“Nobody Is Asking What I *Can* Do!”:
An Exploration of Disability and Sexuality

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ABSTRACT

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This doctoral research explores the various ways in which people with physical disabilities access opportunities for sexual expression and exploration. Through conducting qualitative interviews with twenty-four people with physical disabilities I identify barriers to sexual expression that participants faced and examine how participants negotiated, maintained, and created opportunities for sexual expression in spite of these barriers. The findings of this study show that persons with disabilities continue to encounter alienation, stigmatization, and discrimination, particularly in terms of their sexuality. However, the findings of this study also illustrate the creative ways that disabled people can reject, subvert, and challenge the desexualization that they routinely experience.

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CHAPTER 1

Introduction - Situating Disabled Sexualities

"I've always assumed that the most urgent Disability civil rights campaigns are the ones we're currently fighting for – employment, education, housing, transport, etc., etc., and that next to them a subject such as sexuality is almost dispensable. For the first time now I'm beginning to believe that sexuality, the one area above all others to have been ignored, is at the absolute core of what we're working for…It's not that one area can ever be achieved alone – they're all interwoven, but you can't get closer to the essence of self or more 'people-living-alongside-people' than sexuality, can you?" – Liz Crow, European disability rights activist, artist, and author (1991, p. 13).

Current Issues and Context

This research explores the diverse ways that people with disabilities access and experience their sexuality. These experiences warrant scholarly exploration because research on disability and sexuality remains limited when compared to other disability-related research (Shuttleworth and Sanders, 2010; Jungels and Bender, 2015). In particular, there is a dearth of research that explores the ways that disabled Canadians experience their sexualities, making this study both timely and valuable. While research on disability has helped to highlight inaccessible infrastructure, identified prejudiced attitudes and stereotypes, and revealed discriminatory practices that disable people with disabilities, the many intersections of disability and sexuality have yet to be fully explored (Shakespeare, 2000; Santinele Martino, 2017; Shakespeare and Richardson, 2018). Anne Finger, former president of the Society for Disability Studies, candidly describes the difficulties of addressing the sexual politics of disability in her article titled "Forbidden Fruit" (1992). She writes,

> Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It's easier for us to talk about – and formulate strategies for changing – discrimination in employment, education, and housing than to talk about our exclusion from sexuality and reproduction (p. 9).

Despite the lack of research and the difficulties described by Finger, the amount of research on disability and sexuality has increased over the past three decades, creating a number of exciting research opportunities for scholars to pursue. Moreover, there has been a call from activists (Trace, 2014; Gurza, 2017), disability studies scholars (Shuttleworth and Sanders, 2010; Liddiard, 2018), as well as gender and sexuality scholars (Jungels and Bender, 2015) to further explore the sexual politics of disability. This study seeks to answer these calls for further research by advancing a more nuanced and robust understanding of the ways that disabled people access and experience their sexualities.

Through conducting semi-structured, in-depth interviews with twenty-four individuals who self-identify as physically disabled, I examine how they access and engage in their sexual lives amid practices that work to desexualize and discriminate against them. As I will establish throughout this dissertation, many disabled people encounter discrimination, stigmatization, and alienation, *particularly* in terms of their sexuality and gender (see Shakespeare et al., 1996; Shuttleworth and Sanders, 2010; Liddiard, 2018). This is evidenced by eugenic practices such as institutionalization, forced sterilization and abortion (Broberg and Roll-Hansen, 1996; Grekul, et al., 2004; Malacrida, 2015), high rates of sexual abuse (Hassouneh-Phillips and McNeff, 2004; Cotter, 2018), barriers to adequate sexual healthcare or reproductive services such as family planning clinics (Anderson and Kitchin, 2000; Waxman-Fiduccia, 1994), and the lack of sex education available to people with disabilities (Wong, 2000; Gougeon, 2009; Löfgren-Mårtenson, 2012).

This discrimination and desexualization is further evidenced by common myths and stereotypes that surround disability and sexuality. For instance, disabled people are often faced with a double bind insofar as they are subjected to a set of stereotypes that position them as either asexual innocents in need of protection, or conversely, promiscuous and licentious sexual 'deviants' (Esmail et al., 2010). These stereotypes are readily found in popular culture and are informed by ableist and heterosexist understandings of disability and sexuality that deny disabled peoples' sexual agency, and can negatively impact their self-esteem (Haller, 2010; Shakespeare, 1999, 2000; Waxman-Fiduccia, 1999). Loosely defined as discrimination directed toward disabled people, ableism refers to the "ideas, practices, institutions and social relations that presume ablebodiedness, and by doing so, construct persons with disabilities as marginalized…and largely invisible" (Chouinard, 1997 p. 30). Although the definition of ableism lacks consensus, Kumari-Campbell notes, "a chief feature of an ableist viewpoint is a belief that impairment or disability (irrespective of 'type') is inherently negative and should the opportunity present itself, be ameliorated, cured or indeed eliminated" (Kumari-Campbell, 2009, p. 5). As several scholars have demonstrated, these ableist attitudes can become reified into social policy, public spaces, and law, thereby further preventing disabled peoples' chances for sexual exploration, expression, and satisfaction (see Anderson and Kitchin, 2000; Bahner, 2012; Hollomotz, 2011; Kulick and Rydström, 2015; Campbell, 2017; Liddiard, 2018).

State-sanctioned sterilizations of people with disabilities and the various eugenic movements associated with these campaigns serve as the most overt and inhumane examples of how ableist attitudes become reified into social policies that target disabled people (see Bashford and Levine, 2010; Kevles, 1998; Snyder and Mitchell, 2006). Meaning 'well-born', eugenics refers to attempts to manipulate and 'improve' upon the genetic make-up of the population that often target not only people with disabilities but also indigenous people; single mothers; racial, religious, and ethnic groups; and LGBTQ individuals, among others (Hubbard, 2006; Kevles, 1998; Malacrida, 2015; Mitchell and Snyder, 2010; Shakespeare, 2014). The enforcement of involuntary sterilization laws such as Canada's Sexual Sterilization Act of 1928 (Grekul et al., 2004; Kevles, 1998; Malacrida, 2015) and similar laws in Europe and the United States (Broberg and Roll-Hansen, 1996; Hubbard, 2006) continued into the late 1900s and violated the human and sexual rights of hundreds of thousands of people with disabilities. In Alberta , the first Canadian province to introduce involuntary sterilization laws and the last to repeal them, 4739 residents were recommended for sterilization, resulting in the sterilization of roughly 3000 people in this province alone (Grekul et al., 2004).

One of the more notable cases of eugenic sterilization involved Leilani Muir, the first Canadian woman to successfully file a lawsuit against the Canadian government for the abuses she endured at the Michener Centre in Red Deer, Alberta. Shortly before her eleventh birthday in 1955, Muir was admitted to the Michener Center and at the age of fourteen she was sterilized without her consent. Muir did not discover that she had been sterilized until she had left the Center and was attempting to start a family. In 1996, Muir successfully sued the Alberta government for wrongful sterilization and wrongful confinement. She received a settlement for the multiple and irreversible traumas that she endured. In the summary of the verdict from the trial, Honorable Joanne Viet, the judge presiding over Muir's case, noted that, "The circumstances of Ms. Muir's sterilization were so high-handed and so contemptuous of the statutory authority to effect sterilization, and were undertaken in an atmosphere that so little respected Ms. Muir's human dignity that the community's, and the court's, sense of decency is offended" (Veit, 1996, p. 696). Several subsequent lawsuits followed this landmark legal case given that Muir's experiences of institutionalization, dehumanization, and abuse were not atypical. Thousands of individuals who were labeled as disabled or 'unfit' to reproduce were sterilized in various Canadian provinces and Alberta's sexual sterilization laws were not repealed until 1972 (Malacrida, 2015).

While eugenic movements might seem like an outmoded way of thinking that disappeared long ago, eugenic strategies persist to this day. Scholars are pointing to new, more subtle forms of eugenics, often described in the literature as neo-eugenics or newgenics (Saxton, 2006, Shakespeare, 1998). Neo-eugenics move "beyond biological and medical interventions, to encompass systematic barriers to education, services, policy and supports for disabled people in terms of sexuality and reproduction" (Eugenics to Newgenics, 2017, para. 3). Scholars have identified examples of neo-eugenic practices, including prenatal testing and diagnosis, selective abortion, restrictive immigration laws[1], and a lack of social policies that support disabled parents as well as disabled people who choose to get married (Desjardins, 2012; Goggin and Newell, 2004; Hubbard, 2006; Rock, 1996). For instance, in Canada and the United States, when some disabled people get married they risk losing their social assistance benefits (Shakespeare, 2018). The loss of what is often meagre but vital financial assistance deters some disabled people from marrying and penalizes those who *do* get married. These neo-eugenic practices pose a variety of challenges to the reproductive and sexual opportunities of disabled people, and task scholars with the challenge of identifying sociocultural and legal contexts that constrict disabled people's opportunities to participate in sex, romance, parenthood, and love.

In spite of the historic and present-day desexualization of disabled people, there is an increasing amount of literature that details the various ways that disabled people have challenged and pushed passed oppressive practices to enjoy fulfilling sex lives (see Shakespeare et al., 1996; Guldin, 2000; Guter and Killacky, 2004; Kulick and Rydström, 2015; McRuer and Mollow, 2012; Shuttleworth and Sanders, 2010, 2012; Kafer, 2013; Shakespeare and Richardson, 2018). This literature helps to round out the relative lack of disability-sexuality research and points to a changing landscape in which disabled people are contributing to a burgeoning "sexual culture for disabled people" (Siebers, 2012, p. 37). Activists and academics have fought against practices and policies that restrict disabled peoples' sexual agency by creating events that promote their sexual

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[1] In 2016, Felipe Montoya, a professor at York University who came to Canada from Costa Rica was denied permanent residency because of his son's genetic condition: Downs syndrome (McQuigge, 2016). More recently, in 2017 the Warkentins, an American family of six that settled in the small town of Waterhen, Manitoba were denied permanent residency because a family member, four-year-old Karalynn, has an intellectual disability (Russell and Hill, 2017).

expression and exploration, and, importantly, by initiating conversations about disability and sexuality that center the voices and experiences of disabled people. For example, here in Canada, events like the Toronto Disability Pride Parade March, which has been organized by Melissa Graham since 2011, and the annual Mad Pride Parade, also held in Toronto, serve as examples of spaces in which disabled people can both challenge and participate in dominant sexual cultures. Importantly, the struggle to dismantle practices and policies that restrict disabled peoples' sexual agency is not limited to Canada. For instance, Ireland's recent 'Right to Love' legislation has acknowledged the rights of people labeled with intellectual disabilities to be sexual by changing discriminatory laws and social policies that controlled, and in many ways, denied their sexual rights. Previously, romantic and sexual relationships had been banned for people with intellectual disabilities (Arstein-Kerslake and Flynn, 2015). Other examples like Toronto's Planned Parenthood's SexAbility program, and Queerability, an organization devoted to LGBTQ+ participants with disabilities based in Kentucky, US, provide what is often inaccessible, yet extremely important, sexual health care and information for disabled people and their partners. Moreover, these initiatives foster an accessible and empowering environment in which disabled people can come together to discuss their experiences with love, relationships, and sex.

The Deliciously Disabled Party is another example of an environment that successfully supported and celebrated disabled people's sexual expression. Organized by Andrew Morrison Gurza, Fatima Mechtab, and Stella Palikarova in 2015 and held at the Buddies in Bad Times Theatre in Toronto, this event was an accessible and sex-positive space that promoted sexual exploration amongst disabled people and their partners. The party included a playroom for sexual activity, a workshop on sex toys, burlesque performances, and a number of other artistic performances. Events like the Deliciously Disabled Party are especially important since many spaces commonly associated with dating and sexual activity are often inaccessible to disabled people; restaurants, theatres, nightclubs, transportation services, and sexual health clinics for example (see Anderson and Kitchin, 2000; Bahner, 2012). Together, the organizers and attendees of the aforementioned event subverted some of the stigma that shrouds disability and sexuality by creating an opportunity for dialogue and an accessible venue for social interaction in which disabled people's bodies and sexualities are celebrated.

These examples illustrate the changing landscape of disability and sexuality in Canada and it is within this changing landscape that I position my research. On the one hand, I am optimistic that we are on the cusp of a new phase of disability and sexuality politics, one that challenges narrow constructions of both disability and sexuality and acknowledges the sexual agency of disabled people (see Santinele Martino and Campbell, 2019). Yet, on the other hand, I remain critical of how structures can quash the recent gains made by activists and academics. For instance, scholars have pointed to a recent retrenchment of social services and rights afforded to disabled people in Canada (Prince, 2009; Stienstra, 2012), and in the U.S since the election of Donald Trump (Harnish, 2017), a person who has openly mocked disabled people. Moreover, disabled people's strides for sexual acceptance and agency occur within a predominantly ableist culture and against a backdrop of neoliberalism (Prince, 2009; Fritsch, 2015). As Aronson and Neysmith (2001) argue, the exclusion and marginalization of disabled people "is deepened by neoliberal conceptions of citizenship that prize self-sufficiency and independence, disparage need and dependence and, thus, permit receding state intervention and greater privatization" (p.153). This is particularly troubling since recent research details how disabled Canadians "confront persistent barriers to participation in politics, education, the labor market, and other realms of community living" (Prince, 2009, p. 3). For instance, a recent study by Statistics Canada shows that, compared to 79 percent of Canadians without disabilities only 49 percent of Canadians with disabilities between the ages of 25 and 64 are employed (Statistics Canada, 2017).

Other research shows that as many as one in five disabled Canadians aged 15 to 64 live below low-income thresholds or the 'poverty line' (Stienstra, 2012a). This situation is even more acute for visible minorities and indigenous people who live with a disability since the rate of poverty among indigenous people with disabilities is double the rate among non-indigenous disabled people (Stienstra, 2012a). These studies highlight the precarious situation that many disabled Canadians inhabit as well as their struggles for social inclusion and self-determination. As I argue throughout this thesis, the eradication of barriers to sexual expression that disabled people face hinge upon broader sociocultural and legal changes that support the sexual and intimate lives of disabled people. As Shakespeare (2014) asserts,

> The more that societies are inclusive of disabled people – in terms of physical and virtual space, but also in terms of access to education, employment and public space – the more that disabled people will have the cultural, social and economic capital to participate fully in the world of emotions, sex and relationships (p. 213).

It is worthwhile to note that only a small number of studies that explore issues related to disability and sexuality have been conducted at the PhD level here in Canada (see Esmail, 2005). My valued and knowledgeable colleague Alan Santinele Martino is currently conducting his PhD research at McMaster University in this area. Specifically, he explores the romantic and sexual experiences of Ontario adults with intellectual disabilities. However, according to my knowledge, he is the only other PhD candidate who is conducting research in this area and while our research is complementary, it is also quite different. With this in view, this research project will contribute to an area of inquiry that is understudied.

A 2012 study published by Statistics Canada reported that roughly 3.8 million Canadians aged 15 and over live with a disability (Statistics Canada, 2013). This number will increase over time due to Canada's aging population and the well-established correlation between aging and disability (see Shakespeare, 2018). Thus, individuals living with a disability will constitute an increasingly large percentage of the Canadian population, and yet there is a dearth of empirical research that explores how Canadians with disabilities experience their sexuality. This research project helps to advance our understanding of how disabled Canadians access opportunities for sexual expression and makes important contributions to the sociological study of disability by advancing a more nuanced understanding of the sexual politics of disability.

Research Questions & Objectives

This research focuses on experiences that lie at the intersection of disability and sexuality. It is situated within a theoretical analysis of disability and sexuality and bolstered by empirical research consisting of twenty-four qualitative interviews. By conducting this research, I aim to explore the varied means through which persons with disabilities experience their sexual and intimate lives, particularly in the context of disabling stereotypes and discriminatory practices that work to limit their sexual expression and ultimately their sexual pleasure. Through conducting twenty-four semi-structured, in-depth interviews that privilege individual knowledge and self-interpretations of experiences that lie at the intersections of sexuality and disability, I respond to two research questions.

1) **How do individuals with physical disabilities access opportunities for sexual expression and what barriers influence their experiences?**

My primary focus in this question is on the actual embodied experiences of participants. The goal of this question is to explore how participants understand their sexual opportunities and experiences. This question also aims to understand the strategies that participants deploy in order to actualize their sexual selves. Similarly, it seeks to identify any barriers to sexual expression that participants encounter as well as the nature of these barriers. In order to access information that helps answer this question, I inquire how participants go about forming sexual relationships and if they have sexual relationships that they define as rewarding. If not, in their own terms, what prevents them from doing so? If so, what helps them to maintain or engage in these relationships? The multiple answers to this question illustrate some of the ways in which participants construct their sexual selves and how they experience their opportunities for sexual expression and activity.

2) **How are dominant social constructions of sex and sexuality – such as the importance of penetration and genital orgasm in sex, or aesthetic ideals of what constitutes a “sexy” body – challenged and/or reinforced through the experiences of disabled individuals?**

My second research question is more theoretical in nature than the first as it aims to explore how traditional constructs of sexuality and disability apply to the lives of participants. This question will explore if norms that surround sex, such as the notion that sex occurs between two unassisted, ‘able’ heterosexual people and ends in genital orgasm, are expanded upon or challenged by participants. In particular, how do these norms play out in the lives of participants? Do participants invoke or criticize these norms in the narratives that they share during interviews? In its entirety, this question attends to the interplay between agency and structure by exploring the diverse ways that participants both resist and reinforce dominant cultural constructions of sexuality and by examining how they interpret and create meanings suited to their own embodied realities.

While one of the overarching objectives of this research is to empirically explore how disabled people access opportunities for sexual expression and exploration, the second objective and theoretical consideration of this research is to question ideas of normalcy and to re-examine ableist and heteronormative notions of sexuality. Although the physical act of sex is certainly an aspect I explore in this thesis, I am careful not to overstate the importance of sexual intercourse and I employ a broad definition of sexuality in my work. While I discuss theories of sexuality at length in my theoretical perspectives chapter, here I briefly conceptualize sexuality as a fluid set of ideas, practices, experiences, attractions, and emotions that relate to an individual’s sexual desires and identity, and may or may not align with their assigned sex or gender. By conceptualizing sexuality in this way, this research does not just focus on intercourse or physical aspects of sex and sexuality, but also attends to other important aspects of sexuality such as intimacy, companionship, love, validation, heartbreak, rejection, and consensual sexual experimentation.

The knowledge generated from this inquiry will contribute to both empirical and theoretical knowledge regarding disability and sexuality. My expectation is that this investigation will shed light on how to ensure and better uphold the sexual rights of Canadians with disabilities, an area of study that requires further scholarly attention. Additionally, this research project will provide valuable information on theoretical and ethical issues associated with studying disability and sexuality. In its entirety, this research challenges ableist, heterosexist, and phallocentric notions of sex and illustrates the diverse ways that participants access and experience their sexuality.

Note Regarding Terminology

Research on disability makes use of both 'person-first' phraseology (e.g. people with disabilities) as well as 'identity-first' phraseology (e.g. disabled people), yet there is little consensus among scholars regarding which phrase is better. The language that is used to describe disability varies depending on political orientation and group affiliation. By placing the person first and the impairment or disability second, person-first phraseology seeks to emphasize the personhood of the individual and the "common humanity" among non-disabled people and people with disabilities (Shakespeare, 2014, p. 19). Proponents of person-first phraseology argue phrases like 'disabled people' or 'the blind' emphasize the disability rather than the personhood of the individual and consequently dehumanize people with disabilities (Albrecht, Seelman, and Bury, 2003). Person-first phraseology is often viewed as the more politically correct phrase as it signals a shift away from dated and derogatory terms that have been used to describe disability (Albrecht et al., 2003; Davis, 2002; Shakespeare, 2014; Titchkosky, 2001).

However, person-first phraseology is not without its critics. Several scholars and disabled people have criticized the phrase 'people with disabilities' because it implies it is possible to separate the experience of being disabled from an individual's identity and because it implies that "disabilities are individual deficits" (Shakespeare, 2014, p. 19; see also Linton, 1998; Titchkosky, 2001). These implications are offensive to some disabled people, particularly those who experience disability as an inseparable part of their identity and culture and as a source of pride and empowerment (Albrecht et al., 2003; Shakespeare, 2014; Watson, et al., 2012). Those who prefer “identity-first” phraseology (e.g., disabled person, deaf woman, and autistic man) generally embrace the term “disabled” as a way to emphasize their membership to or involvement in “minority group identity politics” (Albrecht et al., 2003, p. 3). In light of these debates, and in an attempt to respect and include the varied interests and perspectives of people with disabilities, I make use of both person-first and identity-first language throughout this dissertation.

Overview of Thesis

Throughout this chapter I have begun to introduce this research project, the context in which it occurs, the research questions that guide analysis, and the overarching aims of this study. In the chapter that follows, I discuss some of the epistemological and ontological traditions that guide this research and provide a rationale for my research design and methodology. In the subsequent literature review, I unpack why this area of study has been neglected and survey research related to disability and sexuality. I focus on research that addresses challenges to sexual expression that people with disabilities experience as well as some of the positive and pleasurable aspects of disabled peoples’ sexual lives. This chapter is followed by a discussion of the theoretical perspectives that I use to conceptualize both disability and sexuality. I then present the findings of this study and identify the numerous and persistent barriers to sexual expression that participants faced. In addition, I illustrate the diverse and complex ways that participants work to create opportunities for sexual expression amid these barriers. Finally, I conclude by reflecting on the limitations of this study and by providing suggestions for future research.

CHAPTER 2

Methodology - Researching the Intersection of Disability and Sexuality

"We are helping to awaken humanity to the reality that all people are flawed and yet beautiful, and each one limited in his or her unique way and yet powerful" – Jim Derksen, Canadian Disability Activist, (quoted in Driedger, 1989, p. 115).

Conceptual Framework: Ontology & Epistemology

It is important to begin this chapter by identifying the paradigms and assumptions that underpin this inquiry for as Bryman and Teevan (2005) contend, "methods are not simply neutral tools; they are linked with how social scientists envision the connection between different viewpoints about the nature of social reality and how it should be examined" (p. 2). Adopting a qualitative approach best suited my goals of developing a better understanding of the social realities that lie at the intersection of disability and sexuality because it promotes "deep understanding of a social setting or activity as viewed from the perspective of the research participants" (Bloomberg and Volpe, 2008, p. 7-8).

My research methodology is situated within an interpretivist epistemological tradition which holds that individuals are capable of creating and understanding multiple versions of reality or truths. Within this tradition there is no universal or singular reality. Instead, there are simultaneously multiple and competing realities which are co-constructed by individuals through interaction and social action (Lincoln and Guba, 1998, 2000). In accordance with an interpretivist stance, I view knowledge production and acquisition as a co-constituted enterprise that is continually under revision, bound to various historical and sociocultural contexts, and influenced by power structures. In recognition of the fact that some knowledges or interpretations are accorded more power than others, I employ a critical-constructionist approach that does not deny the role that structures of power (i.e. law, capitalism, medical or scientific discourses, etc.) play in influencing and constraining individual agency. Nevertheless, I consider people to be "active creators" as opposed to "passive reactors" and recognize their capacity to create, change, or overthrow power structures (Bryman and Teevan, 2005, p. 2). In other words, 'ordinary' people can create, rework, reify, and challenge systems of meaning through their interactions and in their everyday lives.

Neuman (2006) suggests that some key questions for an interpretive researcher include; "How do people experience the world? What do people believe to be true? What do they hold to be relevant? How do they define what they are doing?" (p. 90). An interpretivist methodology has allowed me to better explore answers to questions such as; how do participants define meaningful or healthy sexual relationships? How do they experience opportunities for sexual expression and exploration? What prevents them from engaging in a sexual life and what assists them in doing so? Keeping in mind that I seek to better understand how disabled people access and engage in a sexual life – specifically how they form, maintain, and define their opportunities for sexual expression – an interpretive approach that emphasizes experience and understanding facilitates an inquiry that centres the voices and experiences of participants.

This research is further guided by a critical-constructionist ontology which asserts that "the beliefs and meanings people create and use fundamentally shape what reality is for them" (Neuman, 2006, p. 89). This ontological position emphasizes how the "categories people employ to help them understand the natural and social world are in fact social products" (Bryman and Teevan, 2005, p. 14), given that people generally "take most things around them 'for granted' and act as if they were as natural, objective, and part of fixed reality" (Neuman, 2006. p. 89). However, this does not mean that these social products are not real or tangible in their effects. Neuman (2006) succinctly argues, "Do not think that because what people see and experience is socially constructed makes it illusionary, immaterial, or unimportant. Once people accept social relations as being facts, or as real, very real consequences follow" (p. 89). Thus, a constructionist ontology embodies the view that meanings are socially produced, multiple, and contextual insofar as they are created under particular sociocultural conditions, change over time, and vary cross-culturally.

Importantly, a constructionist position acknowledges that research is influenced by researcher interpretations and lived experiences. According to Bloomberg and Volpe (2008), constructionist researchers "recognize and acknowledge that their own background shapes their interpretation, and they thus 'position' themselves in the research to acknowledge their own cultural, social, and historical experiences" (p. 9). The knowledge claims that I make in this study are co-constructions created through interactions with participants. My accounts are socially constructed insofar as they paint a specific view of reality that has been contoured by not only my interactions with participants, but through my interpretation of their experiences and my *own* positionality. In order to produce research that is both reflexive and transparent I account for the ways that my positionality and identity have influenced this research in the following section of this chapter.

The afore mentioned ontological and epistemological commitments informed how I identified appropriate methods to collect and analyze data. For instance, in keeping with interpretivist principles, I used semi-structured, in-depth interviews as a means to facilitate and foreground the voices and experiences of disabled people. Individuals whose voices and experiences that have historically been neglected in scholarly accounts of disability. A critical-constructionist stance promoted an examination of essentialist and biologically reductionist definitions of disability, as well as an investigation into the boundaries of what constitutes an 'able' and 'disabled' body. Similarly, the following 'reflexivity' section adheres to principles of interpretivist and constructionist traditions that require researchers to address the ways in which their values, identity, and positionality influence their research. In the following section, I address the values that underlie this research and explore some of the ways that my identity, embodiment, and personal experiences have influenced this research.

Reflexivity

Reflexivity is an important aspect of qualitative research and is a "practice that is central to disability and feminist research" (Liddiard, 2013, p.2, see also Wilkinson, 1988, Reinharz, 1992, 2010; England, 1994; Crooks, Owen, and Stone, 2012; Rinaldi, 2013). While the meaning and purpose of reflexivity can be conceptualized in a variety of ways (see Finlay, 2002, 2002a, Denzin, 1997; Marcus, 1998; Pillow, 2003), it is generally "based on a belief that knowledge obtained from research is dependent on the assumptions underpinning it and the methods used to obtain it" (Oliver, 1992, p. 109). Reflexivity involves sustained and critical consideration of the "subjective, institutional, social and political processes whereby research is conducted and knowledge is produced" (Alvesson, 2007, para. 1). Adopting a reflexive approach – in which the role of the researcher is acknowledged and critically examined – entails exploring questions like, "how does who I am, who I have been, who I think I am, and how I feel affect data collection and analysis" (Pillow, 2003, p. 176). These questions can be difficult to answer and as Brown and Boardman (2011) caution, "engaging in truly reflexive work can be uncomfortable" (p. 24). Yet, the challenge of adopting a reflexive approach is to explore and analyze these questions in-depth, rather than provide a 'neat and tidy' answer to them (Pillow, 2003).

Conducting a thorough and continuous exploration of the ways that subjective and inter-subjective elements influence both data collection and analysis can enhance the "trustworthiness, transparency, and accountability" of research (Finlay, 2002a, p. 211). According to Brown and Boardman (2011), it is important that qualitative researchers studying disability "account for their role in the development of a research project and identify factors that shape the work they do" (p. 23). Failure to analyze the various ways that a researcher's embodiment, identity, and values shape the research process can "produce an illusion of objectivity that is potentially deceptive" (Brown and Boardman, 2011, p. 24). Similarly, Stone and Priestley (1996) assert that reflexive practices are particularly important for non-disabled researchers who conduct research involving disabled people because "the inherent power relationship between researcher and researched is accentuated by the unequal power relations which exist between disabled people and non-disabled people in the wider world" (p. 700). In order to address these asymmetrical power relations Stone and Priestley suggest that scholars "introduce more vulnerability into our research projects" and endeavour to create research that is reflexive (1996, p.700; see also Crooks et al., 2012).

Adopting a reflexive approach has provided further insight into the influence that my embodiment, identity, values, and subjectivity has on this research. Moreover, employing a reflexive approach challenged me to critically consider the underlying assumptions that shape this research project. As opposed to claiming an "objective, disembodied voice, without any particular vantage point or value" (Rice, 2009, p. 249), I acknowledge that my understanding of this research is partial, co-constituted, and bound to a specific social context. Furthermore, I consider the knowledge and meanings produced through interviews to be an embodied engagement that is, "negotiated between researcher and researched within a particular social context so that another researcher in a different relationship will unfold a different story" (Finlay, 2002, p. 531). I do not claim that that this research is value-free or objective. Instead, I endeavor to interrogate and lay bare the values and assumptions that guide this research project, as well as my motivations for conducting exploratory research in this area.

A central value which guides this research is my belief that like non-disabled people, disabled people deserve opportunities to experience romantic love, heartbreak, consensual sexual experimentation, intimacy, and companionship, if they so choose. Additionally, an underlying assumption that contours this research is my position that people with disabilities face a number of sociocultural and legal barriers in accessing and engaging in a sexual life (Campbell, 2017). My motivations for conducting this research are threefold. Firstly, I seek to advance a more nuanced and robust understanding of the sexual politics of disability by contributing to an area of study that is relatively under-researched. Secondly, I plan on returning the results of this study to the people who it came from. Finally, I am motivated by my personal, professional, and political commitment to the rights of people with disabilities as well as my own professional goals (i.e. completing my PhD).

In addition to interrogating some of the assumptions that underlie this research, I have explored the various ways that my identity and position as an atheist, white, working-class, cisgender woman who lives with a chronic illness have influenced this research project; from inception to interviews and analysis. Attending to what Broom, Hand and Tovey (2009) describe as the "intersectionality of the interview environment" (p.61), has allowed for an examination of the various ways that my gender intersects with other aspects of my identity (e.g. age, race, education), as well as an examination into the ways in which my identity intersects with both the setting of the interview (e.g. time, place, interviewee's identity), and the topic under discussion (e.g. stigma, sexual pleasure, sexual function). Similarly, Broom, Hand, and Tovey (2009) contend,

> Gender permeates all aspects of social life and the qualitative interview involves processes of performance and impression management; processes whereby interviewers and interviewees seek commonalities and differences, as well as enacting socio-cultural expectations regarding such things as 'femininity', 'manliness', 'professionalism' and so on (p. 52, see also Herod, 1993; Padfield and Proctor, 1996; Oakley, 1981; Schwalbe and Wolkomir, 2001; Williams and Heikes, 1993).

Upon reflection, I recognize that I performed my gender and femininity differently during each interview context. My performance of gender was co-constructed insofar as it depended on the interviewee, my interpretation of what they thought to be appropriate gender performance, and the availability of the range of socially constructed symbols, scripts and gender norms that I drew on in order to express my gendered self (West and Zimmerman, 1987, 2009; Golombisky, 2006; Butler, 1990, 2004). As Butler (2004) argues, "One does not 'do' one's gender alone. One is always 'doing' with or for another, even if the other is only imaginary" (p. 1). My sense of gender was further mediated by other relevant aspects of my identity such as my age, embodiment, socioeconomic status, education, and sexual orientation (Crenshaw 1989, 2017; Hill-Collins and Bilge, 2016). In general, I sought to perform or 'do gender' in a way that was flexible, however my performance was ultimately an enactment that relied upon heteronormative socio cultural expectations or 'scripts' of what it means to be a woman (Simon and Gagnon, 1986; Kessler and McKenna, 1978; Butler, 1990, 2004). During interviews, I worked to avoid any potential sexualization by participants by dressing modestly and if I was asked about my relationship status, I responded that I was currently in a long-term, monogamous relationship with a male partner.

Throughout the data collection and subsequent analysis my gender identity functioned as both a "resource and limiting factor" (Schwalbe and Wolkomir, 2001, p. 53). There were times during certain interviews with heterosexual male participants when my gender identity heightened the level of discomfort that they experienced, particularly when discussing topics like rejection from potential partners, sexual satisfaction, or physical changes they had experienced upon becoming disabled (see Broom, Hand and Tovey, 2009; Hutchinson, Marsiglio and Cohan, 2002; Schwalbe and Wolkomir, 2001). This heightened level of discomfort was apparent in several interviews. For instance, one male participant expressed at the beginning of our interview that he hadn't expected me to be so young. This participant remarked that he felt a bit uncomfortable talking about sex with "a woman half his age". These feelings could have prompted this particular participant to withhold or gloss-over particularly sensitive, painful, or potentially emasculating details regarding his sexual life (Broom, 2004; Pini, 2005; Liddiard, 2013). Conversely, it is possible that I was seen by both male and female participants as a nonthreatening and even maternal figure due to stereotypical ideas that position women as nurturing, sensitive, and 'good listeners' (see Arendell, 1997; Winchester, 1996; MacDowell, 1988; Oakley, 1981). These traditional and stereotypical ideas regarding femininity could have fostered a sense that I would be an appropriate and empathetic person to whom they could easily divulge personal details to (Hearn, 2013; Liddiard, 2013; Pini, 2005). As Gurney (1985) argues, like other female researchers, I found myself working especially hard to "achieve an impression combining the attribute of being non-threatening with that of being a credible, competent professional" (p. 43).

During interviews with women, I was keenly aware of my status as both an 'insider' and 'outsider' (see Ahmed, et al., 2010; Cotterill, 1992; Goodley and Tregaskis, 2005; Reinharz and Chase, 2001; Riessman, 1987; Seymour, 2001, 2007). On the one hand, I could be considered an insider in the sense that these participants and I both identified as women and therefore ostensibly share a common bond based on our shared gender identity. Yet, on the other hand, I was an outsider in the sense that I do not identify as disabled (Barnes and Mercer, 1997; Stone and Priestley, 1996; Brown and Boardman, 2011; Tregaskis and Goodley, 2005). Song and Parker (1995) assert that, "where two people may claim commonality on one dimension, they may fall apart on another" (p. 24). With this in view, although I might share a common gender with some participants, this commonality did not always extend along racial, ethnic and religious lines. Furthermore, while some female participants and I might share a common sex or gender, this did not mean that we have had similar gendered experiences. Significantly, feminist scholars Doucet and Mauther (2007) argue, "Even where researchers and respondents share structural and cultural similarities of, for example, gender, ethnicity, class, and age, this does not guarantee knowing, or 'better' knowing" (p. 40).

While interviewing female participants, I noticed how some of these women would invoke a royal 'we' when they referred to women in general. In contrast, when these women referred to men in a general sense they would often use the word 'they' which implied a separation between us (women) and them (men), and signified an underlying commonality. When discussing issues like sexism or socially constructed ideals of beauty, some women would make comments like "you know", "you get what I mean", or "that's the type of stuff that we have to put up with". While these women could have thought that I understood what they were expressing because I was conducting research on sexuality, statements like these also carried the implication that as a woman I might have access to similar experiences as them and therefore might be able to better understand or relate to some of the experiences they described (Schwalbe and Wolkomir, 2001). According to some research, it is possible that our shared gender identity could have encouraged female identifying participants to share or express themselves more freely during interviews (see Oakley, 1981; Pini, 2005; Ahmed et al., 2010). However, there were times that both female and male participants located me as an 'outsider' by using language like "us disabled people" or "we disabled people". Similarly, there were times when I got the sense that both male and female participants worked to explain their experiences in great detail because they were aware that we did *not* share certain similar experiences. In sum, depending on the individual, participants might have been more or less willing to divulge details regarding their intimate experiences because of my gender and/or age, embodiment, sexuality, race, etc.

As previously mentioned, my gender identity is undoubtedly mediated by a range of other relevant aspects of my identity such as my age, race, education, embodiment and so on. In light of this fact, it is important to inspect and reflect upon the ways in which my gender identity intersects with these experiences and identities. In some interviews, it was apparent that my gender identity and age combined to diminish my status as a professional or 'expert'. This was evidenced by comments like "I didn't expect you to be so young", or the comment made by the male participant which highlighted both my gender and age, potentially inferring inexperience and naivety on my behalf. However, I recognize that my gender and age sometimes functioned to mitigate power dynamics or 'level the playing grounds' and put some participants at ease (Liddiard, 2013). Yet, in a small number of interviews it was obvious that the participant looked to me as an expert who might be able to shed light on their individual situation or issues related to gender and sexuality more broadly (Oakley, 1981). This was evidenced by several participants' requests for advice regarding relationship problems or questions related to sex and gender. When participants asked me these sorts of questions I did my best to answer as accurately and honestly as possible. Although I am in the process of becoming an expert in this area of study, and although I recognize the level of power that I had in this research project in terms of defining the topic, the scope of the research, accessing the field, and in interviewing participants, I did not consider myself an expert on participants' individual experiences. Instead, I relied on their individual, embodied knowledge of their experiences regarding sexuality and disability in order to make sense of and explore their individual realities.

Reflectively accounting for the ways that my race and ethnicity intersect with other aspects of my identity proved to be a difficult task that was not as straightforward as my examination of the ways in which my gender identity and other biographical factors influenced this research. My experience of attempting to account for the influence of my race and ethnicity during data collection and analysis was similar to the experiences that Liddiard (2013) had while conducting research on disability and intimacy in the UK. In describing how she worked to inspect the various ways that her racial identity influenced her research Liddiard notes how her white privilege enabled her to feel as though her whiteness was "indistinct" and "invisible", one of the central functions of white privilege (Liddiard, 2013, p. 5). Like Liddiard, my white privilege obfuscated my status as a racialized white person insofar as it often rendered my race invisible and at times, intangible to me. Although I am familiar with intersectional feminism and black feminist theory (see Crenshaw, 1989, 2017; Hill-Collins, 1990, 2004; hooks, 1981, 1984, 2003), and although I made efforts to include Black, Indigenous, and persons of colour in this study, it was not until participants from different ethnic, racial, and religious backgrounds shared their narratives that I realized how I had failed to truly appreciate and interrogate the ways in which my ethnicity and race influenced this research. As a result, I did not problematize or reflect upon my racial and ethnic identity to the extent that I did with other aspects of my identity. Once participants shared information about their experiences that were contoured by race, ethnicity, and religion, I began to inspect my whiteness and atheism in a new light. Regrettably, like Liddiard (2013), "my social, cultural and scholarly knowledges of disability rested not only upon my own embodied whiteness, but were inevitably exacerbated by the stark whiteness of disability studies as a discipline" (p. 5). This starkness is evidenced by the disproportionately large number of white disability studies scholars and the resulting dearth of disability studies scholarship on race and disability (see Bell, 2011; Stienstra 2012, 2012a).

Attempting to account for the ways that my embodiment and experiences with chronic illness influenced the research proved to be a messy and iterative process. As noted by Finlay (2002a), "The process of engaging in reflexivity is full of muddy ambiguity and multiple trails as researchers negotiate the swamp of interminable deconstructions, self-analysis and self-disclosure" (Finlay, 2002a, p. 2009). In order to organize my thoughts and provide an 'audit trail' that documented changes in both my thinking and the research project I maintained a reflexive research diary (Nadin and Cassell, 2006). My reflexive research diary provided a space to record details regarding the progression of the project as well as reflexive writing that detailed my emotions and experiences as they unfolded throughout the research (Bradbury-Jones, 2007; Lincoln and Guba, 1985; Malacrida, 2007). This diary was also a place to document developments in my thinking and to take note of particularly poignant experiences or thoughts that occurred during data collection and analysis. On a more personal note, writing in my reflexive research diary proved to be a cathartic exercise that helped me work though methodological, ethical, and personal issues that I encountered during the research process. I maintained and made use of my reflective research diary through the entire course of the research project.

In the diary, I wrote about my reflections on individual interviews and overall progress. In addition, I engaged with questions like "why did I decide to conduct research in this area?" and, "what is my relationship to disability and how does that relationship shape this research project?". While the answers to these questions are not straightforward, I found the practice of engaging with them to be productive in the sense that this process shed light on my motivations for conducting this research and prompted thoughtful consideration of how I will disseminate the results of this project. Finally, maintaining this diary compelled me to further consider the ways that my personal experiences with chronic illness have influenced this research process.

In the following section I have attempted to summarize my experience of being diagnosed with a chronic illness and provide some thoughts on the various ways that my embodiment has impacted this research project, particularly in terms of disclosing my experiences with chronic illness to participants. This reflexive statement regarding my standpoint is intended to provide readers with an understanding of how I have approached this research as well as a more holistic and transparent account of the context in which this research took place. In addition to my reflexive statement regarding my standpoint and experience with illness, I have included an excerpt from my reflexive research diary in the appendix (See Appendix Section A). I have included this particular excerpt because it illustrates flaws and ableist assumptions in my thinking, how this type of thinking influenced the initial interview guide that I developed, and how I worked to correct these issues. The inclusion of this entry in the appendix is meant to show progression in my thinking and has been included in an effort to be as transparent and reflexive as possible.

Reflexive Statement Regarding my Standpoint and Relationship with Chronic Illness

I recognize that I approach this research with a significant amount of ablebodied privilege. For most of my life my relationship to my body has been rather uncomplicated and I haven't endured the stigmatization, discrimination, or issues of inaccessibility that many people with disabilities experience on a regular basis (Clare, 1999; Wendell, 1996; Mairs, 1996; Prince, 2009; Shakespeare, 2014). In short, my body has usually done my 'bidding' and rarely asserted its own will. Until rather recently, my sense of self was largely predicated on my physicality and my ability to use my body for physical labor. Growing up on a farm and in a protestant household that valued hard work instilled a sense that my value was based on hard work and good deeds. As a teenager and young adult, I prided myself on my ability to work as hard (or harder) than others and drew much of my self-worth from this perception. I am sure it was this same sense of pride in my work ethic that encouraged me to apply to work as a tree planter in New Brunswick, a notoriously difficult job. I worked in this industry for seven seasons and although I have many fond memories of my summers spent in clear cuts, I don't think I ever realized the strain that I was exerting on my body. Furthermore, I did not have a full appreciation of the able-bodied privilege I carried with me until my body began to 'fight back' and exert its own will.

My body began to 'fight back' in 2014 when I began to experience debilitating back pain. I initially assumed the pain was a consequence of a productive tree planting season and that it would subside after a little while. Unfortunately, my back pain persisted to the point where I was immobile for days at a time and required assistance with daily living activities (e.g. eating, getting to the washroom, bathing, etc.). I sought out medical assistance by making an appointment with my Doctor at the Concordia Health Clinic and began the long and difficult process of diagnosis. After several x-rays, blood tests, countless sessions with physiotherapists, numerous consultations with specialists, and an MRI, in January of 2016 I was ‘officially’ diagnosed with ankylosing spondylitis, a form of arthritis that affects spinal joints, specifically the sacroiliac joints.

As I adjusted to my new embodiment my connection to my research project took on a more personal dimension. Issues that I had previously only read about such as dealing with pain, judgement, and issues of inaccessibility became more tangible as I experienced them in my own life. I learned first-hand how pain, immobility, and ableism can affect one’s sense of self, and more pointedly, one’s sex life. Like Murphy (1987), who candidly describes his experiences of cancer diagnosis and disablement in his book *The Body Silent*, I felt as though it was not just my body that had changed, but also my identity and my sense of self. Murphy (1987) writes,

> I had an increasing apprehension that I had lost much more than the full use of my legs. I had also lost a part of my self. It was not just that people acted differently toward me, which they did, but rather that I felt differently toward myself. I had changed in my own mind, in my self-image, and in the basic conditions of my existence (p. 85).

My pain and immobility often caused me to feel burdensome and ugly. This is despite the fact that I had immersed myself in disability studies scholarship, was a staunch supporter of disabled people’s rights, and knew that disabled people or individuals who are chronically ill are valuable and beautiful. This disjuncture between what I knew academically and what I felt personally exposed a gap in my experiences and uncovered some uncomfortable truths. For instance, I realized there was a need to critically interrogate why my sense of self was so deeply connected to my body and why I felt I was of less value now that I had an illness and experienced my body in a radically different way. Before I became chronically ill, I inhabited a comfortable distance or ‘ivory tower’ of sorts that was far away from the lived reality of physical impairment. In light of this fact, I don’t think I had an appropriate appreciation for the pain, isolation, and self-doubt that can accompany impairment, the onset of illness, and disablement. Additionally, my experiences of pain showed the flaws within the social model of disability, albeit in a very painful way. My experiences of chronic illness highlighted how there were times where the social world caused me to be impaired, but there were other times where my pain had very little to do with the social world and the environment in which I lived. This further highlighted the need for theoretical models to be able to account for people's pain and embodied experiences.

Although I do not identify as disabled, I do identify as an individual who lives with a chronic illness. My experience of chronic illness has allowed me to experience *some* of what I had been reading about in scholarly accounts of disability and sexuality and through listening to the participants involved in this study. I have reflected on how my personal experiences collided with my academic interests and in an attempt to introduce greater vulnerability and further transparency into my work I have included a few reflections on how my illness has affected my romantic relationship with my significant other. My illness affected my relationship in several ways. For instance, during my worst bouts of inflammation and pain I relied on my partner for my everyday care, including transport in and out of bed, food preparation, bathing, and using the washroom. On the one hand, this reliance would put stress on our relationship and could be an uncomfortable experience both physically and emotionally. Yet, on the other hand, this reliance and the care I received showed me how intimate personal care can be, and how flexible desire can become. There were many days where I was unable to physically engage in any sexual activity with my partner because I was immobilized by pain. My inability to be mobile or engage in sexual relations bred insecurities about my partner leaving me because I was no longer able to engage in not only sexual activity, but activities that we had routinely done as a couple such as snowboarding and hiking. Although this experience has not been easy for either of us, I recognize I am fortunate that I had someone who was willing to care for me and I'm fortunate because the experience has helped to solidify our relationship. Ultimately, my experience with chronic illness has forced me to reconcile and reconfigure my sense of self. In particular, it has forced me to reflect upon how my sense of self-worth and value was so largely predicated on my ability to 'do things' with my body, no doubt a vestige of the ableist, capitalist, and sexist values I had absorbed throughout my life. With time and reflection, I have worked through these feelings of inadequacy that were largely based on my new corporeality and continue to consider how my relatively newfound embodiment impacts this research project.

One particular impact that my embodiment has had on this research relates to the issue of disclosing the fact that I am chronically ill to participants. I was aware that this disclosure could alter the course of the interview, but initially I was unsure if I should disclose this information to participants, or how I should go about disclosing it. Several scholars note how this process of disclosure is fraught with uncertainty and multiple potential outcomes (see Barnes and Oliver, 1996; Brown and Boardman, 2011, Tregaskis and Goodley, 2005). For Brown and Boardman (2011), "impairments may assist rapport building with participants, but also introduce complex dilemmas concerning whether, when and how to disclose them, and the consequences of doing so" (p. 23). Similarly, according to Engelsrud (2005), the researcher's body can be "understood as both access and limitation to the acquisition of knowledge" (p. 281). After consulting research on this particular issue, I came to the conclusion that even though my impairment is not always particularly visible, it was important to express my positionality to participants in a concise and candid fashion (Ellingson, 2006; Brown and Boardman, 2011; Smith-Rainey, 2015).

With reflection and hindsight, I can see that I was worried about disclosing my experiences with illness for several reasons. Firstly, since my experiences with chronic illness were relatively new to me at that time, there was a small part of me that hoped I would 'recover' and that my pain and illness was temporary. It is possible that I was apprehensive about disclosing my experiences due to some unconscious ableism and deep-seated ablebodied privilege that encouraged me to 'preserve' my ego by distancing myself from my participants and the label of disabled or chronically ill. I also entertained worries about how my experiences with illness and pain compared to the individuals that I interviewed, particularly those whose pain was far worse than mine and whose pain had been present throughout their entire lives. Finally, due to the relative invisibility of my illness, I worried that I would be judged by participants because I did not consistently 'appear' to be chronically ill unless I was using my cane (see Tregaskis and Goodley, 2005; Ellingson, 2006; Seymour, 2007; Brown and Boardman, 2011).

As the research project progressed, I became more comfortable with disclosing my experiences to participants. However, it was important to maintain a delicate balance. I wanted the focus to be on the participants and certainly did not want my experiences to compete with or overshadow theirs. I also felt it was important to maintain some professional distance and boundaries with participants (Denzin and Lincoln, 2000). Since I was still adjusting to my new embodiment and since the process of diagnosis coincided with the early stages of this research project, I had legitimate worries that I would become emotional or say something that was offensive to participants when discussing my own experiences. I knew that saying something like 'this has been the hardest thing that I have ever dealt with' to a participant would not only have crossed some professional boundaries but could have been perceived as an ableist and offensive remark. It was therefore important that I developed a plan for disclosure that was attentive to participants, my own vulnerability, and ethical codes of conduct.

In light of the fact that many of these experiences and emotions were new to me, my disclosure of living with an illness was uneven. During the first seven interviews, I did not discuss my experiences of illness and impairment. Guided by Oakley's (1981) axiom that there can be "no intimacy without reciprocity" (p. 49), I later incorporated my experiences into a spiel that I gave at the beginning of each interview so that the disclosure would be consistent across all remaining interviews. Although I was apprehensive about discussing my personal experiences with participants, disclosing my relationship to impairment and chronic illness allowed me to introduce more vulnerability, reflexivity, and reciprocity into this research project. Although "impairment does not automatically give someone an affinity with disabled people" (Barnes, 1992, p. 121), some participants would offer practical tips and suggestions while other participants seemed to noticeably relax when I disclosed that I identified as chronically ill. A few participants and I would relate and commiserate based on some of our common experiences. For example, when describing her experiences within the Canadian medical health system, a female participant said "well…you know how awful the wait times can be", indicating that we shared a common experience of navigating the Canadian medical health care system.

The process of disclosing and discussing my relationship to chronic illness helped to shift some of the power dynamics embedded within the interview setting insofar as it allowed me to invert some of the 'social relations of research production' (Oliver, 1992). As Brown and Boardman (2011) contend, the inequalities within a researcher-researched relationship are often "exacerbated by the imbalance of disclosure, such that the researcher remains remote and unknown to the participant" (p. 28). By opening myself up to questions that participants had about my experiences with chronic illness and disablement, they were effectively able to interview *me*. For instance, during one interview, a male participant asked me if I ever experienced hand cramps or got callouses from gripping my cane. Another female participant asked me about how my chronic illness influences my sex life and how I have dealt with this in my own romantic relationships. Questions like these allowed participants to stray from the interview guide and indicated that they felt empowered to ask their own questions. Additionally, exchanges like these proved to be an important and productive experience that generally made interviews a more reciprocal and rewarding process. As Oakley (1981) argues, "the goal of finding out about people through interviewing is best achieved when the relationship of interviewer and interviewee is non-hierarchical and when the interviewer is prepared to invest his or her own personal identity in the relationship" (p. 41). Addressing my relationship to chronic illness, investing my own identity into the research, and discussing some of my experiences with participants allowed me to better consider and counteract some of the power dynamics inherent in a researcher-researched relationship (Finlay, 2002, 2002a). Although reflexive and reciprocal practices cannot eliminate all of the power dynamics and inequities in an interview setting, injecting reflexivity and vulnerability into this research project helped to mitigate some of the inequities inherent in interview settings (see Oakley, 1981; Reinharz, 1992; Wasserfall, 1997; Arendell, 1997; Finlay, 2002, 2002a).

In conclusion, reflexivity proved to be an effective tool that helped me work through methodological, ethical, and personal problems that arose throughout the research. As part of conducting reflexive and transparent research, I have acknowledged that my data is mediated by my individual subjectivity. I have worked to explore and declare my relationship to disability and chronic illness in an attempt to "strike a balance, striving for enhanced self-awareness but eschewing navel gazing" (Finlay, 2002, p. 541). In addition, I have pushed myself to critically consider the underlying assumptions that guide this project, and to inspect the ways that my race, age, gender, sexual orientation, religion, socioeconomic status, and embodiment functioned as "determining factors which influenced the power dynamics of the researcher/researched relationship and thus contoured the ways in which stories were told – often quite literally" (Liddiard, 2013, p. 4). Adopting a reflexive approach has not only assisted in creating more ethical and transparent research but also in producing research that is more self-critical and methodologically rigorous (Finlay, 2002, 2002a; Crooks et al., 2012; Pillow, 2003).

Participant Recruitment

Once I obtained my certificate of ethical approval from Concordia's Research Ethics Unit, I began to recruit participants using a combination of purposive and snowball sampling techniques. Purposive sampling allows researchers to recruit individuals according to a set of sampling criteria that are central to their research questions (Patton, 2002; Merriam, 1998). In order to answer my research questions, I recruited individuals aged 19 years or older who self-identified as physically disabled and were willing to discuss their experiences related to disability and sexuality for the purposes of research. I made use of snowball sampling because this sampling technique is an efficient methodological tool that can allow researchers access to "hidden" and "socially stigmatized" populations (Atkinson and Flint, 2001, para. 2).

In spite of several benefits to using snowball sampling, there are some limitations that need to be addressed. Firstly, snowball sampling often carries the assumption that "a 'bond' or a 'link' exists between the initial sample and others in the same target population, allowing a series of referrals to be made within a circle of acquaintance" (Atkinson and Flint, 2001, para. 4). While this assumption is generally a key component to snowball sampling that is useful in research scenarios where scholars seek to examine specific social groups or networks, it has some drawbacks that become particularly apparent when conducting research involving people with disabilities. To presume that disabled people are a discreet group of individuals who know one another and are part of a community that is based on their shared experiences of disablement would be a gross simplification and an ableist assumption. As noted by Canadian Disability Studies scholar Michael Prince (2009), the Canadian disability community is "highly differentiated" (p.119) and its "boundaries are not always clear or agreed upon. Nor do these boundaries remain fixed" (p.113-114). Additionally, an ableist sentiment underlies the assumption that disabled people only associate with other disabled people and the assumption that people with impairments automatically identify as disabled or as part of a 'disability community'. Throughout the process of recruitment, I carefully balanced the assumptions inherent to the snowball method with the knowledge that disabled people do not just associate with other disabled people, and that many do not consider themselves to be a part of a 'disability community' (e.g. 'capital D' Deaf persons).

A second limitation of the snowball sampling technique is the possibility that some participants might know one another, which could ultimately compromise aspects of confidentiality and anonymity. Similarly, if some participants *do* know one another, it is possible that they share common characteristics or similar life experiences (e.g. work at the same establishment, hold similar views, are of similar socioeconomic status). Commonalities among participants can potentially limit the overall diversity of the research population which could lead to unrepresentative results (Neuman, 2006, 2011). Many of these concerns regarding the limitations of snowball technique were abated by the fact that the large majority of participants came to the study independently and without a referral.

This research project consisted of several concurrent strategies for participant recruitment. One aspect of my participant recruitment strategy involved posting call for participants posters in public spaces in Ontario, Quebec, New Brunswick, Nova Scotia, and Prince Edward Island. Calls for participants were often posted on communal bulletin boards and in accessible public spaces (See Appendix Section B). In addition to this, I posted a digital version of the same call for participants poster to various online groups using different social media platforms such as Facebook and Twitter. I posted my call for participants in both physical and virtual spaces roughly 8-10 times (depending on the location) over the course of six months. In addition to widely posting my call for participants in various forums, I contacted various organizations dedicated to disability rights that are located in Eastern Canada (e.g. Regroupement des Activistes Pour l'inclusion au Québec, The Rose Centre for Love, Sex, and Disability, PEI Council of People with Disabilities, etc.) and asked them to relay my invitation to participate amongst their colleagues and clients. I also created a Wordpress website that detailed information about the study and included my call for participants.

The second component of my participant recruitment strategy involved the use of snowball sampling methods. I began the snowball sampling trend by inviting four individuals to participate in the research project. In addition to participating in an interview these individuals provided me with the names of four other individuals who might be interested in taking part in the research. I contacted these persons individually via email and received a response from three of them. These three individuals agreed to participate and two became key informants throughout data collection. I continued the snowball trend throughout the data collection phase by asking participants who answered my call for participants after viewing it either online or in a physical space if they knew of another individual who fit the inclusion criteria and might be willing to partake in the research.

Throughout the participant recruitment phase of this research I found the pattern of participants rarely passing along the information of a potential participant to be quite common. The reluctance to pass along information about this study could be for several reasons. A few participants who declined to refer a potential participant mentioned how they did not feel comfortable discussing the project with someone else because it might mean that they had to discuss their *own* participation. This was a task that some participants were understandably not willing to do, and serves as a reminder of some of the limitations of employing a snowball sampling technique. Other participants simply stated that they did not know of anyone who would meet the criterion for participating in the study and therefore could not refer anyone. Another possible reason for this reluctance could be related to the contentious history of disability related research. Several scholars have shown how research on disability has a long history of excluding and objectifying people with disabilities (see Oliver, 1990, 1992; Shakespeare et al., 1996; Barnes, 2013). As Stone and Priestly (1996) contend, “decades of ‘scientific’ research have perpetuated the marginalization of disabled people, justifying segregationist policies, eugenics, and the systematic denial of human rights" (p. 701). This type of research has been criticized by people with disabilities for being "in violation of their experience, irrelevant to their needs and as failing to improve their material circumstances and quality of life" (Morris, 1992, p.158; see also Hunt, 1981; Barnes and Oliver, 1996; Siebers, 2002). In light of this history and in recognition of the fact that people with disabilities are often asked to participate in research or work for free (Shakespeare, 1997, 2014), they are justified in their circumspection and wariness.

Reluctance to participate could also be attributed to the sensitive nature of topics that were explored during interviews. It is plausible that some potential participants felt it would be inappropriate to ask a friend or colleague to divulge intimate details about their sexual experiences to a stranger. These feelings are once again certainly understandable and justifiable. It is also possible that participants did not enjoy the experience of being interviewed or perhaps did not like me personally (i.e. failure to build rapport), and therefore did not want someone they knew to undergo an interview. With that said, in some cases participants would enthusiastically share my contact information to a potential participant or refer me to someone they thought might be willing to partake in the project, thus allowing for some success with the snowball method. Yet, for the most part, participants contacted me without a referral after hearing about the project through word of mouth or seeing a call for participants poster either online or posted in a physical space.

The third and final component of my participant recruitment strategy occurred rather organically as I was approached by a journalist who requested an interview regarding the research project. I accepted their request for an interview and proceeded to secure another, short interview with a different media outlet (See Appendix, Section C). This media coverage generated some awareness about the project which ultimately helped to locate a number of potential participants as my contact information was included in both of these interviews. It should be noted that some individuals who contacted me and expressed interest in the study self-identified as disabled by mental illness such as obsessive-compulsive disorder or depression. Although their experiences certainly warrant scholarly investigation, in accordance with my certificate of ethical approval from Concordia University which states that persons involved in this study should be in good mental health standing, these individuals were not included in the study.

Research Participants

The participants involved in this research include twenty-four individuals who self-identify as physically disabled and who reside in Ontario, Quebec, and the Maritimes. Although I relied on participant's individual and embodied knowledge regarding their bodies and disabilities, I operationalized physical disability as physical conditions or impairments that place limitations on a person's ability to engage in activities of daily life such as eating, sleeping, using the bathroom, dressing, mobility and transportation, etc. Since I felt it was important to have a range of embodiments represented in this research, participation was not limited to one particular type of physical disability. Like Smith-Rainey (2016), who conducted research on sexuality and disability, I made a conscious decision to adopt a "pan-disability" approach, which included people with different types of impairments (Smith-Rainey, 2016, p. 89). Not only did this allow for more diversity of experience among participants, but adopting a pan-disability approach is more aligned with tenets of the social model of disability, such as its assertion that people can be disabled by social and political conditions as opposed to the bodies they inhabit (Smith-Rainey, 2016). Although my initial sampling criteria specified that I would recruit individuals aged 19 years or older who self-identified as physically disabled and were willing to discuss their experiences related to disability and sexuality, these criteria slightly changed as the research progressed. Through listening to participants' narratives, it became increasingly clear that rigid distinctions between different 'types' of disabilities (e.g. cognitive, sensorial, physical, etc.) are not so easily siloed. For instance, some participants lived with multiple disabilities and thus experienced a range of cognitive, sensorial, and physical implications. I return to this issue and problematize rigid distinctions between different types of disabilities in my theoretical perspectives section by exploring how what constitutes a physical disability is contentious, ever-changing, and can overlap with other kinds of impairments or disabilities.

Participants' disabilities ranged from hearing impairment to spinal cord injury, and from limb loss to cerebral palsy. Of the twenty-four participants, fifteen were born with an impairment while nine others became disabled later in life. Nine participants required personal care from a professional disability support worker, and many participants made use of different aids such as wheelchairs, canes, prosthetics, and hearing aids. In terms of living arrangements, four participants lived in assisted care facilities, another four lived with family members, and the remaining participants lived on their own or with roommates. The ages of participants ranged from 21 to 65, with an average age of 36. Thirteen participants were women and the remaining eleven were men. In terms of sexual orientation; thirteen participants identified as straight, three identified as gay, another four identified as queer, two identified as bisexual, one identified as lesbian, and one participant identified as pansexual. At the time of interviews, nine participants were involved in a long-term, monogamous, romantic relationship. Although each participant involved in this research was living in Canada at the time of interviews, not all participants were Canadian citizens. Three participants have nationalities other than Canadian but were living in Canada at the time of interviews. Sixteen participants were White and the remaining participants identified as either Black, Asian, or First-Nations Canadian. In terms of religiosity, participants identified as Christian, Hindu, Muslim, Atheist, and Agnostic.

Data Collection

The data collection phase of this research project took place between September, 2015 and May, 2016. Over the course of roughly eight months, I conducted 24 semi-structured, in-depth interviews. These interviews explored participants' experiences and attitudes regarding sexuality and disability and privileged their individual knowledge and self-interpretations of their experiences. Interviews ranged from 42 minutes to two hours in length and were recorded using a digital audio recorder. All face-to-face, Skype, and telephone interviews were transcribed verbatim one to two weeks after they occurred. The one interview that took place over email was transcribed by cutting and pasting the original email that the participant had sent which contained their answers to my interview guide, and by transferring the text from our subsequent email interchanges. While transcription can be a tedious and time-consuming process, it is a "key phase of data analysis within interpretive qualitative methodology" that requires attention to detail and consideration of the ways that processes of transcription can influence the type and quality of data obtained (Bird, 2005, p. 227). As Kvale (1996) notes, interviews are "evolving conversation[s] between two people", yet transcripts become "frozen in time and abstracted from their base in a social interaction" (p. 166). With this in view, I have developed a more holistic and contextualized transcript by noting as many verbal and non-verbal communications as possible (i.e. pauses, laughter, scoffing, gestures, tone, repetition, etc.). As a means to reinscribe context and remind myself of the particulars of each interview, I consulted both interview audio files and interview transcripts during data analysis. Finally, as a measure to protect the identities of participants, their names have been replaced with pseudonyms and certain identifying details have been omitted or changed in the final analysis.

Semi-structured, in-depth interviews proved to be an appropriate data collection technique for this study for a number of reasons. Firstly, this type of interviewing allows researchers to obtain data about experiences that are not easily observable such as emotions, attitudes, and recollections (Neuman, 2006, 2011; Brinkmann, 2013). Secondly, semi-structured interviews present researchers with an opportunity to "understand the world from the subjects' point of view and to unfold the meaning of their lived world" (Kvale, 2006, p. 481). Thirdly, the open and inductive nature of semi-structured interviews leaves room for participants to discuss topics that the researcher does not anticipate and in this way, privileges the voices and experiences of participants (Rubin and Rubin, 2005). For Berg (2007), semi-structured interviews allow for "in-depth probing while permitting the interviewer to keep the interviewee within the parameters traced out by the aim of the study" (p. 39). By using semi-structured interviews, I did not fully determine what topics would be up for discussion and therefore was better able to probe areas as suggested by the participants answers (Neuman, 2006, 2011; Rubin and Rubin, 2005). Subsequently, participants felt empowered to guide the discussion, to ask me questions about myself, and inquire about the research project more generally. The open-ended nature of interviews facilitated a more reciprocal exchange which allowed me to gain a different and more nuanced understanding of topics.

Interviews followed Kvale's (1996) criteria for interviews and consisted of a combination of open-ended questions, exploratory questions, descriptive questions, explanatory questions, and probes. Questions were organized around a set of four key themes, including sexual education and socialization, relationship and dating history, sexual expression, and barriers to sexual expression. Questions were organized and asked in a chronological order, beginning with questions related to puberty, adolescence, and then adulthood. When the interviews came to an end, I asked participants if there anything that we did not discuss that they would like to bring to my attention and asked if they had any questions for me. The first interview guide that I developed underwent revisions after the first three interviews so that I could address an oversight in my line of questioning. In the initial interview guide that I developed I asked participants to "tell me about their *first* sexual experience". This question carries the assumption that participants must have had some sexual experience, which was not the case for two participants involved in this study. Similarly, this question neglects the experiences of asexual individuals who may not engage in sexual activities (see Kim, 2011). I therefore revised this question and asked participants if they *had* engaged in a sexual or romantic relationship.

In terms of data saturation, as Hagaman and Wutich (2017) note, "when and how saturation is reached depends on the number and complexity of data, the number of coders, the size of the research team, and investigator experience and fatigue" (p. 27). In this study, data saturation was defined as “the point in data collection and analysis, when new information produces little or no change to the codebook” (p. 25). Due to such a small number of participants, the use of non-probability sampling techniques, and the exploratory nature of this research, interview data is not considered to be representative of the experience of all Canadians with disabilities, but rather as exploratory and experimental. Nevertheless, I am satisfied with both the quantity and quality of interviews as they were generally lengthy exchanges that were rich in detail and provided insight into the lived experiences of disabled people that pertain not just to sexuality, but their bodies and identities.

Interview Management

The majority of interviews took place in a private office on a university campus. However, several interviews occurred at a location that participants and I had mutually agreed upon. I tried to be as flexible as reasonably possible in regards to the location of interviews due to the sensitive nature of this research and issues relating to finding an accessible space. My intentions of being as flexible as possible were an effort to accommodate the people that I research, to put their choices and preferences first, and to recognize the diverse and agentic ways that disabled people can communicate. An example of this flexibility involves a circumstance in which a non-verbal individual expressed interest in participating in the research but also expressed concerns regarding confidentiality if a translator were present during the interview. I followed the lead of this participant and together we devised a plan for participation in which they partook in an interview by writing their answers to my interview guide and through emailing back and forth with me. Similarly, if meeting in person for an interview would cause a participant undue financial, physical, or emotional stresses (i.e. having to hire a personal attendant for the interview or organize and pay for accessible transport), I would offer to pay for these expenses, come to their home, or use a platform such as Skype to help facilitate the interview. On three separate occasions participants and I opted to use Skype as a platform for our interview and in one instance a participant and I opted to conduct the interview over the telephone. It was important for me to make use of non-traditional and multi-format data collection techniques because, I argue, certain participants would not have participated in this research without them.

The interviews that took place at participants’ homes and online added significantly to the overall quality of data. There were a few instances during these interviews where participants would use their personal effects to help illustrate their response or story, such as showing old photos of themselves or showing me mobility aids – even sex toys they use and proudly endorse. I am exceptionally grateful for those moments as they offered further insight into participant experiences. I am equally grateful for the warm and accommodating welcome that I received from participants who opened up their homes to me. At the end of each interview I gave each participant a thank you card with twenty dollars enclosed. It would not have been possible for me to provide this monetary token of my appreciation if I had not been endowed with an SSHRC grant.

Upon the recommendation of the Concordia Research Ethics Advisory Committee, I took several steps to ensure my safety during interviews. In order to ensure my safety, I implemented a variation of the 'buddy system' (Neuman, 2006; Braun and Clarke, 2013). In this version of the buddy system a trusted colleague was informed that I would be engaging in an interview at a certain time and they were asked to contact me if they did not hear from me by a prearranged time. If I did not respond within a reasonable amount of time the colleague had instructions to enter my apartment where I had left a note with information regarding the location and time of the interview. There were no instances where I felt threatened or unsafe and I was able to ensure participant confidentiality by promptly calling this colleague as soon as interviews ended.

In sum, while planning and managing interviews it was important to privilege and respect the individual preferences of participants. Making use of alternative interview formats, inquiring about participant preferences, and considering their comfort made data collection a more enriching and egalitarian enterprise. Furthermore, in some cases, making use of alternative and multiple interview formats helped to reduce potential discomfort as well as potential financial costs for participants. Working to accommodate the people that I research has allowed me to better access my research population; a group of individuals whose experiences have generally been under-researched and under-represented.

Data Analysis

Data was analyzed using thematic analysis which can be defined as "a method for identifying, analysing and reporting patterns (themes) within data" (Braun and Clarke, 2006, p. 79). Data analysis was comprised of four different phases. The first phase consisted of familiarizing and immersing myself in interview data. This was achieved by continually reading and listening to the entire data corpus. Once I had sufficiently familiarized myself with the data, I began the second phase of analysis in which I developed a broad and preliminary list of codes. In order to do so, I searched across the dataset to find and then assign codes to "repeated patterns of meaning" as well as "issues of potential interest" (Braun and Clarke, 2006, p. 86; see also Coffey and Atkinson, 1996; Boyatzis, 1998). This initial list was produced by interpreting data that represents certain ideas, actions, experiences, etc. and attaching it to specific codes. Coding was an iterative process that involved reading and rereading transcripts as well as going back and forth between the initial list of codes that I developed and the data itself (Saladaña, 2009).

The third phase of data analysis involved sorting and collating the initial list of codes into potential themes. According to Braun and Clarke (2006), "a theme captures something important about data in relation to the research question, and represents some level of patterned response or meaning within the data set" (p. 82). This process required consideration of the interconnections between different codes and their implications. During this phase of data analysis, I reduced the initial code list by jettisoning or combining similar codes. In order to sort codes into different themes the name of each code was written on a post-it note and then organized in a thematic map on my office wall (Attride-Stirling, 2001). This visual representation helped me to refine codes into themes and allowed me to group data within these themes.

During the fourth phase of analysis I reviewed and fine-tuned the provisional themes that I developed. Like coding, this too was an ongoing, iterative process that involved going back to the entire data corpus and rereading it once again. Rereading helped to ensure that themes accurately reflect data and provided an additional opportunity to code any data that I had missed. In order to further refine and conceptualize themes, I explored how they relate to one another and in particular, I examined how they relate to the research questions that underpin my analysis. Themes were developed based on prevalence and relevance to my research questions. In this way, my approach to data analysis was both data and theory-driven and therefore both inductive and deductive. This is because I had engaged with literature related to disability and sexuality while writing my thesis proposal, this dissertation, and while working on publications. Since I already had an understanding of scholarship related to disability and sexuality, it was inevitable that this literature influenced how I approached data analysis. Therefore, it would not be correct to characterize data analysis as a purely inductive process. In the final stage of phase four, I worked to identify the "essence" of what each theme is about and began to write "the story they tell about the data" (Braun and Clarke, 2006, p. 92).

Ethical Considerations

Since this research explores deeply personal topics like sexuality and gender, and in recognition of the fact that many people with disabilities have been discriminated against or stigmatized in some way, it is crucial that I approached this work with sensitivity and maintained high ethical standards. In order to ensure that I maintained best practices, I familiarized myself with the Canadian Sociological Association's Code of Ethics and made sure that this research conformed to the principles laid out in the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (2014), as well as the guidelines provided by Concordia's Research Ethics Committee. While research ethics are undoubtedly an important aspect of *any* research project involving human subjects, irrespective of the discipline, as Sullivan (2013) contends, "nowhere more so than in disability studies have the questions on what constitutes ethical research been so hotly contested" (p. 3). Thus, in addition to consulting the afore mentioned guidelines, I canvassed a range of interdisciplinary scholarship that explores how to best conduct research on disability (see Barnes and Mercer, 1997; Barnes et al., 2002; Zarb, 1992; Sullivan, 2013; Lorenz and Berger, 2015). Surveying debates that examine the politics of non-disabled researchers who conduct research on disability (see Hunt, 1981; Oliver, 1990; Stone and Priestley, 1996; Duckett, 1998; Tregaskis and Goodley, 2005; Seymour, 2007; Brown and Boardman, 2011), as well as debates regarding issues of informed consent among people whose physical, sensorial, or cognitive impairment might constrain their ability to comprehend the risks and benefits of participation or their ability to communicate consent (see Murphy, 2003; Hollomotz, 2011; Löfgren-Mårtenson, 2004; Fish, 2016; Sullivan, 2013), enhanced the levels of care and ethical rigour that I have applied to this study.

I obtained my Certificate of Ethical Acceptability for Research Involving Human Subjects from Concordia University in April of 2015. As stated in the Summary Protocol Form that I submitted to Concordia University's Research Ethics Unit, no forms of deceptions were used throughout this research project and no other researchers were involved in this study. I am the only person who knows the true identities of participants and certain identifying details have been changed or removed as a means to protect the identities of participants. Participant consent was obtained through both verbal and written means (See Appendix, Section D). I made sure to read through the consent form with participants and to answer any questions they had. Consent was treated as ongoing and participants were continually reminded that they could withdraw from the study without penalty. However, no participants withdrew from this research at any point. All consent forms have been stored in a locked filing cabinet and will be destroyed by paper shredding once I have successfully defended my thesis. Any electronic files associated with this study have been saved on a password-protected folder on my personal computer which is also protected by password. Maintaining strict confidentiality of participants' identities and securing records of the study has helped to safeguard participant anonymity.

I employed a number of strategies in order to put participants at ease during interviews and to further safeguard their anonymity. At the beginning of each interview I ensured that participants were briefed on the research process and that they clearly understood the aims of the research, its implications, and their involvement in the project. I emphasized to each participant that they had some control over the interview in the sense that they did not have to answer questions that they did not want to, that they could withdraw their consent at any time without penalty, and that they were the expert of their own experiences. Additionally, I stressed that their identity would remain confidential but explicitly informed participants of instances wherein my legal responsibility to report certain wrongdoings would make it necessary for me to violate confidentiality (e.g. reporting child abuse or neglect, physical or sexual abuse, etc.). If a participant appeared to be experiencing duress or a negative emotional response during the interview I planned to inquire if the participant would like to stop the interview and reminded them of their ability to discontinue participation. Fortunately, this did not occur throughout the interview stage and therefore I did not have to utilize the number of resources that I had prepared in the event of a heinous disclosure or traumatic discovery. After each interview, I allotted time to debrief with participants so that we could discuss their reactions, feelings, and if any, their concerns. It was important that I maintained a space to discuss and debrief after the interview had ended as this helped to ensure that participants didn't leave the interview with negative feelings (van de Sande and Schwartz, 2011; Brinkmann, 2013). Moreover, I felt it was important to maintain this space so that I could learn from any feedback that participants were willing to provide.

As mentioned, I was prepared with a number of resources in case of a heinous disclosure or traumatic discovery. As an additional safety precaution, all participants were provided with the contact information of a registered social worker who agreed to consult with them via email and/or telephone if they required further support. To my knowledge, no participants contacted this social worker, leading me to believe that they did not require post-interview counselling. Before I began the interview stage of this research I prepared myself by completing a Mental Health First Aid course offered by the Mental Health Commission of Canada, and was trained in the Sexual Attitudes Assessment Seminar offered by the Montreal based company Sexpressions. In addition to these measures, I contacted participants via email roughly one week after their interview took place to inquire how they were doing and to make sure that no issues had arisen since the interview took place. In several cases participants and I maintained contact with one another and I was fortunate enough to have left the interview stage with not only compelling data, but several valued relationships.

While preparing to embark on this research project, I carefully weighed both the risks and benefits of participation in a critical fashion. Each participant was informed of potential risks of participation such as experiencing emotional or psychological discomfort due to the line of questioning used in the interview. Similarly, I was realistic and honest with participants about the potential benefits of participation as well as the potential outcomes of this research project. In order to further consider the outcomes of this research I engaged with questions like; "What will the research achieve in terms of improving the lives of those whose selves become 'sources' and whose meaning becomes 'material? Will it achieve any more than furthering academic careers and publication lists?" (Stone and Priestly, 1996, p. 703). It is possible that this project provided participants with an opportunity to discuss topics that are traditionally treated as taboo or an opportunity to air grievances related to inaccessible infrastructure and ableist policies. Yet, I was not naïve to think that our interview would be a life-changing experience for participants, that all participants would benefit from participation, or that positive social change would be an automatic and direct result of this research. Although I sincerely hope to effect some form of positive social change with this research, I remain realistic about the potential outcomes of this research as well as its scope and limitations. Similarly, I acknowledge the fact that I will personally gain from successfully defending this dissertation.

Kvale (1996) argues that, "ideally there should be a reciprocity in what the subjects give and what they receive from participation in the study" (p. 116). Although I paid participants for their time and did my best to reciprocate, in some ways I feel as though I could never truly repay my participants. In order to reciprocate on *some* level, I made sure to interject vulnerability and honesty into all my interactions with participants, to incorporate participant feedback whenever possible, and to keep participants informed at various stages of the research project. Additionally, as a means to interject further reciprocity into this research project I incorporated the advice of several disability studies scholars who encourage researchers to challenge the social relations of research production by placing their "skills at the disposal of disabled people to use" (Sullivan, 2013, p. 7; see also Oliver, 1992). When appropriate and possible, I shared whatever skills or resources that I had access to with participants. For example, I shared copies of books, movies, and articles that certain participants were interested in. When a participant asked for a course outline that I had developed I promptly sent it to them, and finally, several months after we conducted our interview a participant stayed at my apartment in Montreal as they traveled across Canada. Although these gestures paled in comparison to the efforts that participants put into this research project, they facilitated reciprocation insofar as they allowed participants to put some of my services to use.

In addition to the afore mentioned measures, I plan to return the results of this research to the people who generously offered their stories and experiences. Participants were offered the option to receive updates about the progression of this research and each participant will receive a copy of the final results of this study. Disability studies scholars such as Barnes (2013) have presented compelling arguments that show how some disability research has a history of being elitist in terms of how it presents and disseminates its findings. Barnes notes how the results of some of this research is "overly complex, generally couched in academic and technical language and, therefore, accessible to research experts only" (p. 3). In recognition of this history, I am committed to disseminating a final report amongst participants that is written in an accessible and informal manner. Similarly, I am committed to sending participants future articles and publications that arise out of this research and I will notify them when this dissertation has been deposited on Spectrum, Concordia University's online research repository.

While discussing the politics of knowledge production Kvale (1996) rightfully observes that "the broader consequences of interview research involve political judgements about the desirable uses of the acquired knowledge" (p. 117). Indeed, this research project required consideration of how the data itself would be used. Much like Shakespeare (1997), I was aware of the fact that this research could produce data that could be considered titillating material for voyeurs. Since disabled people are so often "displaced as subjects" and "fetishized as objects" it was crucial that I was prepared to remove details that might be used to objectify participants while still doing my best to maintain the integrity of their narratives (Shakespeare et al., 1996, p. 3). While I have taken certain precautions to safeguard participants in this respect, I am cognizant of the fact that "even the most conscientious researcher cannot guarantee that the published words will not be interpreted or used in a manner antithetical to the original intention of the work" (Ashby, 2011, p. 10).

I am also aware of critical issues associated with 'giving a voice' and 'speaking for others' (see Spivak, 1983; Bogdan and Biklen, 1998; Alcoff, 1991; Ashby, 2011). Alcoff (1991) contends that, "Rituals of speaking are politically constituted by power relations of domination, exploitation, and subordination. Who is speaking, who is spoken of, and who listens is a result, as well as an act, of political struggle" (p. 9). With this in view, it is important that I unpack some of the issues associated with 'giving voice'. Bogdan and Biklen (1998) define giving voice as "empowering people to be heard who might otherwise remain silent" (p. 204). Yet, they also point to some of the issues inherent in the idea of giving voice. According to Bogdan and Biklen, "While qualitative research provides readers with access to the world of people they would not otherwise know and to some extent allows these people's stories to be told, the subject never actually tells his own story" (1998, p. 204). In other words, it is important to acknowledge my role in selecting, interpreting, and mediating participants' accounts. It is not the participants' voices that have been amplified and explored, but my *interpretation* of their voices. It is also important to acknowledge that the "researcher often benefits more from the telling than the researched" (Ashby, 2011, p. 5). Finally, there are some problematic assumptions attached to the notion of 'giving voice' that need to be further examined, particularly in research scenarios that involve individuals or groups that have been marginalized. Some issues associated with seeking to 'give voice' to research participants include the underlying assumptions that participants have no voice, that they lack agency, or that they require someone else to draw out and/or amplify their voice (Alcoff, 1995; Blatt, 1981; Fine, 2002; Ashby, 2011).

Ashby (2011) challenges narrow and ableist interpretations of 'giving voice' by showing how this approach can deny the fact that "individuals have their own voice and can (and do) choose to exercise it" (p. 10). In a similar vein, Ashby explores some of the complexities and ethical considerations associated with 'giving voice' to individuals who do not use verbal speech as their primary means of expression. Ashby asks, "What is the meaning of giving voice when that voice does not present itself as spoken speech?" (2011, p. 6). Since I interviewed one non-verbal individual throughout the course of this research project it was important that I established accommodations to ethically facilitate this interview. I also tangled with other questions that Ashby posed, like, "Was I really giving voice? Was it mine to give? Whose voice is it really? Who benefits from the telling? Is spoken voice preferable?" (2011, p. 5). Ultimately, I chose to navigate this difficult terrain by focusing on creating a space in which I could *listen* to the voices of participants, and when appropriate speak *with* as opposed to *for* them. Since people with disabilities have historically been silenced, discriminated against, and desexualized, it was important to hold a space that attended to and validated the experiences of participants. In an effort to dismantle and disrupt the ableist structures of power that work to marginalize and silence people with disabilities, I sought to render the participants' experiences more visible and make their 'voices' more audible (Ashby, 2011; van de Sande and Schwartz, 2011; see also Smith, 1987, Harding, 1987). As the principal researcher, my role was to listen, validate, interpret, and importantly, to represent participant experiences in an ethical manner.

In conclusion, I often found myself racked with anxieties about how to best approach and access the field while working to make certain that this research conformed to ethical codes of conduct. In particular, I found myself concerned with reciprocation, the privileges and power that I hold, the politics of abstracting, interpreting, and transforming participants' experiences into data, and questions of who controls this research. While I write this dissertation with both trepidation and enthusiasm, like Gloria Anzaldúa (2009), "I write because I'm scared of writing, but I'm more scared of not writing" (p. 30). Put differently, broader issues of inequality and certain scholarly debates have required me to examine some difficult questions and continue to cause me concern. Yet, my desire to better understand participants' individual experiences and my belief in working to create a more just social world has compelled me to continue this research. The strong ethical foundations upon which I have laid this research will help to mitigate these anxieties and ensure that this project has been conducted with both accountability and care.

Chapter Summary

Throughout this chapter I have reflexively accounted for my position as principal researcher, and have explored some of the ways that my values and personal experiences have influenced data collection and analysis. In addition to this, I have identified the methodological tools and techniques that I use throughout this study and discussed the ethical considerations associated with this research. The following chapter offers a review of relevant literature that helps to situate this study within other academic inquiries.

CHAPTER 3

Literature Review - Disabilities and Sexual Expression

"Whenever I had been naked before – always in front of nurses, doctors, and attendants – I'd pretend I wasn't naked. Now that I was in bed with another naked person, I didn't need to pretend: I was undressed, she was undressed, and it seemed normal. How startling! I had half-expected God – or my parents – to keep this moment from happening" – Mark O'Brien, American author and activist (1990, para. 42).

Origins of the Field

Historically, professions such as medicine, physical rehabilitation, and special education have dominated the ways that disability has been studied and defined (Thomas, 2004, 2006, 2007; Titchkosky and Michalko, 2009; Watson et al., 2013)[2]. Furthermore, these professions have traditionally dominated the study of disability and sexuality (Cheng, 2009; Jungels and Bender, 2015; Liddiard, 2014; Shakespeare et al., 1996; Wentzell, 2006). According to Shuttleworth and Mona (2002), issues related to disability and sexuality historically have been "framed in medicalized, apolitical, and individualist terms" (para. 2). While research conducted by medical professionals has made some valuable contributions to the field, the voices and experiences of disabled people have a history of being absent from this medical literature (Clare, 2001; Hughes, 2000; Shakespeare et al., 1996). As Shakespeare, Gillespie-Sells, and Davies argue in their influential work, *The Sexual Politics of Disability* (1996),

> There is quite an industry producing work around the issue of sexuality and disability, but it is an industry controlled by professionals from medical, psychological and sexological backgrounds. The voice and experience of disabled people is absent in almost every case. As in other areas, disabled people are displaced as subjects, and fetishized as objects (p. 3).

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[2] Certain parts of this literature review have been published in the peer-reviewed journal *Sociology Compass*. This is the peer reviewed version of the following article: Campbell, M. (2017). Disabilities and Sexual Expression: A Review of the Literature. *Sociology Compass*. 11:e12508, which has been published in final form at http://journals.sagepub.com/doi/abs/10.1177/1363460716688682. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Use of Self-Archived Versions.

Similarly, some of this medical literature has been criticized for its biological reductionism (Block et al., 2012; McRuer, 2006; Rembis, 2009a, 2009b; Shakespeare et al., 1996; Siebers, 2012;). As Rembis (2009a) argues, research conducted from a medical perspective has a tendency to view people with disabilities as,

> Not only broken or damaged, but also incompetent, impotent, undesirable or asexual. Their inability to perform gender and sexuality in a way that meets dominant societal expectation is seen as an intrinsic limitation, an 'unfortunate' but unavoidable consequence of inhabiting a disabled body (p. 51).

Sociologists, disability and sexuality studies scholars have neglected issues surrounding sexuality and disability, traditionally leaving studies and research around this important topic to medical professionals. However, there has been a marked increase of interest and publications beginning in the late 1980s and carrying into the 1990s (Shakespeare, 2014; Shakespeare et al., 1996; Waxman-Fiduccia, 2000). Beginning with a number of feminist texts that addressed the earlier neglect of these topics, sociologists, disability, and sexuality studies scholars began to explore various dimensions of disability and sexuality, often through compelling personal memoirs (see Abu-Habib, 1995; Appleby, 1993; Clare, 1999; Ferri and Gregg, 1998; Fine and Asch, 1988; Finger, 1990, 1992; Gerschick and Miller, 1994, 1995; Grealy, 1994; Hahn, 1981; Mairs, 1996; Morris, 1989, 1991, 1993; O'Brien, 1990; Shakespeare et al., 1996; Thomas, 1999; Waxman-Fiduccia and Finger, 1989, 1991; Waxman-Fiduccia and Gill, 1996). Unlike previous medical research on disability and sexuality, these texts focused on the *lived* experience of disability by prioritizing the voices and experiences of disabled people and, as a result, began what Sherry (2004) has dubbed the "deconstruction of the public/private divide" in disability-sexuality research (p. 776).

The earlier neglect of these topics by sociologists and disability studies scholars is partly attributed to the ways in which pioneering activists and scholars initially prioritized the vast range of social problems that continue to affect persons with disabilities (Liddiard, 2014; Shakespeare et al., 1996). Early disability studies scholars and activists often viewed serious social problems such as discrimination, inaccessibility, and poverty as more pressing than issues principally related to sexuality (Kulick and Rydström, 2015; Shakespeare, 2000, 2014). This led to a focus on "survival level issues" (Waxman-Fiduccia, 2000, p. 168) and the prioritization of "instrumental, public, rational and material" concerns over more private or "domestic" concerns (Shakespeare et al., 1996, p. 7). Like Liddiard (2014) contends, "the oppressions experienced by disabled people in their sexual and intimate lives have long been overshadowed by their wider fights for their rightful place within civil and public life" (p. 115).

This overshadowing and neglect has been lamented by the 'mother' of disability-sexuality studies, Barbara Waxman-Fiduccia, and the former president for the Society of Disability Studies, Anne Finger. They write,

> The disability rights movement has never addressed sexuality as a key political issue, though many of us find sexuality to be the area of our great oppression. We may well be more concerned with being loved and finding sexual fulfillment than getting on a bus (Waxman and Finger, 1991, p. 1).

Yet, in spite of this history of neglect and omission, over the past thirty years, academics from a range of disciplines – most notably sociology, disability, sexuality, gender, and queer studies – have increasingly investigated issues related to disability and sexuality. Accordingly, they employed a range of conceptual and theoretical resources such as feminist theory, queer theory, crip theory, social constructionism, phenomenology, post-structuralism, symbolic interactionism, and Marxism. Since the 1990s, persons with disabilities have continued to lend their voices to academics and still share their experiences of sexuality through personal memoirs (see Clare, 2001; Frank, 2000; Muir, 2014; O'Toole, 2015; Smith-Rainey, 2011; Trace, 2014; Vane, 2015).

Insights from feminism, disability studies, and queer theory are some of the most influential and widely used in disability-sexuality research (Cheung, 2009; Garland-Thompson, 1996, 2005; Hall, 2015; Kulick and Rydström, 2015; McRuer, 2003, 2006; McRuer and Mollow, 2012; Morris, 1991, 1993; Rich, 1980; Shakespeare at al., 1996; Shuttleworth and Sanders, 2010; Tremain, 2000; Wilkerson, 2002). Early feminist texts which sought to break down the public/private divide that plagued research on disability for so long effectively politicized sexuality as a disability rights issue (Kulick and Rydström, 2015; Shakespeare, 2000; Shakespeare et al., 1996; Sherry, 2004; Siebers, 2012; Wendell, 1989). Furthermore, feminist analyses of disability and sexuality have shed light on not only sexual forms of discrimination that disabled people face but forms of intersectional discrimination as well (Abu-Habib, 1995; Caldwell, 2010; Morris, 1993; Stienstra, 2012a, 2012b). The feminist theory of intersectionality is of particular value to disability-sexuality research because it presents scholars with a means to further examine disability and sexuality in relation to social identities and experiences such as race, religion, ethnicity, age, socioeconomic status, gender, and sexual orientation. Intersectional approaches attend to the multiple and intersecting forms of discrimination that people with disabilities experience and help to demonstrate the interconnectedness of ableism and other structures of discrimination such as racism, ageism, xenophobia, homophobia, transphobia, and sexism.

Scholars who have made use of queer theory in their analyses of disability and sexuality such as Butler (1997, 2004), Butler (1999), Clare (2001), Samuels (2003), Kafer (2003, 2013), McRuer (2003, 2006), Guter and Killacky (2004), McRuer and Mollow (2012), and Noonan and Gomez (2011), have also made several novel contributions to the field through various critiques of conventional theories of sexuality that neglect alternative expressions of gender performance, sexualities, and embodiments. Through challenging widely held presumptions regarding the 'naturalness' and 'normalcy' of heterosexuality and 'able-bodiedness', theories from disability and queer studies often complement and reinforce one another (Cheung, 2009; Santinele Martino, 2017; McRuer, 2003, 2006; McRuer and Mollow, 2012; Wilkerson, 2002). For instance, queer studies scholars draw several parallels between the experiences of LGBTQ persons and disabled people. Some of these include similarities between 'coming out' as gay and 'coming out' as disabled, passing as either non-disabled or heterosexual and cisgender, and similarities between the oppressing and alienating outcomes of ableism, homophobia, heterosexism, and the various forms of discrimination they entail (McRuer, 2003, 2006; McRuer and Mollow, 2012; O'Toole, 2000; Samuels, 2003; Shakespeare et al., 1996; Wilkerson, 1998). Moreover, historically both homosexuality and disability have been stigmatized, medicalized, pathologized, and even viewed as the result of sin or immorality (McRuer and Mollow, 2012; Oliver and Barnes, 2012; Shakespeare et al., 1996; Wilkerson, 1998, 2002).

An especially noteworthy contribution that queer theorists have made to the field of disability-sexuality studies is the development of crip theory. An offshoot of both queer theory and critical disability studies, crip theory merges insights from these intellectual traditions to demonstrate and deconstruct the pervasive ableism and heterosexism that is engrained in many societies (McRuer, 2006; McRuer and Mollow, 2012; Löfgren-Mårtenson, 2013). Crip theory is gaining momentum within the field as it invites scholars to take note of the different ways people with disabilities can 'crip' culture. This involves drawing attention to the compulsory able-bodiedness and compulsory heterosexuality of culture, producing new forms of crip culture, and "demonstrating how the compulsory able-bodiedness that stigmatizes them is a nimbus of power that defines and regiments identities, relationships, social structures, and cultural hierarchies of value" (Kulick and Rydström, 2015, p. 14).

One of the first texts to explore disability and sexuality from a disability rights perspective and a disabled standpoint was *The Sexual Politics of Disability: Untold Desires* (1996). Written by Tom Shakespeare, Katherine Gillespie-Sells, and Dominic Davies, this seminal text is touted as the first thorough sociological investigation into the sexual and intimate experiences of persons with disabilities. Relying on narrative data collected from forty-two participants living in the U.K, this text expertly demonstrates how barriers to sexual expression that disabled people face often have more to do with the societies in which they live, as opposed to the bodies they inhabit. According to Shakespeare, one of the key messages of this text is "the problem of disabled sexuality is not 'how to do it' but 'who to do it with'" (Shakespeare, 2000, p. 161). While the literature has evolved since the publication of *The Sexual Politics of Disability,* and the research population used was skewed toward white, politically inclined, LGBTQ+ Anglophones, the findings and approach of this text remain insightful and original to this day.

Shakespeare recently revisited the *Sexual Politics of Disability* (1996) in an article coauthored with Sarah Richardson titled, "The Sexual Politics of Disability, Twenty Years On" (2018). Shakespeare and Richardson present longitudinal qualitative data they collected by interviewing eight of the forty-two participants involved in Shakespeare's original study. The follow-up study examined "what has changed for participants since the 1996 research" (Shakespeare and Richardson, 2018, p. 84). Several participants cited the importance of the internet in functioning as a resource for information, communication, consciousness raising, and providing "another channel for meeting sexual and romantic partners" (p. 89). A large majority of participants noted how processes of ageing helped to make them feel more confident, empowered, and in control of their sexuality. While participants also experienced complications and comorbidities as they aged, they spoke of an "equalizing process" in which there was a "leveling effect" with non-disabled people (p. 85). A male participant noted how he felt "less different" because "everyone is getting older", and a female participant stated how they felt more prepared to deal with ageing because they had lived with various health conditions throughout their entire life (p. 84). When asked about the impact of ageing on her sexuality this female participant asserted, "I certainly won't stop having sex, because I already know how to manage those things. Whereas it might be a shock to a non-disabled person, suddenly realizing that their back is not as good as it was" (p. 84). And although many participants had gained confidence with age, they still struggled with maintaining a long-term relationship and with the fact that social attitudes regarding disability remain largely negative. Some participants felt that attitudes toward disability had slowly evolved, but not by much. As Shakespeare and Richardson note, “the prevailing social attitude was that it was okay to be disabled as long as you are beautiful and symmetrical” (p. 88). Even though the authors acknowledge that the amount of disability-sexuality research has increased since the publication of *The Sexual Politics of Disability*, they contend that, “studies reporting on the lived experience of disability and sexuality continue to be thin on the ground” (p. 82), and conclude by encouraging a “new generation of social researchers” to explore issues related to disabled people’s intimacy and sexuality (p. 91).

Despite the many valuable contributions made by queer theorists, feminists, sociologists and disability studies scholars, the lived experience of disability and sexuality remains under-researched at all levels of analysis and gaps in the literature exist. For example, research on the sexual experiences of people with disabilities is mostly carried out in ‘developed’ Western countries (Liddiard, 2018). Similarly, there is more research that explores the sexual experiences of heterosexual, cisgender people with disabilities than the experiences of LGBTQ people with disabilities. These gaps within the literature present scholars with a number of opportunities to contribute to research on disability and sexuality, a point I will return to at the conclusion of this chapter.

The following two sections of this chapter review two areas of research that encompass a number of topics related to sexual expression and barriers to sexual expression. In order to present a systematic and comprehensive review of literature that helps to situate the findings of this research, I have identified two broad yet key areas for review: first, the sexual expression and activity of people with disabilities, and second, barriers and challenges to sexual expression that people with disabilities often experience. I have chosen to focus on these two areas of study primarily because of the variety of topics they encompass and the breadth of discussion that results from their inclusion. Furthermore, the inclusion of these two areas is important because they address burgeoning areas of inquiry within the field of disability-sexuality studies, some of which have recently received scholarly attention. Lastly, when viewed alongside one another, these two areas offer a balanced overview of both the positive and negative aspects of the sexual lives of people with disabilities. In order to begin from a place of affirmation and positivity, I first review literature on the sexual expression and activity of people with disabilities. Next, I review literature that has identified a range of barriers and challenges to the sexual expression of people with disabilities. Finally, this chapter concludes by offering suggestions for future disability-sexuality research.

Sexual Expression and Activity

Despite deeply rooted ableism, eugenic practices, and the historic desexualization of people with disabilities, many disabled people lead healthy, exciting, and fulfilled sexual lives and partake in a range of diverse forms of sexual expression. In fact, a number of studies detail how sexual pleasures experienced by persons with disabilities can actually be *enhanced* by their impairment or disability (see Guldin, 2000; Kaufman et al., 2007; McRuer, 2003, 2006; McRuer and Mollow, 2012; O'Toole, 2000; Siebers, 2012; Smith-Rainey, 2011). According to Siebers (2012), the array of sexual and erotic acts that disabled people engage in are often based on "different conceptions of the erotic body, new sexual temporalities, and a variety of gender and sexed identities" (p. 47).

Research that explores the intimate experiences of disabled people illustrates just how flexible sexual desire and erotic sensation can be (Guter and Killacky, 2004; Kafer, 2013; Kulick and Rydström, 2015; O'Toole, 2000; Shakespeare, 2000; Shakespeare et al., 1996; Siebers, 2012). For example, literature on paralysis and spinal cord injury has shown that although some people with these impairments may lose sensation in traditional erogenous zones, they can also *gain* erotic sensation in other parts of their body (Barrett, 2014; Seibers, 2012; Waxman and Gill, 1996; Whipple et al., 1996). For instance, Andrew Vahldieck provides a frank account of how he experiences pleasure post spinal cord injury. He writes, "My erotic self need not be solely localized at the tip of my cock, where I've lost much sensation; I have learned that other areas of my body can be erotically sensitive and responsive. Sensation is mobile" (quoted in McRuer and Mollow, 2012, p. 48). Similarly, literature has provided descriptions of non-genital orgasms – what Guldin (2000) describes as "more abstract orgasms" (p. 235) – among people with disabilities; including mental, spiritual, heart, and full-body orgasms (see Block et al., 2012; Kaufman et al., 2007; McRuer and Mollow, 2012; O'Toole, 2000; Shakespeare et al., 1996; Shuttleworth and Sanders, 2010).

Literature on sexual activity draws attention to the ways in which disability can function as a sexual advantage and details how some disabled people experience their disability as "not a defect to be overcome to have sex but as a complex embodiment that enhances sexual activities and pleasure" (Siebers, 2012, p. 47; see also McRuer, 2006; O'Toole, 2000; Shakespeare, 1996).

Several researchers document how the onset of disability can enhance or heighten sexual pleasure and attribute this enhancement to either a greater awareness of the body or physiological changes related to disability (Kaufman et al., 2007; Shakespeare et al., 1996; Siebers, 2012). Similarly, some studies detail instances wherein disabled people subvert the stigma associated with disability and sexuality by marketing their disability as a sexual advantage (see Guldin, 2000; Kafer, 2013; Kaufman et al., 2007; McRuer and Mollow, 2012; O'Toole, 2000; Shakespeare et al., 1996). O'Toole (2000) offers the example of Connie Panzarino who marched in an American gay pride parade in the 1990s wearing a sign that read, "Trached dykes eat pussy all night without coming up for air" (O'Toole, 2000, p. 212). According to O'Toole, Connie Panzarino's disability became an "advertisement for a sexual partner" and effectively turned her disability into a "distinct sexual advantage" (O'Toole, 2000, p. 220-21). As a female participant in Shakespeare et al.'s (1996) seminal study expressed,

> If you are a sexually active disabled person, and comfortable with the sexual side of your life, it is remarkable how dull and unimaginative non-disabled people's sex lives can appear. I am often left feeling surprised – and smug – when I hear my non-disabled friends bemoan the stale approach of lovers, the tedium of flopping into the same sexual position, the lack of open communication (p. 203).

Research on the sexual and intimate lives of people with disabilities has examined the various ways that disability can challenge, reshape, and/or reinforce conventional sociocultural norms regarding sexual activity. This type of research illustrates how these norms are often based on heterosexist and ableist conceptions of both sex and disability (Guldin, 2000; Kafer, 2013; Kulick and Rydström, 2015; McRuer and Mollow, 2012; Shakespeare, 2014; Shakespeare et al., 1996; Shuttleworth and Dune, 2009; Waxman and Gill, 1996). For example, disabled people involved in Guldin's (2000) research simultaneously rejected and reified "dominant cultural ideas related to sexuality – such as the importance of orgasms and the aesthetic ideal of a 'sexy' body" (p. 234). Guldin's research offers a nuanced example of a female participant who self-identified as a 'slut', which, according to Guldin (2000), "enabled her to challenge the cultural desexualization of her body as well as that of her parents who told her that someday a man would love her enough to sleep with her despite the disability" (p. 237). However, as Guldin points out, although the self-identification of this participant as a 'slut' challenges the historic desexualization of disabled people and the notion that both disabled and non-disabled women should not be promiscuous, this self-identification simultaneously reinforces traditional sexual mores, such as the idea that is morally wrong or shameful to engage in a sizeable number of sexual acts.

Block et al. (2012) offer sexual facilitation as another example of how disabled sexuality can challenge conventional ideas regarding sex, pleasure, and intimacy. Defined as "assistance with a sexual activity provided to a disabled client by a personal assistant or other provider", sexual facilitation can include assistance with a variety of sexual or romantic acts including, "positioning the disabled person for masturbation or for sex with a partner, helping her or him undress, assisting with stimulation, transferring them to a bed or couch, transporting them to a partner's residence, purchasing condoms, or providing reminders about using birth control" (Block et al., 2012, p.166; see also Earle, 2001; Hamilton, 2002; Kulick and Rydström, 2015; Mona, 2003; Shapiro, 2002; Tepper, 2000; Willock, 2013). Several scholars detail how forms of facilitated sex "transgress the cultural view of sex as private and as an autonomous project of the self", and note that depending on the socio-legal context, people who assist disabled people with sexual activities may be at risk of legal and social ramifications (Block et al., 2012, p.166; see also Fritsch et al., 2016; Kulick and Rydström, 2015; Mona, 2003; Shildrick, 2007).

Kulick and Rydström's (2015) comparative analysis of the sexual facilitation and sexual rights of severely disabled people living in Denmark and Sweden expertly demonstrates how individual attitudes, legal and policy frameworks, and sociocultural norms can greatly impact the sexual lives of disabled people. This cross-cultural research reveals drastic differences in the types of sexual facilitation offered in Denmark and Sweden and demonstrates that while Denmark is not an 'erotic utopia', disabled people living there have "some of the best possibilities in the world to be able to discover sexuality, explore it, and affirm it as a vital part of their lives" (Kulick and Rydström, 2015, p. 255). In Denmark, social workers can enroll in an eighteen-month long program that trains them to become sexual advisors to disabled people. Similarly, since 1989, social workers in Denmark have had access to a set of national guidelines regarding disability and sexuality entitled 'Guidelines About Sexuality Regardless of Handicap'. According to Kulick and Rydström's research, there are roughly 400 certified sexual advisors in Denmark that make use of these guidelines (Kulick and Rydström, 2015). Although Denmark's laws do not codify these guidelines, the authors show how these guidelines paired with frank discussions about sexuality and disability help regulate the conduct of those who work and care for people with disabilities. With this in view, Kulick and Rydström argue that "documents like this, together with discussion groups and role-playing sessions, contribute to an atmosphere that makes it clear to residents that sexuality is a possible and acceptable topic of discussion" (Kulick and Rydström, 2015, p. 110).

Furthermore, Kulick and Rydström confirm that these guidelines make it abundantly clear that persons with disabilities are entitled to "not just a sexuality, but sex, and they obligate helpers to be observant about sex and to provide or find someone who can provide help to anyone who expresses a desire for such help" (2015, p. 107).

A significant portion of recent literature regarding sexual activity and expression explores how to uphold the sexual rights of people with disabilities and how to enhance disabled people's opportunities for sexual access (Bahner, 2012; Fritsch et al., 2016; Hamilton, 2002; Kangaude, 2007; Kulick and Rydström, 2015; Sanders, 2007; Shakespeare, 2014; Shuttleworth and Mona, 2002; Shuttleworth and Sanders, 2010). In doing so, this literature has identified a variety of campaigns, policy contexts, spaces, and groups dedicated to supporting the sexual rights and expression of disabled people (see Fritsch et al., 2016; Liddiard, 2014; Shakespeare, 2014; Shakespeare et al., 1996, Santinele Martino and Campbell, 2019). Examples of these various advocacy groups include The Outsiders Club (United Kingdom), Touching Base (Australia), DiSAYbled (Canada), and Kassandra (Germany). Nightclubs such as the Krocadile Club (United Kingdom) and the Beautiful Octopus Club (United Kingdom), or events like the sex-positive play party hosted by Deliciously Disabled and held at the Buddies in Bad Times Theatre in Toronto, Canada, also serve as examples of spaces that support the sexual rights and expression of people with disabilities.

Recent research on sexual access and sexual rights has made valuable contributions to the literature on sexual expression and activity by identifying how the attitudes and actions of governments, communities, family members, and professionals who work and care for disabled people can potentially support or undermine the sexual lives of people with disabilities. Research in this area has further confirmed the importance and need for spaces, services, policies, and attitudes that support the sexual intimacy of disabled people. For example, in her analysis of intimate discrimination that people with disabilities face, Liz Emens (2009) argues that governments should ensure marriage equality for disabled people by eliminating financial penalties that often occur when they get married. Similarly, Emens argues that governments should ensure that people with disabilities have access to appropriate sex education and adequate sexual health services. Shakespeare (2014) echoes the arguments put forth by Emens (2009) and recommends personal attendants, social workers, and other professionals working with disabled people "audit their services to ensure that they are not being delivered in ways that undermine the possibilities for intimacy" (p. 222). In a similar vein, Emens (2009), Shakespeare (2014), Shuttleworth (2014), and several other scholars contend that governments, artists, and media producers should promote more positive imagery of disability and sexuality as a means to challenge the historic desexualization of disabled people (see also Block, 2000; Gowland, 2002; Haller, 2010; McRuer and Mollow, 2012; Shildrick, 2007, 2009; Shuttleworth and Sanders, 2010; Waxman-Fiduccia, 1999). Shuttleworth (2014) supports this effort and argues that, "The proliferation of local and transitional media representations of the sexual lives of disabled people and importantly less stereotypical images certainly counters the long-standing cultural perception of their asexuality" (p. 80).

Research that explores the diverse array of sexual expressions and activities among people with disabilities comprises an important area of study within the field of disability-sexuality studies because it evidences the many positive, pleasurable, and creative aspects of sexuality and disability. Furthermore, this type of research is extremely useful as it helps to combat long-standing assumptions that people with disabilities are not sexual beings, or that they lead unfulfilled sexual lives. Literature that addresses positive experiences among people with disabilities helps to round out the large amount of literature that details negative experiences and barriers to their sexual expression. Moreover, this literature illustrates disabled people's agency and power to change norms and confront structures that limit their sexual expression. The following section of this chapter is devoted to reviewing research that has identified a range of challenges and barriers that can limit or prevent people with disabilities from engaging in sexual activity and expressing their sexualities.

Barriers to Sexual Expression

Some of the most challenging and persistent barriers to the sexual expression of people with disabilities are the attitudes that non-disabled people often hold regarding the sexual experiences of disabled people (Kulick and Rydström, 2015; Shakespeare, 2014; Shuttleworth and Sanders, 2010). A significant portion of literature concerning disability and sexuality has examined attitudes towards disability and sexuality, particularly attitudes held by those who work with and care for people with disabilities (e.g. personal attendants, medical professionals, parents of disabled children, etc.) (see Addlakha, 2007; Cuskelly and Bryde, 2004; Deal, 2003; DeLoach, 1994; Desjardins, 2012; Esmail et al., 2010; Gilmore and Chambers, 2010; Hamilton, 2002; Kaufman et al., 2007; Kulick and Rydström, 2015; Lewiecki-Wilson, 2011; Pebdani, 2016).

Inquiry into this topic has led to the identification of a range of stereotypes that label disabled people as infantilized asexual-innocents in need of protection, as undesirable partners, as unfit or unable to have sex or children, and as deviant if they *do* engage in sexual relations (Abu-Habib, 1995; Brodwin and Frederick, 2010; Esmail et al., 2010; Malacrida, 2007; McRuer and Mollow, 2012; Olkin, 1999; Parchomiuk, 2014; Prillentsky, 2003; Shakespeare et al., 1996; Shuttleworth and Dune, 2009). This body of literature shows that disabled people are often faced with a 'double bind' insofar as they are subject to a set of stereotypes that position them as either asexual and sterile or, conversely, promiscuous and predatory (see Finger, 1992; Kulick and Rydström, 2015; McRuer, 2003; Shildrick, 2009; Siebers, 2012; Smith-Rainey, 2011).

Sex and relationships are often mistakenly viewed as 'luxuries' that people with disabilities cannot afford, as they are perceived as 'too ill' to be concerned with sex (Kulick and Rydström, 2015; Shakespeare, 2014; Shakespeare et al., 1996; Shuttleworth and Sanders, 2010). Disabled people, specifically those with cognitive or intellectual impairments, are often presumed to be vulnerable and unable to comprehend the complexities of sexual relationships and experiences (Hollomotz, 2011; Löfgren-Märtenson, 2004; Shakespeare, 2014). Women with disabilities are particularly perceived as vulnerable to sexual exploitation (Feely, 2016; Fish, 2016; McCarthy, 1999), whereas men with cognitive or intellectual impairments are often stereotyped as predatory and licentious (Barrett, 2014; Bedard et al., 2010; Desjardins, 2012; Parmenter, 2001; Shuttleworth and Sanders, 2010). Unfortunately, as literature on this subject has shown, the concept of vulnerability can be invoked in order to "deny people with intellectual disabilities the right to make choices, take risks and live independently" (Shakespeare, 2014, p.219; Feely, 2016; Hollomotz, 2011). As Hollomotz (2011) argues, "undue protection from risks and opportunities associated with everyday life may disable individuals from becoming competent social and sexual actors and from accessing information and services that have the potential to reduce sexual 'vulnerability'" (p. 1). Research in this area highlights the importance of engaging in conversations about disability and sexuality, listening to people with disabilities about what works best for them in terms of their sexual expression and activities, and the importance of striking a balance between safety and consensual sexual activity.

People who are romantically and sexually involved with disabled people also find themselves subject to prejudiced attitudes and stereotypes. Olkin (1999) notes how non-disabled individuals who are romantically or sexually involved with disabled individuals are often subject to suspicion or perceived as either deviant or settling for someone less than they deserve. Smith-

Rainey (2011) echoes and extends Olkin's arguments by drawing upon both interview data and her personal experiences of being in a long-term heterosexual relationship with a man with Multiple Sclerosis. Smith-Rainey notes how some non-disabled persons assume that the romantic partners of disabled people are their caregivers rather than their lovers. Similarly, non-disabled partners are often perceived as 'exceptional' persons, implying that dating someone with a disability is a difficult, burdensome task that requires a 'special kind of person' (Shakespeare et al., 1996; Smith-Rainey, 2011). Assumptions such as these uncover hidden biases that deny the reality that people with disabilities are sexual beings and display the pervasive ableism within society.

Disabled LGBTQ+ persons often find themselves subjected to a specific set of stereotypes that question their gender identity and sexual orientation (see Baril, 2015; Bedard et al., 2010; Butler, 1999; Chappell, 2015; Guter and Killacky, 2004; Kafer, 2003, 2013; McRuer, 2006; McRuer and Mollow, 2012; Samuels, 2003). People often question the sexual orientations of LGBTQ+ persons with disabilities and mistakenly view them as symptoms of sexual and gender 'confusion' related to having a disability (Kafer, 2003, 2013; Löfgren-Mårtenson, 2009; McRuer and Mollow, 2012). Kafer (2003, 2013) documents how LGBTQ+ people who are disabled are sometimes viewed as *having* to 'resort' to a lesbian, gay, or queer lifestyle because they are presumed to be unable to engage in a heterosexual relationship due to their perceived lack of sexual function, asexuality, or sterility. This view rests on a set of heteronormative attitudes that shore up traditional ideas of sex as an unassisted, heterosexual, penetrative, and phallocentric act that ends in mutual genital orgasm and/or procreation. Tilley (1996), as well as Guter and Killacky (2004) and O'Toole and Bregante (1992), show how heteronormative assumptions can become imbued in rehabilitation resources offered to individuals with physical disabilities for these resources often focus on heterosexual, penetrative sex as the "only means of sexual expression" (Tilley, 1996, p.141). Lastly, some disabled LGBTQ+ persons have experienced homophobic treatment at the hands of personal care attendants and fear if they disclose their gender identity and/or sexual orientation to attendants that this disclosure will alter the quality of services provided (Caldwell, 2010; Clare, 2001; Gordon and Rosenblum, 2001; Kafer, 2003, 2013; McRuer and Mollow, 2012; O'Toole and Bregante, 1992).

Aforementioned attitudes and the stereotypes that they are based upon, reflect the stigma associated with disability, illustrate the pervasiveness of ableism, and can negatively affect the self-esteem and body image of disabled people (Shakespeare, 1999, 2000). Furthermore, these attitudes become reified in laws, social policies, and public spaces that deny the fact that people with disabilities are sexual beings. Ultimately, these laws, social policies, and public spaces concretize attitudinal barriers into structural and institutional barriers that prevent or limit disabled people's opportunities for sexual expression and sexual activity (Block et al., 2012; Shuttleworth and Sanders, 2010). The fact that marriage equality remains elusive for many disabled people serves as an example of an institutional barrier that disabled people face. As noted in my introduction, in many cases, if disabled people choose to get married they risk losing their social assistance benefits (Block et al., 2012; Shakespeare, 2014; Smith-Rainey, 2017; Turner and Crane, 2016). This loss of benefits effectively deters some disabled people from the institution of marriage and penalizes those who do get married (Oliver and Barnes, 2012; Sanders, 2010). Furthermore, laws that require people with intellectual disabilities to obtain permission from their guardian in order to get married are still in effect in a number of countries such as Austria and Greece (Shakespeare, 2014).

Institutional and structural barriers prevent disabled people from enjoying a healthy sexual lifestyle by way of physical exclusion, omission, through denial of rights and services, and even through bodily harm (Malacrida, 2015). Literature on disability and sexuality demonstrates how inaccessible infrastructure can function as a barrier to the sexual health and sexual fulfillment of people with disabilities (Anderson and Kitchen, 2000; Bahner, 2012; Emens, 2009; Shakespeare, 2014). For instance, many public spaces are often inaccessible to disabled people; this includes transport systems or spaces associated with dating, sexual health, and sexual activity such as nightclubs, theaters, and sexual health clinics. Emens (2009) argues that, "by deciding the form of our communities' institutional and physical infrastructure, the state has shaped who meets whom, who interacts with whom, who has the chance to fall for whom" (p. 1380). Inaccessible infrastructure limits the romantic and sexual possibilities of people with disabilities insofar as they reduce the "number of venues through which people meet sexual and intimate partners" and "make it difficult for individuals and couples to engage in common dating and relationship activities" (Jungels and Bender, 2015, p. 173, see also Bahner, 2012; Shakespeare, 2000, 2014; Shakespeare et al., 1996).

Current research on disabled women's experience of sexual health services suggests women with disabilities "find their questions regarding sexual pleasure, childbirth, and body image ignored by physicians and personal care attendants" (Cheung, 2009, p.115; Malacrida, 2007; May and Simpson, 2003). Tilley's (1996) research details how women with disabilities are less likely to receive basic sexual health services such as breast cancer examinations, STI testing, or pap smears. These findings are consistent with the findings of Anderson and Kitchen (2000), who examined the physical environments of 34 family planning clinics in Northern Ireland and collected narrative data from both disabled parents and medical health practitioners. They found that information pertaining to sexual health is often inaccessible or unavailable for disabled people and demonstrate how common stereotypes surrounding disability and sexuality dubiously provide legitimacy for medical inattention and inaccessible infrastructure. As Anderson and Kitchen (2000) assert, “cultural ideologies are reproduced and reflected in how family planning clinics are designed and built, and in the levels and types of services they offer to disabled people” (p. 1167).

Existing literature on the ways men with disabilities experience sexuality and gender suggests that they often find their masculinity questioned by others and in turn also question their own. Themes such as physicality and muscularity, breadwinner or employment status, heterosexuality, sexual prowess and the ability to attain an erection, have traditionally informed normative notions of heterosexual masculine gender identity. As Jenny Morris (1991) notes,

> The social definition of masculinity is inextricably bound with a celebration of strength, of perfect bodies. At the same time, to be masculine is not to be vulnerable. It is also linked to a celebration of youth and of taking bodily functions for granted (p. 93)

Literature on disabled men’s sexuality and gender shows that the experience of men with disabilities has the potential to disrupt or subvert these themes. In their research on masculinities and disability, men’s studies scholars Thomas Gerschick and Adam Miller (1994) have identified three dominant strategies of gender identity formation and negotiation employed by men with disabilities. The first strategy dubbed “reformulation” entailed men redefining masculinity according to their own terms, beliefs, and experiences. The second strategy identified by the authors was “reliance”, which consisted of men internalizing traditional meanings of masculinity and attempting to continue to meet these expectations. The last strategy identified by Gerschick and Miller was “rejection”, which was generally about fashioning and creating alternative masculine identities (pp. 189-191). In their discussion of ‘rejection’ strategies Gerschick and Miller refer to the manner in which men who renounced masculinity did so as “a process of deviance disavowal” for they “realized it was societal conceptions of masculinity, rather than themselves, that were problematic and in doing so, they were able to create alternative gender practices" (p. 202). This particular study bolsters our understanding of the range of existing and ever-changing masculinities and highlights the variations in disabled men's experiences of masculine gender identity.

Other analyses of masculinity and disability include Shakespeare's (1999) article "The Sexual Politics of Disabled Masculinity" and Shuttleworth, Wedgwood, and Wilson's (2012) article titled "The Dilemma of Disabled Masculinity". Shakespeare makes the important assertion that, "one of the problems, for disabled men, and men in general, is that male sexuality is conceived traditionally in a phallocentric and oppressive way" (1999, p. 57). He also draws important connections between cultural imagery of disabled male sexuality and myths surrounding disability and masculinity. Shakespeare notes how films like Coming Home (1978), Born on the Fourth of July (1989), Waterdance (1992), and Forrest Gump (1994) all, "reinforce the idea of disabled men being excluded from sexual activity because of erectile failure, and consequently of being less than men" (p. 57). Other more recent films such as Avatar (2009), The Sessions (2012), Silver Linings Playbook (2012), and The Theory of Everything (2014), add to Shakespeare's list of cultural imagery that reinforces ableist understandings of masculinity, disability, and sexuality. In their article that reviews literature on disability and masculinity, Shuttleworth et al. (2012) argue that future studies should attempt to "open up the concept of intersectionality to accommodate a range of differences in bodily, cognitive, intellectual, and behavioral types (impairments) in their interaction with masculinities and to show in more explicit detail how context and life phase contribute to this dynamism" (p. 189).

Tilley (1996), McCabe (1999) and Löfgren-Mårtenson (2004, 2012) document how people with disabilities are less likely to participate in formal sex education programs than 'non-disabled' counterparts and identify a lack of sexual health information that is tailored to the needs of disabled people (see also Wong, 2000; Thomas, 2006; Löfgren-Mårtenson, 2012). Several researchers have documented how an overwhelming majority of group homes and long-term care facilities "purposefully destroy opportunities for disabled people to find sexual partners or to express their sexuality" (Siebers, 2012, p. 45; see also Fish, 2016; Fritsch et al., 2016; Hamilton, 2002; Kulick and Rydström, 2015; Liddiard, 2014; McRuer and Mollow, 2012). Presuppositions that view disabled people as not sexually desirable, as unsuitable parents, or as incapable of being sexually active are often related to ableist and eugenic beliefs, such as the belief that disabled people should only date other disabled people or the belief that 'disability breeds disability' (Hubbard, 2006; Malacrida, 2007, 2015; May and Simpson, 2003; Pfeiffer, 1994; Saxton, 2006; Shildrick, 2009;

Tilley et al., 2012). Both scholarship and a range of historical events confirm that many intellectually disabled people experience involuntary sterilization, are pressured into various forms of prenatal testing, and face forms of sexual violence more frequently than non-disabled counterparts (see Calderbank, 2000; Desjardins, 2012; Hubbard, 2006; Leung, 2012; Malacrida, 2015; Mays, 2006; Pfeiffer, 1994; Plummer and Findley, 2012). Saxton (2006) and Hubbard's (2006) research on prenatal testing and selective abortion highlights the complex challenges that pregnant women with disabilities face by showing how a woman's "right to choose" is constrained by "oppressive values and attitudes" that surround disability (Saxton, 2006, p. 94). Saxton and Hubbard show that while some non-disabled women must fight for the right to *have* an abortion, some disabled women are pressured by their families and medical health professionals to terminate their pregnancy and therefore must fight for the right *not* to have an abortion.

The barriers mentioned above are often invisible to or taken for granted by non-disabled people and can be harmfully internalized by disabled people (Bahner, 2012; Kulick and Rydström, 2015; Liddiard, 2014; Shakespeare, 2014). Furthermore, these barriers reflect ableist sentiments and heteronormative ideas of gender and sexuality that attempt to deny the fact that people with disabilities are sexual beings and ultimately function to limit their sexual expression. As scholars conducting research in this area have shown, the barriers to sexual expression that people with disabilities face are "primarily to do with the society in which we live, not the bodies with which we are endowed" (Shakespeare, 2000, p. 161). Like non-disabled people, disabled people deserve opportunities to experience romantic love, heartbreak, consensual sexual experimentation, intimacy, and companionship.

The eradication of barriers to sexual expression that disabled people face hinges upon broader sociocultural and legal changes that support the sexual and intimate lives of disabled people. As Shakespeare (2014) contends, "The more disabled people achieve their other civil and social rights, the more they will have the confidence, self-esteem and desirability that make relationships possible" (p. 220). The challenges and barriers to sexual expression and sexual activity that disabled people face are significant, but they are not necessarily insurmountable. If proper laws, policies, and adequate supports are in place, people with disabilities can continue to confront these barriers and engage in a wide array of sexual and erotic acts (Bedard et al., 2010; Fritsch et al., 2016; Hamilton, 2002; Kulick and Rydström, 2015; Shakespeare, 2014; Shuttleworth and Sanders, 2010). Ultimately, we are required to think differently about the intersection of sexuality and disability for as Siebers (2012) and Wentzell (2006) argue, "thinking about disabled sexuality broadens the definition of sexual behavior" (Siebers, 2012, p. 38), and "poses a broader challenge to the hegemonic conceptions of sexuality entrenched in society as a whole" (Wentzell, 2006, p. 371).

Concluding Remarks and Suggestions for Future Research

Previous research has shown that persons with disabilities – whether they are acquired, congenital, cognitive, intellectual, physical, and/or sensorial impairments – historically have and continue to encounter alienation, stigmatization, and discrimination, particularly in terms of their sexuality. Through delving into the sociopolitical and interpersonal aspects of sexual relationships that involve disabled people, research has demonstrated that although many people with disabilities lead healthy, pleasurable and fulfilled romantic and sexual lives, barriers to their sexual expression and full participation still exist. Below I detail some suggestions for future research and propose ways that scholars could work to improve the field of disability and sexuality research.

At present, most disability-sexuality related research makes use of small sample populations and qualitative methodologies. These smaller, more in-depth studies are extremely valuable contributions in terms of the richness of detail, insight, and level of sophistication that they offer. Yet, the use of small sample sizes within the literature has led to a greater number of small-scale micro level studies, while more quantitative, large-scale macro analyses of disability are lacking (Santinele Martino, 2017). In light of the prevalence of small samples within the literature, when possible, researchers should attempt to incorporate larger sample populations and make use of mixed-methods (Jungels and Bender, 2015; Santinele Martino, 2017; Shakespeare, 2000). However, this is not an easy task because large-scale quantitative studies, can be time-consuming, labor-intensive, and costly. In order to pilot large-scale studies more funding for disability-sexuality research is required (Jungels and Bender, 2015; Shakespeare, 2014; Shakespeare and Richardson, 2018). Ultimately, the addition of *both* small and large-scale research in this field will allow for a more comprehensive understanding of the diverse range of topics addressed within disability-sexuality research.

Moving forward, research on disability and sexuality should strive to include sexual, racial, and religious minorities in their sample populations as the experiences of these groups are often absent from the literature (Bell, 2011; Gordon and Rosenblum, 2001; Stienstra, 2012b). For instance, there is more research on heterosexual, cisgender people with disabilities than people with disabilities who identify as LGBTQ+ or asexual (Caldwell, 2010; Noonan and Gomez, 2010). Santinele Martino (2017) highlights this issue and asserts that "queer people with disabilities have generally been invisible and marginalized in both the queer and disabled communities" (p. 1), and the "pervasive heteronormativity" within the literature has "obscured the rich array of sexualities among individuals with disabilities" (p. 6). Incorporating insights from queer theory and adopting an intersectional approach can help researchers to further understand how intersecting and compound forms of discrimination impact opportunities for sexual expression and sexual satisfaction, and ultimately will help to rectify this dearth within the literature.

Future research should explore how people who live with 'significant impairments' (e.g. persons with no mobility and no verbal speech) experience their sexuality (Kulick and Rydström, 2015; McRuer, 2006). Currently, there is a tendency of research to focus on people with physical disabilities, particularly people with verbal speech and who are for the most part mobile (Caldwell, 2010; Kulick and Rydström, 2015; O'Toole, 2000). Additional research involving people with 'significant' impairments is important and according to Kulick and Rydström, these individuals are often "the ones who need the most help in exploring their sexuality" (Kulick and Rydström, 2015, p. 3). Although research involving people with intellectual disabilities and people with no mobility and/or little verbal speech is increasing (see Fish, 2016; Hamilton, 2002; Kulick and Rydström, 2015; Löfgren-Mårtenson, 2004, 2009; Shuttleworth, 2000; Turner and Crane, 2016), the lack of research has left people with these types of impairments relatively under-studied when compared to people with other impairments (Block et al., 2012; Santinele Martino, 2017; Noonan and Gomez, 2011). Unfortunately, this gap within the literature not only obfuscates the complexity of intersectional experiences of discrimination that people with disabilities face when exploring and expressing their sexuality, but also their positive and pleasurable experiences. Moreover, this gap could reflect an inadvertent omission within the academy that tends to exclude intellectually disabled people, people with limited mobility, and those who experience no verbal speech, from research on sexuality. Fortunately, this gap in the literature presents scholars in this area with an avenue to build upon existing research and contribute to a relatively under-researched area of study.

Equally absent within the literature is research conducted in non-Western countries (Block et al., 2012; Shuttleworth and Sanders, 2010). While research has been carried out in diverse geographic locations, including the United Kingdom, the United States, Canada, Australia, New Zealand, Europe, India, and Africa, the majority of research in this field takes place in 'developed', industrialized countries (Ingstad, 2007; Shakespeare, 2000; Shuttleworth and Sanders, 2010). Additional research carried out in non-Western and 'developing' countries will provide useful information related to both cross-cultural differences and similarities as well as a more global view of how people with disabilities experience their sexualities. Like Block et al. (2012) contend, "In a globalizing world, we are obliged to understand how people in other societies deal with these issues" (p. 165). Lastly, additional research in non-Western countries will better illustrate how the socio-legal contexts of various geographic locations can affect disabled people's opportunities for sexual expression and activity, the ways in which people with disabilities challenge structures that limit their sexual expression, and, further, how to help uphold both the human and sexual rights of people with disabilities.

When possible, research ought to focus more on sexual pleasure and satisfaction among disabled people and attend to the potentially positive aspects that disability can have on sexuality, rather than continue to focus on the negative aspects of disability and sexuality (Gomez, 2012; Kattari, 2014; McCabe, 1999; Shakespeare, 2000, 2014; Shuttleworth and Mona, 2002; Siebers, 2012; 2002; Tepper, 2000; Turner and Crane, 2016; Sakellariou, 2012). Additional research that attends to the positive aspects of disability and sexuality will provide a more balanced, nuanced, and holistic understanding of the sexual lives of people with disabilities.

The overall lack of research on disability and sexuality presents scholars with an opportunity to collaborate across disciplines – perhaps by beginning to bridge the vast divide between medical and social constructionist approaches to disability and sexuality. Similarly, researchers should make use of and create opportunities to collaborate with disabled people as co-researchers and co-authors. The inclusion of people with disabilities as co-researchers or co-authors in research is relatively uncommon, yet it could open up new possibilities and areas for research (Block et al., 2012; Chappell et al., 2014). Such an approach recognizes disabled people's expertise and agency and helps to ensure that scholars are held accountable to the communities and people they research. The inclusion of disabled people as co-researchers, additional cross-cultural research, and more diverse sample populations will allow for a more inclusive, robust, and nuanced understanding of the sexual politics of disability (Block et al., 2012; Brown and Boardman, 2011; Caldwell, 2010).

In conclusion, the sociological study of disability and sexuality presents scholars with an opportunity to reexamine ableist and heteronormative notions of not only sexuality but also gender. Furthermore, it presents an opportunity to challenge the boundaries between disability and ability, and to open up rather narrow conceptualizations of sex that view intercourse as a heterosexual, phallocentric act involving two unassisted ‘able’-bodies and ending in mutual genital orgasm. Although it may seem to be a daunting task, the results would be beneficial for not only people with disabilities but for all citizens.

Chapter Summary

Throughout this chapter I have canvassed literature pertaining to disability and sexuality, particularly literature that pertains to the ways that people with disabilities navigate barriers to sexual expression. Persons with disabilities—whether they are acquired, congenital, intellectual, physical, and/or sensorial impairments— continue to encounter alienation, stigmatization, and discrimination, particularly in terms of their sexuality. However, this review of literature has indicated that if proper laws, policies, and adequate supports are in place, people with disabilities can further challenge and push past these barriers to engage in a wide array of sexual and erotic acts. In the following chapter I introduce and unpack some of the theoretical perspectives and concepts that inform my analysis of interview data.

Chapter 4 - Theorizing Disability and Sexuality: Interactions, Opportunities, and Constraints

"Disability marks the last frontier of unquestioned inferiority because the preference for able-bodiedness makes it extremely difficult to embrace disabled people and to recognize their unnecessary and violent exclusion from society" – Tobin Siebers, American Academic and Activist, (Siebers, 2008, p. 6).

Introduction and Chapter Overview

In this chapter, I identify and discuss the various theoretical perspectives that underpin and guide this research. I adopt an inductive approach to data analysis and therefore the theories that help to guide this research have been informed by the interview data. Since the experiences of people with disabilities are "too complex to be rendered within one unitary model or set of ideas", I adopt a theoretically eclectic approach that engages with ideas that emanate from diverse theoretical trajectories. These include social constructionism, symbolic interactionism, feminism, phenomenology, and postmodernism (Shakespeare and Corker, 2002, p. 15). Although some of these theoretical perspectives may conflict with one another, their individual insights converge to illuminate multiple and complex issues.

This chapter is divided into two sections. The first section of this chapter begins by briefly exploring how disability is defined and moves on to explore major theoretical developments within disability studies. In particular, I address the social model of disability, its impact, and limitations. I then address how scholars drawing upon feminist, postmodern, and phenomenological theoretical traditions have rejected, revised, and in many ways moved beyond the social model to theorize aspects of disability that have often been overlooked. In doing so, I identify conceptualizations of disability and impairment that guide my analysis and theoretical approach. The second section of this chapter begins by defining sexuality and then offers an overview of the theories of sexuality that inform my understanding of, and engagement with, the interview data. In particular, I discuss Simon and Gagnon's (1973) theory of sexual scripts and conclude by discussing how this theory is suitable to the aims of this research. Altogether, this chapter provides an overview of the theories and concepts that guide my analysis.

Defining and Theorizing Disability

It is very difficult to arrive at a concise yet inclusive definition of disability since the term attempts to encompass a range of diverse identities, impairments, and embodied experiences (Bury, 1996; Wendell, 1996; Grönvik, 2007; Shakespeare, 2014). Ultimately, disability is a complex personal, social, and medical construction that involves "biological, social, and experiential components" (Wendell, 1996, p. 23). What 'counts' as a disability and who has the authority to decide what 'counts' varies over time and cross-culturally. The question of how to define disability is important for disabled people because definitions can significantly influence their self-identity and can provide a basis for solidarity, political organizing, and activism (Siebers, 2008; Shakespeare, 2014). This question is also important to organizations that work with disabled people such as the World Health Organization or the Council of Canadians with Disabilities. The many different 'official' definitions of disability that are used by organizations and governments inform their policies and thereby determine the quality of disabled people's "legal and practical entitlement to many forms of assistance, provided assistance is available" (Wendell, 1996, p. 11). These 'official' definitions can change, compete, and conflict with one another, and as Wendell (1996) notes, "it is not uncommon for people with disabilities to find themselves fitting some bureaucracies' definitions of disability and not others" (p. 24). While different definitions of disability reflect the diverse and heterogeneous nature of disability as well as debates over how to define disability, they also mirror the disparate values and missions of various organizations and governments.

Typically, scholars distinguish between different types of disabilities (i.e. physical versus intellectual disability). Yet, defining disability as either an intellectual or physical experience perpetuates a Cartesian mind-body dualism. Furthermore, this distinction obfuscates the reality that disability can encompass a combination of physical, cognitive, sensorial, and emotional experiences that are not easily separated from one another, which was often the case with participants involved in this study. Other distinctions are drawn between onset (i.e. congenital versus acquired), severity (i.e. minor vision loss versus paraplegia), and visibility (i.e. 'invisible' versus 'visible' disabilities and the ability to 'pass' as non-disabled versus the inability to 'hide' one's disability) (Rohrer, 2005; Grönvik, 2007). While these distinctions can be useful in both practical and theoretical terms, many disability studies scholars are hesitant to provide an exact definition of disability. Instead, they prefer to define disability as a "cultural and minority identity"

(Siebers, 2008, p. 4) which entails a "shifting nexus of both physical and mental states that resists full and final definition" (Shildrick, 2012, p. 3). This definition may seem rudimentary to some but it is significant because it recognizes that disability is not simply the product of an individual's biology but rather an "elastic social category both subject to social control and capable of effecting social change" (Siebers, 2008, p. 4).

Defining disability in this way is radical because it challenges common ideas that consider disability to be an individual and medical issue. This idea is frequently held because disability has historically been defined in biomedical terms by medical professionals. The medical model of disability has traditionally defined disability as "an individual defect lodged in the person, a defect that must be cured or eliminated if the person is to achieve full capacity as a human being" (Siebers, 2008, p. 3). This conception of disability profoundly influences everyday understandings of disability that position it as a personal tragedy or as a purely biological condition that should be identified, treated, and possibly, eliminated. In fact, Mitchell and Snyder (2006) suggest that, "nearly every culture views disability as a problem in need of a solution…[which] situates people with disabilities in a profoundly ambivalent relation to the cultures and stories they inhabit" (p. 205). Although professionals who subscribe to the medical model of disability have made many commendable advancements in terms of treating illness and disability, the perpetual search for prevention and cures has "prevented and relieved, but also caused, a great deal of suffering' (Wendell, 1996, p. 111). Furthermore, the biological reductionism inherent to the medical model of disability leaves "cultural assumptions that structure the normal unquestioned…[and] disability as a political issue, a social construction, and a category of inquiry remains unacknowledged" (Garland-Thompson, 1996, p. xvii). Unfortunately, this narrow, medicalized definition of disability does not account for the ways that institutions, infrastructures, and ableist values disable individuals, and supports a binary between what is considered to be 'normal' (i.e. non-disabled) and 'abnormal' (i.e. disabled) parameters of embodiment.

Fortunately, activists and scholars have worked to develop more holistic understandings of disability that examine social experiences of disability that *do* account for the ways in which sociocultural relations and structures oppress persons with disabilities. Emerging out of opposition to individualizing medical models of disability, first-wave disability studies scholars and activists of the late 1970s and early 1980s – most notably members of Britain's Union of the Physically Impaired Against Segregation (UPIAS) such as Vic Finkelstein (1980) and Paul Hunt – developed what is known as the social model of disability. Heavily influenced by Marxist principles and theory, members of UPIAS placed “the blame for disabled peoples’ oppression clearly at the feet of economic relations in capitalistic society” (Meekosha and Shuttleworth, 2009, p. 55; see also, UPIAS, 1976; Oliver and Barnes, 2012). Similar to how second-wave feminists like Anne Oakley (1972) drew conceptual distinctions between gender (i.e. the social) and sex (i.e. the biological), disability studies scholars and activists began to distinguish between *impairment* (i.e. the biological) and *disability* (i.e. the social).

The distinction between impairment and disability serves as the foundation upon which the social model of disability is built. Within the social model, the term impairment refers to physical conditions (e.g. paralysis), whereas the term disability refers to the various ways that sociocultural relations can function to marginalize and oppress people with disabilities (e.g. inaccessible infrastructure). Impairments are characterized as a part of human diversity whereas disability is characterized as a form of social oppression (Oliver, 1990, 1996, 2004; Finkelstein, 1996). Proponents of the social model assert that impairments are not the cause of disability and that the term ‘disabled’ is a restrictive label that is imposed *on top* of physical impairments by way of discrimination, stigma, and exclusion (UPIAS, 1976; Shakespeare and Watson, 1997, 2001, 2014; Galvin, 2003). By redefining disability as a structural and social experience rather than an individual attribute, the social model challenges the biological essentialism of the medical model, “prevailing ideas concerning the transhistorical or universal character of disability” (Thomas, 2007, p. 53), and serves to politicize disability as a social justice and human rights issue.

The ideological underpinnings of the social model began in Britain with the work of UPIAS. However, the distinction between impairment and disability did not become known as the ‘social model’ *per se* until Mile Oliver (1983, 1990) coined the term. This radical re-conceptualization of disability has allowed for crucial explorations into the ways in which disability is socially constructed and socially produced. Moreover, it is important to note that the social model holds a great deal of symbolic and transformative value (Thomas, 2007; Barnes, 2012; Shakespeare, 2014). Many disabled people identify the social model as a source of empowerment and liberation because it provides a basis for solidarity, offers a “positive sense of collective identity” (Shakespeare, 2006, p. 199), and acknowledges that it is “society at fault, not them” (Shakespeare, 2014, p. 13; see also Thomas, 2007; Watson et al., 2012). In fact, several of ‘my’ participants identified the social model as a source of empowerment in their lives. Indeed, some scholars assert that the social model has been so transformative that it has “saved lives” (Crow, 1996, p. 207).

The social model of disability is undoubtedly one of the major contributions that activists and disability scholars have made to social-scientific understandings of disability and, as a result, it is often referred to as "the big idea" of disability studies (Hassler, 1993, p. 17). Still, the distinction between impairment and disability has been widely debated and hotly contested. Similar to the manner in which feminists later saw flaws in drawing distinctions between sex and gender (see Butler, 1990, 1993, 2004; Fausto-Sterling, 1993, 2000), scholars began to identify issues within the social model of disability. Specifically, they criticized the rigidity of the disability/impairment distinction, the dichotomies it reifies (i.e. social vs biological), and have worked towards bridging the conceptual divide between impairment and disability (see Thomas, 2007; Hughes and Patterson, 1997; Gabel and Peters, 2004). According to Shakespeare (2014), it is both the "strength and simplicity" of the social model that has "created as many problems as it has solved" (p.14).

Academics have criticized the social model for neglecting embodied experiences of impairment and for failing to consider how individuals with disabilities experience their bodies (Hughes and Patterson, 1997; Thomas, 1999, 2004, 2007; Shakespeare and Watson, 2001, 2002; Liddiard, 2018). For example, within the social model, complications that accompany disability, such as illness, pain, and fatigue can be eclipsed from view and therefore remain under-explored, un-problematized, and under-theorized. With this in mind Meekosha (1998) contends, "focusing only on the disabling effects of a prejudiced and discriminatory society…leaves the impaired body as untouched, unchallenged; a taken-for-granted fixed corporeality" (p. 175). Thus, in many ways, the social model's failure to explore the embodied experiences of disability and impairment resembles many of the limitations of a biomedical approach to disability. Yet, rather than adopting an individualized and medicalized approach to the body and disability, the social model takes on an over-socialized approach and treats impairment as a biological reality that is removed from and unaffected by social forces. According to Hughes and Patterson (1997),

> There is a powerful convergence between biomedicine and the social model of disability with respect to the body. Both treat it as a pre-social, inert, physical object, as discrete, palpable and separate from the self. The definitional separation of impairment and disability which is now a semantic convention for the social model follows the traditional, Cartesian, western meta-narrative of human constitution (p. 329).

By maintaining such a strict division between impairment and disability, the social model risks becoming a disembodied theory that overlooks individual agency, the subjective experiences of impairment, the body, and embodiment. This is problematic because impairment can be a significant aspect of disability that warrants sociological investigation. Jenny Morris (1991) acknowledges the dangers of overemphasizing the social and structural aspects of disability. She contends that, "we can insist that society disables us by its prejudice and by its failures to meet the needs created by disability, but to deny the personal experience of disability is, in the end, to collude in our oppression" (p. 183). Thus, although the objectives of the social model such as barrier removal, politicization, and empowerment are very worthwhile and necessary goals, sometimes the solutions for assisting and accommodating different groups of people with disabilities are not compatible. For example, people with visual impairments might find tactile sidewalks to be useful in aiding their movements, whereas people who use wheelchairs might find these sidewalks to be difficult to navigate. This does not mean that efforts to eradicate structural barriers should be abandoned, but it does signal that there are instances wherein changes to social conditions would not ameliorate the physical and emotional pain that many disabled people experience. It is therefore important to "acknowledge that social justice and cultural change can eliminate a great deal of disability while recognizing that there may be much suffering and limitation that they cannot fix" (Wendell, 1996, p. 45). Adopting such a perspective therefore emphasizes the need to explore the lived and embodied experiences of disability rather than shy away from the "hard physical realities" that disabled people experience (Wendell, 1996, p. 45).

Feminists have criticized the social model for its androcentrism, somatophobia, conceptual rigidity, and for its failure to include those with cognitive or sensorial impairments (Morris, 1991; Crow, 1992, 1996; Corker, 1998; Ferri and Gregg, 1998; Thomas, 1999, 2007). Since the majority of UPIAS members were white, heterosexual, male wheelchair users, the origins of the social model were primarily based on the experiences of this impairment group and therefore tended to omit the diversity of experiences of women, people of color, LGBTQ+ persons, and people with cognitive disabilities (Barnes, 2012; Shakespeare, 2014). Other feminist scholars criticized the social model's "inability to recognise sexual agency" (Gabel and Peters, 2004, p. 594), and the fact that it has "little or nothing to say on the subject of sexuality and has no place for the question of desire in particular" (Shildrick, 2007, p. 228; see also Liddiard, 2018). As noted earlier in my literature review, many of these critiques were lodged through compelling personal narratives written by disabled feminists who candidly discussed their experiences of ableism and impairment

(See, Clare, 1999; Fine and Asch, 1988; Finger, 1990, 1992; Mairs, 1996; Morris, 1989, 1991, 1993; Waxman-Fiduccia and Finger 1989, 1991; Wendell, 1996). Although some of these works were derided as 'sentimental autobiography' by a small number of scholars who were deeply committed to Marxist theoretical perspectives (see Barnes, 1998), feminist insistence on attending to embodiment, impairment, and gender was critical in identifying some of the issues within the social model and initiated calls for a "renewed social model of disability" (Crow, 1996, p. 218). As Morris (1996) notes,

> There was a concern amongst some disabled women that the way our experience was being politicised didn't leave much room for acknowledging our experience of our bodies; that too often there wasn't room for talking about the experience of impairment, that a lot of us feel pressurised into just focusing on disability, just focusing on social barriers (p. 13).

It is worthwhile to note that although many feminists with disabilities worked to carve out a place for the experiences of women with disabilities, the concerns and experiences of disabled women have typically been neglected by mainstream feminist scholars and feminist movements (Morris, 1991, 1996; Thomas, 1999, 2006, 2007; Lafrance, 2007; Siebers, 2008; Kafer, 2013; Israelite and Swartz, 2013; Odette, 2013). Liddiard (2018) acknowledges this dissonance, arguing that,

> It was disabled feminists' *own* engagement with these ideas that instigated important changes for disabled women, rather than via support from their non-disabled sisters whose 'narrow notions of womanhood' (Wilkerson, 2002, p. 39) have largely excluded and overlooked the experiences of disabled women (p. 19).

The exclusion that Liddiard identifies is related to the fact that some feminist scholars have excluded embodied experiences from their theorizations and research (Grosz, 1994; Lafrance, 2007; Garland-Thompson, 2002; Namaste, 2000). This exclusion is also related to the fact that disability remains a peripheral concern for many scholars, regardless of theoretical orientation or discipline. Davis highlights this concern and argues that, "the majority of academics do not consider disability to be a part of their social conscience" (p. 32). Similarly, Shildrick (2012) contends that issues related to disability are "dismissively seen as a minority concern of real interest only to those who are themselves disabled" (p. 17).

Although the social model is theoretically important and politically useful, it is "conceptually and empirically very difficult to sustain", and more significantly, it is not complex enough to sufficiently account for the lived reality of disabled peoples' lives (Shakespeare, 2014, p.22). In working to move beyond the social model of disability – while still retaining many of its important aims such as changing the sociocultural conditions and structures that marginalize disabled people – scholars have focused their attention toward theorizing the impaired body (see Wendell, 1996; Hughes and Patterson, 1997; Thomas, 1999, 2007; Shakespeare and Watson, 2001; Gabel and Peters, 2004; Rembis, 2010; Shildrick, 2012). Early disability studies scholars once avoided impairment and the body, instead theorizing how ableism operates on a social, structural, and interpersonal level. However, like other areas of sociology, disability studies scholars soon sought to 'bring the body back in' (see Shilling, 1993, 2012; Synnott, 1993; Turner, 1984, 2008). Eventually, even the most hard-line social model theorists, such as Michael Oliver, conceded that "an adequate social theory of disability must contain a theory of impairment" (Oliver, 1996, p. 42). In working to theorize impairment and embodied experiences of disability these scholars have utilized a number of theoretical resources in order to rectify the dearth of scholarship that failed to explore embodiment, impairment, gender, and sexuality, some of which I detail below.

Feminist scholars have pursued a number of different avenues to theorize impairment, subjective experiences of disability, and the gendered character of ableism (Garland-Thompson, 2002, 2005; Thomas, 1999, 2006; Hall, 2011; Shildrick, 2012). Feminist examinations into the intersections of disability, sexuality, and gender have helped to disrupt the persistent presumption that disabled people not only lack sexual identity and agency, but also gender identity and expression. By applying an intersectional lens to the experiences of people with disabilities, feminists have identified some of the multiple and interconnected oppressions that many disabled people experience (see Davis, 2008; Meekosha and Shuttleworth, 2009; Erevelles, 2010; Ben-Moshe, 2014). Moreover, an intersectional feminist approach further established the fact that the "powers and processes that construct gender and disability are intimately connected and tightly bound" (Liddiard, 2018, p. 20). Intersectionality has been an important theoretical tool for as Goodley (2011) points out, "a body or mind that is disabled is also one that is raced, gendered, trans/nationally sited, aged, sexualized, and classed" (p. 33).

Tremain (2002, 2005), Rembis (2010), and Shildrick (2012) have echoed and extended feminist criticisms of the social model, but have done so by adopting a postmodern approach and by drawing upon the work of Michel Foucault (1978). For Foucault, "the human subject in modernity is constituted by disciplinary techniques of bio-power which structure, produce, and optimise the capabilities of the body, enhancing its economic utility and ensuring its political docility" (Hughes and Patterson, 2002, p. 332). According to the postmodern paradigm, the body and impairment are "socially constructed through medical regulatory practices and related systems of power" (Thomas, 2007, p. 126-127). Postmodern scholars generally reject the idea that there is a natural, 'normal', trans-historical, or pre-social body and view binaries such as impairment/disability, social/biological, and male/female, as in need of "deconstruction and transcendence" (Thomas, 2007, p. 125; see Rembis, 2010; Davis, 2002; Siebers, 2008). For example, McRuer (2002) works to transcend the binary of ability and disability by arguing that every individual has the potential to become disabled and therefore non-disabled people should be considered 'temporarily able-bodied' or 'TAB' (see also Zola, 1982, 1993; Davis, 2002; Siebers, 2008; Shildrick, 2012; Titchkosky and Michalko, 2009). Drawing upon the work of Rich (1980) and Butler (1990, 2004), McRuer (2002) suggests that,

> Everyone is virtually disabled, both in the sense that able-bodied norms are intrinsically impossible to embody fully and in the sense that able-bodied status is always temporary, disability being the one identity category that all people will embody if they live long enough (p. 95).

This argument is in keeping with the postmodern understanding of the self as perpetually "interdependent, fluid, and endlessly in process" and draws attention to the tenuous nature of all forms of embodiment (Shildrick, 2012, p. 10).

While adopting a postmodern approach allows scholars to deconstruct what constitutes ability and/or disability, and although it usefully illuminates the fleeting and often impermanent nature of ability, there are limitations to this approach. For instance, assertions that "everyone is virtually disabled" (McRuer, 2002, p. 95; see also Goodley, 2010), not only gloss over differences between non-disabled people and disabled people but also obscure differences among people with disabilities. Similarly, as Thomas (2007) argues, "problems arise when impairment is presented as entirely discursively constructed, as a cultural artefact" (p. 128, see also Mitchell and Snyder, 2000). Similar to the ways in which the social model can omit lived experience, once again, the lived, embodied, realities of disabled people, as well as their individual agency, can slip from view within the postmodern paradigm. In fact, Hughes and Patterson (2002) have charged postmodern approaches with supplanting a form of biological essentialism that is found in medical models for a kind of discursive essentialism (see also Hughes, 2002, 2005; Shakespeare, 2018).

Hughes and Patterson (2002) suggest that while a postmodern approach can shed light on the nature of impairment, "the nature of the body it promotes is, on close investigation, something of a phantom" (p. 333). In order to address this issue, they turn to the work of Maurice Merleau-

Ponty (1962) and suggest that adopting a phenomenological perspective can facilitate more nuanced explorations of impairment and subjective experiences of disability. Influenced by the work of Martin Heidegger, Merleau-Ponty argued that our bodies constitute the basis of 'being in the world', insofar as perception emanates and originates from within the body, and because it is through the process of "interweaving with other bodies, that actualizes our social and personal identities" (Shildrick, 2012, p. 25). Adopting a phenomenological approach to embodiment allows for the recognition that we are all implicated in a "lifelong process of becoming *with* others" which "constitutes both self and other" (Shildrick, 2012, p. 28). Furthermore, the phenomenological model of embodiment shows how any "intercorporeal encounter is about a mutual crossing of boundaries that enacts the very means through which embodied subjects are constituted, and undone" (Shildrick, 2012, p. 23).

In keeping with tenets of phenomenology, Hughes and Patterson (2002) argue that the body, impaired or otherwise, is an "experiencing agent", a "site of meaning" and a "source of knowledge of the world" (p. 334). Yet, they also contend that impairment and embodiment are not purely physical experiences. Hughes and Patterson (2002) suggest that, "impairment (as physicality) cannot escape wider cultural meanings and beliefs or its embeddedness in social structure", and that, "oppression and prejudice, not only belong to the political body, but become embodied as pain and 'suffering'" (p. 336). In doing so, they draw attention to the fact that oppression or marginalization can be *felt* and embodied. Moreover, that a structural barrier can heighten or exacerbate impairment, and similarly, that impairment is an embodied experience that is socially constructed. Their argument is in keeping with the phenomenological understanding that "biological, social, and discursive bodies are equally unfixed and mutually constitutive" (Shildrick, 2012, p. 25). This argument finds support from Shakespeare and Watson (2001), who have proposed that impairment should be placed on a spectrum or continuum but not completely separated from disability. Shakespeare and Watson (2001) contend,

> Impairment and disability are not dichotomous, but describe different places on a continuum, or different aspects of a single experience. It is difficult to determine where impairment ends and disability starts, but such vagueness need not be debilitating. Disability is a complex dialectic of biological, psychological, cultural and sociopolitical factors, which cannot be extricated except with imprecision (p. 22).

Like Shakespeare and Watson, I argue that if impairment refers to the embodied experiences that occur alongside of disability, the two cannot be separated and in many ways, they interact with and constitute one another. Similarly, as Wendell (1996) argues, "the distinction between the biological reality of a disability and the social construction of a disability cannot be made sharply, because the biological and the social are interactive in creating disability" (p. 35). In other words, it is not always possible to draw a clear distinction between impairment (i.e. the limitations of the body) and disability (i.e. the limitations that are imposed upon the body by society).

With this in view, I contend that impairment, much like disability, is an embodied experience that consists of biological, psychological, emotional, and sociocultural components. Furthermore, impairment is comprised of both "human variation encountering environmental obstacles *and* socially mediated difference that lends group identity and phenomenological perspective" (Snyder and Mitchell, 2006, p. 10). Conceptualizing impairment in this way does not deny the powerful role that structures and discourses play in constructing, controlling, and influencing the body. Indeed, in an age marked by pressure to work on and perfect the body via body projects and body work (see Giddens, 1991; Shilling, 1993, 2012; Synnott, 1993; Turner, 1984, 2008), the role that institutions, corporations, and governments play cannot be discounted. Still, while structural and discursive aspects need to be accounted for, individual agency and embodied experiences are also important, and so is the interplay between the two. Ultimately, as Sawchuk (2014) contends, "Impairment is neither simply subjective, nor medical, nor a part of the built environment. It is a state of perpetual being that is relational, contingent, material, and temporal" (p. 417).

Attending to the narratives of participants and privileging their self-interpretations of experiences that lie at the intersection of disability and sexuality ensures that their lived realities do not slip from view and become theoretical abstractions. Mairs (1996) has movingly described some of the tensions between academic theories of disability and the lived reality of disability in her memoir *Waist-High in the World: A Life Among the Disabled.* She writes,

> Marginality thus means something altogether different to me than what it means to social theorists. It is no metaphor for the power relations between one group of human beings and another but a literal description of where I stand (figuratively speaking): over here, out of bounds, beneath your notice. I embody the metaphors. Only whether or not I like doing so is immaterial (p. 59).

As this quote from Mairs implies, it is imperative that this study attends to participants' experiences of disability first and highly theoretical conceptualizations of disability and impairment second. Similarly, as highlighted in my literature review, scholarship on disability and sexuality has had a tendency to exclude the voices of disabled people. In light of this fact, this research prioritizes the narratives and 'voices' of participants. Furthermore, given both the strengths and limitations of postmodern and social constructionist theories of disability and impairment, I have chosen to select elements of each paradigm in order to inform and operationalize my understanding of disability and impairment. Specifically, from the social model I retain the insight that meanings attached to disability change over time and across cultures, that disability is produced through social structures, and finally, that experiences of impairment are exacerbated by ableist attitudes, policies, and institutions. Postmodern theories of disability inform my understanding of disabled bodies as disciplined and highly regulated. Furthermore, adopting elements of a postmodern approach allows me to question and destabilize the boundaries between disability and ability as well as what constitutes normality/abnormality. Lastly, from a phenomenological perspective I adopt the axiom that body and mind are an inseparable experiencing agent that is integral to our interactions and identities, and a symbol that is forever in process.

Finally, while it is important to identify how I operationalize disability and impairment, fundamental norms of what constitutes 'normal' human embodiment must also be considered. Cognition, mobility, bodily control, independence, autonomy, verbal capacity, and sanity are all hallmarks of 'normal' human embodiment and existence (Shildrick, 2012; Seibers, 2012; Kulick and Rydström, 2015). Similarly, Cartwright and Goldfarb (2006) contend, "purposeful mobility, like speech and gesture, is a key signifier of human agency and personal expression" (p. 139-140). Yet, the bodies of disabled people can exist outside of these parameters. Disabled bodies are 'unruly' in that they defy normative standards, disrupt the pernicious myth that we can control our bodies, and potentially remind non-disabled individuals that they too could become disabled. Shildrick (2012) argues that disabled bodies "signal threat and danger insofar as they undermine any belief in the stability and consistency of bodies in general. Paradigmatically, such bodies elicit anxiety for they remind others of their own vulnerability and precariousness" (p. 20-21). Disabled philosopher Susan Wendell (1996) describes how her very existence often reminds other people of their susceptibility to disability, pain, and illness. She writes,

> If we tell people about our pain, for example, we remind them of the existence of pain, the imperfection and fragility of the body, the possibility of their own pain, the inevitability of it…They may want to believe they are not like us, not vulnerable to this; if so they will cling to our differences, and we will become 'the Others'. (p. 91-92).

Wendell's experiences show that when non-disabled individuals interact with disabled individuals, non-disabled people may have to confront the fact that the boundaries between disability and ability are more fluid and penetrable than previously thought. Indeed, part of what makes disability so threatening is the "indistinctness and permeability of its boundaries" (Couser, 1997, p. 178).

In addition to reminding non-disabled people of the potential limitations of their own bodies, disabled bodies can produce fear and anxiety because they are frequently viewed as sources of disease and/or contamination (Kevles, 1998; Shildrick, 2001, 2012). With this in view, disabled people can come to symbolize danger or risk and are therefore often subject to both control and alienation. In many ways, disabled people have literally been cordoned off from society through institutionalization and through social isolation (see Malacrida, 2015). The hesitance to accept disabled people and their bodies is partially a product of the stigma and limitations that are already associated with disability. Additionally, the lasting effects and historical tenacity of eugenic beliefs also impact the acceptance of disabled people. Fears of contagion can be linked to eugenic programs which seek to manipulate, and in many cases, destroy disabled peoples' opportunities for life. These fears become particularly acute with regards to sexuality because of misguided assumptions that believe "disability breeds disability" (Cornelius et al., 1982, p. 2; Shildrick, 2012). In addition, contagion often implies that a boundary has been breached, which can serve as another reminder that both bodies and the boundaries between ability and disability are more porous than previously thought.

Fears of contagion and the disabled body can be productively interpreted through Julia Kristeva's (1982) theory of the abject. For Kristeva, the abject is something that exists in liminal spaces and in-between states, straddling the borders between self/other, human/nonhuman, normal/abnormal, able/disabled, etc. In addition, the abject provokes disgust and horror and is usually something that we are compelled to expel and reject. Importantly, the abject has the potential to confound and destabilize boundaries while breaking down meaning and potentially undermining an established system of 'order'. Kristeva's concept of the abject is particularly useful because it shows that "the issue is not so much that the body of the other is horrifying in and of itself, but rather that it might infiltrate the space of my own body and effect the very transformations that would unsettle my claim to autonomous selfhood" (Shildrick, 2012, p. 22). This is because processes of abjection can also function as a means of individuation wherein people form and assert their identity as an individual (i.e. disabled/non-disabled). As Shildrick (2012) notes, "In Kristevan terms, any form of anomalous embodiment – and particularly that which overtly contests the discursive ideal – is highly productive of anxiety, insofar as it threatens to overflow the boundaries of the 'self's clean and proper body'" (p. 22). Since the disabled body cannot be neatly controlled or classified, it can be considered an abject form of embodiment, one that people react to with disgust and avoidance. Furthermore, people with disabilities experience abjection insofar as they are subjected to marginalization and rejection. And so, it is through rejecting and alienating disabled people that non-disabled people affirm their identity as non-disabled and 'normal'.

Returning to the question of what fundamental norms structure and underlie the parameters of 'normal' human embodiment, the body is site that is read as an indicator of a human's morals, worth, and status. Moreover, since our social world privileges corporeal wholeness and generally assumes ablebodiedness, ability therefore becomes the "supreme indicator of value when judging human actions, conditions, thoughts, goals, intentions, and desires", and the "ideological baseline by which humanness is determined…the lesser the ability, the lesser the human being" (Siebers, 2008, p. 10). This baseline or standard is central to the hierarchy that places certain modes of embodiment at the top and other forms of embodiment lower down and is utilized by both ablebodied and disabled people. For example, Deal (2003) and Kulick and Rydström (2015) have identified a hierarchy of disability among disabled people that positions people with physical impairments at the top. At the very bottom of this hierarchy are people with cognitive impairments and/or those who have little to no mobility and no verbal speech. Deal (2003) notes that much like non-disabled people, disabled people "do not always wish to be associated with other impairment groups" (Deal, 2003, p. 897). This hierarchy illustrates some of the fundamental norms that constitute 'normal' human embodiment (i.e. verbal capacity, mobility, independence, etc.), and traces of this hierarchy can be found within some of the participant's narratives.

The question of who has a 'normal' body and what is considered 'normal' human embodiment is very complex and I do not think that a singular answer to this question is sufficient. This is partly because what is considered to be 'normal' or 'abnormal' changes drastically over time and across cultures. Moreover, this question is caught up in ethical, sociological, political, and biomedical debates that are outside the scope of this research. However, in order to help guide my thinking, I rely on many of the concepts and theories detailed above and Siebers' (2012) theory of the 'ideology of ability'. According to Siebers, at its simplest form the ideology of ability is the "preference for able-bodiedness" and at its most radical state it "defines the baseline by which humanness is determined, setting the measure of body and mind that gives or denies human status to individual persons" (2012, p. 8). For Siebers, this ideology marginalizes and represses disability by positioning the able body as "normative in the definition of the human" (Siebers, 2012, p. 111). From this work, I take the understanding that the ability to *do* things with our bodies, to have productive, predictable, and controllable bodies is a key signifier of human worth in our culture. Similarly, this project takes up Siebers' call to explore how "the ideology of ability determines how we think about sex" (Siebers 2012, p. 139). I continue this discussion in the following section as I explore whether and how people with disabilities gain entry to the symbolic systems that mark someone as not only a valuable and 'normal' human being but as a viable *sexual* being. This exploration begs the question, if someone is not viewed as a human being, how could they be viewed as a sexual being? And further, who counts as a sexual being?

To summarize and conclude this section, then, the conceptualizations of impairment and disability that help to guide this research project are informed by numerous and diverse theoretical perspectives. By conceptualizing disability and impairment as inseparable experiences that are informed and shaped by both individual experiences and sociocultural practices that often discriminate against and desexualize those with disabilities I work to move beyond the valuable but inadequate insights of the social model. This is done in an attempt to maintain a better focus on and attain a better understanding of embodiment as well as the intersectional and subjective experiences of disability and sexuality. As Shuttleworth (2010) and Smith-Rainey (2017) point out, impairment and disability need not operate solely as a source of pain and discomfort, rather they can open up new and pleasurable possibilities. In fact, a small number of the participants involved in this study credited their disability and impairments as a means through which they heightened their sexual pleasure. With this in view, I consider disabled peoples' opportunities for sexual activity to be contoured by their individual agency as well as their individual embodied experiences of impairment, including the potential possibilities and limitations that impairment and disability can entail. In addition, I consider these opportunities to be simultaneously shaped by ableist attitudes, interactions, policies, and structures that function to restrict disabled peoples' opportunities for sexual expression and fulfillment.

Theorizing Sex and Sexuality

The ability to have sex is considered a hallmark of human agency and adulthood that is marked by many cultures through rites of passage and coming of age ceremonies (see Holland et al., 1996; Wilkerson, 2002; Gill, 2015; Herdt, 1987, 2008, 2013). However, since disability is routinely associated with vulnerability and dependency, disabled people are regularly infantilized and therefore not seen as full adults (Siebers, 2010; Plummer et al., 2015). This infantilization has a number of negative implications for disabled people's sexualities considering "childhood is frequently equated with a state of innocence, which is in turn conflated with sexual ignorance" (Scott and Scott, 2010, p. 101). In particular, this infantilization perpetuates the belief that children and disabled people are vulnerable, in need of protection from information related to sex and sexuality, and lacking sexual desires or capabilities (Kulick and Rydström, 2015; Liddiard, 2018). Subsequently, sex and sexuality are seen as particularly problematic with regards to disabled people and can be considered threats to their psychological well-being or safety. Like Kulick and Rydström (2015) contend,

> Sexual agency is a decisive marker of adult status in society. The idea that people with disabilities somehow aren't interested in sex, or shouldn't be interested in it, both derives from and reinforces the patronizing stereotype that disabled adults are like children (p. 6).

While the boundaries between childhood and adulthood are socially constructed and "by no means clearly demarcated" (Scott and Scott, 2010, p. 103), the idea that children and disabled people lack sexualities is related to a larger issue of who is seen as a viable sexual being in our culture. Put differently, it points to the question of who is allowed to be sexual in our society? On an anecdotal but related note, when I described this research project to friends, strangers, or relatives, I would often receive a response that was a variation of "well, they [disabled people] are still human". This response is encouraging in the sense that it shows that not all people view those with disabilities as nonsexual. However, the frequency of this response is indicative of the prevalence of the idea that sexuality is essential to an individual's personhood. More pointedly, this response demonstrates the belief that if an individual's ability to engage in sex is jeopardized, so is their status as a valuable and (re)productive human. The assumption that the inability to engage in sexual relations can strip an individual of their personhood and status as a competent adult is candidly described by American author and advocate Mark O'Brien who offers his experience of physical therapy in a clinical setting. He writes,

> We watched a movie about disability and sexuality. The movie consisted of four or five able-bodied men joking and laughing about how they once lugged their crippled friend up a flight of stairs to a whorehouse…After the movie, a doctor talked about disability and sexuality…I will always remember his closing line: 'You may think you'll never have sex again, but remember…some people do become people again' (O'Brien and Kendall, 2003, p. 80).

This account illustrates the equation of personhood with sexuality, the stigmatizing effects of a medical 'gaze', and the fact that medical professionals are often the 'gatekeepers' of disabled peoples' sexualities (Shakespeare et al., 1996; Liddiard, 2018). Importantly, within this account the doctor is positioned as *the* expert on patients' sexualities. Moreover, the doctor's statement carries the implication that patients have lost their status as full persons and will not regain it until they have been rehabilitated through medical assistance. Thus, while it is important to recognize that sexuality can function as a fundamental aspect of an individual's identity, it is equally important to recognize that sexuality is often denied to disabled individuals. Subsequently, it is important to consider the ways in which sexuality functions as a mechanism of social control and is also a "major site of state intervention" (Shildrick, 2007, p. 55). As Shildrick (2012) contends, "There is an extraordinary reluctance to acknowledge that disabled people have any sexuality at all, with the result that their sexual expression is highly regulated, if not invalidated or silenced completely" (p. 11). Indeed, the innumerable barriers that people with disabilities face when having relationships, remaining sexual, and becoming parents have been well-documented and are discussed at length in my literature review (see, for example, Jungels and Bender, 2015; Shuttleworth and Sanders, 2010). Many of these barriers can be traced to a variety of medical, social, and legal practices that regulate, control, and in some cases, deny or destroy opportunities for sexual expression among disabled people. In the following section, I focus on the ways in which medical practices and knowledges control and marginalize disabled peoples' sexualities. Following this brief discussion, I explore the value that Foucauldian and interactionist perspectives have to bear on the topic of disability and sexuality.

Much like disability, sex and sexualities have historically been defined and studied from a medical and scientific perspective (Shakespeare et al., 1996; Shuttleworth and Sanders, 2010). This perspective has typically adopted an essentialist approach to sexuality, treating sex and sexuality as innate, heterosexual, biological and pre-social phenomena and therefore seeking to measure or classify human sexual behaviours (Weeks, 1986; Scott and Scott, 2010). Within this perspective, reproduction and the ability to reproduce is seen as paramount. Consequently, "sexuality is both definable and explicable in terms of a reproductive imperative" (Jackson, 1999, p. 5). Since reproduction figures so heavily within this paradigm and because "sexual rights have always and only been awarded to those who are proclaimed to deliver quality offspring" (Waxman-Fiduccia, 2000, p. 169), the reproductive and sexual rights of disabled people are closely monitored and curtailed, with the expectation being that if disabled people reproduce "the results will be tainted" (Siebers, 2010, p. 140). Furthermore, Tepper (2000) argues that the medical model has generally adopted a "genitally focused and performance orientated conception of sexuality" (p. 288). This genitally-focused conception can have unfortunate consequences for people with disabilities whose sexual and erotic acts are often based upon "a different sexual geography both for the body and the places where bodies express their sexualities" (Siebers, 2012, p. 152). Thus, by creating and maintaining a set of physiological norms that are generally unrealistic for people with disabilities, this medicalized conception of sexuality can erase disabled peoples' experiences by rendering them outside of the rubric of potential, acceptable, and legitimate sexual activities.

Regrettably, the medical approach to disability and sexuality tends to conceive of sexual problems as inherent limitations or by-products of inhabiting a disabled body rather than problems that are potentially produced by ableist understandings of sexuality and social life (Shakespeare, et al., 1996; Rembis, 2009; Liddiard, 2018). Moreover, since medical and scientific knowledge is often seen as the highest form of knowledge, the medicalized understanding of disabled sexuality profoundly influences the 'layman's' everyday understanding of disability and sexuality (Scott and Scott, 2010). As a consequence, a medicalized conception of disabled sexuality can legitimize the monitoring, controlling, and curtailing of disabled peoples' sexual opportunities both inside and outside of a medical or clinical setting. Like Siebers (2010) contends, "the medical model too often makes the world a hospital where the disabled are obliged to be perpetual patients and the non-disabled have the right to play doctor" (p. 147).

The regulation, control, and denial of disabled sexualities through medical practices and knowledge can be productively interpreted through Foucault's (1978) theory of sexuality. Meekosha and Shuttleworth (2009) suggest that applying a Foucauldian lens to disability and sexuality is particularly useful because it "performs a radical de-familiarization of modern institutions and practices as caring and benevolent and reveals technologies and procedures that classify, normalize, manage, and control anomalous body projects" (p. 2009, p. 57). For Foucault, sexuality is a modern construct that was established through an 'incitement to discourse' which "orders bodies and pleasures into what we know as 'sex'" (Scott and Scott, 2010, p. 17). According to Foucault (1978), sexuality is regulated through polymorphous forms of power and diverse sources like "demography, biology, medicine, psychiatry, psychology, ethics, pedagogy, and political criticism" (p. 33). Thus, sexuality is seen as an "instrument of power's designs", insofar as it functions as a means to surveil, discipline, and control populations, and importantly, as a means to induce populations to discipline *themselves* (Foucault, 1981, p. 152). The Foucauldian insight that sexuality is socially constructed through discursive and regulatory mechanisms makes space for an examination of the multiple ways that disabled sexualities are marginalized, constructed as deviant, and disciplined through discourses that place disabled people at the "margins of human sexuality" (Liddiard, 2018, p. 26).

Yet, Foucault's theory of power does not leave much room to explore individual embodied experiences or the ways that disabled people make sense of their sexual opportunities and selves, issues that are central to this research. As stated in chapter one, the primary aim of this research is to explore the ways that participants experience their opportunities for sexual expression and the barriers that influence their experiences. In particular, I seek to understand what is important to participants in terms of their sexual and romantic relationships and to learn about the strategies they deploy in order to actualize and express their sexualities. With this in view, it is important that I incorporate theories that facilitate this line of inquiry. Therefore, I turn to symbolic interactionism as a means to theorize how the sexual opportunities of disabled people materialize and unfold, namely, the ways in which their sexualities are understood, restricted, and/or facilitated through their interactions.

The prevalence of symbolic interactionism within Canada is characterized by Low (2016) as "waxing and waning" (p. 199). Thus, by employing this theoretical perspective I modestly contribute to overall increases in its use. I use an interactionist understanding of sexuality to decipher what resources disabled people draw upon in order to make sense of their sexual opportunities and experiences and to identify what resources are available to them. This is done in an attempt to gauge if normative understandings of sex and sexuality apply to the lives of the participants and to attend to the ways that participants interpret and create meanings suited to their own embodied realities. Moreover, I have opted to use an interactionist approach because, as stated by Jackson and Scott (2007), "the meaningful social reality of embodied sexual encounters is constituted not only through discourse but also through the meaning-making emergent from, and negotiated within, situated everyday interaction" (p. 97).

Interactionist theories posit that sexuality entails "actively 'doing sex', not only in terms of sexual acts, but also as making and modifying sexual meaning" (Scott and Scott, 2010, p. 14). This approach centers both agency and experience by placing emphasis on how individual ideas of what activities are considered sexual or 'sexy' are derived from "a complicated set of layered symbolic meanings which might not be the same even for participants in the same sexual drama" (Gagnon and Simon, 1974, p. 23). Through the acknowledgement of the role of experience and individual agency, an interactionist approach allows for a more nuanced understanding of the ways in which sexuality is produced by and through interactions. In addition, interactionism sheds light on the ways that individuals reify, negotiate, and resist meanings as they make sense of their sexual selves through symbols, interpretation, and the narratives they construct. This focus on the ways that individuals reify, negotiate, and importantly, resist meanings is well-suited to the goals of this project, which include centering the 'voice', experience, and individual agency of participants. In particular, by attending to individual agency this paradigm acknowledges the participants' capacity to reify and/or reject dominant medicalized understandings of sexuality.

An interactionist understanding holds that sexuality occurs in the context of everyday interactions that are inevitably and simultaneously shaped by wider social relations. The assertion that sex and sexuality exist in everyday moments helps to disrupt the idea that sex and sexuality are private matters that should be relegated to the private sphere. The view that sex and sexuality are private matters has particularly acute consequences for disabled people who have often been denied privacy or have an altogether different understanding of the concept (Wilkerson, 2002; Kaufman et al., 2003; Liddiard, 2018). Therefore, by relocating sexuality in everyday moments an interactionist perspective helps to disrupt the private/public divide that many disability studies scholars and feminists have identified as a source of oppression (Sherry, 2004; Siebers, 2012; Kulick and Rydström, 2015). As Scott and Scott (2010) note,

> This [interactionist] view of sex is radical in that it runs counter to much commonsense thinking. Sex is usually seen as special, outside, and apart from routine sociality, uniquely eliciting and transforming, raising us above the mundane quotidian – or alternatively as a dangerous force with the power to undermine 'civilization' and reduce us to barbarism (p. 14).

Simon and Gagnon's (1974) theory of sexual scripts is located firmly in the interactionist tradition and provides a schema to help theorize how participants understand their sexual opportunities. Pioneered by Simon and Gagnon (1974, 1986, 2003) and later expanded upon by scholars like Wiederman (2005, 2015) and Kimmel (2007), sexual script theory has been extremely influential within the discipline of sociology. It has been so influential that Kimmel (2007) asserts that Simon and Gagnon's work on sexual scripts "heralded the new paradigm from which all subsequent readings of sexuality in the social sciences and humanities have sprung" (p. ix). The basic premise of this theory is that all sexual behavior is socially constructed and socially scripted (Wiederman, 2015). Individuals learn what behaviors are considered normal and appropriate or abnormal and inappropriate through interpreting and internalizing metaphorical scripts which function as "guides for sexual conduct" (Simon, 1996, p. 40). Importantly, these scripts do not determine sexual conduct and furthermore, they can change and compete with one another. Thus, these scripts represent the merging of a "stock of cultural knowledge about sexuality" with interpretation and individual agency (Scott and Scott, 2010, p. 15). The theory is summarized succinctly by Simon and Gagnon (1974), who write,

> Scripts are involved in learning the meaning of internal states, organizing the sequencing of specifically sexual acts, decoding novel situations, setting the limits on sexual responses and linking meanings from nonsexual aspects of life to specifically sexual experience (p. 17).

Simon and Gagnon (1974) identify three levels of sexual scripts including cultural scenarios, interpersonal scripts, and intrapsychic scripts. Cultural scenarios are the "larger frameworks and roles through which sex is experienced" (Kimmel, 2007, xii). Interpersonal scripts represent the "routine patterns of social interaction that guide behaviors in specific settings" (Kimmel, 2007, xii). Intrapsychic scripts refer to the ways that "social action is always conducted with an on-going internal dialogue about internalized cultural representations" (Kimmel, 2007, xii). In conceptualizing three levels of scripts that can be internalized or *revised*, the theory of sexual scripts, "facilitates a view of disabled people as active subjects, architects and negotiators of their sexual and gendered selves, and the meanings attached to such experiences" (Liddiard, 2018, p. 31). Together these three levels of scripts help to unpack the complex relationship that exists between interaction, social structure, and individual agency.

It is important to note that sexual scripts are gendered and dispersed in an uneven and inequitable way. For example, disabled people can be prevented from accessing parts of or all of a sexual script (Liddiard, 2018; Dune and Shuttleworth, 2009). As Liddiard argues, "if sexual scripting is based on a notion of normative (gendered) sexual socialization or the learning of sexual behaviors mediated through normative bodies, encounters and interactions, then it is likely that disabled people may have been denied access" (2018, p. 33). This denial is the result of hegemonic scripts that marginalize disabled sexualities by perpetuating normative understandings of sex as a heterosexual activity, spontaneously occurring between two able and unassisted bodies and ending in genital orgasm and/or reproduction. I argue that many of the dominant sexual scripts that are available within our culture have not been 'written' with disabled people in mind and thus many participants found themselves excluded by dominant constructions of sex and sexuality. This is problematic on number of levels, but particularly because "without the proper elements of a script that defines the situation, names the actors, and plots the behavior, nothing sexual is likely to happen" (Simon and Gagnon, 1974, p. 19).

Even though dominant sexual scripts have not been written with disabled people in mind, the theory of sexual scripts can still be usefully applied to their lives. Importantly, individuals are both actors of scripts and "agent[s] of their formulation" (Dune and Shuttleworth, 2009, p. 99). With this in view, those who are marginalized by hegemonic sexual scripts can reject, negotiate, and revise scripts so that they are better suited to their lives and experiences. Thus, the theory of sexual scripts allows for an exploration into if and how dominant sexual scripts apply to the lives of participants involved in this study. Moreover, it allows for an investigation into the ways that participants internalize and edit sexual scripts. Within this study, the ability to challenge dominant ideas of sexuality was central to participants defining their sexual lives as fulfilling and enjoyable, an issue that I explore in the following chapters. Ultimately, I have opted to make use of an interactionist understanding of sexuality because it "permits a more nuanced analysis of how sexual scripts emerge, evolve and change and are sustained culturally, interpersonally and subjectively, and allows for individual agency and variation without assuming voluntarism" (Scott and Scott, 2010, p. 15).

In conclusion, in this section I have argued that a symbolic interactionist approach is well suited to the goals of this study and that the theory of sexual scripts can be productively applied to the sexual lives of the participants involved in this study. While a Foucauldian conceptualization of sexuality can be productively used to investigate how sexuality is regulated and controlled, it does not allow for a nuanced understanding of everyday processes of meaning-making or the role of individual agency. In light of this fact, I have chosen to adopt a theoretical approach that makes room for individual agency and interpretation. In this chapter I have also argued that dominant sexual scripts are "heterosexual, private, ideally reproductive and above all autonomous" and that these scripts can serve to marginalize disabled people (Shildrick, 2009, p. 70). Yet, I also contend that disabled people have the ability to 'change the script'. Furthermore, it may be the case that the sexual activities and opportunities of disabled people remain largely 'unscripted'. It is at this juncture that I situate my research and inquiry into the sexual lives of disabled people. In the following chapters I discuss the scripts that participants make use of in their everyday lives and unpack the ways in which they internalize, write, and revise these scripts. Specifically, I work to answer my original research questions and discuss the strategies that participants used to actualize and express their sexual selves.

CHAPTER 5

Findings - Identifying Barriers to Opportunities for Sexual Expression

"I had scheduled a Pap smear at a clinic new to me, on the eighth floor of the hospital at the center of the Arizona Health Sciences Center. In this building, I can't reach higher than the '3' on the elevator buttons, so I must make sure someone else gets on with me. When I arrived at the clinic, the doors weren't automated: another wait till some other woman came along. The counter was too high for me to reach the sign-in sheet – so high, in fact, that I couldn't see the receptionist to ask for help. After a thirty-five-minute wait, a nurse escorted me into a windowless cubicle with a standard examining table, although I had specified when booking the appointment that I required a model that can be lowered and tilted. 'I can't use that', I said. 'You can't?' She sounded skeptical and slightly aggrieved. 'No, my legs are too weak to climb up. That's why I use a wheel-chair" – Nancy Mairs, American author and disability rights advocate (2009, p. 3).

Introduction and Chapter Overview

In this chapter, I explore the various ways that participants created, negotiated, and maintained opportunities for sexual exploration and ostensibly, sexual pleasure. This chapter offers answers to the research questions that guide this analysis, namely, how do participants access opportunities for sexual expression and what barriers influence their experiences? A thematic analysis of the interview data shows that participants had difficulty accessing opportunities for sexual pleasure and encountered similar barriers to sexual expression. Specifically, my analysis reveals that participants consistently identified certain contexts as particularly challenging to navigate and as inhibiting their opportunities for sexual expression. Additionally, analysis illustrates that participants developed a number of different strategies in order to deal with and better navigate these contexts. These strategies were not always successful and were deployed in different ways.

I begin this chapter by identifying the contexts and social situations in which participants experienced the most difficulty accessing and expressing their sexual selves. In particular, I focus on two areas identified by participants; sexual education (both formal and informal), and medical and clinical settings. These contexts often exacerbated participants' experiences of desexualization, and in some cases put restrictive limits on their sexualities. I start here in order to identify the particular factors that influenced participants' opportunities for sexual expression, specifically practices that worked to limit their sexual expression, and to illustrate recurrent themes within the data. In the following chapter, I turn to explore how participants negotiated and maintained opportunities for sexual expression amid this desexualization by identifying strategies that they deployed in order to express their sexuality and agency. In particular, I examine how the participants worked to correct the assumptions and practices that served to marginalize and desexualize them. Altogether, the following two chapters seek to provide answers to the research questions that guide this study, to illustrate themes within the data, and to explore some of the tensions between occupying an identity that is routinely desexualized and the reality of being an agentic individual with wants, needs, and desires.

Disabling Contexts

The participants in this study acquired information about sex from a variety of sources and in diverse contexts. For the most part, participants learned about sex from parents, peers, educators, medical health professionals, and from the internet. However, participants were quick to note how difficult it was to access information about sex, particularly information that included or addressed disabled people. Most were denied information altogether and the contexts in which people usually acquire knowledge about sex were consistently characterized as particularly challenging to navigate. For instance, the participants often noted that their experiences of formal sex education across different educational settings were fraught with exclusion and embarrassment. Similarly, many participants discussed how they were routinely denied informal sex education or conversations about sex within their peer and family groups.

While conversations regarding sex can be uncomfortable for any individual, the participants' narratives made it clear that some of the traditional spaces where people acquire knowledge about sex were not only off-limits, but could actually function to heighten the discrimination, desexualization, and alienation that they experienced. For example, in addition to being denied forms of sex education, the participants were often excluded from activities and spaces that are associated with dating and sexual activity (e.g. parties, dances, bars, etc.) due to negative attitudes or issues with accessibility. Additionally, the analysis of the participants' narratives showed that the spaces where people usually receive sexual health information and care (e.g. STI testing, pap smears, etc.) generally worked to restrict their opportunities for sexual expression. Finally, the participants regularly discussed how their interactions with personal attendants and other medical health professionals tended to promote or intensify feelings of desexualization and inadequacy. In the following sections I identify some of the barriers that negatively influenced opportunities for sexual expression and unpack some of the consequences of being denied information and activities that can be essential to sexual exploration and expression.

Formal Sex Education

In many instances, the participants discussed their unfortunate experiences of being denied formal sexual education altogether. Of the twenty-four participants, nine received no formal sexual education. These participants were precluded from formal sex education for a number of different reasons and expressed that their lack of formal sex education left them feeling unprepared and as though their bodies and sexualities were inadequate. Indeed, one of the participants, Daphne, a queer woman with cerebral palsy discussed how she did not receive any formal sex education throughout her adolescence. In this instance, her parents made the decision to remove her from her school's sex education program. Daphne felt that this decision was based upon her parents' religious beliefs and noted that her younger sister was also removed from formal sex education. However, Daphne's older brother was not removed from sex education. During our discussion, Daphne lamented how her exclusion from sex education contributed to her being thought of as "weird" and perhaps even as nonsexual amongst her peers. The fact that Daphne's older, non-disabled brother was allowed to attend formal sex education indicates that her parents' expectations were deeply gendered. I suggest that the decision to deny Daphne and her sister sex education worked to reinforce gender stereotypes that position men as the instigators of sexual activity and women as disinterested and passive recipients. Moreover, the decision to deny Daphne formal sex education functioned as a barrier to her sexual expression. Fortunately, Daphne was able to find information regarding sexual health and activity through using the internet, and in doing so, she forged a route around the barriers that were erected by her parents.

> **DAPHNE:** *Little did they know, they couldn't keep me from that stuff. I mean, they tried but I was curious from a young, young age (laughs). I just literally used my phone to find info online. I was so hungry for information, like so interested. I found some good stuff too. A couple blogs and sites run by disabled folks. I didn't*

> *have data so I had to be careful where I got signal from because some places would block sites with any provocative stuff on them, but for the most part it [the internet] was like my go-to.*

In the passage above, Daphne expresses her interest in matters related to sexuality and sex 'from a young age' which counters ideas that disabled people are uninterested in sex. Moreover, by transgressing her parents' wishes, Daphne asserted her agency as a young disabled woman, thereby rejecting some of the gendered expectations of her parents and society. Despite being denied formal sex education in school, Daphne developed strategies to access information about sex that aided in her sexual expression. Daphne was certainly not the only participant to develop strategies for sexual expression, nor was she the only participant to reference the importance of the internet in accessing information, a theme that I focus on in the following chapter.

While Daphne could work around some of the limitations placed on her ability to acquire information related to sex, others were not able to do the same. The small number of participants who grew up or lived in institutional settings (n=6) were afforded even fewer opportunities to explore matters related to sex. These participants expressed how an institutional setting worked to limit their opportunities for sexual exploration while intensifying experiences of both isolation and desexualization. The impact of institutionalization was highlighted by Kathy's narrative, a woman in her fifties who lived most of her childhood and teenage years within an institution and was refused any information related to sex. Like Daphne, Kathy was denied information related to sex. Yet, unlike Daphne, Kathy alluded to how living within an institution posed a number of additional barriers to obtaining information about sex, and in doing so, restricted her opportunities for sexual expression.

> **KATHY:** *...Like, I grew up in a hospital. I came to [location] at seven to live in a hospital so like it was very different there. My schooling was there up until the end of grade eight and then by high school I still lived in the hospital but I was out in the day to go to school because they didn't have high-school available in the hospital. So, I had this kind of two-world view, right? There was like the world outside which I considered like the real world or the normal world and then this very artificial place (emphasis) that was just all kids with disabilities and that kind of thing. Umm, but I focused on schooling, I enjoyed it because I didn't like the institution at all and schooling was just like something I could sink my teeth into and be a part of. There weren't that many of us that got to go out to go to school, only the those of us that were seen to have the potential I guess to do well in that environment. And so, it was just a handful of kids that ever went, maybe only two or three. You know at school like kids are dating and going out and I*

> *never did any of that in high school. There were like lots of different barriers... like I was in this weird environment so I didn't know what to say if there was someone that I liked or was interested in. Even to think about well how would we go out because like I'm not going to be able to get on the bus or y'know just like logistic things which for another kid the same age as you like they are not going to know what to do so they will just move on to something else.*
>
> **INTERVIEWER:** *I'm wondering, did you have a sexual education program that you went to at either the hospital or the high school? Did they talk about any of this stuff?*
>
> **KATHY:** *Um, at the time that I was there it was actually pretty much taboo. The staff were not to discuss that with the kids. At all. The most that I recall getting in terms of sex education was a nurse gave us pamphlets about what menstruation was. So, that was about it. I don't recall ever having sex ed in high school. Maybe that happened in grade school, which I didn't go to.*

This interchange with Kathy reveals how institutions can regulate the everyday lives and intimate conduct of individuals. Notably, Kathy describes living within two different worlds, straddling a bifurcation of experience in which one world was characterized as "normal" and another world as 'abnormal' and "artificial". The "normal" world was a place that Kathy was routinely denied access to, while the artificial and abnormal world was the place in which she was confined. It is evident that Kathy sought to separate herself and assert her identity as distinct from the institution by focusing on school, a place located within the "normal" world. This effort to separate herself could be seen as a strategy to counter some of the objectifying and homogenizing treatment she experienced while institutionalized.

Kathy asserted that the staff were instructed to keep matters of sex from her and the other people who lived in the institution, highlighting how institutions can "purposefully destroy opportunities for disabled people to find sexual partners or to express their sexuality" (Siebers, 2012, p. 45). This mandate implies that, to provide a disabled person with information about sex is to expose them to danger, or conversely, to potentially put other people at risk. Importantly, Kathy's comment regarding "logistics" and that other kids would "just move on to something else" captures some of the broader themes within the dataset. One of these themes centers around issues of inaccessibility and the other relates to negative attitudes about disability and sexuality. The participants routinely expressed concerns regarding inaccessible infrastructure and consistently identified other people's attitudes as barriers to their sexual expression and exploration, two themes that I explore later in this chapter.

Like Kathy, other participants also recalled painful memories of being denied and excluded from formal sex education. Many of these participants noted that sex education in their school system was part of a physical education curriculum, from which they were exempt on the basis of their disability. This meant that their sexual education was not only overlooked, but in many cases denied. For instance, Tammy a woman in her twenties with a spinal cord injury characterized her sexual education as something that was "swept under the rug".

> **TAMMY:** *They just never mentioned it. Swept it under the rug.... like I wasn't even there. Well, it was like, I was exempt from gym class and that's where they talked about that stuff and did that unit or whatever. I thought maybe they would make arrangements for me to attend but nope.*
>
> **INTERVIEWER:** *Did you ever try bringing that to anyone's attention and let someone know that you had been overlooked?*
>
> **TAMMY:** *Oh yeah, like I mentioned but no one was interested. It was all like 'oh, we will look into that' and they never mentioned it again. I knew better than to press the issue, I mean, it was just lip service, it was obvious they thought it was not stuff I needed to learn. I don't remember exactly what I said to my teacher at the time but I remember how red-faced he got when I asked him [scoffs and laughs].*

Tammy's experience illustrates an intentional disregard for her sexual education rather than an innocent omission. The fact that Tammy addressed her lack of education to her educators should have been cause for change. Instead, the educators willfully ignored the issue. In fact, when Tammy broached the issue with an educator, he was embarrassed, thus signaling an apparent discomfort with disability and sexuality. In this instance, the comfort of educators was prioritized beyond the education of students. Moreover, in this instance, Tammy's gender identity and age are important factors to be considered. Since Tammy was a young woman, she was perceived as too young to know about sex, and the male authority figure sought to shield or 'protect' her from this information. Unfortunately, Tammy's experience of being ignored was common among other participants and has been identified as a discriminatory factor in other research on sex education among disabled people (see Löfgren-Mårtenson, 2012; Treacy, Taylor, and Abernathy, 2017).

When participants *did* receive formal sex education many noted that the curriculum was inadequate, abstinence-based, and steeped in heteronormative attitudes. Participants routinely expressed that the sexual education they received was irrelevant to their bodies. In particular, they discussed their concern and regret regarding the fact that people with disabilities and LGBTQ+

folks were rarely, if ever, acknowledged within formal sex education. After discussing the level and type of sexual education that participants received, I would then ask them if they felt as though the education that they had received (if any) was applicable and useful. The responses that I received suggest that the vast majority of the participants were not provided with information that could be considered sufficient or useful. Moreover, participants' experiences with sex education left them feeling invisible, ashamed, and unprepared.

> **BRITNEY:** *Sex ed in my opinion was way too conservative and for people with disabilities, we don't necessarily fit into the guidelines that we were given. There were a few things where it was like 'I can't do that'. Like, there was this guy in a wheelchair in my sex ed class who was like 'how am I supposed to flop on top of the chick if I can't feel my legs' (laughs). So, we were kind of like in the same boat, we just chilled out at the back of the class. And at school everything on the computers was blocked, so even if we wanted to find out information that actually worked for us we couldn't. It wasn't until like 10th grade when I got my laptop at home and started to Google some of this stuff, and then got in trouble with my mother (laughs) cause she looked at my history.*
>
> **BRENNA:** *Yeah! I mean, gender should have been addressed. Sexuality should have been addressed. It never was. It was so cut and dry and it was always, you know, straight! It was never about gay sex or lesbian sex with many partners it was very hetero, very conservative, probably even homophobic when I think about it...I mean, thankfully it wasn't like you need to get married before. It wasn't um, (pauses). What's the word? Sustaining? Abstinence! (laughs) It wasn't anything like that but it certainly didn't address all of the identities in the room, like mine. It sucked, really.*
>
> **JOCELYN:** *It was like, where was my body? I just didn't see myself. But, then again, at the time I don't think I thought about it like that. I was just like 'oh this is sex ed' and I am not normal so I don't get it or whatever. Just another thing that didn't apply to me. I don't think I realized how much information was lacking until I got older. It is a shame. I mean, it was a shame. Actually, I guess I (emphasis) was shame.*
>
> **RYAN:** *If you want to call it education, yeah. I mean, I had basic education. Although, from what I recall it was mostly like 'these are all the diseases you can get! Don't get them! You know how you know you don't get them?! You don't get them by abstaining from sex!'. Which is true in a sense, but ineffective. I mean it just didn't work.*
>
> **MARK:** *Honestly…I got the message that sex was something that only able-bodied people did. I mean, I am amazed I was even included in that section of health class but like, looking back, I had questions that went unanswered. I didn't ask any of them cause I was way too embarrassed but yeah...I guess, in a way I'm glad that I*

> *was included but it was essentially just a waste of my time. I mean, look, I won't ever be able to put a condom on without help, I know that. They don't teach that stuff in sex ed, they just don't. Or at least they didn't when I was in school.*

These excerpts exemplify some of the different challenges associated with navigating a formal sex education. More pointedly, these excerpts illustrate the ways that exclusion and omission can heighten feelings of insecurity. Jocelyn's characterization of herself as "not normal" and as the literal embodiment of shame indicates, that she felt that it was *her* fault that the curriculum did not apply to her. In other words, since Jocelyn did not see representations of disabled people in her sex education curriculum, she internalized the oppressive idea that sexuality was "just another thing that didn't apply" to her. Jocelyn's experience reveals that when "disabled children or adolescents receive negative messages about their sexuality from trusted authority figures it is likely that these will be accepted as truth" (Shakespeare et al., 1996, p. 19).

In Mark's case, there was a failure to provide him with the most basic information about how a person with his impairment (spinal cord injury) might practice safe sex. This narrow focus on non-disabled bodies subsequently led Mark to feel as though "sex was only something able bodied people did" and that time spent in sex education was "wasted", a sentiment that was common among other participants. The exclusion that Jocelyn, Mark, and numerous other participants faced in formal sex education promoted a sense of inferiority, insecurity, and shame. Ultimately, those participants who did receive some form of formal sex education were subjected to attitudes and curriculum that neglected their bodies, sexualities, and identities.

When the participants who became disabled later in life were asked about the type of formal sex education that they received they noted how it would have benefitted them to have had information that reflected the lives of people with disabilities.

> **JOELLE:** *I mean, looking back now, it would have been great to have had more inclusive sex education. I had to do a lot of work to get to know myself in that way again, like what worked and what didn't after I became disabled. I've had to find new ways to be sexy and to feel sexy. Maybe if they had of included some material on what it is like to have sex as a disabled person then it wouldn't have felt like such a battle.*
>
> **SHANE:** *We had just finished up a unit on sex ed a few months before I got injured and when I got out of rehab and went back home I had a lot of time on my hands. One day I came across my binders and school stuff and saw some of that material and I was gutted. I put it away instantly and I can remember being pissed. I was angry a lot during that time so maybe it wasn't about the material or sex ed*

> *but I definitely had a moment where I questioned why they never talked about people who were like sick or disabled…like at all. Not just in sex ed did they forget but I can't remember any discussions about disability in other classes either.*

> **THERESA:** *Well, they didn't touch on disability…at least not that I can remember. But, I guess at the same time I wouldn't have been aware of it. I think that like when you don't have a disability or don't have some sort of personal connection with it you are just unaware and just don't have a reason to care about it. That was kind of me like before the accident…ah, so yeah, they didn't touch on disabilities and it makes me wonder how many kids in the sex ed class had either an invisible disability that they were wondering about or like somebody with a disability cause like yeah…it implies that we aren't sexual beings you know?*

These participants, therefore, were able to reflect upon their experiences with formal sex education and expressed concern over the fact that information about disability and sexuality were not provided. On the one hand, many participants lamented the fact that they had not been supplied with adequate information and on the other hand, some acknowledged that it was not something that they had really thought about. In Shane's case, he recalled painful memories of realizing that he would have to reinterpret the information about sex that he had just been given in light of his new embodiment. Shane's experience was unique because he was placed in a position in which he had to counter the assumptions he recently internalized via formal sex education. So, in addition to having to navigate his teenage years while adjusting to his new embodiment, Shane had to simultaneously deal with the fact that he was not provided with information that was applicable to his life.

Only one participant had experiences with sexual education in a formal setting that could be characterized as positive. When I asked Mick about the sex education that he received and whether it suited his needs he shared that he had a positive and rather formative experience.

> **MICK:** *Um, I was actually really fortunate, when I took sex ed. Um, we had this teacher, she was a former art teacher. Very much a hippy and so she had an awesome take on sex. She was saying words like penis and vagina and intercourse before you were allowed to in school. She talked about safety but she also talked about pleasure and like accepting different people and sexualities and bodies. So, it was really cool to have that and I think that's probably like what started my views of sexuality now. So, I was fortunate that way.*

Mick's response highlights the importance of having, not only access to information about sex, but also the importance of addressing different sexualities and embodiments. While Mick's experience was fortunately a positive one, it was also an exception to the rule. The overwhelming majority of participants involved in this study received either no formal sex education or sex education that was insufficient to their needs. The participants who received sex education were subject to a curriculum that was rooted in ableist and heteronormative understandings of sex. The lack of sex education and outright denial of sexual education to people with disabilities has been well documented within the literature on this subject (see Löfgren-Mårtenson, 2012; Treacy, Taylor, and Abernathy, 2017; Bahner, 2018). The implications of not receiving sex education can be wide-ranging and profoundly negative. For example, Hollomotz (2011) and Shakespeare (2014) have documented how failing to provide sexual education to people with disabilities is related to paternalistic attitudes that position disabled people as vulnerable and nonsexual. As these scholars show, the lack of an adequate sexual education can actually increase chances of sexual assault and victimization, paradoxically making people with disabilities more vulnerable to predation. More generally, inadequate sexual education can also lead to higher rates of sexually transmitted infections and increased instances of unplanned pregnancy (Cotter, 2018). Finally, as the participants' narratives illustrate the failure to provide disabled people with adequate formal sex education negatively impacts their opportunities for sexual expression insofar as it compounds experiences of shame and isolation by reinforcing the expectation that sex occurs between two non-disabled heterosexual persons (Shakespeare et al., 1996; Liddiard, 2018). Deviating from the expectations embedded within this 'hidden curriculum' often caused the participants to feel frustrated, ashamed, and anxious about their sexual prowess and potential.

In the following section, I move on to discuss difficulties associated with accessing information about sex in informal settings. I focus on informal discussions about sex and relationships in order to illustrate how these contexts posed challenges to participants' sexual exploration and expression. Specifically, I point to the ways that participants were isolated from engaging in informal discussions and activities that surround sex and then discuss how this negatively impacted their opportunities for sexual expression.

Informal Sex Education

The informal sex education that participants received usually occurred during discussions with peers and parents, through consuming media, by observing others, and finally, through use of the internet. Like formal sex education, participants were often prevented from accessing informal sex education and their experiences of informal sex education were fraught with barriers, exclusion, and shame. For example, participants routinely noted that information related to sex was not something that other people (e.g. peers, family, etc.) were willing to discuss with them. This caused participants to feel as though they were "missing out" or as though they were "left in the dark".

> **COURTNEY:** W*hen I rolled up they all just shut up and I could tell that they had just been giggling about so-and-so and going on about their latest boyfriends. I don't know if they thought they were doing it to be kind and to like not hurt my feelings but it stung a bit. Like, what? Can I not talk dirty? Can I not dish? I've got shit to share!*
>
> **JOSH:** *We never really talked about that stuff in our house. My parents weren't overly strict or anything like that, they just didn't go there. Maybe they did with my brothers but I was left in the dark.*
>
> **NADIA:** *You feel like you are missing something that other kids are into and so that was probably a source of angst or discomfort. And that affected me feeling just like 'oh what's wrong with me? Am I ever going to meet somebody that I'll click with', you know?*
>
> **ANNE:** *...I have been with a group of friends or something and they go around the table and just ask everybody y'know like what are you doing now? Like, are you in a relationship? That kind of stuff and a lot of times I will be passed over, like they don't really ask me and I am like, well why wouldn't you ask me the same question. It is almost like they don't expect it of me.*

These passages illustrate common concerns that many participants experienced and some of the barriers that they would encounter. For instance, Courtney and Anne were excluded from informal discussions about dating and 'gossip' by a group of peers, an issue that many participants dealt with. Being excluded from informal discussions about sex was a painful experience which meant that participants often missed out on opportunities to learn about sexual scripts and were unable to participate in important social processes that surround sexuality. I suggest that an unwillingness to discuss issues related to dating or sex with disabled people should be considered a barrier to sexual expression insofar as it often prevented participants from engaging in or learning from interactions in which sexuality is performed and discussed. Moreover, Nadia's worry that she was missing out on important activities and information caused her to feel as though there was something wrong with *her*. The fact that she was left out of activities and discussions about sex intensified her worry that she might never find a romantic or sexual partner. Like Nadia, many participants expressed their concerns over finding a partner and discussed times where they felt as though it was their fault that they were excluded from informal discussions or activities related to sex. Similarly, participants discussed how they once entertained fears over being a "late bloomer" and felt "different" or inadequate for not engaging in sexual activity as early or as often as their peers.

Fears and insecurities around finding a romantic partner or engaging in sexual activity were often exacerbated and in some cases affirmed by peers, parents, and authority figures like teachers or medical health professionals. These fears were affirmed when participants were instructed to "not think about it", that dating and sex were "not something you need to worry about", or that they shouldn't get their "hopes up". Statements like these sent participants the message that having sex was not something for them and that their sexuality was perceived as unviable, incompetent, or damaged. Messages like these could be harmfully internalized by participants and in turn reinforced the resounding belief that disabled people are not and should not be sexual. When participants were asked to discuss if they felt as though any expectations had been placed on them in terms of their romantic and sexual opportunities many expressed feeling as though they were subjected to assumptions that desexualized them.

> **BRITNEY:** *I remember going to my mom and telling her about a crush in like junior high and I mean I didn't expect her to be super encouraging about it, that's just not her…but like, she really burst my bubble. She first tried to be soft about it and said something like 'he's a nice guy, why not just be friends', but eventually she just kinda came out with it and said like 'don't put yourself up for that rejection'. She could have been right but I mean, that sucked. I didn't expect her to offer to chaperone a date but I didn't expect her to basically tell me I had no chance either.*
>
> **MARK:** *All the guys were talking about their weekends or whatever and going out to the bars. I wasn't part of the conversation really, I was off doing my own thing but I overheard them talking and one of them said something like, 'you think he's getting any' and laughed. Fucking dicks.*
>
> **ANNE:** *I don't think my parents see me as sexual, no. Like, they love my sister's boyfriend and are so interested and I guess like invested (emphasis) on them having kids. I'm sure that's a lot of pressure for them [participant's sister and partner] but it would be nice to think that they cared about my (emphasis) relationships and maybe me having kids someday or just like thought of me in that way, you know?*

> **COURTNEY:** *Yeah, well the funny thing is that people don't even expect me to have sex, they are like can you even have sex? Can you have babies? So, that's the first thing. People assume my boyfriend to be somebody who is disabled or not attractive, like so many (emphasis) women in my life, not friends, but like other people, like a girl at my old work she was like 'oh my god, I saw a picture of your boyfriend and he is hot!' Like, she is shocked that he is actually this built guy and that he is not in a wheelchair. And you know, people assume that stuff so much.*
>
> **RICARDO:** *...people judge me based on all of these paradigms around inability and they automatically assume what I can't do, nobody is asking what I can do (emphasis).*
>
> **JIM:** *People definitely think of you differently, they don't automatically think you are a sexual person and that, you know...it's almost like it's just stripped away. It is almost like people think, 'oh their disability is so overwhelming to them that they wouldn't even think of that stuff, that they wouldn't even be interested in that kind of stuff. When you have a disability, like, it tends to almost be the last thing on your mind, like, I don't think every day like 'oh my god, I'm in a wheelchair'. I mean it just becomes a background thing and you don't think about it until you're at a set of stairs and you can't get up or something y'know?*

These informant experiences exemplify some of the desexualizing assumptions that participants encountered in their everyday lives. These assumptions posed barriers to the sexual expression of participants by placing them in a position in which they had to account for or 'prove' their sexual viability. For instance, in Courtney's experience she was routinely perceived to be unable to engage in sexual activity and as not sexually desirable. In addition, as her narrative implies, if Courtney was to find a partner, it was assumed that her partner would be unattractive or disabled. The fact that Courtney was subjected to the incredulous questions and desexualizing assumptions of people that she had little to no relationship with is indicative of the voyeurism that many disabled people regularly experience (Shakespeare et al., 1996; McRuer and Mollow, 2012; Siebers, 2012). Shakespeare et al. (1996) confirm that, "disabled people face a considerable amount of curiosity and voyeurism as to their sexual lives", an issue that I return to in chapter seven (p. 66).

In Britney's case, her optimism and infatuation was quashed by her mother's perception of her sexual viability and by her intent to protect Britney from potential rejection and/or romantic activity. Regrettably, Britney's mother assumed that her daughter would automatically be rejected by her romantic interest, further signaling her doubt in her daughter's ability to find a partner. Interactions like this left participants feeling as though those closest to them felt that they were undesirable and/or unfit for sexual relationships. Moreover, these interactions and negative assumptions could contribute to participants' own struggles with self-esteem and often fostered doubts about their sexual opportunities and abilities.

Like Mark, other participants were bullied on the basis of sexuality during their adolescence and sometimes into their adulthood. For instance, a participant who was paralyzed on one side of her body recalled being teased "a lot" in middle school because she was "stick thin, like 90 pounds soaking wet", and because she had a "huge bump" by her ribcage. This participant told me that she was called "four boobs" by other students in her middle school. Like other participants who experienced bullying in regards to their bodies and sexualities, this participant was saddened, frustrated, and angered by this type of treatment. Teasing people with disabilities about their sexualities is an issue that has been problematized in other research (Duncan, 2013; Kattari, 2014), and is recognized as a central way that people with disabilities are "discounted as sexual by peers" (Duncan, 2013, p. 113). While many non-disabled individuals also encounter experiences of bullying in adolescence, Duncan (2013) argues that the motivations for bullying disabled people on the basis of sexuality differ. He suggests that disabled people are not bullied because they are "competitors for the desired popular status" but rather because they are "symbols of 'the Other': that which the subject fears because of contamination, infection, or association" (Duncan, 2013, p. 116). Overall, participants' narratives suggest that ableist attitudes about disability and sexuality were one of the most persistent and challenging barriers to sexual expression that they experienced.

Inaccessibility

In addition to being denied informal conversations about sex, participants were often prevented from accessing spaces where activities related to dating and sexual activity occur. Social spaces such as bars, theatres, and restaurants, as well as events like parties or dances were often inaccessible to participants. Many of the participants discussed how inaccessible infrastructure and transport systems presented a substantial barrier to their sexual expression. Specifically, the participants who experienced the most significant issues with inaccessible infrastructure were wheelchair users and the participants who lived with impairments that significantly limited their mobility.

> **TAMMY:** *I was social and everything but there were barriers. I got invited to stuff, but like the big thing at my school was beach parties which I couldn't go to because I couldn't get down the cliff. I guess that if you never go people stop inviting you after a while. And that kind of goes into your adulthood like if you are not used to being at parties, going to bars, things like that, and if you then get the chance to do them you really don't have that life experience to know how it works and like what to do, like, yeah.*
>
> **BOWIE:** *Bars, completely inaccessible. Completely inaccessible. Just inaccessible (emphasis). [City name]'s gay scene, totally inaccessible. Some doctor's offices, inaccessible. Ah, the most accessible place for me to be sexual is the internet. I know that sounds weird, but it is true.*
>
> **KATHY:** *My husband and I have to really think about where we will go for a date or if we are just planning to go out with friends. A lot of places are not accessible to someone in a chair and we can't go just wherever we want. With that said, through trial and error we have found some really great spots for date night, it just took a bit of extra effort.*
>
> **MICK:** *I frequent the [bar name] a lot and that is a really hard place, like I even find for myself that going up the stairs there is literally no accessibility to that place. But I mean, I dunno, it is a tough thing to deal with. Like I worked at [location] last summer and another employee had cerebral palsy, fully wheelchair bound, like electric wheelchair and it was very interesting. The way it worked was, you go out for a week and come back for the weekend and she would take an accessible bus to and from. The bus was there for everyone but it had a wheelchair lift. But um, one of the favorite things of like all employees was to stop at this store to grab a beer, there is a little liquor store on your way back to the city so, stop, grab a beer, smoke a joint, hang out, you know, like debrief from the week. She never got to do that because the bus didn't stop there. We all had rides, so, like things like that.*

These passages exemplify the central concerns that the participants experienced with issues related to inaccessibility. As the participants' accounts indicate, inaccessible infrastructure and transport systems prevented the participants from interacting with or even observing people in spaces where activities associated with romance, dating, and sexual activity can occur. For example, Mick's coworker was prevented from "hanging out" and accessing social engagements that involved the opportunity to bond with others and be involved in jokes, games, and gossip. Similarly, Bowie was unable to access nightlife and certain aspects of the local "gay scene" which meant that he had to create other ways to access opportunities for sexual exploration and the gay community. Finally, Tammy notes that the negative implications of being excluded from activities associated with dating and sex during adolescence continued into adulthood. As her narrative indicates, not having the chance to participate in social processes surrounding dating made participants feel unsure about how to act within these spaces and could prevent them from exploring these spaces and social processes later in life. Ultimately, in many cases, participants were denied access to and thus dislocated from the dominant discourses and social processes that surround sex and romance. Alas, even if participants were able access a space like a bar or club, they still encountered negative attitudes about disability and sexuality. As Ricardo expressed, "Even if there is a place that is physically accessible, the attitudinal barriers are still there, the next hurdle is that".

Overall, the participants' accounts support the notion that most disabled people are "excluded from most of the dominant socialization processes that help teach and prepare people for love, sex, and intimacy" (Davies, 2000, p. 181). Data analysis showed how the participants routinely dealt with a lack of adequate information and education regarding sexuality, negative attitudes that desexualize and stigmatize people with disabilities, and issues with inaccessible infrastructure and transport. As a consequence, the participants were often denied opportunities to learn about dominant sexual scripts. When participants *did* access opportunities, they were subjected to scripts that omitted their experiences. Similarly, participants were subjected to scripts that position people with disabilities as not sexually viable and as undesirable. For example, sexual education (or lack thereof) tended to reinforce dominant sexual scripts that define sex as an activity that occurs between non-disabled people. This kind of sex education perpetuated sexual scripts that have not been written with disabled people in mind and thus precluded people with disabilities. As I have shown, contexts in which people acquire information and experiences that relate to sexuality were difficult to navigate and sometimes off-limits for the participants involved in this research. Significantly, it was often through interactions with other people that participants experienced the most acute desexualization. Although the attitudes behind these actions may be upheld by mandates, codes of conduct, policy, and law, the participants' narratives made it abundantly clear that interactions with others had the potential to validate or invalidate them as a viable sexual being.

In the following section, I explore how medical and clinical settings functioned as contexts that could heighten the desexualization that participants experienced. In particular, I unpack how interactions within medical and clinical settings often posed barriers to participants' opportunities for sexual expression and exploration. In addition, I discuss how participants who had routine contact with personal attendants or care workers faced a different set of barriers to opportunities for sexual expression.

Experiences Within Medical and Clinical Settings

Contexts that involved interactions with doctors, physiotherapists, personal attendants, and other medical professionals posed both direct and indirect challenges to the participants' opportunities for sexual expression. Interactions within these contexts were significant for as Wilkerson (2002) argues, medical discourses have the ability to "shape not merely our sexual options but a sense of ourselves as sexual beings, and ultimately our very identities for ourselves and others" (p. 34). One of the most common challenges that arose within these contexts was that participants were not offered information about sexuality or sexual health. When I asked the participants to discuss the quality of sexual health care that they received they routinely noted that medical health professionals rarely initiated discussions related to sex. The onus to address these topics therefore fell on participants and many of them felt ignored, uneducated, and embarrassed. These constraints often led them to refrain from raising issues related to sexuality, to limit the number of questions they asked, or to find the information that they needed elsewhere.

> **LILITH:** *I was never asked if I needed birth control or if I was having sex. I think he just assumed that I didn't need it and that I wasn't. Of course, I actually did (emphasis) need birth control, and I did end up getting it but it was something that I had to address. And like, who knows? Maybe he didn't bring that stuff up with his other patients either, I dunno. You really have to be your own advocate in the system.*
>
> **TYLER:** *After my accident, I wanted to talk to someone about those issues, someone who might have some answers for how I could adapt my, y'know, like, my sex life. And it was hard to find someone who was willing to talk, let alone anyone who could point me in the direction of information that actually worked.*
>
> **KATHY:** *When I asked about how my condition might affect my pregnancy my family doctor told me that he really wasn't sure if he could speak to that. He was nice enough about it and seemed like he wanted to help, but essentially what he told me was that kind of stuff would have to wait until I got booked in with a specialist in the city.*
>
> **SHANE:** *I remember asking them [team of doctors] how I might work around it [participant was experiencing issues with erectile function and could not take prescription medications like Viagra], they were just kind of like 'well, you might*

> *just have to learn to deal with it'. And yeah, for sure, they are right, but like how? That's what I'm asking here. Y'know?*

The fact that medical health professionals did not routinely broach topics related to sex suggests that the sexualities of participants were invisible to or denied by many medical health professionals. As Lilith's narrative indicates, participants were assumed to be nonsexual and had to advocate for their sexual health needs within a system that often failed to provide them with adequate care. Kathy's difficulty accessing information about her pregnancy has been identified in other research that highlights how "the reproductive journeys" of disabled women who have children are "strewn with social barriers of an attitudinal, ideological, and material kind" (Thomas, 1997, p. 630). Like Kathy and Tyler, the participants routinely experienced difficulty and delay when they attempted to find information about sexual health or how their impairment might affect their sexuality. Similarly, many found it hard to find medical professionals that were well versed in these topics. The lack of discussion and adequate information regarding sex often meant that the participants felt that they were left unprepared for sexual opportunities, and in some cases, uncertain about their sexual health status.

Unsurprisingly, the lack of discussion around sex translated into a lack of sexual health care for some participants. As the informant experiences below reveal, several of the participants were forced to go to great lengths to access standard sexual health services. Deficiencies in sexual health care were further evidenced by the paucity of resources that were available to participants, particularly LGBTQ+ participants. Discussions and resources such as pamphlets or videos were generally framed in a heteronormative manner and tended to focus on the dangers associated with sexual activity. For example, Bowie, a queer man in his mid-thirties, was offered information and resources regarding sex but the counselling that he received assumed heterosexuality. Another example that involved a lesbian participant in her late thirties occurred during an interaction with a medical health care professional in which she was asked about her "husband". While the vast majority of participants highlighted the fact that discussions regarding sexuality and sexual health with medical professionals were uncommon, on the rare occasions that these topics were broached, participants often encountered attitudes that rendered them as nonsexual, heterosexual, or as problematic burdens.

> **BOWIE:** *All they talked about was risks…risk of a person with a disability being raped or abused which is all very possible and true and they should have that there*

> *but they also need to focus on the positives of disability. The pleasure of sex and disability. Disability and sexuality together not disability and risk. Also, the resources they gave were totally hetero. Like, the talk they gave about risk and safety mostly applied to heterosexual people. I had to come out and be like 'hey, I need different stuff here, this just won't work'. They are not doing that and that's where I have a problem with it.*
>
> **THERESA:** *They were trying but I felt like nobody had straightforward answers about where I could go to get tested [pap test]. There just seemed to be a lot of unanswered questions and a lot of separation between the different parts of the hospitals, so I dunno, it was all very strange. It is easier being on your own, away from the healthcare system.*

These narratives illustrate a number of the challenges that participants encountered when attempting to access various forms of sexual health care. Firstly, participants were often unable to access sexual health information and experienced delays in their care. Failure to provide these services posed a barrier to many of the participants' sexual expression and left some feeling as though it was "easier being on your own, away from the healthcare system". As Theresa's narrative implies, some participants would avoid interactions with medical health care professionals because they were so difficult to navigate. This avoidance coupled with a lack of resources and services ostensibly put participants' health at risk. Secondly, the lack of sexual health care negatively impacted participants' opportunities for sexual expression because sexual health care is an essential aspect of sexuality. As such, if one is denied, so is the other. Put differently, being in good sexual health has been shown to "enhance life quality and pleasure, personal relationships and communication, and the expression of one's sexual identity" (Lottes, 2000, p. 9). Finally, the experiences of LGBTQ+ participants illustrate some of the multiple and compound issues that this group of participants experienced in general.

In addition to being subjected to the assumption that they were nonsexual, LGBTQ+ participants often had to work against heteronormative assumptions that reinforced dominant heterosexual scripts. Like Bowie, other gay, lesbian, and queer participants problematized the fact that medical professionals presumed heterosexuality and were frustrated by the rehabilitation resources that were offered to them that were often couched in heteronormative terms. Heteronormativity continues to permeate both medical practices and discourses and is defined by Beagan, Fredericks, and Goldberg (2012) as,

> The powerful interlocking set of assumptions and institutional practices that construct everyone as heterosexual unless shown to be otherwise and that view heterosexuality as the preferred, normal – indeed only thinkable – sexual orientation. In heteronormative contexts, heterosexuality is descriptively normative (statistically "normal") as well as prescriptively normative (p. 47-48).

The heteronormative assumptions that are embedded within most clinical settings forced Bowie to come out as queer and required him to bear any of the negative consequences of doing so. Notably, Bowie's account highlights how disabled peoples' sexualities are constructed as risky and deviant within medical contexts. As Bowie explained, medical professionals failed to focus on sexual pleasure among non-heterosexual couples and did not explore the "positives of disability". Many of the LGBTQ+ participants that I interviewed discussed how they felt as though the medical health system had left them to figure out issues related to sex on their own. They also explained how they themselves were forced to advocate for basic forms of sexual health care that are regularly afforded to non-disabled heterosexual people.

The aforementioned barriers to sexual health care were further exacerbated by inaccessible infrastructure. Specifically, the participants who used wheelchairs and those who lived with impairments that significantly impacted their mobility were the participants that most often cited how doctors' offices and medical health clinics could be inaccessible to them.

> **MARK:** *I had never been tested before and wasn't really sure what was gonna be involved so I made an appointment with my doctor. When I got to the appointment I told the nurse that I was there to get tested and she told me that I would have to make other arrangements because there is no way for me to get out of my chair at the office. Like, it shouldn't be that hard.*
>
> **TYLER:** *…I ended up having to switch doctors because that guy's clinic was in this old building downtown that was not accessible for people in chairs.*

These informant disclosures illustrate how medical and clinical settings were spaces that were not only emotionally difficult to navigate, but in some cases, they were physically impossible to navigate. This finding is supported by existing literature that shows how people with disabilities are excluded from "family planning clinics, sex education, and sexual health" (Anderson and Kitchin, 2000, p. 1164). The lack of accessible facilities reflects social constructions that assume disabled people are nonsexual and as a result, negatively impacts disabled peoples' sexual lives. For instance, Mark was delayed in his quest for care because this particular clinic was not designed with disabled people in mind and was therefore not adequately prepared to handle their needs. Delays in sexual health care negatively impacted participants' opportunities for sexual expression because these delays meant that participants had to wait to learn about their sexual health status. When participants were unsure of their sexual health status or were ill-equipped with sexual health information they were far less likely to seek opportunities for sexual activity. Ultimately, inaccessibility, desexualizing assumptions, and delays within medical and clinical settings not only impeded participants' opportunities for sexual expression, but could also jeopardize their health.

In addition to facing the afore mentioned barriers, participants' experiences of desexualization could be heightened through their interactions with personal care workers and attendants. In particular, concerns about care were most often voiced by the participants who had daily contact with personal attendants (n=9). These participants explained how the attitudes, practices, and even the presence of personal attendants could either facilitate or suppress their opportunities for sexual expression. For example, the participants who required help from attendants to prepare for dates or other opportunities for sexual expression were often denied any assistance. While some attendants were willing to help participants get ready for potential romantic and sexual encounters by applying makeup, shaving various body parts, providing a shower, or arranging transport, other attendants were not willing to do so. The narratives of participants who had daily contact with personal attendants point to the multiple and complex issues that are embedded within these contexts.

> **TAMMY:** *There are times where I need a bit of extra care to help me get ready to go out or to go on a date and sometimes that isn't possible because it all depends on what attendants are working or on call that day.*
>
> **BOWIE:** *Attendant care can sometimes be a barrier because you know hookups generally happen at one in the morning and you don't always know the person and they come over. So, you have to explain to your attendant like 'hey I have a friend coming over at 1am and they will be like 'it's 1:30 what do you mean a friend?' and it's like don't ask questions. So, that's a barrier. Like, I've had friends come over, just friends, and the attendant will like whisper to me 'who is in your house' or 'who's that'. So, it makes you think like how am I ever going to have a partner if you are whispering so weird about it? Like, how could I ever bring somebody long-term into this environment if my care can't get over themselves. And so, like that's what I'm worried about...if I found somebody that I fell in love with or wanted to spend time with or somebody that I just want to fuck around with on a regular basis, whatever it is.*

> **NADIA:** *...typically the attendant care in the community where I live is paid for by the government and it's provided on-site through an agency. So, I don't get a say in who works there. I don't get a say in who comes in, I don't get a say in how the care is administered. I am simply a body to be taken care of and I have to constantly be dealing with that. Ah, in terms of sexuality, well, it is really hard when you say 'oh, I am going to have a guy over'. I want to share that with my attendants so that they know what I am doing in case something went wrong but I often can't because then I know they would be talking to each other and I don't want them gossiping about it. So, I try to keep it very private.*
>
> **JIM:** *I had once had an attendant who was like, 'oh I just don't agree with your lifestyle, but I like you'. I stopped her there and I was like, 'well, actually, that means that you don't like me if you don't agree'. Dealing with her was so awful.*

These narratives exemplify some of the common concerns of participants who had routine contact with personal attendants and care workers. Nadia's narrative is especially troubling as it hints at how her interactions with attendants left her objectified and dehumanized, she felt, "I am simply a body to be taken care of". Notably, Nadia was not able to choose her attendants which indisputably affected her sense of agency and bodily autonomy. Although, Nadia wanted to be open with her attendants about her potential sexual encounters, she also worried about how they might perceive her sexuality. Like Nadia, other participants were often concerned about how attendants would perceive their sexualities and discussed how attendants' perceptions could pose barriers to their sexual opportunities. For example, Bowie worried about how he might have sexual or romantic encounters with attendants who "couldn't get over themselves". In many cases, attendants' attitudes – and what could be labeled a voyeuristic interest in their client's personal lives – prevented the participants from bringing home a sexual partner and thus curtailed their opportunities for sexual expression.

Participants concerns about how their sexualities might be perceived by attendants were not unfounded. In Jim's case, for example, he had to deal with a homophobic attendant that "didn't agree" with his "lifestyle". Fortunately, Jim had more control over his care than Nadia and could secure another attendant. However, this could have been a potentially dangerous situation for Jim and was undoubtedly an "awful" experience. In a similar vein, Tammy was not guaranteed assistance preparing for dates and other social events. In particular, she needed support with her presentation of self, given that she wanted to wear makeup and have her legs shaved for dates (Goffman, 1959). Yet, Tammy was not always provided the assistance she required. This lack of assistance influenced her opportunities for sexual expression by negatively impacting her confidence as well as her ability to express her sexuality, perform her gender, and gain entry into the symbolic systems of meaning that surround sexuality.

Finally, as the informant experiences above suggest, those participants who had daily contact with attendants struggled to a great degree with privacy and the lack thereof. In many ways, their sexualities were more closely monitored than those who lived alone and this monitoring often curtailed their opportunities for sexual exploration and expression. Similar to Nadia and Bowie, these participants had concerns about privacy and yearned for more of it in their everyday lives. However, their living arrangements, impairments, and attendant care did not necessarily allow for any level of privacy. The late artist and disability rights activist, Cheryl Marie Wade, has problematized and frankly discussed the lack of privacy that is afforded to disabled people who need regular care. Wade contends,

> To put it bluntly – because this is as blunt as it gets – we must have our asses cleaned after we shit and pee. Or we have others' fingers inserted into our rectums to assist shitting. Or we have tubes of plastic inserted inside us to assist peeing or we have re-routed anuses and pissers so we do it all into bags attached to our bodies…The difference between those of us who need attendants and those who don't is the difference between those who know privacy and those who don't (Kulick and Rydström, 2015, p.121).

Ultimately, there were differences in the types of opportunities for sexual expression that different groups of participants had and many of these differences stemmed from issues related to privacy and care. Notably, participants who required daily attendant care had fewer opportunities for sexual expression than participants who did not. On the one hand, a lack of privacy inhibited some participants' opportunities for sexual expression. On the other hand, social constructions of privacy can sometimes be utilized in ways that "discourage engagement with the erotic lives of people with disabilities" (Kulick and Rydström, 2015, p. 114). As Kulick and Rydström (2015) show, in some instances the concept of privacy can be invoked at "precisely the moment when helpers [personal attendants] might be called upon to do something positive or helpful in relation to the sexual lives of disabled people" (p. 114). The idea that sexuality is a private matter, "would appear, on the surface, to express respect for the integrity of people with disabilities", yet, framing sexuality and privacy in this way can sometimes erect a "shield or defense" that demarcates the boundaries around what activities attendants are willing to assist their clients with (Kulick and Rydström, 2015, p. 114). While privacy is an important aspect of sexuality that should be maintained, the insistence that sex is a private matter is not always about "accommodating or facilitating a private life as ensuring that such a life never emerges" (Kulick and Rydström, 2015, p. 114).

The lack of privacy within institutions has significantly negative consequences for disabled people's opportunities for sexual expression and exploration. Moreover, this lack of privacy should be considered a serious harm. Wilkerson (2002) has argued that,

> Sexuality is vital, interpersonal connection, personal efficacy, and acceptance of one's body and of self more generally, all goods which might be useful to disabled persons in nursing homes. Furthermore, because one's autonomy is already compromised by residing in a nursing home, the violation of both sexual agency and personal security imposed by this loss of privacy should be recognized as a serious harm (p. 34).

Overall, the stories that the participants shared about their experiences with attendants and medical professionals in relation to sexuality indicated a severe lack of training and awareness about issues related to disability and sexuality. Attendants and other medical professionals are in a unique position to initiate discussions about sex and to provide the care and assistance that is often crucial to accessing opportunities for sexual expression. Yet, participants' narratives consistently described how interactions with medical health professionals could pose numerous barriers to their opportunities for sexual expression. In particular, LGBTQ+ participants, those with mobility restrictions, and the participants who had routine interactions with personal attendants, faced unique and compound barriers. Within each of the above-mentioned contexts, the participants faced barriers as a result of other people's attitudes. I return to these barriers in the final chapter of this thesis and I will discuss ways to mediate some of the issues that the participants encountered.

While the afore mentioned barriers were well-established, they were also not fixed. Fortunately, many participants managed to create ways around the barriers that they encountered and in the following section I discuss how participants worked beyond these barriers. In particular, I explore how participants developed strategies that allowed them to bypass, correct, or subvert some of the desexualizing treatment they experienced.

CHAPTER 6

Findings - Identifying Strategies for Sexual Expression

"But what if disabled people were sexy? And what if disabled people were understood to be both subjects and objects of a multiplicity of erotic desires and practices, both within and outside the parameters of heteronormative sexuality?" – Robert McRuer, American Disability Studies scholar (McRuer, 2011, p. 107).

Strategies for Sexual Expression

In this chapter I explore how participants managed some of the desexualization that they routinely experienced. In particular, I illustrate the strategies that the participants developed in order to access opportunities for sexual expression. I first explore experiences that were grouped and subsequently analyzed under the theme of education. This theme captures the ways in which participants informed other people about their sexualities, and to a lesser extent, the ways that participants went about finding information about sex. Informing themselves about sex enabled some participants to rectify the failures of formal and informal sex education. Similarly, providing others with information about disability and sexuality allowed some participants to challenge the desexualizing assumptions that negatively impacted their opportunities for sexual expression. Following this, I turn to explore data coded under the theme of subversion, a strategy that allowed some participants to challenge norms surrounding sexuality and disability. This theme represents the creative and agentic ways that participants fashioned and asserted their sexualities. Importantly, the ways that participants subverted norms of disability and sexuality both confirmed and challenged prevailing social constructions. In sum, the following two sections reveal how the participants developed strategies to negotiate, create, and ensure opportunities for sexual expression that they were otherwise routinely denied.

Education

Education was a central strategy that participants used to correct desexualizing assumptions and practices that served to marginalize their sexualities. This strategy consisted of a range of different actions that included finding information about sex and disability, teaching others about their bodies and sexualities, and contributing content related to disability and sexuality to a variety of sources including publications and social media pages. Educating other people about issues related to disability or sexuality was a process that was laden with forms of emotional labor and was not always a successful endeavor. Moreover, not all of the participants opted to educate and this strategy was not used in uniform ways. Yet, this strategy did allow some of the participants to maintain and secure opportunities for sexual expression. By teaching and dialoguing with others, these participants were able to take more control over common narratives that surround disability and sexuality. In this way, education provided a means to dispel stereotypes and allowed some of the participants to assert their sexual selves. Finally, education was used as a strategy to facilitate sexual encounters, to assure prospective partners of participants' sexual viability, and in some cases, their 'normalcy'. The following collection of narratives illustrates some of the ways that the participants sought to educate other people (usually non-disabled people) about their bodies and sexualities.

> **RICARDO:** *He said something like, 'I don't expect you and (partner's name) will have kids eh'? And I was like, hold up. No. I mean, I guess it is not really typical work chat but I told him that there was nothing preventing me and (partner's name) from having kids or sex, cause I think that really might have been what he was trying to get at, like 'can you have sex, can you get it up'? But yeah, I just asked him why he would expect that and I think told him to look up Mark O'Brien – do you know who I mean? I told him to look him up and do some research and really just called him out on his ableism. I think I kind of shut him down a bit, like, in a good way...like I got him to actually think about what he just said and how he might be wrong (scoffs).*
>
> **BOWIE:** *People assume that I am passive or that I don't want it or it is impossible or that it is going to hurt or it will hurt me or that they have to take care of me all of the time afterward. Yes, my sexual experience does require you to get me undressed, you need to get me out of my chair, you need to take my...cause I'm wearing a piss bag right now...you need to take that off, you will have to do all that but I will lay that out for you beforehand so you know what to do and what to expect. I will help you and I will show you and if done appropriately it can be sexy, it can be part of the play, it can be a really intimate thing. People are so scared because they don't know. The trouble is they don't want to say the wrong thing. Nobody wants to offend me so nobody asks me, they just assume and then they get scared. That is why I always say 'be incorrect and ask me and I will correct you'. I mean, I can't get an erection, um, I can't ejaculate...all of these things, but if you come into my world you could see that some of what you think is true and some of that is not, but let me show you first hand. Like, let me tell you how it can be done. I want them to be comfortable with it because they should be. And I get it, I mean, if I met a guy with four arms or two dicks or whatever it is, I would be a little bit like*

> *'oooookaayyy, how do we do this?' It is not their fault, they just need to be given some education.*
>
> **JOCELYN:** *I was talking with this guy on Tinder (dating app) and things were getting kind of heated, like sexual, you know (laughs). I mean, it is Tinder, people are on there for a very specific reason (laughs). So, yeah, we were chatting and he started to ask a few questions about like what kind of positions I am into and that kind of thing and I just told him, 'look, I am just like anybody else'. He wasn't being rude about it and we ended up getting together but yeah, sometimes you just have to like go right out and say it; 'I can have sex, it is okay, you won't break me!'*
>
> ***NADIA:*** *After the accident I think my husband and I were both a bit worried about that stuff, like how we would resume, you know? We still very much wanted to be intimate in that way and so I just started searching for information. I went online, I went to sex shops, I bought books, whatever I could get. And then I made him read them (laughs). It was a bit of an adaptation but he wanted to learn…we wanted to learn. I sent him links to this site that talks about sex if you have like CP, spinal cord injury, paralysis, a whole bunch of different disabilities and I was like 'read this'…and meet me later (laughs).*
>
> **SHANE:** *Like, thank god for writing. That's what I do when I get upset. I think about it for a while, I let it percolate and then I come up with the idea and I write it out and put it out there and I put it on my Facebook all the time. When something happens with attendant care, I write it out. When someone says something ignorant to me, I write it out. When I get stood up or have a bad date with someone, I will write about it. Not because I want to be pitied or anything, I don't want anyone to take pity on me but I want them to see the reality. Um, and Facebook and social media is a great way to show that to people without them having to do much. You know, you don't have to go read a book on disability, they can just see here I am and they can learn from me, we can have that conversation (emphasis). We don't have enough of these types of conversations in popular culture and we need to start talking about it…like, normalizing it, you know?*

These passages illustrate the diverse ways that the participants used education as a strategy to address the barriers that they faced in their romantic and sexual lives. Specifically, these passages speak to the agentic and creative ways in which the participants maintained their opportunities for sexual expression in spite of the desexualization they experienced. Like Ricardo, the participants would sometimes use the uninformed and ableist comments that other people projected onto them as an opportunity to challenge assumptions that desexualized them. In Ricardo's case, he "shut down" the desexualizing remarks that he received by interjecting his own experience and by alluding to resources his colleague could consult. The comments directed toward Ricardo attempted to undermine his status as a sexual being that is both capable and interested in becoming a parent. Moreover, these comments called Ricardo's gender into question.

As his narrative shows, Ricardo felt as though what his colleague was actually trying to assess was his ability to have an erection, something that is inextricably linked with dominant social constructions of masculinity. Thus, Ricardo was not only asked to account for his sexual viability but also his masculine gender identity. His experience supports scholarship that has conceptualized disabled men as being subjected to "symbolic castration" (Shakespeare, 1999, p.57) and as a threat to "all the cultural values of masculinity" (Murphy, 1990, p. 94). Ultimately, both the male and female participants encountered oppressive gender role expectations and sometimes felt as though they could not approximate the socially constructed ideals associated with their gender, an issue that I address in my conclusion. Fortunately, Ricardo seemed to manage this interaction well and rather than have his sexuality 'shut down', he "shut down" his colleague's ableism.

While education was often a means to challenge desexualizing assumptions, this strategy was also frequently used as a way to assure potential partners of the participants' sexual capabilities. Bowie's narrative illustrates how participants taught and explicitly informed partners about what a sexual encounter with them might entail. These participants would "adapt their impairments using different sexual positions and various sexual aids to facilitate sexual fulfillment" (Shuttleworth, 2010, p. 3). By doing so, participants made both subtle and explicit claims to their identities as viable sexual beings. Bowie's passage exemplifies how some participants unequivocally addressed their particular sexual needs so that their partners could "know what to do and what to expect". Informing others about their specific needs helped to ensure both safety and pleasure. Furthermore, 'owning' their sexuality in this manner was a profoundly agentic act that contested the oppressive idea that disabled people should 'take what they can get'. Bowie's statement that sometimes people "just need to be given some education" was an attitude that was expressed by many of the participants.

Like Bowie, other participants were often explicit about their bodily limitations and how they might not meet conventional phallocentric standards. For Bowie, this allowed him to mitigate his potential partners' apprehensions, manage their expectations, and possibly improved his opportunities for sexual activity. Moreover, Bowie's account shows how participants challenged assumptions around care and the idea that disabled people are 'burdens' to their sexual or romantic partners. Specifically, he contested the assumption that care is always a negative, dispassionate, or clinical experience. Rather, for Bowie and those participants who required assistance before, during, and after sex, care could be experienced in a very sexual and intimate way. The more intimate dimensions of care have been explored by scholars like Smith-Rainey (2018), whose work on the ‘pleasures of care’ suggests that “rather than only being a barrier, the need for care can be reframed to be an erotic and satisfying aspect of sexual relationships” (2018, p. 273, see also Smith-Rainey, 2011, 2016). Finally, educating sexual partners worked to challenge dominant sexual scripts. For instance, the participants often spoke of taking time to discuss, “plan”, and “storyboard” their sexual experiences. Planning the particulars of sexual activity contradicts the conventional understanding of sex as a spontaneous and ‘unspoken’ activity and usually helped these participants to have more positive sexual encounters. Thus, the notion that spontaneity “makes for the ‘best sex’, although functioning as sexual script, is in fact a myth” (Dune and Shuttleworth, 2009, p. 98). Like Bowie, the participants who had limited mobility could not always engage in certain sex acts (e.g. penetration, ejaculation, keeping legs open, using arms to touch a sexual partner, etc.). These participants found ways to adapt their sexual experiences, and in doing so, they operationalized more expansive understandings of sex that often exceeded “the sociocultural normatives of sexuality in a productive way” (Shildrick, 2009, p. 13).

The participants frequently encountered the belief that sexual activity would be harmful or would “hurt” them. As Bowie notes, it was assumed that sex with him might hurt him. A similar concern was expressed by Jocelyn, a participant who stated that having sex “won’t break” her. The assumption that disabled people are too fragile to engage in sexual activity is rooted in ableist stereotypes that construct disabled people as passive, childlike, and ‘too sick’ to be concerned with sex. Participants frequently spoke of having to combat the assumption that sexual relations were somehow dangerous to their health. This is exemplified in Jocelyn’s narrative, which illustrates how education could also be used as a normalizing strategy. Importantly, Jocelyn assured her sexual partner that she was “just like anybody else”. In this instance, ‘normalcy’ was emblematic of the ability to engage in traditional sex acts. Jocelyn’s insistence that she was “just like anybody else” helped to bolster her opportunities for sexual expression and further illustrates how the participants used education as a strategy to assure potential partners of their sexual viability, albeit in diverse ways. While participants like Bowie employed expansive definitions of sex in their lives that often rejected the importance of things like penetration, other participants opted to use more traditional definitions of sex. Thus, the findings of this research project are complex insofar as they point to the diverse ways that the participants negotiated strategies for sexual activity. Specifically, the results of this thesis are complicated by the fact that the narratives of some participants reject or resist dominant sexual scripts, whereas others reify and reaffirm these scripts. I return to this issue in the following section when I explore how the participants used subversion as a strategy to express their sexualities.

Nadia's account of educating both her husband and herself after becoming disabled demonstrates another way that the participants used education as a strategy to help ensure opportunities for sexual activity. Furthermore, Nadia's account is representative of the ways in which the participants rectified their lack of sexual education. In addition to using education as a way to inform others, participants often educated *themselves* about issues related to disability and sexuality. This is undoubtedly related to the lack of sex education that was afforded to the participants. When I asked the participants how they acquired information about sex, the vast majority of them explained that the internet was essential to finding information that was applicable to their sexual lives. Using the internet to find information pertaining to sex was thus the most common way that the participants found information about their sexualities.

The internet also assisted some of the participants in educating others by providing a platform for their experiences. As Shane's narrative denotes, a small number of participants discussed how they used their experiences to educate others and mentioned that the internet allowed them to have a larger platform through which they could share their experiences. By drawing upon their personal experiences, these participants contested ableist ideas and contributed to conversations about issues that are often shrouded in silence and stigma. Creating forms of content and initiating conversations related to disability and sexuality allowed the participants to have more control over narratives that depict disabled people as nonsexual. For example, sharing his experiences with others proved to be a cathartic and agentic activity that allowed others to understand Shane's "reality". Moreover, as Shane noted, sharing experiences with others via social media was an expedient and relatively accessible way to normalize the taboo idea that disabled people are sexual beings. As Shane said, people did not have to conduct research or even "do much", they just had to listen to his experiences with an open mind.

When I asked the participants how they typically went about forming romantic and sexual relationships, many of them informed me that their preferred way to meet potential partners was through the internet. While some participants preferred meeting people face-to-face, others opted to use internet dating sites and various applications such as Tinder, Bumble, Ok Cupid, and Grindr for example. Those who preferred using the internet, frequently mentioned how it allowed them to bypass the inaccessibility that they routinely encountered, specifically the inaccessibility within spaces that are associated with dating and sexual activity discussed earlier in this thesis.

Additionally, these participants sometimes explained how online dating enabled them to disclose to other people that they live with a disability before meeting in person. This type of disclosure allowed participants to talk with partners about their impairments before a potential sexual or romantic encounter which could subsequently help to assuage any anxiety that the participants and their prospective partners experienced. The collection of participant accounts below captures the ways the participants used the internet to connect with potential partners and to further their opportunities for sexual expression.

> **LILITH:** *I go online. I put my cards on the table with my profile like, okay, I am a person with a disability. I don't always message people because I know not everyone wants to deal with that and some people think like more long term and like, will being with her be an expense for me later on? So, I wait for people to message me for the most part. I guess it like lets me separate the good from the bad, you know? Like who is willing to look past it and those who can't get over it.*
>
> **JIM:** *It used to be that everything was face-to-face but now I can just go online. That's been a huge change, but a good change. I don't have to worry as much you know? Like, I get to chat with them before going to the effort to meet and we both get a chance to see if we might actually click. If it looks like we are going to hit it off then we can get together. I guess it also helps with like just the practicality of everything, like I said earlier about the pubs and restaurants downtown, just so inaccessible.*
>
> **BRITNEY:** *I have found that online it is much easier to find people that are more open-minded, especially since I am a super-geek (laughs). So, I am like, I am a person with a disability, I put it out there…It goes hand in hand with my sexuality too (pansexual). I put it right in my profile and it just gets everything out of the way.*
>
> **MARK:** *Well, I've tried different things but one thing I've started doing in the last while is the whole online dating thing, like Tinder and all that. I dunno…it [online dating] is good cause I don't have to go out and deal with [transport service designed for people with disabilities]. But, on the other hand, I can meet people like wherever I am too if I am traveling or something. Like I was staying in [city name] for a few months last year and I really don't think I would have gone out as much if I didn't use that app.*

The narratives of Lilith, Jim, Britney, and Mark illustrate how the internet and online dating permitted the participants to decipher who might be sexually interested in them and possibly avoid potentially negative sexual experiences. Similarly, online dating allowed the participants to gauge if they were compatible with partners. Putting additional effort into avoiding negative experiences could be seen as a way to mitigate the immense amount of discrimination that is directed toward people with disabilities. Like Lilith, the vast majority of the participants were aware that they were not perceived as sexual beings and felt as though people avoided them because they were disabled. The fact that Lilith did not initiate contact when using online dating sites hints at her low sexual self-esteem, an issue that many of the participants struggled with. Lilith's plan to wait until other people contacted her could be considered a strategy to avoid rejection from potential partners and to help her separate "the good from the bad".

Jim and Mark's narrative exemplifies how participants opted to meet potential partners via the internet because it proved to be a more accessible and 'practical' strategy. Britney also found online dating to be the most effective way to form romantic partnerships. Like Britney, other participants discussed how online dating allowed them to find partners who were more "open-minded", which could be representative of people who did not discount them on the basis of their disabilities and sexualities. Britney's narrative captures some of the additional challenges that were imposed upon LGBTQ+ participants. Many LGBTQ+ participants spoke of having to do additional work in education, in the sense that they had to teach others about their disability *and* their sexual orientation. This additional layer of disclosure meant that the LGBTQ+ participants had to do the work of coming out not only as disabled but also as non-heterosexual. Gender and sexuality scholars have consistently shown that coming out is a continual and deeply personal process that includes a significant amount of emotional labor and risk (Gagne, Tewksbury, and McGaughey, 2008; Serano, 2013; Fredericks, Harbin, and Baker, 2017). Thus, this added layer of stigma could pose additional challenges for the LGBTQ+ participants and often involved a significant amount of explaining and legitimizing their sexuality. Ultimately, the opportunities for sexual expression that LGBTQ+ participants encountered were "deeply shaped by the interplays of intersecting systems of inequality", and in many ways, were often fraught with different challenges when compared to the heterosexual participants (Santinele Martino and Fudge Schormans, 2018, p. 6). Some of these challenges are summarized within the passage below.

> **MARK:** *It's funny because I've come out as queer and that's no problem, but coming out as disabled and gay is a huge thing. And you would think that like having [participant's age] years of living with my disability coming out as disabled would be a piece of cake. But, actually it has been really hard sometimes because every single space that I occupy with every single person, even if they know that I am the guy in the chair, I have to show them different parts of my disability. Every single time, and that's again coming out saying 'ah here I am, there is my disability'. Everything I do is tied to my disability. And you can't separate your identity, like which is what many of us signify when we say disabled man, you are*

> *owning that your disability does come first. But like, yeah, you can't separate your identity. I'm coming out as disabled and coming out as gay all the time.*

As previously stated, the strategy of education was laden with emotional labor and fraught with difficulty. Although emotional labor is a concept that is operationalized in different ways, I employ a broad definition of the concept and consider it to be the time, effort, and emotion management that is "required to deal with one's own feelings and those of others" (Exley and Letherby, 2001, p. 115). The significant amount of emotional labor that was involved in educating others is exemplified within Mark's narrative. Although Mark's narrative is unique, in that it alludes to challenges that are particular to the LGBTQ+ participants, like Mark, many participants expressed how this strategy presented limitations regardless of their sexual orientation. To be clear, education was not always an effective strategy and it could cause participants to feel a range of negative emotions. The following excerpts illustrate some of the issues associated with this strategy.

> **TAMMY:** *I mean, it can be a bit tedious answering the same old questions. That is kind of a downside to it, like you get tired of explaining it to people, you know?*
>
> **BRENNA***:* *Like it is quite obvious my disability so I have a lot of curious people that don't even say 'hey, how ya doing' they just look at me and ask 'what happened to you'? And for a period of time I would answer and feel like shit afterwards. And one day I was just like I don't have to answer these questions. I guess I just got tired of it. I mean I can answer if I feel like it but it all depends on the way that I have been approached or spoken to.*
>
> **MICK:** *Sometimes you have to leave people in their ignorance. I mean, I believe in giving people a chance and that we can learn from listening to each other but, like, some people just aren't willing to learn.*
>
> **BOWIE:** *Like that guy that I met online who got freaked out, he was only focusing on what he read about my disability on WEB MD or Wikipedia or whatever. And I said to him, just talk to me or have that coffee with me or whatever. And he was like, 'I don't know dude it really weirds me out'. And I was like, 'okay, that is fair and I appreciate you telling me that, thank you, but if you had just asked me' because he was like 'oh I read CP can cause seizures and blah blah blah'. And yeah it can, but not in this case, you are fine, you are set! Let me tell you what it is! But we never talked again because he was freaked out...*

These passages expose some of the challenges that the participants encountered when attempting to use education as a strategy to further their opportunities for sexual expression.

During the interviews, some of the same participants who had highlighted of the benefits of this strategy also discussed its disadvantages. For instance, like Tammy and Brenna, participants spoke of feeling tired from continually being asked questions about their bodies and sexualities by other people. When I enquired if there were any issues that the participants had encountered when educating others, many of them expressed how these interactions could leave them feeling exhausted, objectified, and depressed. For instance, Brenna told me that educating other people and dealing with invasive questions left her feeling "like shit". The immense amount of energy that these participants expended while educating others meant that they would avoid interactions in which they might be asked to educate. Moreover, participants did not always experience the benefits of education first-hand. Bowie and Mick's narratives show that people were not always willing to be educated. In Bowie's case, his attempt at educating the individual that he referenced was superseded by medicalized knowledge. Instead of learning from Bowie's lived experience, this individual used websites that provide predominantly medical information (e.g. Web MD) to learn more about Bowie's life. This speaks to the power that medical discourses import and the ways in which they can be used to invalidate disabled peoples lived realities. Unfortunately, when participants made attempts to educate others, they did not always elicit a positive reaction. In fact, educating others sometimes meant that participants were subjected to negative comments or harassment. For example, Shane referred to the importance of sharing his experiences on social media, but he also showed me a comment that he received on a post he had made to one of his social media accounts; it read, "Dude, your disabled. We get it. Get over it".

Overall the strategy of education was deployed in diverse ways and had a range of results. The participants often spoke of the benefits of education but were also acutely aware of its limitations. Additionally, as the participants' narratives suggest, the internet was an important resource for the vast majority of them. The internet and online dating therefore helped to maximize and facilitate their opportunities for sexual expression. However, as I discuss in chapter seven, the internet could also open up additional avenues for unwanted interactions and voyeurism. In sum, education was used as a strategy to manage stigma and mediate desexualization, as a means to maximize opportunities for sexual expression, and as a tactic that provided many of the participants with the means to show that they are viable sexual beings. In the following section, I explore how the participants used subversion as a strategy to challenge desexualization and dominant sexual scripts.

Subversion

Throughout this section, I unpack how the participants used subversion as a strategy to challenge the desexualization that they experienced. In addition, I explore how subverting desexualizing assumptions enabled the participants to assert their sexualities and sexiness. The data analysis revealed how the participants used this strategy as a way to create and enhance opportunities for sexual expression that they were routinely denied. Specifically, attitudes and behaviors that worked to challenge and undermine dominant social constructions of disability and sexuality were coded as subversive. Data grouped under this theme illustrates the agentic and creative ways that the participants worked to resist desexualizing assumptions that were imposed upon them. Not all participants made use of this strategy and, as previously stated, the ways in which participants subverted constructions of disability and sexuality both confirmed and challenged prevailing social ideals. The data shows that those participants who used this strategy would expand upon and therefore redefine certain meanings or values that are associated with particular sex acts. However, the data also shows that the participants did not wholly reject prevailing social constructions and dominant sexual scripts. Thus, through the participants' narratives and actions they both defied and reified dominant sexual scripts.

The participants subverted dominant sexual scripts such as the importance of ejaculation, penetration, or specific sex acts in diverse ways. Most commonly, participants would cite how they had found ways to feel sexy and be sexual despite their bodily limitations and the desexualization they experienced. Significantly, for those participants who made use of this strategy, their accounts highlight the ways in which they compensated for their bodily limitations by emphasizing the various things that made them good sexual partners. In fact, some participants felt as though they *had* to amplify other aspects of their sexualities or bodies in lieu of the fact that they could not engage in certain sexual acts. Thus, the participants' narratives clearly indicate the complexity of this strategy and how some participants still struggled with their sexualities and self-esteem, despite them using subversive strategies. Similar to educational strategies, subversion was not always a straightforward or successful strategy for sexual expression.

The data analysis shows that the participants used subversive strategies as a means to revise – and in some cases, completely rewrite – dominant sexual scripts so that they were tailored to their own lives. During the interviews, many of the participants referred to sexual scripts that have value or 'erotic capital' (Hakim, 2010), but in ways that worked to reframe what constitutes a pleasurable sexual experience and what it means to be sexy. By doing so, participants adjusted and redefined dominant sexual scripts so they were applicable to their own bodies and subjective lived experiences. The collection of participant narratives below exemplifies some of the principal ways in which the participants employed subversion as a strategy to directly challenge desexualizing assumptions, assert their sexualities, and revise dominant sexual scripts.

> **ANNE:** *I might not be able to like jump around or like give the best hand-job ever (laughs). But there is lots of other stuff to do, right? Like, sex can be lots of different things. So, yeah, no hand-jobs here, but I still have fun and I've never had any complaints about how I give head (laughs).*
>
> **MICK:** *Ah, I am pretty confident in my cunnilingus skills. Actually, that's an assumption that people can have (laughs) a lot of people accurately predict that I am good at cunnilingus.*
>
> **JOSH:** *A lot of the women that I have been with tell me that I am a good lover and that I am sexy and I think that has a lot to do with how I am with them. Like, because, I really try to communicate with them, to like slow down, and put my partner's pleasure first. I enjoy it too, paying attention to all that stuff is what makes me a better lover. I guess that it…I mean, look, I am no Brad Pitt…being thoughtful and putting her pleasure first, all the stuff I do, it all adds to the whole experience and it sorta helps to make up for how I can't be the most physical guy.*
>
> **COURTNEY:** *And the thing is…like I think about how all through high-school I had like no boyfriends and like I had a pretty face, I had cool style, but like no boyfriends, right? And yeah, just people didn't see me that way and it was only until I started like wearing different clothes that were a little more provocative. Like I always (emphasis) have a low cleavage line. I have great boobs so …It's all about taking what you have and like, you know…I don't have the long awesome legs that are like frigging so tall but I got a great rack. But, like, I wear more sexier things and then people see me as sexier but like….It is a weird thing to think about because it is not like I was putting myself out there because I wanted everyone to fuck me but it was like I needed to be looked at that way. Yeah, it is weird and then some people always joke like 'why do you always have your boobs out' and like my tops are always like this (points to chest) and most girls have higher tops…like look what you are wearing compared to me…and it is because really, it's all I got, not really, I have a big ass too (laughs). But like really play up your assets and I think everyone should depending on what you think your assets are.*

As these excerpts reveal, the participants frequently stressed their capacity to provide and receive sexual pleasure. Given the innumerable barriers to sexual expression that the participants faced, this was a subversive act in and of itself. More pointedly, these excerpts are representative of the ways that the participants would often emphasize aspects of their bodies, personalities, or sexualities that they felt would compensate for and even supersede the fact that they couldn't always engage in conventional sex acts, such as penetration or stimulating someone's genitals with their hands. Anne and Mick, for example, both highlighted their oral sex skills, something that both of these individuals took pride in. Anne did not seem to be deterred by how she couldn't give hand-jobs since she does not have hands. Instead, she creatively employed a rather broad definition of what constituted a positive sexual experience by suggesting that sex can be "lots of different things" and that "there is lots of other stuff to do". Although Anne still invoked aspects of dominant sexual scripts such as the importance of pleasing one's sexual partner and genital orgasms, she was not bound to these scripts and would adjust them according to her own interpretation.

Like Anne, Mick also stressed his ability to give oral sex and asserted his sexual prowess in doing so. Similar to other male participants who could not always achieve erection, Mick resisted constructions of sex that were predicated on the importance of erection and penetration. Mick asserts that he felt as though his tongue could provide partners with more pleasure than his penis. Moreover, Mick's narrative implies how he used other people's desexualizing assumptions to his benefit. Rather than internalizing the desexualizing assumptions of others, Mick inverted them and then briefly reveled in them with humor. While Mick challenged phallocentric ideas of sex by emphasizing the importance of his tongue, he left certain gendered expectations and sexual scripts intact. Namely, he affirmed the important role of genital orgasms in his sexual life and in many ways, he subscribed to gendered stereotypes that frame the ability to provide sexual pleasure as central to being a masculine man. Mick's narrative is representative of other male participants who could not achieve or maintain an erection as many of these participants highlighted the other ways that they could please their sexual partners. Many of these men employed definitions of sexuality and masculinity that were not contingent on having a fully functioning or erect penis. Yet, as Mick's narrative shows, these participants simultaneously inverted and affirmed aspects of gendered sexual scripts associated with masculinity. This is not to say that female participants did not invoke gender norms, but to note some of the gendered implications of the strategy of subversion for male participants.

Like Anne and Mick, Josh also drew a sense of satisfaction from his ability to pleasure sexual partners. The positive feedback about Josh's sexual performance most likely boosted his confidence. He credited this positive feedback to his communication skills, how he prioritized his partners' pleasure, and how he worked to slow down sexual experiences (values that are traditionally associated with women). Employing these sexual skills helped Josh offset the fact that he was not “Brad Pitt”. Notably, Josh paused to state that he was not Brad Pitt. This comment suggested that Josh did not feel physically attractive or confident in his looks, an issue that a large number of the participants consistently struggled with. Yet, Josh’s narrative also implied that his disability had given him specific sexual advantages when compared to non-disabled men. As he explained in his narrative, Josh felt that his sexual experiences were more thorough and thus more rewarding for both him and his partner. Indeed, many of the participants expressed that their sexual experiences were more fulfilling because they had taken time to modify, work on, and think about their sexual practices. Similarly, the participants often amplified other aspects of their personalities or sexualities in order to compensate for limitations imposed by their impairments and as a strategy to access opportunities for sexual expression. In doing so, these participants redefined sexual scripts and meanings associated with sex in light of their corporeality.

The passage from Courtney’s narrative reveals some of the difficult circumstances that frequently motivated participants to subvert and challenge the desexualization they experienced. Courtney discussed her painful experiences of being isolated in high school, having no sexual partners or boyfriends during this time, and how she endured different forms of desexualization. Even though Courtney embodied some conventional beauty standards in that she had a “pretty face” and “cool style”, he peers failed to recognize her as a sexual or sexy being. In light of this, Courtney started wearing more provocative clothing (e.g. low-cut tops) as a means to amplify and play up her sex appeal, a form of self-expression that Courtney continued into her adulthood. Indeed, having a “pretty face” and “cool style” was not enough for people to perceive Courtney as sexual. Rather, she had to hypersexualize herself in order to be noticed and ostensibly to be seen as sexual by others. In order to do so, Courtney opted to highlight the parts of her body that conformed to corporeal standards and that gave her confidence. Although Courtney resisted the desexualizing assumptions of her peers by dressing provocatively and by subverting the idea that people with disabilities aren’t sexy, she simultaneously confirmed dominant sexual scripts by performing her sexuality and gender in ways that meet conventional expectations. Namely, in her narrative, Courtney reifies the idea that women’s bodies are to be subjected to the ‘male gaze’ and thus objectified for the sexual pleasure of others. As Courtney noted, it was important for her to “be looked at in that way” and to be perceived as sexy. Being validated as sexy or as a viable sexual partner was important for all the participants and had a significant impact on their opportunities for sexual expression and exploration.

As Courtney's narrative illustrates, the participants recognized, and to varying degrees internalized, dominant ideas of what constitutes a sexy body. Thus, the data shows that subversion often entailed a complex interplay of accepting and rejecting certain aspects of socially constructed sexual scripts. The process of accepting and internalizing these scripts influenced the participants' feelings of inadequacy. However, it also offered them opportunities to reject and revise sexual scripts. Courtney's experiences were representative of the vast majority of the participants who felt as though they were at a deficit when it came to being seen as sexual and thus used subversion as a means to rectify this deficit. Like Courtney, other participants often felt as though they should "play up their assets". In many ways, a "great rack" or muscular arms could supersede the importance of long legs, mobility, or other traditional markers of sexiness. Relatedly, the participants sometimes expressed that they *had* to emphasize certain aspects of their bodies in order to be seen as sexually viable. Like Courtney, these participants often did so because they felt as though it was 'all they had'. Other participants did so because they felt it allowed them to challenge other people's expectations and change their perceptions of who and what can be sexy. In fact, subverting social constructions associated with disability allowed some participants to surpass the low expectations that were placed on them. In doing so, these participants often inverted the idea that people with disabilities don't make good sexual partners, that they are uninterested in sexual relations, or that they aren't sexually desirable.

A small number of participants who used the strategy of subversion did so in a way that wholly revised dominant sexual scripts. The participants who did so were confident that their disability worked to make them a better sexual partner as opposed to a less desirable partner. For these participants, their disabilities were viewed as an integral part of their identity that actually *enhanced* sexual pleasure. This group of participants explained how their impairments were advantages that could positively influence their sexual experiences. Therefore, they inverted the deeply rooted idea that people with disabilities are at a deficit in terms of their sexualities and the ableist idea that disability always negatively impacts upon a person's sexuality. The following collection of participant narratives exemplifies the ways that this group of participants challenged both desexualization and ableism, and how they experienced their limitations as advantages.

> ***SHANE:*** *I just hate the way people assume that to love somebody with a disability you have to love them past their disability. Or like to assume that we don't want to have flings or one night stands too. I mean, why can't disabled people just have sex? Why can't they be just as promiscuous and irresponsible as the next person?*

> *So, when people say things like 'oh, you will find someone who will take care of you someday' I always laugh at them and say no, I don't want the one, I'm not looking for long-term care here, I want somebody right now (emphasis). I'm looking to get laid. I am not looking for somebody to love me past my disability. I am actually looking for somebody to love me or not whatever they choose, because (emphasis) of my disability, and to have disability be a selling point.*
>
> **BRITNEY:** *Like I said earlier, people might assume that I can't have sex because I am disabled but, honestly, I'm like 'let me show you how wrong you are'. I know (emphasis) my body and what it can and can't do. Like, let me show you, you know? I mean, it (participant's impairment) is part of who I am and what makes me so open and adventurous. People are so surprised when I tell them I am into BDSM and that I've been involved in like some pretty wild sexual stuff. But, yeah, like I said, it (participant's impairment) certainly doesn't stop me from having fun, just the opposite. (laughs).*
>
> **MARK:** *I can't top, obviously. But, let me take you for another kind of ride (points to wheelchair). This thing can get in the way but it can also be handy in the bedroom (laughs). I'm serious. A guy I used to be with loved like incorporating the chair into things. It is all in your perspective, you know? Like, keep an open mind and see what happens.*
>
> **DAPHNE:** *I mean, I'll be honest. I love sex. I'm a self-identified slut and unashamed about it. I am not going to let double-standards or someone else stop me from living my life in that way. Like, I mean, I am safe and everything, but I have fun. I am young and I want to experiment a little bit before I settle down, if I ever do!*

The narratives included above indicate the agentic and diverse ways that the participants constructed their sexualities and created opportunities for sexual expression. Similar to Shane and Britney, these participants experienced their impairments as an integral and inseparable aspect of their identity and as advantages that made them good sexual partners. The manner in which these participants expressed their sexuality subverted the idea that disability naturally or intrinsically impacts sexuality in a negative way, and forged routes around the barriers to sexual expression that they experienced. In this way, subverting oppressive ideas at the intersection of disability and sexuality also served to challenge dominant sexual scripts that tend to deny and denigrate the sexualities of people with disabilities.

The passionate excerpt from my interview with Shane illustrates how participants were not looking for someone to "look past" their disability. Instead, most of the participants wanted their potential partners and other people to value their perspectives and experiences as people with disabilities. Importantly, they were not interested in separating aspects of their identity for the benefit of others. When Shane questioned why people with disabilities couldn't be perceived as "just as promiscuous and irresponsible as the next person", he was challenging the persistent assumption that they are 'fragile' and must be especially safe if they engage in sexual activity. Furthermore, his rhetorical question refuted the idea that disabled people must 'latch on' to whoever they can, or that they must be only interested in long-term relationships because their 'needs' make them undesirable and therefore desperate. Shane's experience of having other people confuse care with sexual attraction was something that other participants experienced. This attitude illustrates how the only frame of reference that others used to understand people with disabilities was one that failed to conceive of them as valuable or sexual. It was this very same frame of reference that the participants sought to challenge by subverting the oppressive expectations and desexualizing assumptions of other people.

Both Britney and Mark acknowledged that there might be some things that their bodies could not do. Yet, similar to other participants who used subversion as a strategy, they credited their impairment with enriching aspects of their sexual lives. For Britney, her impairment was a central part of her identity and therefore a central element of what made her so sexually adventurous and desirable. Mark also felt as though his impairment enhanced his sexuality and sexual prowess. While he acknowledged that his impairment also imposed some limitations in that he couldn't assume certain sexual positions, these limitations became a way to improve his sexual experiences through creatively repurposing his wheelchair as a sex toy. In doing so, Mark turned an instrument that often symbolizes dependence into something that symbolized pleasure and possibility.

Daphne also resisted dominant constructions of sexuality by reclaiming the typically derogatory term "slut". As she noted, she was unashamed and ostensibly derived a sense of self-worth from using this label. Through identifying as a "slut" Daphne subverted the idea that disabled people are not sexual as well as the gendered expectation that women should not engage in numerous sexual experiences. Daphne refused to feel 'ashamed' about her body or sexuality, and in fact, reveled in her sexuality. This was a common sentiment among participants who experienced their limitations as inseparable aspects of their identity and as advantages within their sexual and romantic lives. Like Daphne, these participants expanded upon and redefined sexual scripts by creating new scripts that centered on participants experiences, needs, and desires.

Overall, the participants who used subversion as a strategy to assert their sexualities rejected some aspects of sexual scripts and reaffirmed others. The participants' narratives I included in this section point to the subversive behavior and emotional labor involved in creating new sexual scripts. Moreover, the narratives point to the complex ways in which the participants made claims as sexual beings and the diverse ways that they deployed subversion as a strategy to access opportunities for sexual expression. The data included in this section offers answers to one of the research questions that guides this analysis. Namely, how are dominant sociocultural constructions of sex and sexuality – such as the importance of penetration and genital orgasm in sex, or aesthetic ideals of what constitutes a "sexy" body – challenged and/or reinforced through the experiences of disabled individuals? Ultimately, the data shows how the sexualities of participants who used subversion as a means to ensure opportunities for sexual expression were not overdetermined by or rigidly bound to dominant sociocultural constructions. Instead, they simultaneously resisted and reified dominant sociocultural constructions that typically position people with disabilities as nonsexual and not sexually desirable. Thus, this data clearly illustrates the creative and agentic ways in which the participants created opportunities for sexual expression amid the numerous barriers they faced.

CHAPTER 7

Additional Issues - Desexualization, Hypersexualization, and Devotism

"As an amputee, I have had the doubtful pleasure of knowing two such men. I was newly divorced after a long marriage with the only man I had ever slept with. So, I was not only very vulnerable but very naïve too and I ended up sleeping with him. I really thought he was interested in me, but the morning after, he was moody and seemed to regret the intimacy – once I even caught a look of distaste on his face. The second man was developing a fetish for amputees. He carried photos of his former amputee girlfriend only showing the empty side of her skirt taken from a back view of her! He also carried a photo of her artificial leg. When I caught him taking a similar photo of me, from behind, that was it for the relationship. I find men are very devious in hiding their fetishes. We disabled women must be careful." – Excerpt from an anonymous letter published in Disability Now (May, 1994).

Managing Desexualizing Assumptions and Hypersexual Advances

Throughout this dissertation I established how the participants involved in this study encountered innumerable barriers to their sexual expression and experienced different forms of desexualization. Although the overwhelming majority of the participants experienced routine desexualization, a small number of them (n=5) were not exclusively desexualized. Rather, these participants experienced a complex combination of both desexualization and hypersexualization. Of the twenty-four participants, five discussed instances in which they were hypersexualized, and in some cases fetishized by 'devotees'. Thus, these participants' experiences of desexualization were contoured, and in many ways, compounded by the hypersexualization that they experienced. While only a small number of participants experienced some form of hypersexualization, it is important to address and unpack their experiences as they point to a rarely discussed paradox within disability-sexuality related research. Namely, that disabled people are desexualized on the one hand, and fetishized on the other.

Devotism and the hypersexualization of people with disabilities has not undergone extensive empirical study and there is little research that explores this phenomenon from a sociological or feminist perspective (Shuttleworth, 2007; Kafer, 2012; Limoncin et al., 2013). Shuttleworth (2007) contends that devotism and sexual attraction to disabled people has remained "virtually unstudied" (p. 1). Similarly, the question of how to define devotism lacks consensus and is heavily debated among psychologists, sexologists, and disability studies scholars. Some researchers argue that devotism is a psychological disorder and should therefore be understood as a "deviant desire that requires therapeutic attention" (Shuttleworth, 2007, p. 1; see Money and Simcoe, 1986; Limoncin et al., 2013). However, others contend that devotism is yet another example of sexual preference for particular body parts or types, and question how framing devotism as a form of pathology can have negative implications for people with disabilities (see Moser and Kleinplatz, 2005). For instance, Kafer (2012) asks, "If we cast devotees as 'pathological,' then what are we saying about the desirability of disabled women?" (p. 333). In addition, there are accounts from disabled people that "exalt the opportunity and pleasure they access via the devotee community" (Shuttleworth, 2007, p. 2; see Aguilera, 2000). Whereas there are contrasting accounts wherein disabled people highlight the exploitative, dehumanizing, and potentially dangerous aspects of this phenomena (see Shakespeare et al., 1996). In light of these debates, the existing and limited amount of scholarly literature on devotism is extremely polarized.

In order to accurately represent participants' lived experiences and avoid pathologizing devotees, I have opted to employ a rather broad definition of devotism in this dissertation. I define devotism as sexual attractions that are explicitly directed towards impairments and use the term devotee to refer to individuals who are "specifically interested in and sexually aroused by people with disabilities" (Limoncin et al., 2013, p. 51). It is often the case that devotees are attracted to a particular type of impairment and it is possible that it is a disabled person's "crutches, prosthesis, or another adaptive device that drives a particular devotee's desire" (Shuttleworth, 2007, p. 1). The limited number of academic studies that explore devotism suggest that devotees most commonly pursue people with limb differences, especially those with amputations. In addition, existing research has consistently noted that the number of female devotees is greatly surpassed by the number of male devotees (Shuttleworth, 2007; Kafer, 2000, 2004, 2012).

During the interviews with participants, the topic of devotees most commonly arose when I asked them whether they experienced unwanted comments about their appearance or if they had received unwanted sexual advances (i.e. cat calling, e-mails, etc.). The following narratives from the small number of participants who did address devotism during their interview show how they managed interactions with devotees in different ways. The large majority of these participants voiced a number of concerns specifically with respect to safety, exploitation, and privacy. Significantly, there was only one participant who had positive experiences with devotism and felt that devotism is a legitimate form of sexual attraction. The following collection of narratives illustrate how the majority of participants who had contact with devotees managed and dealt with these interactions.

> **THERESA:** *Oh yeah! Like, two different ways. One where people will stop and ask 'can I hug you? Oh my god you are so amazing. Wow, you are an inspiration', stuff like that. And then like, I guess the second, well, I get messages from some guys that are like 'hey, I'm into you, can I get a picture, preferably one with crutches if you have them.' Like, what the fuck? Who are you? I don't even have (emphasis) crutches! It's like they expect me to be so desperate that I will be like 'oh right away sir, here you go' (scoffs). Look, I am not going to be some box on somebody's list that they are trying to tick off.*
>
> **COURTNEY:** *Um, well it is funny that you brought that up…I have had a lot of men, especially in the Myspace days, contact me saying they are devotees. I am sure you have heard of this term only because of what you do because nobody else here would know this term. And they are like 'I am a devote, blah blah blah, I find you attractive…' this and that and I am like 'ew'. Like I am all about having your kink, your thing that turns you on, whatever. But, I feel like that [devotism] is not a fetish that is more like…. I guess, in my experience, guys that are only into women that are missing limbs I feel like that stems back to helplessness and the need for a man do you know what I mean? Because I have been asked to be a model for these people who are like 'you are beautiful, blah blah blah, we would love to feature you in our online thing, blah blah blah', and then you go and check it out and it is all women with like either um disabilities or missing limbs and it is like 'stair struggles', 'doing makeup', like it is showing. I mean, like there was this one girl wearing those ancient braces on her legs, you know those wooden ones? And she was like going up the stairs and struggling up the stairs and these were like the fucking model portfolios…No, that's not fetish, that is exploitative. That's disgusting. And a lot of these women don't find themselves attractive, they don't have self-worth so they are like 'what you think I'm beautiful, you want me to be a model?' I am like 'I have done modeling for non-disabled websites so, fuck off!' You know? But I am lucky that I have that confidence you know? And even on Facebook I will get friend requests with no friends in common or two friends in common, and they are two friends that I have that are missing limbs and then I look and all of their friends are women that have missing limbs…Like I don't think that is fetish. I think that is objectification. Like we all have what we are attracted to, but the fact that I am missing arms and legs, like c'mon? I even had a guy on Myspace be like 'I'm a police officer in the States and I just want to let you know that I have your photo printed out on my front foyer when I come home I see you every day'. And I was like 'that is fucking creepy'! And he was like 'I was wondering if you could send me some more photos, where you are wearing more provocative clothing.' Ugh. The funny thing is like [partner's name] is attracted to me a lot but he is not attracted to me because I'm missing limbs. He has never been attracted to another girl with missing limbs, it is not about that – it is part of it but cause it is part of who I am and like whoever is going to be attracted to me has to be attracted to the whole package. But, it is not like that is what attracted him, not at all. So,*

> *like I guess that if this whole thing is a fetish it has to be like all parties comfortable and all parties okay with it, you know? Like my major concern with devotees or whatever is that women that aren't that confident might end up with men who are like that because they don't feel like anyone else will love them. That's sad.*
>
> **JOELLE:** *Um, social media is pretty intense that way. Um, after the accident, I started receiving like a lot of friend requests from people I had no idea who they were, like from across the world and I honestly didn't think too much of it. I was just adding people like whatever (laughs) and then I saw a website that suggested like these people to watch out for [devotees] like they are known to steal people's identities and pictures of themselves and they like create Facebook accounts that use girl's pictures to try and access other girl's pictures. So, I looked at the list and it had like three of my friends on the list. So, it like really freaked me out and I like deleted them right away and like everyone else that I didn't know.*

While autobiographical and empirical literature have shown that some disabled women enjoy positive sexual relationships with devotees, the participant narratives included above show that the female participants who discussed their experiences with devotism did so in a solely negative light. All of the female participants who discussed their experiences with devotism voiced frustrations and concerns surrounding agency, privacy, safety, and exploitation. For instance, note the anger and exasperation in Theresa's narrative. Yet, there are also elements of agency and defiance in the sense that she refused to be a "box on somebody's list", and sought out sexual experiences that were on her own terms. Like the other participants who had experiences with devotees, Theresa received unwanted sexual advances predominantly through social media platforms. While she and other participants also received unwanted comments in person, these comments were usually not sexually explicit. Theresa tellingly connects her experiences of hypersexualization to her other experiences of voyeurism. Her narrative indicates that strangers perceived her in one of two ways, as an form of 'inspiration porn' or as a sexual object.

Similar to the other narratives included in this chapter, Theresa's narrative alludes to some of the contradictions and tensions of being hypersexualized. In her narrative, Theresa expressed that devotees thought she was sexually attractive. However, she also explained how devotees thought of her as "so desperate" which suggests that they also saw her as undesirable. Thus, through her interactions with devotees, Theresa was subjected to a complex combination of both desexualization (disgust) and hypersexualization (desire). This is reminiscent of Kafer's (2012) notion of 'devotee exceptionalism', a concept which refers to the ways in which devotees frequently define themselves as "not simply as people sexually attracted to amputees but as the *only* people sexually attracted to amputees" (p. 335). Therefore, while it might seem as though devotees only desire disabled people, Theresa's experience indicates that devotism often "relies as heavily on disgust for disabled bodies as it does desire" (Kafer, 2012. p. 335).

The rather long but revealing narrative from Courtney makes important connections between voyeurism and the dehumanizing portrayals of people with disabilities in popular culture, an issue that I return to at the end of this chapter. Courtney explained how her interactions with devotees prompted sadness, anger and disgust, characterizing devotism as "exploitation" and "objectification". She expressed a number of concerns about how other disabled women might manage the hypersexualization of devotees and felt she was "lucky" that she had the "confidence" required to reject their requests. Importantly, Courtney noted that in her experience, devotism fostered oppressive gender role expectations, namely, the erotization of male dominance and female submission. Her narrative clearly indicates that she strongly felt devotees seek out people with disabilities "for reasons which can only be described as exploitative" (Shakespeare et al., 1996, p. 124). While Courtney affirmed that people engage in a wide array of erotic behaviors that could be considered 'kinky', she expressed that devotism is "not fetish, that's exploitative". Toward the end of her narrative, Courtney emphasized the importance of agency within relationships that involve devotism, stating that "if this whole thing is a fetish it has to be like all parties comfortable and all parties okay with it". Overall, Courtney's narrative illustrates how managing interactions with devotees could be an exceptionally challenging experience that was fraught with a variety of negative emotions and tension.

Devotees contacted each of these participants were solely through social media and the internet. For example, Courtney received messages "from a lot of men" on different social media platforms such as Myspace. Similarly, Joelle characterized social media as "pretty intense that way" and discussed how she received messages and Facebook friend requests from devotees located "across the world". Joelle had no contact with or knowledge of devotees until she became disabled. Furthermore, she did not realize that she had been in contact with devotees until she learned about the phenomenon through a website. When Joelle realized that her Facebook account and privacy had been compromised by devotees she was alarmed, upset, and "freaked out". Interactions with devotees sometimes prompted these participants to become suspicious of *any* person who contacted them, which ostensibly worked to limit opportunities for finding sexual and romantic partners given that participants frequently used online dating as a means to form romantic and sexual partnerships.

These particular narratives show that social media and the internet played an important role in facilitating contact with devotees. Earlier in this dissertation, I suggested that the internet played an important and positive role in facilitating participants' opportunities for sexual expression. However, the experiences of these participants indicate that the internet could also be used in ways that negatively impact opportunities for sexual expression. These participants' narratives suggest that forms of 'new media' and information communication technologies like the internet can amplify and thus increase interactions with devotees even though "sexual fascination with various impairments can be traced throughout the history of Western societies" (Shuttleworth, 2007, p. 2).

Although the majority of participants who had contact with devotees were female, two male participants also experienced some form of hypersexualization. In the following narrative, Mick implies that he is desexualized to the point of being *hypersexualized.* Thus, although the hypersexualization and desexualization that disabled people face might appear to be on two opposite ends of a spectrum, I suggest that it would be more apt to consider these forms of oppression as related and interconnected.

> **MICK:** *Well, I find the biggest thing that I try to stomp out is the attitudes people have. Like, sometimes when I go out to a bar or a party I would like to wear a shirt that says 'I am not going to hump your leg', you know what I mean? Cause, I find that, um, well like I hate to generalize but when I meet females they kinda look at my situation as like 'oh he must never have sex so like when he comes and talks to me that must be what he wants'. And yeah, so there's like the biggest stereotype in my opinion…that people wouldn't regard someone like myself to have sexual experiences. Yeah. So, like if I am going with that approach there is this general thing that has to be talked through or explained. I need to educate people about who I am and that's again why I would wear like to wear a shirt that says 'I am not here to hump your leg, you look interesting and I want to talk with you', you know what I mean? Just like regular human interaction.*

Mick's experiences of desexualization are telling and complex. In his narrative, he explained that the "biggest stereotype" that he encountered was the assumption that he "must never have sex". Mick also explained that he would like to wear a shirt that read 'I am not going to hump your leg' because it would help him to counter the desexualization that he faced in certain social situations. Desexualizing assumptions positioned Mick as undesirable and non-sexual, but at the same time positioned him as hypersexual and licentious. These beliefs were predicated on the assumption that Mick was profoundly undesirable and *so* sexually inexperienced that he *must* be rabidly looking to find any potential sexual partner. I use the word rabidly here with intent as

Mick's narrative evokes the image of a dog 'humping' a person's leg. This is an utterly dehumanizing connotation that suggests that he was perceived by others as an uncontrollable animal. As Mick's narrative implies, it was assumed that he was so undesirable and desperate that he turned every interaction into a potential sexual encounter. Thus, his intention to engage in "regular human interaction" was routinely perceived as an expression of sexual interest.

One of the ways that Mick managed some of the tensions and contradictions that are inherent to occupying an identity that is perceived as both non-sexual and hypersexual was by educating other people. While his hypothetical shirt would have presumably helped him to educate others in a rather frank and expedient fashion, he spoke of needing to "educate people" and that "there is this general thing that has to be talked through or explained". Thus, in many ways, his narrative harkens back to strategies of education that some participants used to correct the desexualization that they experienced, and the emotional labor that this strategy often involved. Ultimately, the complex form of both desexualization and hypersexualized that Mick experienced worked to limit his opportunities for sexual expression by positioning him as simultaneously non-sexual and sexually deviant.

Thus far, all of participants' narratives have indicated that hypersexualization and interactions with devotees were objectifying, unsettling, and unwanted experiences. The following narrative from Bowie counters some of the sentiments expressed in the narratives included above by alluding to the affirming and pleasurable aspects of relationships with devotees.

> **BOWIE:** *I think devotism is…it's cool. Like, in one way because I have fetishes. I like guys with red hair, big muscles, and huge dicks (laughs). That's a fetish so, um, why can't somebody like me because of my chair. Like, I am down with most chair-chasers. The trouble is if you use it as a power struggle to disempower me, that's when I have a problem. Listen, if my wheels can get me in your pants, let's go man!*

Unlike Courtney, Bowie considered devotism to be a legitimate form of sexual attraction. In fact, Bowie suggested that being sexually attracted to "guys with red hair, big muscles, and huge dicks" could also be considered a form of fetish. He also challenged taboos surrounding devotism in his narrative by questioning why someone couldn't be sexually interested in him because of his impairment. He was emphatic when he informed me that if his wheelchair could help facilitate opportunities for sexual expression that he would capitalize on them. Bowie's wheelchair was perceived as something that enhanced his sexiness in his interactions with devotees. In contrast, non-devotees perceived his wheelchair as something that undermined his sexuality and sexiness.

What connects these two seemingly opposing perceptions is the fact that his disability was the crux that determined his sex appeal and value.

In many ways, Bowie opted to use interactions with devotees as a way to explore his sexuality. However, Bowie clearly expressed his discomfort when devotees would turn an interaction with him into a "power struggle" that "disempower[ed]" him. When I probed about what he meant by "power struggle" he explained that, "It's when they wanna disable me more (emphasis) or make it more the contributing factor to the play, you know? That's where I have an issue with it". In this way, Bowie held some reservations about devotees, or 'chair-chasers' as he called them, and was concerned about how unequal distributions of power might manifest in these relationships. For instance, he expressed unease about how some devotees might try to exacerbate or contribute to his disability and objectify him by doing so. It was important for Bowie to be an "equal partner and someone whose own pleasure is valued" in relationships with devotees rather than a "means to the sexual gratification of others" (Shakespeare et al., 1996, p. 125). Although Bowie thought devotism was "cool" and had several positive experiences with 'chair-chasers', he was apprehensive about their intentions and how they might negatively impact his opportunities for sexual pleasure and his individual autonomy.

The narratives of these five participants show that devotism may represent opportunities for sexual expression. However, these opportunities are also fraught with complex and numerous issues. For the majority of these participants, the opportunities for sexual expression that devotees offered them were not the agentic forms of sexual expression that they were looking for. While autobiographical and empirical literature has illustrated how "devotee desire can sometimes lead to genuinely intimate relationships", the women involved in this study who had experiences with devotism did not regard these experiences as opportunities for positive sexual encounters (Shuttleworth, 2007, p. 2; see also Aguilera, 2000; Duncan and Goggin, 2002; Kafer, 2000, 2004, 2012). These narratives complicate and add nuance to my finding that participants in this study encountered routine desexualization. Although the lines between "acceptable preference and unhealthy obsession may not always be clear cut" (Shakespeare et al., 1996, p. 124), these narratives illustrate that in addition to being viewed as non-sexual, disabled people are also viewed as "inherently kinky, bizarre, and exotic" (Kafer, 2003, p. 85). With this in view, I contend that when participants were desexualized *or* hypersexualized they were denied any control over their sexualities. Furthermore, I suggest that both these forms of oppression maintain an unequal power dynamic between non-disabled people and disabled people in the way that a disabled person's value as a sexual or romantic partner becomes overdetermined by their disability. Similarly, both desexualization and hypersexualization keep misconceptions about disability intact and can stem from the same impetus to dehumanize disabled people for the 'needs' of non-disabled people.

The hypersexualization of this small group of participants (n=5) is related to wider experiences of voyeurism that disabled people regularly encounter. As discussed in chapters five and six, the participants involved in this study were routinely subjected to interactions in which other people would lodge questions and comments about their bodies, sexualities, and disabilities. Participants' experiences with voyeurism can be productively analyzed through Reeve's (2002) concept of the 'able-bodied gaze' which refers to the ways that people with disabilities are viewed by non-disabled people through predominantly ableist frameworks. The able-bodied gaze both "invites and incites pity, admiration, approval and awe" (Liddiard, 2014, p. 97) and the "disciplining power of the gaze can leave disabled people feeling ashamed, vulnerable, and invalidated" (Reeve, 2002, p. 499). While participants managed the able-bodied gaze in different ways (i.e. education, subversion, etc.), their narratives show how the gaze has the potential to construct disabled people as non-sexual, hypersexual, or sometimes both.

I suggest that the voyeurism that the participants experienced is related to the ways in which people with disabilities are represented in media and popular culture. Many of the participants were perceived as objects of 'inspiration porn', which is a dominant mode of representing people with disabilities in media. Inspiration porn (or 'cripspiration') refers to the ways that disabled people are represented as inspiring or special even though they are simply "doing everyday activities, rather than anything actually heroic or inspiring" (Liddiard, 2014, p. 94). This mode of representation is particularly insidious because disabled people are used as "props for the emotional epiphanies of able-bodied characters" (Haller, 2010, p. 142), and as a means to "inspire or otherwise shape the behaviors and/or attitudes of the audience or viewer" (Liddiard, 2014, p. 94). Inspiration porn often functions as a reminder for non-disabled people that their lives are 'not that bad' or that 'things could always be worse'. Given that ableist modes of representation like inspiration porn both mirror and inform social attitudes about disability, it is not wholly surprising that participants were perceived as simultaneously inspiring and pitiful by other people.

Participants' experiences with devotism raise many issues and questions that are beyond the scope of this research but should be explored in further studies. For instance, a more thorough investigation into the ways that the internet and social media platforms can facilitate interactions with devotees would help to illuminate the positive and negative influences that the internet can have on disabled people's opportunities for sexual expression. Similarly, posing difficult questions like "what does labeling disability fetishism as pathological say about the cultural perception of impaired bodies?" (Shuttleworth, 2007, p. 2), or, "how can we desire disability, disabled bodies, without falling into the exceptionalist logic of desire and disgust that pervades devotees?" (Kafer, 2012, p. 348), will allow for more critical and complex analyses of the sexual politics of disability. As Shuttleworth (2007) suggests,

> What is especially needed is systematic qualitative research among devotees and the disabled people who chose to interact with them in order to begin to understand the either exceptional or normative, depending on the point of view, psychological, social, and cultural dynamics that are being articulated (p. 2).

Including and analyzing the experiences of this small group of participants helps to illustrate the range of diversity among the participants' experiences. Moreover, the experiences of these participants nuance and add to the overall complexity of the research findings. Additional research on devotism is required in order to illuminate how this phenomenon impacts disabled people's opportunities for sexual expression. Yet, Kafer (2012) cautions, "If a feminist and queer disability studies is about fundamentally questioning the processes by which certain bodies, desires, and practices become normalized, then perhaps searching for a single answer to the question of devotism is a misguided approach" (p. 349). The data included in this chapter offers multiple answers to the ways that devotism can impact disabled people's opportunities for sexual expression and points to some of the challenges that can be associated with managing interactions with devotees.

In this chapter, I have explored some of the tensions of occupying an identity that is routinely desexualized but also periodically hypersexualized. I have argued that desexualization and hypersexualization are interconnected and similar in the sense that they maintain an unequal power dynamic among people with disabilities and non-disabled people and often stem from the same impetus to objectify and dehumanize people with disabilities. Yet, I have also acknowledged that devotism raises questions that are beyond the scope of this research, and have stressed the need for further empirical research in this area. In the following chapter, I continue to discuss and further contextualize research findings and conclude by exploring how to better uphold disabled people's opportunities for sexual expression.

CHAPTER 8

Conclusion - Answering the Original Research Questions

"Writing this book, we have tried to perform a balancing act. On the one foot, we have had to discuss the oppression and marginalization experienced by disabled people, the barriers, the prejudice and the abuse. On the other foot, we have wanted to give a positive account, celebrating the resistance of disabled people, the delight and the joy of disabled peoples' sexual and emotional lives, the essential 'normality' of the disability experience. Some disabled readers will think our approach too optimistic – others will think it pessimistic and grim" – Tom Shakespeare, Katherine Gillespie-Sells, and Dominic Davies in The Sexual Politics of Disability (Shakespeare et al., 1996, p. 209).

Introduction and Chapter Overview

This study sheds light on the diverse ways that disabled people access and negotiate opportunities for sexual expression, an area of research that has been overlooked and understudied. Through conducting twenty-four interviews with physically disabled people that privileged their individual knowledge of experiences that lie at the intersection of sexuality and disability, I explored how they access opportunities for sexual expression and identified a range of barriers that they encountered. In order to pursue this line of inquiry, I posed two different research questions. First, how do individuals with physical disabilities access opportunities for sexual expression and what barriers influence their experiences? Second, how are dominant social constructions of sex and sexuality – such as the importance of penetration and genital orgasm in sex, or aesthetic ideals of what constitutes a 'sexy' body – challenged and/or reinforced through their experiences?

In this chapter, I conclude the dissertation by summarizing and further contextualizing the key findings that have been presented across chapters five, six, and seven. I begin this chapter by identifying the most common barriers that the participants experienced and address how these barriers manifested in different ways for certain groups of participants. I then move on to identify some of the limitations associated with this research. To conclude, I outline how to mitigate some of these barriers and discuss how to better ensure disabled people's opportunities for sexual expression.

Summary of Key Findings

My analysis reveals that the participants experience their sexualities in diverse and pleasurable ways. However, the participants were frequently prevented from doing so by a range of barriers. As a result, their opportunities for sexual expression were restricted, regulated, and routinely denied. Although some of the participants managed to forge routes around these barriers, other participants had less room to negotiate the restrictions that they faced. Participants were frequently excluded from spaces and social processes in which they could observe, practice, and learn about sexual scripts. Furthermore, many of the contexts in which people acquire information and experiences related to sex were difficult to navigate for participants and they experienced some of the most acute forms of desexualization within these contexts. The various ways that participants were excluded from many of the "dominant socialization processes that help teach and prepare people for love, sex, and intimacy" impeded their opportunities for sexual expression by fostering a sense of inadequacy, and by further perpetuating the belief that disabled people are not sexual (Davies, 2000, p. 181). Overall, the findings of this research support Liddiard's (2018) recent argument that ableism "continue[s] to shape the extent to which disabled people acquire knowledge about sex and sex-related topics such as contraception, sexual health, reproduction and intimate relationships" (Liddiard, 2018, p. 60).

The participants in this study often acknowledged that their impairments prevented them from engaging in certain sexual activities. However, participants' narratives made it abundantly clear that ableist attitudes limited their opportunities for sexual expression far more than their impairments did. Ableist attitudes and desexualizing assumptions unequivocally posed the most pervasive and persistent barriers to participants' sexual expression. The participants in this study felt that people with disabilities were rarely perceived as sexual beings and encountered numerous and sometimes contradictory assumptions about their sexualities. In particular, participants were routinely ascribed paradoxical sexual identities by others. While some participants were seen as non-sexual innocents, a small number of participants were also viewed as hypersexual deviants. There is a particularly painful irony in the ways that the participants were so highly visible in their difference, but also simultaneously invisible in terms of their sexualities.

Another common barrier that many of the participants in this study faced was inaccessible infrastructure. Inaccessibility prevented them from accessing spaces that are associated with romance, dating and sexual activity which consequently curtailed their opportunities for sexual expression. This was a significant problem that many of the participants encountered and is especially problematic because ableism "thrives on inaccessibility" (Livingston, 2000, p. 184). In turn, inaccessibility fosters ableism by, "making people with disabilities less visible, minimizing their chances of social interaction, and making isolation and stigma likely" (Livingston, 2000, p. 184). While participants could occasionally correct the desexualizing assumptions projected onto them, the biases embedded within the brick and mortar of our social world were much more difficult to correct. Like Kafer, (2012), I argue that "sexual marginalization is deeply connected to political and social marginalization" and suggest that dominant social constructions of disability which deny the reality that disabled people are sexual beings are both embedded within and reinforced by inaccessible infrastructure (p. 338). In this way, these two forms of oppression provide support for one another.

Barriers to sexual expression were not experienced equally by all of the participants and some participants had more difficulty accessing opportunities for sexual expression than others. For instance, issues with inaccessibility posed the most significant challenges to the participants who used wheelchairs or various mobility aids. In general, the participants who could not approximate the elusive and oppressive norms that constitute 'normal' embodiment, such as bodily control and independence, mobility, and verbal capacity or clear speech, experienced the most profound barriers and the most acute desexualization. Many of these participants required the services of personal attendants in their everyday lives, which meant that they were usually denied the privacy, assistance, and, in some cases, the autonomy that they required in order to access opportunities for sexual expression. For example, the participants who required assistance from attendants to prepare for dates or other opportunities for sexual expression were often denied the services that they needed. Thus, it was often the participants that needed the most assistance in accessing opportunities for sexual expression that experienced the most compound and complex barriers.

Similarly, LGBTQ+ participants often faced different barriers to sexual expression than heterosexual participants. Dominant social constructions of heterosexuality that position sex as an unassisted, heterosexual, penetrative, and phallocentric act could be problematic for any of the participants, regardless of their sexual orientation or gender identity. However, these constructions were especially detrimental to the LGBTQ+ participants who faced unique and intersecting barriers. In addition to being subjected to the belief that they were non-sexual, LGBTQ+ participants had to work against heteronormative presumptions that reinforced dominant heterosexual scripts. For example, *if* LGBTQ+ participants received some form of sexual education, the curricula that they were presented with generally precluded them on the basis of their disabilities and sexual orientations. In many ways, LGBTQ+ participants occupied “multiple, devalued and stigmatized identities”, and were therefore subjected to layered forms of stigma which greatly hindered their opportunities for sexual expression (Santinele Martino, 2017, p. 2).

Data analysis also shows that there were differences between the ways that the participants who became disabled later in life experienced and negotiated their sexuality, when compared to the participants who were disabled from birth. Many of these differences were related to the ways in which these two groups of participants were socialized. For instance, many of the participants who became disabled later in life had internalized a different set of expectations regarding romantic and sexual activity than those who were disabled from birth. Unlike participants who were born with their disability, these participants were implicitly and explicitly encouraged by others to date, get married, have children, and engage in other activities associated with romance and sex. During interviews, the participants who became disabled later in life often discussed how, prior to becoming disabled they had internalized ableist ideas of what it means to be disabled, had very little knowledge about disability, and had limited contact with disabled people. Much of this changed with the onset of impairment and disability, however, expectations and socialization did not merely disappear.

Moving from non-disabled to disabled was an immensely difficult process for participants who experienced onset of disability later in life. In addition to dealing with the challenges associated with adjusting to a new embodiment, or what Bury (1982) refers to as “biographical disruption”, these participants were faced with the challenge of reinterpreting various sexual scripts in light of their new corporeality. Some of these participants went through a period in which they felt as though they would never be sexually viable or ‘beautiful’ again. In the following narrative, Vanessa, a female participant who became paralyzed later in life, illustrates how the onset of disability could drastically influence the ways in which participants were perceived.

> **VANESSA:** *I was married at the time of my accident so, um, my husband told me that it took…it was within the first twenty-four hours of my injury that, ah…I was [age], I was beautiful, I was pregnant, I miscarried, but it took someone under twenty-four hours to mention to my husband that ‘oh, you could always divorce her and marry someone else’…So, I went from being extremely desirable to being disposable within the hour, within the same day. So, I have to tell you that, yeah, it was a pretty awful time for me. I was dealing with a lot but I think it was worse for*

> *me then because I felt really undesirable and just not like the beautiful person I knew.*

Vanessa's narrative reveals how becoming disabled was a process that was rife with pain and difficulty. Her account indicates that becoming disabled not only affected her sense of self as a sexually desirable person, but also her gender identity. Vanessa frankly expressed how she went from "being extremely desirable to being disposable within the hour" and explained how other people encouraged her husband to divorce her when she became disabled. While Vanessa's husband did not leave her, the suggestion that he could "always divorce her and marry someone else" shows that other people saw Vanessa as a worthless and unsuitable partner because she had become disabled. Ultimately, Vanessa's narrative implies that some people in her social circle predicated her value as a romantic partner on her beauty and her reproductive capacity. Like Vanessa, the other participants who became disabled later in life frequently expressed that they were ostracized and desexualized by other people once they became disabled.

Some of the participants who experienced onset of illness and impairment later in life explained how they went about developing new ways to feel sexy and discussed some of the emotional labor that was involved in this process. For instance, Joelle, a young woman with limb differences, discussed how she worked to become more comfortable with removing her prosthetic limb before intercourse, and explained that she put a good deal of effort and thought into how she would go about removing it in a "sexy" manner.

> **JOELLE:** *Well, coming from the experience of not having a disability for so long and then having one, like one of the main differences that I have noticed in my sex life is the removal of my leg, or whatever medical device I'm wearing. It is not a really sexy act and it seems almost out of place but there is no real way around it (laughs). Like, if you want to have sex, you have to take it off. You just have to get used to it. It took me a while to work that in and be okay with it though. I'm still working on doing it in a way that's like sexy, you know (laughs)?*

Participants who became disabled later in life often struggled with some of the expectations embedded in the sexual scripts that they internalized. Yet, as Joelle's narrative implies, the participants involved in this study worked to make new and alternative scripts that were tailored to their individual embodied realities. As discussed in chapter six, the participants developed a range of strategies in order to access and enhance opportunities for sexual expression that they were so frequently denied. Many of the participants resisted the desexualization that they experienced by taking on the role of an educator. This often allowed these participants to correct the desexualizing assumptions that they faced and functioned as a means to manage the stigma and desexualization they encountered. Helping other people to unlearn their ableist assumptions was a process that was laden with emotional labor. As noted in chapter six, educating other people could often be a tedious, tiring, and downright depressing process for participants. While this strategy was sometimes used as a means to maximize participants' opportunities for sexual expression, it was not without its complexities and limitations.

Subversion was another strategy that participants employed in order to correct desexualizing assumptions and access opportunities for sexual expression. The participants who made use of this strategy often did so in ways that both resisted and reinforced dominant social constructions of sex and sexuality. While some of the participants challenged the importance of ejaculation and penetration in sex in their narratives, they also confirmed the importance of things like genital orgasms in sex. Similarly, the number of sexual experiences or romantic partners that participants had was often invoked as testimony of their sexual prowess and value as a sexual being. Although the participants were not rigidly bound to dominant social constructions, they continued to utilize them in their everyday lives and in the narratives that they shared with me. While many participants employed broad definitions of what constitutes positive sexual experiences, the exclusion from "oppressive sexual systems did not automatically equate to meanings of sexual emancipation or liberation" and many participants struggled with shame, stigma, and discrimination (Liddiard, 2018, p. 175).

In conclusion, the findings from this study indicate that certain disabled people are viewed as more suitable candidates for sexual lives than others. LGBTQ+ participants, those with significant mobility restrictions, and participants who had routine interactions with personal attendants faced multiple and compound barriers to sexual expression and were usually the participants who were viewed as the least suitable candidates for sexual lives. The participants were desexualized both explicitly and implicitly and a small group of participants were subjected to a complex form of both hypersexualization and desexualization. I contend that desexualization and hypersexualization are not two opposite ends of a spectrum, but rather interconnected forms of objectification and dehumanization. Finally, the data analysis shows that despite deeply-rooted barriers to sexual expression, the participants often managed to challenge, subvert, and push past the barriers they faced. In the following section, I briefly outline limitations associated with this research. I then move on to identify possible ways to dismantle some of the barriers that the participants experienced and discuss how we might better ensure and uphold their opportunities for sexual expression.

Limitations

This study has several limitations that need to be addressed. Firstly, the sensitive and personal nature of the topics explored during interviews might have resulted in the participants withholding information due to embarrassment or apprehension (Renzetti and Lee, 1993). Moreover, the personal (but also deeply political) nature of these topics may have influenced who was interested in participating in this research by possibly attracting people who are passionate about this area of inquiry or people who are politically inclined.

Second, the use of non-probability sampling, the small number of participants involved in this research, and the exploratory nature of this research could all contribute to limiting the extent to which the research findings can be applied generally. Although the data produced by this study is rich in detail and sheds light on the diverse experiences of a group of people who have typically been underrepresented in research, it is not representative of the experiences of all Canadians who live with a physical disability.

Thirdly, a possible limitation of this study stemmed from the way that I framed the initial research questions that guide this analysis. The research question 'how do individuals with physical disabilities access opportunities for sexual expression and what barriers influence their experiences' and subsequent interview guide were framed in a way that did not elicit narratives about the participants' relationships. Moreover, the question was perhaps *too* focused on access and opportunities as opposed to experiences within relationships. Similarly, this research produced a significant amount of data about the contexts and spaces that tend to inhibit disabled people's opportunities for sexual expression. While this is undoubtedly valuable information, future research should explore which spaces and contexts help to facilitate opportunities for sexual expression. Further, what is it about these spaces that helps foster opportunities for sexual expression, and ostensibly, sexual pleasure?

Finally, the ways in which gender influenced the participants' experiences was neglected in order to examine the most prominent themes within the dataset and as a way to limit the overall scope of this research project. Throughout the course of this research it became apparent that oppressive gender role expectations could negatively impact the participants' opportunities for sexual expression. The lack of attention that has been given to gender could certainly be viewed as a limitation as it is an important issue that requires further attention and analysis. I plan to place more focus on issues related to gender in future analyses of data and publications that result from this research project.

Breaking Down the Barriers

Many of the participants in this research were excluded from formal sex education or were provided with inadequate information on this important issue. The lack of adequate sexual education had a number of negative consequences for participants and overhauling formal sex education programs so that they better include the experiences of disabled people and LGBTQ+ individuals is an essential step in dismantling some of the barriers that participants faced. Adequate sex education programs have the potential to "discredit the myths and stereotypes that exist, encourage healthy sexual behaviors, and provide children and youth with physical disabilities accurate and positive perceptions of sexuality" (Esmail et al., 2010a, p. 14).

A community-based research project piloted by Esmail et al. (2010a) that explored how to make guidelines for more effective sexual health education suggests the following; firstly, that individuals with disabilities should receive the same sexual education as other students and not be "singled out in a classroom amongst peers" (p. 39). More importantly, the sex education that all students receive should include topics like diversity, the psychosocial dimensions of sex, and "an overview of the impact of disability on sexuality without highlighting a specific student's needs in a given presentation" (Esmail et al., 2010a, p. 40). This would assist in making *all* of the students aware that people with disabilities are sexual beings. This research emphasizes that youth with disabilities should not be treated differently than their peers within the classroom, but rather be provided with additional resources that are customized to their needs in a smaller setting, through specialists or peer-mentors, or online. Doing so will help to ensure equal access to sexual health resources for both disabled and non-disabled individuals. Esmail et al. (2010a) also recommend that sexual education programs make use of multiple methods of delivery when providing sexual health information (e.g. braille, audiovisual resources, physical demonstrations for students with hearing impairments, etc.). Finally, this research strongly recommends using peer-mentors in formal sex education, or, at the very least, an instructor who is comfortable with and knowledgeable about disability and sexuality. Adopting the afore recommendations would undoubtedly address the lack of sexual education that participants received and could help to ensure that people with disabilities are perceived as sexual beings.

In addition to overhauling sex education curriculum, there is a need for medical health professionals, personal attendants, social workers, and other people who work with disabled people to "audit their services to ensure that they are not being delivered in ways that undermine the possibilities for intimacy" (Emens, 2009, p. 222). The participants in this research routinely discussed how interactions in medical settings or with personal attendants posed various challenges to their sexual health and expression. In many ways, the places and people that perhaps had the most to offer to the participants in terms of assistance and information tended to be the most persistently problematic. For instance, the lack of privacy that was afforded to the participants who had daily interactions with personal attendants was a significant factor in shaping their opportunities for sexual expression. Similarly, participants encountered delays when attempting to access information or services related to sex from their medical health providers.

Guidelines that help to train and guide the conduct of medical professionals and personal attendants would help to address some of the multiple and complex issues that participants encountered. Denmark's national 'Guidelines About Sexuality Regardless of Handicap' that I detailed in chapter three provide a model for such guidelines. Documents like these can help to provide practical and ethical information regarding what attendants should and should *not* do to help facilitate their clients' sexualities (Kulick and Rydström, 2015). Fortunately, attendants and other medical professionals who reside in Canada now have access to training that specifically addresses issues related to disability and sexuality. In 2017, the University of Alberta established an online Graduate Certificate in Sexual Health that is specifically designed to address the gap in awareness and training about issues related to disability and sexuality among medical professionals. Programs like this have the potential to break down some of the barriers that people with disabilities face in their interactions with medical health professionals and can rectify the lack of attention that is currently given to issues related to disability and sexuality.

Lastly, throughout this dissertation I have drawn connections between the ways that the participants were perceived in their everyday lives and the ways that people with disabilities are represented in media and popular culture. Improving the utterly dehumanizing ways in which disabled people are represented in media could help to break down the stigma and silence that surrounds disability and sexuality. Lamb and Layzell (1994) also problematize the ways in which people with disabilities are represented and link this to the desexualization and discrimination that they encounter. They argue that,

> There is an unspoken taboo about relationships and disabled people. Disabled people's sexual and emotional needs are rarely included in any discussion or representation in everyday life, whether this is in the newspapers and magazines we read, or the movies we watch. This reinforces the public's attitudes and expectations towards disabled people as seeing them as 'sick and sexless', rather than participating in full sexual and family relationships. It is perhaps one of the most pernicious ways in which society has blanked out disabled people from a fundamental area of social life (Lamb and Layzell, 1994, p. 21).

As Lamb and Layzell argue, people with disabilities are largely precluded from media and popular culture. In addition, mainstream Hollywood movies tend to hire non-disabled actors to play disabled characters, fail to consult disabled people during production, and invoke a number of ableist tropes (Haller, 2010). For instance, many Hollywood films focus on a disabled character, particularly a man's inability to perform sexuality or 'do' gender in a traditional and heteronormative way and entire plotlines therefore revolve around questions of erectile functioning (Shakespeare, 1994; see also Block, 2000; Gowland, 2002; McRuer and Mollow, 2012; Shildrick, 2007, 2009; Waxman-Fiduccia, 1999). This is problematic for a number of reasons but especially because "many people have no contact with disabled people and so they gain their knowledge of disability from mass media" (Harris, 2002, p. 144). With this in view, there is a need for more positive and realistic depictions of disabled people in media, particularly a need for better portrayals of love, sex and disability. More nuanced and less stereotypical representations of disability and sexuality in media and popular culture have the potential to challenge the widespread belief that disabled people are non-sexual.

To summarize and conclude this section, then, the eradication of barriers to sexual expression that disabled people face hinges upon broader sociocultural changes that support their sexual and intimate lives. Prioritizing some of the afore mentioned suggestions would help to ensure that disabled people are given equal opportunities for sexual expression and sexual fulfillment.

Parting Words

Inspired by Shakespeare et al.'s (1996) landmark study on the sexual politics of disability, I concluded each interview by asking participants if they had any advice that they would share with other disabled people about sex and relationships. The responses that I received were wide-ranging, insightful, and profound. In order to prioritize the 'voices' and experiences of the participants I have chosen not to analyze these excerpts and to let them stand for themselves. Overall, the following collection of narratives point to the multifaceted, agentic, and diverse ways that the participants understand sexuality and all that it can entail.

> **JOCELYN**: *Do your research. Know your limits. Don't try to push yourself because your partner thinks that's how it should be done. What you are comfortable with doesn't mean that's what is the norm.*
>
> **RICARDO**: *Create your own spaces and ah, let people in.*
>
> **DAPHNE**: *Definitely don't settle. And…be adventurous, and have fun! I dunno, I am trying to think of some good stuff. I think being in a relationship you have to be open-minded to what the other person wants and like sometimes the things they want sexually may be not what you are into. As long as it doesn't make you feel shitty… like I have done stuff where it was like 'okay I'll try it'.*
>
> **JIM**: *Ah, I dunno if I have any advice that, um, lemme think…I guess I would say, like get to know your body and I guess that your gonna enjoy your life more if you can love your body. I think that can have like unexpected benefits in relationships, like being confident in yourself and loving who you are. What do they say? You can't love somebody else or be loved by somebody else if you don't like love yourself. That's important.*
>
> **VANESSA**: *Hmm, don't worry about rejection and go for it. There are plenty of fish in the sea and life is too short not to at least try…And don't worry if you have to wait to find the right person for you either.*
>
> **MICK**: *Um, I guess not to let some of the stuff we talked about get you down. If people don't think your sexy then that's on them. You are sexy!*
>
> **THERESA**: *I think my best advice is to take time to figure out what works for you and what doesn't and try to own that. That's all we can do really, right? I mean, yeah. Just like don't be afraid to voice what you need and figure out what feels good for you. I think that can be a hard thing to do sometimes, especially for us women.*
>
> **BOWIE**: *Ah, just stay open. Stay open to anything and everything because, you know, someone with a disability is someone still by and large ah a minority demographic you are going to go into a world, the sexual world, um basically in unchartered territory. You are going in without any preconceived concept of what sex is going to be like to you so like the biggest thing if I were to go back and talk to myself ten years ago that is what I would say, 'stay open and don't look at anything as a negative experience'. Just be easy and it will work itself out. And*

> *that's what sexuality is to me it's like being comfortable in everything in all aspects of experience and so like that would be like, simply stay open.*

In conclusion, this research has explored the ways in which people with disabilities experience and access their opportunities for sexual expression. As shown, the participants in this study encountered innumerable barriers to opportunities for sexual expression. The participants in this study are not victims and they countered many of these barriers with resiliency, strength, and agency. The refusal to accept and value disabled people's sexualities is a social justice issue with far-reaching consequences. It is important for all people to consider how we might contribute to a culture that upholds and affirms disabled people's right to a sexual life. Although it may seem like a daunting task, the results would be beneficial for not only people with disabilities, but for all citizens.

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Appendices

Appendix A:

Excerpt from Reflexive Research Diary

The following excerpt has been selected from my reflexive research diary. I have chosen to transcribe this entry verbatim because it more accurately reflects the emotions, reactions, and reflections that I was experiencing while writing. This entry captures some of the issues that I encountered while conducting interviews and collecting data. As noted in Chapter 2, maintaining a reflexive research diary was a way to take note of important observations and provided a place for my reflexive writing.

Today's interview was rough. It felt like I got some good data but it also was obvious that I wasn't always asking the right questions. I'm reflecting now on how my ableist assumptions are influencing this project in ways that I really hadn't thought about. Like the fact that I assumed that this participant would have had some sexual experiences. I'm also trying to use this as a learning experience and not get too bogged down but ultimately, I need to go back to the drawing board and revise my interview guide. I probably made this participant feel uncomfortable and as much as I'm feeling like an idiot I have to keep that in mind. I don't know, interviews are a lot harder than I thought they might be. I guess I am realizing that talking about sex in the abstract to a bunch of students is a lot easier than questioning someone about their sex life. Particularly someone who hasn't had any sexual experiences. Big learning curve and unlearning curve, I guess.

Anyway, other than totally feeling like I put my foot in my mouth, it was a good interview. He was totally frank, super smart, and also really kind. It is interesting to think about how all of his different diagnoses and disabilities intersect with his identity as a straight male. Another good thing about this interview is that he was another participant that was above the age of 35. Good to get another perspective from someone that is a bit older than the people that I've interviewed so far. This was an especially sad interview though. I'm gonna check back with him soon just to follow up. This guy had some really awful but interesting experiences with sex ed. Note the love for Breaking Bad and how he mentioned he was a "history buff". Good interview location and data.

Appendix B:
Calls for Participants

Sociology & Anthropology Department
Concordia University

Social Sciences and Humanities Research Council of Canada
Conseil de recherches en sciences humaines du Canada
Canada

CALL FOR PARTICIPANTS

Participants needed for research on disability and sexuality

The purpose of this research is to gather information on the various ways that people with disabilities experience and create their gender and sexuality. This research is undertaken in an effort to address and reduce the stigma surrounding disability and sexuality.

You are eligible to participate if:

- **You self-identify as disabled.**
- **You are above the age of 18.**
- **You live in one of the following locations: Montreal, New Brunswick, Nova Scotia, Prince Edward Island, or the Greater Toronto Area.**
- **You are willing to discuss your experiences of disability, particularly those that are related to sex, sexuality, and gender.**

As a participant in this study you will be asked to participate in an hour-long interview with the researcher. The interview will be scheduled at your convenience, you will be compensated for your time, and your identity will remain confidential. You will be asked demographic questions (e.g. age, gender, ethnicity) and questions about your ideas and experiences that relate to sex and gender. **For more information about this study or to volunteer, please take one:**

Email:sarahmargaretcampbell @gmail.com **Website:**https://sexualityand disability.wordpress.com	**Email:**sarahmargaretcampbell @gmail.com **Website:**https://sexualityand disability.wordpress.com	**Email:**sarahmargaretcampbell @gmail.com **Website:**https://sexualityand disability.wordpress.com	**Email:**sarahmargaretcampbell @gmail.com **Website:**https://sexualityand disability.wordpress.com	**Email:**sarahmargaretcampbell @gmail.com **Website:**https://sexualityand disability.wordpress.com	**Email:**sarahmargaretcampbell @gmail.com **Website:**https://sexualityand disability.wordpress.com	**Email:**sarahmargaretcampbell @gmail.com **Website:**https://sexualityand disability.wordpress.com	**Email:**sarahmargaretcampbell @gmail.com **Website:**https://sexualityand disability.wordpress.com	**Email:**sarahmargaretcampbell @gmail.com **Website:**https://sexualityand disability.wordpress.com

Appendix B:
Calls for Participants

Sociology & Anthropology Department
Concordia University

Social Sciences and Humanities Research Council of Canada
Conseil de recherches en sciences humaines du Canada
Canada

CALL FOR PARTICIPANTS:

Participants needed for research on disability & sexuality:

The purpose of this research is to gather information on the various ways that persons living with a physical disability experience and create their gender and sexuality. This research is undertaken in an effort to address and reduce the stigma surrounding disability and sexuality.

You are eligible to participate if:

- **You self-identify as disabled or live with an impairment.**
- **You are above the age of 18.**
- **You are willing to discuss your experiences of disability (read: physical impairment), particularly those that are related to sex, sexuality, and gender.**

As a participant in this study you will be asked to participate in an hour-long interview with the researcher. The interview will be scheduled at your convenience, your identity will remain confidential, and you will be compensated for your time. You will be asked demographic questions (e.g. age, gender, ethnicity) and questions about your ideas and experiences that relate to sex and gender. **For more information about this study or to volunteer for this study please take one:**

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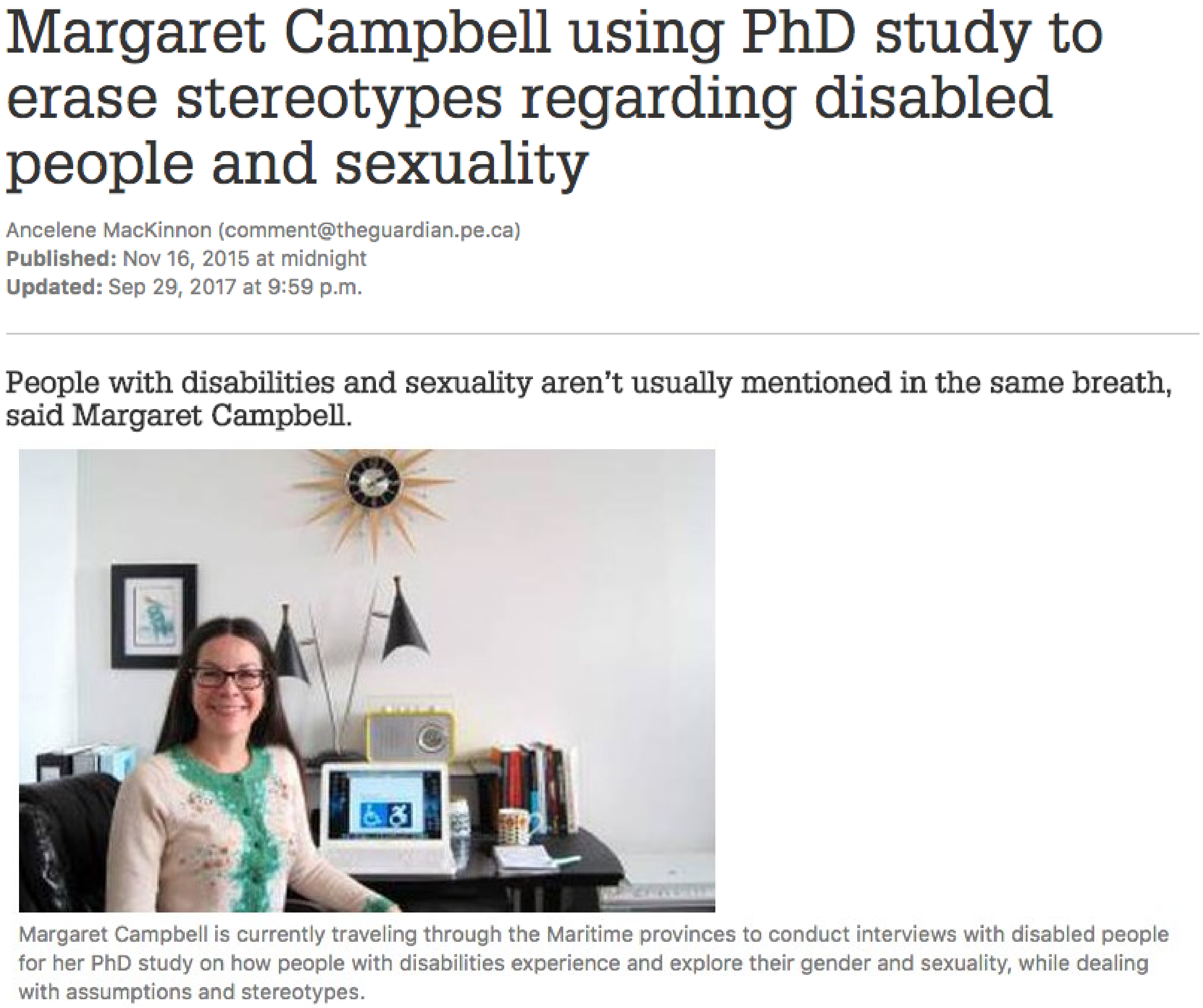
Appendix C:
Media Coverage



Margaret Campbell using PhD study to erase stereotypes regarding disabled people and sexuality

Ancelene MacKinnon (comment@theguardian.pe.ca)
Published: Nov 16, 2015 at midnight
Updated: Sep 29, 2017 at 9:59 p.m.

People with disabilities and sexuality aren't usually mentioned in the same breath, said Margaret Campbell.

Margaret Campbell is currently traveling through the Maritime provinces to conduct interviews with disabled people for her PhD study on how people with disabilities experience and explore their gender and sexuality, while dealing with assumptions and stereotypes.

That's part of what Campbell is trying to change with her PhD study.

"What I'm looking at in my PhD research is the various ways people with disabilities experience and explore both their gender and sexuality in the midst of sociocultural assumptions and stereotypes that have traditionally worked to desexualize individuals with disabilities," she explained.

A large portion of her research has gone into identifying physical or attitudinal barriers people with disabilities experience in an attempt to reach a fulfilling and actualized gender or sex life, she said.

"What has been excellent is listening to my participants share their experiences and the creative ways they dealt with the issues they face.

"My goal with the study is to give these voices a forum. In Canada, we unfortunately don't have a comprehensive act or law around disability. People will say they feel limited. I'd like to make some concrete policy suggestions in terms of disability support services."

Appendix C:
Media Coverage

Campbell, who is in her fourth year of the Social and Cultural PhD program at Concordia University in Montreal, said Statistics Canada shows 4.4 million people live with a disability.

She's looking to speak with 30 people with disabilities, whether they were born with them or became disabled later in life, and she has already conducted interviews across the country.

She has been interviewing men and women, gay and straight, with hearing impairments, people that are wheelchair users, people that are missing limbs, and some that have facial deformities or diseases that affect their bodies.

A federal grant has allowed her the opportunity to travel, and provide compensation to those she interviews.

"It's been really great to go and meet these people and forge a connection."

Participants have opened up to her about the physical barriers, such as having difficulty entering a nightclub or bar, a place traditionally used to possibly meet someone.

"But then there are a lot of attitudinal barriers that able-bodied people may think about those with disabilities. Often we think they can't have sex, they're not interested in having sex, or that people with disabilities can't be competent parents," she said.

The study is important to her because disability paired with employment, education, and accessibility are public concerns; however, the private concerns like gender and sexuality have been left behind.

"There were times when it has been sad to hear some of the experiences these people had, and other really brilliant times where these people have really rejected problematic perceptions of masculinity and femininity and said, 'no, I'm going with my own version.'"

In one word, having the opportunity to conduct this research makes her feel 'privileged'.

"Some days it's overwhelming, but I feel there's a responsibility to my participants to make sure they are represented accurately, and to make sure this goes someplace and impacts people's lives in Canadian culture."

Campbell will be on the Island in the next week, and anyone with a disability interested in participating in her study can contact her at sarahmargaretcampbell@gmail.com.

Appendix D:
Consent Form

CONSENT TO PARTICPATE IN
Examining Myths & Questioning Normalcy: Exploring Disability, Gender, & Sexuality

I understand that I/the participant have/has been asked to participate in a study conducted by Margaret Campbell, a third-year doctoral student in the Department of Sociology and Anthropology at Concordia University in Montreal Quebec. Margaret can be reached by email at gzqtk@stu.ca or by phone at 1-438-777-7878.

A. PURPOSE: I have been informed that the purpose of this research is to interview persons who have a physical disability (i.e. impairment) in order become familiar with how persons with physical disabilities experience gender and sexuality. I understand that the principal researcher (Margaret Campbell) will pose questions regarding my understanding of masculinity, femininity, sexual expression, and barriers to sexual expression.

B. PROCEDURES: I understand that I will participate in one, hour-long interview with Margaret Campbell. I understand that this interview will explore topics such as my experience of physical disability, my opinions on topics such as representations of disability and sexuality in television and Hollywood films, my thoughts and feelings regarding my gender and sexual orientation, the sexual education I have received, and my relationship status. I am aware that the interview will be audio-recorded and then transcribed. I understand that my information will be kept confidential and that my name will not be associated with or appear on either the audio recording or the transcription of the interview. I am aware that the researcher will replace my name with a pseudonym and that some of my information will be coded in order to ensure my anonymity. I also understand that the researcher has plans to publish the results of this study and that any publications will not contain my name or identifying information. I understand that in addition to participating in an hour-long interview, I will receive follow up information related to the study via e-mail, and if possible, I will recommend one other person with a physical disability to the researcher for a potential interview.

C. RISKS AND BENEFITS: I understand that there is a certain level of risk associated with this study as it deals with topics of a personal and often sensitive nature such as disability, ableism, sexuality, gender, and dating. Potential risks associated with this study include experiencing embarrassment or emotional discomfort, and being reminded of painful past experiences such as a bad break up or the death of a loved one. I certify that I have been informed of these risks by the researcher and that the researcher has informed me of my right to stop the interview at any point during the interview without any negative consequences. I also certify that the researcher has informed me that if I decide to withdraw my participation after the interview has taken place I have until the date of June 1st 2015 to do so. I am aware that I might or might not personally benefit from participating in this research. I am aware that some of the potential benefits associated with this study include: the opportunity to discuss topics that are underexplored and traditionally treated as taboo and air grievances related to inaccessible infrastructure, exclusion, and ableism.

D. CONFIDENTIALITY: I understand that my identity will remain confidential and the researcher will protect my information by coding and the development of a pseudonym. I understand that information associated with this study will be kept under lock and key in a secure environment and that data associated with this study will be destroyed after five years. I understand that the researcher has a legal and ethical responsibility to report certain types of information to relevant authorities. For example, information that details situations where participants plan to inflict serious harm to him/herself or others, or other situations where an external party is harming participants in some way will be reported to the relevant authorities.

E. CONDITIONS OF PARTICIPATION: I understand that I do not have to participate in this research study. I understand that there is no obligation to participate in this study and that participation is purely voluntary. I understand that if I do not want my information used in this study I have until June 1st 2015 to notify the researcher. I understand that there will be no negative consequences if I decide to not participate, if I choose to stop the interview, or if I ask the researcher not to use my information.

F. PARTICIPANT'S DECLARATION: I have carefully read and understand this form. I have had the chance to ask questions and my questions have been answered. I agree to participate in this research under the conditions described above.

NAME (please print) ____

SIGNATURE ____

DATE ____

If you have questions about the scientific or scholarly aspects of this research, please contact the researcher. Their contact information is on page 1. You may also contact their faculty supervisor. If you have concerns about ethical issues in this research, please contact the Manager, Research Ethics, Concordia University, 514.848.2424 ex. 7481 or oor.ethics@concordia.ca.

RESEARCHER CONTACT INFORMATION:

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