involvement was made evident in the research results. None of them identified their representation in research results as a success or reward for involvement in previous studies. Rather, they spoke of their frustration at research that either ignores or conflates the diversity of experiences and opinions among persons with disabilities. This approach has been referred to as "unidimensional": "The dominant 'unidimensional' approach examines diversity across a single dimension at a time (e.g. by race or sex)" (Gopaldas & DeRoy, 2015, p. 1). For example, Noella spoke passionately of her frustration with researchers "checking off the disability box" rather than using an intersectional approach to participant recruitment and data analysis. Participants' belief that researchers fail to adequately attend to diversity can lead to cynicism, as indicated by the participants in my research. Researchers' inattention to participants' diversity can lead to research results that continue to exclude or minimize the complexity of participants' lives (Gopaldas & DeRoy, 2015).

In addition, women with disabilities are often made invisible by the theoretical frames, methodologies, methods, and data analysis utilized by researchers. Some participants in my study spoke of passing on opportunities to participate in research because of what Rosemarie Garland-Thomson would refer to as misfitting. For instance, Noella talked about the barriers she has encountered when attempting to participate in research-related events planned without consideration for accessible parking and other transportation-related issues. Several women drew a direct link between their transportation needs and their decisions to participate in research.

Data gathering methods and instruments can also negatively affect the participation of women with disabilities. Women in my study noted some of the challenges that can emerge with focus groups, such as barriers related to transportation, fears of gender-based violence related to time of day or other circumstances, and the self-confidence required to share oneself in a focus group setting. Survey questionnaires may address some of these issues, but the questions may be the basis for non-participation. Maxine, for instance, spoke of not participating in research when she felt the research questions were too narrow to capture her perspective and experience.

Participants discussed the flawed recruitment efforts of researchers (and others) and the resulting lack of diversity in terms of representation. Here, April asserted, "I have a different perspective on the world than someone who uses a wheelchair [or] a person who is deaf or hard of hearing, or a person who has autism, so I think all of our perspectives are different but they're also equally valuable."

Opportunities to learn about and participate in research are often dependant on access to computers or personal computerized devices and the internet. This was certainly the case for my research. I used the telephone to initially determine who to forward introductory material to within the Immigrant Settlement Association of Nova Scotia and to ensure the correct email addresses for contacts in other organizations, but all other preliminary communication required internet connectivity. This might require potential research participants to access public computers or additional internet content. An intersectional analysis reveals that participant recruitment that depends on internet connectivity should also take forms of online oppression such as ableism, racism and homophobia into account (Skjerve, Giannoumis, & Naseem, 2016).

5.2.2. Recommendation 2

Researchers need to intentionally attend to the inclusion and reflection of women with disabilities, building a body of literature focusing on the critical exploration of research methodologies, methods, analytical tools, and results. Participants in my study spoke of the "disability first" approach they have experienced with participant representation within research. Women in all three discussions recognized that application of an intersectional lens would reveal previously undocumented differences in the social experiences of people with disabilities. The attribution of expert status to a small group of individuals living with disabilities is just one way in which diverse voices and experiences are excluded from research and all that it informs, including government programs and policies. The women shared ideas about how to bring seldom-heard voices of women to the table and suggested an intersectional approach to the recruitment of research participants, data analysis, and the reporting of research results to more accurately reflect the involvement of women with disabilities.

Women participating in the final thematic discussion expressed an interest in developing a grassroots organization that would serve as a research institute for women with disabilities. Based on findings of the literature review, this could have a positive impact on the future of academic research and literature that includes women with disabilities in Nova Scotia and elsewhere.

There are also institutional practices and processes that are effective in structuring out the inclusion of new and experienced researchers who themselves identify as women with disabilities. For example, I, like many other social science researchers, was required to submit information about my research with humans to Saint Mary’s University Ethics Review Board on an annual basis. The forms were difficult for sighted people to complete, according to my sighted assistants, but they were impossible for me to complete independently. In fact, this was one of the few times in my life where I have signed and submitted a form without being able to hear its contents. I know what the questions were, and I know the details of my answers, but I remain disappointed that this remains a discriminatory practice.

5.2.3. Recommendation 3

The relationship between research and women with disabilities can be recalibrated and transformed through a research praxis that is guided by greater emphasis on reciprocity.

Participants in my study spoke of their frustration at being asked to participate in research that seems to duplicate previous research. They called for transparency from researchers about the research goals, how research results will be used, and the extent to which diversity among participants will be sought. Participants in my study called on researchers to conduct research with the intention of being transformative to the community, rather than to support the academic or other-focused careers of the researchers. My findings raise the notion of researchers valuing knowledge and sharing ownership of research benefits with participants, including the data. One of the participants in my study made the comment that, “the data should be shared with the people who participated.” I look forward to presenting the results of my research to women with disabilities in the near future.

5.3. Future Research

My thesis research experience has led me to think about exciting opportunities for future study and activism. Of particular interest to me is the idea of working with women with disabilities to further explore the development of a research agenda and research-related protocols that reposition women with disabilities as agents of change and holders of valuable knowledge. A research agenda by and of the disability community could be designed to be intersectional and transformative. Researchers like me also need to think beyond binary gender identities to be responsive to the experiences of individuals who rest “across and within gender boundaries” (Beigi & Cheng, 2010, p. 124). There is much to learn from individuals who identify as queer[24] and as having disabilities who have also largely been absent in research concerned with gender and disability (Whitney, 2006).

There is also much more to learn from an in-depth analysis of the interactions among participants within research-related group situations. As Hollander (2004) notes:

> The social contexts of focus groups—that is, the relationships among the participants and between the participants and the facilitator, as well as the larger social structures within which the discussion takes place—affect the data that are generated in ways that have not yet been widely acknowledged by focus group researchers. (p. 604)

I have come to appreciate the efficiency with which focus groups allow researchers to "…listen and gather information. It is a way to better understand how people feel or think about an issue, product, or service" (Krueger & Casey 2000, p. 4). Yet, as Hollander (2000) points out, research reports do not do a good job generally of conveying the complexity involved in having multiple participants together. I have tried to parse out some of the underlying complexities involved in the interactions that occurred amongst the women who participated in my research. One of my methods has been to include some of these interactions throughout my findings (Kitzinger, 1994). I am intrigued by what could be learned from a more in-depth exploration of various aspects of conducting focus groups, analyzing, and presenting data using a feminist intersectional lens.

5.4. Conclusion

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[24] People in queer communities use a range of identity terms, including lesbian, gay, bisexual, transgender, non-binary, gender-queer, and so on. While the word "queer," in particular, is controversial, but in this context, it is useful as an umbrella term.

Research still tends to be oriented to the medical model, but the social model of disability has begun to be considered within non-traditional spheres such as public health discourse (Krahn, Walker, & Correa-De-Araujo, 2015). The findings of my research provide a basis for three recommendations to conceptualize, plan and conduct research that encourages the participation of women with disabilities. Lastly, I have identified two potential areas for future study that I believe can benefit women with disabilities and researchers. I hope to develop my doctoral research around the opportunities for future research I have identified, in partnership with women with disabilities.

It seems only right to conclude this thesis with the words of a woman who participated in my research. I reflect on many moments and voices from my research but this one is particularly powerful to me. Subratta was gracious and optimistic about future research supporting women with disabilities: “When we know better, we do better, but it takes time to know.” I know I must be intentional in applying the lessons learned from my research. At the same time, I hope this thesis helps other researchers who want to support women with disabilities to participate in, and benefit from, research.

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Appendices

List of Appendices:

Appendix A: Agenda – Group Discussion

AGENDA – GROUP DISCUSSION

Embedding Intersectionality in Inclusive and Accessible Research with Diverse Women with Disabilities

1. Welcome & Self-Introductions
2. Ethics Protocols Associated with This Research
3. Julianne’s Thesis Research - What is it? What will be the result? How does this discussion fit in?
4. Discussion Group Questions

Thank you very much for participating.

Appendix B: Confidentiality from Allies

Julianne Acker-Verney

Graduate Student, Women and Gender Studies

Saint Mary's University

923 Robie Street

Halifax NS, B3H 3C3

Telephone: 1-902-456-9913

Email: julianne.acker-verney@smu.ca

Confidentiality Agreement To Be Signed By Allies Of Participants Of The Study: Embedding Intersectionality in Accessible & Inclusive Research with Diverse Women with Disabilities

Date ____________

I understand you will be providing disability-related support for a person who has agreed to participate in research I am conducting as part of my Master's thesis. This study has been granted clearance according to the recommended principles of Canadian ethics guidelines, and the Saint Mary's University Research Ethics Board (SMUREB).

I understand that the person you are providing support to tells you how to provide the support they require to engage in a small group discussion. The purpose of this discussion is to hear their stories and opinions about how research can be planned, conducted, and results conveyed so that it supports the full and meaningful participation of women with disabilities. You are invited to participate fully in the group discussion if you identify yourself as a woman with one or more disabilities. In that case, please read and complete the consent form for participants instead of this form.

If you do not consider yourself a woman with one or more disabilities, please refrain from participating in the group discussion from your own perspective.

By signing this agreement, you agree to not share details of who participated or what is said during the small group discussion. This confidentiality agreement is permanent. This is essential to respecting the privacy and confidentiality of all who attend the group discussion in whatever role they perform.

Where can you get more information?

If you have any questions or would like further information with respect to this study, you may contact Julianne Acker-Verney at 1-902-902-456-9913 or by email at julianne.acker-verney@smu.ca.

The Saint Mary’s University Research Ethics Board has reviewed this research. If you have any questions or concerns about ethical matters or would like to discuss the rights of research participant, you may contact the Chair of the Research Ethics Board at ethics@smu.ca or at 1-902-420-5728.

*Please find the confidentiality agreement to be signed on the next page.

Confidentiality Agreement for Allies of Participants in the Study: Embedding Intersectionality in Accessible & Inclusive Research with Diverse Women with Disabilities

Your role in supporting a woman with disabilities to participate in this study is entirely negotiated between you and the woman you are supporting.

1. Your signature below indicates that you have received a copy of this confidentiality agreement for your own records.

Printed Name: ___________________________

Your Signature: ___________________________

Date: ___________________________________

2. Your signature below indicates that you agree to be audio taped while you perform your duties in supporting a woman with disabilities to participate in this research.

Printed Name: _____________________________

Your Signature: ___________________________

Date: ___________________________________

3. Your signature below indicates that you will do your part to maintain the confidentiality of everyone in the study (this includes not sharing the details of who attended or the thoughts and experiences they shared during the small group discussion) with anyone after it is over.

Printed Name: ____________________________

Your Signature: ___________________________

Date: ___________________________________

*Please return this portion to Julianne Acker-Verney.

Confidentiality Agreement for Allies of Participants in the Study: Embedding Intersectionality in Accessible & Inclusive Research with Diverse Women with Disabilities

Your role in supporting a woman with disabilities to participate in this study is entirely negotiated between you and the woman you are supporting.

1. Your signature below indicates that you have received a copy of this confidentiality agreement for your own records.

Printed Name: ___________________________

Your Signature: ___________________________

Date: ___________________________________

2. Your signature below indicates that you agree to be audio taped while you perform your duties in supporting a woman with disabilities to participate in this research.

Printed Name: _____________________________

Your Signature: ____________________________

Date: ____________________________________

3. Your signature below indicates that you will do your part to maintain the confidentiality of everyone in the study (this includes not sharing the details of who attended or the thoughts and experiences they shared during the small group discussion) with anyone after it is over.

Printed Name: _____________________________

Your Signature: ____________________________

Date: ____________________________________

*Please retain this portion for your records.

Appendix C: Consent – Participants

Embedding Intersectionality in Accessible & Inclusive Research with Diverse Women with Disabilities

Julianne Acker-Verney
Graduate Student, Women and Gender Studies
Saint Mary's University
923 Robie Street
Halifax NS, B3H 3C3
Telephone 1-902-902-456-9913
Email: julianne.acker-verney@smu.ca

SMU REB File No. _ _-_ _ _

Thesis Research Supervisors:

Michele Byers; Telephone: (902) 420-9856; Email: byersmichele@gmail.com

Deborah Stienstra; Telephone: (204) 474-9971; Email: Deborah.stienstra@umanitoba.ca

Date ___________________

I invite you to participate in research I am conducting as part of my Master's thesis under the direction of Dr. Michele Byers and Dr. Deborah Stienstra. This study has been granted clearance according to the recommended principles of Canadian ethics guidelines, and the Saint Mary's University Research Ethics Board (SMUREB).

What is the study? *Doing Inclusive and Accessible Research* focuses on the absence of women with disabilities in the planning and conducting of accessible and inclusive research. I have been supported to do this project by a Nova Scotia Research and Innovation Graduate (NSRIG) scholarship.

The objective of the research project is to use multiple research methods to learn what researchers must do to support diverse women with disabilities to participate fully and meaningfully in research projects.

What will you be asked to do? Four to six individuals who self-identify as women with one or more disabilities will be asked to participate in one small group discussion lasting 1 ½ to 2 hours. The purpose of this discussion is to hear your stories and opinions about how research can be planned, conducted and results conveyed so that it supports the full and meaningful participation of diverse women with disabilities. I do not want proof that participants have disability(ies). You need only to self-identify as being a woman and as having one or more disabilities.

The discussion group will be held in a physically accessible venue in Halifax (to be determined). The questions and discussion will be in English. I will lead the discussion, asking questions and making sure everyone has a chance to share their stories and thoughts. I will send you the questions before the group discussion in your preferred format (hard or electronic copy, Braille, etc.). You will be asked to fill out a voluntary questionnaire, which will also be distributed in advance of the group discussion.

In addition to attending the initial small group discussion, a small number of participants will be invited to comment on general themes that emerge from multiple focus groups. Details of a meeting for this part of the research will be provided to women who agree to attend. The terms of consent you agree to when participating in the initial focus group will extend to include additional involvement, including providing comments on general themes.

How will I protect your confidentiality? Because you will be sharing your thoughts with other women in a group setting, I cannot guarantee complete confidentiality, but everyone who attends will be required to agree to not share details of the discussion with anyone afterward. In addition, I can promise you that your name and other identifying information will not be used in the research results including my thesis, fact sheets or any other material made publicly available based on this research.

All information you provide about how to contact you and your disability-related accommodation needs will also be kept private and securely encrypted during and after your participation in this research.

I take seriously the responsibility of protecting the privacy of women who participate in my research, which is why all women who participate in the group discussion, and any other person who attends in support of a participant, will be required to sign an agreement (see below) to protect the confidentiality of fellow participants. Hard copy records will be held in a locked cabinet and all electronic information related to this research will be password protected and encrypted to ensure their security.

Please note that there are legal limits on information researchers can promise to keep confidential. I will, for example, have to comply with reporting obligations, warrants or subpoenas as required by law. For example, all Nova Scotians are required to report known or suspected abuse or neglect of children and adults over the age of 16. For more information, please see Family Law Nova Scotia website at www.nsfamilylaw.ca.

What if you would like to withdraw from the study? Participation in this research is completely voluntary. You can change your mind and withdraw from the discussion group without the need to explain your reasons and without negative consequences. If you decide to withdraw from the research during the discussion group, your comments will not be transcribed or included in analysis of the discussion group data.

What are the risks of participating? The risks involved in this research are minimal. You might feel uncomfortable or become upset describing personal details about your life in a group setting, but you will control the information you provide. The topics we will talk about in the small group will not be any more sensitive than your existing experiences with, and opinions about, research participation. Please also note that you will not be paid, or reimbursed for expenses incurred, to participate in this research.

What are the benefits of participating? Any risk associated with participating in this project must be balanced with the potential benefits for you and your wider community. You may experience frustration at your own or other women's experiences with research, but both negative and positive experiences with research are equally valuable information to gather. Participation in the group discussion will provide an opportunity for you to express and discuss your thoughts and experiences with others who may have similar experiences. The overall goal of this research is to share with other researchers lessons about how to do accessible and inclusive research with diverse women with disabilities. Your voice, experiences and opinions as a woman with disabilities are valuable ones that are rarely heard by researchers and decision-makers.

The results of my research, of which the small group discussion is one part, will be published in a thesis and available through the Saint Mary's University library. I will look for other opportunities to distribute what I learn from this research. As a result, there may be more academic and community-based researchers who plan and conduct their projects in ways that encourage and support women with disabilities in particular to participate and feel that their voices are reflected in research results.

How will this research be used? The information gained from this study will be used in community presentations, academic papers and conferences. They may also be used in support of my PhD research. Community-based, plain-language documents (such as fact-sheets) may be developed. A community-based event may be held at the end of the project to talk about the results and discuss future possibilities for using the lessons learned.

Where can you get more information? If you have any questions or would like further information with respect to this study, you may contact me, Julianne Acker-Verney, at 1-902-456-9913 or by email at julianne.acker-.verney@smu.ca. You may also contact either of my thesis co-supervisors, Dr. Michele Byers or Dr. Deborah Stienstra. Dr. Byers can be reached at 1-902-420-9856 or by email at byersmichele@gtmail.com. Dr. Stienstra can be reached by phone at 1-204-474-9971 or by email at Deborah.stienstra@umanitoba.ca.

The Saint Mary’s University Research Ethics Board has reviewed this research. If you have any questions or concerns about ethical matters or would like to discuss your rights as a research participant, you may contact the Chair of the Research Ethics Board at ethics@smu.ca or at 1-902-420-5728.

Thank you for taking the time and energy to participate in this research. Please find the consent form to be signed on the next page.

Consent Form for Participants in the Study:

Embedding Intersectionality in Accessible & Inclusive Research with Diverse Women with Disabilities

Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time without needing to explain why and without negative consequences.

1. Your signature below indicates that you have received a copy of this consent form for your own records and that you consent to participate in this study as follows:

I understand what this study is about, and appreciate the risks and benefits. I understand that by signing below I agree to take part in this research study and do not waive any rights to legal recourse in the event of research-related harm. I understand that my participation is voluntary and that I can end my participation at any time without penalty. I have had adequate time to think about the research study and have had the opportunity to ask questions.

Printed Name: ________________________________

Participant Signature: __________________________

Date: _______________________________________

2. Your signature below indicates that you agree to be audio taped.

Printed Name: ________________________________

Participant Signature: __________________________

Date: _______________________________________

3. Your signature below indicates that you will do your part to maintain the confidentiality of everyone in the study (this includes not sharing the details of who attended or the thoughts and experiences they shared during the small group discussion) with anyone after it is over.

Printed Name: ________________________________

Participant Signature: __________________________

Date: _______________________________________

Please return this portion to Julianne Acker-Verney.

Consent Form for Participants in the Study:

Embedding Intersectionality in Accessible & Inclusive Research with Diverse Women with Disabilities

Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time without needing to explain why and without negative consequences.

1. Your signature below indicates that you have received a copy of this consent form for your own records and that you consent to participate in this study as follows:

I understand what this study is about, and appreciate the risks and benefits. I understand that by signing below I agree to take part in this research study and do not waive any rights to legal recourse in the event of research-related harm. I understand that my participation is voluntary and that I can end my participation at any time without penalty. I have had adequate time to think about the research study and have had the opportunity to ask questions.

Printed Name: ________________________________

Participant Signature: __________________________

Date: _______________________________________

2. Your signature below indicates that you agree to be audio taped.

Printed Name: ___________________________________

Participant Signature: ____________________________

Date: ____

3. Your signature below indicates that you will do your part to maintain the confidentiality of everyone in the study (this includes not sharing the details of who attended or the thoughts and experiences they shared during the small group discussion) with anyone after it is over.

Printed Name: ___________________________________

Participant Signature: ____________________________

Date: ____

Please retain this portion for your records.

Appendix D: Demographic Information Survey

Embedding Intersectionality in Accessible & Inclusive Research with
Diverse Women with Disabilities - Demographic Information Sheet

This is a voluntary survey. I will use the information it gathers in tandem with the results of the small discussion groups to reach a deeper understanding of the ways researchers can support women with disabilities to participate in, and benefit from, research. The information you share here will be kept private, secure and confidential. Please answer the following questions to the best of your knowledge.

1. What is your name?

2. What is the best way to reach you? (Please provide the telephone number, email address, etc. that I can use to advise you of the details on the small discussion group or other information related to this research; please provide details of the communication method you are most likely to use or check most often.)
   Telephone:
   Email:
   Text message:
   Other:

3. Where do you live? (Name of village, town or city in Nova Scotia)

4. How old are you?

5. How would you describe your gender (female, male, other)?

6. If you are a newcomer to Canada, what is your nation of origin?

7. Do you identify as a member of a racialized group, and if so, which one(s)?

8. How do you identify your sexual orientation (gay, lesbian, heterosexual, bisexual, trans, other)?

9. How do you describe your disability/disabilities?

10. Are you presently (mark an X beside all that describe you):

    The primary caregiver to children _____

    A homemaker ______

    Unemployed _____

    Retired or pensioned _____

    A student _____

    A volunteer _____

    Employed part-time _____

    Employed full-time _____

Providing ongoing support to friends/family _______

Other (please describe): _________

11. How would you describe your relationship status (single, married, common law, other)?

12. What is the highest level of education you have completed?

13. On average, what is your household income (Per year or per month)?

Thank you for providing this information.

SMU REB File No. _ _-_ _ _

Appendix E: Discussion Group Questions

Embedding Intersectionality in Accessible & Inclusive Research with Diverse Women with Disabilities

Think about research projects that you have been involved with for these questions:

3. What was asked of you? Were you asked to fill out a questionnaire, attend a focus group, recruit other people for the research, etc.?
4. Why were you asked to participate in the research project(s)? Was it because the project(s) focused on persons with disabilities? Was it because you are a woman? Have there been other reasons?

Now, think about the times you have enjoyed being a research participant.

2. What was it about those experiences that made them feel good? Did the researcher(s) seem to value what you had to say? Did it feel easy to participate? Did you feel your participation was making a difference? Other reasons?

Now think about times when you did not enjoy participating in research.

1. What was it about those experiences that made them feel bad? Was it difficult to participate in the research for some reason? Other reasons?

Appendix F: Email to Service Providers

Subject: Doing Accessible and Inclusive Research with Diverse Women with Disabilities in Nova Scotia

Dear: _________________

My name is Julianne Acker-Verney, and I am a student in the Women and Gender Studies graduate degree program offered by Saint Mary’s University and Mount Saint Vincent University of Halifax, Nova Scotia. I am a woman with multiple disabilities, and I live in Nova Scotia where I work and attend Saint Mary’s University. I am contacting you to ask if you would please share an opportunity for diverse women with disabilities currently living in Nova Scotia to participate in my research (SMUREB File No. _____). A plain-language invitation is attached for distribution. Please contact me if you have any questions or would like to discuss this with me further.

Thank you very much,

Julianne

Julianne M. Acker-Verney (M.A. Cand.)

Telephone: 1-902-456-9913

Email: julianne.acker-.verney@smu.ca

Appendix G: Emerging Themes for Discussion

EMBEDDING INTERSECTIONALITY IN RESEARCH WITH WOMEN WITH DISABILITIES

Julianne Acker-Verney (M.A., Cand.)

Emerging Themes for Discussion

November 9, 2017 (6–8pm AST)

The themes outlined below emerged clearly from the small group discussions conducted already as part of this research. I present them here in random order and without judgement about their level of priority:

- **Women defining ourselves is important, who we are and what we bring to the conversation**
  - Many women who participated in the discussions shared details and experiences as women with disabilities freely.
  - Possible Questions:
    - Is it important that researchers ensure this opportunity be given sometime in the process?
    - Is this part of reciprocity between researchers and the community?

- **Our participation in research is influenced by gender and disability in ways that are similar to our participation in community more generally.**
    - Women's ability to participate in research is linked to individual financial and other personal support, community capacity (number of accessible cabs, booking protocols associated with accessible public transportation, and the ability of researchers to be flexible to individual preferences for participation (doing an interview instead of focus groups, going to the woman's house, holding focus groups at the best time of day and week, etc.).
    - Other socioeconomic factors including availability of child care, employment status and ability to make decisions around time; social expectations of what it means to be a parent and a mother in particular can influence decisions around participation.
    - Possible Questions:
        - What can researchers do to make the expenditure of time, energy and other resources worth participating?

- **Researchers tend to attribute expert status or community-wide representation to individual women with disabilities.**
    - Women talked about the problems associated with researchers making the mistake of, and doing a disservice by, attributing expert status on single individuals to act as spokespeople for a larger segment of, or the entire, disability community. "I am only the expert in me." Women agreed that this does more of a disservice to

members of the community, and research in general, than it does to contribute to positive change for the community.

  - Possible Questions:
    - How can researchers guard against this potential pitfall?
    - How can we challenge this as a community of diverse women?

- **All research and researchers wield power and should not underestimate their potential influence.**
  - Researchers' behaviour and approach toward women with disabilities tends to reflect and perpetuate that of the general public (failing to recognize the specific contributions of, and challenges experienced by, women with disabilities; assuming knowledge of a woman's needs and preferences; etc.)
  - Women want to see the research they participate in reflect their involvement rather than the "same old, same old."
  - Possible Questions:
    - What steps can researchers take to become better allies to women with disabilities on an ongoing basis?

- **Women experience tension around identifying as having disabilities and understanding the value in our differences.**
  - Possible Questions:
    - Are there strategies women with disabilities currently use or can use to challenge labels in research?

Appendix H: Funding Request

Embedding Intersectionality in Inclusive and Accessible Research with Diverse Women with Disabilities in Nova Scotia

To: Dr. Michele Byers
From: Julianne M. Acker-Verney (M.A. Cand.)
Date: June 8, 2017

Dear Dr. Byers:

I am a Saint Mary's University graduate student in the Women and Gender Studies degree program at Saint Mary's University in Halifax, Nova Scotia. I am writing to enquire about the possible availability of financial support to allow for reimbursement of transportation and child care costs for women with disabilities who participate in focus groups associated with my thesis research. As the enclosed budget shows, I have secured a contribution for accessible room rental from a community organization embedded within the local disability community and private sponsorship for light refreshments. I am able to cover the cost of American Sign Language (ASL) interpretation. I am seeking support to cover the cost of Communication Access Real Time Captioning (CART) for people who are Deaf or hard of hearing, transportation costs, and/or child care costs that might discourage women from engaging in my research.

The purpose of my research is to learn — and be able to share — how to best support women with diverse and multiple disabilities to participate in research such that researchers can plan and conduct research in ways that help women feel valued, included in decisions and reflected in research results.

Women can participate in my research if they:

- Are 16 years of age and older
- Currently live in Nova Scotia
- Self-identify as a woman
- Self-identify as having one or more disabilities (medical diagnosis or certification is not necessary)
- Are willing to share their research-related experiences within a small group of 3 to 5 other women.

There will be four focus groups with four to 6 women in each group, held during the summer months of this year. I am planning my research to be inclusive of adult women with disabilities who will have a variety of disability-related and other needs. The figures below are estimated.

Thank you for considering my request. Please contact me if you require additional information or clarification. I can be reached by phone at 1-902-456-9913 or by email at jackerverney@me.com.

Sincerely,

Julianne Acker-Verney (M.A. Cand.)

Appendix I: List of Resources

List of Resources

Embedding Intersectionality in Inclusive and Accessible Research with Diverse Women with Disabilities

Please see the following list of community resources in the event that you experience emotional distress as a result of participating in this discussion:

Canadian Mental Health Association
45 Alderney Drive
Dartmouth, Nova Scotia B2Y 2N6
Tel: 902-466-3300
Toll Free: 1-877-466-6606

Nova Scotia Mental Health Crisis Telephone Line
Tel: 902-429-8167
Toll Free: 1-888-429-8167

Nova Scotia Telecare
Tel: 811

For information on other community and government resources, please call 211 Nova Scotia

Tel: 211

Appendix J: Recruitment Letter

Invitation: Doing Accessible and Inclusive Research with Diverse Women with Disabilities in Nova Scotia

My name is Julianne Acker-Verney, and I am a graduate student in the Women and Gender Studies graduate degree program offered by Saint Mary's University and Mount Saint Vincent University of Halifax, Nova Scotia. I am a woman with multiple disabilities, and I live in Nova Scotia where I work and attend Saint Mary's University. I am conducting research as part of the requirement for me to write a thesis so I can receive my Master's degree.

Reason for this research

I will learn — and be able to share with other researchers — how to best support women with different, and with one or more disabilities to participate in research so researchers can plan and conduct research in ways that help women feel valued, included in decisions and reflected in research results.

What will you be asked to do?

You will be asked to attend one meeting with three to five other women with different disabilities. You and the other women will be asked questions about your experiences participating in research. The meeting will be held in a physically accessible site in Halifax and will last 1 ½ to 2 hours after it starts. I will ask you and the other women questions about your past experiences participating in research to learn about times when you enjoyed the experience and why. I will also ask about when the experience was not so enjoyable and the reasons for this.

Who can participate?

Women can participate in this research if they:

- are 16 years of age or older;
- currently live in Nova Scotia;
- self-identify as a woman;
- self-identify as having one or more disabilities (medical diagnosis or certification is not necessary); and
- are willing to share their research-related experiences within a small group of three to five other women.

When?

This gathering of women with disabilities will take 1 1/2 to 2 hours, and will happen during July or August 2017. A time and date will be determined.

Where?

You will be advised of all details including the time and place of the meeting if you decide to participate. Please note that you will not be paid or reimbursed for expenses incurred to participate in this research.

Please contact me if you want to learn more and if you are interested in participating in this research. I can be reached by phone at 1-902-456-9913 or by email at jackerverney@me.com.

The Saint Mary's University Research Ethics Board has reviewed this research. If you have any questions or concerns about ethical matters or would like to discuss your rights as a research participant, you may contact the Chair of the Research Ethics Board at ethics@smu.ca or at 1-902-420-5728.

Kind regards,

Julianne Acker-Verney

*SMU REB File No. _______

Appendix K: SMUREB Ethics Certificate

Certificate of Ethical Acceptability for Research Involving Humans

This is to certify that the Research Ethics Board has examined the research proposal:

SMU REB Registration Number: 17-334

Title of Research Project: Embedding Intersectionality in Accessible and Inclusive Research with Diverse Women with Disabilities

Faculty, Department: Arts, Sociology and Criminology

Faculty Supervisors: Dr. Michele Byers and Dr. Deborah Stienstra (University of Manitoba)
Student Investigator: Julianne Acker-Verney

This concludes that in all respects the proposed project meets appropriate standards of ethical acceptability and is in accordance with the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans (TCPS 2) and Saint Mary's University relevant policies.

Approval Period: June 19, 2017 – June 19, 2018

Continuing Review Reporting Requirements

Adverse Event: Adverse Event Report: http://www.smu.ca/academic/reb/forms.html
Adverse events must be immediately reported no later than 1 business day.
SMU REB Adverse Event Policy: http://www.smu.ca/academic/reb/policies.html

Modification: Form 2: http://smu.ca/academic/reb/forms.html
Research ethics approval must be requested and obtained prior to implementing any changes or additions to the initial submission, consent form/script or supporting documents.

Yearly Renewal: Form 3: http://www.smu.ca/academic/reb/forms.html
Research ethics approval is granted for one year only. If the research continues, researchers can request an extension one month before ethics approval expires.

Closure: Form 5: http://www.smu.ca/academic/reb/forms.html
The completion of the research must be reported and the master file for the research project will be closed.

Please note that if your research approval expires, no activity on the project is permitted until research ethics approval is renewed. Failure to hold a valid SMU REB Certificate of Ethical Acceptability or Continuation may result in the delay, suspension or loss of funding as required by the federal granting Councils.

On behalf of the Saint Mary’s University Research Ethics Board, I wish you success I this research.

Dr. Jason Ivanoff, Ph. D.

Chair, Research Ethics Board, Saint Mary’s University

Appendix L: Agenda – Emerging Themes Discussion

EMBEDDING INTERSECTIONALITY IN RESEARCH WITH WOMEN WITH DISABILITIES

Julianne Acker-Verney (M.A., Cand.)

Agenda - Emerging Themes Discussion

November 9, 2017 (6–8pm AST)

1. Welcome and self-introductions

2. Review of research to date, purpose of this discussion.

3. Confidentiality reminder

4. Terms that may be used
    - Intersectionality
    - Reciprocity
    - Reflexivity

5. Theme discussion

- Summary distributed identifies themes, not necessarily consensus among women on all points
- Will try in this discussion to take a broader view (a bit back from the personal)
- How should we move through document based on the women present for this discussion?

6. Next steps