Dissertation Proposal

The Romantic and Sexual Experiences of Adults with Intellectual Disabilities in Ontario, Canada

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INTRODUCTION

This dissertation will examine the sexual and intimate lives of adults with intellectual disabilities by putting into conversation theories from both the sociology of sexualities and the field of critical disability studies. The intersection of disabilities and sexualities remains a taboo topic in our society (Esmail et al. 2009; Shakespeare 2014). Research on the intersection of disabilities and sexualities remains under-researched and under-theorized in both the sociology of sexualities and critical disability studies, resulting in significant gaps in our understanding of the sexual and intimate lived experiences of disabled people (Erel et al. 2011; Kattari 2015; Liddiard 2011, 2013; McRuer and Mollow 2012).

The field of disability studies has done the radical work of not only placing disability at the center of analysis, but also shifting our attention from understandings of disability based on medical, charity, and individualized approaches to a more structural one (Beckett 2006; Shakespeare 2006, 2015). However, people with intellectual disabilities have commonly been seen as being incapable of having sexual desires and as being ‘eternal children,’ and many are shocked that people with intellectual disabilities have sexual desires or are sexually active. On the other hand, people with intellectual disabilities are also understood to have deviant and ‘excessive’ sexualities, which often leads to calls for restrictions on their sexual rights (Alberty and Lewiecki-Wilson 2008; Esmail et al. 2009; McRuer 2015; Shakespeare 2014).

Further, disability studies and activism have historically considered sexualities to be an apolitical or personal matter (Finger 1992; Liddiard 2011; Shakespeare et al. 1996; Shuttleworth and Mona 2002). While some scholars in the field of disability studies have invigorated the study

of sexualities among people with disabilities (McRuer 2011; McRuer and Mollow 2012; Shakespear 2000; Wilkerson 2011), much of this research has studied the issue theoretically or from an individualized approach. However, people with intellectual disabilities have romantic and sexual feelings, needs and desires and therefore should be entitled to the same sexual rights, protections, and choices as non-disabled people (Aunos and Feldman 2002; Dupras 2015; Goodley 2003; Löfgren-Mårtenson 2004; Saxe and Flanagan 2014). Yet, there is sufficient evidence that people with intellectual disabilities experience innumerable barriers to remain sexual and exercise choices concerning sexual partnerships and intimacy (Gill 2015; Kulick and Rydström 2015). Hence, empirical research is needed on the intersection of disabilities and sexualities, applying a multi-level analytic methodology. As Shuttleworth and Mona (2002:2) have appropriately noted, the “individualizing focus” on disabilities and sexualities:

has tended to draw attention away from the socio-structural relations between disabled and non-disabled people, the symbolic meanings of disability and desirability in the larger culture, and the psychological implications of experiencing multiple barriers to sexual expression and establishing sexual relationships.

In contrast to the largely individualistic approach of disability studies, the sociology of sexualities has applied a multi-level approach that takes into account micro- and meso-level social processes that include sexual identities, desires and encounters, as well as macro-level processes that involve politics, culture, social institutions, and the economy, all of which shape the construction of sexualities (Bernstein 2013). Also, whereas previously, non-normative sexualities were often examined through the lens of social deviance, sociologists of sexualities have turned the focus instead on the social and historical constructions, institutionalization, and regulation of sexualities that constitute normal and deviant sexualities (Bernstein 2013). Scholars in the sociology of sexualities are now paying more attention to intersectionality and how

sexualities are intertwined with other stratification systems (Bernstein 2013; Collins 2005; Gamson and Moon 2004; Plummer 2012). Yet, despite the awareness that social categories intersect to shape sexual experiences and sexualities of individuals and social groups, sexualities researchers have paid little attention to the experiences of disabled people (Erel et al. 2011; Kattari 2015).

Overall, there is a limited body of literature that specifically addresses the sexual desires and interests of people with intellectual disabilities. With this in mind, one rich theoretical approach to the question of sexual desire – both on a micro-level and macro-level – is the sexual fields framework (Green 2014; Martin and George 2006), and I suggest that it is an ideal approach to analyzing the sexual lives of people with intellectual disabilities. This theoretical framework not only places desire “out in the open for all to see,” but also gives us the analytical tools to systematically explore the *nonrandom* organization of desire, as well as “the ‘negative’ of desire: rejection” (Lizardo 2014:xi-xii). Hence, the sexual fields approach provides a rich set of concepts, which have not been applied in the context of disabled people’s sexual lives, and can help us better understand the sexual experiences of people with intellectual disabilities, including sexual fields, sexual capital, and erotic habitus (Green 2015).

It is important to note that sexualities and disability studies scholarship have only recently been put into dialogue (Jungels and Bender 2015). Nevertheless, as Jungels and Bender (2015:179) have noted, “there is a great potential and urgent need for disability and sexuality scholars to bring their fields together to more fully understand the sexual lives and needs of people with disabilities, especially given the ability to create positive changes in the lived experiences of disabled individuals.” This research will build on this nascent interdisciplinary conversation to: 1) provide new theoretical tools that disability studies can use to understand the

ways that individuals with intellectual disabilities negotiate sexual desire and experience, and 2) contribute to the sexual fields framework by examining new ways to conceptualize sexual fields, sexual capital and erotic habitus by applying these to the study of the experiences of people with intellectual disabilities.

This research will employ a qualitative research approach and, in particular in-depth interviews, with four groups of adults with intellectual disabilities in Southern Ontario, including those living in 1) controlled group homes; 2) in supported independent living; 3) in family homes; and 4) independently. In-depth interviews allow for a detailed exploration of the sexual and intimate lives of people with intellectual disabilities “in their own words and ... on their own conditions [as] they may express views, give words to their experiences and describe events and situations” (Boeije 2010:32). In this way, my research will make space for people with intellectual disabilities to share their experiences with love and intimacy, challenging the invisibility of the sexualities of people with intellectual disabilities, and contributing to a growing body of literature that is finally listening to people with intellectual disabilities themselves (Rushbrooke, Murray and Townsend 2014). The literature has also tended to ignore the agency of people with intellectual disabilities (Gill 2015) who, despite all challenges, have agency and engage in subversive acts to become and remain sexual (Gill 2015; Löfgren-Mårtenson 2004; Noonan and Gomez 2011), which I will explore in my research.

Most studies drawing on the sexual fields framework have used an ethnographic approach focusing on particular sexual sites and sexual fields (Farrer 2010, 2011; Farrer and Dale 2014; Green 2008, 2011; Weingberg and Williams 2010, 2013). Considering the well-documented social isolation, restrictions, and surveillance experienced by many people with intellectual disabilities who are often unable to access a significant array of sexual sites (Clement

and Bigby 2008; Cummins and Lau 2003; Löfgren-Mårtenson 2013), an ethnographic approach to studying sexual fields that focuses on particular sites is inadequate to capturing the experiences of people with intellectual disabilities.

My research will address 3 main interrelated research questions concerning the sexual and intimate lives of people with intellectual disabilities:

- 1) What sexual fields, including both physical and online spaces, do people with intellectual disabilities navigate (or aspire to navigate) in their pursuit of love, romantic intimacy, and sex?
 - o What kinds of opportunities and barriers do people with intellectual disabilities face to access sexual fields?
 - o What role do people with intellectual disabilities have in making decisions about access to sexual fields?
- 2) What forms of sexual capital do people with intellectual disabilities draw on?
 - o Are these forms of sexual capital similar or different from those proposed by Green (i.e. physical appearance, affective presentations, and eroticized socio-cultural styles)?
 - o What do people with intellectual disabilities desire in sexual partners?
 - o What strategies do people with intellectual disabilities use to attract and obtain sexual partners of their choosing?
- 3) How is the erotic habitus of people with intellectual disabilities, which includes erotic dispositions, knowledge and tools, shaped by their access and barriers to sexual capital and sexual fields?
 - o How do people with intellectual disabilities learn about sexuality?
 - o How do the sexual and romantic experiences and knowledge (or lack thereof) shape how individuals with intellectual disabilities navigate sexual fields and negotiate sexual encounters?

In the following sections, this proposal will discuss the sexual fields framework, its potential to shine new light on the structures of desirability for those with intellectual disabilities, and its potential to contribute to disability studies, as well as the ways that applying a disability studies framework might contribute to our understanding of sexual fields.

LITERATURE REVIEW

The Sexual Fields Framework

The sexual fields framework has been responsible for a “landmark theoretical turn” within sociology by focusing on sexual stratification as a “particular kind of social order in its own right,” an area for which “sociology, in general, and social theory, more specifically, have paid too little attention” (Green 2011:246). Though not a simple task, the framework brings to view the connection between individual desire and sexual experience on one hand and the collective sexual life as a system of stratification on the other (Green 2008a, 2011). In their pursuit of sexual partnering, people navigate sexual fields, which “are by their nature arenas of sociality, pleasure-seeking, and competition” that are inherently uneven (Green 2008b:35). “Playing” the field requires that sexual actors understand the structure of the sexual field itself, including who is desirable, and where they fit within the field (Green 2011).

Sexual capital shapes who is desirable within sexual fields and positions people differently within sexual fields (Craig 2016; Green 2008a). Sexual capital should be understood as a person’s attributes, resources, and competencies that create an erotic response in another and provides status to sexual actors within sexual fields (Green 2014; Leschziner and Green 2013). Rather than approaching desire as an individual characteristic, the sexual field framework places desire and sexuality as a part of erotic habitus (Craig 2016). The concept of erotic habitus refers to unconscious dispositions that predispose sexual actors towards particular kinds of sexual partners. These dispositions are then tied to larger social structures and hierarchies of desirability that reproduce inequalities (Green 2008, 2014).

Previous studies using the sexual fields framework have made a significant contribution to the sociology of sexualities by demonstrating, empirically, how desire and desirability are collectively produced (Moon 2015). This body of literature has illuminated, for instance, new forms of sexual capital (e.g., alien sexual capital, interracial sexual capital; Farrer 2010); the

complexly dynamic parameters of desirability and the interactional underpinnings of desires and desirability in sexual fields (Weinberg and Williams 2014); the ways in which sexual fields may produce and/or accommodate desires that are not mainstream (Farrer and Dale 2014; Weinberg and Williams 2014); instances that suggest that not all sexual fields are sites of hierarchies and struggles (Hennen 2014); how sexual actors exchange and convert forms of capital to increase their erotic capital within sexual fields and their chances for partnering (Craig 2016; Farrer 2010; Willey 2010); the ways that social locations like race, gender, ethnicity, and citizenship intersect to shape the experiences of sexual actors in sexual fields (Farrer and Dale 2014; Green 2008; Lewis 2014; Schilt and Windsor 2014); the consequences to the psychological and emotional wellbeing of individuals attempting to maximize their erotic capital (Farrer 2010; Green 2008). This literature has also mapped out “sexual circuits” – sexual sites that are spread out and where people who may not know each other frequently rub shoulders (Adam and Green 2014) – and explored the “anatomy” of particular sexual fields including their unique tiers of desirability and distributions of erotic capital (Green 2008, 2014).

On the other hand, the current literature also has significant limitations, especially when we try to apply the sexual fields framework to the romantic and sexual experiences of people with intellectual disabilities. A secondary contribution of this dissertation will be to illuminate how certain aspects of disability may trouble and complicate some taken-for-granted assumptions in the sexual fields framework. For instance, the existing research on disabilities and sexualities suggests that the patterns of romantic and sexual relationships of people with intellectual disabilities are considerably different from that of non-disabled people as questions of when, where, how and with whom to be sexual are significantly more complex, and the choices more restricted for people with intellectual disabilities (Gill 2015; Kulick and Rydstrom

2015; Löfgren-Mårtenson 2013). The sexual and intimate lives of people with intellectual disabilities have been marked by a history of protectionism, infantilization, and paternalism (Winges-Yanez 2014). As a consequence, people with intellectual disabilities have experienced significant restrictions in terms of exploring their sexuality, accessing and navigating sexual fields, and developing their sexual capital in comparison with non-disabled people. This lack of access to opportunities for sexual exploration, experimentation, and relationships has an impact on the sexual capital and erotic habitus of people with intellectual disabilities. When automatically understood as not having sexual and romantic desires, or being child-like, people with intellectual disabilities are presumed to have no need for developing sexual capital. Conversely, if perceived as having a deviant sexuality, people with intellectual disabilities' sexual capital should also be presumably contained, discouraged, and restricted. The current sexual fields literature, however, has not taken into account the consequences of such historical marginalization and exclusion on the experiences of sexual actors within sexual fields.

The line separating public and private spaces is often blurred in the lives of people with intellectual disabilities who may live with and receive care supports from family members and support workers and, due to protectionism, infantilization, and restrictions, commonly experience a lack of privacy (Gill 2015; Hollomotz and The Speakup Committee 2009; Lesseliers and Van Hove 2002). Secondly, for some people with intellectual disabilities, regardless of their age, various forms of sexual expression, which are often taken for granted in previous studies using the sexual fields framework, including accessing sexual sites on their own or having casual sex, may be discouraged or prohibited (Löfgren-Mårtenson 2013). That is to say that my research will generate insights that can also contribute to the theorizing of the sexual fields framework.

Conversely, in relation to disabilities, Ignagni et al. (2016:132) has noted that we know “little about the spaces people [with intellectual disabilities] may easily access and claim, and how these may shape intimate subjectivities, relations and practice,” and thus, it is relevant to explore the sexual fields that people with intellectual disabilities navigate (or aspire to navigate) in their pursuit of love, intimacy and sex. It might be the case that, similar to previous studies drawing on sexual fields, I too will find forms of “specialized erotic worlds” that people with intellectual disabilities navigate (Green 2008:27). There have also been a few studies exploring how some people with intellectual disabilities use communication technologies for accessing potential partners (Löfgren-Mårtenson 2008; Löfgren-Mårtenson, Sorbring and Molin 2015). Löfgren-Mårtenson (2008:125), for instance, found that some people with intellectual disabilities viewed the Internet as a place where they can be “like everybody else,” thus increasing their chances of partnering. Some of my participants may use the Internet as a sexual field and, for that reason, it is important to look at virtual spaces as well. By thinking about sexual fields, both in terms of physical and online sexual sites, we will be able to better understand the barriers and opportunities for people with intellectual disabilities to access spaces for sexual exploration and encounters as well as how they experience and negotiate these spaces.

Further, we have limited knowledge about the dating patterns of people with intellectual disabilities, including how they select their romantic and sexual partners as well as how they make sense of and reflect on their own position as a sexual actor within hierarchies of desirability as they choose or not to pursue the potential romantic and sexual partners they have chosen (Bates et al. 2016). Not surprisingly, though, it has been suggested that people with intellectual disabilities have their own “hierarchy of attraction,” or desirability, when it comes to selecting partners (Löfgren-Mårtenson 2004:203). Therefore, through the sexual fields

framework, my dissertation will contribute to the sociological literature on sexualities by investigating who and what people with intellectual disabilities desire as sexual actors; how they assess their sexual capital, as well as that of others; how they make decisions about whether or not to pursue certain potential sexual partners; how they develop their own hierarchies of desirability as well as how they respond to hegemonic hierarchies of desirability; and what strategies they use to increase their chances of partnering. By asking these questions, my research will explore whether the forms of sexual capital that people with intellectual disabilities draw on are similar or different from those proposed by Green (2014).

With this mind, my research will apply a sexual fields framework to shed new light on the sexualities and sexual experiences of people with intellectual disabilities. The sexual fields framework will help us better understand the inequalities, power struggles, challenges, resources, and forms of resistance experienced by people with intellectual disabilities who, as a sexual group, often occupy a “low sexual status” (Green 2014:153). On a micro-level, the sexual fields approach allows us to explore what sexual actors desire in a sexual partner and what they need to do in order to attract and obtain such a partner (Green 2015). In addition, on a macro-level, the sexual fields framework points us to the “hegemonic systems of judgment related to desirability” that “creat[e] differential probabilities for partnering across individuals” (Green 2011:246-247). Within these hegemonic systems, sexual actors are stratified and granted “differential status [...] based on characteristics that include age, race, ethnicity, and class” (Green 2011:246) and, as I suggest in this research, disability as well.

The sexual fields framework suggests that, considering their marginalized sexualities, people with intellectual disabilities likely occupy a position of “low sexual status” which can have a deep impact on their self-esteem as a sexual agent, their willingness to even try to “play

the field,” and their agency and significance within sexual encounters (Green 2014:51). In the following section, I discuss the limitations of disability studies to understand the stratification of people with intellectual disabilities. I argue that putting theories from disability studies and sexual fields into conversation, we will be able to better understand how people with intellectual disabilities attempt to acquire or convert different forms of capital to increase their opportunities to engage in sexual interactions as well as identify other elements that make up the notion of erotic capital.

The Missing Discourse of Disability and Pleasure

The sexual and intimate lives of people with intellectual disabilities have been marked by a history of protectionism, infantilization, and paternalism (Winges-Yanez 2014). People with intellectual disabilities have experienced significant restrictions in terms of exploring their sexuality, accessing and navigating sexual sites and sexual fields, and developing and negotiating their sexual capital in comparison with non-disabled people. Whether people with intellectual disabilities are perceived to be “potential victims” or are expected to express “unacceptable sexual behaviors,” their sexual rights are commonly restricted (Noonan and Gomez 2011:177; Gill 2015).

People with intellectual disabilities experience innumerable barriers to becoming and remaining sexual (Bahner 2015; Gill 2015; Kulick and Rydström 2015; Sanders 2007; Shakespeare 2000; Shuttleworth and Sanders 2010). This includes, for example, living arrangements that are not conducive for people with intellectual disabilities to maintain romantic relationships and experience sex (Eastgate et al. 2012; Frawley 2003; Löfgren-Mårtenson 2004); a consistent lack of access to (appropriate) sex education (Galea, Butler and Iacono 2004; Murphy and O’Callaghan 2004); workers and family members who may struggle finding a

balance in letting people with intellectual disabilities make their own decisions regarding their sexual lives (Löfgren-Mårtenson 2004); and the experience of growing up with negative messages about their sexualities and consequently developing negative beliefs and attitudes towards sexuality (Cuskelly and Bryde 2004).

Altogether, these barriers that people with intellectual disabilities face have actual consequences on their sexualities as “repeated experiences of exclusion, discrimination, and ableism can impact one’s self-esteem and belief in one’s self as a sexual being” (Jungels and Bender 2015:174; Azzopardi-lane and Callus 2014; Bender 2012; May and Stone 2010). As Shakespeare (2000:161) has noted, “being sexual demands self-esteem [...] yet disabled people, are systematically devalued and excluded by modern Western societies.” One could argue that such devaluation and exclusion can have an impact on the erotic habitus of people with intellectual disabilities, including their willingness and ability to auspiciously “play the field.”

This dissertation will examine the *consequences* of disenfranchising the rights of adults with intellectual disabilities to be sexual actors. It will examine how such disenfranchisement can influence their desire to be active sexual actors (or not) within sexual fields; shape their strategies and choices for sexual partners; and influence their sexual practices, perhaps pushing them to engage in sexual practices that they do not desire but are willing to do in order to satisfy potential sexual partners. By examining these questions, my dissertation will shed light on the common habitus of my participants as well as how the erotic habitus of my participants affect their sexual practices.

As a whole, the empirical literature looking at the sexual and intimate lives of people with intellectual disabilities has taken a quite narrow focus (Gill 2015). Studies have focused on questions of sexual abuse of disabled people (Dickman and Roux 2005), as well as at disabled

sexual offenders and their potential risk to other community members (Cantor et al. 2005; Lunskey et al. 2007; Steptoe et al. 2006). Studies have also explored the perceptions and attitudes of a range of social actors regarding the sexualities of people with intellectual disabilities, including parents and family members (Dupras and Dionne 2014; Pownall, Jahoda and Hastings 2012); support workers (Gilmore and Chambers 2010; Meaney-Tavares and Gavidia-Payne 2012); teachers and special educators (Parchomiuk 2012; Wilkenfield and Ballan 2011); university students (Franco, Cardoso and Neto 2012); social service providers (Bazzo et al. 2007); and the general public (McConkey and Leavey 2013; Sankhla and Theodore 2015).

Another focus of this literature has been on how people with intellectual disabilities have access to sexual knowledge and their ability to understand relationships and consent to sex, as well as the availability of sex education and its effectiveness (Ballan 2001; Dukes and McGuire 2009; Gougeon 2009; Howard-Barr et al. 2005; Murphy and O'Callaghan 2004; O'Callaghan and Murphy 2007). There is a consensus that a lack of information about sexuality can make people with intellectual disabilities more vulnerable to sexual abuse. Studies have shown that people with intellectual disabilities are more likely to experience sexual abuse in comparison with non-disabled people (Murphy 2003; Sequeira and Halstead 2001). The estimations of cases of sexual abuse vary greatly, ranging from approximately 10% to 80% of people with intellectual disabilities experiencing sexual abuse at some point in their lives (Hollomotz 2011). Most studies regarding sexual abuse have, however, problematically focused their analysis on people with intellectual disabilities and their individual attributes and self-defense skills rather than the structural arrangements that produce vulnerability among people with intellectual disabilities (Hollomotz 2009).

The focus on risk and ‘appropriate’ sexual behaviors present in the existing literature “tends to deflect attention from the wider sexuality and sexual needs” of people with intellectual disabilities (Cambridge and Mellan 2000:294), and keep analysis at the micro-level. For instance, though more focused on the experiences of people with physical disabilities, Tepper’s (2000:283) claim of a “missing discourse of pleasure” and sexual satisfaction also speaks to the experiences of people with intellectual disabilities. There are a few studies examining sexual pleasure and satisfaction among people with disabilities; however, most of these studies have focused on the experiences of people with physical impairments (i.e., Connell et al. 2014; Tepper et al. 2001) rather than the experiences of people with intellectual disabilities (Turner and Crane 2016).

Being “primarily a theory of desire” (Lizardo 2014:8), a sexual fields approach will address this gap in the literature by exploring and locating the sexual desires and notions of desirability of people with intellectual disabilities within multi-level social processes that shape the sexualities of this group that is often de-sexualized. Taking a sexual fields approach will allow me to explore the sexual and intimate experiences of people with intellectual disabilities from a multi-level analysis that can reveal how at the meso-level people with intellectual disabilities are embedded within larger stratification systems and hegemonic systems of desirability. At the same time, an analysis of people with intellectual disabilities’ stories of rejection and successes in the pursuit of love and intimacy can shed light on the ways that people with intellectual disabilities resist or reproduce constructions of sexualities, privileged forms of sexual capital, and hierarchical relations of desirability in their everyday lives.

Theorists in disability studies have considered the question of whether disabled people should attempt to join mainstream understandings of sexualities or challenge ableist

understandings of sexualities and claim their own “sexual culture” (McRuer and Mollow 2012; Shakespeare 2000; Siebers 2008). For example, Siebers (2008) talks about “sexual culture” in terms of exploring how sexualities can take a different shape for disabled people and how the sexualities of disabled people may challenge ableist sexual norms. Building on that insight, McRuer (2006) has proposed a crip theory that sits at the intersection of disability studies and queer studies. Disabled people have shown both agency and creativity by reconstructing sex and sexualities in ways that go beyond normative sexualities (Fritsch et al. 2016; Guter and Killackey 2004; McRuer and Mollow 2012). These scholars have not only affirmed how disabled people are “subjects and objects of a multiplicity of erotic desires and practices” (McRuer 2011:107-108), but have also theorized how disability can “transform sex, creating confusions about ‘what and who is sexy’ and ‘what counts as sex’” (McRuer and Mollow 2012:32; McRuer 2011; Shakespeare 2000; Wilkerson 2011). This scholarship in disability studies has focused predominantly on the sexual experiences of people with physical impairments, failing to study the experiences of people with intellectual disabilities (Abbott 2015; Löfgren-Mårtenson 2013).

Nonetheless, I suggest that crip theory, which has not yet made its way into mainstream sociology, should be brought into the field to help us think about new possibilities for understanding the intersection of disabilities and sexualities. Because the sexual fields framework has been mostly used as a “theory of only male sexuality,” more specifically (non-disabled) gay men sexuality (Martin 2014), it is important to apply the framework to other groups of people (Paik 2016; Plante 2015), including people with intellectual disabilities, that can bring to view other arenas of sexual organization and help us refine the framework’s main sensitizing concepts. The insights from crip theory will allow me to make sense of cases in

which the experiences of my participants may complicate or transform the sensitizing theoretical components of the sexual field framework.

RESEARCH METHODS

I will use a qualitative approach to make space for people with intellectual disabilities to share their perspectives and challenges as well as potential subversions and triumphs concerning romance and intimacy. Through in-depth interviews I will be able, for example, to better understand the challenges and opportunities for people with intellectual disabilities to become and remain sexual; the sexual fields that people with intellectual disabilities navigate or aspire to navigate; how participants make sense of their position and experiences as sexual actors; how they go about finding and obtaining a romantic or sexual partner of their choosing; and the strategies they use to increase their chances of partnering. My decision to conduct interviews, rather than engage in ethnographic work, stems from my wish to include a broad range of narratives that can shed light on different experiences of sexual agency among people with intellectual disabilities while attempting to recruit those that have not had as much space in previous studies.

Based on the literature and my previous research experience, I expect to find different levels of sexual agency among people with intellectual disabilities, which are shaped by various factors including, for example, their living arrangement, guardianship status, self-advocacy experience, and caregivers' understandings of the possibilities and limits for their sexual expression. I expect that, like in my previous research, some people with intellectual disabilities, such as self-advocates and individuals living in less disempowering living arrangements, may be able to exercise more sexual agency and decision-making power in their lives and access some sexual fields; however, that might not be the case for some with less room for sexual agency.

This is not to say that people with intellectual disabilities are not having romantic and sexual relationships nor it is to say that some people with intellectual disabilities do not have access to sexual fields at all. People with intellectual disabilities, indeed, have different experiences of sexual agency, find ways to remain sexual, and use public and/or private spaces to remain sexual (Gill 2015).

I am aware that it can be challenging to recruit people with intellectual disabilities who may experience less decision-making power in their lives (Goldsmith and Skirton 2015). Due to more pragmatic reasons, including the challenge of gaining access to social spaces created by and/or for people with intellectual disabilities as a junior scholar with limited time and funding, interviews are the best fit for this project. My research makes a methodological contribution to the sexual fields framework by shedding light on how qualitative interviews can also help us identify the systems of stratification that work to contain a particular sexual field, and capture certain dimensions of sexual fields (including questions of barriers and access to sexual fields) that would go unnoticed if we focused on specific sexual sites/fields. Based on the literature and previous research experience, I expect to find different levels of sexual agency among people with intellectual disabilities based on their past and current living arrangement.

SAMPLING

I will sample four groups of adults with intellectual disabilities for this research, which will include those living in 1) controlled group homes; 2) supported independent living; 3) family homes; and 4) independently. I will use both purposive and snowball sampling methods. Based on previous experience, I expect snowball sampling (through self-advocates and agency workers) to be especially useful for recruiting participants, especially those living under more

constrained living arrangements, and considering that this research involves a sensitive research topic.

To be eligible to take part in the research, participants must self-identify as having an intellectual disability, be over 18 years of age, and live in Southern Ontario. My research will include both adults with intellectual disabilities who are their own guardian and can sign a consent form, as well as adults with intellectual disabilities under guardianship arrangements who will sign an assent form along with a consent form signed by their legal guardian. My research focuses on the experiences of people with intellectual disabilities because, in the well-known “hierarchy of disabilities/impairments” within disability circles (Deal 2003; Kelly 2016; Ryan and Runswick-Cole 2008; Shakespeare 1996), people with intellectual disabilities have had a different response to their sexual expression and sexual rights (Gill 2010; Shildrick 2015). As Gill (2010:210) writes, although “[m]ost, in the disability communities, would argue that disabled adults should have unrestricted access to sexuality,” when it comes to people with intellectual disabilities, they are “seen as special exceptions, deserving a different approach, primarily because of their impairment diagnosis.” I have chosen to recruit adults with intellectual disabilities first because gaining access to youth can be difficult in comparison with adults. Also, I want to contest a tendency within disability scholarship to focus on young disabled people (Chivers 2011; Priestley and Rabiee 2002), as well as an assumption in the sexual fields literature that assumes that adulthood automatically allows for a broad range of sexual practices. The choice of Southern Ontario to conduct interviews will provide a range of potential participants from diverse backgrounds.

I will seek to recruit a diverse group of participants. Disability studies scholars have emphasized the importance of taking an intersectional lens when examining the experiences of

disabled people with sexuality and intimacy (Greenwell and Hough 2008; Rembis 2010; O'Toole 2000, 2015). Yet, as Greenwell and Hough (2008) have found, even though most studies mention participants' demographic information, only a few of them unpack those social locations and their intersections. I believe that my research will generate some insights that may contribute to a more intersectional approach to research on disabilities and sexualities.

Finally, while keeping in mind the challenges involved in recruiting a significant number of people with intellectual disabilities, which I address in the next section, I will aim for approximately 10-15 in-depth interviews within each of the four groups or more until I reach theoretical saturation (Morse 2004). While I acknowledge that caregivers are important decision-makers in the lives of people with intellectual disabilities, I am going to concentrate on interviewing people with intellectual disabilities to gain greater insight from this important and frequently overlooked group. I plan to begin recruitment in February 2017 and complete the interviews by July 2017.

RECRUITMENT

The difficulties and complexities involved in recruiting people with intellectual disabilities have been well-documented (Becker et al. 2004; Evenhuis et al. 2004; Iacono 2003; Nicholson, Colyer and Cooper 2013). People with intellectual disabilities are commonly assumed to be unable to make their own decisions, including that of whether or not to participate in research, and speak on their own behalf (Nind 2008). As a result, people with intellectual disabilities have often been excluded from research, having fewer opportunities to share their experiences in their own words in comparison with other social actors in their lives (Booth and Booth 1996; Elderton et al. 2013; Kelly et al. 2009; Lewis and Porter 2004; Wilcox and Whittington 2003). Gaining access to people with intellectual disabilities can involve going

through a series of gatekeepers, informing them about the research, building rapport, and discussing the importance and benefits of the research (Lennox et al. 2005; Nind 2008). Depending on guardianship arrangements, family members or other legal guardians may need to provide consent along with the participant's assent (Lennox et al. 2005).

I will use a “complex and multi-layered” recruitment strategy (Nicholson, Colyer and Cooper 2013:654) to recruit as many participants as possible from the four groups I have mentioned. My recruitment strategy will include calls for participation posted through public places including putting up recruitment posters in grocery stores, libraries, community agency offices, self-advocacy group offices, online forums and chat spaces within disability organizations, and social media channels. In order to facilitate the recruitment process, especially of adults with intellectual disabilities living in more controlled living arrangements, I will also ask others, including agency workers and self-advocates, to pass on recruitment “postcards” to potential participants. Self-advocates and agency workers are particularly well-positioned in terms of knowing and having some access to adults with intellectual disabilities who may be living in more controlled settings. I will also approach local agencies, self-advocacy groups, and parent-led groups asking if I could attend one of their meetings and give a brief presentation about my research. I have compiled a list of service agencies and self-advocacy groups which I will contact as a part of my recruitment process, and I have started building connections with community partners that will facilitate the recruitment process.

Finally, I am taking into account some of the recommendations that people with intellectual disabilities themselves have presented to researchers in previous studies (McDonald, Kidney and Patka 2012; Swaine et al. 2011). For instance, recruitment materials will be written in an easy-to-read manner (Swaine et al. 2011). Also, considering how people with intellectual

disabilities are sometimes coerced in their everyday lives into doing things that they may not wish to do, I will ensure that potential participants do not feel coerced into participating in my research (Cameron and Murphy 2006; Nicholson, Colyer and Cooper 2013).

INTERVIEW PROCESS

I will start conducting interviews once I obtain approval from the ethics board at McMaster University. I will audio-record the interviews with participants' permission. Considering the sensitivity of the research topic, the interviews will be conducted in a mutually agreeable location that allows participants and me to feel comfortable and safe, at a time of their choosing. The length will range from 1 to 2 hours, depending on the participant. If necessary, the interview can be conducted in two separate parts. In case participants choose to be interviewed at their homes, I will maintain a "buddy system," notifying a trustworthy colleague when I go to a participant's home to conduct an interview. This colleague will have certain details of the interview (e.g. name of participant, date, time, expected duration and location), but will only access them if there is an actual problem. I will make sure to notify this colleague, with a brief phone call, that I have safely completed the interview.

I will explain the research and go through the consent form with participants in an accessible language. Once an individual has agreed to meet for an interview s/he will be informed at the time of reviewing the consent form that his or her participation is voluntary. I will tell participants that they are not required to answer any questions that they are uncomfortable with and that they may withdraw their consent for sections or all of the interviews at any time. I will tell participants that, following the interview, and any time before the conclusion of the project, they may withdraw from the research without any penalty. I will provide my name, address and email address on the consent/assent form, a copy of which will

remain with participants, with a statement inviting participants to contact me at any time with questions or concerns, including withdrawal. If a participant chooses to withdraw from the study, the information gathered will be destroyed, and it will not be included in my dissertation or future publications. I will start the interviews by filling out a short questionnaire asking participants for some basic demographic information and then proceed with the interview questions.

There is a body of literature addressing best practices for interviewing participants with an intellectual disability (Beail et al. 2015). As previous studies have shown some evidence of acquiescence bias among people with intellectual disabilities when responding to more directive questions (McVilly et al. 2008), I will focus on eliciting narratives as much as possible (Beail et al. 2015; Booth and Booth 1996; McVilly et al. 2008). People with intellectual disabilities may also have a more limited vocabulary, experiencing some challenges articulating and describing their experiences in detail (Booth and Booth 1996; Beail et al. 2015; Clarke et al. 2005), which does not mean that they cannot share their experiences and perspectives in rich ways. Although these are important points to consider, it is also important to remember that people with intellectual disabilities are a heterogeneous group of people and that different interview approaches may be more suited to different participants (Goodley 1998).

DATA ANALYSIS

I will transcribe the interviews verbatim and assign them identification codes using the Express Scribe transcription software as soon as each one of them is done. I will keep footnotes and side notes on the transcripts throughout the transcription process to tentatively identify some codes and themes. After transcribing interviews, I will read the interview transcripts multiple

times to further familiarize myself with the data and generate an initial list of codes. I will conduct the formal coding of my interviews using NVivo.

My coding strategy will start with the open coding of the interview transcripts, meaning a line by line reading of the transcripts, which will allow me to translate the interview “data [in]to codes” and eventually establish broader themes and concepts (Boeije 2010:108). I will start with a basic code list based on the first few interviews, which will then be used in the analysis of subsequent interviews. However, as I develop new themes throughout the coding process, I will also go back to my first interviews to code them based on my updated code list. The coding process will be both “theory-driven,” approaching the data with specific questions and a theoretical framework in mind, as well as “data driven” with codes “depend[ing] on the data” itself (Braun and Clarke 2006:18). The final stage of the coding process will involve looking at the interviews for common themes and shared experiences among the participants. Thematic analysis is helpful for “identifying, analyzing, and reporting patterns [or themes] within data” (Braun and Clarke 2006:6).

ETHICAL CONSIDERATIONS

The protection and ethical inclusion of people with intellectual disabilities in research are a serious matter, especially considering precedents of unethical research (Iacono 2006; McDonald, Kidney and Patka 2012), and how disable people, more broadly, have a long history of experiencing exploitation, abuse, and being denied privacy (Liddiard 2011). At the same time, it is also unethical to assume that people with intellectual disabilities cannot make their own decisions and, though greater care is needed, people with intellectual disabilities have the right to share their perspectives and speak on their behalf. Belonging to a “vulnerable group” should not

serve as an excuse to silence people with intellectual disabilities or automatically foreclose opportunities for their participation in research (Iacono and Murray 2003).

I will strive to create a sensitive and supportive space for my interviewees. Although I anticipate that people with intellectual disabilities will be keen to speak about their experiences, I also know that, for some people, talking about previous relationships and their sexual life can be difficult and painful. I will keep that in mind during my interviews and will remind participants that we can take a break, that they do not have to answer any questions that they are uncomfortable with, and that they are also free to end the interview at any time. As part of my “ethics of care” (Lincoln as cited in Ellis 2009:308), I will also debrief with participants at the end of the interview to see if the person is feeling comfortable with the interview. I will also make extra efforts to connect participants with an appropriate community contacts in case they become upset during the interview.

Some participants might also have concerns about having their interviews shared with authority figures such as their parents or support workers, and thus, I will assure my participants that identifying information will not be made available to any member of their community, or to their peers, or to any service providers, guardians or family members (an exception to this would occur when/if participants reveal information about illegal activities, such as physical or sexual abuse, which must be reported). I will also include information on the consent forms for individuals with intellectual disabilities and parents/guardians concerning my obligation to report any disclosures concerning unsafe and/or illegal situations. I will note that this research is not being funded by any service agency and that the services and funding that participants are currently receiving will not be affected by their participation in the research. I will endeavor to protect all participants’ identities by disguising certain details including names and identifying

features. I will ensure that the individuals or agencies that refer potential participants will not receive any information from me as to the outcome of those referrals. Furthermore, the interview data will only be reported in aggregate for the most part, and illustrative examples will be presented in such a way that no identifying feature of the individuals will be included.

REFLEXIVITY AND RECIPROCITY

As a part of being reflexive, I would like to briefly note my “relationship with/to disability and disablement” (Crooks, Owen and Stone 2012:47; O’Toole 2013), which comes primarily in the shape of being a loyal and loving brother of a young man with a physical impairment. Even though I have a disabled brother, and have consequently witnessed various instances of ableism, I know that I carry the privileges of a non-disabled person, and thus, have a different insight into ableism. My engagement with critical disability studies as well as my experience serving as a volunteer at organizations delivering services to people with intellectual disabilities have been particularly valuable for understanding some of the experiences of individuals with intellectual disabilities. As a non-disabled ally, I am committed to making space for people with intellectual disabilities to share their experiences with sexuality and intimacy and pushing sociological scholarship forward to help advance the sexual rights of people with intellectual disabilities. In my previous research work, I have found that journaling and talking to colleagues, committee members, and community partners to be useful reflexive tools, and I hope to continue this practices throughout my dissertation work as well.

Regarding reciprocity, unfortunately, due to budgetary restrictions, I am unable to provide any financial compensation to my research participants, and I will make sure that is clear during recruitment and interviews. Previous studies have nonetheless noted that participating in research can be a positive experience for people with intellectual disabilities who may appreciate

having an opportunity to have their voices heard, especially in hopes that their narratives can help make a difference in the lives of other people with intellectual disabilities (McDonald, Kidney and Patka 2013; Nicholson, Colyer and Cooper 2013). Also, for some, participating in studies like mine can be a first-time opportunity to more freely talk with someone about love, sexual desires, and sexual pleasure (Liddiard 2013). The consent letter will note, however, that the research will not benefit participants directly. I will tell my participants that the interviews will be analyzed and used in my dissertation as well as in future publications and conference presentations in an anonymized manner.

Inspired by Patricia Hill Collins's (2000:viii) work, I am committed to making this dissertation "intellectually rigorous, well researched, and accessible to more than the select few fortunate enough to receive elite education." I am committed to sharing my research findings with people with intellectual disabilities, both within and outside of academia, and make sure that is done in an accessible manner (Dalton and McVilly 2004; Lewis and Porter 2004; Liddiard 2013). I will include a section in the consent form where participants can let me know of their interest in receiving a brief research write-up in plain language and large print at the completion of the research. I will also offer self-advocacy groups and service provider agencies to deliver short presentations about the results of the study. I will also make a copy of the final dissertation available at the McMaster University Library, and send participants (if they wish) copies of future publications along with brief summaries in plain language.

RESEARCH CONTRIBUTIONS

My research will make a contribution to a growing body of literature bringing an intersectional approach to the sociology of sexualities, focusing on how sexualities intersect with disabilities. It will address the need for more research that focuses specifically on sexuality as

part of people with intellectual disabilities' everyday lives and examines how that sexuality is structured within a broader society that marginalizes people with intellectual disabilities' sexuality. By applying the sexual fields framework to explore the consequences of sexual stratification on the sexual and intimate experiences of people with intellectual disabilities, this dissertation will contribute to the current literature by shedding light on instances of agency or disempowerment experienced by people with intellectual disabilities, including their complex strategies to remain sexual. Whereas disability studies has provided limited structural accounts of the ways that sexualities are stratified among people with intellectual disabilities, a sexual fields framework provides a more systematic approach to the study of sexual stratification through its multilevel approach, which allows us to have a more complete understanding our collective sexual life (Green 2014). The sexual fields framework, as Taylor (2014:11) has suggested, "likely will set the research agenda for the sociological study of sexuality over the next several decades," making this a promising avenue for theoretical exploration.

APPENDIX A: TIMELINE

Project Component	Description	Start Date	End Date
Ethics Clearance	Project clearance through McMaster REB	February 2017	March 2017
Data Collection	Interviews	March 2017	August 2017
Analysis of Data	Ongoing throughout data collection and following	March 2017	October 2017
Dissertation Writing	First Draft	March 2017	November 2017
Committee Meeting			May 2017
Draft Revisions	Addressing revision suggestions	November 2017	February 2018
Draft Revisions	Addressing revision suggestions	February 2018	July 2018
Committee Meeting			May 2018
Submission of final draft and defence preparation		July 2018	August 2018

APPENDIX B: TENTATIVE CHAPTER OUTLINE

Chapter Topics	Contents
Chapter One – The Problem and Its Context	<ul style="list-style-type: none"> - Introduction to the Chapter - Background to the Problem - Specific Research Questions - Methods of the Study - Significance of the Problem Area - Overview of the Dissertation
Chapter Two – Review of the Literature	<ul style="list-style-type: none"> - Introduction to the Chapter - The Context of the Research Problem - Review of the Literature in Specific Areas of My Study - Review of the Theories - Conclusions in the Context of the Literature Reviewed
Chapter Three – Methodology	<ul style="list-style-type: none"> - Introduction to the Chapter - Design of the Study - Data Collection - Participants - Data Analysis - Conclusion to the Chapter
Chapter Four – Findings (Access and Barriers to Sexual Fields)	<ul style="list-style-type: none"> - Introduction to the Chapter
Chapter Five – Findings (Opportunities and Barriers for Developing and Negotiating Sexual Capital)	<ul style="list-style-type: none"> - Introduction to the Chapter
Chapter Six – Findings (Erotic Habitus of Adults with Intellectual Disabilities)	<ul style="list-style-type: none"> - Introduction to the Chapter
Chapter Seven – Conclusions, Implications, and Recommendations	<ul style="list-style-type: none"> - Introduction to the Chapter - Conclusions of the Study - Discussion of the Study - Limitations of the Study - Implications of the Study - Future Directions

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