THE ROMANTIC AND SEXUAL LIVES OF ADULTS WITH INTELLECTUAL DISABILITY

THE ROMANTIC AND SEXUAL LIVES OF ADULTS WITH INTELLECTUAL DISABILITY IN ONTARIO, CANADA

By ALAN SANTINELE MARTINO, B.A. (Hons.), M.A.

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

McMaster University

McMaster University DOCTOR OF PHILOSOPHY (2020) Hamilton, Ontario
(Sociology)

TITLE:	The Romantic and Sexual Lives of Adults with Intellectual Disability in Ontario, Canada
AUTHOR:	Alan Santinele Martino, B.A. (St. Lawrence University), M.A. (University of Lethbridge)
SUPERVISOR:	Dr. Melanie Heath
COMMITTEE MEMBERS:	Dr. Tina Fetner Dr. Ann Fudge Schormans
EXTERNAL REVIEWER:	Dr. Nancy Fischer

NUMBER OF PAGES: v, 184

Abstract

The intersection of disability and sexuality remains a taboo topic. Along with this taboo, people with intellectual disabilities are rarely afforded the opportunity to share their experiences and desires when it comes to their intimate lives. This research examines the romantic and sexual lives of adults with intellectual disabilities in Ontario, Canada, by putting into conversation theories from the sociology of sexualities and critical disability studies. It uses a sexual fields analytic framework (Green, 2014) to explore the consequences of sexual stratification on the experiences of disabled people. Drawing on semi-structured interviews with 46 adults with intellectual disabilities, this research explores how they are kept out of sexual fields through a series of disabling social processes. It also examines how participants make sense of their gender and sexual identities based on gender habitus acquired in their lives and how they are often confined to "hetero-romantic" forms of sexual expression and traditional gender roles. Finally, this project explores how participants navigate the sexual fields available to them and their strategies for negotiating those fields. This research brings to view previously unexplored sexual fields within the existing sexual fields literature. I discuss what I call intellectual disability sexual fields, spaces exclusively for people with intellectual disabilities, as well as more mainstream sexual fields.

Dedication

To Bruno Santinele Martino, my loving brother and best friend.

Acknowledgements

This dissertation means a lot to me and I could not have done it without the commitment, mentorship, and support of many people in my life. I have so many to thank for and not enough space here.

First, I would like to express my deepest appreciation to my supervisory committee. Thanks to my supervisor, Dr. Melanie Heath, whose feedback, support, and mentorship were invaluable. I cannot thank you enough for reading my multiple drafts, asking me the hard questions, and being patient with me. I am also extremely grateful to Dr. Tina Fetner. You challenged me and made me a more confident scholar. Thanks for being this kind and committed committee member. I am also deeply indebted to Dr. Ann Fudge Schormans who has been such a incredibly generous mentor to me. I cannot express my gratitude enough and I look forward to continue co-authoring papers with you. Appreciation is also due to Dr. Nancy Fischer for her insightful comments and questions.

Thanks to the faculty members at the Department of Sociology at McMaster University, especially Dr. Dorothy Pawluch, Dr. Neil McLaughlin, Dr. Marisa Young, and Dr. Lisa Kaida. Many thanks to Corinne Jehle and Olga Cannon for their warm support and for pushing me to get this done. I am also indebted to my incredible colleagues: Dr. Nicole Andrejek, Dr. Casey Scheibling, Allison Leanage, Sarah May Lindsay, Andrey Kasimov, Leili Yousefi, Dr. Julie Gouweloos, Dr. Rachel Barken, Dr. Becky Casey, Dr. Erica Speakman, Dr. Jessica Braimoh, Dr. Allyson Stokes-McLevey, Dr. John McLevey, Dr. Katie Duong, Dr. Margaret Campbell, and Rod Missaghian. I am also grateful to my ASA colleagues and friends, especially Kyle Shupe, Brittney Miles, Jeremy Brenner-Levoy, Ian Callahan, Dalton Stevens, and Jen Brooks.

I am also thankful to all of those who have served as mentors and role models to me at different points in this journey, including Dr. Patrice LeClerc, Dr. Karen Yoshida, Dr. Patty Douglas, Dr. Heather Dillaway, Dr. Brian Grossman, Dr. Kirsty Liddiard, Dr. Allison Carey, and Dr. Laura Mauldin. Thanks also to all the members of the Re:searching for LGBTQ2S+ Health team at the University of Toronto.

I wish to acknowledge my family, especially my brother (Bruno), mother (Geni), father (Gerson), and grandmother (Ariadene). Their unconditional love and acceptance have motivated to continue my studies. I am grateful to my partner, Tony, who has supported my career and mental health. Thanks to my dog, Mojo, for his companionship, cuddles, and comfort. Finally, I am appreciative of my friends, including Namrata Bagaria, Anona Kosmack, Jan Van Heuzen, Valérie Auger-Voyer, and Jennifer Reynolds.

Thanks to all the self-advocacy groups and organizations that supported this project. Finally, and most importantly, I could not have completed this dissertation without the generosity and openness of the research participants. I appreciate you entrusting me with your sexual stories and I promise to do my best to share your stories with respect and care. Your stories shall be heard!

Chapter 1: Introduction

Introduction

During an improvisation exercise in the arts program of a community-based organization in upstate New York, a young man with Down syndrome takes the stage. Accompanied by two other actors with intellectual disabilities, the young man starts his scene acting out an encounter with friends. The conversation goes on until the friends start talking about romantic relationships. The young man then asserts, "Love is natural, we all love." The rest of the room, consisting of other disabled people, organization staff, and volunteers smile in agreement with the man's statement. A person in the room is heard saying, "Aww!" Just a few seconds later, as the scene proceeds, the young man raises his hand up in the air and enthusiastically adds, "S.E.X., that's what we want." The statement completely changes the vibe in the room, now filled with discomfort and nervous laughter. Not knowing what to do, the lead staff member in the room quickly changes the topic of the conversation by stating, "Isn't the weather beautiful today?" The scene then ends and we move on to the next group of actors.

I was a volunteer in that room when that moment took place. I felt extremely uncomfortable with how this young man's feelings and sexual desires were simply shut down, treated as being "out of place". I wondered to myself what message we are sending to this young man and others in the room when we treat sexuality that way. There must be a better way of moving forward that acknowledges the sexuality of disabled people. That particular episode sparked an interest in me to explore the intersection of intellectual disability and sexuality.

For this dissertation, I have spoken with many community members with intellectual disabilities who illustrate the multiple barriers that continue to discourage and block disabled people from having an intimate life. Sexuality and sexual expression are important parts of everyday life and, above all, a fundamental human right (Rogers, 2016; Whittle & Butler, 2018). Yet, when it comes to adults with intellectual disabilities, the same expectations do not seem to apply. On the one hand, people with intellectual disabilities are often seen as being vulnerable, child-like, and innocent and thus unable to supposedly make informed decisions regarding their intimate lives (Ditchman et al., 2017; Murphy & Young, 2005; Swango-Wilson, 2009). On the other hand, they are also seen as having problematic, dangerous, and uncontrollable sexualities (Aunos & Feldman, 2002).

People with intellectual disabilities have the same romantic and sexual desires as non-disabled people. Their sexualities, however, are shaped by myths that desexualize and stigmatize them. As a social group, they have often been denied the opportunity to form romantic and sexual lives (Swango-Wilson, 2009) and have experienced repression and institutionalization to curtail their sexual expression (McDaniels & Fleming, 2016). Furthermore, the intersection of disabilities and sexualities remains a taboo topic in our society (Medina-Rico, López-Ramos, & Quiñonez, 2018). Research on this topic 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 lives of disabled people (Erel et al., 2011; Kattari, 2015; Liddiard, 2011, 2013; McRuer & Mollow, 2012).

To address this gap, this dissertation examines 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. To accomplish this, I conducted in-depth interviews with 46 adults with intellectual disabilities in Ontario to better understand their experiences, aspirations, challenges, and forms of resistance to maintain sexual lives. The first chapter provides a brief overview of the existing literature on intellectual disability and sexuality. I also introduce the theoretical framework guiding this project. Finally, I share the roadmap of this dissertation.

Intellectual Disability and Sexuality

The sexual and intimate lives of people with intellectual disabilities have been marked by a history of protectionism, infantilization, and paternalism (Winges-Yanez, 2014), resulting in experiences of sterilization without their consent and sometimes without their knowledge, institutionalization, and sexual repression (McDaniels & Fleming, 2016). 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 compared to 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 & Gomez, 2011, p. 177; Gill, 2015).

As a whole, the empirical literature looking at the sexual and intimate lives of people with intellectual disabilities has taken a narrow focus (Gill, 2015). Studies have focused on questions of sexual abuse of disabled people (Dickman & Roux, 2005) as well as disabled sexual offenders and their potential risk to other community members (Cantor et al., 2005; Lunsky 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 & Dionne, 2014; Pownall, Jahoda & Hastings, 2012), support workers (Gilmore & Chambers, 2010; Meaney-Tavares & Gavidia-Payne, 2012), teachers and special educators (Parchomiuk, 2012; Wilkenfield & Ballan, 2011), university students (Franco, Cardoso, & Neto, 2012), social service providers (Bazzo et al., 2007), and the general public (McConkey & Leavey, 2013; Sankhla & Theodore, 2015).

People with intellectual disabilities experience countless barriers to becoming and remaining sexual (Bahner, 2015; Gill, 2015; Kulick & Rydström, 2015; Sanders, 2007; Shakespeare, 2000; Shuttleworth & Sanders, 2010). This includes 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, & Iacono, 2004; Murphy & O'Callaghan, 2004), workers and family members who may struggle with balancing letting people with intellectual disabilities make their own decisions regarding their sexual lives with their own worries and desire to protect disabled people (Löfgren-Mårtenson, 2004), and the experience of growing up with negative messages about their sexualities and consequently developing negative beliefs and attitudes toward sexuality (Cuskelly & Bryde, 2004).

In all, these barriers faced by people with intellectual disabilities have real consequences on their sexualities as "repeated experiences of exclusion, discrimination, and ableism can impact one's self-confidence and belief in one's self as a sexual being" (Jungels & Bender, 2015, p. 174; Azzopardi-Lane & Callus, 2014; Bender, 2012; May & Stone, 2010). As Shakespeare (2000) notes, however, disabled people are "systematically devalued and excluded by modern Western societies" (p. 161). One could argue that such devaluation and exclusion can have an impact on the experiences of people with intellectual disabilities, including their willingness and ability to auspiciously "play the field". This dissertation examines the consequences of disenfranchising the rights of adults with intellectual disabilities to be sexual actors. It explores how such disenfranchisement influences their desire to be active sexual actors within sexual fields, shapes their strategies and choices for sexual partners, and influences 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.

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 & 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 queercrip 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 & Killacky, 2004; McRuer & 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, p. 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 & Mollow, 2012, p. 32; McRuer, 2011; Shakespeare, 2000; Wilkerson, 2011).

This scholarship in disability studies has predominantly focused on the sexual experiences of people with physical impairments, failing to study the experiences of people with intellectual disabilities (Abbott, 2015; Löfgren-Mårtenson, 2013). As Löfgren-Mårtenson (2013) articulates, crip theory often "proceeds from people with physical disabilities, i.e., individuals who have a voice, who can write about their situation, and organize dissent, and who is often found in the international disability rights movement" (p. 420). This dissertation highlights how some people with intellectual disabilities attempt to "crip" sexualities. While most participants strived to achieve normative performances of gender and sexuality when participating in sexual fields, a few participants shared examples of how they attempted to question and transform those very normative constructions. These examples provide new insights in terms of how sexual actors navigate sexual fields.

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 multi-level approach, allowing us to have a more complete understanding of our collective sexual life (Green, 2014). The sexual fields framework, as Taylor (2014) suggests "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 (p. 11). This research is a part of my program of research, which has primarily focused on bridging disability studies and the sociology of sexualities, two fields that have only recently been put into dialogue, in order to theorize and empirically examine the perspectives, challenges, and triumphs of people with intellectual disabilities concerning sexuality. This is an exciting and growing area of research that reflects the complexities and importance of addressing issues in the private sphere.

My research also contributes to a growing body of literature bringing an intersectional approach to the sociology of sexualities, focusing on how sexualities intersect with disability. It addresses the need for more research that specifically focuses on sexuality as part of the everyday lives of people with intellectual disabilities and examines how that sexuality is structured within a broader society that marginalizes the sexuality of people with intellectual disabilities. 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 contributes to the current literature by highlighting instances of agency or disempowerment experienced by people with intellectual disabilities including their complex strategies to remain sexual.

I would like to acknowledge right from the start the concern I have for the ways that disabled people are made vulnerable. Family members and service providers often struggle to find a balance between protecting disabled people from risk and harm and respecting their rights to make their own decisions (including their right to make mistakes) in their intimate lives (Brown & McCann, 2018). We know that people with intellectual disabilities are at a higher risk of experiencing different forms of abuse compared to non-disabled people (Bryne, 2018; Shapiro, 2018). We know that sexual violence among the general population tends to be underreported and underprosecuted (McGell et al., 2002; Myhill & Allen, 2002). This challenge of violence disclosure can be further accentuated for people with intellectual disabilities. Disabled people are more likely to be abused by people providing them care (e.g., caregivers, family members) (McCormack et al., 2005; Sobsey, 2006). This can make some disabled people reluctant to report such instances (Akbas et al., 2009). People with intellectual disabilities are also less likely to be believed when they do disclose and sometimes have to remain living with perpetrators (Shapiro, 2018). In addition, the literature suggests that very few cases are actually addressed. For example, out of 1,400 sexual abuse yearly reports against people with intellectual disabilities in the United Kingdom, typically only six percent make it to court and one percent result in conviction (Bryne, 2018).

The challenge, however, is that the focus on risk and harm can also lead to a lack of access to sexuality and intimacy among disabled people. While my research shows that those risks and harm were present in some of the participants' accounts, in this context of increased risk, however, we should still ask ourselves whether it is right to deny disabled people access to an intimate life as a means for keeping them safe, or if there is perhaps a different path forward for a safe and satisfying sexual life for disabled people. People with intellectual disabilities are entitled to intimate citizenship (Ignagni et al., 2016), which refers to our "rights to choose what we do with our bodies, our feelings, our identities, our relationships, our eroticisms, and our representations" (Plummer, 1995, p. 17). People with intellectual disabilities have also consistently noted their desire to be heard and have their desires respected (Bane et al., 2012; Fitzgerald & Withers, 2013).

Theorizing Disabled People's Sexualities: 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, p. 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, p. 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). Lacking that "feel for the game" can lead to forms of disadvantage that shape sexual actors' experiences and opportunities for partnering.

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 provide status to sexual actors within sexual fields (Green, 2014; Leschziner & 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), a concept that refers to unconscious dispositions that predispose sexual actors toward particular kinds of sexual practices and partners. These dispositions are tied to larger social structures and hierarchies of desirability that reproduce inequalities (Green, 2008a, 2014).

Previous studies using the sexual fields framework have significantly contributed to the sociology of sexualities by empirically demonstrating 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 complex dynamic parameters of desirability and the interactional underpinnings of desires and desirability in sexual fields (Weinberg & Williams, 2014), how sexual fields may produce and/or accommodate desires that are not mainstream (Farrer & Dale, 2014; Weinberg & 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 shape the experiences of sexual actors in sexual fields (Farrer & Dale, 2014; Green, 2008b; Schilt & Windsor, 2014), and the consequences to the psychological and emotional well-being of individuals attempting to maximize their erotic capital (Farrer, 2010; Green, 2008a). 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 & Green, 2014) – and explored the anatomy of particular sexual fields including their unique tiers of desirability and distributions of erotic capital (Green, 2008b, 2014).

Alternatively, the current literature also has limitations especially when applying the sexual fields framework to the romantic and sexual experiences of people with intellectual disabilities. This dissertation also illuminates how certain aspects of disability trouble and complicate some assumptions in the sexual fields literature. For instance, the existing research on intellectual disability and sexuality 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 & Rydström, 2015; Löfgren-Mårtenson, 2013). The goal of this research is to demonstrate how this dialogue between the sociology of sexualities and critical disability studies can provide a new conceptual vocabulary for theorizing the social forces that structure (and disadvantage) the sexualities of disabled people as well as the embodied experiences and practices of this social group.

Bringing Together Disability and Sexual Fields

People with intellectual disabilities experience significant restrictions in accessing opportunities for sexual exploration, experimentation, and relationships, which impacts their sexual capital and gender/erotic habitus. 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 a gender and sexual identity and sexual capital, nor accessing sexual fields. Conversely, if perceived as having a deviant sexuality, people with intellectual disabilities' sexual capital is one to be contained, discouraged, and restricted.

The current sexual fields literature, however, has not taken into account the consequences of such historical marginalization and exclusion on disabled 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 from family members, non-family members, and support workers. Due to protectionism, infantilization, and other restrictions, they may also experience a lack of privacy and decision-making power (Gill, 2015; Hollomotz & The Speakup Committee, 2009; Lesseliers & Van Hove, 2002). For some disabled people, 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). As 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 disabled people who can bring to view other arenas of sexual organization and help refine the framework's main sensitizing concepts.

As Ignagni et al. (2016) notes, we know "little about the spaces [disabled] people may easily access and claim, and how these may shape intimate subjectivities, relations and practice" (p. 132). Thus, it is relevant to explore the mainstream and disability-specific sexual fields that people with intellectual disabilities navigate or aspire to navigate in their pursuit of love, intimacy, and sex. Similar to previous studies drawing on sexual fields, I too found forms of "specialized erotic worlds" (Green, 2008b, p. 27) that disabled people with intellectual disabilities claim and navigate.

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, & Molin, 2015). Löfgren-Mårtenson (2008), 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 (p. 125). Some participants have used the Internet and mobile dating applications as sexual fields and, for that reason, it is also important to look at virtual spaces. By thinking about sexual fields – both in terms of physical and online sexual sites – we can 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.

Furthermore, 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 (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 selecting partners (Löfgren-Mårtenson, 2004, p. 203). Therefore, my dissertation contributes 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 decide whether to pursue certain potential sexual partners, how they develop their own hierarchies of desirability and how they respond to hegemonic hierarchies of desirability, and what strategies they use to increase their chances of partnering.

The sexual fields framework helps us to better understand the inequalities, power struggles, challenges, resources, and forms of resistance experienced by disabled people. On a macro level, people with intellectual disabilities are embedded within larger sexual stratification systems. The sexual fields framework points us to the "hegemonic systems of judgment related to desirability" that lead to different probabilities for partnering for individuals and social groups (Green, 2011, p. 246-247). Within these hegemonic systems, sexual actors are stratified and granted differential status based on their social location, including age, race, and class (Green, 2011), in addition to disability. At the same time, an analysis of people with intellectual disabilities' stories of rejections and successes in the pursuit of love and intimacy highlights how they resist or reproduce constructions of sexualities, privileged forms of sexual capital, and hierarchical relations of desirability in their everyday lives. The sexual fields approach allows us to explore what sexual actors desire in a sexual partner and what they need to do to attract and obtain such a partner (Green, 2015). Considering their marginalized sexualities, people with intellectual disabilities often occupy a position of low sexual status, which has a deep impact on their self-confidence as a sexual agent, shaping their willingness to play the field and their agency within sexual encounters (Green, 2014).

Research Questions

My goal was to better understand the romantic and sexual lives of adults with intellectual disabilities and the social forces shaping those sexualities. More specifically, my research addressed three main interrelated research questions concerning the intimate lives of disabled people:

1. What are some of the systematic barriers that prevent adults with intellectual disabilities from participating in sexual fields?
2. How do people with intellectual disabilities make sense of their gender and sexual identities based on gender habitus acquired in their lives?
3. How do adults with intellectual disabilities navigate the mainstream and specialized sexual fields available to them to increase their chances of intimate partnering?

Overview of the Dissertation

This dissertation is divided into six chapters. Chapter 1 presents the research topic and questions, introduces the theoretical framework, and highlights the significance of this project. Chapter 2 introduces the methodological considerations that underpin this project and reports on my strategies in terms of recruitment, reflexivity, ethical considerations, interviewing, and the analytic framework.

Chapter 3 attends to the particular disabling social processes including infantilization, lack of information, forms of boundary work, and psycho-emotional disablism, which keep people with intellectual disabilities out of sexual fields. Drawing on the notion of sexual access, I address a gap in the existing sexual fields literature in terms of theorizing the experiences of sexual actors who do not participate in those sexual fields, whether by their own choice or, more importantly, by the choice of others in their lives.

Chapter 4 turns attention to the experiences of participants who have accessed sexual fields, paying particular attention to how they make sense of their gender and sexual identities based on gender habitus acquired in their lives. I highlight how people with intellectual disabilities are often confined to “hetero-romantic” forms of love and traditional ideas around gender identity and gender roles. Many participants had been offered very few options in terms of “doing gender” and were often held accountable to properly performing those expectations.

Chapter 5 focuses on how participants navigate and negotiate the sexual fields available to them. This chapter brings to view previously unexplored sexual fields within the existing sexual fields literature. Specifically, I discuss what I call intellectual disability sexual fields, spaces exclusively for people with intellectual disabilities such as group homes and day programs. Additionally, I discuss participants’ experiences negotiating more mainstream virtual and physical sexual fields available to them.

Chapter 6 highlights the main contributions of this research, addresses the limitations of this study, discusses potential applications for practice, and proposes directions for future studies.

Chapter 2: Methodology

Introduction

This dissertation analyzes qualitative data collected from semi-structured in-depth interviews to better understand the romantic and sexual lives of adults with intellectual disabilities. Qualitative research "seeks to establish the meaning of a phenomenon from the views of participants" (Creswell, 2009, p. 16). Additionally, in-depth interviews are useful for making space for participants to contextually share their experiences and express their perspectives as they make sense of our social world (Boeije, 2010, Ramazanoğlu & Holland, 2002). This approach allowed me to make space for disabled people to share their perspectives and challenges as well as instances of subversions and triumphs concerning romance and intimacy on their own behalf. Through interviews, I explored the challenges and opportunities for people with intellectual disabilities to become and remain sexual, the sexual fields that they navigate or aspire to navigate, how participants make sense of their gendered identities and experiences as sexual actors, how they find and obtain a romantic or sexual partner of their choosing, and the strategies used to claim sexual spaces and increase their chances of partnering.

As Bryman and Teevan (2005) appropriately articulate, "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). This research is grounded on a critical-constructionist framework which understands that there are different versions of 'truth' and that they are always partial, locally situated, and fluid (Bloomberg & Volpe, 2012; Guba & Lincoln, 1994). A critical-constructionist framework also suggests that 'reality' is always "multiple", "intangible", "experientially based", and "situated" (Guba & Lincoln, 1994, p. 110). In essence, participants shared their views and perspectives as they understood them at the time of the interview. Finally, a critical-constructionist framework understands that these 'truths' are embedded within unequal power relations. Thus, it is important to keep in mind how disabled people's knowledge and views have historically been discredited and underrepresented. My research attempts to highlight some of those power relations and report on how disabled people negotiate them. My ontological and epistemological approaches guided my choice in terms of my research method. In keeping with a critical-constructionist framework, I used in-depth, semi-structured interviews to center the knowledge, voice, and experiences of people with intellectual disabilities.

This chapter explains the importance of making space for people with intellectual disabilities to share their experiences and perspectives as meaning makers of their own lives. I also outline the research design, the logistical details of the study, ethics, participant eligibility and recruitment, the interview process, and provide a profile of participants. In an effort to be reflexive, I also address my positionality as a researcher, including my "relationship to disability" (O'Toole, 2014). Lastly, I describe my procedures to analyze the findings.

Nothing About Us, Without Us

In their efforts, the disability rights movement has long advocated for nothing about us, without us (Charlton, 1998). People with intellectual disabilities have highlighted the importance of speaking about their experiences (Fudge Schormans et al., 2011; McDonald et al., 2015) but are commonly seen as not being capable enough to participate in research (Lai, Elliott, & Ouellette-Kuntz, 2006). At one point, for example, I was asked by a member of an ethics review committee whether disabled people were "able to give [me] any good data at all". Instead, this person suggested, I was "highly encouraged to speak with the parents or support workers" of disabled people instead. The gatekeeping around disabled people is so common that they have generally had fewer opportunities to speak about their experiences and perspectives, especially regarding their romantic and sexual lives (Santinele Martino & Fudge Schormans, 2018).

It was extremely important for me to center the voices of people with intellectual disabilities, acknowledging them as agents and meaning makers of their own lives. I am inspired by feminist methodology, which aims to center the experiences and voices of those at the margins (Pole & Lampard, 2002). As Foucault (2003) explains, subjugated knowledge refers to a "whole series of knowledges that have been disqualified as non-conceptual knowledges, as insufficiently elaborated knowledges: naïve knowledges, hierarchically inferior knowledges, knowledges that are below the required level of erudition or scientificity" (p. 7). In this way, my research makes space for people with intellectual disabilities – and their often-subjugated knowledge – allowing them to share their experiences with love and intimacy, challenging the invisibility of their voices and sexualities by contributing to a growing body of literature that is finally listening to people with intellectual disabilities (Rushbrooke, Murray, & Townsend, 2014).

When listening to people with intellectual disabilities, their protection was extremely important to me, especially considering precedents of unethical research with this social group (Iacono, 2006; Mcdonald, Kidney, & Patka, 2012). People with intellectual disabilities have a long and painful history of abuse and exploitation, sometimes done by researchers (Fudge Schormans & Sobsey, 2007). Yet, at times, research involving disabled people is seen as simply "too risky" and not "valuable enough to outweigh potential risks" to the extent that researchers – especially junior scholars – are actively discouraged from engaging with this social group (Santinele Martino & Fudge Schormans, 2018, para 3). This is highly problematic as articulated by Santinele Martino and Fudge Schormans:

> It is [also] unethical to assume that people labeled with intellectual disabilities cannot make their own decisions and, though greater care may be needed, people with intellectual disabilities have the right to share their perspectives and "speak" on their own behalf – in their daily lives as well as through their active inclusion in research (para. 1).

This project was an opportunity for people with intellectual disabilities to participate in knowledge construction (McDonald, Conroy, Olick, & The Project Ethics Expert Panel, 2016) and help change general community opinions about their sexual rights (Fudge Schormans, 2015). I am a firm believer in the power of sexual stories (Plummer, 1995) and understand that telling stories is an important part of creating new and more diverse sexual cultures (Santinele Martino & Fudge Schormans, forthcoming; Siebers, 2008). By sharing participants' sexual stories, I hope to advance "disabled people's political struggles" and help "to eradicate disabling barriers in society" (Barnes, 2008, p. 7).

My Relationship to Disability

Reflexivity should be an ongoing process that walks with us in every stage of research. As Guillemin and Gillam (2004) note, a reflexive researcher does not only report the "facts" but "actively constructs interpretations (what do I know?), while at the same time questions how those interpretations came about (how do I know what I know?)" (p. 274). This helps develop rigorous research through thoughtful ethical practices. I agree with Liddiard (2013) that reflexivity is a "practice that is central to disability and feminist research" (p. 2). Inspired by O'Toole's (2013, 2015) call for more open discussions regarding researchers' relationship to disability, I would like to share my own relationship with disability. My interest in disability studies was inspired by my experience growing up with an older sibling with a physical impairment. His experiences and challenges around sexuality encouraged me to immerse myself in this body of literature to find ways to better support disabled people and their families in this aspect of life.

My passion for this research area was emboldened by my volunteer work with disabled people, self-advocacy groups, and community-based organizations. I have also worked alongside incredible critical disability studies scholars as a research assistant and collaborator in a variety of research projects. I count myself lucky to be a part of a supportive network of scholars and activists in Canada and abroad who have challenged, reinforced, and contributed to my understanding of disability as well as my own positionality. I feel a strong sense of commitment to using my privileges to make space for people with intellectual disabilities to share their experiences. At the same time, I understand that reflexive practices are even more important for non-disabled researchers considering how "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" (Stone & Priestley, 1996, p. 700).

Inspired by Patricia Hill Collins' (2000) work, I have been committed to making this dissertation "intellectually rigorous, well researched, and accessible to more than the select few fortunate enough to receive elite education" (p. viii). I am committed to sharing my research findings with people with intellectual disabilities – both within and outside of academia – and ensuring that this is done in an accessible manner (Dalton & McVilly, 2004; Lewis & Porter, 2004; Liddiard, 2013). I included a section in the consent form where participants could list their interest in receiving a brief research report in plain language and large print at the completion of the research. I have also offered to deliver short presentations about the study results to self-advocacy groups and community-based organizations. Finally, I have also committed to making the final dissertation available at the McMaster University Library and to send participants copies of future publications along with brief summaries in plain language.

Research Design

Most studies drawing on the sexual fields framework have used an ethnographic approach, focusing on particular sexual fields (e.g., Farrer, 2010, 2011; Farrer & Dale, 2014; Green, 2008b; Weingberg & Williams, 2013). No previous studies have used a sexual fields approach to examine the intimate lives of people with intellectual disabilities and the more specific sexual fields they navigate. My project contributes to the sociologies of disability and sexualities by applying and extending the sexual fields framework to the study of the romantic and sexual experiences of people with intellectual disabilities. It offers a new theoretical vocabulary as well as a multi-level analytical approach to understanding the experiences of this social group which has been commonly desexualized and restricted from forms of sexual expression.

For different reasons, I spoke with disabled people instead of other social actors such as family members and support workers for this project. Firstly, this is because more attention has been paid to the views and experiences of other people in disabled people's lives when it comes to sexuality (Santinele Martino & Fudge Schormans, 2018). Secondly, research sometimes "dilute[s] disabled people's voices by including their voices *only* alongside those of non-disabled people" (Liddiard, 2011, p. 82, emphasis added). People with intellectual disabilities can provide rich, insightful snapshots as they make sense of and navigate their everyday lives. Furthermore, this project focused on the experiences of people with intellectual disabilities because they have usually had a different response to their sexual expression and sexual rights compared to people with other disability labels (Gill, 2010; Shildrick, 2015). As Gill (2010) writes, "[M]ost, in the disability communities would argue that disabled adults should have unrestricted access to sexuality", however, when it comes to individuals with intellectual disabilities, they are "seen as special exceptions, deserving a different approach, primarily because of their impairment diagnosis" (p. 210). Additionally, due to misguided ideas around capacity and ability, this social group has "historically been afforded few opportunities to communicate their experiences and desires concerning their personal and intimate lives, including their friendships, parenting, family relationships, or romantic and sexual experiences" (Santinele Martino & Fudge Schormans, 2018, para. 2). In taking this particular focus, my intention has not been to reinforce a hierarchy of impairments (Deal, 2003) but rather to attend to specific experiences and needs of a social group which is not often heard.

I recruited adults because gaining access to disabled children and underage youth can be significantly difficult due to gatekeeping, infantilization, and protectionism, especially when it comes to talking about sexuality. These are, of course, important voices that also deserve further attention especially as children and youth experience a critical time in terms of learning about sexuality and developing relationships. At the same time, it is also important to contest a tendency within the disability scholarship to focus on young disabled people (Chivers, 2011; Priestley & Rabiee, 2002) as well as an assumption in the existing sexual fields literature that assumes that chronological adulthood automatically grants sexual actors autonomy to make choices in their intimate lives and access to an array of sexual fields and sexual practices. As my findings highlight, merely being an "adult" (chronologically speaking) may not lead to the "permission" or to opportunities for people with intellectual disabilities to navigate sexual fields.

This project used purposive sampling to select participants who met certain criteria (more details in the recruitment guideline section) for inclusion and who had the knowledge and experience necessary to address this project's research questions (Aurini, Heath, & Howells, 2016; Cresswell & Plano Clark, 2011; Patton, 1990). I strived to recruit people with intellectual disabilities living in different housing arrangements including group homes and assisted living facilities, with family members, and independently. The reason for recruiting participants in different housing arrangements – especially those in more protective and constrained living environments – was to capture important nuances regarding different forms of boundary-work (Lamont & Molnár, 2002) disabled people experience, sexual agency in the lives of disabled people, and ways that their sexual access is shaped. To achieve that, I drew on my existing connections with community-based organizations and self-advocacy groups.

Gaining access to disabled people who are more isolated or sheltered is challenging. However, I have built trusting relationships with self-advocates and service providers which allowed me to rely on them to reach out to a more diverse group of disabled people. These connections shared information about the study with potential participants who had a choice whether to contact me and participate in the study. A challenge with snowball sampling is that participants may then know one another, creating certain risks in terms of anonymity and confidentiality. To handle that concern, I never disclosed to my connections whether people decided to participate in the study. I also informed participants about risks in participating and that I would not tell others about their research participation. Of course, participants themselves may have chosen to disclose their participation to others in their lives, which was outside of my control. When asked about their current living arrangement, the majority of the 46 participants lived in group homes or assisted living facilities (n=20), while some lived with their intimate partners (n=5), family members (n=12) including parents, siblings, and uncles, and a few live independently (n=9). As can be seen, most participants live either with their families or other people with intellectual disabilities (80 percent), placing most participants in living arrangements where they may have less access to privacy and opportunity to initiate and maintain romantic and sexual relationships.

This research primarily draws on in-depth interviews with adults with intellectual disabilities.[1] In-depth semi-structured interviews allowed for a detailed exploration of the intimate lives of participants "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, p. 32; Kvale, 2006). They also grant researchers access to non-observable aspects of people's lives including their emotions, views, and sexual stories (Brinkmann, 2013; Neuman, 2011). Most importantly, interviews allowed me to elicit narratives, or sexual stories, directly from participants – a format that tends to be the most successful for this social group. The interview guide consisted of questions about their intimate lives including how they had learned about sexuality, the spaces they navigated to meet intimate partners, the barriers and opportunities to having a romantic and sexual life, and their strategies for remaining sexual. It contained different types of questions, including open-ended, exploratory, and probing (Kvale, 1996). In wanting to apply a sexual fields framework to this particular social group, the interview guide was also organized in a way that allowed me to theorize concepts such as erotic habitus, sexual capital, and sexual fields in the context of participants' lived experiences. As Kvale (1996) notes, interviews are not a "reciprocal interaction of two equal partners" as interviewers usually "defin[e] the situation, introduc[e] the topics of the conversation, and through

---

[1] For the purpose of this study, instead of relying on medical and diagnostic procedures, I included community members who self-identified as having an intellectual disability. Considering the level of stigma unfortunately associated with this disability label, it is highly unlikely that a non-disabled person would opt to associate with the label. Additionally, prior to the interviews, I ensured that participants understood the purpose of the study and the criteria for participation.

further questions stee[r] the course of the interview" (p. 126). For that reason, participants also had the opportunity to raise other relevant questions and topics that were not previously included in the interview guide. A semi-structured interview approach allowed participants to also shape the interview and allowed me to ask additional questions regarding anticipated topics they raised (Neuman, 2011; Rubin & Rubin, 2005). As a form of reciprocity, I also always asked participants if they had questions about the project or myself to the extent to which I felt comfortable.

The benefit of interviews is that they allow us to understand the experiences of people who do not actively participate (either by choice or lack thereof) in sexual fields. Indeed, as my findings demonstrate, many people with intellectual disabilities face countless barriers to accessing a rich array of sexual sites. My work importantly highlights the centrality of considering the question of access to sexual fields – whether people can access or claim sexual spaces and how they enter these spaces in particular, gendered ways – before focusing on certain sexual fields. Thinking about sexual access in this context highlights the experiences of a group of sexual actors who are often out of "the game" (Green, 2014), either by choice or due to restrictions from others in their lives. Additionally, due to more pragmatic reasons, including the challenge of gaining access to social spaces created by and for people with intellectual disabilities as a junior scholar with limited time and funding, interviews were then the best fit for this project. That said, my interview data is complemented by some participant observation conducted in community-based organizations, self-advocacy group meetings, day programs, and group homes which allowed me to gain a more contextualized understanding of the spaces where some people with intellectual disabilities spend a significant amount of their time.

The data presented in this dissertation derives from 46 in-depth, semi-structured interviews with adults with intellectual disabilities, generating 990 pages of interview transcripts. It has been noted that "there are no rules" in terms of sample size in qualitative research (Patton, 2002, p. 244). Instead, it is about having "enough data to tell a rich story" (Braun & Clarke, 2013, p. 56). Having conducted 46 in-depth interviews – a significant number in my area of research – gave me ample data to write a rich and complex story. Additionally, noticing reoccurring codes and themes coming through my interviews, I felt comfortable concluding the interview process (Hagaman & Wutich, 2017). These interviews took place between June 2017 and December 2018. In addition, I kept field notes throughout the research process based on my observations and reflections during fieldwork.

Recruitment

The difficulties and complexities involved in recruiting people with intellectual disabilities have been well documented (e.g., Becker et al., 2004; Iacono, 2003; Nicholson, Colyer, & Cooper, 2013). People with intellectual disabilities are commonly assumed to be unable to make their own decisions, including whether to participate in research and "speak" on their own behalf (Nind, 2008; Santinele Martino & Fudge Schormans, 2018). As a result, people with intellectual disabilities have often been excluded from research, provided with fewer opportunities to share their experiences compared to other social actors in their lives (Elderton et al., 2013; Kelly et al., 2009; Lewis & Porter, 2004). Gaining access to people with intellectual disabilities can often involve going through a series of gatekeepers, including family members and service providers, as well as 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 also need to provide consent along with the participant's agreement (Lennox et al., 2005). In this study, all participants were their own legal guardian.

This project used a "complex and multi-layered" recruitment strategy (Nicholson, Colyer, & Cooper, 2013, p. 654) to garner participants from four cities: Hamilton, Toronto, Ottawa, and Kingston, Ontario. Participants were recruited through 1) service providers and self-advocacy groups; 2) presentations about the project at self-advocacy group meetings; 3) a local radio show; 4) posted recruitment posters (appendix D) in public places (e.g., grocery stores, libraries, community agency offices, self-advocacy group offices, parent-led groups); 5) posters shared via social media (e.g., Facebook and Twitter); 6) a website with detailed information about the study, and 7) snowball sampling (appendix A, B, C), an approach that allows for accessing "hidden" and "socially stigmatized" social groups (Atkinson & Flint, 2001, para. 2). To facilitate the recruitment process, especially of adults with intellectual disabilities living in more controlled living arrangements, I also asked agency workers and self-advocates to pass on recruitment "postcards" (appendix E) to potential participants. Self-advocates and agency workers are particularly well-positioned in knowing and having some access to people living in more controlled settings.

In terms of recruitment, I also took into account some of the recommendations that people with intellectual disabilities themselves have presented to researchers in previous studies (e.g., McDonald, Kidney, & Patka, 2012; Swaine et al., 2011). For instance, all of my recruitment materials were written in an easy-to-read manner (Swaine et al., 2011) and further improved through the paid services of a professional trained in translating documents into plain language. Additionally, I reviewed the recruitment documents with two community members with intellectual disabilities who I had collaborated with in a previous project to further ensure accessibility and clarity.

At the beginning of this project, I was unable to provide an honorarium to participants. Fortunately, that changed when I secured research funds and followed the advice from self-advocates who noted that a lack of an honorarium would discourage and make the study less accessible for some people to participate. This is unsurprising considering how disabled people in Canada are more likely to be living on a low income and under the poverty line compared to non-disabled people (Council of Canadians with Disabilities, 2017; Ignagni et al., 2016). I ensured to contact participants who had already been interviewed without compensation to verify that they too received compensation for their study participation.

Considering how people with intellectual disabilities are sometimes coerced in their everyday lives into partaking in activities that may not be of their choosing (Cameron & Murphy, 2006; Nicholson, Colyer, & Cooper, 2013), it was important for me to ensure that potential participants did not feel that way in this research. Throughout the entire project, the decisions from disabled people were respected and prioritized. For instance, I had one mother who, though well-intentioned, contacted me saying that *she* wanted her son to participate in the study. She considered the study to be an opportunity for her son to talk about sexuality with a more “knowledgeable person”. Without hesitation, she then told me that she would “really encourage” her son to participate. While I appreciated her gesture, I respectfully reminded her that it was her son’s decision whether to partake. Her son then opted not to participate and his wish was respected. I followed a similar approach when recruiting through service providers and self-advocacy groups. I wanted to ensure people did not feel pressured to participate because a friend or staff member had encouraged them to do so. I reminded participants that it was their choice whether or not to participate in the study.

Recruitment Guidelines

To be eligible, participants had to be at least 18 years old, self-identify as having an intellectual disability, have a clear understanding of their legal guardianship status, live in Ontario, and have an interest in sharing their romantic and sexual experiences for the purposes of the research. Although I did not ask participants about their specific disability label to further protect their identities and their privacy, my primary recruitment strategy – through self-advocacy groups and service providers – ensured that people had received a diagnosis of an intellectual disability. It is likely that this project included participants identified with a range of intellectual disability labels, but I am unable to specifically note them. Participants communicated verbally in an interview, understood what the research was about, and gave written informed consent.

It was also my goal to address intersectionality. Thus, I sought 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 (Björnsdótti & Rannveig Traustadóttir, 2009; Greenwell & Hough, 2008; Rembis, 2010; O'Toole, 2000, 2015). To achieve this, I used different strategies including sharing information about the study with community-based organizations and social network groups led by other equity-seeking groups while educating myself on different (but still intersecting) social struggles and positive and respectful forms of engagement. My previous research experiences have similarly pointed to the significance of various social categories including gender, sexualities, and religion in shaping participants' intimate lives (Santinele Martino, 2014, 2019). Interestingly, one of the questions I received from the ethics board was about the need to ask participants about their demographic information. While I understand that researchers should make thoughtful decisions about the types of demographic data they collect, it seemed as though there was an assumption that disability status was the only social location relevant to this social group.

As my findings strongly demonstrate, it is crucial to take an intersectional lens to understand the intimate lives of disabled people. For example, the religious background of some participants played a significant role in the sexual fields and intimate partners they privileged (Santinele Martino, under review). After explaining the relevance of collecting demographic information from participants to the ethics board, and making plain to participants that they should share only as much as they felt comfortable doing, I asked participants questions about their social locations using a demographic sheet (appendix M).

For this study, I was unable to include sign language users, people using alternative and augmentative communication devices, non-English speakers, individuals who were unclear about their legal guardianship status, and individuals who were not their own legal guardian and whose legal guardian did not authorize their participation. In the case of participants in this study, they were all their own legal guardian. It is important to note how sometimes, due to protectionism and gatekeeping, researchers end up with "the usual suspects", meaning disabled people "who use traditional forms of communication (i.e., speech), who have been determined to have 'milder' disabilities, who may already have research experience or identify as self-advocates" (Santinele Martino & Fudge Schormans, 2018, para. 28). People with intellectual disabilities form a heterogenous group and further research is needed to better understand the array of experiences *within* this social group. Nevertheless, it is important to note that even the participants in this sample still pointed to significant levels of surveillance, restriction, and isolation in their intimate lives. Those who I was unable to include, and others who are more isolated and have less sexual agency in their lives may experience even more intensified restrictions to their intimate citizenship.

Ethical Considerations

Protection and Rights: Not Mutually Exclusive

The process for receiving ethics approval for this project was lengthy, requiring telephone calls, extensive written responses to the ethics board, one-on-one meetings with ethics officers, and a meeting with the full ethics board. This project received ethics approval through three different research ethics boards including the McMaster University Research Ethics Board, the Mohawk College Research Ethics Board, and Family Service Toronto Research Ethics Board. The process of receiving ethics approval can be particularly challenging in research involving people with intellectual disabilities, especially for studies related to sexuality (Iacono, 2006; Santinele Martino & Fudge Schormans, 2018). These challenges can sometimes discourage researchers, especially students who experience time and funding constraints from engaging people with intellectual disabilities (McDonald et al., 2015; Santinele Martino & Fudge Schormans, 2018). In fact, I was highly discouraged by one ethics board from interviewing people with intellectual disabilities who supposedly may not have "given me any good data". Instead, I was encouraged to pursue interviews with family members and support workers. A significant contribution of this project, however, is precisely that it makes space for people with intellectual disabilities to speak on their own behalf.

Having researched the intersection of intellectual disability and sexuality for almost 10 years now, I am well aware of how this area commonly warrants concern from all sides. Some of these concerns are of course well-founded. Yet, there are better ways of dealing with this vulnerability than simply shutting down opportunities for disabled people to share their hopes, perspectives, and experiences around sexuality. Protection should not be used as a silencing tool, one that precludes disabled people from their human right to sexual expression. For some participants, involvement in this research provided a first-time opportunity to speak openly about their romantic and sexual desires and dreams. Many had previously been discouraged, punished, infantilized, and reprimanded when talking about sexuality. This only made my responsibility – especially in terms of not being judgemental – even greater. It was extremely important for me to create a safe(r) space for participants to comfortably share their thoughts. In our conversations, nothing was "abnormal", "odd" or "taboo". Furthermore, as a social group which is so commonly infantilized, it was important for me to treat the participants like adults who can understand their rights and choices regarding research participation. It was my job to ensure information was delivered to participants in an accessible manner, such as using consent forms written in an easy-read format.

Previous studies have consistently noted that participating in research can be a positive experience for people with intellectual disabilities who 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 (Fudge Schormans, 2015; McDonald, Kidney, & Patka, 2013; Nicholson, Colyer, & Cooper, 2013). Also, for some disabled people, 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).

Ethics Procedures

At the time of the interview, the consent form (appendix F) was provided to participants to read. I also read the consent forms with participants to ensure that the form was understood. Participants were told at this time that they were not obliged to continue if they felt any uncertainty. Participants were provided a copy for their records. I had the information letters and consent forms available in larger fonts (14-point font size) and ensured that the language in the form could be understood by participants. Participants also had a choice to receive the interview questions in advance. In those cases, I sent the participants a second version of the interview guide written in plain language, with questions numbered, without jargon headings, and in larger font (appendix O).

When potential participants responded to the call to participate, I had an introductory conversation with them, an opportunity to talk in-depth about the purpose and nature of the research. I reviewed the research information with interviewees once again at the time of their interviews. This is because previous studies suggest that it can be beneficial to repeat the research information to participants to ensure they understand the research and consent process (Sigstad, 2014; Wennberg & Kjellberg, 2010). I ensured that participants understood what the research was about by asking them “tell-back questions” such as, “Can you tell me what this study is about, in your own words?” and “Can you stop the interview whenever you want?”

I also asked participants whether they could sign a consent form and if they were in a guardianship arrangement. All of the participants were their own legal guardian. If people preferred to have a support person, advocate, or interpreter present during the interview, I accommodated these requests and had these individuals sign confidentiality forms (appendix L). A few participants chose to have a support worker with them during the interview, and their desire was respected. Participants were assured that identifying information would not be made available to any member of their community or to their peers. An exception to this would occur if/when participants revealed information about illegal activities, such as physical or sexual abuse, which was also explained as part of obtaining informed consent.

"Ethically Important Moments"

Ethics should certainly go beyond just the mere requirements and approval of the Institutional Review Boards (Blee & Currier, 2011; Ellis, 2009; Librett & Perrone, 2010). Even if researchers follow these procedural guidelines "relational situations will come up in the field and in the interviews that will make their heads spin and their hearts ache" (Ellis, 2009, p. 310). Still, neither the ethics committees nor ourselves can foresee all of the day-to-day ethical issues we will face (Blackman, 2007; Guillemin & Gillam, 2004). This is where the concept of "relational ethics" becomes particularly relevant to research as it requires us "to act from our hearts and minds, to acknowledge our interpersonal bonds to others, and to initiate and maintain conversations" (Ellis, 2009, p. 308). Guillemin and Gillam's (2004) discussion on "ethics in practice" and "ethically important moments" is particularly relevant (p. 264-265). During my fieldwork, I encountered ethically important moments and I strived to address them to the best of my ability.

There were instances in which participants had been misinformed about sexuality and their sexual rights. I cannot say whether that was done intentionally. For instance, one participant asked me if it was true that people in Ontario are not allowed to get married until they are in their 40s. In these moments, I felt responsible for answering those questions as honestly and accurately as I could. It would be unethical for me to knowingly perpetuate misinformation, especially when participants actively sought out answers from me, a person who some saw in some way as an "expert". My main concern, however, was about how that could potentially cause some tension between participants and other people in their lives. For that reason, I followed up with participants after the interview via brief emails and phone calls just checking on how they were feeling after the interview. All participants reported positive feelings about having had an opportunity to share their perspectives and experiences and, to my knowledge, none of them experienced any conflicts following the interview.

A few participants wanted to remain in touch after the interview. Again, considering the social isolation so commonly experienced by disabled people, their desire for connection should not be surprising. There were also a few instances in which participants showed certain romantic or sexual interest toward me. For example, in one instance, when asked about their ideal partner, a participant not-so-subtlety looked at me from head to toe and clearly started describing me. At other times, I received compliments about my appearance or was asked questions about my relationship status. I approached these moments with kindness and respect toward participants while maintaining clear professional boundaries. I did not want to cause harm, especially to those whom had just spoken about feeling extremely lonely and having low self-confidence. I also am well aware that other sexualities scholars in disability studies have experienced similar instances (see, for example, Liddiard, 2011) and this was not my first time engaging in this type of research. In a previous study, a couple with intellectual disabilities invited me to join them in a threesome. In some of these instances, a subtle nod to my relationship status was enough to help me assert some boundaries. Certainly, being a man shapes the way these interactions unfolded. For women doing similar research, attempts to assert those boundaries may be challenged by participants (Liddiard, 2011).

Finally, it was particularly difficult for me to listen to participants' experiences with abuse and harassment. It undoubtedly triggered difficult memories for me. I count myself lucky though that I have an incredibly supportive network of friends and colleagues who I could count on for debriefing. I have been lucky to have people around me to whom I could open up and cry. For some participants, however, they had only recently been able to recount their experiences with a specialist and to work through those painful memories. I made to sure to follow up with these participants via phone calls. I feel extremely privileged that participants felt comfortable sharing those experiences with me.

Interviews

Once I obtained ethics approval, I started conducting my interviews. I used a semi-structured interview guide to elicit responses from participants while also allowing them to bring up information that they found relevant. There is a body of literature addressing best practices for interviewing participants with an intellectual disability (Beail & Williams, 2014). As previous studies have shown some evidence of acquiescence bias amongst people with intellectual disabilities when responding to more directive questions (McVilly et al., 2008), I focused on eliciting narratives as much as possible (Beail & Williams, 2014; Booth & Booth, 1996; McVilly et al., 2008). People with intellectual disabilities may also have a more limited vocabulary and experience some challenges articulating and describing their experiences in detail (Booth & Booth, 1996; Beail & Williams, 2015; Clarke et al., 2005), which does not mean that they cannot share their experiences and perspectives in rich ways. It was also important to remember that people with intellectual disabilities are a heterogeneous group and that different interview approaches may be more suited to different participants (Goodley, 1998).

It was important for me to respect participants' individual preferences. Considering the sensitivity of the research topic, the interviews were conducted in a mutually agreeable location that allowed participants to feel comfortable and safe sharing their experiences. This included places such as public libraries, a campus office, local agencies, community centers, and participants' residences. In the case of participants who chose to be interviewed at their homes, I maintained a "buddy system", notifying a trustworthy colleague who had certain details of the interview (e.g., name of participant, date, time, expected duration, location), but would only access them if there was a problem. This is a common practice in qualitative research as a way to protect researchers' safety in projects involving interviews at participants' own homes. I did not feel unsafe in any of my interviews. I made sure to notify this colleague with a brief telephone call that I had safely completed the interview. I am extremely appreciative of participants who invited me into their homes and generously shared personal items with me such as family photos and letters that further illustrated the depth and meaning of sexuality, love, and intimacy in their lives.

It was also important for me to establish rapport with the participants prior to the interview in order for them to feel comfortable sharing information about their personal lives. As Charmaz (2006) notes, "Strong bonds build trust and foster open conversations with research participants about areas ordinarily left unspoken" (p. 112-113). By having a two-step process in which I first talked to potential participants and offered them time to think about their participation, I started building that rapport, clarifying their questions, and allowing them to know me a little bit before we met again for the interview. Furthermore, because some participants had heard about the research through community organizations and self-advocacy groups, that allowed for them to feel safer and more willing to share their experiences. I was particularly touched by one participant who returned a few minutes after her interview had concluded with a letter in hand. The handwritten letter thanked me for being "gentle" and "kind" during the interview. I am extremely grateful for those moments during my fieldwork.

Interviews ranged from one to two hours each and were audio recorded with the permission of the participants. Each participant received a $20 gift card in appreciation of his or her time. This amount was suggested by my committee member Dr. Ann Fudge Schormans who has done extensive research with people with intellectual disabilities in Ontario. By providing participants with gift cards, it provides greater flexibility for where they can spend their compensation and avoids potential impacts on disability funding.

I explained the research and went through the consent form with participants in accessible language. Once an individual agreed to meet for an interview, they were informed at the time of reviewing the consent form that their participation was voluntary. I told participants that they were not required to answer any questions with which they were uncomfortable and that they could withdraw their consent at any time. I told participants that, following the interview, and any time before the conclusion of the project, they could withdraw from the research without penalty. I provided my name, address, and email address on the consent form, a copy of which remained with participants, with a statement inviting participants to contact me at any time with questions or concerns, including withdrawal. No one has withdrawn from their interview or the study. I also completed a short questionnaire asking participants for some basic demographic information.

Profile of Participants

The combination of a larger sample size as well as a wide eligibility criterion allowed me to access a diverse sample (see Table 1) including both men and women across different ages. Participants ranged from 23 to 64 years old, with an average age of 41. There were more men (n=33) than women (n=13). This may be a result of a larger culture in which men, both disabled and non-disabled, still have more "permission" to talk openly about sexuality. When it comes to women with intellectual disabilities, who are often desexualized and constructed as particularly vulnerable, there may be additional barriers for their participation in research. Additionally, having a man conduct this research may have discouraged some women, as well as gatekeepers in their lives, from feeling comfortable with participating.

When asked about their relationship status, more than half of my sample was single (n=25), compared with those in a relationship (n=14), married (n=4), and divorced (n=3). My sample unfortunately lacks some diversity in terms of sexual orientation. Among the participants, most people identified as heterosexual (n=42) compared to heterosexual with prior homosexual experience (n=1), bisexual (n=1), queer (n=1), and being unsure (n=1). This is, of course, disappointing considering how I have been invested in making space for LGBTQ+ disabled people to share their experiences (Santinele Martino, 2017, 2020). Evidence from other studies suggest that LGBTQ+ disabled people tend to experience a "double marginalization", facing particular challenges due to marginalization both in the disability and queer communities (Santinele Martino, 2017), which may mean that they lack access to a variety of sexual fields.

Most of the participants self-identified as cis-gender people (n=44). The sample included one transgender man and one transgender woman. Consistent with other studies, these two participants highlighted how ableism, transphobia, transmisogyny, and other systems of inequality work together to create unequal and extremely violent outcomes in their lives. To date, very few studies have focused on the experiences of trans-identified disabled people. Thus, more attention is needed (Santinele Martino, 2017). This is especially important to avoid erasing trans-identified disabled people and reaffirming compulsory heterosexuality, in addition to opening opportunities for a more diverse array of sexualities and gender identities in disability studies and beyond (Slater & Liddiard, 2018).

The sample was also mostly White (n=32) compared to other racial groups: Black (n=4), Asian (n=4), Latino (n=3), and mixed (n=3). This is also disappointing because I am well aware of the risks of perpetuating what has been called a “White disability studies” (Bell, 2006; Miles, Nishida, & Forber-Pratt, 2017). Interestingly, participants rarely spoke about their experiences through the lens of race and ethnicity. In fact, some were a bit unsure about how to identify themselves in terms of race and ethnicity. Nonetheless, considering the existing sexualities literature, which provided empirical evidence that shows that racialized social groups are often the target of control of their sexualities (e.g., Hill Collins, 2005; Fields, 2005), as well as disability studies literature showing how disability and race have been entangled throughout history as a way to justify forms of inequality (Bayton, 2001, 2005; Dolmage, 2018), future studies should examine the intersections of intellectual disability, sexuality, and race.

Finally, in terms of schooling, most participants had had some school experience ranging from elementary school up until grade 12 (n=35), while a few reported having had some experience in college or university (n=11), mostly by taking a specific course. When it came to employment, participants reported being unemployed (n=18), working on a part-time basis (n=18), working on a full-time basis (n=9), and being retired (n=1). It is important to highlight how 78 percent of participants were, in essence, living in a precarious position due to unemployment or underemployment. This precarity affects the ability of disabled people to accumulate economic capital and maintain intimate lives.

Table 1: Demographic Profile of Participants

Pseudonym	Age	Gender	Sexual Orientation	Relationship Status	Race	Religion	Education	Employment	Housing Arrangement
Amanda	44	Woman	Heterosexual	Married	White	Catholic	Grade 12	Unemployed	Living with Partner
Bruce	61	Man	Heterosexual	Married	White	Catholic	Grade 12	Part-Time	Living with Partner
Raul	52	Man	Mostly Heterosexual	Common Law	White	None	Some college	Unemployed	Living with Partner
Iago	39	Man	Heterosexual	Single	White	None	Grade 12	Part-Time	Living with Family
Jenny	40	Woman	Heterosexual	In a Relationship	White	None	Grade 12	Unpaid Work	Living with Family
Mary	24	Woman	Heterosexual	Single	White	Christian	College	Part-Time	Group Home
Aaron	42	Man	Heterosexual	Separated	White	Christian	College	Unemployed	Group Home
Joshua	50	Man	Unsure	Single	White	None	Some college	Temp Jobs	Group Home
Daniel	34	Man	Heterosexual	Single	White	Catholic	Grade 12	Part-Time	Independently
Nathan	61	Man	Heterosexual	Divorced	White	Agnostic / Atheist	Diploma	Unemployed	Independently
Wendy	28	Woman	Queer	In a Relationship	Mixed	None	Some college	Unemployed	Living with Partner
Ethan	41	Man	Heterosexual	Single	White	None	Grade 4	Unemployed	Group Home
Gerald	49	Man	Heterosexual	In a Relationship	Latino	Catholic	Grade 12	Part-Time	Group Home
Alejandro	42	Man	Heterosexual	In a Relationship	Latino	Catholic	Grade 12	Unemployed	Group Home
Jared	28	Man	Heterosexual	Single	White	Secular Judaism	Bachelors	Part-Time	Independently
Walter	33	Man	Heterosexual	Single	White	None	Unclear	Full-Time	Independently

Clayton	34	Man	Bisexual	In a Relationship	Mixed	Catholic / Pagan	High School	Part-Time	Independently
Isabella	23	Woman	Heterosexual	In a Relationship	Black	None	College	Part-Time	Group Home
Nelson	30	Man	Heterosexual	Single	Latino	Christian	Some college	Full-Time	Independently
Jack	53	Man	Heterosexual	Single	White	None	Grade 12	Unemployed	Group home
Amy	61	Woman	Heterosexual	In a Relationship	White	Protestant	Grade 10	Retired	Group home
Jacob	55	Man	Heterosexual	Single	White	Catholic	Grade 1	Full-Time	Independently
Julio	31	Man	Heterosexual	Single	Black	None	University	Part-Time	Independently
Charlotte	51	Woman	Heterosexual	Married	White	Christian	University	Full-Time	Living with Partner
Christopher	39	Man	Heterosexual	Single	White	None	High School	Part-Time	Independently
Patrick	39	Man	Heterosexual	Single	Southeast Asian	Catholic	High School	Part-Time	Living with Family
Charlie	41	Man	Heterosexual	Single	White	Catholic	High School	Unemployed	Group Home
Amelia	45	Woman	Heterosexual	Single	White	Catholic	High School	Part-Time	Living with Family
Leonard	40	Man	Heterosexual	Single	White	Anglican Church	High School	Full-Time	Living with Family
Joseph	37	Man	Heterosexual	Single	White	Catholic	High School	Unemployed	Group Home
Albert	44	Man	Heterosexual	In a Relationship	Asian	Church	High School	Unemployed	Living with Family
Bryan	36	Man	Heterosexual	Single	Black	United Church	High School	Part-Time	Living with Family
Tatianna	45	Woman	Heterosexual	Single	White	Catholic	High School	Part-Time	Group Home
Emerich	39	Man	Heterosexual	In a Relationship	White	None	High School	Part-Time	Living with Family
Ross	38	Man	Heterosexual	In a Relationship	White	None	High School	Part-Time	Living with Family

Hector	40	Man	Heterosexual	Single	Black	Church	Elementary School	Part-Time	Living with Family
Carl	51	Man	Heterosexual	Single	White	None	Unsure	Unemployed	Group Home
Carolyn	64	Woman	Heterosexual	In a Relationship	White	Christian	Middle School	Unemployed	Group Home
Grace	38	Woman	Heterosexual	In a Relationship	Asian	Catholic	High School	Part-Time	Living with Family
Ryan	36	Man	Heterosexual	Single	White	Buddhism	High School	Part-Time	Living with Family
Arthur	34	Man	Heterosexual	Single	White	Catholic	High School	Unemployed	Assisted Living
Keith	24	Man	Heterosexual	Single	White	None	High School	Unemployed	Assisted Living
Chelsea	60	Woman	Heterosexual	Divorced	White	Catholic	High School	Unemployed	Assisted Living
Liam	46	Man	Heterosexual	In a Relationship	Asian	None	High School	Unemployed	Assisted Living
Scott	34	Trans Man	Heterosexual	Single	Mixed	None	High School	Part-Time	Group Home
Virginia	31	Trans Woman	Heterosexual	In a Relationship	White	None	High School	Part-Time	Group Home

Analysis of Interview Data

I followed a multi-step analytical process, starting with broad codes and then constructing categories and themes (Aurini, Heath, & Howells, 2016). Interviews were transcribed verbatim by me and a professional transcriptionist (who signed an oath of confidentiality, appendix L), and included a great level of detail, including pauses, laughter, and repetitions to capture contextualized representations of the interviews (Bloomberg & Volpe, 2012). While I recognize the benefits behind transcribing one's own interviews (see, for example, Bird, 2005), considering the number of interviews and time constraints, I opted for a combination. I assigned identification codes to the transcripts as soon as each was completed. Additionally, I kept notes of my observations of locations where I conducted interviews (e.g., group homes, day programs), interactions with participants, self-advocates, agency workers, and family members, as well as post-interview reflections.

I examined the data from a structuralist-constructivist framework by using a thematic analysis. After transcribing interviews, I read the transcripts multiple times while listening to the audio recordings, keeping notes on preliminary themes. I used ATLAS.ti 8, a qualitative analysis software to store and conduct the formal coding of my interview transcripts and field notes. Initially, I conducted open coding (Corbin & Strauss, 2008), which generated an initial list of broad codes such as lack of privacy, infantilization, economic capital, and loneliness. Through a "line-by-line" coding, my coding was comprehensive, meaning that all parts were assigned a code or sometimes even more (Charmaz, 2008, p. 155).

I then conducted "axial coding" (Charmaz, 2006), which involves identifying relationships between codes that emerged in the open coding process. Finally, I conducted a thematic analysis of the data (Aurini et al., 2016; Braun & Clarke, 2006). The coding process was both "theory driven", approaching the data with certain questions and a theoretical framework in mind, as well as "data driven" with codes "depend[ing] on the data" itself (Braun & Clarke, 2006, p. 18). The sexual fields literature drew my attention to themes such as a lack of access to sexual fields, sexual capital, erotic habitus, and gender habitus. I reread the transcripts at different points in the writing process to ensure that my writing reflected participants' contextualized accounts.

As Kvale (1996) importantly notes, it should not be assumed that research generates "knowledge claims that are so powerful and convincing in their own right [that] they […] carry the validation with them, like a strong piece of art" (p. 252). It is important to maintain some criteria in terms of evaluating qualitative research (Guba & Lincoln, 1994). Ballinger (2006) recommends four main "considerations" for qualitative research scholars. Firstly, "coherence", meaning that choices in terms of the research purpose, research methods, and the role played by the researcher should be coherent (p. 240-241). Secondly, a "systematic and careful research conduct", which involves sharing evidence that the researcher seriously considered in every step of the research process, including recruitment, interviewing, and participants' representation (p. 241). Thirdly, a "convincing and relevant interpretation" of the research data, meaning that the researcher should provide a "credible and compelling" story of their data, such as by backing interpretations through relevant theoretical frameworks (p. 242). Finally, reflexivity and the ways that the researcher has shaped the research process and results should also be clearly acknowledged. In writing this dissertation, I took these considerations to heart with the intention of producing a coherent, thoughtful, convincing, and reflexive contribution to the literature.

Advantages and Limitations of This Study

With a few exceptions, little research has examined the romantic and sexual experiences of people with intellectual disabilities in more restrictive institutional and social settings (Fish, 2016; Rogers, 2016). For example, Löfgren-Mårtenson (2004) conducted participant observations at dances organized for young people with intellectual disabilities in Sweden, finding ways in which parents and staff controlled the sexualities of disabled people as well as how disabled people coped with those challenges. Another study in England used an ethnographic approach to explore the sexualities of women with intellectual disabilities in a secure unit, finding various restrictions to their intimate lives (Fish, 2016).

Considering the well-documented social isolation, restrictions, and surveillance experienced by many people with intellectual disabilities (Feely, 2016), an ethnographic approach to studying sexual fields occupied by people with intellectual disabilities is very difficult, especially for a graduate student. In Ontario, especially, there are significant levels of gatekeeping, particularly when it comes to sexuality. In our province, the opportunities that exist are most commonly created by developmental services. Furthermore, an ethnographic approach focused on particular sexual sites may not appropriately capture the experiences of some people with intellectual disabilities who may not have access to sexual fields.

I also recognize that the metropolitan focus of my sample is a limitation. The disadvantage of convenience samples is that they may not be reflective of the overall population (Saumure & Given, 2012). Being based on voluntary participation, it is also possible that I recruited participants who felt particularly strong about the topic. Interestingly, for many participants, this was nonetheless their first time having an opportunity to discuss their intimate lives with a researcher and in a non-judgmental manner. Additionally, even this set of participants, who tended to live in more urban contexts, spoke about a lack of spaces and adequate services and support groups to learn about and express their sexuality. Nevertheless, more research is needed regarding the intimate lives of people with intellectual disabilities in more rural contexts paying attention to the range of sexual fields available to them as well as the particular challenges and opportunities presented by that geographical context.

Finally, whereas my study provides some preliminary insights into the impact of certain social locations, such as disability, gender, social class, and religion, thus contributing to a growing intersectional body of literature (Naples, Mauldin, & Dillaway, 2018), there is a need for more research into other social locations, including sexualities, trans identities, race, and ethnicity. This work, of course, should avoid an additive approach to intersectionality by “simply” adding disability to the mix as a sort of “fixed” social category (Shuttleworth & Meekosha, 2012) and should instead continue to theorize how these social categories simultaneously interact with one another (Hill Collins, 2015).

Conclusion

This chapter has provided an overview of the chosen research method. A qualitative research approach was ideal for in-depth exploration of how adults with intellectual disabilities negotiate their intimate lives. The following chapters articulate my findings and their implications for the existing literature. In the next chapter, I introduce my analysis by focusing on the main barriers that have prevented some participants from accessing and participating in sexual fields. I then turn to my research findings, specifically the experiences of adults with intellectual disabilities who were being “kept out” of sexual fields due to different disabling social processes.

Chapter 3: Being Kept Out of Sexual Fields

Introduction

In their pursuit for love and intimacy, sexual actors enter and negotiate a range of sexual fields. In these competitive arenas, sexual actors need to quickly learn about the internal logics of each sexual field, understand their position within their hierarchies of desirability, and form strategies to successfully navigate these spaces (Green, 2014). But what about sexual actors who, due to structural barriers, are not allowed access to sexual fields in the first place? What about sexual actors who are unaware of the sexual fields available to them? Before discussing the experiences of participants who entered and negotiated sexual fields, this chapter points to the importance of the sexual fields literature examining the question of who can – and by extension, who cannot – *access* sexual fields.

The question of access is particularly relevant when looking at the sexualities of people with intellectual disabilities considering how as a social group they have historically been the target of great surveillance and social control (Arstein-Kerslake, 2015; Malacrida, 2015; Rembis, 2010). While the existing sexual fields literature understands that some sexual actors may struggle with a lack of sexual capital or participating in sexual fields (e.g., Green, 2008a), it assumes that people nonetheless have a certain level of autonomy that grants them access to sexual fields. Sexual actors who are given adult status are expected to have both some knowledge of sexual fields and the opportunity to access them if they so choose. In other words, some sexual actors may not be prominent players in sexual fields but they can choose to be in the "game" as active players. Shuttleworth (2012) has critiqued the sexualities literature for not considering the importance of "sexual access" in shaping the sexualities of marginalized groups. Some participants sit on the sidelines of sexual fields and are unable to be active players, most often not by choice.

This chapter focuses on the systematic barriers that participants face in participating in sexual fields. It examines their accounts to highlight the complex interplay of structural and cultural social processes, as well as psycho-emotional disablism, which makes it difficult, if not impossible, for some to feel prepared or confident enough to navigate sexual fields, or even be allowed to participate in those spaces. Firstly, this chapter illustrates how some participants have been infantilized by social actors in their lives. Consequently, they have been imposed significant restrictions on their feelings of preparation and confidence and/or their opportunities to enter sexual fields regardless of their adult status. The following section turns attention to participants' access to sexuality education. It demonstrates how for participants with some level of sexual education there has been a disproportionate focus on negative aspects of sexuality. Next, I argue that the lack of adequate tools and information about sexuality has led some to feel as though they "lack a feel for the game". The last section focuses on the sexual self-esteem and confidence reported by some participants who perceived themselves as not being competitive players and felt discouraged from entering sexual fields. In all, these factors restrict the erotic habitus and sexual capital of participants even before they can access sexual fields.

Sexual Fields and Sexual Access

Sexualities scholars have theorized the way that some sexual practices are deemed normal and legitimate and consequently have been recognized and allowed. Some other practices are considered bad, unnatural, and deviant, and thus have been censured, stigmatized, and punished (Rubin, 1984; Valocchi, 1999). The sexuality of marginalized groups in particular is seen as potentially dangerous and disruptive (Fields, 2005; Hill Collins, 1990; McRuer, 2011; Wilkerson, 2002), including people with intellectual disabilities whose sexualities have historically occupied a position of low sexual status similar to other marginalized sexualities including that of women in poverty and people in the prison system (Gill, 2015). For disabled people, their sexualities tend to be further marginalized due to perceptions of inherent vulnerability that commonly place disabled people in a position in which they are deemed to be victims and vulnerable when it comes to their sexual expression. As Gill (2015) articulates through his concept of sexual ableism, the label of intellectual disability tends to disqualify people with intellectual disabilities from collective sexual life as their sexuality is perceived to be either dangerous or needing oversight (Gill, 2015). There is a "cultural anxiety" surrounding the sexualities of people with intellectual disabilities that give rise to "fears" based on myths including "that [disabled people's] unbridled sexuality will become rampant sex offending" (Alexander & Gomez, 2017, p. 117). Whether people with intellectual disabilities are perceived to be "potential victims" or as displaying "unacceptable sexual behaviors", their sexual rights are commonly restricted (Noonan & Gomez, 2011, p. 177; Gill, 2015).

As my findings highlight, these problematic constructions of sexualities of disabled people are further complicated by gendered constructions that shape the sexual lives of men and women with intellectual disabilities in different ways (see Chapter 4 of this dissertation; Björnsdóttir, Stefánsdóttir, & Stefánsdóttir, 2017). Whereas women with intellectual disabilities tend to be desexualized and seen as potential victims of abuse (both by men with and without intellectual disabilities), men with intellectual disabilities tend to be perceived as being oversexed and potentially dangerous to others (Löfgren-Mårtenson, 2013; Wilson et al., 2010; Wilson et al., 2013).

Taking a sexual fields approach addresses the need for research examining the experiences of disabled people in regard to "accessing interpersonal contexts in which sexual negotiations become possible, as well as investigating the impediments to the psychological and sociocultural supports underlying gender and sexual identity formation" (Shuttleworth, 2003, p. 4). At the same time, by thinking about sexual fields in the context of sexualities that are deemed problematic and bad, we can highlight boundary-making processes to identify *who* is allowed to access sexual fields. The experiences of the participants highlight assumptions in the current sexual fields literature. Sexual access, as theorized by Shuttleworth (2003, 2012), is a helpful concept. This concept is about sexual actors' ability to access social and erotic arenas that make romantic and sexual negotiations possible. Although Shuttleworth's work is more focused on the experiences of people with physical impairments, the notion of sexual access is useful for theorizing the experiences of participants with intellectual disabilities as well.

People with disabilities face numerous systematic barriers when accessing "spaces and processes that teach and prepare young people for sex/uality and intimacy" (Liddiard & Slater, 2018), disadvantaging them as sexual actors. As an example, consequent to the dominant myths outlined above, children and youth with intellectual disabilities are not only commonly denied access to the formal sexuality education curriculum but also to the "hidden curriculum" of sexuality that tends to occur through interactions outside of the classroom (Gougeon, 2009). As a consequence, people with intellectual disabilities often face a lack of information and language to speak about their feelings and desires, and may face instances of misinformation about sexuality and their sexual rights based on the limited information provide to them (Schaafsma et al., 2015, 2017; Yau et al., 2013). As a result, they often must explore their sexuality with little support and may, at times, feel ill-prepared to navigate their intimate lives (Gill, 2015). In the context of this study, sexual access involves participants' opportunities and knowledge to participate in sexual fields.

As demonstrated in this chapter, participants' sexual access is shaped by a series of factors including disablism, which can be understood as "a set of assumptions (conscious or unconscious) and practices that promote the differential or unequal treatment of people because of actual or presumed disabilities" (Campbell, 2009, p. 4). Additionally, the notion of the psycho-emotional dimension of disablism (Goodley, 2010; Reeve, 2004; Thomas, 2002) is helpful in articulating how oppression "operates at both the public and personal levels, affecting what people can *do*, as well as what they can be" (Reeve, 2004, p. 9). As theorized by Reeve (2004), psycho-emotional disablism occurs through: 1) internalized oppression; 2) exclusion from physical environments; and 3) routine objectification. By shedding light on the meso-level between structural disablism and psycho-emotional disablism, this chapter addresses the need for a theoretical approach that allows us to simultaneously examine "the political and power-relational, structural, symbolic, interpersonal, and psycho-emotional dimensions of the range of sexual difficulties that disabled people may confront" (Shuttleworth, 2003, p. 4-5).

This chapter also draws on the theoretical concepts of symbolic boundaries (Lamont, Pendergrass, & Pachucki, 2015) and boundary work (Lamont & Molnar, 2002) to make sense of how boundaries to sexual fields can be enforced by social actors in participants' lives, shaping the forms of sexual expression in which they are allowed to engage as well as what sexuality thus looks like to them. Symbolic boundaries refer to established socio-cultural lines that include and exclude certain groups of people, social practices, and topics, thus playing an important role in the reproduction of social inequalities (Epstein, 1992; Lamont, Pendergrass, & Pachucki, 2015). For people with intellectual disabilities, because they are often infantilized, other people in their lives tend to play a significant role in terms of defining the boundaries that delimit their accepted sexual expression and practices. Adulthood is "connected to possibilities and rights" (Starke, Rosqvist, & Kuosmanen, 2016, p. 316), and not being understood to be an adult can lead to various forms of sexual expression being off-limits to people with intellectual disabilities. As proposed in this chapter, the lack of access to opportunities to learn about sexuality, navigate sexual fields, and form relationships impacts the erotic habitus of participants. Infantilization produces what I call an "infantilized erotic habitus", meaning the formation of a particular erotic habitus that is desexualized and blocked from sexual development. Habitus provides agents with the knowledge and tools to participate in the "struggle" for capital, thus providing individuals with a "feel for the game", as Bourdieu (1990) indicated.

With the aim of addressing these gaps in the literature, the following sections examine participants' accounts to highlight the complex interplay of structural and cultural social processes, as well as psycho-emotional disablism, which makes it difficult, if not impossible, for some participants to feel prepared or confident enough to navigate sexual fields.

Findings

Infantilization

People with intellectual disabilities are commonly infantilized and perceived to be "eternal children". For that reason, like children, they are commonly desexualized and blocked from sexual expression and practices (Björnsdóttir & Traustadóttir, 2010; Azzopardi-Lane & Callus, 2014). While it is the norm for non-disabled people – especially adults – to have privacy, romantic relationships, and be sexual, the same expectations do not often apply to people with intellectual disabilities (Gomez, 2012). In fact, for people with intellectual disabilities, reaching the chronological age of adulthood does not necessarily lead to more opportunities for relationships, privacy, and intimacy. As noted by Björnsdóttir and Traustadóttir (2010), this social group experiences various challenges to "accessing adult roles", including in their intimate lives. In such a manner, people with intellectual disabilities ultimately live in a state of "suspended adolescence" (Azzopardi-Lane & Callus, 2014, p. 33), which can result in fewer opportunities for sexual expression. As Kulick and Rysdrom (2014) remark:

> 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. This is a prejudice, a furtive way of denying that disabled adults are adults – or even, in an important sense, that they are fully human beings. [emphasis added]

Indeed, most participants' accounts spoke to this infantilization that curtailed their possibilities for sexual expression, played a significant role in shaping their erotic habitus, and discouraged them from accessing sexual fields.

This infantilization was particularly evident in Randy's experience. Randy is a 39-year-old man who has never had a romantic relationship. He has always lived at home with his mother. In his interview, Randy repeatedly noted that he was not "ready yet" for any kind of romantic relationship. When asked about what made him feel that way, he stated, "My mother told I am not ready." Then, when asked to elaborate, he observed, "I have too much homework. Too much." One could say that being told that one has "too much homework" and that they should prioritize it is something that is typically told to children and adolescents. Moreover, shifting the focus to "homework" allows for sexual expression to be postponed, placing Randy in a position of "suspended adolescence" (Azzopardi-Lane & Callus, 2014, p. 33) where, supposedly, one's time should be spent on non-sexual activities. In an Australian study, drawing on focus groups with 14 young men and 11 young women with intellectual disabilities, Frawley and Wilson (2016) similarly found self-reported feelings about "readiness" that were based on the views of other social actors in the lives of people with intellectual disabilities (p. 476). Some participants also talked about not feeling ready for sex or intimate relationships.

Randy shared that he expects to eventually "be ready" for a romantic relationship, perhaps, as he said, "when I get a bit older, like 50". Waiting until one is 50 years old, even to have a romantic relationship, goes against the normative experiences of sexuality amongst non-disabled adults who tend to form relationships and be sexually active at a much earlier age. It is noteworthy how, in addition to not having romantic relationships, Randy has also refrained from watching pornographic films, an avenue that could provide him with opportunity for, at least, masturbation and pleasure until he feels "ready" to be in a romantic relationship. However, in his case, that is not even an option. As Randy shared, “Mom told me I need to be older to watch that.” Once again, Randy’s account speaks to the experience of being in a state of “prolonged adolescence”, or, expanding on Green’s (2014) idea of erotic habitus, what I would call an “infantilized erotic habitus”. This concept highlights the mechanisms that work to form an erotic habitus that is desexualized and blocked from sexual development. In the case of the participants, a series of strategies are used to discourage them from learning about or engaging in sexual expression, placing them in a position where they are supposed to wait until they are older to be sexual and to have autonomy when deciding whether to engage in sexual expression.

This infantilized erotic habitus can be constructed and constantly reinforced over time through symbolic boundaries imposed by family members of people with intellectual disabilities. One could also argue that, by dictating to Randy what sexual practices he is or is not “ready” for, his mother is engaging in a form of boundary work (Lamont & Molnar, 2002), which places him outside of sexual fields. In Randy’s case, he has not questioned those boundaries. This may not be surprising considering how an important feature of the habitus is that it often guides social practices in unconscious ways as social actors perceive their practices and possibilities as “natural” (Bourdieu, 1984). Further illustrating the relationship between individuals and their social world, Randy’s example demonstrates the insidious ways in which social processes create disability oppression through psycho-emotional disablism (Reeve, 2012; Thomas, 1999), as he internalizes disabling messages regarding sexuality.

Randy was not the only participant who reported having been told that he is “not ready” and who was encouraged to wait. Jacob, also 39 years old and without prior romantic relationships, talked about starting his romantic life at a much later age. He said, “I can't marry too young, you gotta wait. You are too young.” Jacob had also been told by his siblings, with whom he resides, “You're not ready, you're too young.” When asked about what he thought would be a “good age” to get married, he quickly guessed, “You'd be 40.” Seeing as Jacob has never had prior romantic relationships and has been told even now, at age 39 years, he is not yet ready, it is reasonable to assume that marriage will happen for him (if it ever does) even later in life than 40. It is also noteworthy how this “good age” to get married is just one year ahead. An ongoing process of infantilization can rob these men of seeing themselves in terms of their actual age (i.e., that they are adults getting close to middle age). Here, again, we see people with intellectual disabilities confronted with infantilizing messages that encourage them to postpone sexual expression and that construct their sexualities as being “still under formation”, regardless of their desires for intimate relationships.

As another example of the many accounts of infantilization, Thomas, who is 36 years old, also articulated this expectation that he should wait until a later age to consider getting married – in his case until his late 40s, despite the fact that he had never had a romantic relationship. That was something he had heard from both his parents and support workers. Thomas, however, seemed unsure about the age one is legally allowed to marry, posing the following question during his interview: “So, you have to be 36 to get married?” When I informed him that individuals in Ontario are legally allowed to marry at 18, Thomas was surprised. As he remarked, “Okay, so if you are 18, you can get married. Okay, because no one ever tell me about that.” Some studies have found that people with intellectual disabilities can sometimes be purposely misinformed in order to delay, discourage, and prevent sexual expression (Gil-Llario, Morell-Mengual, Ballester-Arnal, & Díaz-Rodríguez, 2018). In Thomas’s case, we see his lack of information – though it is not known whether that was done intentionally – about his right to marriage.

In all, these experiences highlight how the decision to be an “inactive player” in sexual fields is in part shaped by other social actors (primarily those not living with the label of intellectual disability) in the lives of the participants. Family members – even when well-intentioned or because of their discomfort or lack of tools to support people with intellectual disabilities – may participate in the infantilizing socialization of people with intellectual disabilities. This can have a significant impact in shaping their erotic habitus as well as their decision to participate in sexual fields. Additionally, we need to think about who participates in the boundary work of delineating not only whether, but also which sexual practices people with intellectual disabilities are understood to be “ready for” – now or in the future – a boundary work that deprives them of the choice to be active “players” in sexual fields. The above accounts speak to how this infantilization of people with intellectual disabilities can become internalized when participants are confronted with other social actors around them that reproduce particular disabling discourses of disabled sexualities. As relationships and other forms of romantic and sexual expressions are “postponed”, and particular understandings of sexuality are internalized, some possibilities for romantic and sexual exploration become improbable, if not inconceivable, for these participants. We can conclude that “adulthood”, and thus being “ready” to be romantic, sexual, and married, will come at a much later age (if at all) for these participants than most non-disabled people.

The consequences of being told that one is “not ready” for sexual expression are significant. Firstly, it makes participating in sexual fields inconceivable, at least in the short term. Secondly, it maintains an infantilized erotic habitus in a particular way that is not often experienced by non-disabled people. This is not to say infantilization went unquestioned by all of the participants. In a rare example, Michael asserted his adult status by saying that he hopes to have sex in the future because “it's what happens when you're an adult, that happens to people”. This is not to say that having sex is a requirement for adult status. However, for some participants, infantilization can be a powerful desexualizing tool that completely removes sexual engagement and pleasure as a possibility or a right. Nonetheless, for some participants, it was as though sexual expression "regardless of knowledge and desire, becomes almost too risky a proposition to undertake" (Gill, 2015), and the way to deal with that is to tell people that they're "not ready".

Learning about Sexuality

Sexuality, as noted by Herdt and Howe (2007), is "profoundly influenced and learned according to the ways that our families, communities, and culture talk about, understand, and conceive of it" (p. 66). While education in sexuality can certainly occur through a range of social institutions (Fields, Gilbert, & Miller, 2015), school-based sexuality education can be an important source of information for youth (SIECCAN, 2010). The turn to school-based education is often the case with parents of people with intellectual disabilities, who commonly report feeling uncomfortable talking about sexuality with their disables sons and daughters, and/or who may also feel that they lack the appropriate tools to engage in these conversations. They may then be more comfortable passing the responsibility to educational professionals (Wilkenfeld & Ballan, 2011). Receiving sex education is understood to be a part of easing youth's transition to adulthood as they continue to construct their sexual selves and get prepared to engage in sexual expression in safe ways (McDaniels & Fleming, 2016; Wilkinson, Theodore, & Raczka, 2014). Access to sexuality education is understood as crucial for people with intellectual disabilities who now more often live in the community rather than in segregated care and therefore require supports to develop their sexual identities and enjoy safe and fulfilling intimate lives (Frawley & Wilson, 2016).

As noted in other studies, people with intellectual disabilities are less likely to participate in sexuality education than non-disabled people. Making matters worse, they can also be purposely misinformed (Gil-Llario et al., 2018). The lack of information and conversations about sexuality is particularly problematic for people with intellectual disabilities considering how they experience significantly higher rates of sexual abuse compared to non-disabled people (Schaafsma, Stoffelen, Kok, & Curfs, 2013; Swango-Wilson, 2009). Although the estimated frequency of sexual abuse cases varies, projections have found that as many as 80 percent of people with intellectual disabilities experience abuse at some point in their lives (Gil-Llario et al. 2018; Hollomotz, 2011; Schaafsma et al., 2013). Several studies suggest that the lack of sexuality education and opportunities to make their own decisions contributes to this vulnerability experienced by people with intellectual disabilities (Gil-Llario et al., 2018; Hollomotz, 2011). It is important to note how disability studies scholars have shown that structural inequalities and everyday restrictions by other social actors often leave people with intellectual disabilities without the skills and knowledge that make people with them vulnerable, thus placing vulnerability outside of the individual (Alexander & Gomez, 2017; Hollomotz, 2011). Thus, contrary to assumptions about the inherent vulnerability of people with intellectual disabilities, the failure to provide sex education works to make them vulnerable – as a form of vulnerability affected by context, by situation, they are made vulnerable. Furthermore, it appears to negate that people with intellectual disabilities have the same rights as non-disabled people to access accurate and comprehensive education about sexuality (Gomez, 2012; United Nations Convention on the Rights of Persons with Disability, 2008).

For participants with some level of sexuality education, information was solely focused on the "negative" aspects of sexuality including risks, sexual abuse, sexually transmitted infections, and unplanned pregnancies. This extremely narrow view of sexuality not only made participants ill-equipped to form and maintain healthy relationships but also discouraged and scared some people with intellectual disabilities who attempted to engage in forms of sexual expression. As an example, David, who has been in a non-sexual romantic relationship with a woman with an intellectual disability, talked about the sexuality education that he had received:

> David: Well, we talked about the parts, the different parts of the male and the female.
> Interviewer: Mm-hmm (affirmative)
> David: About what STDs, what STIs, what transmitted diseases are. I think we talked about everything. What sexuality is all about.

It is significant that this limited understanding of sexuality – solely focused on biology and sexually transmitted diseases – became internalized by David as being "what sexuality is all about". For most young adults, sexuality involves much more than considerations of STIs, risks, and harm – it is also love, intimacy, sex, and pleasure. These positive aspects of sexuality, however, clearly did not receive equal attention in the sexuality education offered by participants in my study. As a consequence, the erotic habitus of participants is shaped in ways that devalue them as sexual actors, and limit what is possible for them in terms of gender and sexual expression.

There was a clear lack of sexuality education focusing on enjoyable aspects of sexuality, a finding which has been noted in other studies (Schaafsma et al., 2017; Stoffelen et al., 2018). For example, in their study with 20 people with intellectual disabilities in the Netherlands, Schaasfma and colleagues (2017) also found that sexuality education was often limited to questions of safe sex, contraception, and STIs. In my study, most participants received information that only focused on “negative” aspects of sexuality, sometimes to the point of scaring some of them. As an example, Christopher asserted:

> Sometimes they make it scary [...] ‘This is inappropriate’, or ‘this is wrong’, or ‘this is illegal’, or ‘this is dangerous’. This isn’t fun anymore. I don’t want to do it [have sex]. It is not gonna be any good.

While Christopher noted that sometimes information is delivered this way “to prevent teen pregnancy and stuff” and that “it’s probably effective”, he disagreed with this approach to sexuality education. He observed, “I don’t think it’s the appropriate way to do it myself because they rely on you to think you can’t have relationships because they scared you too badly.” It was clear in this study that this approach to sexuality education can discourage some people with intellectual disabilities from even seeking relationships and being sexual. In Christopher’s case, for example, he refrained from having sex, as he stated, “I never really had sex with anybody for a long time because I didn’t think it was appropriate and I never knew how to ask, and I didn’t want to upset them [potential partners].” In her study with people with intellectual disabilities in Sweden, Löfgren-Mårtenson (2013) found that men with intellectual disabilities were sometimes uncertain about whether and when it was appropriate for them to express their sexuality. Furthermore, they were often told to be “cautious” when engaging with women. The concern is that men with intellectual disabilities will engage in inappropriate behaviors that can land them into trouble.

In his interview, Randy also often referred to expressions of sexuality, such as dating, as being “scary”. When elaborating on what makes romantic relationships “scary”, he immediately asserted, “Somebody wants to rape you like that.” One could argue that this primary emphasis on negativity in sexuality education can serve as a mechanism of social control, a means by which to contain the sexualities of people with intellectual disabilities. The choice to remain celibate, or to be extra cautious when pursuing intimate relationships, is perhaps not surprising when considering participants’ experiences of being bombarded with problematic aspects of sexuality. As Liddiard and Slater (2018) articulate, “Biopolitical regimes work to secure the infantilization of disabled young people whilst pacifying those who are considered ‘active’ through misinformation, scaremongering, and demonization” (p. 324). At the same time, in our cultural imaginary, little space is made for disabled sexualities, and much less is devoted for representations that include positive aspects of sexuality (Alexander & Gomez, 2017).

Not only do people with intellectual disabilities receive sometimes exclusively negative messages, sexuality information – when it is provided – can at times be delivered in such limited, ineffective and infantilizing ways that may nonetheless influence some participants' decision-making and experiences for a long time. For example, James, who is currently in his 30s, referenced the well known "birds and the bees" discourse when talking about the sexuality education he received, as he said, "I did the course in my school from the 90s, I did … I know the birds and the bees. How to make the babies. Stuff like that." He said that he found this information "helpful in the right way", as he further explained, "I don't wanna get someone pregnant." It is worth noting his use of the term "in the right way". In James' interview, he spoke about how having a romantic relationship in the "right way" meant not sexually touching his girlfriend, whom he has dated for a few years, or being touched by her, noting, "No touch. I never touch her […] My girl would never, too. I ask her to stop."

Allison shared a similar understanding of dating, which like that between James and his girlfriend, did not involve any form of erotic touching. Allison is a woman in her late 30s who has been in a romantic relationship with a young man with intellectual disability for 10 years. For her, intimate relationships, done in the "right way", do not involve kissing or hugging. Rather, they involve keeping some physical distance from her boyfriend. In her interview, she spoke about the importance of being "always distanced from each other". She added, "I am okay if he's beside me, but not that close." Again, she had learned that from both her family and support workers in her life. While only a few participants spoke directly to this, it is worth noting how these few participants seemed to be engaging in forms of self-surveillance and self-discipline that one could say contribute to the creation of docile bodies (Foucault, 1975). This deserves more attention in future studies.

This focus on not "getting someone pregnant" was commonly noted by man-identified participants. While teenage pregnancy is an issue that often attracts public attention as a 'social problem' (Bonell, 2004) when it comes to youth more generally, people with intellectual disabilities can face even greater pressures to avoid becoming parents (Ignagni & Fudge Schormans, 2016) in part because they are perceived to have a "bad sexuality" (McRuer, 2011; Rubin, 1984). Historically, the sexualities of people with intellectual disabilities have been constructed as 'problematic', and the fear that people with intellectual disabilities may become parents has been a major concern (Alexander & Gomez, 2017). Studies show that adults with intellectual disabilities tend to be actively discouraged from having sex and becoming parents (Aunos & Feldman, 2002; McConnell & IASSID, 2008). Similarly, for almost all of the participants in my study, parenting was not in their horizon. Many perceived parenting as being too much work or just not for them. A few were even directly told by family members that they should not become parents on the assumption that they would not be good parents. Sexuality education can contribute to that form of social control.

As Fields, Gilbert, and Miller (2015) point out, sexual education is informed by broader cultural discourses about gender, race, disability, etc. The forms of sexual education available to people with intellectual disabilities can reproduce discourses that desexualize people with intellectual disabilities or deem them to have ‘out of control’ sexualities, which result in a focus on risk and harm (see, for example, Gill, 2012; Santinele Martino & Fudge Schormans, forthcoming). This is seen in the lack of conversations and information about pleasure in sexuality education for disabled people. This narrow focus “deflect[s] attention from the wider sexuality and sexual needs” of people with intellectual disabilities (Cambridge & Mellan, 2000, p. 294; Gill, 2015), leading for example to a “missing discourse of pleasure” regarding disabled sexualities (Loeser, Pini, & Crowley, 2018; Thompson, 2001; Turner & Crane, 2016). As Gill (2015) articulates, “Pleasures of sex for individuals are lost in a discourse of abuse and disease prevention.” This was indeed the reality for almost all of the participants in this study. This focus on biology and disregard toward sexual pleasure is succinctly illustrated by Richard, who shared, “I went to school in the early years in the Catholic school and they taught about the reproductive system but not how the two parts come together, so to speak.”

Almost half of the participants had not received or could not recollect receiving any form of sexuality education – school-based or otherwise. Participants thus sought other sources of information to guide them regarding sexuality. Participants attempted to glean information from multiple sources including movies, pornography, social actors in their lives, and the Internet. For Damien and Garrett, pornography served as their main source of information about sexuality. As Damien articulated, “I don't believe that there was sex education offered during my schooling. There was access to pornography through my life.” Similarly, Garret noted, ”Learn as you go and experiment a little bit here and there, experiment with boundaries and stuff. At one point, I learned about porn. So, I became, and still am, I'm not heavily addicted, but I like porn. Always have.”

Pornography can be and sometimes is the main source of information about sex, as well as pleasure, for both disabled and non-disabled people (Frawley & Wilson, 2016). At the same time, these sources of information provide partial, and sometimes skewed, understandings of sex, sexuality, and gender roles that can affect how people with intellectual disabilities make sense of their sexual selves and sexual practices (Whittle & Butler, 2018).

In addition to using pornography as a source of information, a few participants also mentioned other people in their lives who have served as “role models” when figuring out how to navigate intimate relationships. Jason, for instance, spoke about coming from a “broken home” and learning about what not to do in intimate relationships from his parents’ relationship:

> I think personally a lot of – a lot of that information that we take in is learned from when we're younger kids, and how our parents, how we perceive our parents and their love and their affection toward each other, and things like that too. I think I – I took on a lot of that which that wasn't necessarily positive.

In Jason's case, his parents' intimate relationship, though not very positive, nonetheless offered him some understanding of intimate relationships.

As another example, Mary also referred to her parents as a positive role model as she tries to learn about how to enjoy positive intimate relationships:

> They're definitely my role models. I definitely like every year on their anniversary I'm so excited for them. They're like, "Why are you excited? It's not your anniversary." I'm like, "My parents." I'm like you've beaten the odds because it's one and two marriages will end worse, right?

Though not common among the participants, the Internet served as the main source of Eliza's advice in navigating intimate relationships. In her case, she used Reddit, a platform where people can post questions and receive answers from other people online:

> People post questions and then a lot of people respond. If you have a question like, I don't know, "How do you communicate with your partner if there's a conflict?" and then you end that question with "Reddit," and you see a bunch of Reddit questions that people have answered those questions. And you can read the different stories, and it pretty much makes you a better partner.

Eliza immigrated to Canada with her parents as a teenager. The immigration process had led her to miss out on sexuality education both in her former country and in Canada. Thus, she has never received any formal sexuality education during her schooling. Coming from a family who has never talked about sexuality with her, Eliza attributed her parents' discomfort to their culture:

> The reason why I would never discuss romantic relationships and sexual relationships with my family, the reason why the sex education didn't – would never come from my parents. It's the reason why the Internet is my primary source of information as opposed to my mom who has more knowledge probably and who knows me more, and can like explain things better for me.

Eliza, nonetheless, wishes that she could count on her family for guidance:

> I have friends who are able to just bring a guy over to their parents and be like, "This is someone who I'm seeing, I don't know … can you like, I don't know, talk to him and see physically that he's well. Do you think he's a great guy? You know me, do you think he's a good fit for me?"

In all, these accounts demonstrate how in the absence of formal sexuality education some participants creatively sought information and advice about sexuality by drawing on different sources. For a few participants, the lack of "tools" combined with the fear of being rejected conspired to keep them out of sexual fields. This is illustrated in Mike's account. When asked if he would be interested in having a girlfriend, he responded:

> Mike: I would like to, but I'm kind of shy and I wish I had the right tools to ask somebody out.
> Alan: Can you tell me a little bit more about these "tools"?
> Mike: Like proper to ask somebody out instead of getting rejected.

Despite having attended a single sexuality education class, Mike noted that the interactional piece of courtship was not included: "We never talked about how to ask somebody out properly." For Mike, the lack of the "right tools" resulted in a lack of a "feel for the game", to draw on Bourdieu's (1998) metaphor (p. 25). As elaborated in the next section, however, Mike was not alone in feeling as though he lacked a "feel for the game".

Lacking a "Feel for the Game"

Sexuality has been commonly understood in individual, biological, and psychological terms as a matter of natural drives that are steeped in human nature (DeLamater & Plante, 2015; Fausto-Sterling, 2000; Seidman, 2015). The sexualities literature, in response, has provided a distinct set of theories to engage in a major project of "denaturalizing" how we understand sexualities and provide empirical evidence in terms of how sexualities are socially learned, shaped, and constructed within particular social and historical contexts (Epstein, 1991; Seidman, 2015). We *learn* what it means to be sexual, what situations should be considered sexual, and the appropriate ways to respond to different sexual encounters. Non-disabled people are typically able to take this learning for granted. As Bourdieu (2000) has noted, some people, because of their particular habitus, "are more likely to bring to consciousness that which, for others, is taken for granted, because they are forced to keep watch of themselves" (p. 163). Participants' accounts demonstrate their attempts to learn, reflect on, and adopt normative ways of being a sexual actor. This matters, as having experience and being familiar with a range of ways of navigating sexual interactions is a part of successfully accessing and navigating sexual fields.

Sexual actors require a certain “feel for the game”, its rules, a sense of how sexual fields operate, how to present oneself, how to interact with other sexual actors, and how to compete. This “feel for the game”, as Lamaison and Bourdieu (1986) point out, is often “gained through experience of the game” (p. 111). Some of the participants, because they had been single for their entire lives and have had limited access to information about sexuality and opportunities for participation in sexual fields, typically have far fewer resources and experiences from which to draw. Multiple social barriers can lead to difficulties in understanding the ‘rules’ in dating (Frawley & Wilson, 2016), thus affecting one’s chances of partnering. Some sexualities are so marginalized and constrained that some sexual actors start the run positioned quite a few meters behind.

This position of marginality placed almost half of the participants at a disadvantage to the point that some reported not even knowing *which* sexual fields were available to them or *how* to go about “playing” the field. Most of the existing sexual fields literature fails to acknowledge this starting position as a possibility. Rather, it is assumed that sexual actors have some knowledge of the sexual fields that are available to them regardless of their decision to actually access those fields. However, sexual actors who do not or are not given the opportunity to learn how to play the field face the risk of being further marginalized and left behind (Green, 2014). Not knowing where to begin and expressing a limited feel for the game, participants repeatedly spoke about their challenges in figuring out where to find a partner, how to take initiative in flirtation in ways that would not land them (especially men) into “trouble”, and how to form an intimate relationship. In all, the lack of tools and lack of experience of the game leads to a decreased familiarity with patterns in sexual fields. Together, these factors constrained both the opportunities and preparedness that people with intellectual disabilities have to successfully participate in sexual fields. This section shares the accounts of a few participants that illustrate the consequences of this lack of a “feel for the game”.

Not even knowing where to start to find romantic and sexual partners and develop intimate relationships was a concern clearly articulated by some of the participants. Iago, for example, shared his frustration:

> I don't know how to engage in conversations. I don't know how to start a conversation and how to find a girlfriend. Like, where do I start? So, that is the toughest one that I have – where to start and how do I make a conversation?

Whereas for many non-disabled people these questions may seem somewhat “trivial” or “straightforward”, people with intellectual disabilities face unique challenges navigating these questions, often with little to no support and sometimes even very explicit barriers that make doing so even harder. Here, Iago faces two challenges as a sexual actor. Firstly, he struggles with knowing “how to find a girlfriend”, which demonstrates that not everybody knows which sexual fields are available to them. Secondly, Iago finds the interactional component of flirtation difficult as well.

Like Iago, Andrew also spoke about not knowing where to begin, stating, “I don’t even know how to start looking. I’ve looked [for a girlfriend] almost all over. Nobody.” It is unfortunate that, like Iago, Andrew has faced this challenge alone, despite his desire for greater support with this part of his life. Despite having asked for help, as Andrew noted, “People don’t help me […] I’d have loved if someone could help me find a girlfriend.” It is striking how most participants had received high levels of support regarding issues in the public sphere such as work and education. However, less attention has been paid to sexuality and sexual expression, issues which are generally considered to be a part of the private sphere. According to Alexander and Gomez (2017), there is a continued prioritization in service provision of needs and issues pertaining to the public lives of people with intellectual disabilities over those in the private sphere. This trend has been noted by early feminist disability studies scholars (Finger, 1992; Waxman & Finger, 1991) and, according to my research data, appear to continue. This failure to better attend to the private sphere meant that some of the participants felt like they were left in a position where they could only “wait and see” what happens. These experiences were reported by people across all types of housing settings.

Participants in this position of not knowing “how to start” repeatedly noted their frustration and often posed questions during their interviews about how to find partners, how to develop a more positive sexual self-confidence, as well as about their sexual rights. This demonstrates the urgency behind a few participants’ desire for greater support regarding information related to sexuality. As Peter expressed in his interview when asking me for support, “Can you write that? Put, ‘I want to get a girlfriend.’ So, where can I go? How can I make it happen? Can you tell me? Can you help me? How can I make this happen?” There is a clear sense of urgency in Peter’s stream of questions and request for information.

These participants spoke about how being single and struggling to figure out how to find an intimate partner was both “hard” and “sad”. Peter, for example, opened up his heart, “Being single, it's hard to be single. It's hard to be single. It's not fair I'm single. That's not fair, you know?” As he went on to share how being single makes him feel, he stated, “You know how I feel? Sad. I'm being single.

Sad. I want to fix that. I want to fix that, okay? Fix it. I want to fix that for me." Yet, facing limited support to help him "fix" that part of his life, he has not figured out ways to participate in sexual fields, much less to find a girlfriend. As observed by Mike, navigating intimate relationships requires some "knowledge", which is rarely provided to people with intellectual disabilities:

> Relationships require knowledge that is not actually taught to you [...] they [school] try to teach you to play nice, and how to play, and what to do to play, but they don't teach you how to play with each other.

Mike suggests that there is a missing component in sexuality education regarding the social and interactional components of dating, which can be difficult for some people with intellectual disabilities. As Mike puts it, whereas "they teach you the game" in sexuality education, "they expect you to pick up the social side of it [on your own]". For many participants, sexuality education did not include information or advice about how people can actually form relationships and negotiate interactions with potential intimate partners. Receiving information about how to form and maintain fulfilling intimate relationships, however, was exactly the type of sexuality information that most participants reported as being important and necessary to have better intimate lives. Learning about the game and the "social side of it" may allow disabled people to have a better feel for the game as they attempt to navigate sexual fields.

It is striking how, while participants lacked knowledge about intimate relationships, and sometimes their sexual rights, they had a great knowledge of the illegal behaviors that could bring them trouble (Galea et al., 2004). For example, Randy articulated that adults should not engage in sexual interactions with under-age people, stating, "Momma taught me, you kiss a little girl, you get caught." In a similar manner in terms of avoiding sexual contact with underage individuals, Joshua also articulated, "A friend of mine told me to be careful because like 15 and 16 teenagers calling you, it is a dark deal. It's very bad." People with intellectual disabilities face "controlling images" (Hill Collins, 1990) that, on the one hand, desexualize them and construct them as innocent eternal children and, on the other hand, construct them as having excessive and potentially disruptive sexualities (Gill, 2015; Kulick & Rydström, 2014). At the same time that participants are seen by non-disabled others as vulnerable, some of their accounts demonstrate a focus on negative aspects of sexuality that paint them – especially men with intellectual disabilities – as potentially dangerous, thus presenting a bad sexuality. These men's account also suggests that the ways in which controlling images impact the sexualities of disabled people are highly gendered with disabled men being more likely to be seen as potentially dangerous to others. As theorized by Hill Collins (1998), dominant social groups often draw on those controlling images (or stereotypes) to justify social inequalities in a way that makes them appear to be natural and inevitable. In fact, disabled people's denial of their sexual rights is often justified on the basis of those controlling images.

A sexuality affected by such controlling images can leak into a person's, a habitus then perhaps that is developed and reinforced throughout adulthood. From birth to their later years, disabled people navigate a social world where disability is commonly tied to notions of undesirability, rejection, and damage, which can lead to internalized oppression (Campbell, 2009). It is likely not surprising that for some participants sexual expression is understood to be a risky endeavor that can land them into trouble. Focusing on illegal behaviors discourages disabled people from sexual expression. In these ways, it is a form of control that makes it easier for families and workers to ignore disabled people's sexual needs and desires.

Nonetheless, participants spoke about wanting to have intimate relationships to feel less lonely. As noted in the literature, people with intellectual disabilities tend to have smaller social networks and often report higher levels of loneliness in comparison with non-disabled people (Kulick & Rydström, 2015; Schaafsma et al., 2016; Sullivan, Bowden, McKenzie, & Quayle, 2016). This loneliness is understood to be the result of a "nexus of structural, psycho-emotional and material dimensions of disability" (Liddiard, 2017, p. 122). Tatianna spoke about not wanting to be alone, as she said, "I want a boyfriend because I don't want to be alone. It is hard. It's very hard finding a boyfriend. I don't want to be single. I want to find the right guy who loves me." Using a metaphor, Jason too shared his frustration, as he stated, "I hate being alone. I just come home […] I've tried so hard. […] I looked and I looked 'til I almost turned purple. That's how hard I looked." Evident in the narratives of both of these participants is the difficulty they experience in finding an intimate partner as well as the lack of support from others for this part of their lives.

For some participants, the fear of always being alone was overwhelming. As Mary expressed, "I don't think I'm worth it [...] [takes deep breath] One of my fears, it is a big fear, I will always be alone." This statement was followed by tears rolling down Mary's face and a pause in the interview. As elaborated upon in the next section, some participants, such as Mary, identified themselves as having low self-confidence and as being "unworthy" of intimate partners – these perceptions also shaped their participation in sexual fields.

Psycho-Emotional Disablism and The Impacts of Low Sexual Self-Confidence

As Shakespeare (2000) appropriately observed, "More than money, being sexual demands self-esteem" (p. 161). One of the participants – Iago – captured this idea, when he said, "I gotta build my self-esteem to meet new people." This is certainly not only the situation for people with intellectual disabilities, but true for sexual actors more generally. Feeling desirable and having sexual self-confidence works to give people the permission to "put themselves out there", to approach desirable sexual partners, and take charge in sexual encounters (Green, 2014). Conversely, when sexual actors deem themselves "to occupy a position of low desirability" they "may be less likely to [even] pursue a desired partner" (Green, 2014, p. 51). As I will make clear in what follows, this was indeed what appeared to be at play for some of the participants. The interplay of the barriers I have noted – infantilization, limited sexuality-related information and supports, and a lack of "feel for the game" sometimes resulted in participants reporting low levels of self-confidence as sexual actors as they considered whether to participate in sexual fields.

It is necessary to note that, to date, little research has been done in terms of theorizing how having a "low sexual status" (Green, 2014, p. 51) and being constructed as having a "bad sexuality" (Rubin, 1984) as a social group can impact the sexualities, specifically the sexual self-confidence, of marginalized groups including people with intellectual disabilities. As Shuttleworth (2003) points out, sexual well-being is "reliant on psychological, social, and cultural supports that sustain a positive sense of one's sexual self". For people with disabilities, however, because they have been – and continue to be – "systematically devalued and excluded by modern western societies" they are "often not in the right place to begin that task of self-love and self-worth" (Shakespeare, 2000, p. 161). For instance, in the cultural sphere, media representations of disabled sexualities continue to perpetuate constructions of people with intellectual disabilities as child-like and naïve and/or deviant and unattractive as intimate partners (Alexander & Gomez, 2017; Renwick, Fudge Schormans, & Shore, 2013). By desexualizing and/or oversexualizing people with intellectual disabilities, their sexualities are often located in a low sexual status.

By exploring the sexual fields framework and critical disability studies and how participants felt about themselves as sexual actors, we can highlight how structural inequalities and sexual stratification work together to shape the identities and self-confidence of people with intellectual disabilities. Previous sexual fields studies have not considered the impacts of ableism on the experiences and sexual selves of sexual actors. In this dissertation, I deliberately refer to participants as sexual actors to highlight that they do indeed have agency, and the right to exercise that agency (United Nations Convention on the Rights of Persons with Disabilities, 2008), even though that agency is often curtailed by a range of structural constraints. This section focuses on the experiences of some participants who felt that they lacked the confidence to be competitive players in sexual fields and "play the field". More specifically, I return again to the concept of "psycho-emotional dimension of disablism" (Reeve, 2004; Thomas, 2004) to theorize how the structural oppression experienced by participants is internalized, how it "operates on the 'inside' as well as on the 'outside'" (Thomas, 2004, p. 40;

Liddiard, 2014), shaping their erotic habitus, their sexual self-confidence as sexual agents, and their willingness to participate in sexual fields. Here, I illustrate the consequences of low sexual self-confidence with respect to participation in sexual fields.

A few participants spoke about feeling as though they did not even "have a chance" as a sexual actor, or that they were just not "worthy" as a prospective intimate partner – both resulted in their deliberate decision to remain "inactive" players in sexual fields. Randy, for example, spoke about his decision to "just let it happen", as he remarked:

> Dating is really, really, really hard. It's not easy to date someone. You don't have a chance, so why bother? So just let it happen. Since you can't really control it. If you try to control it, you'll do more – you'll do more damage than good.

In addition to perceiving himself as not even 'having a chance', and thus being unable to attract a long-term partner, Randy's statement poignantly demonstrates how pursuing relationships was also associated with something that can "do more damage than good". For Randy, any potential misstep in his attempt to take charge in forming an intimate relationship could land him into trouble. In a similar manner, when later talking about his decision to remain celibate, he noted, "I mean, I'll be frustrated, but at least I won't get in trouble." One could say that this fear of getting in trouble can affect how disabled people feel about themselves as well as their self-confidence. The consequence is that some may choose to simply remain at the margins of sexual fields.

The fear of "landing into trouble" was shared by a few other participants, especially men. This fear seems to speak to the internalizing of hegemonic constructions of disabled sexualities, especially masculine disabled sexualities, as 'excessive' and 'dangerous'. For participants who are and how aware of those constructions and of the potential consequences of being understood in these ways, there is then an arguably well-founded reason for lacking the confidence to assert themselves as sexual actors (Wilson et al., 2010; Wilson et al., 2013). Moreover, not only were participants taught about these risks, they also internalized these hegemonic constructions. For Randy, in order to avoid doing "more damage than good", he has taken a back seat as a sexual actor and, as he asserted, "just let it happen". As articulated by Green (2014), when sexual actors perceive themselves to lack sexual capital and occupy a low sexual status, and to violate accepted sexual roles, they may be less likely to be active players, pursue their desired sexual partners, and be assertive as sexual actors.

In our cultural imaginary, Randy's sexuality is often perceived by non-disabled people as a "bad" sexuality that can do only more harm than good. For instance, the concerns that he may get someone pregnant or give someone a sexually transmitted infection are enough for Randy and others to generate suspicion about the dangers behind his sexual expressions. Randy is well aware of the ways that sexualities among people with intellectual disabilities have been constructed and the general fear that "if we open the door to talking about sexuality, then people with intellectual disability will be abused or become sex offenders" (Gomez, 2012, p. 238). In Randy's case, that fear seems to have been internalized.

Other participants also demonstrated little confidence in their own ability to take initiative and assert themselves as sexual actors. Aaron's story provides another example of this. Aaron is a man in his early 50s who earlier in life experienced a traumatic car accident that resulted in a visible impairment. Aaron used the metaphor of a "raft … on the water" to describe his decision to remain an "inactive" player:

> I'm not as good looking as I used to be because of the accident. I don't go out of my way to strut my stuff, I guess, so I don't really feel sexy. If I'm attracted to somebody, they'll know it, but aside from that, I'm pretty much like a life raft. I just ... I'm on the water.

For Aaron, not feeling "as good looking" or "sexy" (which was partly due to his visible impairment acquired earlier in life) impacted his self-confidence to pursue intimate relationships. This is likely not surprising considering how bodies with visible differences tend to be perceived as being undesirable and unattractive (Erickson, 2007; Shah, 2017; Taleporos & McCabe, 2001). Aaron also reported living with both depression and anxiety, which further contributed to his low self-confidence and reluctance to "put himself out there". It is noteworthy how some people with intellectual disabilities may also experience other forms of disabilities and mental health labels, adding a layer of complexity to understanding their romantic and sexual experiences. Mary, for example, opened up her anxiety: "I have Generalized Anxiety Disorder, like I said, I like talking [about her romantic life] but I might cry because it's a little emotional. That's one of those things that I'm kind of insecure about but I want to like share with people why." Aaron's metaphor of a "raft on the water" is also compelling. Being in that state of just "being on the water", as he perceived himself to lack sexual capital, involved not taking initiative as a sexual actor and instead, much like a few other participants, choosing to wait and take whatever happens.

Some participants also pointed out that a willingness to participate in sexual fields also requires some level of confidence. For example, Iago, who had never had a girlfriend despite his interest in having one, asserted, "Gotta be, you know, confident to meet new people." A few participants, however, seemed unsure about how to build that confidence to become more active players in sexual fields. In some interviews – once again demonstrating their lack of support when it comes to sexuality – participants inquired about what to do. Iago, for instance, asked me, “So, what do I do? How do I get confidence, meet people? What do I do?” Feeling that they lacked the “right tools” to build the confidence to successfully participate in sexual fields, some participants opted out of sexual fields.

The existing sexual fields literature assumes that people who opt out of sexual fields choose to do so. I would argue however that the participants in this study are *kept out* of sexual fields because, and consequent to social devaluation, they have not been given the tools they require, resulting in a lack of confidence, fear of rejection, and the internalized assumption that everyone [read, non-disabled people] is better than them. All of these factors keep some people with intellectual disabilities out of sexual fields. Most participants had an interest in participating in sexual fields and desired relationships and intimacy, as seen in their common question to me, “What do I do?”. However, they always felt that supports were unavailable to help them accomplish that.

A fear of rejection, shaped by a low sexual self-confidence, also served as a deterrent, discouraging some participants from “playing the field”. Mike’s lack of sexual self-confidence was made plain when, for example, he spoke about putting up a “protective barrier” in order to avoid rejection:

> I don’t feel good enough in my own mind. I just don’t feel good enough and a lot of the time, again, I push people away because I think that I’m going to be pushed away, so it’s … it’s kind of a wall that I put up.

In a related vein, there was a sense amongst a few participants that there is “always someone better” than themselves, either actual sexual actors around them or a “generalized other” (Mead, 1934). Through interviews with queer men in Toronto, Green (2011) found that participants understood their position within hierarchies of desirability within particular sexual fields – this was indicated by participants noting how “favored individuals are easy to identify in interaction order” (p. 251). Sexual actors assign different sexual status to themselves and to other sexual actors, through a “typification of attractiveness”, which assists them in their efforts to successfully navigate sexual fields (p. 252). Some of the participants in my study have engaged in a similar effort when figuring out which sexual actors are favored as well as their own sexual status within sexual fields.

Some of the participants perceived themselves as occupying a position of low sexual status. Some participants compared themselves to a generalized other who occupied a more favored position within hierarchies of desirability. This is illustrated in Randy’s refusal to participate in sexual fields and “compete”. As he asserted:

> Aaaaand [sigh] um … and they always seem to find anyone better anyways it seems. And then you just feel awful and you don't even feel like it's worthwhile. It's like why do you bother trying?

Referring to a "generalized other", Randy perceives himself as lacking the sexual capital to be a competitive sexual actor. Then, not "feel[ing] like it's worthwhile", he has decided to stay out of sexual fields. Mary shared a similar sentiment as she alluded to this idea of a more desirable "generalized other". As she remarked:

> I have my moments I'm like, I'm beautiful, I can do this, and then, you know, you compare yourself, comparison can be a thief of joy, but it's this day and age where there's always somebody that you think is better than you ever will be.

Conversely, some participants compared themselves to other social actors in their lives including neighbors, siblings, and support workers. In Tony's case, he compared himself with other men in his life, specifically his neighbor and his support worker. Referring to his neighbors, Tony said, "My other neighbor found a girlfriend just like that [snaps his fingers]. My other neighbor found a girlfriend. He goes out and comes back with one." Tony offered yet another example – that of his support worker – as he also shared, "He found a girlfriend like that [snaps his fingers] in college. He found a girlfriend in school." Tony himself had not had an opportunity to attend college, a sexual field that often grants sexual actors with opportunities for sexual exploration and intimate partnership (and which is commonly denied people with intellectual disabilities). Linking back to infantilization, he shared that his mother told him, "You don't need a girlfriend." Tony has also faced the conundrum of wishing to have a girlfriend but not knowing how to find one; as he noted, "I don't even know how to start looking."

It is striking that the only (unhelpful) advice about finding a girlfriend Tony has received, which has come from his support worker, is "just go out, no cigar, no smoke". One can imagine how difficult it must be for marginalized sexual actors who have a desire to participate in sexual fields and who see other sexual actors around them doing so to enter the field due to a lack of support or sexual self-confidence.

Psycho-emotional disablism, as Thomas (2006) notes, "Frequently results in disabled people being made to feel worthless, useless, of lesser value, unattractive, a burden" (p. 182). For some of the participants in this study, this suggested that they have "acquire[d] a sense of erotic capital deficit, internalizing an undesirable looking-glass self and 'negative' reflected self-esteem" (Green, 2011, p. 257). It was evident how, by comparing themselves to other social actors around themselves, whether actual people around them or a "generalized other", some participants reflected on and positioned themselves within hierarchies of desirability. As elaborated on in the next chapter, participants also touched on their own hierarchies of desirability regarding desirable sexual partners, further demonstrating their reflexive work, as well as the existence and power of these hierarchies at play in their lives.

Conclusion

This chapter highlights the importance of considering the question of sexual access when theorizing sexual fields to better understand the experiences of sexual actors who, willingly or not, do not participate in sexual fields. While the existing sexual fields literature has considered the experiences of sexual actors who, in some ways, "opt out" of sexual fields, often because they lack the sexual capital necessary to be competitive "players", it is assumed that they are adults with some level of knowledge and autonomy that would allow them to participate in sexual fields if they chose to do so. My interview data, however, suggests that people with intellectual disabilities are actively kept out of sexual fields through a series of disabling social processes. These processes include the infantilization , a lack of/the failure to provide the group of people with sufficient information regarding sexuality, and the decision to emphasize the negative aspects of sex and sexuality in education that is provided; information related to sexuality; a lack of a "feel for the game"; and low sexual self-confidence. It is worth highlighting how these not merely features of individuals, but social processes that, for example, result in participants not having a feel for the game or experiencing low confidence that keeps out of sexual fields.

A sexuality shaped by these various processes led some people with intellectual disabilities to internalize oppressive and disabling understandings of people with intellectual disabilities, and to come to perceive themselves as unable, not ready, and unworthy. These processes have led to an understanding of sexuality that is artificially limited to negative aspects like risk and danger. To some, this view of sexuality becomes "what sexuality is all about". As illustrated in this chapter, the consequences for participants' erotic habitus, which is then mainly grounded on discussions about risk and harm, damage the erotic habitus of the participants. For the participants in this study, disabled sexualities are then "seldom opened up to the possibility of pleasure" (Liddiard & Slater, 2018, p. 326).

Considering the question of sexual access is crucial when theorizing sexual fields and understanding the experiences of sexual actors who are discouraged from entering sexual fields or denied access to sexual fields. As an example, in western society, older adults are commonly perceived as lacking sexual desire, being sexually undesirable, and having limited cognitive ability (Heidari, 2016; Hillman, 2012; Huffstetler, 2006) despite data showing that the majority of older adults continue to have sexual desires and be sexually active in their later years (Heidari, 2016; Waite, Laumann, Das, & Schum, 2009). Yet, similarly to disabled people's sexualities, sex among older adults represents a "bad" sexuality in the "charmed circle" of sexuality (Rubin, 1984). Sex and sexuality are seen as being solely reserved for young people, while older adults' sexualities are perceived as being "shameful, disgusting, laughable, and non-existent, which can lead to internalized stigma and increased sexual problems for older adults" (Syme & Cohn, 2016, p. 2). Combined, the desexualization, stigma, and infantilization of older adults can lead to restrictions on the forms of sexual expressions that are allowed in this social group (Syme & Cohn, 2016) and limit the sexual fields readily available to these sexual actors. Even though the boundary-making processes may differ amongst these distinct social groups, their exclusion from sexual fields may still resemble one another. Put simply, the notion of sexual access allows us to theorize the experiences of sexual actors who are sometimes kept out of sexual fields not because of their impairments but because of ableism and ageism.

Yet, in contrast with the experiences of participants shared in this chapter, there were some participants who participated in sexual fields and accessed intimate relationships and sexual pleasure. Some participants perceived themselves as being competitive sexual players and shared their experiences of attempting to successfully navigate sexual fields and intimate relationships. The next chapter focuses on the experiences of participants who were able to "play the field" despite facing challenges.

Chapter 4: “Men Are from Mars and Women Are from Venus”: The Gender Habitus of Adults with Intellectual Disabilities

Introduction

Gender scholars have conceptualized how cultural beliefs become shared stereotypes, such as the infamous “men are from Mars and women are from Venus” phrase that permeates popular accounts of gender difference. These stereotypes are transformed into inequality through a variety of social processes (Ridgeway, 2009). It is perhaps then unsurprising that adults with intellectual disabilities also draw on this language to understand their sexuality and intimate lives. To date, the broader literature focused on the experiences of people with intellectual disabilities has paid little attention to gender (O’Shea & Frawley, 2020). Yet, gender plays a significant role in the everyday lives of disabled people in shaping their access to resources and opportunities including in their intimate lives.

This chapter attends to the experiences of participants in sexual fields and engaging in intimate relationships, focusing on how they make sense of their gender and sexual identities based on gender habitus acquired in their lives. In this manner, this research helps build sexual field theory by attending to the role of gender (Plante, 2016; Wade, 2019). As participants discussed their understandings of what it means to be a man or woman, they often reported a shared belief that men and women are completely different and that their roles differ within intimate relationships. However, for the participants, it is not just a matter of drawing on dominant stereotypes. Instead, they have been actively taught simplistic formulas for being a ‘good’ man or a woman, and being sexual, which did not prepare them for real-life situations in sexual fields, much less for exploring the richness of gender identities, sexualities, and sexual practices.

Participants commonly experienced segregated spaces, faced surveillance, and were taught limited scripts, thus limiting the array of possibilities for them to perform masculinity and femininity. This chapter extends the sexual fields framework by articulating the experiences of participants who were often given the least nuanced understandings of gender and sexuality and thus did not feel prepared or had very limited possibilities to engage with the complexities in our collective sexual life. More specifically, this chapter brings to view how gender habitus is shaped differently for men and women with intellectual disabilities mainly due to the social environments in which they live. Broader society creates gender habitus that focuses on difference and hierarchy between men and women, providing heteronormative directives for what men and women do in relationships. People with intellectual disabilities are more strictly confined within these parameters, with women more vulnerable to sexual violence. There are strict gender norms in which everyone partakes. However, people with intellectual disabilities are learning about these norms a bit differently, primarily – if not solely – through the lens of danger and victimhood. These elements become so pronounced in their lives in a way that it not pronounced in the gender habitus of most non-disabled people.

Gender Habitus

In his 1990 publication, *La Domination Masculine*, Pierre Bourdieu's work paid little attention to questions of gender (Thorpe, 2009). His work suggested that gender is an important dimension of the habitus (Bourdieu, 1997) by exploring how men and women use and experience their bodies and how inequality becomes embodied. As defined by Bourdieu (1990), habitus refers to "embodied history, internalized as a second nature and so forgotten as history" (p. 56). In essence, it is about the habitual ways that social actors go about thinking, doing, acting, and being. Through socialization, individuals learn about appropriate ways to navigate different spaces and acquire certain classed, racialized, and *gendered* dispositions which shapes how they respond to their social world (Miller, 2016). The concept of habitus importantly highlights the relationship between individuals and social structures, with the habitus being both a "structured structure" and a "structuring structure" (Bourdieu, 1992, p. 53). The habitus gives social actors a "sense of social orientations" or a "sense of one's place" that is shaped by social structures (Bourdieu, 1979, p. 544). At the same time, the habitus also reproduces social structures and forms of social inequality by producing "individuals with the dispositions needed to make them work" (Bourdieu, 1990, p. 67). The concept of habitus illuminates how, in the form of "symbolic violence", domination is sometimes "exercised upon a social agent with his or her complicity" (Bourdieu, 1992, p. 167). The concept of habitus is particularly useful for highlighting the reproduction of social structure, especially as an embodied social process, which speaks both to feminist and feminist disability studies theorists.

While Bourdieu's analysis of gender has received extensive critique from feminist scholars (Fowley, 2003; McLeod, 2005), others have revisited Bourdieu's concepts, including that of habitus (McCall, 1992; McLeod, 2005; McNay, 1999; Reay, 1995), highlighting the potential in Bourdieu's work for "deepening and developing" (Walby, 2005, p. 376) feminist theorizing. As Bourdieu (1990) noted, the habitus is both "gendered and gendering" (p. 11). Gendered habitus refers to the "social construction of masculinity and femininity that shapes the body, defines how the body is perceived, forms the body's habits and possibilities for expression, and thus determines the individual's identity – via the body – as masculine or feminine" (Krais, 2006, p. 121). Gender habitus is both "embodied" and "naturalized" from social context in which dispositions are acquired. Gendered habitus instilled from an early age leads to both opportunities and constraints in terms of how we navigate the social world as gendered social actors. People acquire the gender appropriate habitus through socialization. At the same time, it is essential to think about masculinities and femininities in the *plural*. As Behnke and Meuser (2001) appropriately note, “A habitus does not manifest itself in uniformity of actions, attitudes and attributes; rather different variations of femininity and masculinity exist” (p. 157).

The field of feminist disability studies has also generated exciting literature that challenges dominant understandings of disability while critically interrogating the gender system (Garland-Thomson, 2002, 2005; Hall, 2011; Wendell, 1996). These scholars have taken an important look at the intersections of disability and gender (Wendell, 1996; Hall, 2015), engaging in the “gendering of disability” and the “disabling of gender” (Garland-Thomson, 2005, p. 1564). Feminist disability studies insights have contributed to feminist theorizing in a variety of ways. Similar to feminist theorists, disability scholars have analyzed the cultural productions of disability that give different meanings to non-disabled and disabled bodies and minds, and taken on an intersectional lens for examining how different systems of inequality operate in conjunction (Garland-Thomson, 2002, 2005). This body of work brings to view how, similarly to gender, which operates as a “social structure” (Risman, 2009), disability also operates in ways that deeply structure our social worlds on different levels of analysis (Garland-Thomson, 2002). The concept of gender habitus helps us understand how this structure becomes embodied by disabled people.

For some people with intellectual disabilities, understanding how sexual fields operate does not always come as easily or naturally, and participating and competing in sexual fields can be further complicated by particular challenges in acquiring the “appropriate” gender habitus to navigate certain sexual fields. The habitus organizes practice including how sexual actors navigate sexual fields and interpret and respond to interactions (Bourdieu, 1977; Inglis, 1997). In line with Bourdieu’s theorizing, many participants, in virtue of their habitus, entered sexual fields with particular ideas about how to best perform gender. The concept of gender habitus allows us to theorize how men and women with intellectual disabilities, who have grown up and developed particular predispositions, experience and interpret gender and sexuality knowing almost automatically what is appropriate or inappropriate, and what can be said and done as a “good” man or woman and not land into trouble. This chapter discusses how some participants have been exposed and encouraged to perform limited, and somewhat traditional, understandings of what it means to be man or woman. Some participants have internalized these constructions of gender and sexuality. It does not account for much variance in human life but becomes important to their gender habitus.

Men are from Mars and Women from Venus: The Importance of Gender Analysis

To date, little attention has been paid to how people with intellectual disabilities develop and make sense of their gender identities (Björnsdóttir, Ástríður, & Stefánsdóttir, 2017; Fitzgerald & Withers, 2011; O'Shea & Frawley, 2020), including how structural factors shape the very possibilities for multi-faceted identities to exist within this social group. This gap is partly due to how people with intellectual disabilities are commonly desexualized and infantilized in ways that assume discussions about gender and sexual identities to be irrelevant (Björnsdóttir, Stefánsdóttir, & Stefánsdóttir, 2017; Fitzgerald & Withers, 2011). It is as though men and women with intellectual disabilities "lack" gender identities and that their disability status is the only relevant social location in their lives (Fitzgerald & Withers, 2011; O'Shea & Frawley, 2020). This is, of course, a false notion. One could also attribute this lack of an intersectional lens to gatekeeping processes that discourage researchers from examining the interplay of interlocking systems of inequalities such as gender, sexualities, and race (Santinele Martino & Fudge Schormans, 2018).

Taking a gender analysis is particularly important for this social group who is assumed to lack the ability to understand and form their gender identities. As articulated by Slater, Ágústsdóttir, and Haraldsdóttir (2018), to be granted the status of adulthood, people with intellectual disabilities "must 'pass' as intelligible by buying into the strict gender binaries of the heterosexual matrix" (p. 417). The consequence of not being able to "pass" is being unintelligible, remaining eternally childlike, being 'othered', and thus, outside of normative understandings of gender and the privileges that come along with embodying normativity (Gill, 2015; Slater, Ágústsdóttir, & Haraldsdóttir, 2018).

The notion that men and women are extremely different is not surprising considering many participants talked about inhabiting not only disability-segregated spaces but also gender-segregated spaces. For example, some participants talked about participating in gender-segregated groups and activities within organizations providing them services, including "women's groups" and "men's groups". These groups aimed to provide them with a range of life and vocational skills. Based on my informal conversations with staff members, along with interviews with participants, the content taught and discussed in these groups seemed to be different from one another, meaning that men and women received different information and guidance. In some group meetings, participants reported that they learned about what it meant to be a woman or a man in the "right way". Other participants, specifically those living in assisted living and group homes, often talked about living in gender-segregated spaces as well. Houses were often divided by floors dedicated to only men or women, or were fully gender segregated. At times, house rules ensured that men and women had little access to each other's space.

From their early experiences and adulthood, participants' formative habitus seemed to emphasize distinct, gendered ways of being in the world. For many participants, the message relayed by this significant gender segregation was clear: men and women are *vastly* different from each other. Indeed, many referred to the old notion that "men are from Mars and women are from Venus". Mary, for instance, went even further by saying, "Men are from Mars. The women are from Venus. The whole spaghetti and waffle thing." As she further explained the metaphor, she drew on gendered notions of brain anatomy, "Men's brains are like waffles. I can't compartmentalize anything. Everything is connected." Daniel echoed a similar idea, "It's like the saying, 'Women are from Venus and Men are from Mars.' If I knew what a woman wanted, I could sell that to every man in the world and they would take it and eat it up." Nathan was another participant who referred to evolutionary notions to explain gender differences, stating, "This is such a deep, deep topic. You can start off with the whole men are driven to procreate, women are driven to protect. Right? And to nurture." While one could say that some members of the general population too hold a similar idea regarding gender, people with intellectual disabilities often face limited options to begin with, which limits the very possibility of considering alternatives to gender binaries and compulsory heterosexuality.

As women and men were seen as being intrinsically different, participants perceived the presence of separate women's and men's groups as normal. In a similar manner, Fitzgerald and Withers (2011) found that women often spent their days in activities in which traditional gender roles (e.g., knitting and sewing) were reinforced. Almost none of the participants questioned the gender binaries and compulsory heterosexuality often enacted and reproduced in these group. As Ross articulated:

> She's [his girlfriend] in women's group. I'm in the men's group. *Separate*. Men's group and women's group is different. […] The girls are just the women, and then men's group is different with the mens. 'Cause you know they are not like mens.

Most significantly, based on participants' descriptions of these life skills groups, it seemed as though the content – or at least the main messages that stuck with them – were different in gendered ways. For men with intellectual disabilities, the formative gender habitus includes ideas of self-regulation and constraint in order to be a "good" man, thus not representing a potential "danger" to women and others in the community, and to stay out of trouble. In contrast, for women, the formative gender habitus emphasized maintaining boundaries with men and being a "proper" woman from the perspective of traditional gender roles to remain safe from men's potential abuse and be respected. We understand that, in our social world, women are more vulnerable than men. However, the way the gender habitus is lived by women with intellectual disabilities, they are pushed to focus on vulnerability. There are many different aspects of gender and sexuality, but the gender habitus of those that I interviewed perpetuated the idea that women are always vulnerable and that men are a danger. In their study with a small sample of categivers of people with intellectual disabilities, Young, Gore, and McCarthy (2012) found that disabled women were commonly perceived to be naïve and vulnerable while disabled men were seen as being more sexual. Not only that, as illustrated in this chapter, participants were well aware that not performing masculinity or femininity in what was considered the "appropriate", "right", or "positive" manner could land them in trouble.

By adhering to traditional gender roles, it is not that participants were in any way doing gender the "wrong" way, but that their way of doing gender was often prescribed to them by others. For many, it seemed as though they were unaware of other options or had not been allowed to have other options. Thus, it is difficult to say whether this was indeed their preferred method of performing gender. When you are only given one option for being in the world, how can you conceive or even experience other ways of being? This is a key tension when theorizing the gender identities of people with intellectual disabilities. To put it differently, because of what has been permitted in their lives in terms of being a man or a woman, participants perform gender in particular ways that are not necessarily wrong, but that appear to some degree to be a matter of the available options. Some, in fact, resist these limited options. At the same time, for example, some women may decide to be in more traditional gender roles. For some, this may have been their own choice and that should be considered valid (O'Shea & Frawley, 2020). As O'Shea and Frawley (2020) importantly note, "Traditionally, feminine gender roles can also be valuable and productive for those who *choose* them" (p. 669, emphasis added). However, in the context of disabled people's lives, it is often not a choice but rather the result of a "limited menu" of options (Fitzgerald & Withers, 2011; O'Shea & Frawley, 2020). Previous studies show how gender stereotypes are commonly reinforced in the everyday lives and activities of women with intellectual disabilities (Bjornsdottir & Traustadóttir, 2010; Burns & Davies, 2011; Fitzgerald & Withers, 2011).

Men with Intellectual Disabilities and Masculinity

There is an exciting, emerging body of literature exploring the still underexplored intersection of intellectual disability, sexuality, and masculinities (e.g., Wilson et al., 2010; Wilson et al., 2012; Wilson et al., 2013; Wilton & Fudge Schormans, 2019). This literature, however, tends to provide less theorizing on intellectual disability and masculinity (Santinele Martino, 2018; Wilson et al., 2012). We still know little about how this social group, which faces particular barriers, makes sense of what it means to be a "man" (Santinele Martino, 2018). As Wilson and colleagues (2010) note, research of men with intellectual disabilities has primarily focused on either inappropriate sexual or criminal behaviors. Studies suggest that men with intellectual disabilities face a “dilemma of masculinity” as “having intellectual disability is often linked with issues of dependence, whereas masculinity is often associated with strength, independence, and power” (Wilson et al., 2012, p. 261-262). Thus, masculinity and disability have often been considered to be in conflict; their masculinity being a “reliant masculinity – the antonym of hegemonic masculinity” (Wilson et al., 2011, p. 739; Wilson et al., 2012). Being able to perform hegemonic forms of masculinity (Connell, 1995; Connell & Messerschmidt, 2005) seems unreachable to most men with intellectual disabilities (Wilson et al., 2012). Nevertheless, many of the men that I talked to still attempted to measure up to ideals of hegemonic masculinity.

(Lack of) Economic Capital as a Barrier

One aspect of hegemonic masculinity is the ability for men to serve as the main breadwinners of their families. Having paid work and economic capital significantly impacts their sense of socially valued masculinity. As many men were drawn to traditional ideas of gender roles, which emphasize men’s ability to provide financially, they often mentioned financial autonomy as being of extreme importance. Yet, structural inequalities and financial limitations have constrained participants’ opportunities to accumulate economic capital and develop and maintain relationships.

The concerns expressed by these young men in terms of having economic capital were not misplaced. Conversely, many of the women I interviewed spoke about preferring men with economic capital. They understandably wanted men who would support them financially and provide a stable life. This is, however, particularly challenging for men with intellectual disabilities who tend to live on a low income or experience unemployment. From participants’ accounts, there were clear differences in their formative experiences. Stereotypical gender roles in which men are “providers” and women are “passive” was an essential aspect of many participants’ gender habitus. The central importance of economic capital for men with intellectual disabilities was illustrated by James:

> Money and apartment. You do need money to take a person out. […] And take a lady out. And pay for the lady, for the movies, for dinner. Stuff like that. Money is easier. Money and apartment. You don’t have it, you cannot be intimate.

At times, having the necessary financial resources to support an intimate partner was seen as a *prerequisite* for being in an intimate relationship. This was clearly articulated by Hector, who stated, “Yeah, you need money. You need money to take a woman out. Movies, you need money to go bowling. Go shopping. Men like to have fun with woman. Have fun.” In his statement, Hector highlights how many parts of dating life require a certain level of economic capital, which may lead to disadvantages for those lacking it.

The lack of economic capital not only led to challenges in terms of accessing a typical dating life, but also meant that some women were “above” these men’s “league”. In other words, these men were often unable to convert economic capital into erotic capital. Daniel’s account speaks precisely to this struggle commonly experienced by the men interviewed:

> It’s hard to communicate with somebody that, you know, is above you, you think is above you, above your league anyways, so you’re going, well, that doesn’t work too well ‘cause she got a job, she’s got everything else, she’s got this, she’s making $70,000, because I only make, what, $30,000 a year.

Daniel’s statement highlights the importance of both economic and linguistic capital as he notes a stark difference between incomes. As shown in Crawford’s (2013) study on employment among people with intellectual disabilities in Canada, the average earning for working-age individuals with disabilities is abysmal. Many participants shared a similar annual income, considering their status either in unemployment or disability supports funding.

Having economic capital was particularly important to James, a young man who hopes to eventually get married and live independently with his intimate partner, and who saw it as his responsibility as a man to “bring the bacon home”. In other words, providing for his future wife. When asked about what he thought he “brought to the table” as an intimate partner, James stated:

> James: Oh, for me, I bring the money.
> Alan: Okay.
> James: I work. I will bring the bacon home. The pay load to support her in a very positive love.
> Alan: So, it seems like in a positive relationship, the husband has the financial condition to help and support the wife. Is that how you see it?
> James: Yes. That's how I see it.
> Alan: Like the husband has a job and brings the bacon home.
> James: Yeah, get bacon and get paid.

In his case, in which he was not currently employed and did not have any prior experience working a full-time job, the ability to “bring the bacon home” seemed out of reach at the moment. While this is an expectation held by some non-disabled men as well, men with intellectual disabilities face additional structural barriers in accessing that role. Globally, multiple studies have shown how people with intellectual disabilities face significant challenges accessing and holding jobs (e.g., Crawford, 2013; Lysaght, Šiška, & Koenig, 2015). Crawford (2013) has found, for example, that Canadians with intellectual disabilities are less likely to be employed compared to people with other disabilities and non-disabled people. Additionally, in some cases people with intellectual disabilities are actually paid less than non-disabled people. One study showed that, in 2005, Canadians with intellectual disabilities were paid $6 less hourly compared to non-disabled people (Crawford, 2013). Finally, there is always a risk of losing the little funds and supports they receive. Holding a job and having a certain number of work hours, or even getting married, may lead to the decrease or termination of social benefits. All of these factors are critical in terms of the ability and economic capital that these men are able to accumulate.

Considering this experience of unemployment and underemployment, some men spoke about the challenge of juggling a low income while having a desire to "impress a girlfriend". This was well articulated by Julio:

> I feel like if I don't work, I'm not able to do the things I want to do. I can't really impress a girlfriend. I can't take her out to dinner or anything. It's like, you know, you're very limited. If you spend all your time working, it's like you don't have much time for a social life. It's like a double-edged sword almost.

This "double-edged sword" illuminates the struggle often experienced by men with intellectual disabilities. In this context, the men I spoke with usually opted to remain single or forgo their ability to perform what they deemed to be an appropriate masculinity. For a few men, having the economic capital and being able to perform masculinity was extremely important to the extent that they preferred not to have intimate relationships until they become more financially independent. This was the case shared by Jared, who asserted:

> I think the most important thing at the end of the day is financial security and that's sort of the main kind of driver in whether I'd want to have a relationship or not. Like, I am financially secure. I just want to make sure that everything is kind of in place.

The challenge, though, is that achieving that level of "financial security" tends to be out of reach for most individuals with intellectual disabilities. This may mean that for some, the "right" time to establish an intimate relationship may come at a much later time or not at all. Yet, we see very clearly in these men's accounts how dominant cultural ideas around manhood and economic capital have become deeply integrated in their gender habitus.

As an exception, Keith shared how he attempted to manage his lack of economic capital in the face of this expectation of performing hegemonic masculinity:

> I might not have the money right then, but I make it up to a girl. Say, me and this girl were paying to go to the movies, I don't got the monies right now so I go, "Yo babe, I'm sorry I don't got the monies right now, how about we just stay at home and watch movies and eat popcorn and I'll take you out to the movies as soon as I can?"

There was some suspicion among a few men that women may take advantage of them, especially financially. Men spoke about a fear of being financially exploited and desiring intimate partners with some level of economic capital and financial stability. The idea of his future wife working and bringing in additional income was appealing to Leonard. When asked if it was important to him that his future wife has a job, Leonard asserted, “So that's perfect. That is very perfect. When both of us have jobs, we would both bring the money, the bacon and the pay in. Both of us would have humongous dinner. That's way better.”

Being a Man “The Right Way” and Staying Out of Trouble

Compared with women, who more often talked more about how to protect themselves and maintain boundaries to prevent potential abuse, men spoke extensively about learning how to be a man and dating in the “right way” or in a “positive way”. Many of the men attempted to follow formulaic understandings of manhood taught to them through workshops or inspired by family members and movie characters, primarily as a way to stay out of trouble with services providers, police officers, and family members of intimate partners. In the context of dating in “the right way” or “the positive way”, men articulated the “types” of love that were seen as being “positive”. For some, “real love” meant remaining celibate until marriage. James, for example, spoke about a “husband and wife type of love” in reference to a positive form of love:

> James: I want real love. Share your love with your loved one, that they get married. That type of love I want.
> Alan: Oh, I see, okay. So, wait until marriage like, to-
> James: No. For me to find a soulmate. And be with your soul mate, that you get married to. Then you wanna have, that type of feelings about the person. Not before we get married.
> Alan: I see. So that's something that is important to you, yeah.
> James: Yeah. And even after we get married. You have different type of love, after you get married. A husband and wife type of love. That love is, is okay. You love a wife in a certain way. You can't

> cheat on a wife with another woman. Type of thing. That won't work out, you better stay with your loved one. Grow old together and die together. Be a happy couple. That type of love I wanna experience.

James has been dating a woman with intellectual disabilities for more than 20 years. They are not married but he hopes to someday get to that point. He says, "Yeah. I never touch her. I put my, like this. [Raising hand up to motion 'stop'] I say, "Excuse me." I say, "Stop right there." It is poignant how some participants' erotic habitus is shaped in a way that being a good man or woman even entails engaging in forms of self-discipline (Foucault, 1975). They not only hold themselves accountable for performing gender right but also other disabled people in their lives. Circling back to what he has learned from participating in a "men's group", James elaborated:

> I have a girlfriend, I've had Mariah for long time, respect to her, advice talk with her. Loving her, being nice. And my being here, this been for almost 20 years … 26 years. And I've been respectful to everybody here. I'm in a men's group.

Marriage and parenting seemed unrealistic as participants often referred to these as being "too much work", and thus, undesirable options. When asked about marriage or children, for example, Ross emphatically stated, "No, no." The reason for him being, "I'm very romantic, that's what I am." As his statement illustrates, being "romantic" meant that touching was out of bounds. Being a good man and in the "right way", Ross further explained, "We are respectful to people, and you have to say something to them. Be positive, be respectful. And I'm a very nice person right now, and I do it." One could clearly argue that these men are learning a different kind of gender habitus compared with most non-disabled men. Most (non-disabled) men are not taught that being "romantic" means excluding possibilities for sex, pleasure, marriage, and parenting in intimate relationships. Rather, intimate relationships are often expected to include and move toward achieving those experiences.

Sometimes this idea of being a man in the right way was tied to a justified fear of landing in trouble. As an example, Carl was evidently fearful about having intimate relationships and potentially getting into trouble for performing any form of sexual expression. In his previous relationship with a woman with an intellectual disability, he reported getting into trouble, as he shared, "Before, I was touching Ellen ... touching Ellen, my girlfriend, and I'd be like that. And Ellen's mom was mad at me and I remember that." For Carl, the message was clear – if he touched somebody in a sexual manner, even with consent, it could only lead to troubles with the police. He explicitly said, "I do not touch anybody. Because if I touch anybody, I will get in ... Because if I do that, I will be charged by the police. And I don't want to go you know where ... to jail. No way." Despite his interest in having a girlfriend and having sex, the fear of landing in trouble was too great for him to engage in such endeavors.

Carl was not alone as other men I interviewed shared a similar fear. The consequences for men who struggled to navigate what many called the "rituals of dating" were different because men with intellectual disabilities were more likely to be perceived as potentially harmful to others. Despite some successes in his intimate life, Ryan spoke about having a "hard time" engaging in sexual interactions. As Ryan articulated, for many non-disabled people, these interactions may seem "easy". However, as he further explained, "You know, picking up on all social cues is not that easy. It's not as simple as people think it is. It's overstimulating." In his case, he shared his struggles in "reading people":

> I still have a hard time reading people in certain social situations, especially when it comes to meeting women, and when you're trying to meet strangers, because they're all different personalities. Of course, it's all up to us to read the cues, but sometimes I even have that problem.

To illustrate how the challenge of decoding the "rituals of dating", as well as the consequences of failing to perform in normative ways are gendered, Ryan spoke about his fear of getting into trouble when misreading women: "There was a few times in my life where I've gotten into trouble for not being able to read women and read them the right way." It is also important to note that we live in a social world that makes women more vulnerable. Ryan's inability to appropriately "read" women may sometimes mean putting women in an uncomfortable or perhaps scary position of having a man approach them in certain public spaces. These interactions need to be understood through a gendered lens.

For a long time, Ryan refrained from approaching women and attempting to form intimate relationships. "I just kept on telling myself, 'I don't want a partner' because I don't want to deal with the bullshit and all the extra drama crap." Although that has recently changed, he succinctly noted, "I'm still afraid of getting into trouble." Men with intellectual disabilities are commonly constructed as being potentially dangerous and prone to be offenders in their communities (Wilson et al., 2010). Based on the particular gender habitus they have developed, the men I interviewed were *well aware* of these constructions of disabled masculinity and recognized the potential consequences of failing to adhere to normative scripts of sexual interactions and be a man the "right way". They often referred to a shared fear of landing into trouble. For them, being a man in this "right way" was a central aspect of their gender habitus.

In the following exchange, for example, we see Ethan relinquishing some of his decision-making power regarding his ability to leave the group home or bring an intimate partner over at any time in order to "stay out of trouble":

> Alan: How do you feel about this? This conversation with a therapist or asking permission from the house people, how you feel about that?
>
> Ethan: Well, if it's going to help me stay out of trouble, I don't mind if they say yes or no.

For a few of the men, ideas about masculinity came from attractive, wealthy, adventurous male characters from TV shows and films. During my fieldwork, I often sat down with people and engaged in many informal conversations with self-advocates and interviewees. The topic of films and TV shows was common. For Patrick, James Bond represented the ideal form of manhood:

> I copy like Sean Connery, like James Bond I copy like. I want to do the same things like him. My dad say just be good with the woman. Don't be mad to her, just be nice to her […] Like my grandma said, just be the man. Just be the man you want.

People with intellectual disabilities are rarely represented in mainstream media or stereotyped reproducing infantilizing constructions (Renwick, Fudge Schormans, & Shore, 2013). To further complicate this, in our cultural context, dominant cultural representations tend to depict people with intellectual disabilities as lacking romantic and sexual desires (Gill, 2015). Jonathan referred to his passion for rap and hip-hop music to explain what it means to be a man. In his case, however, this media source served as a guide in terms of what a good man should *not* be like, as he indicated, "A lot of them look down on women and, to tell the truth, I was raised by my mom and I was raised by women, so you know what? I have nothing but pure respect for women." Jonathan, nonetheless, reaffirmed his ability to 'filter out' these media messages as he asserted, "Very few [rap artists] talk about them [women] in a respectful way. Most of them in a disrespectful way but I have been able to filter out what I want to hear and what I don't like to hear about the women, you know?"

In contrast, for Scott, a transgender man of color, being a man does not follow a simple formula. Instead, for him, being a good man is about being true to himself:

> Well, I can be anything I want to be like. I'm me, what you see is what you get, so that's all I've got to say. Even in my Wheel-trans, I used to get the wrong pronouns, even by the other customers in the

> Wheel-trans. They would call me "she", and I'd be like, "Excuse me? Don't let my voice fool you, I go by male pronouns, thank you very much."

This is a clear example of Scott asserting his gender identity and thinking about masculinity in broader terms but also his struggles with other people recognizing and accepting his gender. As a transgender man, he has struggled to be accepted as a man by some of his family, support workers, and others with intellectual disabilities. Thus, he is prevented from being a good man in his terms because of that lack of recognition so commonly present in his life. Due to his transgender identity, he has also experienced multiple forms of violence. In his interview, he recounted, “Because of my trans life identity and everything like that and I've gotten spit at and called a hermaphrodite.” Additionally, finding an intimate partner has been difficult, as he stated, “It's hard for me to find someone. Especially with being trans.”

Women with Intellectual Disabilities and Femininity

To date, there has been limited attention toward the gendered experiences of women with intellectual disabilities (e.g., Fitzgerald & Withers, 2011; O’Shea & Frawley, 2020). A gender and feminist analysis of oppression can benefit greatly from considering the intimate lives of women with intellectual disabilities. Compared to men with intellectual disabilities, women with intellectual disabilities face “emphasized femininity”, a form of femininity that relies on traditional gender roles (Björnsdóttir, Stefánsdóttir, & Stefánsdóttir, 2017; Fitzgerald & Withers, 2011). Women experience a particular “version of approved femininity”, which limits the array of gender identities available to women with intellectual disabilities (O’Shea & Frawley, 2020):

> Gender is permitted in some sanctioned roles at certain times, often in widely shared videos in which an appropriately dressed young couple attend a school formal and share a dance. Other possibilities which do not align with ideas of appropriate gender performances (e.g., non-normative sexual or gender expression) may be actively forestalled.

Among the women I interviewed, I found both examples of women who relied on and contested emphasized femininity. Almost half of the women either avoided the topic of intimacy and sexual pleasure or emphasized the importance of chastity. They spoke about more traditional gender roles. At the same time, some women also contested desexualizing and infantilizing constructions of disabled women. Certainly, it is important to recognize that being interviewed by a man may have discouraged some women from being more open in talking about certain topics such as intimacy and sexual pleasure. At the same time, based on my own experience in the field, I have commonly come across discourses of "appropriate" femininity that emphasize women's need to learn how to protect themselves from abuse and seemingly only permit non-sexual, romantic forms of love expression (see also Fitzgerald & Withers, 2011).

In a way, the experiences of women with intellectual disabilities speak to what Martin and Kazyak (2009), referring to media messages for children, have called "hetero-romantic love". This is a type of love that is "PG-13 rated", meaning that it does not move beyond heterosexual love, romance, and occasional kissing. Women's feelings toward gender roles and sexuality were strongly influenced by formative influences that have shaped their gender habitus and thus their dispositions. For the women interviewed, there is a sense in which their status is often subject to successfully performing an "emphasized [PG-13 rated] femininity". For instance, Carolyn talked about looking forward to receiving a marriage proposal as she described a movie-like scene, stating, "He's gonna get me a ring … Maybe kneel down, maybe, like guys do." One could say that Carolyn's pride in discussing her desire for such a proposal reflects a form of resistance to dominant discourses that silence disabled people's sexuality and questions their ability to enter the institution of marriage (O'Shea & Frawley, 2020). Further, this is not to say that non-disabled people do not similarly desire "heteroromantic love", but what was evident among many of the participants I interviewed is that for them these romanticized and heteronormative moments were the *only* imaginable or sometimes permissible options.

Additionally, when I explained that I would assign her pseudonym for dissemination purposes by using the names Madonna and Mariah Carey, Amy immediately asserted, "Not Madonna, she's a slut." Amy's statement speaks to her traditional ideas of what it means to be a woman. Madonna, a woman who is famous for her sensuality and open sexual expression, may be seen by Amy as being antithetical to what a "good" woman should be like. The very notion, or even the possibility, to speak openly about sex, have various sexual partners, or self-identify as a feminist was an impossibility for most women. As a rare example among the women I interviewed, Virginia, a transwoman, and the only woman who self-declared as a feminist, stated, "I'm more feminist, I don't care. When people call me by the wrong pronoun, I turn around and say, 'I'm a female, thank you, have a nice day.'"

Whereas most of the men talked about having a sense of responsibility in terms of building and having economic capital, most of the women shared their preference for and expectation that men should pay for daily expenses. It was evident that, from some of the women I interviewed, the chivalrous expectation that men be financially stable was a form of sexual capital that was sought out in intimate partners. For instance, when talking about the aspects she found important in an intimate partner, Tatianna said, "He treats me. Coffee and a doughnut […] Every day. And he always gives me money." Similarly, Amanda spoke fondly of her husband and, as she passionately looked at him, she listed what she appreciated the most, stating, "You buy me stuff, treat me nicely. [You] care for me. Like I care for you." It was also evident that economic capital was a form of sexual capital privileged by most of the women. In other words, these women's preference toward men with financial means speaks to a gender habitus with a disposition to traditional gender roles in which the role of men is that of the primary provider. This is also an important insight considering how little research has looked at what people with intellectual disabilities desire in intimate partners (Bates, 2016).

Experiences of Abuse and Harassment

The fields available to disabled women, along with what most women had been told in terms of doing gender "right", inadvertently made some of the women vulnerable. While none of the men that I interviewed shared having experienced forms of sexual abuse or harassment, six women voluntarily disclosed having had those experiences and spoke about the deep impact. In it, it was half of the women interviewed, a stark number, especially considering how disclosure was done on a voluntary basis, leaving open the possibility that perhaps even more women may have experienced forms of abuse or harassment, but chose not to share those experiences, or lacked the vocabulary to express those experiences. It is essential to listen to these stories from a structural lens, keeping in mind that people with intellectual disabilities are often made vulnerable through social processes, such as a lack of access to sex education as well as disenfranchisement from practicing decision making in their everyday lives (Hollomotz, 2010).

I carefully approached these moments of disclosure with both care and respect for participants who were willing to share these painful experiences. I allowed these participants to share as much information as they desired, without interruptions, except for moments where I wanted to check in with them about how they were feeling. I also ensured to debrief with participants at the end of the interview and share a list of community resources (appendix P). All these participants, however, said that they were fine and that they appreciated the opportunity to share their experiences. Previous studies have certainly suggested high rates of sexual abuse experienced by people with intellectual disabilities, especially women (e.g., Frawley & Wilson, 2016; Gil-Llario et al., 2018). This section shares the experiences of the women who shared their previous experiences with different forms of harassment and abuse.

I start with Mary's account of her experiences with harassment as well as her process of learning about what consent means. As Mary shared:

> Fortunately, I was never abused. I was never raped, but I have been assaulted and harassed. I didn't even think it was assault or harassment, but then I looked it up and it is because I didn't give consent. Some people would be like, "Well, it's just having fun." But I didn’t give consent.

Coming from a family that felt significant discomfort in talking about sexuality, it is particularly poignant in Mary’s experience how she had to take matters into her own hands and “look up” the meaning of assault and harassment to recognize abusive instances, understand the meaning of consent, and to assert her agency in sexual encounters.

At the same time, once again drawing on notions of gender difference by saying that “guys can be visually stimulated”, Mary went back and forth in trying to reconcile her views around women’s agency to choose what to wear and consent to sexual relations, as well as her Christian values around women’s modesty. This is particularly evident in the following statement:

> I'm also pretty modest because for me modesty is important because I want the guy to see me and my personality and my heart and everything. Another thing is I know that guys can be visually stimulated by … because they were made to be visual. I pretty much, for me, I don't want to be the reason why a guy stumbles. Even though a lot of people are fighting the whole, it's not what she's wearing and everything. Somebody even did a thing where, "This is what was I wearing when I got raped or assaulted or whatever." I get that. I don't think it helps. I don't think that … yes, it is a guy. It is a rapist. It is his choice. You don't really have to help the matter by encouraging it. Some people would fight … just like, I can wear what I want and blah, blah, blah. I'm like okay. I was taught it might bring the wrong attention.

While Mary notes that it is men’s “choice” to be a “rapist”, she still places a certain blame on women who “encourage” such acts by drawing the “wrong attention”. This tension in Mary’s statement also needs to be put into her Christian context, which perhaps values modesty and not bringing “the wrong attention” to their bodies. Above all, Mary’s account illustrates how the gender habitus of people with intellectual disabilities is shaped and transformed by a range of discourses around sexualities, for example, religious and feminist ones. Despite the lack of information, disabled people draw on cultural practices as a “tool kit” (Swindler, 1986) to make sense of their gender identities.

Another participant, Wendy, also nodded to the importance of having access to sexuality information in terms of feeling better equipped to navigate (abusive) relationships. She also spoke about a feeling of disempowerment as though she could not say “no” to her former intimate partners, stating, “Maybe it wasn’t necessarily taken advantage of, but I guess not feeling like I could say no. Just meant I was going along with whatever was happening even if it’s not something I wanted so … yeah.” In Wendy’s case, she attributed this disempowerment to a “lack of confidence” along with a lack of access to information and advice for navigating relationships and consent:

> Learning about ways they could be taken advantage of … And to kind of be aware ‘cause I know like … yeah, I guess with myself, disability leads to a lot of lack of confidence and like blurry consent, I guess […] So maybe, yeah. Yeah, just really driving it in that you have a choice […] I feel like I was kind of a space cadet and out of the loop on all things relationships/sex.

Wendy’s account is colored by the effects of psycho-emotional disablism. As she noted, “I guess I was just kind of low confidence ‘cause I was questioning my intelligence, um, and yeah, I didn’t see myself as equal to others because of those difficulties.” As noted in the sexual fields literature, sexual actors who consider themselves to have low sexual capital or be less competitive field players may exercise less agency in intimate encounters and even be more willing to prioritize a partner’s desires and needs over their own (Green, 2008b, 2014). However, that is only a piece of this *gendered* puzzle, considering how gender more broadly structures sexual encounters in ways that can be disempowering for both non-disabled and disabled women.

Sadly, two other women spoke about their first sexual experiences being marked by forms of sexual abuse, which continue to shape their intimate lives. Margaret, for example, opened up about her experience as a sexual abuse survivor and the accompanying feelings of guilt:

> In terms of my sexuality, I carried a lot of guilt for things that happened to my body and things that happened to um … me … It was unwanted but still happened … um … because I had wanted to be pure until I was married and I wanted to give myself just to one person and […] I felt like that was taken away from me … I had in um … so I’m a rape survivor.

Fearful of her parents’ reaction, Margaret faced this painful experience all alone. Only recently she has had the opportunity to talk to a counsellor about this experience. One could only wonder how many cases go unreported because women with intellectual disabilities lack the adequate supports and relationships with whom they feel safe and comfortable to share these experiences. It is especially difficult to see Margaret’s feeling of “guilt” as she shares something that has happened to her without her consent. The notion of “purity”, too, stands out in her account as she referred to her religious beliefs to make sense of her intimate life and to cope with the abuse she experienced. In her interview, she mentioned having conversations with God, hoping that God understands that this was not her choice.

For some people with intellectual disabilities, it can be difficult to make sense of and navigate these so-called “rituals of dating” and sex. Though these rituals may seem to be “common sense”, they are actively learned through interactions and observations and are constantly being negotiated (Green, 2011). Decoding these rituals was a challenge for Margaret who, for example, described her earlier experiences with dating:

> I didn’t do very well for quite a while and I … the typical scenario for me was a guy would show interest in me and I wouldn’t know what to do about that, so I would just accept that, and so they would follow me around and call me and then want to do things and I would just go with that.

In Margaret’s case, her struggle responding to romantic and sexual interest from others led her to, in a way, “just go with the flow”. Taking such an approach can sometimes lead to experiences of risk and vulnerability. Margaret reported growing up in a household where conversations about sexuality were completely absent and seen as inappropriate. Having received little guidance for navigating intimate relationships as a person with an intellectual disability placed her in a vulnerable position, as she mentioned:

> I was trying to figure them [men] out, I wasn’t really interested in them. I mean, I like people … I like everybody, but I just didn’t know really how to say “no” or how to do things that would reduce the risk for me.

After experiencing different situations in which she felt at risk, and even experienced sexual abuse, Margaret has attempted to address that vulnerability by working both with a few select friends who serve as her “buddies” as well as a psychologist who helps her “decode” scripts of dating:

> They help me decode what’s happening. For example, my psychologist said, “If somebody asked you to buy them a cup of coffee at the coffee shop, would you just buy it?” And I said, “Of course!” And he said, “Well, what if it’s a guy?” And I’m like, “Well, what if it’s a guy?” [laughter] … like … well … is that what you mean? So, I don’t … I guess I’m naïve – that’s the word that

> he uses, and I just assume that people mean well, and I don’t do a good job.

While Margaret’s attempt to better “decode” the rituals of dating for her own safety is commendable, it is noteworthy how calling an adult woman “naïve” can sound infantilizing. In a way, both disabled and non-disabled women have “traditionally been seen as products of biology (Williams, 1992) and as irrational, volatile, and unable to make their own decisions” (O’Shea & Frawley, 2020). It was consistent throughout Margaret’s account that people around her (and sometimes Margaret herself) perceived her as being highly vulnerable. The notion that women with intellectual disabilities are vulnerable was echoed throughout my interviews as well as my interactions with support workers during field work.

Amy talked about her first sexual experience which, unfortunately, was sexual assault. She was only 15 years old. According to her, the incident happened in her parents’ basement while they were away. Her parents, however, arrived in time to stop what was happening. As she recounted, “I had sex when I was 15 and my parents are very, very protective of me because of him. Because of what he did to me. He had sex with me.” This experience early on in Amy’s life has had a long-lasting impact on her feelings toward sex as well as her ability to form intimate relationships.

On the one hand, as Amy asserted, this experience changed her feelings toward sex, as she stated, “Well, I just don't like sex. Ever since what happened, I've never liked sex because of him. I just never liked it.” Alternatively, it has also increased the level of surveillance exercised by her family to the extent that it has prevented Amy from having consensual intimate relationships and sex at all ever since. As she indicated, “I can't even kiss a guy. And, Carly [support worker], you've seen how strict they are. If I get caught ever kissing a guy, I'll be in trouble, Carly. Don't you think their protective? My parents.” In such a manner, Amy’s story speaks to the challenge many families experience in balancing the protection and (dis)empowerment of their loved ones (Santinele Martino, 2019). More strikingly, we see Amy being “punished”, in a way, for something that has happened to her without her consent. In her case, the response to her experience of abuse was further disempowerment and decision-making in her intimate life.

In addition to changing her attitude toward sex, Amy’s experience as a sexual assault survivor has also kept her from realizing one of her biggest dreams: getting married. With great sadness, and some visible anger, Amy shared:

> You know what? I could have been married by now, but I never did. I could have been married. This bothers me, don't it, [support worker’s name]? But at 15, I had sex when I was 15, and my

> parents are very, very protective of me because of him. Because of what he did to me. He had sex with me.

In her case, that incident led to additional protection measures on the part of her parents, becoming a blockage from intimate relationships and her dream of getting married, just like her siblings. Like Margaret, only recently Amy has started seeing a counsellor to share her experiences as a sexual assault survivor. In a way, Amy remains in a state of "suspended adolescence". As Tolman (2002) notes with regard to adolescent girls' sexualities: "Our impulse to keep girls safe by keeping them under control seems so necessary that the cost of denying them the right to live fully in their own bodies appears unavoidable" (p. 15). With women with intellectual disabilities, there is a belief that they are not "capable" of being women in the "appropriate way", thus requiring greater levels of protection, surveillance, and restrictions (O'Shea & Frawley, 2020).

Chelsea too shared horrendous experiences of physical and emotional abuse:

> I couldn't stand throwing things around […] I told him to go to anger management. He wouldn't do it, until my sister, she gave me a big teddy bear. He ripped it, threw it in the garbage. And I used to be on Weight Watchers. I had a scale. He threw it in the garbage. Anything was important, I had. My father sent me a Christmas card and he threw it in the garbage and he had a tee pee, as well and he hit me in the back of the head. He said, "Do what I want or I'll send your family a corpse."

According to Chelsea, she remained married to this man for many years despite dealing with multiple forms of abuse and feeling sexually frustrated. For that reason, Chelsea shared that she had sex with other men outside of her marriage who better fulfilled her sexual needs.

Finally, I share the account of Virginia, a white transwoman who also shared her horrific experiences with physical and emotional violence from previous intimate partners:

> I faced a lot of punching of the face, chocking, and gasoline poured on my face, jumping out the window, running to the neighbor, catching this guy to be in jail. It's really graphic stuff, like it's very bad spirit. […] Every time I walk past the gas station, I smell gasoline, I just run. Like it's just a trigger, that fear, that fricken, like, oh my God, this bastard is near me again.

As illustrated in Virginia's statement, these traumatic experiences can have lifelong impacts, generating triggers that women continue to live with, and sometimes discouraging disabled women from being in intimate relationships (Eastgate, Van Driel, Lennox, & Scheermeyer, 2011).

But What about Desire and Pleasure?

The sexual fields framework is "primarily a theory of desire" (Lizardo, 2014, p. 8). The existing sexual fields literature has indeed demonstrated the various fields sexual actors navigate in their pursuit for pleasure and intimacy. In contrast, in my research, the topics of desire and pleasure rarely came up. Even though I only have some data on sexual pleasure, given the importance of the topic to sexual fields theorizing and to some participants, it is worth mentioning how a few participants talked about pleasure in their accounts. In my interviews with women, conversations about sex and pleasure were extremely rare. Furthermore, while some of the men I interviewed spoke openly and somewhat comfortably about sex and pleasure, very few women with the exception of three spoke about these aspects of sexuality. This hesitation to talk about these aspects of sexuality could be partly attributed to having a man conducting the interviews. Despite my efforts to create a safe space for participants to share different aspects of sexuality, I understand that my gender identity shapes the stories that are shared (or not) as well as how they shared.

That being noted, the existing literature emphasizes that women with intellectual disabilities are commonly desexualized and generally blocked from discussions about sexual pleasure (O'Shea & Frawley, 2020). In a similar manner, in a study conducted in Australia with a small sample of women with intellectual disabilities, researchers found an overall silence on sexuality. Indeed, among the women who I interviewed, most focused on non-sexual romantic love. Previous studies have found a similar trend in which women with intellectual disabilities tend to hold conservative and stereotypical views of gender roles (Bjornsdottir & Traustadóttir, 2010; Burns & Davies, 2011; Parkes & Hall, 2006). In my sample, only three women spoke directly about sex and pleasure. Jenny, for example, spoke about the pleasure her current intimate partner, a man with intellectual disabilities, brings to her life:

> Jenny: Yeah. Like me and Casey, we make love. Yes. But, not ... Yeah, we make love.
> Alan: Mm-hmm. So, you have a place where you have privacy to –
> Jenny: In our bedroom.
> Alan: Mm-hmm.
> Jenny: Casey is my favorite guy because I get so many ... so much pleasure, yeah.
> Support Worker: Did you say pleasure?

Jenny: Yes. In bed.

It is particularly interesting to see the support worker’s reaction to Jenny’s statement. In the context of this interview, this was a support worker who demonstrated a strong desire to support people with intellectual disabilities in having a romantic and sexual life.

Chelsea too spoke about pleasure as she referenced her experiences having one night stands with men, stating, “See, I didn't feel loved, so I wanted to have a one night stand with guys and when they were on top of me, I felt it hurt.” In her quest to find sexual partners and experience sexual pleasure, she spoke about approaching men on the street, especially men from a particular race, in a straightforward manner by simply asking, “‘You wanna fuck?’ That's what I would say.”

Unfortunately, Chelsea’s search for sexual pleasure has also opened her up to instances of sexual and financial exploitation. For instance, she recalled an instance in which a man she had sex with stole money from her, stating, “Sex was good and even though we had sex, but then after that, I know he would take my money. […] Then, he admitted he took my money, because he was homeless. He would take my tokens.” Similar experiences among women with intellectual disabilities have been reported in previous studies (e.g., Fitzgerald & Withers, 2011), suggesting that Chelsea’s case is not isolated.

A support worker from the organization sat with us during the interview per Chelsea’s desire and also due to concerns around her vulnerability. Just a few months ago, Chelsea had been involved in a case in which a staff member at her group home had had sexual relations with her for some time in secret. Early on in the interview, the support worker sitting with us even jumped into the interview to share his concern. He stated:

> She arrived here. She finds the one that she called, "Boyfriend," waiting here, because she came and had sex with him, right away after that. This is her way of relationships. Right? Boyfriend, boyfriend, but this is how she mean by boyfriend, but from the other side, it's more getting advantage of her, using her. From her side, she wants to satisfy herself.

In his statement above, the worker shares his concern that Chelsea may be unable to distinguish who counts as a “boyfriend”, and thus, could be trusted by her. To some extent, his concern has relevance as Chelsea spoke about instances in which she was taken advantage. Here, at least, her sexual desires are not in question. Yet, his statement also comes across as judgmental and somewhat condescending as he actively jumps into the interview to state *his* definition of “boyfriend”. This represents, in a way, what Guillemin and Gillam (2004) have referred to as an "ethically important moment", in which ethical questions and tensions arise during qualitative research. The purpose of my research was to understand sexuality from the perspectives of disabled people and thus it was important for me to re-center Chelsea's voice in our interview. This was certainly not my first experience in which support people have intervened during interviews with disabled people. In another interview, also with a woman with an intellectual disability, her support worker jumped in to supposedly "correct" certain information. These unequal power relationships, in which disabled people's voices are often seen as less reliable, need to be carefully approached.

Talking about the incident with the staff member, Chelsea shared more details about her overnight sexual encounterswith the support worker:

> I could tell in his eyes that he wanted sex. In the next room, we'd play chess and we used to have a couch, there and we had the oral sex and vagina, but one day [inaudible] but I would wear wool [inaudible] and he masturbated and I was upset, because he said, "No. I didn't." It was some crazy night and [inaudible] he knows I do things, too. [inaudible] sperm, but I know I need to.

The worker Chelsea is referring to was eventually fired. This experience, however, continues to worry those around her. While her current support worker acknowledges her sexual desires and wishes her to able to satisfy them, it seemed as though not much had happened to support Chelsea in achieving a safe and sexually satisfying life.

Virginia was another participant who felt quite comfortable talking about sexual pleasure. She counts herself lucky for being in a living arrangement that provided her with privacy for sexual exploration, including watching pornography, using sex toys, and masturbating:

> I do watch porn, I'm not going to lie, I watch it on my phone now every night. I pretend that I'm the girl with that black guy, and I pretend that my boyfriend is fucking me. It's fun and I go there, and I touch my breasts and I'm watching, with hormones my breasts get so tender because they're growing. So, I'm massaging, sometimes I use my dildo because it's comfortable. When you first get used to anal sex, not everybody likes it, it's sore, it's uncomfortable, like "I don't want it." But for me it feels good, using the toy and making sure you clean up after yourself and watching pornography of a black man having sex with a white woman.

Through her active involvement in sex-positive community-based social groups and her own participation in multiple sexuality education programs, Virginia's gender habitus has been enriched by this opportunity to develop a rich vocabulary, an impressive repertoire of information about sexual practices and identities, and a unique level of comfort talking about sex, which was uncommon among most of my interviewees, especially women. Virginia was well aware, however, that people with intellectual disabilities often face forms of violence as well as significant forms of restrictions in their intimate lives.

> Porn can be a turn off on certain things, but that still teaches people disabilities […] if you grab it and then you learn from it and you find it very attractive. And use certain words that they use like "you're my bitch", or certain things like that, that really turn you on.

Virginia offers her own living space as a space for others with disabilities to watch porn. "It's great how when you have friends with disabilities that want to get together and learn about sex in different ways. It's fun looking at porn and lots is free." This is an impressive form of resistance, one in which Virginia uses her certain level of privilege (i.e., having access to privacy) to support others who may have less privacy to watch pornography or have open conversations about sex.

Her efforts have gone even further, using her computer skills and access to the Internet where Virginia has helped others with intellectual disabilities to search for an intimate partner. As an example, she proudly shared, "I just helped somebody actually that has a disability too and I designed a very beautiful poster [to be shared on social media] of him." According to Virginia, her efforts to facilitate sexual expression among her friends have been somewhat successful:

> He [her friend] messaged me back a week after, and he said that he already had four girls that like him. I'm like, "I might have friends on Facebook that might be single. I don't know. I can reach out." If they have friends, maybe they can have some friends to help them for boyfriend, girlfriend.

In the face of isolation and constraints, Virginia has intervened in expanding her friend's dating pool. Moreover, counter to dominant discourses, these few women present themselves as sexual beings and pleasure seekers. Their accounts demonstrate forms of resistance in the face of desexualizing and shaming discourses of disabled women's sexuality. More attention needs to be paid to the desires and sexual pleasure of women with intellectual disabilities.

As a final example, now talking about the social scripts behind sex, Andrea, a young woman who has been dating a non-disabled man for a few months, talked about having to figure out “the secret messages of dating” and sexual scripts:

> I don’t pick up on the weird like secret messages of dating [...] I feel like when you are having sex it has to be like a certain behavior, like not making jokes, or being goofy, or anything [laughter] [...] I always think it's weird, you need to be a certain way during [sex].

Evident in Andrea’s account is the need to perform sexuality in a “certain” normative way that defines how sex should happen. When referring to dominant sexual scripts that dictate that jokes and “being goofy” during sex are “out of place” and potentially disruptive, Andrea attempts to de-center that script by calling it “weird”. This is an interesting insight considering how there are often calls for teaching people with intellectual disabilities about normative sexual scripts without considering how dominant sexual scripts or norms can be limiting. This approach also tends to result in the assumption that the “solution” to problems reside on changing disabled individuals and their social practices. However, as Andrea’s statement points to, people with intellectual disabilities are “already ‘cripping’ sexualities” in some way (Santinele Martino & Fudge Schormans, forthcoming).

Conclusion

This chapter focused on how gender habitus is shaped differently for men and women with intellectual disabilities as they navigate different expectations, rewards, and forms of accountability for “appropriately” performing gender. The notion of gender habitus is useful for us to understand these sexualities as *embodied gendered practices* that are uniquely shaped by the intersections of disability, gender, and sexuality. While our social world often reproduces gender habitus that focuses on gender difference and hierarchy between men and women, adults with intellectual disabilities tend to be strictly confined within these parameters, limiting the possibilities in terms of gender identity. Though not represented in my data, it is also worth noting how in a previous study with women with intellectual disabilities Fitzgerald and Withers (2011) found that women had been given “implicit messages” suggesting that “men were somehow better and more valuable than women” (p. 10). These insights have important implications in terms of demonstrating how gender social inequality may be reproduced through the gender habitus of disabled people further marginalizing women with intellectual disabilities.

My findings highlight how participants’ capacity to challenge these messages shaping their gender and sexual identities and sexual practices, or engage in alternative practices, is constrained by how they are held accountable in terms of being an "appropriate" woman or a "good" man. As I have shown, at times, failing to perform gender "right" can result in punishment and further surveillance. Unsurprisingly, many participants continue to strive to follow the limited gender roles offered to them. Moreover, people with intellectual disabilities are rarely granted the opportunity or encouraged to engage in a kind of reflective work in terms of who they are or want to be as men and women. In such manner, participants' accounts expose the (gendered) symbolic violence at play that ultimately limits their possibilities.

Chapter 5: Adults with Intellectual Disabilities Navigating Sexual Fields

Introduction

This chapter analyzes how adults with intellectual disabilities navigate the sexual fields available to them given the barriers and constrains established in previous chapters. The existing sexual fields literature has examined a range of sexual fields including for example a Toronto-based bathhouse occupied by gay men (Green, 2008a), a bar catering to transwomen in San Francisco (Weinberg & Williams, 2014), and Grindr, a gay, bi, transgender, and queer mobile application (Daroya, 2018). These types of sexual fields were unavailable to most of the people I interviewed. Based on the information shared by participants, one could say that the places for sexual interactions and pleasure so often theorized in the sexual fields literature are not typically available to most people with intellectual disabilities. Disabled people rarely have access to social spaces that most non-disabled people take for granted in their everyday lives (Fudge Schormans & Chambon, 2012). Participants rarely discussed navigating sexual fields such as night clubs, bars, and university campuses. This is partly because people with intellectual disabilities rarely have the autonomy and agency to choose the places they want to go (Wilton & Fudge Schormans, in press) or the financial means necessary to access such places, especially when it comes to accessing places for expressing themselves sexually (Lam, Yau, Franklin, & Leggat, 2019; Whittle & Butler, 2018).

As argued in Chapter 3, the current sexual fields literature assumes that: 1) sexual actors have the sexual autonomy and agency to choose the sexual fields they want to navigate, and 2) that they are able to access spaces designed for them. My research contributes to this body of literature by suggesting a different starting point in terms of understanding not only the constraints that limit which sexual fields are available to people with intellectual disabilities, but also shapes how they can participate in sexual fields. As articulated by Bourdieu (1989), fields are organized in ways that reflect social hierarchies among social actors, and sexual actors have to negotiate their own position within those hierarchies of desirability (Green, 2014). Their experiences and the strategies used in their attempts to successfully act in sexual fields are explored. This is in light of how little empirical attention has been paid to their engagement with extant sexual fields and, most importantly, how they attempt to claim spaces in order to remain sexual (Ignagni et al., 2016; Wilton & Fudge Schormans, in press). Furthermore, examining the experiences of adults with intellectual disabilities allows us to better understand how that infantilization and protectionism can have a significant impact on how some sexual actors participate in, and (sometimes) claim, sexual fields.

Plummer's (2003) definition of intimate citizenship includes one's access to public spaces. However, most spaces that enable individuals to meet for sexual encounters or to find a sexual relationship are unavailable to people with intellectual disabilities. As a result, these sexual actors experience fewer spaces where they feel welcome, comfortable participating, and where their sexualities are acknowledged and celebrated. Moreover, previous sexual fields studies have focused on social groups whose adult status is not questioned and thus their access to sites for intimacy and sexual pleasure are not denied in the same way. Due to infantilization, adult status is frequently denied to people with intellectual disabilities (Liddiard & Slater, 2017; Wilkinson, Theodore, & Raczka, 2014). For some people with intellectual disabilities, regardless of their age, sexual agency can be constrained. They have limited opportunity to assert their sexual agency as well as limited access to typical venues for sexual expression and negotiation.

This chapter addresses first participants' strategies for negotiating certain virtual and physical sexual fields in which they may find intimate partners. It then sheds light on previously unexplored sexual fields within the existing sexual fields literature. Specifically, I discuss what I call *intellectual disability sexual fields*, spaces exclusively *for* people with intellectual disabilities. As Green (2014) notes, sexual fields are not limited to the typical "scenes" like bars and nightclubs, and there is a need for more exploration of sexual fields that are not as "explicit, publicly accessible" (p. 6). I found that, because of surveillance, infantilization, and control, people with intellectual disabilities sometimes have to *claim* and *convert* spaces into sexual fields (e.g., day programs, groups homes) – spaces not typically meant to be sexual fields. In other words, my research suggests that sexual fields can be differently constructed by and for people with intellectual disabilities. Without understanding the experiences of this particular social group, we would not recognize certain sexual fields being used for the pursuit of intimacy and love. These are valuable insights that bring to view the ways in which some marginalized sexual actors may covert social fields into sexual fields as a way to respond to a lack of access and exclusion from more mainstream sexual fields. In such manner, disabled people blur the lines of public and private, what counts as a sexual field, and who gets to claim spaces as sexual fields.

These findings illuminate the significant structural barriers and also the forms of resistance and attempts by people with intellectual disabilities to claim space and intimate citizenship in the face of a social world that continues to deny and suppress their sexualities.

Specialized Erotic Worlds

According to Green (2008b), "Modern urban life is increasingly characterized by specialized erotic worlds designed for sexual partnership and sexual sociality" (p. 25). The sexual fields literature has paid great attention to sexual fields within gay communities (Green, 2008b, 2011). Yet, examining the sexual fields approach through the lens of larger structural factors – in this case disability and ableism – allows us to better understand how sexual actors who are often infantilized, desexualized, and blocked from sexual expression attempt to navigate sexual fields. This focus on the experiences of people with intellectual disabilities takes us on a journey into specialized sexual fields that at first glance would likely be missed – not even recognized as potential sexual fields – spaces that are claimed and used by these sexual actors to access intimate relationships. This chapter aims to illuminate not only on how people with disabilities attempt to navigate mainstream sexual fields, but also to introduce new sexual spaces to the sexual fields literature.

Adults with intellectual disabilities often lack access to large networks and, as a consequence, social isolation is common among this group (Normand & Sallafranque-St-Louis, 2016). At times, the primary social network available to people with intellectual disabilities is either other disabled people with whom they share a living arrangement and spend their time during day programs or their own family members (Bates et al., 2017). Unsurprisingly, because of this limited social capital, many of the participants spoke about meeting intimate partners in spaces inhabited mostly by other disabled people and having relationships with other disabled people. Similar to previous studies drawing on sexual fields, I too found certain forms of “specialized erotic worlds” (Green, 2008b, p. 27) that participants used to meet potential partners, which I refer to as intellectual disability sexual fields. These are fields that are primarily designed for and predominantly occupied by people with intellectual disabilities such as group homes, residential facilities, and day programs. As a result of social isolation and limited networks, these spaces served as sexual sites for some participants where they could meet potential partners and form romantic relationships. In most cases, these are not purposely established sexual fields but are spaces used by participants in a way that they *become* or *act* as sexual fields.

These sexual fields, however, were highly monitored and provided few opportunities for couples to publicly and privately express their love and sexual desires toward one another. As a consequence, rather than spaces where certain sexual desires can be freely explored and expressed, these “specialized erotic worlds” both facilitated and limited intimate relationships among participants. They facilitated romantic interactions in the sense that they created potential for meeting potential partners. However, they also restricted romantic and sexual interactions due to rules discouraging such expressions.

Findings

Based on my interviews, there were essentially two types of sexual fields that participants inhabited: 1) mainstream sexual fields, meaning fields dominated by the presence of non-disabled people, such as certain digital sexual fields, strip bars, and churches; and 2) intellectual disability sexual fields, meaning spaces made for and occupied primarily by people with intellectual disabilities, including day programs and group homes. The majority of participants primarily participated in intellectual disability sexual fields. Mainstream sexual fields were often seen as inaccessible, unwelcoming, or simply "off limits" due to constraints by other social actors in their lives. Even for those participating in mainstream sexual fields, access was often temporary, short-lived, and constrained. Next, I will introduce some of the mainstream sexual fields – both digital and physical – that participants discussed. I will then focus on intellectual disability sexual fields.

Mainstream Sexual Fields:

Digital Sexual Fields

In this digital age, the dating landscape and the ways that sexual actors seek sexual and romantic partners has been significantly transformed (Green, 2014). A range of mobile phone applications and dating websites provide new opportunities for sexual actors to meet partners, negotiate their self-presentation, and explore niche desires (Andrejek, Santinele Martino, & Ginic, under review). The Internet has increased access to sexual partners for those with limited access, such as queer people (Correll, 1995; Rosenfeld & Thomas, 2012). Rosenfeld and Thomas' (2012) study demonstrates the importance of online spaces amongst sexual actors who struggle with a limited dating market such as gays, lesbians, and middle-aged heterosexuals, who may rely on the Internet to find their partners. In order to "play the game", even in these online spaces, sexual actors need to strategically engage in impression management (Goffman, 1959; Green, 2011), usually by creating biographical profiles that highlight their most desirable traits, while concealing potentially less appealing traits from prospective intimate partners (Green, 2011).

To date, few studies have explored digital sexual fields and how sexual actors negotiate these arenas specifically employing a sexual fields framework. One of the few examples in this area is Daroya's (2018) use of Grindr as a case study to theorize erotic capital and how such digital sexual fields can perpetuate instead of challenge sexual racism among queer men online. As another example, a study examined how 'sugar daddies' and 'sugar babies' negotiate their sexual capital via Craigslist personal ads (Andrejek, Santinele Martino & Ginic, under review). Similarly, only a limited body of literature has looked at the experiences of people with intellectual disabilities when using the Internet (Sallafranque-St-Louis & Normand, 2017), especially with regards to how they navigate digital sexual fields in their pursuit for a partnership (Löfgren-Mårtenson, 2008, 2015). Echoing the larger literature concerning people with intellectual disabilities, sexuality, and the Internet, the current literature on Internet usage among people with intellectual disabilities has largely focused on questions of sexual risks and safety (e.g., Normand & Sallafranque-St-Louis, 2016). It has been suggested, for instance, that the common isolation, loneliness, and depression experienced by people with intellectual disabilities can increase the risk of online sexual solicitation (Normand & Sallafranque-St-Louis, 2016). Yet, less is known about how people with intellectual disabilities use digital sexual spaces to access romantic and intimate relationships. As noted in Chapter 3, due to certain barriers such as a lack of access to technology, technical knowledge, and necessary economic capital, some participants were unable to participate in digital sexual fields.

Navigating Digital Sexual Fields and Disability Disclosure

For a few participants, digital sexual fields actually led to opportunities to find and start intimate relationships. In all, 11 participants reported having used dating websites and mobile applications with the aim of finding intimate partners at some point, some more successfully than others. Participants reported using a variety of applications and websites including Plenty of Fish, Christian Mingle, OkCupid, and Tinder. For some people with intellectual disabilities, online dating may provide a unique opportunity to develop relationships in the face of social isolation and protectionism (Löfgren-Mårtenson, Sorbring, & Molin, 2015; Molin, Sorbring, & Löfgren-Mårtenson, 2017). Furthermore, digital spaces have been referred to as “free zones” where people with intellectual disabilities can pursue relationships without the oversight of parents and staff (Löfgren-Mårtenson, 2008). In digital sexual fields, participants have an opportunity to manage themselves and navigate disability disclosure (Goffman, 1959) in a way that may affect their chances of partnering.

For the participants who reported experience with digital sexual fields, I asked how they put together their profiles to learn about how they attempt to “sell” themselves. An important aspect of successfully and competitively participating in digital sexual fields is the ability for sexual actors to present themselves in ways that highlights their erotic capital. Considering how disability is generally viewed negatively, one could assume that having a disability label may decrease one’s erotic capital, and thus, I asked participants if they disclosed their disability status in their interactions within digital sexual fields. As was demonstrated in previous studies, I expected that people with intellectual disabilities would choose not to disclose their disability in an effort to mitigate potential negative effects of dominant constructions of disability on their erotic capital (Löfgren-Mårtenson, 2008). Löfgren-Mårtenson’s (2008) groundbreaking study found that some people with intellectual disabilities viewed the Internet as a place where, by choosing not to disclose their disability, they could be “like everybody else” (p. 125). In terms of disclosure, participants carefully considered their decision of whether to disclose their disability, but that a few still opted to disclose. This insight demonstrates disabled people's strategic approach to managing their self-presentation in order to be successful in these sexual fields.

Most participants spoke about withholding that information to avoid rejection due to ableism. Whether based on previous experience or their own presumption, participants understood that their disability label would lower their sexual capital in the eyes of potential partners. Scott, for example, talked about how, in a new relationship, he does not disclose his disability status for some time to avoid having potential partners see him as "less of a person":

> Oh God, I try to hide it. I somewhat tried to hide it. Like I don't let people know until like one or two weeks into the relationship […] I don't want them to look at me as any less of a person. If that makes sense. So, yeah, I don't really let them know until one or two weeks into the relationship. Yeah, I have a disability.

Scott's statement is not without merit. People with disabilities have a long history of being treated as "less of a person" and being dehumanized due to their disability label (Skarstad, 2018; Ward & Stewart, 2008). In our social world, conversations about disability remain grounded in deficit-based discourses that emphasize the limitations rather than the resilience of disabled people (Skarstad, 2018). In their intimate lives, some people with intellectual disabilities may understandably choose not to disclose their disability for fear of being perceived as a less desirable partner.

In a similar manner, Clayton, a bisexual man in his early 30s, spoke about his decision to avoid disclosing his disability, as he shared, "I haven't disclosed any disability online. Like if a person would look at me they'd be like, 'You look like you don't have a disability.' But in reality, I do." In addition to being able to "pass" as not having an intellectual disability, when asked to elaborate on his choice not to disclose his disability, Clayton referred to his experiences in school where he was the target of bullying from other students, stating, "Everybody learns in different ways, but I just sometimes feel like having a reminder of how I was treated in school for being different […] Yup. Back in the '80s and early '90s, there was no way to control bullying." Clayton is well aware of the stigma still associated with having a disability label as well as the potential violence that can come from that.

As another example, Margaret shared that the Internet is a particularly promising venue to meet intimate partners because it allows her to strategically manage her self-presentation, concealing her disability, and to safely pursue relationships:

> Physical [spaces] was always a problem. They could tell that my timing was different and there was something different about me and I always would end up having a problem. Somebody would follow me home or they would get my information and then they would call, you know, and then it was very disorienting.

By using online, and mostly text-based communication, Margaret was able to assert some control over her interactions, setting the time and pace of those communications, being able to better articulate her thoughts, and hiding the fact that her "timing was different". Additionally, digital sexual fields granted Margaret a feeling of safety and control. This was particularly important for Margaret considering that, in addition to experiences of being followed and contacted against her wishes, she had experienced sexual assault as a young woman.

Though not the majority, a few participants disclosed their disability status early on. For instance, when asked if he discloses his disability when meeting someone online, Iago said, "I do that all the time. I'm wide open for that. I don't mind sharing what I have. I'm a human being and that's what I like to do." In his case, Iago not only declares that his disability is not something to hide but he also asserts his humanity in the face of often dehumanizing disability constructions. Iago was the most active participant of digital sexual fields, which was actually his main strategy for finally finding a girlfriend. At the time of the interview, he had used a series of dating websites and mobile applications including Mingle2, OkCupid, Zoosk, and Plenty of Fish. Iago also tried using dating websites specifically for disabled people. In his profile, Iago notes his passion for sports and working out and describes himself as a "fit man" with an "athletic body". According to Iago, his attempts to navigate these sexual fields have been unsuccessful primarily due to his inexperience in forming intimate relationships as well as the views of disability from others.

Another participant, Aaron, also spoke about being open to letting potential partners know about his disability status. For Aaron, this was seen as more of a pragmatic decision to avoid spending time with someone who may not accept him and his disability:

> I try to disclose it early on because I'm involved with counselling and treatment and if I'm to be with someone then they're gonna become aware that, you know, uh, a few of my days throughout the week are based on that.

For Aaron, disclosure is seen as being inevitable as, sooner or later, intimate partners will learn about his disability. He believes that his regular visits to a counsellor and disability-specific community programs would reveal his disability status. While Aaron often chooses to disclose his disability status, he also spoke about how that disclosure has often led to rejection by potential intimate partners who see his disability as a "turn off":

> I think a lot of the women, and I could be uh generalizing as well but, I think they… I think they're somewhat taken aback by that [his disability status], and I… I'm of the belief that the more honest I am about it then the more it's out there and the more it can be discussed but I think definitely in beginning your relationship it- it- uh, it's a barrier.

It is noteworthy how Aaron attempts to make his disability visible. Aaron and a few other participants spoke about needing to educate intimate partners about their intellectual and mental health disabilities. When meeting and dating a non-disabled person, disabled people often have to educate intimate partners. Engaging in this type of labor can be emotionally taxing for disabled people (Kaufman, Silverberg, & Odette, 2007). As Kaufman, Silverberg, and Odette (2007) succinctly articulate, "[P]eople living with disabilities are invariably put in the position of being 'The Ambassadors of Disability.' Because nondisabled people have so many hang-ups about disability, and so little information, if we choose to have sex with nondisabled people we do much of the initiating of conversations."

Despite facing a few challenges, including the lack of access to technology, ableism in digital spaces, and a lack of economic capital needed to access certain digital sexual fields, some participants had an interest and participated in these spaces. While "playing the field", participants considered whether to disclose their disability status based on their knowledge of the "structure of desire" and their "own position within the sexual status order" (Green, 2008a, p. 251) within those particular sexual fields. For most participants, having a disability label (and disclosing that label to potential intimate partners) placed them in a disadvantage in "the game", leading some to not disclose their disability. Participants' accounts demonstrate how they make strategic decisions in order to increase their chances for partnering. Nonetheless, participants made plain that online dating is not the only option available to them as sexual actors. Thus, the next section focuses on sexual fields that were accessed in physical sexual sites.

Physical Sexual Fields

When discussing their participation in physical sexual fields, participants rarely talked about navigating the types of spaces typically noted in the sexual fields literature such as bars, clubs, and university campuses. In fact, almost all of the participants reported feeling uncomfortable navigating such spaces. As Kathryn noted, for example, clubs tend to be “too loud, too many people, too sweaty … The smell … it’s just too much. I haven’t even gone to a club before, so this is just me guessing.” While Kathryn acknowledges never having gone to a club, her understanding of a club is that of a space that holds no appeal for her. The high level of stimulation that is often present in these settings can be quite overwhelming for some people with intellectual disabilities. Additionally, the costs associated with these spaces further discourages people from participating. Having economic capital is an important element for people with intellectual disabilities to fully participate in collective sexual life (Ignagni et al., 2016).

People with intellectual disabilities in Canada are more likely to be living under the poverty line compared to non-disabled people (Council of Canadians with Disabilities, 2015). Many participants disclosed receiving monthly income through the Ontario Disability Support Program (ODSP). The current monthly income for a disabled person without dependents is $631 for basic needs (e.g., food and clothing) plus a $479 shelter allowance (e.g., rent, utilities, property taxes) (ODSP, 2018). Considering this low amount, alongside the rising cost of living, I have commonly heard from people with intellectual disabilities in interviews and fieldwork about their challenges in making financial ends meet and, at times, running out of money before the month ends, forcing some to seek food from food banks. It can be particularly challenging for people living in expensive cities, such as Toronto, where living costs continue to increase. My findings demonstrate how economic capital is a vital component for people with intellectual disabilities to access and successfully compete within sexual fields.

For some disabled people, sex work, phone sex, and strip clubs can serve as venues for sexual pleasure (Bahner, 2015; Fritsch et al., 2016; Kulick & Rydström, 2015). In the interviews, a few men spoke about having had some experiences using the services of sex work or telephone sex professionals, or at least desiring to do so. These men opted to use these services for a variety of reasons: wanting to gain sexual experience and build confidence, dealing with social isolation, and having challenges finding an intimate partner. In contrast, men who shared that they had not used such services mentioned their lack of trust toward sex workers, their fear of contracting sexually transmitted diseases, their preference for monogamous long-term relationships, or simply that they were not interested. Almost all of the men who had accessed those services reported having had positive experiences and many spoke about the pleasure it brought to their lives. As an exception, Ryan referenced a few sexual encounters that were not as pleasurable:

> A few times where some girls are a little more awkward, they're not quite as polite or friendly. There's been times where I've been given that impression. Some times were much better than others in terms of

> what do you like to call, the kissing techniques, massaging techniques, everything, play talk, many different factors involved.

Although this was only a small group of participants, these experiences are important because they highlight particular disabling constraints that people with intellectual disability face when attempting to access typical venues for sexual pleasure. They illustrate how a lack of decision-making power, along with limited economic capital, constrain their participation in these sexual fields. For most non-disabled people, accessing such services is an option. To date, very little research has considered people with intellectual disabilities and their use of sex worker services (Fritsch, Heynen, Ross, & Meulen, 2016).

It is important to note, however, that only heterosexually identified men spoke to me about using services such as telephone sex and sex work. In a context where women with intellectual disability are often desexualized, discouraged from conversations about and experiences of sexual pleasure, and seen as in need of protection (Gill, 2015; Grabois, 2001; O'Shea & Frawley, 2020), women may not have the same access to venues for pleasure as men with intellectual disabilities. To put it simply, access and participation in these fields are not only shaped by disability but also gender. Here, I refer to the experiences of men who had some experience in these sexual fields, even though these were sometimes short-lived (but not by their own choice).

As an example, for Iago who lived on disability benefits but did not have control over his own finances, access to sex workers was not an option. Iago told me that he had never had an intimate relationship. Of all of the participants, Iago had put the most effort into finding an intimate partner. He had tried, for example, speed dating, online dating, mobile dating applications (both general and disability-specialized), singles' walking groups, and meetup groups, all with little success. While he perceived himself in quite positive terms (as a good looking, eligible bachelor), he attributed his challenges to not knowing how to start relationships. As way to still experience some form of intimacy and sexual pleasure, Iago took the initiative to contact a sex worker he found through an advertisement. Due to the high cost of the service, Iago was only able to see the sex worker a few times. This was, however, far from ideal for him. As Iago noted, "I would see her [sex worker] more often but I don't have that option." This was when his support worker, who sat with us during the interview, interposed, "Some people have moral judgments on the issue, right? They don't agree with the idea of an escort." In this instance, Iago faced the opposition of his family.

Iago's support worker, who wished she could advocate on his desire to continue seeing a sex worker, felt disempowered as she considered Iago's parents to be the ultimate decision makers in his life. In my previous research with a small sample of direct care support workers, I found a similar trend of final decision-making power being held by parents (Santinele Martino, 2019). Iago's parents assumed the role of ultimate decision makers on the matter by maintaining control over his budgetary decisions. The result was that Iago was no longer allowed to see a sex worker, his only source of intimacy and sexual pleasure. When asked about how often he would ideally like to see the sex worker, if money was no issue at all, he stated, "I'd like to see her every day. Every day. I'd love to see her [...] 'cause that's the hardest part, it's hard to find a nice girl and to be with – just to be with somebody. I can't find anybody else." Now that this is no longer an option in his life, with great sadness, Iago shared that he feels it is both "upsetting and just lonely. Upsetting."

Logan too spoke about wanting to access sex work but having faced challenges doing so due to a similar lack of economic capital. The experiences reported by Logan and other participants demonstrate that it is important to understand the impact of economic capital, or lack thereof, on the sexual experiences of people with intellectual disabilities. For example, lacking economic capital can lead to men with intellectual disabilities having fewer opportunities to access certain sexual fields and less ability to convert economic capital into erotic capital. For Logan, despite his few previous instances using sex worker services, the finances involved in hiring a sex worker proved unsustainable, especially considering his situation living on disability benefits. He shared, "In a lot of ways, it was great. I mean physically it felt good. There was a lot of good-looking women in there. You know, financially it didn't really put me in a good place." In their choice of a sexual partner, Logan and Iago seek a certain standard of beauty. They appear to draw on the hegemonic understanding of what is attractive. However, the lack of economic capital was commonly cited by participants as a significant barrier to engaging the type of woman they desire in a sexual relationship.

Joshua was another participant who cited financial constraints as a barrier. He used to have a phone that was given to him by his father, but he no longer has one. In the past, he engaged in phone sex. He explained to me the high costs behind this kind of service, stating, "They charge you, yeah. Like $3 per minute or 99 cents per minute. If you're calling for other ads like bum sex or hot teenager. That's $3 and 99 cents or $5.99. […] Yeah. They talk a lot of dirty stuff on the phone with you and stuff like that." Joshua shares a group home with other people with intellectual disabilities. He seemed to enjoy engaging in phone sex as he spoke in detail about the fetishes and sexual practices articulated in that particular sexual field. Phone sex provides callers with the opportunity to construct, explore, and play out their sexual fantasies in a private space (Mattley, 2006). In this particular sexual field, physical appearance (and sometimes disability status) is not as significant as in other physical sexual sites as callers and phone sex workers may describe themselves in whatever way they desire (Mattley, 2006).

Callers may also choose to describe themselves by relying on privileged forms of sexual capital.

Yet, Joshua is no longer able to participate in phone sex. When asked what kept him from doing so, Joshua said that he was told by his parents, “I don't want Joshua using that on his phone. It won't be any good for him.” Joshua no longer has a cell phone, which has made it extra difficult for him to access these services. As he explained, “Well, I need to buy my own cell phone and pay it out of my own pocket. Pay for my own private lines.” Seeing a sex worker was out of reach to Joshua, as he indicated, “I don't think we have that kind of money. $124 for a whip? Just whip in the butt and that's it.” For Joshua, even the cost of purchasing condoms is out of his reach, as he noted, “I didn't have any rubbers. Condoms they cost.” When asked if that had been a barrier, he confirmed, “Yeah, the cost […] I can't afford it.” It is clear in these examples how some people with intellectual disabilities may be kept out of these sexual arenas, or have limited access to them, due to a lack of economic capital and control on the part of their families.

Benjamin, who unlike the other examples comes from a privileged family, spoke about his experience with sex work and his choice to no longer use such services. Benjamin currently lives in his own condo in downtown Toronto. In his interview, Benjamin shared his experience of travelling to Amsterdam with friends where he had a chance to access the services of a sex worker for the first time. He shared his experience, stating, “I was just kind of interested. I mean, I was kind of interested in maybe having sex. Like, I'm not that eager to have it all the time. It's just I'm in a city where it's sort legal so I just thought I'd try it out.” Beyond the trip, Benjamin was not interested in being in any intimate relationship as his energy was mainly focused on accumulating economic capital and becoming financially independent.

For Benjamin, sex work served as an opportunity to experience sexual pleasure without the constraints or responsibilities of a serious intimate relationship, as he said, “I mean, I think to be honest I would maybe consider having it again, but not with a romantic partner. I'd maybe go to a prostitute. I just think it's easier at the end of the day to go to a prostitute rather than get into a relationship with somebody.” When asked to elaborate, Benjamin explained, “I just feel like it would be easier to maybe just not be tied down to a relationship, and just not have to have a girlfriend or boyfriend […] It's kind of like you're renting, if you know what I mean?” His ability to perform that “renting” was facilitated by his economic capital and autonomy, which may not be the case for most people with intellectual disabilities. To put it differently, he had the privilege of engaging in that exchange and, importantly, the privilege of choosing not to participate. This was not the case for the other participants.

Financial constraints were not the only barrier preventing participants from involvement in these venues for sexual pleasure. Charlie's experience is another example of a lack of decision-making power in terms of participating in certain sexual fields. Charlie spoke about having an interest in going to a strip club. He is a young man with no intimate relationships or sexual experiences. During his interview, he seemed unsure about whether his support staff would allow him to go to a strip club:

> Alan: Do you know which places you would go?
> Charlie: Like a strip bar.
> Alan: Have you been to one of those?
> Charlie: No, I haven't. I would like to go but I'm in a group home right now, so it's kind of hard.
> Alan: Why?
> Charlie: Why is it so hard?
> Alan: Yeah.
> Charlie: Because they [support staff] might not let me.

As it can be seen, factors like economics and permission from others can constrain disabled people's access to sexual fields. These insights reinforce the need for more research to understand the structural constraints that prevent people with intellectual disabilities from accessing sex workers and other venues for pleasure seeking. While I acknowledge that accessing such services may be difficult even for some non-disabled people (e.g., financial costs, illegalities), these may, nonetheless, be sexual fields that are more widely available to non-disabled sexual actors than to disabled actors (Fritsch, Heynen, Ross, & Meulen, 2016), particularly people with intellectual disabilities. It is important to understand how disabled people experience unique challenges in their access to these sexual fields. For the men whose experiences I have just shared, having access to a sex worker is a way to experience sexual pleasure that may not be otherwise possible. It is also worth noting that the participants who accessed these types of services were primarily men who had a certain level of independence to choose to use those services. Based on the experiences of the study participants, for most men (and especially women) with intellectual disabilities, participating in these particular fields is unimaginable or simply not allowed. Thus, the argument presented in this chapter highlights how access to certain sexual fields is highly dependent on a sexual actors' level of knowledge, decision-making power, and economic resources. The question of sexual access requires us to also consider the importance of these sexual fields in the lives of men with intellectual disabilities who may not have opportunities to otherwise experience sexual pleasure.

Intellectual Disability Sexual Fields:

Day programs are a common feature in the lives of many people with intellectual disabilities and are relied upon to offer a variety of activities and training opportunities, including educational, employment, and recreational (Frounfelker & Bartone, 2020; Parsons, Rollyson, & Reid, 2004). These programs are also often understood to be spaces where disabled people can learn skills, experience social time, and build social networks to support their increased inclusion in the broader community (Frounfelker & Bartone, 2020). Many of the people that I interviewed spent significant time at day programs, sometimes arriving early in the morning and leaving around supper time, repeating this five times a week. For some, day programs offered a space where they could meet other (disabled) people, form friendships, engage in different leisure activities, take workshops, and sometimes pursue romantic relationships. Even though these spaces have not been purposely set up to serve as sexual fields, it was evident that many participants have nevertheless constructed and tried to use these spaces as sexual fields.

When asked about where they would go to find an intimate partner, participants mentioned a range of activities taking place at their day programs including bowling and dance activities. Adam, for example, mentioned his chess group, stating, "Go play chess, you can find somebody. Yeah. Chess. You can go find somebody, yes. Find somebody there." To further illustrate how these programs can serve as sexual fields, Alejandro talked about meeting his ex-girlfriend at the bowling group at his day program, saying, "Yeah. that's where I met her [girlfriend] in bowling." These settings allowed many participants to counter their social isolation and meet other disabled individuals.

Through interviews and fieldwork, I heard multiple stories of disabled people who had dated, or at least flirted with, other disabled people at their day programs. This perhaps should not come as a surprise as people spend significant time in these settings forming ongoing friendships. Ethan, for example, spoke about meeting girlfriends through his group home and the activities in his day program, stating, "Two of the females I was dating lived at [the group] home. But my other one that I met, her name was Helena, and I met her at bowling. And the other one, Karissa, she was part of the organization." Ethan also spoke about attending dances organized by the organization, which also allowed him to meet women. As illustrated in his statement, sometimes the most commonly inhabited sexual fields were those shared with other people with intellectual disabilities, including day programs and group homes. While creating opportunities, this also limited their dating pool to other people with disabilities. Until now, this has been an unexamined sexual space within the sexual fields literature. Almost all of the participants inhabiting these spaces who had had previous dating experience reported only dating others with disabilities. In a previous pilot study, I found a similar pattern (Santinele Martino, 2014, p. 70) as one participant articulated how many people with intellectual disabilities "don't get out of that little circle because that's all they know", and consequently, "you end up dating what you know" – other people with intellectual disabilities (see also Healy, McGuire, Evans, & Carley, 2009; Kelly, Crowley, & Hamilton, 2009; Laffaerty, McConkey, & Taggart, 2013). As Bernert (2011) shows, sometimes disabled people are not supported when participating in activities in their communities that include non-disabled people.

However, participants were straightforward in that intellectual disability sexual fields have rules in place that constrained expressions of affection. Even seemingly "harmless" normative forms of romantic expression, such as holding hands, was always discouraged or simply not allowed in these spaces. Some participants were actively told that such expressions should only be done outside of the organization's premises. To illustrate this, Ross, who has been in a romantic relationship with Grace, a young woman with an intellectual disability who participates in the same day program, reported being told, "'What we do, we do outside … Not inside.' 'Cause I got in trouble last time. I got in trouble." Ross was told to instead keep his focus on the activities at hand, as he stated, "I have to watch out 'cause today she [support worker] told me I need to focus and not get in my business, do my work, and that's it." Similarly, Bernert (2011) found that displays of affection were prohibited by services providers for women with intellectual disabilities during agency sponsored activities. Bernert found that five women were currently dating men who they had met at those activities. However, they were not allowed to engage in sexual expression during those activities. Three of those women were not permitted to see their partners at their own homes.

For Ross and Grace, who have been in a relationship for more than 10 years, the day program provided the couple with an opportunity to both meet each other for the first time and stay connected ever since. The day program is often the only place where they meet. At the same time, despite their long-term relationship, Ross and Grace only see each other three times a week. In these already limited encounters, they also face organizational rules that prohibit expressions of affection like holding hands and kissing, even on the cheek. Their story echoes those of a few other participants who found their intimate partners through day programs and found themselves also needing to navigate organizational rules and other constraints to maintain those relationships. In the following excerpt, Ross expresses his fear of getting caught and getting into trouble, a fear shared by others:

> Ross: No. Well, we're not doing it here though, we'd get caught.
> Alan: Oh, okay.
> Ross: What we do, we do outside.
> Alan: Oh, I see.
> Ross: No inside. 'Cause I got in trouble last time. I got in trouble.

There was a clear thread amongst participants' accounts, the fear – and sometimes experiences – of landing into trouble for expressing their sexuality in ways that would be acceptable for most non-disabled people of a similar age. Although one could say that expressions of affection do not have a place in a setting like the day program, the fact that for some couples the day program is one of the few (if not only) spaces they can actually see each other and spend time together is indicative of infantilization, being denied control, and oppression. Ross and Grace, for example, live in separate houses, with no plans to eventually live together. Ross lives at a group home while Grace lives with her parents. As explained by Ross, "I cannot take her to our [group] home, and hers [parents' house] didn't allow me to go." In fact, even his telephone communications with Grace were controlled by Grace's parents. Ross mentioned, "Sometimes when I call her late, her father yells at me. They say, "Excuse me? You have no boundaries when you talk to people like that." Arguably, for most non-disabled people in intimate relationships, such restrictions in terms of when telephone communication can happen or when visits from an intimate partner are allowed are simply non-existent.

The above accounts demonstrate how even people with intellectual disabilities in relationships can be infantilized, desexualized, and constrained in such ways that their intimate relationships are only permitted to be little more than friendships. When people like Ross and Grace are denied even the most "harmless" expressions of love in day programs, it becomes clear there will be few – if any – opportunities provided for some level of intimacy.

Tatianna spent a lot of time at a day program engaging in a range of activities with others with intellectual disabilities. Her daily routine was restricted to spending most of her day at the day program and then returning home, sometimes making quick stops for a coffee at a popular coffee shop on her own. On Sundays, she would also attend church service. While staring down into her hands, which were placed on the table, she spoke extensively about her loneliness and the challenges of finding a boyfriend, stating, "I'm looking for a boyfriend. It's not allowed to be any boyfriend from workshop. (one of the workshop rules). Only [out in the] community." The challenge is that Tatianna spends very little time out in the community. Not being allowed to fully utilize the space offered by the day program as a sexual field limits her options in finding an intimate partner.

Tatianna's second potential sexual field – the church – also failed to make available eligible partners. In her interview, Tatianna spoke about enjoying going to church every weekend. Tatianna shared how she had considered her church to be a viable sexual field for meeting the man of her dreams. Yet, it seemed as though her church provided only a limited pool of eligible partners. The reason being, as Tatianna said, that most of the men in congregation are "married. […] They're taken." Tatianna, nonetheless, still employs an easy strategy for identifying potential partners – she looks at men's hands with an eye for a wedding ring.

It is noteworthy, however, that for eight of the participants, their churches not only afforded a network of people to counter some of their social isolation, but also provided them with a pool of potential intimate partners, helped them to make sense of sexuality and their sexual identities, and delivered some guidance about how to develop and maintain intimate relationships. In the sexual fields literature, little research has focused on how religious spaces can serve as sexual fields. As an exception, Willey (2010) looked at an Evangelical church as a sexual marketplace, theorizing abstinence as a form of erotic capital. To date, an extremely limited number of studies have explored the role of religion in the romantic and sexual lives of people with intellectual disabilities, much less examined religious spaces as sexual fields available to adults with intellectual disabilities (Santinele Martino, under review). As Imhoff (2017) appropriately asserted, "Disability studies need more religion" (p. 1).

Indeed, as my data demonstrates, religion is an important aspect in the lives of some participants and, at times, played a significant role in their intimate lives. For example, in his interview, Andy also mentioned his church as a place to find the perfect girlfriend, stating, "Yeah, I'm going to church. And I'm looking for a very different girl […] Because I have to look for a girlfriend at church, and then if she likes me, and then I will take her." For Andy, a woman who goes to church is a "different girl", with more erotic capital than one who does not go to church. When asked if it is important for him that his future girlfriend be an active church-goer, he stressed, "Yeah. For me, because me and them, they go to the same church." More research is needed to understand the role of religion in the lives of people with intellectual disabilities, including their intimate lives.

As previous studies demonstrate, housing arrangements can significant impact the experiences and opportunities of people with intellectual disabilities in terms of sexual expression (Bernert, 2011; Hollomotz & The Speakup Committee, 2008; Löfgren-Mårtenson, 2004; Servais, 2006). Discussing sexual access thus requires thinking about different housing arrangements. People with intellectual disabilities may live in housing arrangements that afford little to no privacy to remain sexual (Hollomotz & The Speakup Committee 2008; Santinele Martino, 2019). Amongst the participants, those living independently with few supports in place enjoyed the most privacy for maintaining intimate relationships and being able to have sex. For example, Amanda and Bruce, who have been married for more than 10 years and currently live on their own (with occasional visits from a support worker who assists the couple with certain tasks including budgeting and cooking), spoke about having privacy to support intimacy. As Bruce briefly asserted before quickly changing the topic, "Yeah, we do [have privacy]." Despite the couple's discomfort in discussing this part of their lives in more detail, it was evident that their living arrangement allowed for the possibility of privacy and intimacy, which was unavailable to others.

To further illustrate the significance of the ways that one's housing arrangement can grant privacy, Natalie, who has been dating and living independently with a man with intellectual disabilities, shared how they maintain an active sexual life at their home. As she noted, "Like me and Neil, we make love […] Neil is my favorite guy because I get so many ... so much pleasure, yeah. I do. I love my other boyfriends, one gives me some ... He gives me some." For me, it is extremely encouraging – though somewhat rare – to listen to experiences like this where people (and especially women with intellectual disabilities) can maintain a private and active sexual life and experience pleasure.

In contrast, participants living in group homes, residential facilities, and with family members faced the most constraints. Importantly, the majority of participants lived in these types of arrangements. Participants living in these settings consistently spoke about "house rules" that limited what was allowed regarding forms of intimacy and sexual expression. In some situations, the rule at some group homes was that visits from friends and intimate partners were allowed as long as staff members were previously notified. Ethan, for example, was allowed to have visitors "as long as you gave notice". Indeed, he said he was able to spend time in his bedroom with his former girlfriend. He also mentioned he had never had sex before, and when asked if it was his own choice rather than because of organizational rules, he said with some certainty, "I think the organization would allow it." What seemed most evident in the accounts of most participants in these living arrangements was that the final decision-making power rested in the hands of the staff who get to determine whether visitations can happen. And, as noted earlier, the fear of landing into trouble was common. As Mike shared, "I first have to tell my staff of everything in that, bringing my girlfriend. If they ... my staff ... said yes or no. Because if you bring your girlfriend, then I have to tell her staff. Because about that. Because I don't want to get in trouble."

Some participants, however, were simply not allowed to have visitors nor bring intimate partners into their private rooms. In some cases, participants shared their bedrooms with roommates, which added to the challenge of having visitors. Amy, for example, who lives in a residential care facility with others with intellectual disabilities, was not allowed to have men in her bedroom.

> Amy: It's got one floor upstairs for the men – I never go upstairs – and one downstairs for the women. The women are not allowed upstairs. 'Cause they're women […] You can't bring men over, right, Linda [support worker's name]?
> Alan: Okay.
> Support Worker: You can't, you need to ask permission.

> Alan: If you have a partner?
> Support Worker: And the lodging home can deny, and yes, she cannot, you cannot have a partner. You cannot have any privacy.
> Alan: Oh.
> Support Worker: She's in a shared room and, no, you cannot invite an outside person to come in.

In some housing arrangements, such as the facility where Amy lives, spaces are gender segregated with women and men not permitted to have people of other genders in their bedroom. This is, of course, also grounded in a heteronormative assumption that women and men with intellectual disabilities would not be interested in having sex with someone of their own gender. As Amy's situation reveals, we once again see decision making regarding sexual expression to be in the hands of staff members. During my fieldwork, one direct care worker informally compared this kind of setting with a "college dorm", except that people "were not allowed to ever have sex or bring people over like [non-disabled] college students are able to."

Jack too lives in a residential facility in which he shares his bedroom with a roommate. Unsurprisingly, given what participants shared, in this setting as well, bringing over a girlfriend and having privacy is off the table. Indeed, during Jack's interview, the support worker sitting with us confirmed, "You're right. You're probably not allowed to have a girlfriend up in your room. And you share a room." Initially, Jack told me he was not interested in having sex. However, soon after, he clarified his need for privacy by stating, "No [sex]. Just make love. That's all." Clearly, for Jack, having sex and making love were different. Indeed, he said that he has made love with women before. As Jack briefly explained, having sex meant "having a baby" while making love meant "just kissing". When asked about where he had made love, he simply stated, "Out in the community." As I further inquired if he remembered what kind of place in the community, Jack humorously, and possibly strategically, asserted, "I can't remember [laughter]." As I have mentioned, Jack had asked his support worker to sit with us during the interview. Based on his response and tone, it seemed to me as though claiming not to remember the answer was a way to avoid disclosing the location in which he was intimate with women. If true, this could also be understood as a form of resistance in the face of the rules in his current housing arrangement that do not allow for sexual expression.

In his interview, Keith angrily remembered his previous living arrangement at a group home in which he was also not allowed to bring people into his own bedroom, stating, "I wasn't able to have people in my room at that place I was at." As a response to that restriction, Keith opted to have sex with women in public spaces, stating, "See, I was in a place like that before. That's why we just went to the parks and forest to go fuck." Keith was not alone. Albert, a middle-aged man who lives with his parents, also talked about parks as a place to express intimacy with an intimate partner. Interestingly, Keith noted, "I'll go to privacy in the park." For most people, parks are not considered to be a private space. Yet, there are other examples in the literature of how, for some sexual actors, parks and other public spaces serve as spaces for "cruising", venues for meeting intimate partners and engaging in sexual acts (see, for example, Anderson, 2018). For people such as Keith and Albert, whose private home spaces do not allow for actual privacy, rather than being an actual choice of a desirable location for sexual interactions, the decision to opt for public spaces may represent a search for spaces outside of the grips of surveillance and house rules (Eastgate, 2011). Similarly, Hamilton (2002) reported the experiences of people with intellectual disabilities using public toilets as a private space, one in which doors can be closed and privacy is available. Combined with what we know about a lack of useful sex education, the ways in which we deny disabled people privacy for sexual expression puts people with intellectual disabilities into situations where they are more likely to make risky decisions (Bryne, 2018; Shapiro, 2018).

To further illustrate how certain "house rules" have limited participants' sexual expression, I turn to Virginia's experience while living in a group home. Virginia identifies as a transwoman and passionate self-advocate. At the time of her interview, she was living in a less restrictive housing arrangement, however Virginia spoke with considerable anger about her years living in a group home where she faced significant restrictions:

> It's extremely different, and very difficult, and very isolating. I couldn't even do basically anything I wanted to do. I couldn't even properly masturbate, at a time, as being a guy at the time; I wasn't able to masturbate. And also, dating, having a relationship and coming out was very hard because group homes didn't really have a lot of services, supports, and anything like that.

Virginia, who came out as bisexual while she lived in the group home, also found that these spaces often do not recognize the potential for queer existence. Interestingly, the participants made clear that gender and heteronormativity are used to regulate the ways people with intellectual disabilities can have relationships and sex. There is an assumption that people with disabilities cannot identify as LGBT (Jungels & Bender, 2015; Santinele Martino, 2017) and, as a result, there is a lack of services and supports focused on the unique challenges and needs of this group (Abbott & Howarth, 2005; Dinwoodie et al., 2016). As Virginia noted, "Growing up in a group home, it was ridiculous, no services. Until I came out, and said I'm bisexual, that's when they kicked up the thing. That's when they kicked it up. I had to say something for them to give me the services."

I also spoke with some participants (12) living with family members including parents, grandparents, siblings, and cousins. While it appeared from participants' stories that some of these family members were open to the idea of participants eventually having relationships, there were still rules in place and decision making rested in the hands of family members. For example, Bryan, who lives with his cousin, shared his experience, stating, "Because I was thinking if I bring her to my own house and then I close the door, and then I have to talk to my cousin … And then he will tell me if I can bring her."

Similarly, when I asked Albert whether he was allowed to bring an intimate partner into his bedroom and close the door, he quickly responded, "I don't know, my dad's going to yell at me if I did that. I know mother is going to yell at me if I do that to my girl." Participants reported a lack of control over one's private space. In the "ideal world", Albert said he wishes he lived in a place that allowed him to spend intimate time with a girlfriend and have sex. My informal conversations with workers of community organizations have confirmed a concern that sometimes people with intellectual disabilities may end up getting into trouble for expressing their sexuality in public spaces. Yet, it is understandable that people who lack access to privacy at their own homes, including their own bedrooms, may feel as though their only option is to use public areas as a sexual space.

Another participant, Randy, was allowed to masturbate in his bedroom but anything beyond that, including watching pornographic films or having someone over, was not acceptable to his family:

> Randy: I do it [masturbate]. I shut my door, do it.
> Alan: And that's something that your mom's okay with you doing?
> Randy: Yeah. Not with girl, like that…
> Alan: So, your mom is okay if you go to your bedroom and if you touch yourself, then that's okay. As long as it's not with someone else, is that what it is?
> Randy: Yeah.

By determining what can be done within his bedroom, Randy's mother engages in a form of boundary work. For Randy's mother, masturbation is the only form of acceptable sexual expression because it does not involve other people. As articulated by Gill (2012), there is a significant focus on solitary forms of sexual expression – specifically masturbation – for people with intellectual disabilities as masturbation is viewed as a "substitute for sexual intimacy to supposedly reduce behavioral issues and tension build-up, while simultaneously enforcing notions that certain groups of people should not engage in sexual intercourse" (p. 487).

Within these sexual fields, hiding relationships served as a form of resistance against attempts to limit their intimate lives. Amy was one of the participants who talked about keeping her intimate relationship with a man with intellectual disabilities a secret from her support worker. Amy reported that, at first, she had asked her support worker to sit with her during the interview. Yet, the moment her support worker left the room for a few minutes to answer a telephone call, Amy quickly whispered to me:

> We're not having sex, but just because we're in love. But don't tell Linda [support worker's name] that, nobody knows about me and him. It's a secret … Don't tell Linda. Promise you won't tell Linda. … Sheldon [her secret boyfriend] never cheats on me. Sheldon doesn't cheat on me … He's my boyfriend and I don't want anybody to know. You won't tell nobody?

At this point, her support worker had returned to the room and the interview continued. I was unable to do a follow-up interview with Amy due to her declining health. However, it is significant that she felt the need to keep her romantic relationship a secret. This, nonetheless, also demonstrates Amy's attempt at asserting her agency by trying to maintain a romantic relationship even if it needs to remain a secret.

Conclusion

The key finding in this chapter is that when romantic and sexual expression is not allowed (and is sometimes even punished) to flourish and thrive – neither in day activities, nor in their living arrangement – people with intellectual disabilities are left with very limited opportunities to develop intimate relationships and become sexual. Echoed in some of the current literature on disability and sexuality is the fear that people with intellectual disabilities will engage in inappropriate behaviors in public spaces (Eastgate, 2011). Yet, considering the level of surveillance and the rules that constrain forms of sexual expression, it should not be surprising that some people may feel as though engaging in sexual behaviors in public spaces, outside of staff or parental oversight, may be their only option. Participants were well aware of the risks of defying the rules in place as they often referred to their fear of getting in trouble. This is particularly problematic considering the few spaces to which participants have access and that social isolation is a common concern among this social group. As a result, many participants have attempted to convert certain spaces shared with other disabled people into sexual fields, including day programs and group homes. While these intellectual disability sexual fields create opportunities for people to meet potential partners, these spaces are typically infused with surveillance and regulation that often prohibits forms of romantic and sexual expression. Nevertheless, this chapter also sheds light on the forms of resistance that some participants used to remain sexual including secrecy and engaging in sexual practices in public spaces.

Chapter 6: Conclusion

Introduction

Drawing on qualitative interviews, I set out herein to better understand the romantic and sexual experiences of 46 adults with intellectual disabilities in Ontario, Canada. Similar to Shakespeare, Gillespie-Sells, and Davies (1996), as well as other scholars in the field (e.g., Liddiard, 2011, 2017), I strove to "perform a balancing act" looking at both experiences of "oppression and marginalization", as well as "positive account[s], celebrating the resistance of disabled people, the delight and the joy of disabled people's sexual and emotional lives" (Shakespeare et al., 1996, p. 209). However, as Liddiard (2017) appropriately notes, sometimes the "collective story" we tell in our research is not the story that we wish we were telling (p. 162). While I did encounter a few positive accounts from participants who demonstrated opportunities for resistance and "cripping" sexualities, in their majority, the sexual stories shared in this dissertation (unfortunately) commonly leads to narratives focused on loneliness, fear, punishment, boundaries, and emotional psycho-disablism.

In their accounts, most participants spoke about their attempts to access and maintain normative gender and sexual constructions – sometimes the same ones that constrained, excluded, and denied their sexualities (Liddiard, 2017). For some, those normative ways of doing gender and being sexual were perceived as the only appropriate and safe options in their lives. Some even shared experiences of being reprimanded or punished for supposedly failing to perform those roles. Their sense of being constantly surveyed in their everyday lives led some to engage in forms of self-surveillance and self-discipline (1975), in which they policed their own forms of affection and sexual practices as well as that of their intimate partners. That is how pervasive surveillance and ableism can be in the lives of disabled people. It is important to mention that disabled people are not doing gender or being sexual "the wrong way". The challenge, rather, is the fact that disabled people's options tend to be limited by other people in their lives from a very early age. These unique social conditions have an impact on their erotic and gender habitus, as well as their access and participation in sexual fields.

My intention is not to deny the agency and forms of resistance and creativity expressed by the participants. Far from wanting to disempower them, my work serves to highlight how the sexualities of disabled people continue to be significantly silenced, constrained, and marginalized in our social world, as well as how the life choices of disabled people are constrained by ableist heteronormative assumptions that lead to the disenfranchisement of their sexual rights. A few participants tried hard to challenge the various social forces managing and controlling their sexualities, including the controlling images (Hill Collins, 1990) of disabled sexualities, which limit their sexualities to sometimes being seen as child-like and innocent, and thus lacking sexual desires, but also seen as being potentially hypersexual and sexually deviant. In a way, participants' accounts demonstrate how, in many ways, ableism, infantilization, and boundary-making processes have played a much more significant role in constraining their intimate lives than their impairments (despite what many non-disabled people may believe). To put it bluntly, engines of inequality, like ableism, (rather than individual characteristics) was often one of the main social forces that compromised their access to intimate citizenship (Liddiard, 2019). Moreover, some participants emphasized their inherent value as human beings and their corresponding desire to be treated with respect and equality. If anything, they did not want to be perceived and treated as "less than human."

This final chapter concludes this dissertation by providing a summary of the main findings and theoretical contributions of this study. It briefly discusses the potential practical implications of the insights provided by this study, as well as my commitment to reciprocity and accessibility. The chapter then concludes by noting the limitations of this study, as well as opportunities for future research addressing the romantic and sexual lives of adults with intellectual disabilities.

Summary of Findings and Theoretical Contributions

This research has focused on bridging critical disability studies and the sociology of sexualities, two fields that have only recently been put into dialogue (Jungels & Bender, 2015), in order to theorize and empirically examine the perspectives, challenges, and triumphs of disabled people concerning sexuality. This is an exciting and growing area of research that is showing the complexities and importance of addressing issues in the private sphere in the lives of disabled people (Santinele Martino & Campbell, 2019). Historically, disability studies and disability rights movements had considered sexualities to be an apolitical or personal matter; as a consequence, the many questions related to disabilities and sexualities were previously neglected, under-explored, and depoliticized. This has changed in the past decades with the emergence of scholarship and activism in this area, which provides rich insights into the consequences of sexual stratification and the contestations by disabled people (Santinele Martino & Campbell, 2019).

Traditionally, people with intellectual disabilities have been marginalized in their communities, and this marginalization is reflected even in social scientific research. Their voices are rarely heard whether in research or in the general community (Santinele Martino & Fudge Schormans, 2018). From my own work and partnerships with disabled people, I know that they are well aware that their voices are rarely included in social narratives, or worse, seen as less credible or valuable in comparison with non-disabled people. This exclusion does not mean that their stories are not important, insightful, or profound, nor does it mean that these individuals have no desire to speak about their experiences. Rather, it means that more space needs to be made for them to speak on their own behalf (Bigby, Frawley, & Ramcharan, 2014; Nind, 2017). This project centers the voices of people with intellectual disabilities and makes space for them to share their sexual stories (Plummer, 1995). My intention is to help foster a more inclusive sexual culture, one in which disabled sexualities can thrive and be celebrated (Siebers, 2006).

For many of the participants, this was their very first opportunity to talk openly and free of judgment about their intimate lives and dreams. Listening to participants' narratives has been an incredible gift for me. Sexual stories can generate possibilities for sexual justice and intimate citizenship, and there is much we can learn through these sexual stories that reveal love, desire, pleasure, as well as pain, loneliness, and heartbreak (Liddiard, 2019). In "cripping" sexualities, disability serves as a powerful "tool for [the] disruption" of normative ways of being romantic and sexual (Liddiard, 2019, para. 11, Santinele Martino & Fudge Schormans, forthcoming), and the construction of a future in which disabled minds and bodies are desirable (Kafer, 2013). Moving beyond narrow understandings of sexualities, desire, and desirability benefits everyone, not only disabled people (Santinele Martino & Campbell, 2019). Moreover, an attention to disability and disability justice (Mingus, 2011) can shed light on aspects that sociologists of sexualities may sometimes take for granted in their theorizing, for example, sexual access (Shuttleworth, 2012). Not only that, the intersection of disability and sexuality reinforces the need to question a "culture of undesirability," in which marginalized sexualities and social groups experience punishment, containment, and surveillance (Erickson, 2016, p. 14; see also Rubin, 1984).

Research Question 1: What are some of the systematic barriers that adults with intellectual disabilities face to participating in sexual fields?

I began this research by addressing a gap in the sexual fields' literature focusing on the notion of sexual access to understand the experiences of participants who are denied access to sexual fields. My work sheds lights on different disabling social barriers that prevent adults with intellectual disabilities from participating in sexual fields in the first place, including infantilization, lack of information about sexuality, a lack of a "feel for the game," and psycho-emotional disablism. In addition, my research extends the concept of erotic habitus (Green, 2014) by proposing a new concept, which I call infantilized erotic habitus. The infantilization commonly experienced by disabled people has led to an erotic habitus that is de-sexualized and barred from sexual expression through boundary-making processes, and held into a prolonged state of adolescence. Further, the chapter highlights how sexual access involves more than architectural changes, like building ramps, but also involves attitudinal barriers that discourage disabled people from entering sexual fields.

Research Question 2: How do people with intellectual disabilities make sense of their gender and sexual identities based on gender habitus acquired in their lives?

In Chapter Four, I focused on how participants make sense of their gender and sexual identities. The role of gender has not received enough attention in the existing sexual fields' literature (Plante, 2016; Wade, 2019). To address this gap, I draw on the concept of gender habitus (Krais, 2006) to bring to view how gender habitus is shaped differently for men and women with intellectual disabilities, often confining them into traditional gender roles and hetero-romantic love. The majority of the women I interviewed had only been offered traditional understandings of womanhood and their sexuality was often framed around vulnerability and protection. At the same time, most of the men interviewed talked about being seen as "potential dangers" to the community and having to be careful about not landing into trouble. It was evident that men and women had received different messages regarding gender and gender expectations. Not only that, the fact that most participants were commonly participating in activities and living arrangements that were gender-segregated has led some to the belief that men and women are extremely different from one another. Participants had a clear understanding that failing to perform gender in the "right" way could result in punishment and further surveillance in their lives. Consequently, many participants worked hard to follow the limited gender roles offered to them in order to stay out of trouble. These findings reinforce the importance of including gender in our analysis of disability and sexuality, as well as how the gender habitus of sexual actors shapes their participation in sexual fields.

Research Question 3: How do adults with intellectual disabilities navigate the mainstream and specialized sexual fields available to them?

Chapter Five attends to the experiences of participants when navigating the sexual fields available to them. My research extends the concept of sexual fields by introducing previously unexplored sexual spaces in the sexual fields' literature. In addition to the mainstream digital and physical sexual fields available to them, participants also navigated what I call intellectual disability sexual fields. These are sexual fields constructed by and for people with intellectual disabilities, materialized in sexual sites such as group homes and day programs. Participants claimed that often these spaces, which were not initially meant to serve as sexual fields, were the main spaces they used to meet potential partners, flirt, start intimate relationships, and engage in certain forms of sexual expression (e.g., hugging and kissing). The challenge, though, is that these spaces are highly controlled and surveyed by staff members, and forms of sexual expressions are commonly discouraged and prohibited. A few participants even got into trouble and were punished for engaging in sexual expression, such as holding hands and kissing other disabled people. In such manner, intellectual disability sexual fields have a contradictory role in which they facilitate opportunities for participants to meet intimate partners, but these spaces also constrain opportunities for actual romantic and sexual expression. My research suggests that sexual fields can be constructed differently for and by people with intellectual disabilities and, without understanding their experiences, we would not recognize certain sexual fields being used for the pursuit of intimacy and love.

Other Implications

As Barton (2005) emphasizes, “relevant research is essentially transformative, informative, contributing to the collective experience and understanding of disabled people over the ways in which disability is socially produced” (p. 318). Moreover, relevant research challenges hierarchies of knowledge and makes space for disabled people as meaning-makers of their own lives. In the early stages of this project, and even during fieldwork, I had the opportunity to meet with different self-advocates and support workers to discuss the purpose and scope of my project. It was reassuring to me to hear such a positive feedback from them. Many told me that they found this project to be both timely and relevant. Many shared their personal and professional experiences and struggles related to the area of sexuality – an area that is commonly kept in the backburner in comparison with other parts of life.

In my interactions with self-advocates, they shared their challenges in terms of building the confidence and having the necessary information and resources to participate in sexual fields, as well as in resisting ableism and restrictions to their sexual rights and that of other disabled people. They importantly reminded me of those who may not have the opportunity to share their views regarding sexuality, as well as those who may not be in a position to advocate for themselves. They consistently asked me to try and make space for those perspectives. Contrary to dominant understandings of disabled sexualities, I encountered individuals with intellectual disabilities who articulated in passionate and compelling ways the importance of sexuality in their lives, their diverse dreams and desires, the ways that they challenged their desexualization and infantilization, and emphasized how the sexual rights of disabled people must be protected. They also commonly noted the disproportionate support they had received regarding issues from the public sphere (e.g., education and employment) compared to those from the private sphere (e.g., intimate relationships and sex). “Why is it that we are so comfortable talking about employment and education while sexuality immediately makes everyone uncomfortable?” said one self-advocate during a group meeting. They advocated for greater supports around sexuality in all of its forms – knowing one’s own body, having a vocabulary to talk about their aspirations and desires, and having access to love and intimacy. On the whole, their accounts further highlighted how the intersection of disability and sexuality remains a taboo topic.

At the same time, in my informal interactions with support workers throughout this project, they spoke about their concerns, challenges, and experiences delivering care and navigating (sometimes conflicting) expectations and values from their clients, clients' family members, and organization staff and leadership. Even those who have tried to support disabled people in accessing certain sexual fields or experiences, they sometimes spoke about being reprimanded by their superiors who instructed them to "stay away from this can of worms," as one support worker informally told me. The common thread in those conversations was that sexuality remains a silenced topic in their everyday practice, a topic to be avoided unless "something happens." My sense was that, generally speaking, only when bad events take place (e.g., a disabled people experiences a form of abuse or performs a behavior deemed to be inappropriate) that sexuality is then talked about and addressed. This approach not only fails to be proactive but also limits discussions about sexuality to negative topics (Santinele Martino, 2014, 2019).

Some people with intellectual disability live in housing settings in which they received supports from direct care workers (Brown & McCann, 2019). Studies have consistently shown, however, that service providers tend to lack policies and guidelines to support these workers when it comes to supporting the sexualities of disabled people (Eastgate et al., 2012; Pebdani, 2016; Saxe & Flanagan, 2014). This study is relevant to service providers and direct care workers. My hope is that service providers and support workers may take participants' insights into account when developing better strategies for supporting disabled people. In fact, I have worked with different community-based organizations helping them to revise their organizational policies and practices when it comes to sexuality. Sometimes all support workers need is an "anchor" or an opening to become true champions within their organizations. Sometimes they want more information and education themselves. I hope this research can help them put sexuality on the map. In the past, my research endeavors have successfully inspired a few service providers and support workers to take on the topic of sexuality as a central issue and start revisiting the organization's practices and guidelines. I feel extremely invigorated when I encounter staff members who strive to transform organizational policies and practices. Staff members need to be involved in the process of rethinking organizations' practices and policies, especially if we desire their buy-in (Rushbrooke et al., 2014).

Finally, many disabled people also live at home with family members (Brown & McCann, 2019). Thus, I hope that family members of disabled people will also appreciate the accounts and insights shared by the participants in this study. In the past, I have had multiple opportunities to discuss my work with family members of disabled people as an effort to better understand their views and provide them with insights into perspectives and desires of some people with intellectual disabilities themselves when it comes to their intimate lives. Moreover, as the sibling of a young man with a disability, and the member of a family who has struggled to support a loved one and his sexuality, I am empathetic to their concerns, challenges, and desire to do the right thing. I certainly understand and share their concern when it comes to ensuring that our loved ones are safe from exploitation and abuse (Ballan, 2012; Eastgate et al., 2012; Pownall et al., 2011). It is essential, however, to listen to disabled people and trust their desire to have intimate relationships, be able to make mistakes and learn from them, and count on their families for support. People with intellectual disability often experience excessive restrictions from family members and other caregivers in their lives (Whittle & Butler, 2018).

I hope this study will help raise awareness among parents and care workers that people who have disabilities have agency, have sexual desires, and make decisions based on their own understanding of the world. Support workers and family members can serve either as supporters or barriers for disabled people to be romantic and sexual and, unfortunately, many caregivers tend to side with protection and restriction (Rushbroke et al., 2014; Whittle & Butler, 2018). It is important that we better attend to the ways that we can be supporters to our loved ones. We need to recognize ways we can be more supportive of disabled people in accessing and navigating sexual fields, and help them to become aware of and able to be the type of men and women they want to be. Furthermore, it is important that family members and support workers work in sync, especially to avoid confusion among disabled people.

I took these insights and perspectives from informants seriously. As a form of reciprocity, especially to disabled people whose contributions often go unrecognized and unpaid, I consistently compensated them for their time and insights (e.g., by providing self-advocates with pizza and drinks to show my gratitude for their willingness to have me in their monthly meeting). In addition, I am committed to disseminating my findings through different channels, including academic (e.g., peer-reviewed journal articles, conference presentations), as well as community-based (e.g., presentations and workshops for self-advocacy groups and service providers, accessible summaries) ones. I am also committed to taking advantage of opportunities to talk about the research findings with the general public, including via podcast interviews, articles in popular media, and blog posts, as an attempt to support a shift in terms of how non-disabled people think about sexualities among disabled people. My hope is that this research may support positive changes to better protecting disabled people and their sexual rights.

Above all, based on my findings, it is evident that ableism continues to shape whether and how disabled people learn about sexuality and express their sexual and romantic desires. While some participants did receive some level of sexuality education - mainly focused on questions of privacy, "appropriate" touching, and safety - what is missing is what Whittle and Butler (2018) have referred to as a "rights-based approach to the sexuality" (p. 80). This means that more attention should be paid to more positive aspects of sexuality, including romance, love, and sexual pleasure. It is crucial to develop a better way forward that acknowledges both the protection and sexual agency of people with intellectual disabilities. Both are equally important.

Limitations of this Study and Opportunities for Future Research

This dissertation is not without limitations. Firstly, while I strived to create a comfortable, non-judgmental interview environment for the participants (King & Horrocks, 2010; Knox & Burkard, 2009), considering that this dissertation addresses a sensitive and personal research topic, it is possible that some of them may still have felt uncomfortable disclosing certain experiences, perspectives, and sexual desires with me (Renzetti & Lee, 1993). It was important for me to make sure that participants knew they could share as much information as they felt comfortable sharing and that their choices were respected. I also understand that my gender identity shapes my interviews and interactions with participants, being both considered as a "resource and [a] limiting factor" (Scwalbe & Wolkomir, 2001, p. 53; Broom, Hand, & Tovey, 2009). My gender identity may have caused a particular discomfort or uncertainty in interviews with disabled women, especially considering how many of them had learned that talking openly about sexuality was either inappropriate or could place them in a vulnerable position. At the same time, some men may have felt at ease talking to another man, sometimes close to their age, about sexual pleasure. As I have noted, the men I interviewed were a lot more open about their views and experiences with sexual desires and pleasure than were the women.

Secondly, inclusive research, which involves disabled people as co-researchers, has increasingly been recognized as particularly valuable for addressing the common exclusion of disabled people in research about their lives (Fudge Schormans et al., 2019; Johnson & Walmsley, 2003; Nind, 2008). At the same time, these methods continue to be mostly underutilized in the general literature (John et al., 2018). Inclusive research can range from having a lived experience advisory approach all the way to a fully collaborative approach (Bigby, Frawley, & Ramcharan, 2014). Crossing these different approaches is the goal to generate research that is, in some level, the result of a meaningful collaboration between disabled and non-disabled people (Nierse & Abma, 2011). Unfortunately, in this project, I had limited financial resources that would not allow me to compensate disabled people for a more extensive involvement in the project. To me, it is highly important that their time and labor are compensated. Yet, I have had the opportunity to speak with self-advocates at different points in this project and gain their insights regarding the project. In addition, I have been extremely lucky in terms of working in different research projects alongside incredible critical disability studies scholars, such as Dr. Patty Douglas and Dr. Ann Fudge Schormans, who have extensive experience doing inclusive research. From them, I have learned rich lessons and experiences, which I will bring with me to my future research endeavors with the aim of allowing disabled people's meaningful participation in inclusive research.

Thirdly, despite my efforts for recruitment, this study has not included adults with intellectual disabilities under guardianship orders who may not typically have the opportunity to share their perspectives regarding sexuality. There are, in fact, many disabled people that often do not get to participate in research including, for example, people under guardianship order, people who communicate using communication devices, people living with more "significant" impairments, and people living in more controlled residential facilities (Kijak, 2013; Kulick & Rydström, 2015; Rogers, 2016; Santinele Martino & Fudge Schormans, 2018; Vehmas, 2019). This omission is – at least in part – due to ethical and methodological concerns around the inclusion of these often-neglected social actors (Vehmas, 2019). Yet, these are the same groups that may experience greater social isolation and even more desexualization and negligence in terms of their erotic lives and rights (Vehmas, 2019; Wade, 2002). Future studies should make space for more diverse narratives by people with intellectual disabilities that can help us better understand other ways of being sexual as well as additional potential constraints to accessing sexual fields. For example, for people with "profound" intellectual disabilities, learning about sexuality might sometimes require "literally, hands-on guidance" to learning forms of sexual expression like masturbation (Vehmas, 2019, p. 536). However, access to sexuality education is often denied to them (Wade, 2002). Above all, every disabled person deserves the opportunity to share their views, represent themselves, and co-produce research that is reflective of their experiences.

Lastly, it is also important to acknowledge that my research focused on the experiences of disabled people living in more urban areas, including Hamilton, Toronto and Greater Toronto Area, Ottawa, and Kingston. As noted in the literature, disabled people living in rural contexts tend to experience greater disadvantages in comparison with people in metropolitan areas (see, for example, Wark, Hussain, & Edwards, 2013), and those disadvantages have an impact on disabled people's intimate lives. Future research should explore rural sexualities among disabled people to better understand, for example, the sexual fields available to them, as well as people's access to basic sexual and reproductive rights' information and supports.

Intellectual Disability and Intimate Citizenship in Times of COVID-19

I will end with a comment about the current pandemic. Whereas I conducted my interviews before the COVID-19 pandemic had emerged, it is important to acknowledge the recent significant changes to social (and intimate) life that have occurred. Little is yet known about the impact of the pandemic on the intimate lives of disabled people. However, there are indications that the recent pandemic may have worsened the social isolation experienced by people with intellectual disabilities (see Santinele Martino, Fudge Schormans, & Campbell, 2020) who even before the pandemic, already articulated feelings of loneliness and isolation (Canadian Association for Community Living & People First of Canada, 2017). Currently, many programs that provided disabled people with opportunities to socialize with others have since then been suspended or moved to online platforms. This is especially problematic for disabled people who could only see their intimate partners in spaces such as day programs. Moreover, this is critical considering how, as my findings suggest, the sexual fields available to disabled people are significantly limited.

In addition, because of the pandemic, disabled people are being told not to touch, or hug, or high-five staff members or even other disabled people living with them in the same household. In my conversations with different support workers in the field, I have learned that many disabled people are still feeling confused with the policies implemented since COVID-19 and some are feeling abandoned because of the fewer visits from family and time spent with others. As Santinele Martino, Fudge Schormans, and Campbell (2020) appropriately articulate:

> For disabled people who have experienced institutionalization, who lack access to the communities where they live, who are unable to visit with family, friends or romantic and sexual partners, the recent separation from community life can take on a different meaning (para. 13).

Researchers should quickly start looking at how the pandemic has and will continue to affect the sexualities of disabled people. Also worth noting, we know that a disproportionate number of disabled women tend to experience forms of abuse and violence in their lives compared to men even prior to the pandemic. One could argue that, based on data related to non-disabled women, the risks may be even higher now for disabled women due to the isolation and stress caused by the pandemic (Santinele Martino, Fudge Schormans, & Campbell, 2020). Thus, more research is also needed to understand the gendered consequences of these unprecedented times on the sexual lives of disabled people, as well as what disabled people wish had been done differently in terms of supporting them during these times.

Conclusion

In this concluding chapter, I summarized how this dissertation contributes to our empirical and theoretical understanding of sexualities among people with intellectual disabilities. The sexual stories I have shared in this dissertation demonstrate the continued stigmatization of disabled people’s sexualities, as well as how participants attempt to navigate the multiple sites of sexual oppression in their lives as active agents of their lives. We undoubtedly need a lot more sexual stories, especially for those who do not often get to share their experiences. Moving forward, my intention is to continue contributing to theory, empirical research, and advocacy that serve to assert disabled people’s intimate citizenship. I will continue taking a leadership role in facilitating dialogues about disability and sexuality, working towards social justice, further complicating what we think we know, and proposing new ways to approach this complex topic.

Bibliography

Abbott, D. (2015). Love in a Cold Climate: Changes in the Fortunes of LGBT Men and Women with Learning Disabilities? *British Journal of Learning Disabilities*, 43(2), 100–105.

Abbott D. & Howarth J. (2005). *Secret Loves, Hidden Lives? Exploring Issues for People with Learning Difficulties Who are Gay, Lesbian or Bisexual. Bristol*. The Policy Press.

Adam, B. D. & Green, A. I. (2014). Circuits and the Social Organization of Sexual Fields. In A. I. Green (Ed.), *Sexual Fields: Toward a Sociology of Collective Sexual Life* (pp. 123-142). Chicago: University of Chicago Press.

Adams, R. (2015). Privacy, Dependency, Discegenation: Toward a Sexual Culture for People with Intellectual Disabilities. *Disability Studies Quarterly*, 35(1), https://dsq-sds.org/article/view/4185/3825.

Akbas, S, Turia, A, & Karabekirolgu, K. (2009). Characteristics of sexual abuse in a sample of Turkish children with and without mental retardation, referred for legal appraisal of the psychological repercussions. *Sexuality and Disability*, 27, 205–213.

Alexander, N. & Gomez, M. T. (2017). Pleasure, sex, prohibition, intellectual disability, and dangerous ideas. *Reproductive Health Matters*, 25(50), 114-120.

Anderson, G. (2018). ‘Why can’t they meet in bars and clubs like normal people?’: The protective state and bioregulating gay public sex spaces. *Social & Cultural Geography*, 19(6), 699-719.

Andrejek, N., Santinele Martino, A. & Ginic, M. (under review). “Put Some Sugar on... You”: Negotiations of Sexual Capital Among Sugar Daddies Soliciting Sugar Babies Online.

Arstein-Kerslake, A. (2015). Understanding sex: the right to legal capacity to consent to sex. *Disability & Society*, 30(10), 1459-1473.

Aunos, M., & Feldman, M. A. (2002). Attitudes towards sexuality, sterilization and parenting rights of persons with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15(4), 285-296.

Aurini, J., Heath, M. & Howells, S. (2016). *The How to of Qualitative Research*. SAGE.

Azzopardi-Lane, C. & Callus, A.-M. (2015). Constructing sexual identities: people with intellectual disability talking about sexuality. *British Journal on Learning Disabilities*, 43, 32-37.

Bahner, J. (2015). Sexual professionalism: for whom? The case of sexual facilitation in Swedish personal assistance services. *Disability & Society*, 30(5), 788-801.

Ballinger, C. (2006). Demonstrating rigour and quality? In L. Finlay, & C. Ballinger (Eds.) *Qualitative research for allied health professionals: challenging choices*. Chichester, East Sussex: John Wiley.

Bane, G., Deely, M., Donohoe, B., Dooher, M., Flaherty, J., Iriarte, E.G., Hopkins, R., Mahon, A., Minogue, G., Donagh, P.M., Doherty, S.O., Curry, M., Shannon, S., Tierney, E. and Wolfe, M. (2012). Relationships of people with learning disabilities in Ireland. *British Journal on Learning Disabilities*, 40, 109-122.

Barnes, C. (2008). An ethical agenda in disability research: Rhetoric or reality? In D. M. Mertens and P. E. Ginsberg (Ed.), *The handbook of social research ethics* (pp. 458-473). London: Sage.

Bates, C., Terry, L., & Popple, K. (2016). Partner Selection for People with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities* DOI: 10.1111/jar.12254.

Bayton, D. (2001). Disability and the Justification of Inequality in American History, in *The New Disability History: American Perspectives*, eds. Paul K. Longmore and Lauri Umansky, 33-57 (New York: New York University Press.

Baynton, D. (2005). Defectives in the Land: Disability and American Immigration Policy, 1882-1924. *Journal of American Ethnic History*, 24(3), 31-44.

Bazzo, G., Nota, L., Soresi, S., Ferrari, L., & Minnes, P. (2007). Attitudes of social service providers towards the sexuality of individuals with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 20(2), 110-115.

Beail, N. and Williams, K. (2014), Using Qualitative Methods in Research with People Who Have Intellectual Disabilities. Journal on Applied Research on Intellectual Disabilities, 27, 85-96.

Becker, H., Roberts, G., Morrison, J., & Silver, J. (2004). Recruiting People with Disabilities as Research Participants: Challenges and Strategies to Address Them. *Mental Retardation*, 42(6), 471–75.

Behnke, C. and Meuser, M. (2001) Gender and habitus: fundamental securities and crisis tendencies among men. In H. Kotthoff and B. Baron (eds) *Gender in Interaction: Perspectives on Femininity and Masculinity in Ethnography and Discourse* 153–74. Amsterdam: John Benjamins.

Bell, Chris. 2006. Introducing White Disability Studies: A Modest Proposal. In *The Disability Studies Reader* (2nd ed) (pp. 275-282). Ed. Lennard J. Davis. New York, NY: Routledge.

Bender, A. A. (2012). Secrets and magic pills. In L. M. Carpenter & J. D. DeLamater (Eds.), *Sex for life: From virginity to Viagra, how sexuality changes throughout our lives* (pp. 198–214). New York: NYU Press.

Bernert, D. J. (2011). Sexuality and Disability in the Lives of Women with Intellectual Disabilities. *Sexuality & Disability*, **29,** 129–141.

Bigby, C., Frawley, P., & Ramcharan, P. (2014), Conceptualizing Inclusive Research with People with Intellectual Disability. *Journal of Applied Research in Intellectual Disability*, 27, 3-12.

Bird, C. M. (2005). How I stopped dreading and learned to love transcription. *Qualitative Inquiry*, 11, 226-248.

Björnsdóttir, K. & Traustadóttir, R. (2010). Stuck in the land of disability? The intersection of learning difficulties, class, gender and religion. *Disability & Society*, 25(1), 49-62.

Björnsdóttir, K., Stefánsdóttir, Á., & Stefánsdóttir, G.V. (2017). People with Intellectual Disabilities Negotiate Autonomy, Gender and Sexuality. *Sexuality & Disability*, 35, 295–311.

Kristín Björnsdóttir & Rannveig Traustadóttir (2010) Stuck in the land of disability? The intersection of learning difficulties, class, gender and religion. *Disability & Society*, 25(1), 49-62.

Blackman, S. (2007). "Hidden ethnography": Crossing emotional borders in qualitative accounts of young people's lives. Sociology, 41(4), 699-716.

Blee, K., & Currier, A. (2011). Ethics beyond the IRB: An introductory essay. *Qualitative Sociology,* 34(3), 401-413.

Bloomberg, L. D. & Volpe, M. (2012). *Completing your qualitative dissertation: A road map from beginning from end*. Los Angeles: SAGE.

Boeije, H. (2010). *Analysis in qualitative research*. Los Angeles: SAGE.

Bonell, C. (2004). Why is teenage pregnancy conceptualized as a social problem? A review of quantitative research from the USA and UK. *Culture, Health & Sexuality*, 6(3), 255-272.

Bourdieu, Pierre (1977). *Outline of a Theory of Practice*. Cambridge: Cambridge University Press.

Bourdieu P. (1979). Symbolic Power. *Critique of Anthropology*, 4(13-14), 77–85.

Bourdieu, P. (1984). *Distinction: A Social Critique of the Judgement of Taste*. London, Routledge.

Bourdieu, P. (1989). Social Space and Symbolic Power. *Sociological Theory,* 7(1), 14–25.

Bourdieu, Pierre, (1990). Structures, habitus, practices. In *The Logic of Practice* (pp. 52-65). Cambridge: Polity..

Bourdieu, P. (1997). The forms of capital. In Halsey, AH, Lauder, H, Brown, P. (eds) *Education: Culture, Economy, Society,* (pp. 46–58). Oxford: Oxford University Press.

Bourdieu, P. (1998). *Practical Reason*. Stanford, CA: Stanford University Press.

Bourdieu, P. & Wacquant, L. P. D. (1992). *An Invitation to Reflexive Sociology*. Chicago: University of Chicago Press.

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.

Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. London: SAGE.

Broom, A., Hand, K., & Tovey, P. (2009). The role of gender, environment and Individual biography in shaping qualitative interview data, *International Journal of Social Research Methodology*, 12(1), 51-65.

Brown, M. & McCann, E. (2018). Sexuality issues and the voices of adults with intellectual disabilities: A systematic review of the literature. *Research in Developmental Disabilities*, 74, 124-138.

Bryman, A., & Teevan, J. J. (2005). *Social research methods Canadian edition*. Oxford, England: Oxford University Press.

Burns, J. & Davies, D. (2011). Same-Sex Relationships and Women with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 24, 351-360.

Byrne, G. (2018). Prevalence and psychological sequelae of sexual abuse among individuals with an intellectual disability: A review of the recent literature. *Journal of Intellectual Disabilities*, *22*(3), 294–310.

Cambridge, P., & Mellan, B. (2000). Reconstructing the sexuality of men with learning disabilities: Empirical evidence and theoretical interpretations of need. *Disability and Society*, 15(2), 293-311.

Cameron, L. & Murphy, J. (2007). Obtaining Consent to Participate in Research: The Issues Involved in Including People with a Range of Learning and Communication Disabilities. *British Journal of Learning Disabilities*, 35(2), 113–20.

Campbell, F.K. (2009). *Contours of Ableism: The Production of Disability and Abledness*. Basingstoke: Palgrave Macmillan.

Cantor, J. M., Blanchard, R., Robichaud, L. K., & Christensen, B. K. (2005). Quantitative reanalysis of aggregate data on IQ in sexual offenders: *Psychological Bulletin*, 131(5), 661.

Charmaz, K. (2006). *Constructing Grounded Theory A Practical Guide through Qualitative Analysis*. London Sage Publications.

Charmaz, K. (2008). Grounded theory as an emergent method. In S. N. Hesse-Biber & P. Leavy (Eds.), *Handbook of emergent methods* (p. 155–170).

Charlton, J. I. (1998). *Nothing about us without us: Disability power and oppression*. Berkeley, CA: University of California Press.

Chivers, S. (2011). *The Silvering Screen: Old Age and Disability in Cinema*. Toronto: University of Toronto Press.

Clarke, C. L., Lhussier, M., Minto, C., Gibb, C. E., & Perini, T. (2005). Paradoxes, Locations and the Need for Social Coherence: A Qualitative Study of Living with a Learning Difficulty. *Disability & Society*, 20(4), 405–19.

Collins, P. H. (1990). *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment*. New York: Routledge.

Collins, P. H. (1998). *Fighting words: Black women and the search for justice*. Minnesota, MN: University of Minnesota Press.

Collins, P. H. (2000). (10th anniversary edition) *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment*. New York: Routledge.

Collins, P. H. (2005). *Black Sexual Politics: African Americans, Gender, and the New Racism*. New York: Routledge

Collins, P. H. (2015). Intersectionality's Definitional Dilemmas. *Annual Review of Sociology*, 41(1), 1-20.

Connell, R. (1995). *Masculinities*. Sydney: Polity Press.

Connell, R. W. & Messerschmidt, J. W. (2005). Hegemonic Masculinity: Rethinking the Concept. *Gender & Society*, 19(6), 829–859.

Corbin, J. & Strauss, A. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (3rd ed.). Sage.

Correll, S. (1995). The Ethnography Of An Electronic Bar: The Lesbian Cafe. *Journal of Contemporary Ethnography*, 24(3), 270–298.

Council of Canadians with Disabilities. (2015). *As a Matter of Fact: Poverty and Disability in Canada*. Accessed September 1, 2020. http://www.ccdonline.ca/en/socialpolicy/poverty-citizenship/demographic-profile/poverty-disability-canada

Crawford, C. (2013). *Looking Into Poverty: Income Sources of Poor People with Disabilities in Canada*. Toronto: Institute for Research and Development on Inclusion and Society (IRIS).

Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches* (3rd ed.). Sage.

Cuskelly, M. & Bryde, R. (2004). Attitudes towards the sexuality of adults with an intellectual disability: parents, support staff, and a community sample. *Journal of Intellectual & Developmental Disability*, 29(3), 255-264.

Dalton, A.J. & McVilly, K.R. (2004). Ethics Guidelines for International, Multicenter Research Involving People with Intellectual Disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 1, 57-70.

Daroya, E. 2018. 'Not Into Chopsticks or Curries': Erotic Capital and the Psychic Life of Racism on Grindr. Damien Riggs(Ed.) *The Psychic Life of Racism in Gay Men's Communities* (pp. 67-80). London: Lexington Books.

Deal, M. (2003). Disabled People's Attitudes toward Other Impairment Groups: A hierarchy of impairments. *Disability & Society*, 18(7), 897–910.

DeLamater, J. & Plante, R. F. (2015). *Handbook of the Sociology of Sexualities*. Dordrecht, NL: Springer.

Dickman, B. J. & Roux, A. J. (2005). Complainants with Learning Disabilities in Sexual Abuse Cases: A 10-Year Review of a Psycho-Legal Project in Cape Town, South Africa. *British Journal of Learning Disabilities*, 33(3), 138–44.

Dickson-Swift, V., James, E. L., Kippen, S., & Liamputtong, P. (2007). Doing sensitive research: What challenges do qualitative researchers face? *Qualitative Research*, 7, 327-353.

Dinwoodie R, Greenhill B, Cookson A. (2020). 'Them Two Things are What Collide Together': Understanding the Sexual Identity Experiences of Lesbian, Gay, Bisexual and Trans People Labelled with Intellectual Disability. Journal of Applied Research in Intellectual Disability, 33(1), 3-16.

Ditchman N., Kosyluk K., Lee EJ., Jones N. (2016). How Stigma Affects the Lives of People with Intellectual Disabilities: An Overview. In: Scior K., Werner S. (eds), *Intellectual Disability and Stigma*. Palgrave Macmillan, London.

Dolmage, J. (2018). *Disabled Upon Arrival: Eugenics, Immigration, and the Construction of Race and Disability*. Columbus: The Ohio State University Press.

Dupras A. & Dionne, H. (2014). The concern of parents regarding the sexuality of their child with a mild intellectual disability. *Sexologies*, 23(4), 79-83.

Eastgate, G., van Driel, M.L., Lennox, N., Scheermeyer, E. (2011). Women with Intellectual disabilities: a study of sexuality, sexual abuse and protection skills. *Australian Family Physician*, 40, 226–230.

Eastgate, G., Scheermeyer, E., Driel, M. V., & Lennox, N. G. (2012). Intellectual Disability, Sexuality and Sexual Abuse Prevention - A Study of Family Members and Support Workers. *Australian Family Physician*, 41(3), 135-139.

Elderton, A., Clarke, S., Jones, C., & Stacey, J. (2014). Telling our story: a narrative therapy approach to helping lesbian, gay, bisexual and transgender people with a learning disability identify and strengthen positive self-identity stories. *British Journal on Learning Disabilities*, 42, 301-307.

Ellis, C. (2009). *Revision: Autoethnographic reflections on life and work*. Walnut Creek: Left Coast Press.

Epstein, S. (1991). Sexuality and Identity: The Contribution of object Relations Theory to a Constructionist Sociology. *Theory & Society*, 20, 825-873.

Erickson, L. (2015). *Unbreaking Our Hearts: Cultures of Un/Desirability and the Transformative Potential of Queercrip Porn*. Dissertation. York University Toronto, Ontario.

Espiritu, Y. L. (2001). "We Don't Sleep Around Like White Girls Do": Family, Culture and Gender in Filipina American Lives. *Signs*, 26(2), 415-440.

Farrer, J. (2010). A Foreign Adventurer's Paradise? Interracial Sexuality and Alien Sexual Capital in Reform Era Shanghai. *Sexualities*, 13(1), 69–95.

Farrer, J. (2011). Global Nightscapes in Shanghai as Ethnosexual Contact Zones. *Journal of Ethnic and Migration Studies*, 37(5), 747–64.

Farrer, J. & Dale, S. (2014). Sexless in Shanghai. In A. I. Green (Ed.), *Sexual Fields: Toward a Sociology of Collective Sexual Life* (pp. 143-169). Chicago: University of Chicago Press.

Fausto-Sterling, A. (2000). *Sexing the Body: Gender Politics and the Construction of Sexuality*. New York: Basic Books.

Feely, M. (2016). Sexual surveillance and control in a community-based intellectual disability service. *Sexualities*, 19(5–6), 725–750.

Fields, J. (2005). "Children-Having-Children": Race, Innocence, and Sexuality Education." *Social Problems*, 52(4), 549-71.

Fields, J., Gilbert, J., & Miller, M. (2015). Sexuality and education: Toward the promise of ambiguity. In J. DeLamater & R. F. Plante, *Handbook of the sociology of sexualities* (p. 371–387). Springer International Publishing.

Finger, A. (1992). Forbidden Fruit. *New Internationalist*, 233, 8-10.

Fish, R. 2016. "They've Said I'm Vulnerable with Men": Doing Sexuality on Locked Wards. *Sexualities*, 19(5–6), 641–658.

Fitzgerald, C., & Withers, P. (2013). “I Don’t Know What a Proper Woman Means”: What Women with Intellectual Disability Think about Sex, Sexuality and Themselves. *British Journal of Learning Disabilities*, 41(1), 5–12.

Foucault, M. (2003). The subject and power. In P. Rabinow, & N. Rose (Eds.), *The essential Foucault: selections from essential works of Foucault, 1954-1984* (pp. 126-144). New York: New Press.

Fowler, B. (2003). Reading Pierre Bourdieu’s Masculine Domination: Notes towards an intersectional analysis of gender, culture and class. *Cultural Studies*, 17(3-4), 468–494.

Franco, G. D., Cardoso, J., & Neto, I. (2012). Attitudes towards affectivity and sexuality of people with intellectual disability. *Sexuality and Disability*, 30, 261-287.

Frawley, P. (2003). *Human relations – barriers for people with an intellectual disability living in group homes*. Paper presented at the NACs Inaugural National Accommodation and Community Support Conference, My Home, My Workplace, October 2, Victoria, Australia.

Frawley, P., & Wilson, N.J. (2016). Young people with intellectual disability talking about sexuality education and information. *Sexuality and Disability*, 34(4), 469–484.

Fritsch, K., Heynen, R., Ross, A. N., & Meulen, E. V. (2016). Disability and sex work: developing affinities through decriminalization. *Disability & Society*, 31(1), 84-99.

Frounfelker, S. A., & Bartone, A. (2020). The importance of dignity and choice for people assessed as having intellectual disabilities. *Journal of Intellectual Disabilities*. https://doi.org/10.1177/1744629520905204

Fudge Schormans, A. (2015). People with Intellectual Disabilities (Visually) Re-Imagine Care. In *Renewing Care: Critical International Perspectives on the Ethics of Care*, edited by M. Barnes, N. Ward, L. Ward and T. Brannelly, 168–182. Canada: Policy Press.

Fudge Schormans, A. & Chambon, A. (2012). The Reworking of Spatial Attribution: People with Intellectual Disabilities and the Micropolitics of Dissensus. *Review of Education, Pedagogy, and Cultural Studies*, 34(3-4), 123-135.

Fudge Schormans, A., Krause, C., MacDougall, K., Wattie, K. (2011). Self-Advocacy. In I. Brown & M. Percy (Eds.) *Developmental Disabilities in Ontario* (3rd Ed.). Toronto: University of Toronto Press.

Fudge Schormans, A. ... . (2020). Research as Activism? Perspectives of People Labelled/with Intellectual and Developmental Disabilities Engaged in Inclusive Research and Knowledge Co-Production. In *The Routledge handbook of disability activism* (pp. 354-368). New York: Routledge..

Fudge Schormans, A & Sobsey, D. (2007). Maltreatment of children with developmental disabilities. In Ivan Brown & Maire Percy (Eds.), *A* *comprehensive guide to intellectual and developmental disabilities* (1st ed., pp.467-487). Baltimore, MD: Paul H. Brookes.

Galea, J., Butler, J., & Iacono, T. (2004). The assessment of sexual knowledge in people with intellectual disability. *Journal of Intellectual and Developmental Disability*, 29, 350-365.

Garland-Thomson, R. (2002). Integrating Disability, Transforming Feminist Theory. *NWSA Journal*, 14(3), 1-32.

Garland-Thomson, R. (2005). Feminist Disability Studies. *Signs*, 30(2), 1557-1587.

Gill, M. (2010). Rethinking Sexual Abuse, Questions of Consent, and Intellectual Disability. *Sexuality Research and Social Policy*, 7(3), 201–13.

Gill, M. (2012). Sex can wait, masturbate: The politics of masturbation training. *Sexualities*, 15(3–4), 472–493.

Gill, M. (2015). *Already doing it: intellectual disability and sexual agency*. Minneapolis: University of Minnesota Press.

Gil-Llario, M. D., Morell-Mengual, V., Ballester-Arnal, R., & Díaz-Rodríguez, I. (2018). The experience of sexuality in adults with intellectual disability. *Journal of Intellectual Disability Research*, 62, 72-80.

Gilmore, L., & Chambers, B. (2010). Intellectual disability and sexuality: Attitudes of disability support staff and leisure industry employees. *Journal of Intellectual and Developmental Disability*, 35(1), 1-22.

Goffman, Erving (1959). The Presentation of Self in Everyday Life. p. 17-25. *From The Presentation of Self in. Everyday Life* (New York: The Overlook Press.

Gomez, M. T. (2012). The S words: Sexuality, sensuality, sexual expression and people with intellectual disability. *Sexuality and Disability*, 30, 237-245.

Goodley, D. (1998). Stories about writing stories. Pp. 113-127, in *Articulating with Difficulty: Research voices in special education,* edited by P. Clough and L. Barton. London, Paul Chapman.

Goodley, D. (2010). *Disability Studies: An Interdisciplinary Introduction*. Los Angeles, Calif; London: SAGE.

Gougeon, N. A. (2009). Sexuality education for students with intellectual disabilities, a critical pedagogical approach: outing the ignored curriculum. *Sex Education*, 9(3), 277-291.

Grabois, E. (2001). Guide To Getting Reproductive Health Care Services For Women With Disabilities Under The Americans With Disabilities Act of 1990. *Sexuality and Disability*, 19(3), 191-207.

Green, A. I. (2008a). Erotic Habitus: Toward a Sociology of Desire. *Theory and Society*, 37(6), 597–626.

Green, A. I. (2008b). The Social Organization of Desire: The Sexual Fields Approach. *Sociological Theory*, 26(1), 25–50.

Green, A. (2011). Playing the (Sexual) Field: The Interactional Basis of Systems of Sexual Stratification. *Social Psychology Quarterly*, 74(3), 244-266.

Green, A. I. (2014). *Sexual Fields: Toward a Sociology of Collective Sexual Life*. Chicago: University of Chicago Press.

Green, A.I. (2015). Sexual Fields. Pp. 23–39 in *Handbook of the Sociology of Sexualities*, edited by J. DeLamater and F. R. Plante. Cham: Springer International Publishing.

Greenwell, A., & Hough, S. (2008). Culture and disability in sexuality studies: A methodological and content review of literature. *Sexuality and Disability*, 26(4), 189–196.

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp.105-117). Thousand Oaks, CA: Sage.

Guillemin, M., & Gillam, L. (2004). Ethics, reflexivity, and “ethically important moments” in research. *Qualitative Inquiry*, 10, 261-280.

Guter, B. & Killacky, J. (2004). *Queer crips: Disabled gay men and their stories*. New York: Harrington Park Press.

Hall, K.Q. (2011). *Feminist disability studies*. Bloomington: Indiana University Press.

Hall, K. Q. (2015). New Conversations in Feminist Disability Studies: Feminism, Philosophy, and Borders. *Hypatia*, 30, 1-12.

Hamilton, C. (2002). Doing the wild thing: Supporting an ordinary sexual life for people with intellectual disabilities. *Disability Studies Quarterly*, 22(4), 40-59.

Healy, E., McGuire, B. E., Evans, D. S., & Carley, S. N. (2009). Sexuality and personal relationships for people with an intellectual disability. Part I: Service-user perspectives. *Journal of Intellectual Disability Research*, 53(II), 905-912.

Hennen, P. (2014). Sexual Field Theory: Some Theoretical Questions and Empirical Complications. In A. I. Green (Ed.), *Sexual Fields: Toward a Sociology of Collective Sexual Life* (pp. 71-99). Chicago: University of Chicago Press.

Herdt, G. & Howe, C. (2007). *21st Century Sexualities: Contemporary Issues in Health, Education, and Rights*. New York: Routledge.

Hollomotz, A. (2010). Sexual “vulnerability” of people with learning difficulties: a self-fulfilling prophecy, in Shuttleworth, R. & Sanders, T. (Eds.), *Sex and Disability: Politics, Identity, and Access*. Leeds: The Disability Press.

Hollomotz, A. (2011). *Learning difficulties and sexual vulnerability: A social approach*. London: Jessica Kingsley Publishers.

Hollomotz, A., & The Speakup Committee (2008). ‘May we please have sex tonight?’ – People with learning difficulties pursuing privacy in residential group settings. *British Journal of Learning Disabilities*, 37, 91-97.

Iacono, T. (2006). Ethical Challenges and Complexities of Including People with Intellectual Disability as Participants in Research. *Journal of Intellectual & Developmental Disability*, 31(3), 173–79.

Iacono, T. & Murray, V. (2003). Issues of Informed Consent in Conducting Medical Research Involving People with Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities*, 16(1), 41–51.

Ignagni, E., Fudge Schormans, A., Liddiard, K., & Runswick-Cole, K. (2016). “Some People Are Not Allowed to Love”: Intimate Citizenship in the Lives of People Labelled with Intellectual Disabilities. *Disability & Society,* 31(1), 131–35.

Ignagni, E. & Fudge Schormans, A. (2016). Reimagining Parenting Possibilities: Towards Intimate Justice. *Studies in Social Justice,* 10(2), 238-260.

Imhoff, S. (2017). Why Disability Studies Needs to Take Religion Seriously. *Religions,* 8(9), 186.

Inglis, T. (1997). Foucault, Bourdieu and the Field of Irish Sexuality. *Irish Journal of Sociology,* 7(1), 5–28.

Johnson, J. & Walmsley, K. (2003). *Inclusive Research with People with Learning Disabilities: Past, Present and Futures*. Jessica Kingsley Publishers, London.

Jungels, A. M. & Bender, A. A. (2015). Missing Intersections: Contemporary Examinations of Sexuality and Disability. Pp. 169–80 in *Handbook of the sociology of sexualities*. Springer International Publishing, Cham.

Kattari, S. (2015). “Getting it”: Identity and sexual communication for sexual and gender minorities with physical disabilities. *Sexuality & Culture,* 19(4), 882-899.

Miriam K., Silverberg, C., & Odette, F. (2007). *The Ultimate Guide to Sex and Disability: For All of Us Who Live with Disabilities, Chronic Pain and Illness*. CA: Cleis Press.

Kelly, G., Crowley, H., & Hamilton, C. (2009). Rights, sexuality and relationships in Ireland: ‘It’d be nice to be kind of trusted’. British Journal of Learning Disabilities.

Kijak, R. (2013). The Sexuality of Adults with Intellectual Disability in Poland. *Sexuality & Disability*, 31, 109–123.

King, N., & Horrocks, C. (2010). *Interviews in qualitative research*. London: Sage.

Knox, S., & Burkard, A. W. (2009). Qualitative research interviews. *Psychotherapy Research*, 19, 566–575.

Krais, B. (2006). Gender, Sociological Theory and Bourdieu’s Sociology of Practice. *Theory, Culture & Society*, 23(6), 119–134.

Kulick, Don. and Jens. Rydström. (2015). *Loneliness and Its Opposite: Sex, Disability, and the Ethics of Engagement*.

Kvale, S. (1996). *Interviews. An introduction to qualitative research interviewing*. London: SAGE.

Lai, R., Elliott, D., & Ouellette-Kuntz, H. (2006). Attitudes of Research Ethics Committee Members Toward Individuals with Intellectual Disabilities: The Need for More Research. *Journal of Policy and Practice in Intellectual Disabilities*, 3, 114-118.

Lafferty, A., McConkey, R., & Simpson, A. (2012). Reducing the barriers to relationships and sexuality education for persons with intellectual disabilities. *Journal of Intellectual Disabilities*, 16(1), 29-43.

Lam, A., Yau, M., Franklin, R.C. et al. (2019). The Unintended Invisible Hand: A Conceptual Framework for the Analysis of the Sexual Lives of People with Intellectual Disabilities. *Sexuality & Disability,* 37, 203–226.

Lamaison, P., & Bourdieu, P. (1986). From Rules to strategies: An interview with Pierre Bourdieu. *Cultural Anthropology,* 1(1), 110–120.

Lamont, L. & Molnár, V. (2002). The Study of Boundaries in the Social Sciences. *Annual Review of Sociology,* 28(1), 167-195.

Lavrakas, P. J. (2008). *Encyclopedia of survey research methods*. Thousand Oaks: Sage.

Lee, R. M. (1993). *Doing Research on Sensitive Topics*. London: Sage.

Lennox, N., M. Taylor, T. Rey-Conde, C. Bain, D. M. Purdie, and F. Boyle. 2005. Beating the Barriers: Recruitment of People with Intellectual Disability to Participate in Research.” *Journal of Intellectual Disability Research,* 49(4), 296–305.

Leschziner, V., & Green, A. (2013). Thinking about Food and Sex: Deliberate Cognition in the Routine Practices of a Field. *Sociological Theory,* 31(2), 116-144.

Lesseliers, J., & Van Hove, G. (2002). Barriers to the development of intimate relationships and the expression of sexuality among people with developmental disabilities: Their perceptions. *Research & Practice for Persons with Severe Disabilities*, 27, 69-81.

Lewis, A. and Porter, J. (2004). Interviewing children and young people with learning disabilities*: guidelines for researchers and multi-professional practice. *British Journal of Learning Disabilities*, 32, 191-197.

Librett, N., & Perrone, D. (2010). Apples and oranges: Ethnography and the IRB. Qualitative Research, 10(6), 729-747.

Liddiard, Kirsty. (2011). *(S)exploring Disability: Sexualities, Intimacies, and Disabilities*. Unpublished PhD thesis, University of Warwick.

Liddiard, Kirsty. (2013). Reflections on the Process of Researching Disabled People's Sexual Lives. *Sociological Research Online*, 18(3).

Liddiard, Kirsty. (2014). The work of disabled identities in intimate relationships. *Disability & Society,* 29(1), 115-128.

Liddiard, K. (2017). *The Intimate Lives of Disabled People*. Routledge: London.

Renwick, R., Schormans, A. F., & Shore, D. (2014). Hollywood Takes on Intellectual/Developmental Disability: Cinematic Representations of Occupational Participation. *OTJR: Occupation, Participation and Health,* 34(1), 20–31.

Liddiard, K., & Slater, J. (2018). ‘Like, pissing yourself is not a particularly attractive quality, let’s be honest’: Learning to contain through youth, adulthood, disability and sexuality. *Sexualities*, 21(3), 319–333.

Lizardo, O. (2014). Foreword. In A. I. Green (Ed.), *Sexual Fields: Toward a Sociology of Collective Sexual Life* (pp. vii-xii). Chicago: University of Chicago Press.

Loeser, C., Crowley, V., & Pini, B. (2017). *Disability and Masculinities: Corporeality, Pedagogy and the Critique of Otherness*. London, UK: Palgrave Macmillan.

Löfgren-Mårtenson, L. (2004). 'May I?' About sexuality and love in the new generation with intellectual disabilities. *Sexuality & Disability,* 22(3), 197-207.

Löfgren-Mårtenson, L. (2008). Love in Cyberspace: Swedish Young People with Intellectual Disabilities and the Internet. *Scandinavian Journal of Disability Research*, 10(2), 125-138

Löfgren-Mårtenson, L. (2013). "Hip to be Crip?" About Crip Theory, Sexuality and People with Intellectual Disabilities. *Sexuality & Disability*, 31, 413–424.

Lunsky, Y., Garcin, N., Morin, D., Cobigo, V., & Bradley, E. (2007). Mental Health Services for Individuals with Intellectual Disabilities in Canada: Findings from a National Survey. *Journal of Applied Research in Intellectual Disabilities*, 20, 439-447.

Lysaght, R., Šiška, J. and Koenig, O. (2015). International Employment Statistics. *Journal of Policy and Practice in Intellectual Disabilities*, 12, 112-119.

Malacrida, C. (2015). *A Special Hell: Institutional Life in Alberta's Eugenic Years*. Toronto: University of Toronto Press.

Martin, J. L. (2014). The Crucial Place of Sexual Judgment for Field Theoretic Inquiries. In A. I. Green (Ed.), *Sexual Fields: Toward a Sociology of Collective Sexual Life* (pp. 171-188). Chicago: University of Chicago Press.

Martin, K. A., & Kazyak, E. (2009). Hetero-Romantic Love and Heterosexiness in Children's G-Rated Films. *Gender & Society*, 23(3), 315–336.

Mattley, C. (2005). Voicing gender: The performance of gender in the context of phone sex lines, In Gagné, P. and Tewksbury, R. (Ed.), *Gendered Sexualities* (*Advances in Gender Research, Vol. 6*) (pp. 79-102). Emerald Group Publishing Limited: Bingley.

May, A. L. & Stone, C. A. (2010). Stereotypes of Individuals with Learning Disabilities: Views of College Students With and Without Learning Disabilities. *Journal of Learning Disabilities*, 43(6), 483–99.

McCall, L. (1992). 'Does gender fit? Bourdieu, feminism and conceptions of social order. *Theory and Society,* 21(6), 837-867.

McConkey, R. & Leavey, G. (2013). Irish attitudes to sexual relationships and people with intellectual disability. *Br J Learn Disabil*, 41, 181-188.

McConnell & IASSID. (2008). Parents labelled with Intellectual Disability: Position of the IASSID SIRG on Parents and Parenting with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 21, 296-307.

McCormack, B, Kavanagh, D, & Caffrey, S. (2005). Investigating sexual abuse: findings of a 15 year longitudinal study. Jo*urnal of Applied Research in Intellectual Disabilities*, 18, 217–227.

McDaniels, B., & Fleming, A. (2016). Sexuality Education and Intellectual Disability: Time to Address the Challenge. Sexuality & Disability, 34, 215–225.

McDonald, K. E., Conroy, N. E., Olick, R. S., the Project ETHICS Expert Panel. (2016). Is It Worth It? Benefits in Research With Adults With Intellectual Disability. *Intellectual & Developmental Disabilities*,, 54(6), 440–453.

McDonald, K.E., Kidney, C.A., & Patka, M. (2013). 'You need to let your voice be heard': research participants:' Views on research. *Journal on Intellectual Disability Research*, 57(3), 216-225.

McLeod, J. (2005). Feminists re-reading Bourdieu: Old debates and new questions about gender habitus and gender change. *Theory and Research in Education*, 3(1), 11–30.

McNay, L. (1999). Gender, habitus and the field. *Theory, Culture & Society*, 16(1), 95-117 .

McRuer, R. (2006). *Crip Theory: Cultural Signs of Queerness and Disability*. New York: New York University Press.

McRuer, R. (2011). Disabling Sex: Notes for a Crip Theory of Sexuality. *GLQ*, 17(1), 107–117.

McRuer, R. & Mollow, A. (2012). *Sex and disability*. Durham: Duke University Press.

McVilly, K. R., Stancliffe, R. J., Parmenter, T. R., & Burton-Smith, R. M. (2006). ‘I Get by with a Little Help from my Friends’: Adults with intellectual disability discuss loneliness. *Journal of Applied Research in Intellectual Disabilities*, 19(2), 191–203.

Mead, G.H. (1934). *Mind, Self, and Society from the Standpoint of a Social Behaviorist*. University of Chicago Press: Chicago.

Meaney-Tavares, R. & Gavidia-Payne, S. (2012). Staff characteristics and attitudes towards the sexuality of people with intellectual disability. *Journal of Intellectual & Developmental Disability*, 37(3), 269-273.

Medina-Rico, M., López-Ramos, H. & Quiñonez, A. (2018). Sexuality in People with Intellectual Disability: Review of Literature. *Sexuality & Disability*, 36, 231–248.

Miles, A. L., Nishida, A., & Forber-Pratt, A. (2017). An open letter to White disability studies and ableist institutions of higher education. *Disability Studies Quarterly*, 37(3), https://dsq-sds.org/article/view/5997/4686

Miller, C.F. (2016). Gender Development, Theories of. In *The Wiley Blackwell Encyclopedia of Gender and Sexuality Studies* (eds A. Wong, M. Wickramasinghe, R. Hoogland and N.A. Naples).

Molin, M., Sorbring, E., & Löfgren-Mårtenson, L. (2017). New Em@ncipatory Landscapes?: Young People with Intellectual Disabilities, Internet Use and Identification Processes. *Advances in Social Work*, 18(2), 645-662.

Moon, D. (2015). Sexual Fields: Toward a Sociology of Collective Sexual Life edited by Adam Isaiah Green. *American Journal of Sociology*, 120(4), 1272-1274.

Murphy, G. H., & O'Callaghan, A. (2004). Capacity of adults with intellectual disabilities to consent to sexual relationships. *Psychological Medicine*, 34, 1347-1357.

Murphy, N. & Young, P. C. (2005), Sexuality in children and adolescents with disabilities. *Developmental Medicine & Child Neurology*, 47, 640-644.

Myhill, A., & Allen, J. (2002). *Rape and Sexual Assault of Women: The Extent and Nature of the Problem. Home Office Research Study 237*. London: Home Office Research, Development and Statistics Directorate.

Naples, N. A., Mauldin, L., & Dillaway, H. (2019). From the Guest Editors: Gender, Disability, and Intersectionality. *Gender & Society*, 33(1), 5–18.

Nicholson, L., Colyer, M., & Cooper, S.A. (2013), Recruitment to intellectual disability research: a qualitative study. *Journal of Intellectual Disability Research*, 57, 647-656.

Nierse, C. J. & Abma, T. A. (2011). Developing voice and empowerment: the first step towards a broad consultation in research agenda setting. *Journal of Intellectual Disability Research*, 55, 411-421.

Nind, M. (2008). *Conducting Qualitative Research with People with Learning, Communication, and other Disabilities: Methodological Challenges*. Economic and Social Research Council National Center for Research Methods. Retrieved from: http://eprints.ncrm.ac.uk/491/1/MethodsReviewPaperNCRM-012.pdf

Nind, M. (2017). The practical wisdom of inclusive research. *Qualitative Research*, 17(3), 278–288.

Noonan, A., & Gomez, M. T. (2011). Who's Missing? Awareness of Lesbian, Gay, Bisexual and Transgender People with Intellectual Disability. *Sexuality & Disability*, 29, 175–180.

Normand, C.L. & Sallafranque-St-Louis, F. (2016). Cybervictimization of Young People With an Intellectual or Developmental Disability: Risks Specific to Sexual Solicitation. *Journal of Applied Research on Intellectual Disabilities*, 29, 99-110.

ODSP, 2018. *ODSP Rates for Income Support*. Retrieved from: https://www.odsp.info/benefit-rates.html

O'Shea, A. & Frawley, P. (2020). Gender, sexuality and relationships for young Australian women with intellectual disability. *Disability & Society*, 35(4), 654-675.

O'Toole, C. J. (2000). The View from Below: Developing a Knowledge Base about an Unknown Population. *Sexuality & Disability*, 18(3), 207-224.

O'Toole, C. J. (2015). *Fading Scars: My Queer Disability History*. Fort Worth: Autonomous Press.

O'Toole, C. J. (2013). Disclosing Our Relationships to Disabilities: An Invitation for Disability Studies Scholars. *Disability Studies Quarterly*, 33(2).

Paik, A. (2016). Sexual Fields: Toward a Sociology of Collective Sexual Life. *Contemporary Sociology*, 45(2), 181-183.

Parchomiuk, M. (2013). Model of Intellectual Disability and the Relationship of Attitudes Towards the Sexuality of Persons with an Intellectual Disability. *Sexuality & Disability*, 31(2), 125–39.

Parkes, G., & Hall, I. (2006). Gender Dysphoria and Cross-Dressing in People with Intellectual Disability: A Literature Review. *Mental Retardation*, 44(4), 260–271

Parsons, M. B., Rollyson J. H., & Reid, D. H. (2004). Improving day-treatment services for adults with severe disabilities: a norm-reference application of outcome management. *Journal of Applied Behavior Analysis*, 37(3), 365–377.

Patton, M. (2002). *Qualitative evaluation and research methods*. London: SAGE.

Plante, R. F. (2016). Book Review: Sexual Fields: Toward Sociology of Collective Sexual Life edited by Adam Isaiah Green. *Gender & Society*, 30(3), 550–552.

Plummer, K. (1995). *Telling sexual stories: Power, change, and social worlds*. London: Routledge.

Plummer, K. (2003). *Intimate citizenship: Private decisions and public dialogues*. Seattle, WA: University of Washington Press.

Pole, Christopher J. & Lampard, Richard. (2002). *Practical social investigation : qualitative and quantitative methods in social research*. Harlow, England

Pownall, J. D., Jahoda, A., & Hastings, R.P. (2012). Sexuality and sex education of adolescents with intellectual disability: mothers' attitudes, experiences, and support needs. *Intellectual & Developmental Disabilities,* 50(2), 140-154.

Priestley, M. & Rabiee, P. (2002). Same Difference? Older People's Organisations and Disability Issues. *Disability & Society*, 17(6), 597-611.

Ramazanoğlu, C., & Holland, J. (2002). *Feminist methodology: Challenges and choices*. Thousand Oaks: SAGE.

Reay, D. (1995). “They employ cleaners to do that”: Habitus in the primary school. *British Journal of Sociology of Education*, 16(3), 353-371.

Reeve, D. (2004). Psycho-emotional dimensions of disability and the social model. In C. Barnes and G. Mercer (eds), I*mplementing the Social Model of Disability: Theory and Research*, (pp. 83-100). Leeds: The Disability Press.

Rembis, M. A. (2010). Beyond the Binary: Rethinking the Social Model of Disabled Sexuality. *Sexuality & Disability*, 28(1), 51–60.

Renwick, R., Schormans, A. F., & Shore, D. (2014). Hollywood Takes on Intellectual/Developmental Disability: Cinematic Representations of Occupational Participation. *OTJR: Occupation, Participation and Health*, 34(1), 20–31.

Renzetti, C. M. & Lee, R. M. (1993). *Researching Sensitive Topics*. Newbury Park, CA: SAGE.

Ridgeway, C. L. (2009). Framed Before We Know It: How Gender Shapes Social Relations. *Gender & Society*, 23(2), 145–160.

Risman, B. J. (2009). From Doing To Undoing: Gender as We Know It. *Gender & Society*, 23(1), 81–84.

Rogers, C. (2016). Intellectual disability and sexuality: On the agenda? *Sexualities*, 19(5–6), 617–622.

Rosenfeld, M. J., & Thomas, R. J. (2012). Searching for a Mate: The Rise of the Internet as a Social Intermediary. *American Sociological Review*, 77(4), 523–547.

Rubin, G. (1984). Thinking Sex: Notes for a Radical Theory of the Politics of Sexuality In *Pleasure and Danger: Exploring Female Sexuality* (pp. 267–319), ed. Carole S. Vance. Boston: Routledge and Kegan Paul.

Rushbrooke, E., Murray, C. & Townsend, S. (2014). The Experiences of Intimate Relationships by People with Intellectual Disabilities: A Qualitative Study. Journal of Applied Research in Intellectual Disabilities, 27, 531-541.

Sallafranque-St-Louis, F., & Normand, C. L. (2017). From solitude to solicitation: How people with intellectual disability or autism spectrum disorder use the internet. Cyberpsychology: *Journal of Psychosocial Research on Cyberspace*, 11(1), Article 7.

Sanders, T. (2007). The politics of sexual citizenship: commercial sex and disability. *Disability and Society*, 22(5), 439–455.

Sankhla, D. & Theodore, K. (2015). British Attitudes Towards Sexuality in Men and Women with Intellectual Disabilities: A Comparison Between White Westerners and South Asians. *Sexuality & Disability*, 33(4), 429–45.

Santinele Martino, A. *The Role of Religion in the Intimate Lives of Adults with Intellectual Disabilities*. Under review.

Santinele Martino, A. (2014). "*It is totally a power struggle": Struggles over the sexuality of some intellectually disabled individuals in Southern Alberta*. ProQuest Dissertations Publishing.

Santinele Martino, A. (2017). Cripping sexualities: An analytic review of theoretical and empirical writing on the intersection of disabilities and sexualities. *Sociology Compass*, 11(5), e12471–n/a. https://doi.org/10.1111/soc4.12471

Santinele Martino, A. (2018). Book Review: Phallacies: Historical Intersections of Disability and Masculinity & Disability and Masculinities: Corporeality, Pedagogy and the Critique of Otherness. *Men and Masculinities*, 21(4), 576-578.

Santinele Martino, A. (2019). "It is totally a power struggle": Struggles over the sexuality of individuals with intellectual disabilities in Southern Alberta. In *Dis/consent: Perspectives on Sexual Violence and Consensuality* (pp. 98-107), edited by K. Malinen. Fernwood Press.

Santinele Martino, A. (2020). Also Here, Also Queer: The Work of Queer Disabled Activists/Scholars in "Cripping" Sexualities. In *Young, Disabled* *and LGBT+: Voices, Identities and Intersections* (pp. 13-28), edited by A. Toft, A. Franklin and E. Langley. New York: Routledge.

Santinele Martino, A. & Campbell, S. M. (2019). "Exercising Intimate Citizenship Rights and (Re)Constructing Sexualities: The New Place of Sexuality in Disability Activism." In *The New Disability Activism: Current Trends, Shifting Priorities and (Uncertain) Future Directions (*pp. 97-109), edited by M. Berghs, T. Chataika, Y. El-Lahib and K. Dube. New York: Routledge.

Santinele Martino, A, & Fudge Schormans, A. (forthcoming). Theoretical Developments: Queer Theory Meets Crip Theory. In Routledge Handbook of Disability and Sexuality, edited by R. Shuttleworth and L. Mona. Routledge.

Santinele Martino, A, & Fudge Schormans, A. (2018). When Good Intentions Backfire: University Research Ethics Review and the Intimate Lives of People Labelled with Intellectual Disabilities. *Forum: Qualitative Social Research*, 19(3):Art. 9.

Santinele Martino, A., Fudge Schormans, A., & Campbell, M. (2020). *COVID-19 has isolated disabled people from family, love, sex*. Retrieved from: https://theconversation.com/covid-19-has-isolated-disabled-people-from-family-love-sex-142262

Saumure, K. & Given, L. M. (2012). Convenience Sample. In: *The SAGE Encyclopedia of Qualitative Research Methods*. Thousand Oaks: SAGE.

Schwalbe, M., & Wolkomir, M. (2001). The Masculine Self As Problem and Resource in Interview Studies of Men. *Men and Masculinities*, 4(1), 90–103.

Schaaf, M. (2011). Negotiating Sexuality in the Convention on the Rights of Persons with Disabilities. *Sur International Journal on Human Rights,* 8(14), 113.

Schaafsma, D., Stoffelen, J.M.T., Kok, G. and Curfs, L.M.G. (2013). Exploring the Development of Existing Sex Education Programmes for People with Intellectual Disabilities: An Intervention Mapping Approach. *J Appl Res Intellect Disabil*, 26, 157-166.

Schaafsma, D., Kok, G., Stoffelen, J.M.T., & Curfs, L.M.G. (2017). People with Intellectual Disabilities Talk About Sexuality: Implications for the Development of Sex Education. *Sexuality & Disability*, 35, 21–38.

Schilt, K. & Windsor, E. (2014). The Sexual Habitus of Transgender Men: Negotiating Sexuality Through Gender. *Journal of Homosexuality*, 61(5), 732-748.

Seidman, S. (2015). *The Social Construction of Sexuality*. New York and London: W. W. Norton & Company.

Servais, L. (2006). Sexual health care in persons with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, 12, 48-56.

Shakespeare, T. (2000). Disabled sexuality: Toward rights and recognition. *Sexuality & Disability*, 18(3), 159–166.

Shakespeare, T., Gillespie-Sells, K., & Davies, D. (1996). *The sexual politics of disability: Untold desires*. London: Cassell.

Shapiro, J. (2018). *In Their Words, Adults With Intellectual Disabilities Tell Their Sexual Assault Stories*. Retrieved from: https://www.npr.org/2018/01/18/578956859/in-their-words-adults-with-intellectual-disabilities-tell-their-sexual-assault-s

Shildrick, Margrit. (2015). "Sex." In *Keywords for Disability Studies*, edited by R. Adams, B. Reiss and D. Serlin. New York: New York University Press.

Shuttleworth, R. P. (2003, September). *The case for a focus on sexual access in a critical approach to disability and sexuality research*. Paper presented at the First Disability Studies Association Conference, Lancaster, UK.

Shuttleworth, R., Wedgwood, N., & Wilson, N. J. (2012). The Dilemma of Disabled Masculinity. *Men and Masculinities*, 15(2), 174–194.

Shuttleworth, R., & Meekosha, H. (2013). The Sociological Imaginary and Disability Enquiry in Late Modernity. *Critical Sociology*, 39(3), 349–367.

Shuttleworth, R., & Sanders T. (eds). (2010). *Sex and Disability: Politics, Identity and Access*. Leeds: The Disability Press.

Siebers, T. (2008). *Disability Theory*. Ann Arbor: University of Michigan.

SIECCAN. (2010). *Sexual health education in the schools: Questions & Answers 3rd Edition*. Retrieved from: http://sieccan.org/wp-content/uploads/2018/05/SIECCAN_Q-A-Sexual-health-education-in-the-schools.pdf

Sigstad, H. M. H. (2014). Characteristic interviews, different strategies: methodological challenges in qualitative interviewing among respondents with mild intellectual disabilities. *Journal of Intellectual Disabilities*, 18, 188–202.

Skarstad, K. (2018). Human rights through the lens of disability. Netherlands *Quarterly of Human Rights*, 36(1), 24–42.

Slater, J., Ágústsdóttir, E., & Haraldsdóttir, F. (2018). Becoming intelligible woman: Gender, disability and resistance at the border zone of youth. *Feminism & Psychology*, 28(3), 409–426.

Slater, J. & Liddiard, K. (2018). Why Disability Studies Scholars Must Challenge Transmisogyny and Transphobia. *Canadian Journal of Disability Studies*, 7(2), 83-93.

Sobsey, D. (2006). Violence & disability. In W. M. Nehring (Ed.), *Health promotion for persons with intellectual/developmental disabilities: The state of scientific evidence*. Washington, DC: American Association on Mental Retardation.

Starke, M., Rosqvist, H.B., & Kuosmanen, J. (2016). Eternal Children? Professionals' Constructions of Women with an Intellectual Disability Who are Victims of Sexual Crime. *Sexuality & Disability*, 34, 315–328.

Steptoe, L., Lindsay, W. R., Forrest, D., & Power, M. (2006). Quality of Life and Relationships in Sex Offenders with Intellectual Disability. *Journal of Intellectual & Developmental Disability*, 31(1), 13–19.

Stoffelen, J., Kok, G., Hospers, H. and Curfs, L.M.G. (2013). Homosexuality among people with a mild intellectual disability: an explorative study on the lived experiences of homosexual people in the Netherlands with a mild intellectual disability. *Journal of Intellectual Disability Research*, 57, 257-267.

Stone, E., & Priestley, M. (1996). Parasites, pawns, and partners: Disability research and the role of the non-disabled researchers. *The British Journal of Sociology*, 47, 699-716.

Sullivan, F., Bowden, K., McKenzie, K. and Quayle, E. (2016). The Close Relationships of People with Intellectual Disabilities: A Qualitative Study. *J Appl Res Intellect Disabil*, 29, 172-184.

Syme, M. L., & Cohn, T. J. (2016). Examining aging sexual stigma attitudes among adults by gender, age, and generational status. *Aging Mental Health*, 20(1), 36–45.

Swaine, J., S. L. Parish, K. Luken, & L. Atkins. (2011). Recruitment and Consent of Women with Intellectual Disabilities in a Randomised Control Trial of a Health Promotion Intervention. *Journal of Intellectual Disability Research*, 55(5), 474–83.

Swango-Wilson, A. (2009). Caregiver perceptions and implications for sex education for individuals with intellectual and developmental disabilities. *Sexuality and Disability*, 26(2), 75-81.

Swindler, A. (1986). Culture in Action: Symbols and Strategies. In *American Sociological Review*, 51(5), 273-286.

Taleporos, G., & McCabe, M.P. (2001). The Impact of Physical Disability on Body Esteem. *Sexuality & Disability*, 19, 293–308.

Taylor, V. (2014). Preface. In A. I. Green (Ed.), *Sexual Fields: Toward a Sociology of Collective Sexual Life* (pp. xii-xv). Chicago: University of Chicago Press.

Thomas, C 2002, Disability theory : key ideas, issues and thinkers. in C Barnes, M Oliver & L Barton (eds), *Disability studies today.* Polity Press, Cambridge, pp. 38-57.

Thomas, C. (2004). How is disability understood? An examination of sociological approaches. *Disability and Society*, 19(6), 569-583.

Thomas, C. (2006). Disability and Gender: Reflections on Theory and Research. *Scandinavian Journal of Disability Research*, 8(2-3), 177–185.

Thompson, D. (2001). "Is Sex a Good Thing for Men with Learning Disabilities?" *Tizard Learning Disability Review*,6(1), 4-12.

Thorpe, H. (2009). Bourdieu, feminism and female physical culture: Gender reflexivity and the habitus-field complex. *Sociology of Sport Journal*, 26(4), 491-516.

Tolman, D. L. (2002). *Dilemmas of desire: Teenage girls talk about sexuality*. Harvard University Press.

Turner, G. W., & Crane, B. (2016). Pleasure is paramount: Adults with intellectual disabilities discuss sensuality and intimacy. *Sexualities*, 19(5–6), 677–697.

United Nations. (2006). *Convention on the rights of persons with disabilities*. New York, NY

United Nations Committee on the Rights of Persons with Disabilities . (2014). *General Comment no. 1*. Retrieved from https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement

Valocchi, S. 1999. The Class-Inflected Nature of Gay Identity. *Social Problems*, 47, 207-224.

Wade, L. 2019. Doing Casual Sex: A Sexual Fields Approach to the Emotional Force of Hookup Culture. *Social Problems*, https://doi.org/10.1093/socpro/spz054

Walby, S. (2005). The sociology of gender relations. In C. Calhoun, C. Rojek, & B. Turner (Eds.), *The Sage handbook of sociology* (pp. 367–380). London: Sage.

Ward, T., & Stewart, C. (2008). Putting Human Rights into Practice with People with an Intellectual Disability. *Journal of Developmental and Physical Disabilities*, 20, 297–311.

Wark, S., Hussain, R., & Edwards, H. (2013). Rural and Remote Area Service Provision. *Journal of Policy and Practice in Intellectual Disabilities*, 10, 62-70.

Waxman, B. F., & Finger, A. (1991). The politics of sexuality, reproduction and disability: Sexuality Update. *National Task Force on Sexuality and Disability*, 4(1), 1-3.

Williams, C.J., Weinberg, M.S., & Rosenberger, J.G. (2013). Trans Men: Embodiments, Identities, and Sexualities. *Sociological Forum*, 28, 719-741.

Weinberg, M. S. & Williams, C. J. (2014). Sexual Field, Erotic Habitus, and Embodiment at a Transgender Bar. In A. I. Green (Ed.), *Sexual Fields: Toward a Sociology of Collective Sexual Life* (pp. 57-69). Chicago: University of Chicago Press.

Wendell, S. (1996). *The Rejected Body: Feminist Philosophical Reflections on Disability*. London: Routledge & Kegan Paul.

Wennberg B, & Kjellberg A. (2010). Participation when using cognitive assistive devices--from the perspective of people with intellectual disabilities. *Occup Ther Int*, 17(4), 168-176.

Whittle C, & Butler C. (2018). Sexuality in the lives of people with intellectual disabilities: A meta-ethnographic synthesis of qualitative studies. *Research in Developmental Disabilities*, 75, 68-81.

Wilkenfeld, B. F., & Ballan, M. S. (2011). Educators' attitudes and beliefs towards the sexuality of individuals with developmental disabilities. *Sexuality & Disability*, 29(4), 676-684.

Wilkerson, A. (2002). Disability, Sex Radicalism, and Political Agency. *NWSA Journal*, 14(3), 33–57.

Wilkinson, V.J., Theodore, K. & Raczka, R. (2015). 'As Normal as Possible': Sexual Identity Development in People with Intellectual Disabilities Transitioning to Adulthood. *Sexuality & Disability*, 33, 93–105.

Willey, R. D. (2010). *Discovering the Evangelical Sexual Marketplace: An Ethnographic Analysis of the Development, Exchange, and Conversion of Erotic Capital in an Evangelical Church* (Master's thesis). University of Alberta, Edmonton, AB.

Wilson, N. J., Parmenter, T. R., Stancliffe, R. J., Shuttleworth, R. P., & Parker, D. (2010). A masculine perspective of gendered topics in the research literature on males and females with intellectual disability. *Journal of Intellectual and Developmental Disability*, 35, 1–8.

Wilson, N. J., Shuttleworth, R., Stancliffe, R., & Parmenter, T. (2012). Masculinity Theory in Applied Research with Men and Boys with Intellectual Disability. *Intellectual & Developmental Disabililities*, 50(3), 261–272.

Wilson, N. J., Parmenter, T. R., Stancliffe, R. J., & Shuttleworth, R. P. (2013). From diminished men to conditionally masculine: sexuality and Australian men and adolescent boys with intellectual disability. *Culture, Health & Sexuality*, 15(6), 738-751.

Wilton, R. & Fudge Schormans, A. (2020). 'I think they're treating me like a kid': intellectual disability, masculinity and place in Toronto. Canada, *Gender, Place & Culture*, 27(3), 429-451.

Winges-Yanez, N. (2014). Why All the Talk About Sex? An Authoethnography Identifying the Troubling Discourse of Sexuality and Intellectual Disability. *Sexuality & Disability*, 32, 107–116.

Young, R., Gore, N., McCarthy, M. (2012). Staff attitudes towards sexuality in relation to gender of people with intellectual disability: A qualitative study. *Journal of Intellectual and Developmental Disability*, 37, 343–347.

Appendix A: Recruitment Email Script (Self-Advocacy Groups)

Sample E-mail Subject Line: McMaster study about the romantic and sexual lives of people with intellectual disabilities

Email Subject Body:

Hello,

My name is Alan Santinele Martino. I am a Ph.D. student in the Department of Sociology at McMaster University. As a part of my research, I am doing interviews with adults with intellectual disabilities about their romantic and sexual lives.

The goal of this project is to give people with intellectual disabilities a space to talk about their romantic and sexual lives. This space will let people with intellectual disabilities to talk about what is good and not so good in their romantic and sexual lives. I want to learn what could help people with intellectual disabilities to have safe and pleasing romantic and sexual lives.

If someone agrees to be in the study, I will interview them for around 1 hour. The interview will take place at a location we both agree on. The interview will be informal. People must choose to be part of the study. No one else can make people agree to the interview if they do not want to.

In this email I have sent:

- The *letter of information* with more details about the study
- The *research poster* with my contact information

Feel free to pass on the message below to the self-advocates in your group.

Please do contact me with any questions or suggestions you have about the project.

Sincerely,

Alan

-------------------- Message to be passed on to Self-Advocates----------------------

Alan Santinele Martino asked us to tell you about his study on the romantic and sexual lives of people with intellectual disabilities. Alan is a sociology graduate student at McMaster University in Hamilton, Ontario.

Alan would like to interview you. The interview will take around 1 hour. He will work out the details with you. He wants to learn about your views with love and intimacy.

This includes questions like:

- What do you look for in a romantic or sexual partner [boyfriend, girlfriend]?
- Where do you go to find a romantic or sexual partner [boyfriend, girlfriend]?
- How do you go about meeting potential romantic or sexual partners [boyfriend, girlfriend] and forming relationships?
- What kinds of supports or barriers have you faced in having the romantic or sexual life you want?

If you are interested in participating in this study or want more information about it, please ***contact Alan directly*****: Tel: 905-745-2965** or **santina@mcmaster.ca**.

Alan will not tell me or anyone at _________________________ if you were interviewed or not. This research is *not* being funded by any service agency. If you want to be interviewed, or not, there will be *no* effect on any services that you receive.

Alan has said that you can leave the study at any time during the interview. You can choose not to answer questions that you are not comfortable with and still be interviewed. He has asked me to give you a copy of his information letter and recruitment poster. The letter and poster have more details about his study.

This study has been reviewed and cleared by the McMaster Research Ethics Board. If you have questions or concerns about your rights as a participant or how the study is being conducted, you may contact:

McMaster Research Ethics Board Secretariat
Telephone: (905) 525-9140 ext. 23142
Gilmour Hall – Room 305 (ROADS)
E-mail: ethicsoffice@mcmaster.ca

Sincerely,

Appendix B: Recruitment Email Script (Service Providers)

E-mail Subject Line: McMaster study about the romantic and sexual lives of people with intellectual disabilities

Email Subject Body:

Hello,

My name is Alan Santinele Martino. I am a Ph.D. student in the Department of Sociology at McMaster University. As a part of my research, I am doing interviews with adults with intellectual disabilities about their romantic and sexual lives.

The goal of this project is to give people with intellectual disabilities a space to talk about their romantic and sexual lives. This space will let people with intellectual disabilities to talk about what is good and not so good in their romantic and sexual lives. I want to learn what could help people with intellectual disabilities to have safe and pleasing romantic and sexual lives.

If someone agrees to be in the study, I will interview them for around 1 hour. The interview will take place at a location we both agree on. The interview will be informal. People must choose to be part of the study. No one else can make people agree to the interview if they do not want to.

In this email I have sent:

- The *letter of information* with more details about the study
- The *research poster* with my contact information

Feel free to pass on the message below to the clients and staff in your organization.

Please do contact me with any questions or suggestions you have about the project.

Sincerely,

Alan

--------------------- Message to be passed on to Self-Advocates--------------------

Alan Santinele Martino asked us to tell you about his study on the romantic and sexual lives of people with intellectual disabilities. Alan is a sociology graduate student at McMaster University in Hamilton, Ontario.

Alan would like to interview you. The interview will take around 1 hour. He will work out the details with you. He wants to learn about your views with love and intimacy.

This includes questions like:

- What do you look for in a romantic or sexual partner [boyfriend, girlfriend]?
- Where do you go to find a romantic or sexual partner [boyfriend, girlfriend]?
- How do you go about meeting potential romantic or sexual partners [boyfriend, girlfriend] and forming relationships?
- What kinds of supports or barriers have you faced in having the romantic or sexual life you want?

If you are interested in participating in this study or want more information about it, please ***contact Alan directly*****:** **Tel: 905-745-2965** or **santina@mcmaster.ca**.

Alan will not tell me or anyone at _________________________ if you were interviewed or not. This research is *not* being funded by any service agency. If you want to be interviewed, or not, there will be *no* effect on any services that you receive.

Alan has said that you can leave the study at any time during the interview. You can choose not to answer questions that you are not comfortable with and still be interviewed. He has asked me to give you a copy of his information letter and recruitment poster. The letter and poster have more details about his study.

This study has been reviewed and cleared by the McMaster Research Ethics Board. If you have questions or concerns about your rights as a participant or how the study is being conducted, you may contact:

McMaster Research Ethics Board Secretariat
Telephone: (905) 525-9140 ext. 23142
Gilmour Hall – Room 305 (ROADS)
E-mail: ethicsoffice@mcmaster.ca

Sincerely,

Appendix C: Recruitment Email Script (Parent-Led Groups)

Sample E-mail Subject Line: McMaster study about the romantic and sexual lives of people with intellectual disabilities

Email Subject Body:

Hello,

My name is Alan Santinele Martino. I am a Ph.D. student in the Department of Sociology at McMaster University. As a part of my research, I am doing interviews with adults with intellectual disabilities about their romantic and sexual lives.

The goal of this project is to give people with intellectual disabilities a space to talk about their romantic and sexual lives. This space will let people with intellectual disabilities to talk about what is good and not so good in their romantic and sexual lives. I want to learn what could help people with intellectual disabilities to have safe and pleasing romantic and sexual lives.

If someone agrees to be in the study, I will interview them for around 1 hour. The interview will take place at a location we both agree on. The interview will be informal. People must choose to be part of the study. No one else can make people agree to the interview if they do not want to.

In this email I have sent:

- The *letter of information* with more details about the study
- The *research poster* with my contact information

Feel free to pass on the message below to the clients, parents, and staff in your organization.

Please do contact me with any questions or suggestions you have about the project.

Sincerely,

Alan

-------------------- Message to be passed on to Self-Advocates---------------------

Alan Santinele Martino asked us to tell you about his study on the romantic and sexual lives of people with intellectual disabilities. Alan is a sociology graduate student at McMaster University in Hamilton, Ontario.

Alan would like to interview you. The interview will take around 1 hour. He will work out the details with you. He wants to learn about your views with love and intimacy.

This includes questions like:

- What do you look for in a romantic or sexual partner [boyfriend, girlfriend]?
- Where do you go to find a romantic or sexual partner [boyfriend, girlfriend]?
- How do you go about meeting potential romantic or sexual partners [boyfriend, girlfriend] and forming relationships?
- What kinds of supports or barriers have you faced in having the romantic or sexual life you want?

If you are interested in participating in this study or want more information about it, please **contact Alan directly:** **Tel: 905-745-2965** or **santina@mcmaster.ca**.

Alan will not tell me or anyone at ________________________ if you were interviewed or not. This research is *not* being funded by any service agency. If you want to be interviewed, or not, there will be *no* effect on any services that you receive.

Alan has said that you can leave the study at any time during the interview. You can choose not to answer questions that you are not comfortable with and still be interviewed. He has asked me to give you a copy of his information letter and recruitment poster. The letter and poster have more details about his study.

This study has been reviewed and cleared by the McMaster Research Ethics Board. If you have questions or concerns about your rights as a participant or how the study is being conducted, you may contact:

McMaster Research Ethics Board Secretariat
Telephone: (905) 525-9140 ext. 23142
Gilmour Hall – Room 305 (ROADS)
E-mail: ethicsoffice@mcmaster.ca

Sincerely,

Appendix D: Recruitment Poster

McMaster University

We know that
people with
intellectual disabilities
rarely have a space to share their
experiences with romance and intimacy

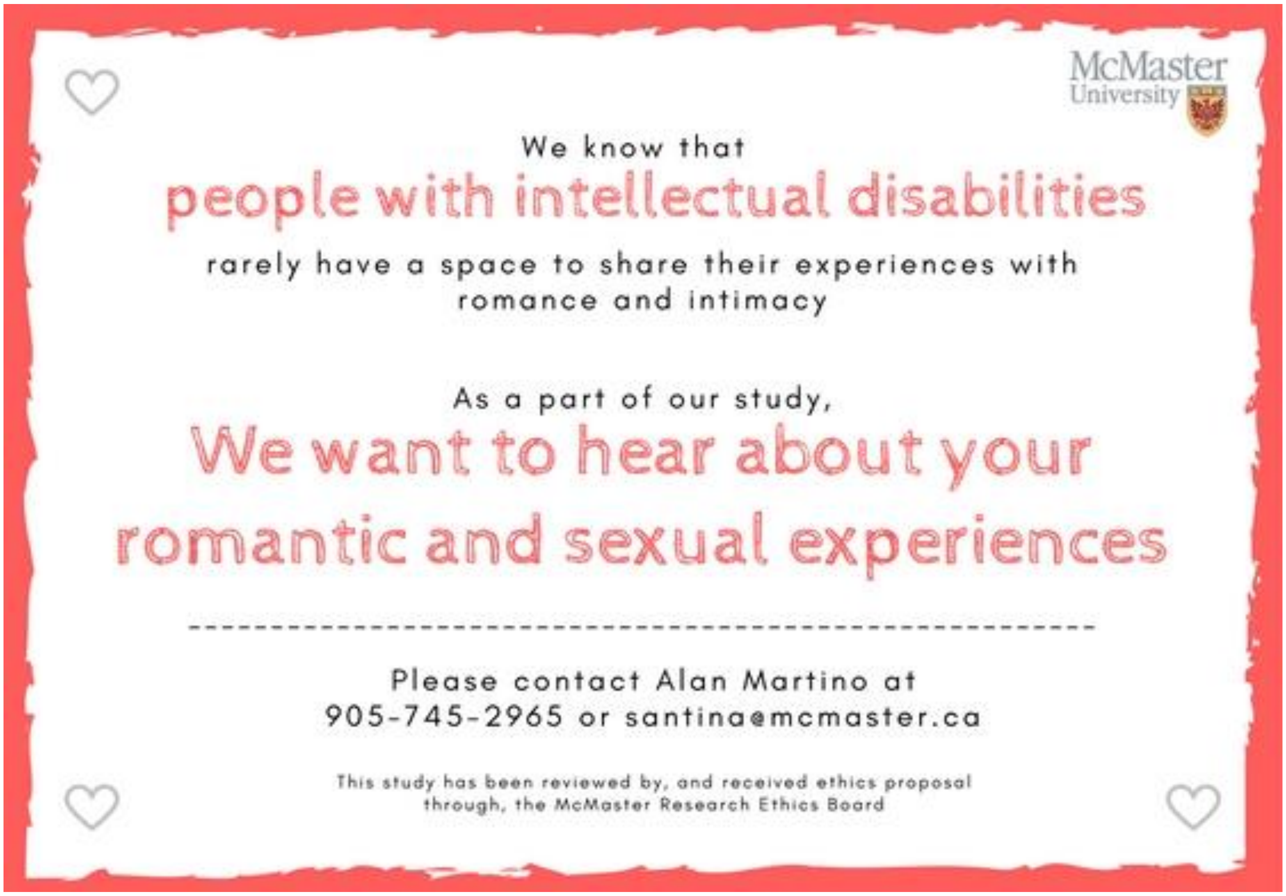
As a part of our study,
We want to hear about
your romantic and
sexual experiences

Participation will involve a 1-hour interview

Please contact Alan Martino at
905-745-2965 or santina@mcmaster.ca

This study has been reviewed by, and received ethics proposal through, the McMaster Research Ethics Board

Appendix E: Recruitment Postcard



McMaster
University

We know that

people with intellectual disabilities

rarely have a space to share their experiences with
romance and intimacy

As a part of our study,

We want to hear about your romantic and sexual experiences

Please contact Alan Martino at
905-745-2965 or santina@mcmaster.ca

This study has been reviewed by, and received ethics proposal
through, the McMaster Research Ethics Board

Appendix F: Sample Letter of Information / Consent Form

DATE: ________

LETTER OF INFORMATION / CONSENT

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

Principal Investigator:
Alan Santinele Martino
Department of Sociology

McMaster University
Hamilton, Ontario, Canada
(905) 745-2965
E-mail: santina@mcmaster.ca

Faculty Supervisor:
Dr. Melanie Heath
Department of Sociology

McMaster University
Hamilton, Ontario, Canada
(905) 525-9140 ext. 23620
Email: mheath@mcmaster.ca

The study:
You are invited to join my research project. If you agree, I will interview you. I will ask you about your romantic and sexual lives. I will talk to other people with intellectual disabilities about these same experiences. This research project will give people with intellectual disabilities a chance to talk about their romantic and sexual lives. I will write about the happy, sad, and angry times people with intellectual disabilities have in their romantic and sexual lives.

Who am I?
I am Alan Santinele Martino. I am a graduate student in the Department of Sociology at McMaster University in Hamilton, Ontario. I have done research about disability and sexuality since my undergrad. My past work with people with intellectual disabilities made me want to learn more about disability and sexuality.

What will happen during the study?

1. I will tell you about my project.
2. I will ask if you want to be interviewed.
3. If you agree, we will agree on a time and place for me to interview you.
4. The interview will take 1 hour.
5. The interview will be informal.
6. I will ask if I can record the interview. The recording will help me to not forget anything important.

7. I will also take notes by hand.

What do we talk about during the interview?
I will ask you about your romantic and sexual experiences. Some questions may be:

- What do you look for in a romantic/sexual partner [boyfriend, girlfriend]?
- Where do you go to find a romantic/sexual partner [boyfriend, girlfriend]?
- How do you go about meeting potential romantic/sexual partners [boyfriend, girlfriend]?
- How do you form and maintain romantic/sexual relationships?
- What kinds of supports have you faced in accessing the romantic/sexual life you want?
- What kinds of barriers have you faced in accessing the romantic/sexual life you want?

Are there any risks to doing this study?
It is not likely that bad things will happen if you choose to be interviewed. You might feel uncomfortable answering some questions that are asked. I also know talking about past relationships and sexual life can hard at times. You do not have to answer any questions that make you uncomfortable or that you do not want to answer. You can end the interview at any time without any consequences.

If I do or ask something that makes you feel uncomfortable, please tell me. I will change what I am doing or asking.

Are there good things about the study?
Being interviewed will not change your life or change the services you receive. Being interviewed will let you tell non-disabled people what is important to you when it comes to your romantic and sexual life. You may feel happy after telling me your story. However, if you feel upset, I hope that you will let me know. I can help you find someone to talk to. I can also help you make a plan for finding agencies who can provide you with support.

What do I do with all the information you share with me?
1. I will listen to what you and the others tell me.
2. After looking over what I was told, I will make connections between different peoples romantic and sexual lives.
3. I will write my dissertation, which is a long research paper. This is part of my graduate program at McMaster University.
4. I will write articles about the experiences people talked about in the study.

5. I will make presentations to universities, agencies, policy-makers, and other people interested in the project.

Your personal information will not be in articles or presentations.

I hope that by sharing the views in these ways, non-disabled people will learn about issues that are important to people with intellectual disabilities. I hope that academics, service providers, family members will better understand the issues people with intellectual disabilities have with sexuality and relationships. I want these people to learn how to support people with intellectual disabilities to have satisfying romantic and sexual lives.

Who will know what you said in the study?
Sometimes, when people read or hear a story, they can tell who the story is about. Please, keep this in mind during the interview. You can tell anyone you like about the interview. I will not tell anyone you were interviewed. I will treat what you say or write as confidential. Only my supervisor (Dr. Melanie Heath) and I will be able to see or read what you said during the interview. I will not use your name in any articles or presentations about this study.

If you allow me, I will record our interview. I will listen to the interview and transcribe it. This means I will type out the interview onto a document that I can read. When I type up the interview it will be anonymized. This means I won’t include your name. Instead, I will use a fake name. I will give fake names of people, places and organizations that you talk about. This will protect your identity and keep your personal information private. If you wish to see the written document of your interview, you can ask me for it.

I will keep any notes, recordings, or transcripts private. They will be locked in a cabinet in my home office. Any notes on my computer will have a password. The information shared in the interviews will be available only to me and my supervisor (Dr. Melanie Heath) who is bound by ethical protocols to maintain confidentiality and anonymity. I will only share anonymized interview transcripts with my supervisor. Once the study is finished, I will the destroy the recordings and notes. I will keep the anonymized interview transcripts for 5 years.

b) Legally Required Disclosure:
I will do my best to protect details from our interview. I may have to report details to the authorities to protect your health or safety. If you tell me about illegal situations (for example, sexual abuse), I need to report these details to the appropriate persons. I will do my best to protect your interests if I have to tell the authorities.

What happens if you don't want to be interviewed or if you change your mind later?
It is your choice to be part of the study. No one else can make you agree to be interviewed. If you want to be interviewed, you can ask to stop at any time. If you already signed the consent form, or are have started the interview you can ask to stop. If you ask to stop at any time I will not ask you anymore questions. You can ask to skip certain questions if you are uncomfortable.

You can tell me that you do not want to be in the study anymore at any time during the interview. Just let me know that you no longer wish to be a part of this study and we can end the interview.

You can also tell me that you do not want to be in the study anymore after the interview. You can let me know by sending me an email, or sending me a letter, or calling me on the phone. You can find my contact information in this letter. If you want to stop the interview any information you shared will be deleted, unless you say otherwise. You can tell me not to include your interview up until December 31st, 2017.

This study is not being funded by any human services agency. Your decision to join the study or not to join the study will not affect your access to any services you are receiving. If you choose to leave this study, any information you have provided me will be destroyed, unless you tell me not to.

How do you find out what was learned in this study?
I plan to be done with the study by August 2018. If you would like a brief summary of the results, let me know how to send it to you.

☐ Please send me a copy of the final report.

☐ Please send me plain language summaries of other articles published from this study.

Name:
Address:
Telephone:
Email:

Can you contact me if you have more questions?
You can **email** me at santina@mcmaster.ca Or you can call me on the phone. My phone number is **(905) 745-2965.**

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

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

Consent Form

I have read the details in the information letter about a study being conducted by Alan Santinele Martino, of McMaster University. I have had the chance to ask questions about my part in this study. I have also had the chance to receive any extra details I wanted to know about the study.

1.

- I agree to be interviewed in this study.
- I understand that I may skip any question I do not want to answer.
- I know I do not have to answer questions that make me uncomfortable.
- I understand that I can choose to stop the study at any time.
- I have been given a copy of this form.

☐ **YES**

☐ **NO**

2.

- I consent to being **audio-recorded** during the interview.
- I understand that this is so that Alan can be sure he correctly understands my answers to his questions – that he gets it right.

☐ **YES**

☐ **NO**

3. I agree to be contacted about a possible follow-up interview, and understand that I can say no to that.

☐ **YES** Please contact me at ____________________________________

☐ **NO**

Participant Name: ____ (Please print)

Participant Signature: ____

Date: ______________________

Appendix G: Sample Assent Form

LETTER OF INFORMATION / ASSENT

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

Principal Investigator:
Alan Santinele Martino
Department of Sociology

McMaster University
Hamilton, Ontario, Canada
(905) 745-2965
E-mail: santina@mcmaster.ca

Faculty Supervisor:
Dr. Melanie Heath
Department of Sociology

McMaster University
Hamilton, Ontario, Canada
(905) 525-9140 ext. 23620
Email: mheath@mcmaster.ca

The study:
You are invited to join my research project. If you agree, I will interview you. I will ask you about your romantic and sexual lives. I will talk to other people with intellectual disabilities about these same experiences. This research project will give people with intellectual disabilities a chance to talk about their romantic and sexual lives. I will write about the happy, sad, and angry times people with intellectual disabilities have in their romantic and sexual lives.

Who am I?
I am Alan Santinele Martino. I am a graduate student in the Department of Sociology at McMaster University in Hamilton, Ontario. I have done research about disability and sexuality since my undergrad. My past work with people with intellectual disabilities made me want to learn more about disability and sexuality.

What will happen during the study?

8. I will tell you about my project.
9. I will ask if you want to be interviewed.
10. If you agree, we will agree on a time and place for me to interview you.
11. The interview will take 1 hour.
12. The interview will be informal.
13. I will ask if I can record the interview. The recording will help me to not forget anything important.

14. I will also take notes by hand.

What do we talk about during the interview?
I will ask you about your romantic and sexual experiences. Some questions may be:

- What do you look for in a romantic/sexual partner [boyfriend, girlfriend]?
- Where do you go to find a romantic/sexual partner [boyfriend, girlfriend]?
- How do you go about meeting potential romantic/sexual partners [boyfriend, girlfriend]?
- How do you form and maintain romantic/sexual relationships?
- What kinds of supports have you faced in accessing the romantic/sexual life you want?
- What kinds of barriers have you faced in accessing the romantic/sexual life you want?

Are there any risks to doing this study?
It is not likely that bad things will happen if you choose to be interviewed. You might feel uncomfortable answering some questions that are asked. I also know talking about past relationships and sexual life can hard at times. You do not have to answer any questions that make you uncomfortable or that you do not want to answer. You can end the interview at any time without any consequences.

If I do or ask something that makes you feel uncomfortable, please tell me. I will change what I am doing or asking.

Are there good things about the study?
Being interviewed will not change your life or change the services you receive. Being interviewed will let you tell non-disabled people what is important to you when it comes to your romantic and sexual life. You may feel happy after telling me your story. However, if you feel upset, I hope that you will let me know. I can help you find someone to talk to. I can also help you make a plan for finding agencies who can provide you with support.

What do I do with all the information you share with me?

6. I will listen to what you and the others tell me.
7. After looking over what I was told, I will make connections between different peoples romantic and sexual lives.
8. I will write my dissertation, which is a long research paper. This is part of my graduate program at McMaster University.
9. I will write articles about the experiences people talked about in the study.

10. I will make presentations to universities, agencies, policy-makers, and other people interested in the project.

Your personal information will not be in articles or presentations.

I hope that by sharing the views in these ways, non-disabled people will learn about issues that are important to people with intellectual disabilities. I hope that academics, service providers, family members will better understand the issues people with intellectual disabilities have with sexuality and relationships. I want these people to learn how to support people with intellectual disabilities to have satisfying romantic and sexual lives.

Who will know what you said in the study?
Sometimes, when people read or hear a story, they can tell who the story is about. Please, keep this in mind during the interview. You can tell anyone you like about the interview. I will not tell anyone you were interviewed. I will treat what you say or write as confidential. Only my supervisor (Dr. Melanie Heath) and I will be able to see or read what you said during the interview. I will not use your name in any articles or presentations about this study.

If you allow me, I will record our interview. I will listen to the interview and transcribe it. This means I will type out the interview onto a document that I can read. When I type up the interview it will be anonymized. This means I won't include your name. Instead, I will use a fake name. I will give fake names of people, places and organizations that you talk about. This will protect your identity and keep your personal information private. If you wish to see the written document of your interview, you can ask me for it.

I will keep any notes, recordings, or transcripts private. They will be locked in a cabinet in my home office. Any notes on my computer will have a password. The information shared in the interviews will be available only to me and my supervisor (Dr. Melanie Heath) who is bound by ethical protocols to maintain confidentiality and anonymity. I will only share anonymized interview transcripts with my supervisor. Once the study is finished, I will the destroy the recordings and notes. I will keep the anonymized interview transcripts for 5 years.

b) Legally Required Disclosure:
I will do my best to protect details from our interview. I may have to report details to the authorities to protect your health or safety. If you tell me about illegal situations (for example, sexual abuse), I need to report these details to the appropriate persons. I will do my best to protect your interests if I have to tell the authorities.

What happens if you don't want to be interviewed or if you change your mind later?

It is your choice to be part of the study. No one else can make you agree to be interviewed. If you want to be interviewed, you can ask to stop at any time. If you already signed the consent form, or are have started the interview you can ask to stop. If you ask to stop at any time I will not ask you anymore questions. You can ask to skip certain questions if you are uncomfortable.

You can tell me that you do not want to be in the study anymore at any time during the interview. Just let me know that you no longer wish to be a part of this study and we can end the interview.

You can also tell me that you do not want to be in the study anymore after the interview. You can let me know by sending me an email, or sending me a letter, or calling me on the phone. You can find my contact information in this letter. If you want to stop the interview any information you shared will be deleted, unless you say otherwise. You can tell me not to include your interview up until December 31st, 2017.

This study is not being funded by any human services agency. Your decision to join the study or not to join the study will not affect your access to any services you are receiving. If you choose to leave this study, any information you have provided me will be destroyed, unless you tell me not to.

How do you find out what was learned in this study?

I plan to be done with the study by August 2018. If you would like a brief summary of the results, let me know how to send it to you.

☐ Please send me a copy of the final report.

☐ Please send me plain language summaries of other articles published from this study.

Name:
Address:
Telephone:
Email:

Can you contact me if you have more questions?

You can **email** me at santina@mcmaster.ca Or you can call me on the phone. My phone number is **(905) 745-2965.**

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

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

Consent Form

I have read the details in the information letter about a study being conducted by Alan Santinele Martino, of McMaster University. I have had the chance to ask questions about my part in this study. I have also had the chance to receive any extra details I wanted to know about the study.

2.

- I agree to be interviewed in this study.
- I understand that I may skip any question I do not want to answer.
- I know I do not have to answer questions that make me uncomfortable.
- I understand that I can choose to stop the study at any time.
- I have been given a copy of this form.

☐ **YES**

☐ **NO**

2.

- I consent to being **audio-recorded** during the interview.
- I understand that this is so that Alan can be sure he correctly understands my answers to his questions – that he gets it right.

☐ **YES**

☐ **NO**

3. I agree to be contacted about a possible follow-up interview, and understand that I can say no to that.

☐ **YES** Please contact me at
____

☐ **NO**

Participant Name:
____ (Please print)

Participant Signature:
____

Date: _______________________

Appendix H: Sample Consent Form (Legal Guardian of Participant Signing an Assent Form)

DATE: ________

LETTER OF INFORMATION / CONSENT

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

Principal Investigator:	**Faculty Supervisor:**
Alan Santinele Martino	Dr. Melanie Heath
Department of Sociology	Department of Sociology
McMaster University	McMaster University
Hamilton, Ontario, Canada	Hamilton, Ontario, Canada
(905) 745-2965	(905) 525-9140 ext. 23620
E-mail: santina@mcmaster.ca	Email: mheath@mcmaster.ca

The study:
I would like to invite _________________________ to participate in an interview for my research project. I will ask _________________________ about their romantic and sexual lives. I will talk to other people with intellectual disabilities about these same experiences. This research project will give people with intellectual disabilities a chance to talk about their romantic and sexual lives. I will write about the happy, sad, and angry times people with intellectual disabilities have in their romantic and sexual lives.

Please find attached a copy of the letter of information / assent, which will be given to _________________________.

Who am I?
I am Alan Santinele Martino. I am a graduate student in the Department of Sociology at McMaster University in Hamilton, Ontario. I have done research about disability and sexuality since my undergrad. My past work with people with intellectual disabilities made me want to learn more about disability and sexuality.

What will happen during the study?
First, I am going to spend a few minutes telling you about my project. I will then ask you if you agree with ________________________’s participation in the

research. If you agree, I will interview ________________________. The interview should take 1 hour. The interview will take place at a location agreed to by both of us. It will be relatively informal. If you agree, I will record what he/she tells me on an audio recorder so that I can make sure I do not forget any of the important information that ________________________share and that I understood it correctly. I will also take handwritten notes during the interview.

What will I talk about with him/her during the interview?
I want to learn about ________________________'s romantic and sexual experiences. This includes questions like:

- What do you look for in a romantic/sexual partner [boyfriend, girlfriend]?
- Where do you go to find a romantic/sexual partner [boyfriend, girlfriend]?
- How do you go about meeting potential romantic/sexual partners [boyfriend, girlfriend]?
- How do you form and maintain romantic/sexual relationships?
- What kinds of supports have you faced in accessing the romantic/sexual life you want?
- What kinds of barriers have you faced in accessing the romantic/sexual life you want?

Are there any risks to doing this study?
It is not very likely that anything bad will happen if he/she chooses to participate in the study. He/she might feel uncomfortable answering some questions that are asked. I also know that discussing previous relationships and sexual life can sometimes be difficult and that talking about them can be potentially painful. Please know that he/she does not have to answer any questions that make him/her uncomfortable or that he/she does not want to answer. He/she can also end the interview at any time he/she wishes without any consequences.

My goal is to have a conversation with ________________________ about his/her experiences of love and intimacy. If there is anything that I do or ask that makes him/her feel uncomfortable, he/she can tell me, and I can change what I am doing.

What good things could happen if he/she participates in the study?
Participating in this study will not change ________________________'s life or change the services he/she receives. Participating in the study will give him/her an opportunity to tell non-disabled people about what is important to him/her when it comes to his/her romantic and sexual life. He/She may indeed feel pleased and positive after telling me his/her story. However, if he/she feels upset, I hope that he/she will let me know. I can help to provide someone to talk with him/her. I can also give him/her a list of agencies that can provide him/her with more supports.

What do I do with all of the information he/she shares with me?
I will be listening to everything he/she and the other participants tell me and will make conclusions from all of these interviews. I will write my dissertation as a part of my current graduate program at McMaster University. I will also write articles about the views and experiences of the people who participated in the study. I will also make presentations to universities, agencies, policy-makers, and other people interested in the project. No personal information about _________________________ will be attached to these articles and presentations.

I hope that by sharing the information in these ways, non-disabled people will have a better understanding about the issues that are important to people with intellectual disabilities. I hope that what is learned in this study will help other people like academics, service providers, family members, to understand some of the issues surrounding sexuality and relationships for adults with intellectual disabilities. I also want them to learn what is needed for people with intellectual disabilities to have satisfying romantic and sexual lives.

Who will know what he/she said in the study?
I will remind _________________________ that sometimes, if people read or hear a story, they can identify or know whose story it is, and thus, I will ask him/her to please keep this in mind when answering the interview questions. He/She can tell anyone he/she likes about the research, but I will not tell anyone he/she is participating. I will also treat whatever he/she says or write as confidential. Only I will be able to see or read it. I will not use his/her name in any presentations or reports about the research.

If he/she gives me permission, I will be audio-recording our interview. I will then listen to the interview and transcribe it – this means I will type out everything that was said onto a document that I can read over. When I type it up, I will anonymize it, which means I won't include his/her name but will use a pseudonym (or fake name) instead. I will also change the names of some of the people, places and organizations that he/she talks about. This is to protect his/her identity and to keep his/her personal information private. If he/she wishes to see the transcript of his/her interview, he/she will have access to it through me.

The transcripts and the audio-recordings and any notes that I write will be kept private. They will be kept in a locked cabinet in my home office. Any information kept on my computer will be protected by a password. Only I will be able to access any of this information. Once the study is finished, all of the audio recordings and hand written notes will be destroyed after transcription, but the anonymized interview transcripts containing pseudonyms, and changes in place names, organization names and family details, will be kept for 5 years.

b) Legally Required Disclosure:

I will do my best to protect information from this interview. However, I may have to report information to authorities to protect his/her health or safety. If he/she tells me about illegal situations (for example, sexual abuse) I will be required to report the findings to the appropriate persons. I will do my best to protect his/her interests even if I am required to tell the authorities.

What happens if he/she doesn't want to participate or if he/she changes his/her mind later?

It is his/her choice to be part of the study or not. No one else can make him/her participate if he/she does not want to. If he/she decides to participate, he/she can decide to stop at any time - even if he/she already signed the consent form, and even if he/she are already part-way through the study. He/She can also refuse to answer certain questions if they make him/her uncomfortable.

He/She can tell me that he/she does not want to be in the study anymore at any time during the interview. He/She can just let me know that they no longer wish to be a part of this study and we can end the interview.

He/She can also tell me that he/she does not want to be in the study anymore after the interview. He/She can let me know by sending me an email, or sending me a letter, or calling me on the phone. He/She can find my contact information in this letter. If he/she wants to stop the interview any information he/she shared will be deleted, unless he/she says otherwise. He/She can tell me not to include his/her interview up until December 31st, 2017.

This research is not being funded by any human services agency. His/Her decision whether or not to be part of the study will not affect his/her continuing access to any services he/she is currently receiving. If he/she chooses to leave this study, any data he/she has provided will be destroyed unless he/she indicates otherwise.

Can you contact me if you have more questions?

You can **email** me at santina@mcmaster.ca Or you can call me on the phone. My phone number is **(905) 745-2965.**

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

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

Consent Form

I have read the information presented in the information letter about a study being conducted by Alan Santinele Martino, of McMaster University. I have had the opportunity to ask questions about _________________________’s involvement in this study. I have also had the chance to receive any extra information I wanted to know about the study.

I agree to _________________________’s participation in this study. I understand that he/she may skip any question he/she does not want to answer and that he/she does not have to participate in discussions that make him/her uncomfortable. I understand also that he/she can choose to leave the study at any time. I have been given a copy of this form.

☐ **YES**

☐ **NO**

I consent to having _________________________’s interview be **audio-recorded**. I understand that this is so that the researcher can be sure he correctly understands _________________________’s answers to his questions – that he gets it right.

☐ **YES**

☐ **NO**

3. I agree to be contacted about a possible follow-up interview, and understand that I can say no to that.

☐ **YES** Please contact me at

____

☐ **NO**

Participant Name: ____ (Please print)

Participant Signature: ____

Date: ______________________

Appendix I: Sample Guardian Letter of Information

Sample Guardian Letter of Information

Research Study: The Romantic and Sexual Lives of Adults with Intellectual Disabilities in Ontario, Canada

To the Guardian of: ____

The above person has expressed an interest in participating in a research project about the romantic and sexual experiences of adults with intellectual disabilities. As a researcher and member of the community, I believe that this is an important project, and that the stories that people with intellectual disabilities have to tell about this important aspect of their lives are narratives that need to be told. I hope you will agree.

Research participation will be strictly voluntary, and the above person will not have to answer any questions they are uncomfortable with. The project will involve participation in an interview of 1 hour, which will be audio recorded and transcribed if you and ________________________ agree. The participant can withdraw his/her participation and end the interview at any time if he/she chooses. As well, confidentiality and anonymity will be respected, as outlined in the attached consent form.

Please read the attached consent form for details on the project, and sign your name on that form if you agree to his/her participation. You can return the signed consent form to me in different ways. As a scanned file by email: **santina@mcmaster.ca**; or give it to ________________________ prior to his/her interview with me; or mail the form to me at the following address:

Alan Santinele Martino, PhD Student
Department of Sociology
McMaster University
1280 Main Street West
Hamilton, Ontario
Canada L8S 4L8

Please do not hesitate to contact me with any questions or suggestions that you may have about the project.

Sincerely,

Alan Santinele Martino
Ph.D. Student
Department of Sociology
McMaster University
905-745-2965
Email: santina@mcmaster.ca

Appendix J: Oral Consent Script

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

Researcher: Alan Santinele Martino

Oral Consent Script

Introduction:

Hello. I'm *Alan Santinele Martino.* I am conducting interviews about the romantic and sexual lives of people with intellectual disabilities. I am a graduate student in the Department of Sociology at McMaster University in Hamilton, Ontario. I'm working under the direction Dr. Melanie Heath of McMaster's Department of Sociology. I have done research about disability and sexuality since my undergrad. My past work with people with intellectual disabilities made me want to learn more about disability and sexuality.

The study:

You are invited to join my research project. If you agree, I will interview you. I will ask you about your romantic and sexual lives. I will talk to other people with intellectual disabilities about these same experiences. This research project will give people with intellectual disabilities a chance to talk about their romantic and sexual lives. I will write about the happy, sad, and angry times people with intellectual disabilities have in their romantic and sexual lives.

What will happen during the study?

1. I will tell you about my project.
2. I will ask if you want to be interviewed.
3. If you agree, we will agree on a time and place for me to interview you.
4. The interview will take 1 hour.
5. The interview will be informal.
6. I will ask if I can record the interview. The recording will help me to not forget anything important.
7. I will also take notes by hand.

What do we talk about during the interview?
I will ask you about your romantic and sexual experiences. Some questions may be:

- What do you look for in a romantic/sexual partner [boyfriend, girlfriend]?
- Where do you go to find a romantic/sexual partner [boyfriend, girlfriend]?
- How do you go about meeting potential romantic/sexual partners [boyfriend, girlfriend]?
- How do you form and maintain romantic/sexual relationships?
- What kinds of supports have you faced in accessing the romantic/sexual life you want?
- What kinds of barriers have you faced in accessing the romantic/sexual life you want?

Are there any risks to doing this study?
It is not likely that bad things will happen if you choose to be interviewed. You might feel uncomfortable answering some questions that are asked. I also know talking about past relationships and sexual life can hard at times. You do not have to answer any questions that make you uncomfortable or that you do not want to answer. You can end the interview at any time without any consequences.

If I do or ask something that makes you feel uncomfortable, please tell me. I will change what I am doing or asking.

Are there good things about the study?
Being interviewed will not change your life or change the services you receive. Being interviewed will let you tell non-disabled people what is important to you when it comes to your romantic and sexual life. You may feel happy after telling me your story. However, if you feel upset, I hope that you will let me know. I can help you find someone to talk to. I can also help you make a plan for finding agencies who can provide you with support.

What do I do with all the information you share with me?
1. I will listen to what you and the others tell me.
2. After looking over what I was told, I will make connections between different peoples romantic and sexual lives.
3. I will write my dissertation, which is a long research paper. This is part of my graduate program at McMaster University.
4. I will write articles about the experiences people talked about in the study.
5. I will make presentations to universities, agencies, policy-makers, and other people interested in the project.

Your personal information will not be in articles or presentations.

I hope that by sharing the views in these ways, non-disabled people will learn about issues that are important to people with intellectual disabilities. I hope that academics, service providers, family members will better understand the issues people with intellectual disabilities have with sexuality and relationships. I want these people to learn how to support people with intellectual disabilities to have satisfying romantic and sexual lives.

Who will know what you said in the study?

Sometimes, when people read or hear a story, they can tell who the story is about. Please, keep this in mind during the interview. You can tell anyone you like about the interview. I will not tell anyone you were interviewed. I will treat what you say or write as confidential. Only my supervisor (Dr. Melanie Heath) and I will be able to see or read what you said during the interview. I will not use your name in any articles or presentations about this study.

If you allow me, I will record our interview. I will listen to the interview and transcribe it. This means I will type out the interview onto a document that I can read. When I type up the interview it will be anonymized. This means I won't include your name. Instead, I will use a fake name. I will give fake names of people, places and organizations that you talk about. This will protect your identity and keep your personal information private. If you wish to see the written document of your interview, you can ask me for it.

I will keep any notes, recordings, or transcripts private. They will be locked in a cabinet in my home office. Any notes on my computer will have a password. The information shared in the interviews will be available only to me and my supervisor (Dr. Melanie Heath) who is bound by ethical protocols to maintain confidentiality and anonymity. I will only share anonymized interview transcripts with my supervisor. Once the study is finished, I will the destroy the recordings and notes. I will keep the anonymized interview transcripts for 5 years.

b) Legally Required Disclosure:

I will do my best to protect details from our interview. I may have to report details to the authorities to protect your health or safety. If you tell me about illegal situations (for example, sexual abuse), I need to report these details to the appropriate persons. I will do my best to protect your interests if I have to tell the authorities.

What happens if you don't want to be interviewed or if you change your mind later?

It is your choice to be part of the study. No one else can make you agree to be interviewed. If you want to be interviewed, you can ask to stop at any time. If you already signed the consent form, or are have started the interview you can ask to stop. If you ask to stop at any time I will not ask you anymore questions. You can ask to skip certain questions if you are uncomfortable.

You can tell me that you do not want to be in the study anymore at any time during the interview. Just let me know that you no longer wish to be a part of this study and we can end the interview.

You can also tell me that you do not want to be in the study anymore after the interview. You can let me know by sending me an email, or sending me a letter, or calling me on the phone. You can find my contact information in this letter. If you want to stop the interview any information you shared will be deleted, unless you say otherwise. You can tell me not to include your interview up until December 31st, 2017.

This study is not being funded by any human services agency. Your decision to join the study or not to join the study will not affect your access to any services you are receiving. If you choose to leave this study, any information you have provided me will be destroyed, unless you tell me not to.

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

McMaster Research Ethics Board Secretariat
Telephone: (905) 525-9140 ext. 23142
c/o Research Office for Administration, Development & Support (ROADS)
E-mail: ethicsoffice@mcmaster.ca

I would be pleased to send you a short summary of the study results when I finish going over our results. Please let me know if you would like a summary and what would be the best way to get this to you.

Consent questions:

- Do you have any questions or would like any additional details?
- Do you agree to participate in this study knowing that you can withdraw at any point with no consequences to you?

Appendix K: Oral Consent Log

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

Alan Santinele Martino

RESEARCHER'S LOG FOR RECORDING VERBAL CONSENT

Participant's Unique ID number (i.e. 08-A01)	Participant's name	Date:

Appendix L: Oath of Confidentiality

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

Alan Santinele Martino

Oath of Confidentiality

(*Check the following that apply*)
I understand that as:
[ ] an interpreter
[ ] transcriber
[ ] audio assistant
[ ] video assistant
[ ] research assistant
[ ] other (*Please specify*) ____
for a study being conducted by ____________________________ of the
Department of ___________________________, McMaster University, under the supervision of Professor
____, confidential information will be made known to me.

I agree to keep all information collected during this study confidential and will not reveal by speaking, communicating or transmitting this information in written, electronic (disks, tapes, transcripts, email) or in any other way to anyone outside the research team. I also agree to not speak for or attempt to influence the participant's responses during the interview.

Name: _______________________ Signature: ____________________________
(Please Print)

Date: _________________________
Witness Name: ________________ Witness Signature: ______________________

Appendix M: Demographic Form

[form filled out by researcher after the interview – asked verbally]

Demographic Form

I will start by asking you some basic questions about you. If you do not feel comfortable answering any of these questions, just let me know.

- Age:
- Gender:
- Gender Pronoun:
- Sexual Orientation:
- Relationship Status:
- Race and/or Ethnicity:
- Religion:
- Highest Education Level:
- Type of Education (i.e. mainstream, special, both):
- Employment Status:
- Living Arrangement:
- Kinds of Supports Currently Receiving:

Appendix N: Semi-Structured Interview Guide

Semi-Structured Interview Guide

Introduction: I really appreciate you taking the time to speak with me today. This interview will be open-ended (not just “yes or no” answers). I might sometimes ask you to elaborate on certain answers, and you are also free to share information that you feel is important even if I don’t directly ask about it. Do you have any questions about me, my research, or our interview before we begin?"

I think we could start by talking about how you have learned about relationships and intimacy. Would that be okay?

Participants’ Erotic Habitus (RQ 3):

- Can you describe for me how you learned about relationships and intimacy?
    - What kinds of information have you received about sexuality?
    - Did you receive any sex education throughout your time in school?

- Do you talk about relationships and intimacy with anyone?
    - Have you gotten advice on girlfriends/boyfriends? What kind of advice? From whom?
    - What do you think about the information that you have received about relationships and intimacy?

What do people with intellectual disabilities desire in sexual partners? (RQ2)

[If participant is currently in a relationship or have a sexual partner]

- Are you currently in a relationship or have a sexual partner?
    - Probes: If yes, can you tell me a little bit about your partner and this relationship? How did you meet? What got you interested in this person? How would you describe this person in terms of personality and physically? What kinds of things do you like to do together?
    - What do you like about this relationship? What do you dislike about this relationship? In your opinion, what are some of the most important things in a romantic/sexual partner?
    - How do you express sexual intimacy with this person?

[If participant is NOT currently in a relationship or DOES NOT have a sexual partner]

- Are you currently looking for a romantic/sexual partner?
    - Have you had romantic or sexual relationships before? Can you tell me about the previous relationships you've had?
    - How do you feel now about having a romantic/sexual partner?
- If you are not actively looking for a partner
    - Can you tell me about what has influenced your decision not to pursue potential intimate relationships?

- What would you look for in a potential partner? How would you describe this person (both in terms of personality and physically)?
    - Probes: How old would your ideal person be? What would he/she/they look like? What kind of person would he/she/they be like? Would it be important for him/her/them to be religious or have a particular religion? Would it important for the person to be educated or have a job? Would you consider both disabled and non-disabled partners?

Navigating Sexual Fields (RQ 1) and Negotiating Sexual Capital (RQ2):

- How do you see yourself meeting your ideal romantic/sexual partner?
    - Where do you usually look for partners (e.g. bars, coffee shops, dances, shopping mall)? How often do you go to these places?
    - Are you able to go to these places alone? How do you feel about that?
    - Are there places that you do not feel comfortable going to? Are there places that you are not allowed to go to?
    - What other methods have you used to meet prospective partners?

- Tell me about a time you were romantically or sexually interested in someone you just met at [place mentioned by participant].
    - What did you do or say to get that person interested in you?
    - How did people respond?

- Have you used the internet (e.g. dating sites, chat rooms, social networking sites, online gaming) to look for a partner or sex?
    - If so, can you tell me about these experiences? Do you disclose your disability on the internet? If so, when? Do you share/receive photos? Does that influence your decision to meet the person?
    - If not, how do you feel about using the internet to find partners?

- How do you think others feel about you as a potential romantic or sexual partner?
    - Do you feel attractive or sexy? When are these times?

  - Do you ever feel that your disability affects your self-confidence/esteem?
  - Do you compare yourself to other people? How does this make you feel?

- Do you think your disability has impacted your romantic/sexual life? If so, how?

Supports and Barriers (RQ 1):

- Has it been easy or difficult for you to find and maintain romantic/sexual partners?
  - If it has been easy, can you tell me more about this? What has helped you to find and maintain partners?
  - If it has been difficult, can you tell me about the challenges that you have experienced?
  - Do you have ways around these challenges?

- Can you tell me a bit about your current housing situation?
  - Are you allowed to bring people into the house? What are the rules about that?
  - Are there ‘house rules’ in the place you live? If so, what are they? How do you feel about them?
  - Do you have privacy? Do you have your own bedroom in the house? Are you allowed to locks the doors?

- Has your family affected your romantic and sexual life in any way?
  - If so, please tell me about this.
  - Have they been mostly supportive or unsupportive?

- Do you receive supports from a regular support worker?
  - If so, do you think this relationship affected your romantic and sexual life in any way? If so, tell me how they have affected your romantic and sexual life.
  - Have they been mostly supportive or unsupportive?

- Please tell me about the kind of supports you think would be the most helpful to you in regards when it comes to romantic relationships and sex.

- Is there anything else you’d like to share or anything we haven’t talked about?

Thank you very much for your time.

Appendix O: Semi-Structured Interview Guide (Plain Language Version)

Interview Guide

Introduction: Thanks for talking with me today. This interview will be open-ended (not “yes or no” answers). I may ask you to talk more on certain answers. You are free to share details that you feel is important, even if I don’t ask about it. I want to remind you that it is up to you if you want to be interviewed or not. Some questions may make you feel uncomfortable. If you want to skip a question, just tell me. You could say "next question' to let me know you want to skip a question.

Do you want to ask me anything? About my research, or our interview?

[Learning about Relationships and Sexuality]

We can start by talking about how you have learned about relationships and sexuality. Would that be okay?

- Can you tell me about how you learned about relationships and intimacy?
    - What kinds of details have you been given about sexuality?
    - Did you receive any sex education while you were in school?

- Do you talk about relationships and intimacy with anyone?
    - Have you gotten advice on girlfriends/boyfriends?
    - What kind of advice?
    - From whom?
    - What do you think about the details you got about relationships and intimacy?

[If you have a boyfriend or girlfriend]

- Can you tell me a little bit about your boyfriend/girlfriend? Your relationship?
- How did you meet?
- What got you interested in this person?
- How would you describe this person in terms of body? Personality?
- What kinds of things do you like to do together?
- What do you like about this relationship?
- What do you dislike about this relationship?
- In your opinion, what are some of the most important things in a boyfriend or girlfriend?
- How do you express sexual intimacy with this person?

[If you do not have a boyfriend or girlfriend]

- Are you looking for a boyfriend or girlfriend?
    - Have you had romantic or sexual relationships before?
    - Can you tell me about the previous relationships you've had?
    - How do you feel now about having a romantic/sexual partner?
  - If you are not actively looking for a boyfriend or girlfriend:
    - Can you tell me about what made you choose not to look for a boyfriend or girlfriend?

- What would you look for in a future boyfriend or girlfriend? How would you describe this person (body and personality)?
    - How old would your ideal person be?
    - What would he/she/they look like?
    - What kind of person would he/she/they be like?
    - Would it be important for him/her/them to be religious or have a particular religion?
    - Would it important for the person to be educated or have a job?
    - Would you consider both disabled and non-disabled partners?

[Thinking about your ideal boyfriend or girlfriend]

- How do you imagine meeting your ideal boyfriend or girlfriend?
    - Where do you usually look for a boyfriend or girlfriend (e.g. bars, coffee shops, dances, shopping mall)?
    - How often do you go to these places?
    - Are you able to go to these places alone? How do you feel about that?
    - Are there places that you do not feel comfortable going to?
    - Are there places that you are not allowed to go to?
    - What other ways have you used to meet a future boyfriend or girlfriend?

- Tell me about a time you were romantically or sexually interested in someone you just met at [place mentioned by participant].
    - What did you do or say to get that person interested in you?
    - How did people respond?

- Have you used the internet (e.g. dating sites, chat rooms, social networking sites, online gaming) to look for a boyfriend or girlfriend?
    - If yes, can you tell me about these experiences?

  - Do you disclose your disability on the internet? If so, when?
  - Do you share/receive photos? Does that influence your decision to meet the person?

  - If not, how do you feel about using the internet to find a boyfriend or girlfriend?

- How do you think others feel about you as a future boyfriend or girlfriend?
  - Do you feel attractive or sexy? When are these times?
  - Do you ever feel that your disability affects your self-confidence/esteem?
  - Do you compare yourself to other people? How does this make you feel?

- Do you think your disability has impacted your romantic/sexual life? If yes, how?

[Potential challenges and supports to having a boyfriend or girlfriend]

- What has it been like for you to find a boyfriend or girlfriend? What about keeping a boyfriend or girlfriend?
  - If it has been easy, can you tell me more about this?
  - What has helped you to find and maintain a boyfriend or girlfriend?
  - If it has been difficult, can you tell me about the challenges that you have experienced?
  - Do you have ways around these challenges?

- Can you tell me a bit about your current housing situation?
  - Are there ‘house rules’ in the place you live? If so, what are they?
  - How do you feel about these ‘house rules’?
  - Are you allowed to bring people into the house?
  - Do you have privacy? Do you have your own bedroom in the house? Are you allowed to locks the doors?

- Has your family affected your romantic and sexual life in any way?
  - If so, please tell me about this.
  - Have they been mostly supportive or unsupportive?

- Do you receive supports from a regular support worker?
  - If so, do you think this relationship affected your romantic and sexual life in any way? If yes, tell me how they have affected your romantic and sexual life.
  - Have they been mostly supportive or unsupportive?

- Please tell me about the kind of supports you think would be the most helpful to you in regards when it comes to romantic relationships and sex.

- Is there anything else you'd like to share or anything we haven't talked about?

Thank you very much for your time.

Appendix P: List of Support Services for Participants

[For participants in other locations I will identify community-based services and have these available at the time of the interview.]

Places that Offer Services and Supports in Southern Ontario

The Salvation Army - Lawson Ministries (Lisa Schumph)
533 Main St. E.
Hamilton, Ontario L8M-1H9
Phone: 905-527-6212
Email: lisaschumph@lawsonministries.org

Community Living Hamilton
191 York Boulevard
Hamilton, Ontario L8R-1Y6
Phone: 905-528-0281
Email: info@clham.com

Family Service Toronto
202-128A Sterling Rd,
Toronto, ON M6R-2B7
Phone: 416-595-9618

Adult Protective Service Worker Program (Brenda McBride)
APSW/Hamilton FASD Intake, 447 Main St. E., Unit 201
Hamilton, Ontario L8N-1k1
Phone: 905-527-3823 ext. 259
Email: bmcbride@cfshw.com

People First Ontario
2495 Parkedale Ave. Unit #4
Brockville, Ontario K6V 3H2
Phone: 519-560-3599
Email: mlatimer.peoplefirst.on@gmail.com

Community Living Toronto
20 Spadina Road
Toronto, Ontario M5R-2S7
Phone: 416-968-0650

Griffin Centre
1126 Finch Avenue W., Unit 16
Toronto, Ontario M3J-3J6
Phone: 416-222-1153

Email: contact@griffincentre.org

For more information about community services in Hamilton you can also visit: http://informationhamilton.ca/redbook

You can also contact Developmental Services Ontario at http://www.dsontario.ca/contact-us for information about service providers all around Ontario.