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(In)Dependence, Socio-sexual Relationships, and Sexual Health Among Adults with Mild Intellectual Disability (MID): A Critical, Qualitative Exploration

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Abstract

The purpose of this critical, qualitative study was to explore how adults with mild intellectual disability navigate independent socio-sexual relationships in settings where they are highly dependent upon caregivers and family members who exert significant control over most aspects of their lives. Data were gathered during one-on-one interviews conducted with adults with MID (n=15), and parental caregivers (n=6). Theoretical insights from critical disability studies and sexual citizenship were used to analyze the findings, which are presented thematically by study population. Participants with MID faced challenges to establishing and maintaining meaningful relationships, including a lack of choice about where and how they interact with others, a lack of privacy for intimacy, and not being afforded adequate knowledge of healthy relationships and sexual health by their caregivers. These challenges were directly shaped by the perspectives of caregivers, who perceived their adult children with MID as being inherently vulnerable and in need of their intervention. Their intervention often took the form of paternalistic practices that curtailed the activities and aspirations related to day-to-day life activities, peer-relationships, and sexuality for the adults with MID. These study findings contribute fresh, compelling insights to this important research, especially in relation to the topics of assumed vulnerability, sexual boundaries, sexual violence, and reproduction among adults with MID. The potential impact of these data on disability policies and practices, particularly those that affect the social, spatial, and sexual health of adults with MID are discussed, and recommendations for policy and advocacy are offered.

Keywords

Summary for Lay Audience

People with mild intellectual disability are entitled to the same rights and freedoms associated with citizenship as people without mild intellectual disability. Even though they are entitled to these same rights and freedoms, people with mild intellectual disability do not always receive them. People with MID have stated that they want more opportunity to develop relationships and sexuality, but this is an area of their lives that they are frequently excluded from. This may be because of their dependence on family and professional caregivers. This dependence is not necessarily a bad thing, but it can create difficulties for adults with MID when they attempt to participate in activities that are thought to be potentially harmful. Caregivers that are depended on sometimes take on a controlling approach towards people with MID in their lives to protect them. These protective measures however, limit adults with MID's ability to exercise freedom in their lives that other adults are typically allowed to have. The protective measures also create more risk for people with MID as they attempt to make decisions in their social and sexual lives without having the education and support, they may need to do so safely. The goal of this study was to understand how adults with MID navigate these issues while trying to develop meaningful social and sexual relationships, and how these issues may affect their sexual health. The study involved interviews with caregivers including six parents of an adult with MID, and fifteen adults with MID themselves. The findings show that people with MID had to navigate their relationships in very strict parameters set by caregivers and other institutions involved in their care (such as support agencies and government).

Co-Authorship Statement

Some aspects of this dissertation were developed with the input and guidance of my supervisor and supervisory committee; however, I was the primary contributor of writing and content. The chapter entitled *Mediators of Inclusion: Challenges to Including Adults with Mild Intellectual Disability in Qualitative Research*, was co-authored by my supervisory committee: Drs. Orchard, Kinsella, and Cushing. I was, however, the primary writer and contributor of content. I have been granted permission to use that chapter in whole or in part for inclusion in this dissertation, as part of my contributor's agreement through Oxford University Press (See Appendix B: 1, 2, and 3).

Acknowledgments

Dr. Treena Orchard, thank you for accepting me as a grad student all those years ago. Thank you for encouraging and guiding me over the bumps along the way. Thank you for celebrating my successes and believing that I could do it. Thank you for not letting me disappear. I absolutely could not have completed this without you.

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I would like to thank Dr. Taunya Johnson, who helped me tie up my loose ends and make it to the finish line. Thank you to the study participants who shared their lived experiences and without whom the study could not have been completed. Thank you to my colleagues and people I have worked with and for over the years who kept me motivated and inspired me to keep going.

Finally, to my family, thank you for providing me with love and support through this journey; it was all the fuel I needed to persevere.

Table of Contents

List of Tables

List of Appendices

Preface

My interest in studying the issues on the intersection of health and people labelled as having an intellectual disability began when I was seventeen and my life crossed paths with that of a woman labelled as having an intellectual disability. We were both in a medical setting where we were being treated for similar issues. It did not take long, however, before I became painfully aware of how different her treatment was to mine. It baffled and saddened me that the very same professionals who treated me, mostly, with basic respect, did not extend the same to her. This was my first time being a witness to inequities and injustice faced by people labeled as having an intellectual disability.

During this same period of time, I developed a connection with a music therapist who kindly offered me a position working in her music camp for children with intellectual disabilities. This experience showed me that the opposite could be experienced by people with intellectual disabilities; the contrast was immense. Everyone there was encouraged to participate, no one was left out, no one rolled their eyes at anyone else's behaviour; everyone was accepted. The stark and painful contrast between these experiences ultimately sparked a passion for studying and working in the disability field. I wanted to understand why this difference in treatment existed and what could be done to change it. This led me to disability studies at Mount Royal University in Calgary and then ultimately to pursuing this doctorate in health promotion, with a focus on people with intellectual disabilities.

While studying, I have worked in a variety of roles in disability services in both Calgary and London. This has included direct residential and community support work, education assistance, occupational therapy and speech therapy assistance, providing respite for a handful of families over the years, and for the last four years, working as a direct

support professional with adults with intellectual disabilities in the London area. I also held volunteer roles as a bowling coach for the Special Olympics, and as a Lead volunteer in a life-skills based class at a local nonprofit.

My work as a service provider most certainly influenced my doctoral research, and my doctoral research also influenced my work. There were many times throughout this journey that these two parts of my life intersected in ways that both challenged and enabled my progress in completing this dissertation. The challenges included what is commonly found in shift work in general; inconsistent schedules and anti-social hours of work. This, along with my own personal struggles as a woman and a student with a disability, made finding routine in my day-to-day life difficult, including making time for writing and keeping up with the literature. During the pandemic, this was all made even more difficult, as I had to choose how to use my limited energy, and most often I chose to prioritize the people in front of me who needed it, rather than the research itself.

My doctoral research also influenced my work, in that it gave me new ways of thinking about my role as a caregiver. During the uncertainties of the pandemic I noticed that I was engaging in practices that were not much different than what was found among caregivers in this study. For example, I found myself redirecting away from conversations that made me uncomfortable or that I did not have a clear answer to. Additionally, I redirected away from conversations in an attempt to protect the person I was supporting from feeling upset should an answer be distressing to them. In these ways, I used my power to control the conversations with people I support in order to ultimately alleviate my own discomfort. Viewing my behaviour in this way is itself discomforting, however, I believe it is necessary to examine these everyday oppressive practices in order to challenge and change them, regardless of the intents behind them.

Regardless of the challenges and detours faced along this journey, I am grateful for the opportunity to have engaged in this process. I am grateful for every challenge that supplied me with more to consider about the issues, as well as the wisdom and strength to do more in the future.

Chapter 1

1   Introduction

1.1   Introduction

The purpose of the critical, qualitative study featured in this dissertation is to explore how adults with mild intellectual disability (MID) negotiate the development of social and sexual relationships within life settings where they are highly dependent on family caregivers. Dependence on caregivers is often necessary for people with MID to function and participate in their communities on an equitable basis (Baumbusch et al., 2017; Namkung et al., 2018; Nelson-Goff et al., 2016; Thackeray & Eatough, 2015; Young-Southward et al., 2017). However, the power differences between people with MID and their caregivers, especially when they are family members with significant vested interests in the wellbeing of their children, often express themselves in complex ways that can feel very controlling by adults with MID and protective on the side of the caregivers. This is especially relevant in issues related to sexuality and relationships, which are often deemed dangerous or risky and can involve paternalistic approaches by caregivers versus allowing individuals with MID to experience the challenges of these aspects of life more autonomously (Aunos & Feldman, 2008; Eastgate et al., 2012; Mahoney & Poling, 2011; Shakespeare, Gillespie-Sells, & Davies, 1996). These issues are embedded in and influenced by long-standing issues of societal concerns regarding sexuality and reproduction among people with intellectual disabilities.

Historically in Ontario and other Western contexts, people with intellectual disabilities have been subject to oppressive regimes of control based on intertwining eugenicist fears and neoliberal ideals related to racial purity and re(production) from which they were thought to deviate from (Harris-Zsovan, 2010; Kempton & Kahn, 1991; Simmons, 1991; Trent, 1994). Because of their perceived deviance, people with intellectual disabilities were, for decades, segregated from the rest of society in large institutional settings where they would live out their lives as inmates (Kempton & Kahn, 1991; Simmons, 1991; Trent, 1994). Since the operators of these institutions were encouraged and rewarded by governments to keep the costs of these places as low as possible, the living conditions were often extremely poor (Kempton & Kahn, 1991; Simmons, 1991; Trent, 1994). People with intellectual disabilities were also routinely subject to forced sterilizations under the auspices of ensuring they did not 'taint' the gene pool and to reduce the possibility of more of these devalued individuals being born (Kempton & Kahn, 1991; Simmons, 1991; Trent, 1994). While the province of Ontario never issued legislation enforcing sterilization measures, it did place legal restrictions on marriage for people with intellectual disabilities, and mandated segregation by sex in institutional settings (Simmons, 1991).

There is evidence that surgical sterilization continues to occur among people with MID (Barton-Hanson, 2015; Li et al., 2018). For men with MID, the justification is explained in terms of allowing them more sexual freedom (Barton-Hanson, 2015), whereas for women with MID, controlling the pain and trouble assumed to be associated with menstruation is more often the justification behind these procedures (Li et al., 2018). Although these punitive and dehumanizing approaches to controlling the lives and

sexualities of people with disabilities are much less common than in the past, members of this population still struggle for social inclusion and to exercising their human rights on an equal basis as others (Devlin & Pothier, 2006; Fine, 2019; Rioux &Valentine, 2006; Seibers, 2008; Shakespeare and Richardson, 2018; Shildrick, 2012).

Policies asserting the rights and entitlements of people with intellectual disabilities have been acknowledged at the International, Federal, and Provincial levels (See: Canadian Charter of Rights and Freedoms, 1982; Canadian Human Rights Act, 1985; Ontario Human Rights Code, 1990; Ontario Health Care Consent Act, 1996; The UN declaration of Human Rights, 1948; and the UN Declaration on Rights of Disabled People) but it is unclear how or if these entitlements are experienced by people with intellectual disabilities, particularly within the context of dependence on caregivers for support in their daily lives. Existing research on policies and practice regarding supporting the social and sexual life of adults with MID are overwhelmingly dominated by the voices of others who speak on their behalf, with the lived experiences and subjectivities of these adults going relatively unexplored in the theoretical and applied literatures (Ignagni et al., 2016; Liumputtong, 2007). This is important, as the voices of people with MID are critical and should be the basis for guiding and developing policy and practice guidelines and recommendations for caregivers and others as they have the power to ultimately shape their lives in significant ways, including their social and sexual lives (Bates et al., 2017; Bates et al., 2020; Devlin & Pothier, 2006; McCarthy et al., 2022; Rioux & Valentine, 2006). This inquiry aims to address this pressing gap in the current research literature on sexuality, adults with MID, and dependence on parental caregivers, and it is one of the only Canadian studies that examines these issues.

1.2   Research Statement

The main objective of this critical, qualitative study is to explore how adults with mild intellectual disability negotiate the development of socio-sexual relationships (i.e., friendships and romantic, and/or sexual relationships) within a context of dependence on caregivers and/or care environments.

1.2.1 Research Questions

Three research questions were designed to achieve the above stated objective:

1) What role does the issue of independence play in the development of socio-sexual relationships among adults with mild intellectual disability?

2) To what (if any) extent do caregivers and others in the social/care environment create barriers in the development of these socio-sexual relationships? And;

 3) How do these experiences with and potential challenges related to relationship formation affect the social and sexual health of adults with mild intellectual disability?

1.3   Chapter Overview

This dissertation is divided into five chapters, beginning with this chapter as the introduction. The format of this dissertation is Integrated Article, and chapters two, three, and four are written in a publishable format. Each chapter contains an overview of the literature pertinent to the background of the study. Chapter Two is a chapter published in the book entitled, *Cognitive Disability and Difference: Ethics, Autonomy,*

Inclusion, and Innovation (Cascio & Racine, 2019, Eds.). I have adapted this publication to expand on the methods used for this study. I have permission to use all or part of this publication in my dissertation (See Appendix B for OUP author entitlements). Chapter Three, "I'm just trying to talk to somebody…" is an article presenting and discussing findings from the interviews with adults with MID, and Chapter Four, "I'm the one that's still pulling the strings…" is an article presenting and discussing findings from the interviews with parental caregivers. The Concluding chapter features a discussion of the study significance within the context of the relevant research literature and the implications of the findings for contributions to theoretical discussion, policy, and praxis.

1.4   Definition of Terms

The following terms are relevant to this study and are conceptualized for the purpose of this dissertation as follows:

1.4.1 Mild intellectual disability

For this research study, I use the term 'mild' in conjunction with 'intellectual disability'. Sometimes used interchangeably with developmental disability, the participants in this study, all Ontario residents, would have been labelled as having an intellectual disability as defined in the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act (SSPSIDDA, 2008). This Act states that the person with an intellectual disability would have "significant limitations in cognitive functioning and adaptive functioning" (SSPSIDDA, 2008, Section 3(1). The Act also stipulates that along

with this requirement, the limitations must, "have originated before the person reached 18 years of age; are likely to be life-long in nature; and affect areas of life activity, such as personal care, language skills, learning abilities, the capacity to live independently as an adult or any other prescribed activity" (2008, Section 3(1)).

The definition used in the SSPSIDDA draws on the diagnostic criteria for intellectual disability as it is in the Diagnostic and Statistic Manual of Mental Disorders (DSM 5 TR, 2022). As the DSM 5 is the diagnostic system used in Canada, all of the participants with MID would have been assessed and diagnosed by a clinician in order to access financial and service benefits under SSPSIDDA (SSPSIDDA, 2008) Within this definition, as well as described in the DSM 5, people with mild intellectual disabilities are those who are perceived to have less cognitive impairment and difficulty with adaptive functioning than those who are perceived as having moderate, severe, or profound degrees of cognitive impairment and difficulty with adaptive functioning (DSM 5 TR, 2022). To maintain consistency and clarity throughout this dissertation, I use the term mild intellectual disability when referring to participants who have been labelled as such. When referencing the literature on intellectual and developmental disabilities, I use intellectual disability without the functional label.

It is important to note that the category of mild intellectual disability and intellectual disability are highly subjective, and have changed and evolved along with political, economic, and social values throughout history (Berkson, 2006; Kempton & Kahn, 19911; Nancollas, 2012; Scheerenberger, 1982; Simmons, 1982; Trent, 1994). The definition laid out in SSPSIDDA takes an individualistic or biomedical approach; that is, it does not explicitly acknowledge the disabling influences of society on people with

intellectual impairments as a social model of disability would (Barnes, 2012; Goodley, 2001; Oliver, 1990; Oliver & Barnes, 2012; Seibers, 2008; Shakespeare & Watson, 2001; Shakespeare, 2004; Shildrick, 2012). Furthermore, labels, including functional labels such as "mild" used in conjunction with disability categories have been harmful to people with disabilities. This is because while diagnostic categories are used to receive social benefits, they also contribute to social stigma, which has a negative influence on the lives people labelled as such (Davies, 1998). In line with critical disability studies approaches to disability, the underlying assumption taken in this dissertation is that disability is dialogic. That is, it assumes that disability is an embodied experience arising from complex interactions between impairment effects and ablest societal structures, values, and norms (Meekosha & Shuttleworth, 2009; Seibers, 2008; Shildrick, 2012).

1.4.2 Sexuality

Like 'mild intellectual disability', sexuality is also a concept that has changed over time along with social, political, economic and cultural norms and values (Bristow, 2011; Foucault, 1990; Parker, 2009; Richardson, 2018; Weeks, 1986). When referring to sexuality throughout the dissertation, I am utilizing Richardson's (2018) conceptualization of sexuality where sexuality includes "sexual attraction, desires, practices and related identities" (p. 9), but is also socially constructed; influencing and being influenced by institutions such as the family, social and cultural meanings, everyday interactions and practices, and the sense of self, including sexual and gendered identities (2018, p. 9).

1.4.3 Socio-sexual relationships

When using the term socio-sexual relationships, I am referring to the interpersonal dynamics of sexuality (Merriam-Webster, n.d.). These dynamics are assumed to go beyond the individual to encompass the myriad of contextual and relational factors influencing sexual identity, behaviour, and desire (Dewitte, 2014; See: Richardson, 2018).

1.4.4 Sexual Health

When referring to sexual health, I am using the WHO's current working definition which is:

> "…a state of physical, emotional, mental, and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination, and violence. For sexual health to be attained and maintained the sexual rights of all persons must be respected, protected, and fulfilled (World Health Organization, 2010, p. 10).

Chapter 2

2 Mediators of Inclusion: Challenges to Including Adults with Mild Intellectual Disability in Qualitative Research

2.1 Introduction

Researchers wishing to include people with cognitive impairments must grapple with how to ensure these participants are able to exercise autonomy, have free choice, and that they understand that their involvement is voluntary. Adults with mild intellectual disability (MID) are frequently excluded from qualitative research out of the belief that intellectual impairment hinders autonomy, rendering them child-like and in need of protection (Hall, 2013). Instead, professionals and family members often speak *for* them in qualitative research. This poses a significant problem for people with MID because it renders their valuable first-hand experiences invisible and reinforces the assumption that others are more equipped to make decisions for them and speak on their behalf. Addressing this important inequity is critical to developing evidence-based policy and programming based on their lived experience (Ignagni et al., 2016; Liumputtong, 2007). To this end, critical qualitative research can be part of the shift in making room for adults with MID to speak on their own behalf in research (Scotland, 2012).

The purpose of this chapter is to discuss the methodological challenges of including adults with MID in qualitative research. The data for this study come from a larger, qualitative study that explored independence, social relationships, and sexuality among adults with MID and caregivers. I begin with a discussion of how sensitive topics,

namely, sexuality, intersects with vulnerability in research settings and everyday life for adults with MID. These complex intersections often produce concerns about the need to protect these adults from any harms or tensions regarding sexuality, which are often heightened in discussion about adults with MID in ways that are unique compared with other marginalized or vulnerable groups. I argue, however, that their vulnerabilities should not preclude their participation in research and the rare and valuable insights gained from the inclusion of these adults in this study demonstrates that it can be done. Following this discussion of sensitive topics and vulnerability, I describe the design and primary methods employed in the study. This is then followed by an analysis of the themes regarding caregiver control over public and private spaces, challenges to research inclusion, and the experiences of adults with MID participating in the study. The chapter concludes with a discussion of the contributions this data makes to the disability and sexuality research literatures and provides several recommendations regarding study design and approach that will be valuable to other researchers who seek to include adults with MID in their scholarly work.

2.2 'Sensitive' Topics and Vulnerability

Sensitive topics in qualitative research are those that make participants, and sometimes researchers, uncomfortable to discuss, and they also include those that can pose certain kinds of ethical or cultural challenges to the safety and discretion of participants (Wellings et al., 2000). Sexuality, operationalized here as sexual identities, behaviours, and preferences, is a complex issue that is often considered sensitive, contentious, and as something more safely discussed in the private realm. However, sexuality does not only

occur in the private realm and in its various forms it has long been used as a technique of political governance through part of the larger social and state-mandated efforts to marginalize, contain, and discipline certain populations, as well as practices (Foucault, 1990; Weeks, 1998). Including members of vulnerable groups, who are often assumed to be easily coerced or exploited (Bracken-Roche et al., 2017; Iacono, 2006), in research studies that explore sexuality or other sensitive topics can be challenging to researchers (see Liamputtong, 2007). Institutional, social, and more intimate family forces can conspire to make this kind of work exceedingly difficult, prolonged, and circumscribed in focus, which has historically led many researchers to exclude these groups from participating altogether (Liamputtong, 2007).

Adults with MID do not enjoy the same sexual freedoms and reproductive autonomy afforded to more powerful groups in society (Codd & Hewitt, 2021; Foley, 2018; Kammes et al., 2020; Lofgren-Mateson, 2012; Shakespeare and Richardson, 2018; Shildrick, 2012; Tamas et al., 2019). This is exemplified in the eugenics movement of the early-to mid-twentieth century, in which people with mild intellectual disability were forcefully sterilized or had legal limits placed on marriage (Kempton and Kahn, 1991; Simmons, 1982; Trent, 1994). Although these legal sanctions regarding the regulation of their sexual and reproductive behaviours have been lifted, these adults still experience restrictions on their socio-sexual behaviour and in many realms related to the maintenance of their personal health and bodily autonomy (Abbot & Horwath, 2007; Foley, 2012; Healey et al., 2009; Kelly et al., 2009; Seibers, 2008; Shakespeare et al., 1996; Walker-Hirsch, 2007). These challenges are often attributed to fears of pregnancy and sexual abuse, as well as assumptions of child-like innocence and asexuality (Abbot &

Horwath, 2007; Seibers, 2008; Shakespeare et al., 1996; Walker-Hirsch, 2007). Adults with MID also experience exclusion in the context of sexuality research, which then reinforces ableist assumptions that the sexualities of adults with MID are unimportant as compared to other groups in society. Including the lived experiences of adults with MID in sexuality research can expose the challenges to inclusion in social and sexual life faced by these adults, and can also illuminate the ways in which their sexual lives are similar to those without MID.

2.3   Study Purpose and Methodology

The purpose of the featured study was to explore how adults with mild intellectual disability exercise independence in the development and maintenance of socio-sexual relationships within the context of familial and social/care environments. These are issues that are woefully under-researched in the disability studies field, and it is unclear how or if dependence on others affects the ability of people with MID to form and maintain social and sexual relationships. We also do not know the ways in which this dependency informs the social and sexual wellbeing of these adults. This was a qualitative study, which is well-suited for gaining rich understandings of the meanings given to a particular phenomenon, as the researcher is committed to seeing "through the eyes" of the participants (Snape & Spencer, 2003).

Critical research seeks to emancipate oppressed groups through analyzing environments, processes, and practices, with the aim to advance social changes and inform programs and policies that address social and structural inequalities (Crotty, 2012; Hinchey, 2008; Kemmis et al., 2014). Drawing on a key element of critical action-

oriented methodology, an additional role of the researcher is to open up a "communicative space" (p. 34) with participants and others involved in a practice in order to reveal and engage in dialogue about these structural arrangements (Kemmis et al., 2014). In line with this aspect of critical action research, findings from this study are intended to be disseminated in ways that are not only accessible to people with MID, caregivers, and other entities involved in the lives of adults with MID, but also in ways that provide opportunities to discuss and strategize for solutions. These entities upon which adults with MID are dependent on include the education system, family, community support agencies, and the government ministries that set priorities and guidelines that affect various aspects of people with MID's lives. People with MID are often left out of these conversations that occur at higher levels of organization, but they are the most affected by the policies that they set out (Devlin & Pothier, 2006).

2.3.1 Data Collection and Recruitment

With respect to data collection, I conducted individual, semi-structured interviews with twenty-one participants, including adults with MID (n=15; 7 women, 8 men), and parents of an adult with MID (n=6; all women). The interview guides differed according to participant group, but all consisted of questions designed to explore the first- hand experiences of independence, socio-sexual relationships, and sexuality of adults with MID from the varying perspectives (See Appendices F and G for interview guides). The I used a relaxed, conversational style, probing deeper at times, and encouraging storytelling as examples. The interviews were held in locations chosen by each participant and included coffee shops in the community, the participant's homes, my

University office, and a meeting room at a local agency. In addition to the interviews, descriptive and reflexive notes were recorded after each interview that described the interview context and setting as well as the feelings and emerging insights regarding the research interaction.

Recruitment was purposive, as I sought to find participants that are experts in the phenomena under investigation (Baeill & Williams, 2014). For this research, therefore, I aimed to recruit twenty adults with mild intellectual disability, and eight parents of an adult with mild intellectual disability. The literature on qualitative methods posits that data saturation may be reached between 6-12 interviews, particularly when the participants are a fairly homogenous group in terms of their experiences with the topic of inquiry (Guest, Bunce, & Johnson, 2006). This made aiming for 8 parents a good choice, providing a buffer should we not reach at least six. Six parents of an adult with MID ultimately participated, however, only mothers were represented which made it a more homogenous group than we anticipated. A larger number of people was chosen for participants with MID for two primary reasons; Firstly, the perspectives of parents and other caregivers greatly outnumber that of adults with MID in the literature, particularly on socio-sexual issues, and secondly, these participants may share a label of MID, but they varied in age, gender, abilities, experiences, and socio-economic status. With this variability in participants, it would be expected that it would take a larger number of participants to reach data saturation (Guest, Bunce, & Johnson, 2006).

Caregivers were recruited by advertisements in community agency newsletters, as well as word of mouth from gatekeepers at these agencies and other participants. Finding adults with MID for the study required the help of community agencies to identify and

inform potential participants who fit the inclusion criteria about the study, as traditional methods such as flyers or advertisements may not have been effective for this population due to differences in literacy ability.

2.3.2 Data Analysis

Data analysis was thematic, following a process as outlined by Braun and Clarke (2006). Broadly, this process begins with immersing oneself in the data, identifying initial ideas, or codes, and then organizing the codes into overarching themes (Baeill & Williams, 2014; Braun & Clarke, 2006; Sparkes & Smith, 2013; Taylor, Bogdan, & DeVault, 2016). Immersion in the data began with self-transcription of each interview. All audio-recorded interviews were transcribed verbatim using a transcription pedal. Immersion for the one participant who chose not to be audio-recorded involved reading interview notes captured during and immediately after the interview. I organized the interview transcripts into separate binders according to participant group so that I could manually interact with the pages as I began to actively read through each one. Actively reading each interview involves taking note of patterns and meanings that emerge while reading (Braun & Clarke, 2006). The used sticky-notes, highlighters, and pens to jot down ideas while reading through each interview. Descriptive and reflexive notes were taken on each participant, along with a summary of key ideas taken from their interview. These data items, along with the transcribed interviews themselves, made up the "data corpus" of the study (Braun & Clarke, 2006, p. 79).

Initial code generation was done manually. I began by re-reading interviews and other data items such as post-interview notes and searching for semantically or

thematically relevant ideas. Semantically relevant ideas are those that are explicit in the sense that they are surface-level ideas, and not, on their own, relevant to underlying theoretical ideas (Braun & Clarke, 2006). For example, in the interviews with parents of adults with MID it was noticed that the topic of government funding came up frequently. Semantically, this is interesting, as government funding was not in the interview guides, but the frequency with which it was brought up led me to flag it as a potential code. In contrast but complimentary to semantic codes, thematically relevant codes were those directly pertinent to the research questions and the underlying theoretical perspectives of the study (Braun & Clarke, 2006). For example, when talking about people with MID, parental caregivers often compared them to those without MID according to age expectations when talking about their children's social and sexual lives; this was therefore flagged this as a potential code it is relevant to both critical disability theory and sexual citizenship as an example of comparing people with disabilities against established norms, and then using this to justify their exclusion in certain social and sexual practices.

After the initial coding of data, I began sorting through the codes to organize them into potential themes. This process was messy and involved creating visual representations of the coded data and potential overarching themes using sticky notes, lists, drawing out idea trees and mind maps. Braun and Clarke (2006) posit that what counts as a theme can vary, but it should be consistent and transparent; it can be based on prevalence, frequency, nuance, or what they call "key-ness", a term used to describe a set of codes that say something directly pertinent to the research question (2006, pg. 82).

The next phase of data analysis was a review of each theme, along with re-reading the data sets to make sure they fit together; that is, ensuring the codes are representing the

theme in a meaningful way (Braun and Clarke, 2006). To this end, coded sections of interview text were removed and placed in a table that labeled each theme. I then went through the table, manually, and used highlighter and sticky notes again to review the codes within each theme, crossing out those that did not seem to fit meaningfully within them. Then, interviews were re-read and compared to the list of themes to ensure that the interviews, codes, and chosen themes fit together meaningfully. This was a cyclical process that involved analysis of the "essence" of each theme (Braun & Clarke, 2006, p. 92), that is, how each theme relates to the broader research questions. The final task of analysis involved choosing the best examples of each theme from the data sets and placing it in context to the research questions and relevant literature to share the story of the data (Braun & Clarke, 2006).

2.3.3 Theoretical Frameworks

Concepts central to critical disability theory and the theory of sexual citizenship shaped interpretation of study data.

2.3.3.1   Critical Disability Theory

Emerging from a desire to move beyond the materialist Social Model, Critical Disability Theory is a form of cultural critique of oppression stemming from being disabled in an ableist society (Goodley, 2013). Critical Disability Theory draws on ideas from intersectionality, feminism, critical race, and queer theories (Goodley, 2013), as well as postmodernism, phenomenology, and psychoanalysis (Shildrick, 2012).

Scholarship in critical disability theory has grown to be very broad, as it has grown it its interdisciplinary nature (Meekosha & Shuttleworth, 2009). Meekosha and Shuttleworth posit that it is perhaps more apt to call it critical disability studies, as this is more reflective of the increasingly interdisciplinary usage of concepts that are central to critical disability theory (2009). One key aspect of critical disability theory is that disability is viewed as "both a lived reality in which the experiences of people with disabilities are central to interpreting their place in the world, and as a social and political definition based on societal power relations" (Reaume, 2014, p. 1248). A key goal of critical disability studies is understanding the lived realities and experiences of people with disabilities in order to challenge the ideological assumptions that contribute to their oppression and exclusion (Devlin & Pothier, 2006; Shildrick, 2012).

2.3.3.2   Sexual Citizenship

Theories of sexual citizenship arose in opposition to normative notions of sexuality; namely, those that privileged certain groups in society based on their adherence to norms regarding sexual identity and behaviour (Richardson, 2000; Richardson, 2018; Weeks, 1998). Sexual citizenship theory, also known as intimate citizenship (Igngani et al., 2016), is useful for analyzing the ways in which a particular group is denied access to certain aspects of citizenship on account of their deviance from norms regarding sexuality (Richardson, 2000; 2018).

Sexual citizenship involves the attainment of sexual rights (Richardson, 2000; Richardson, 2018). Richardson identifies three main sub-streams within "sexual rights discourse": 1) conduct-based rights claims; 2) identity-based rights claims; and 3)

relationship-based rights claims (2000, p. 107). Conduct-based rights claims include the right to participate in sexual activity, the right to pleasure, and the right to sexual and reproductive self-determination (Richardson, 2000). Identity-based rights claims include the right to self-definition, self-expression, and self-realization (Richardson, 2000). Finally, relationship-based rights claims include the right to consent to sexual practices in personal relationships, the right to freely choose sexual partners, and the right to publicly recognized sexual relationships (2000).

2.3.4 Ethical Considerations

The study received approval from my institutional research ethics board (See Appendix A for the statement of ethical approval). All names of participants and others referenced by participants used in this chapter and throughout the dissertation are pseudonyms.

2.4   Key Findings

2.4.1 Socio-sexual Relationships: the Roles of Space and Caregivers

One of the most significant study findings was the integral role of parents and support workers in mediating the social and sexual lives of adults with MID, primarily through control over access to public and private spaces. Most of the study participants with MID spent a significant amount of time in supervised, segregated spaces such as day programs, employment classes, and sports activities such as Special Olympics. Participants valued these spaces in important ways, and they were integral to making and connecting with

friends and partners. Some of the adults, however, wanted more free time with friends, rather than the regulated activities that characterize these spaces:

I: Where do you meet most of your friends?

A: At work [day program/classes]. Yeah.

I: Do you ever see them outside of work?

A: Uh, I see some of them go bowling. Yeah some of my friends go bowling…

I: Do you wish that you saw some of them more?

A: Yeah. Yeah…

I: What do you think gets in the way of seeing them more?

A: Um, just my, my social life, like bowling and my weekend. I wish I could see them on the weekends.

I: What would you want to do with them on the weekends?

A: Um, I don't know. Maybe go to a movie, maybe? Yeah, go to a movie, just hang out.

Parents and support workers also reported that it was common for adults with MID to have limited opportunity to socialize outside of these structured activities. Caregivers attributed this to either a lack of ability and/or willingness on their behalf to support opportunities for independent socializing. These opportunities, particularly for those who do not live independently, are frequently mediated by their reliance on others, thus compromising autonomous participation in social activities, as well as participation in

research. Reliance on others for transportation, scheduling, permission due to safety concerns, and caregiver rules has significant implications for the capacities of adults with MID to be included in research.

Some participants with MID had romantic partners but could only spend time with them within the context of structured, supervised spaces such as day program classes. This was more common among participants who lived in the parental home and were associated with feelings of frustration during the interviews. Here is an excerpt from the interview with Nathan, a participant with MID in his early thirties who is not allowed to date officially, even though him and his girlfriend have been together for a number of years:

I: Do you see her outside the [day program] like, do you go to her house, or does she go to your house?

N: I want to see her outside the [day program] but our moms haven't met yet.

I: Oh, OK.

N: We met each other, like I've met her mom and she's met my mom, but our moms haven't met yet. So that's why we haven't kind of done anything yet like dating.

I: So your mom likes to meet the mom of who you're dating before you can hang out?

N: Yeah. It's been a rule since the caveman days! [Laughs]

I: [Laughs]. How do you feel about that rule?

N: I don't really like it. I don't think I would meet my son's or daughter's

parents, well you know what I mean… um their girlfriend or boyfriend's

parents, like, I'd just let them date!

I: Yeah, OK, how long have you had this girlfriend?

N: Um, we've been on and off, but we've probably been together four

years.

This excerpt demonstrates the level of control that parents are capable of wielding over the romantic relationships of the adults with MID that depend on them via restrictions on the spaces they may interact with partners. This ultimately leaves these adults with no choice but to navigate their romantic and sexual lives within a context of near-constant surveillance by others, restricting opportunities to engage in sexual behaviour that are typically afforded more freely to adults without MID. An example of this challenge came from Chantelle, who, facing a lack of privacy at home and in day program activities, tried to be intimate with her partner by sneaking away to a locker room, and was ultimately reprimanded when caught by staff: "The staff caught us once and I'm like, 'Oh my God!' And then after, the staff is like, 'You guys shouldn't be doing that anyway, Chantelle'…"

2.4.2 Challenges to Research Inclusion

One of the most pressing challenges to including adults with MID in the study was a lack of interest and support from community agencies. Only one of five agencies that work with adults with MID on a regular basis responded to requests to discuss gaining access to this population for recruitment purposes. The rationale behind agency disinterest

remains unclear, as attempts to open up communication have been unsuccessful. While the participating agency helped immensely, to have had the support of the other agencies would have increased the number of adults with MID who could have been notified of the research opportunity. Having participants from various agencies would have also provided more opportunity to unpack some of the differences and similarities in the experiences of adults with MID who get primary support from other agencies. Additionally, because only one agency was involved, and support workers told their own service users about the study, adults with MID had an additional risk to their anonymity to consider on account of these caregivers being aware of who showed interest in participating. Ultimately, 19 adults with MID expressed interest in participating, but 15 were interviewed in the end, which may have been influenced by this risk to anonymity.

A second issue that presented a challenge to including the adults with MID was that I, at times, was regarded as a potential threat by caregivers to the well-being of the adult with MID that they support. One example of this suspicion occurred while making plans over the phone to meet with an adult with MID, Miranda, who had expressed interest in the study. Miranda said that she would prefer to meet at her own home; her support worker then go on the phone and after a discussion about the study the support worker stated, "You'll need a police check before meeting at the house," and said that she would call her head office to find out if I was permitted to do the interview there. The rationale for the support worker's interruption was not clear, but it reflects how Miranda's decisions in regard to participation are not entirely her own. The interview was ultimately held in Miranda's home, and no police checks were required.

A third challenge to the inclusion of adults with MID in the study was that, for a number of participants, the time and location of the interview had to coincide with the availabilities of their parents and support workers. In many cases, I was passed by phone from the adult with MID to a caregiver to discuss logistics of meeting. While this may be attributed, in part, to cognitive challenges associated with intellectual impairment, it also reflects, as with the previous example, the degree to which their availabilities are tied up in the schedules of those around them. For example, one support worker, said, "Can we do it in the morning so we can get groceries done by the end of my shift?" This interconnectedness between the caregiver and adult with MID's schedules demonstrates the power held by these caregivers to facilitate or constrain participation in research. Chantelle, a participant with MID, demonstrated the power that this reliance on her mother's availability has on her decision-making: "I gotta ask my mom first before I make decisions because, in case we might be busy, and I don't even know about it."

Parents and formal caregivers also have the power to take control of certain aspects of participation for adults with MID, particularly as it related to privacy. This occurred during the study on more than one occasion. For example, one parent took the phone from her son, Vince, to organize where and when the interview would take place. Her preference was that it would be at their home. Even though I requested privacy, throughout the interview Vince's mother hovered in an adjacent room, at times entering to clean. As a result, Vince was visibly uncomfortable discussing sexuality because his mother was within earshot. Sensing this and out of respect for him, I did not probe for more information when it came to this more sensitive topic, and at times, omitted questions, especially regarding sexual behaviour. Had Vince's mother allowed privacy

for the interview, more of Vince's perspectives could have been elicited, which would have added to the depth and overall quality of the interview.

2.4.3 Adults with MID Reflect on Research Participation

Adults with MID played an active role in negotiating their participation in the study. This involved requesting additional information prior to giving consent and consenting to some aspects of the study but not others. Each potential participant with MID and I engaged in conversations prior to obtaining consent, during which time the details of the study were explained, from its purpose to its voluntary nature. Potential participants often asserted themselves by asking questions to clarify details that were unclear to them and sought out the information they needed in order to make an informed decision. For example, one adult with MID called me a few times before meeting to ask questions and seek clarification about what the study would involve. These questions included asking about where and how the interview would be written about, how the quotes would be anonymized, and who would hear the interview. I brought an example of a qualitative journal article to the interview to show her a visual representation of the way it would be written, and the way quotes remove real names and specific identifiers. This collaborative process of ensuring consent was voluntary and fully informed for this participant demonstrates the capability of these adults to be active in this process of obtaining knowledge necessary to make an informed choice.

Participants with MID demonstrated an ability to be assertive in negotiating aspects of the study that they did not want to partake in. For example, Vicky originally said that she would be fine with audio-recording but changed her mind about this before

beginning. This act demonstrated that she felt uncomfortable with this particular aspect of participation, but she was capable and assertive enough to decide this and communicate her altered decision. Similarly, a number of participants felt uncomfortable with certain questions and communicated a desire to not answer either explicitly or implicitly. The following excerpt is an example of Jeff responding to probing in regard to whether or not he had wanted to have sex with his ex-girlfriend:

> J: I'll just say, "not available."
>
> I: Oh, OK, you'd prefer not to answer?
>
> J: That's correct. I'll just say, "not available'"

Even if participants did not communicate discomfort with the line of questioning in as explicit a way as Jeff did, there were participants who showed their discomfort in nonverbal ways and I noticed and changed topic accordingly. For example, Linda was asked whether she had engaged in sexual activity and she immediately began to blush profusely, and did not respond immediately. I responded to this nonverbal communication by switching to asking if she had had sex education, which immediately changed her demeanor along with this less personal line of questioning. The significance of this is that even though Linda was struggling to verbalize her discomfort she still communicated it in a way that could be understood by the lead researcher.

Each interview ended by asking what each adult with MID thought could be done to better support them in their relationships. Asking this question gave these participants the opportunity to provide explicit feedback to guide policy and practice for supporting

socio-sexual well-being. Chantelle, like a number of these adults, took the opportunity to offer advice to those who support her regarding helping her to talk about difficulties with her current romantic and sexual partner:

> *C: Um, maybe the staff should help me talk about it instead of saying-*
> *cause every time I ask for help they don't wanna get involved. They*
> *would say, "Oh. I don't wanna hear about it."*
>
> *I: Like talking about your relationship problems?*
>
> *C: Yeah, that's what they say, "I don't wanna hear about it, I don't*
> *wanna hear about it."*

Tom used the opportunity to propose a guy's night out idea where he could meet with and hang out with other men to do things like shoot pool together. Having the adults with MID take part in identifying issues and proposing solutions is practical for guiding expert informed policy and practice.

2.5   Discussion

This chapter explored findings relevant to ethical and methodological challenges of including adults with mild intellectual disability in qualitative research; particularly, that which is of a sensitive nature. The data supports findings on research inclusion that adults with MID often require the support of caregivers as well as researchers to participate in studies (McDonald, 2012). This supports a relational view of autonomy whereby the decision (or not) to participate is embedded in the social context within which the

participant resides (Shewin & Winsby, 2010). The findings contribute new insights in regard to the vulnerability of adults with MID in research inclusion; that they are capable of negotiating their own participation, even when discussing sensitive topics. Researchers can support this by attending to relational autonomy and being reflexive during the research process (Guillemin & Gillam, 2004, Phelan & Kinsella, 2013; Sherwin & Winsby, 2010).

In the current study, community agencies and caregivers were capable of both facilitating and restricting opportunities for adults with MID to be included in the study. Gaining the interest and support of these entities was, therefore, necessary, however, this presented the most significant challenge to research inclusion. The reliance on caregiver schedules and ability to support the logistical aspects of participation reflects the important roles played by these supportive others in research inclusion (McDonald, 2012). There were, however, instances where this power was used in such a way as to undermine the autonomy of the adult with MID when I was regarded with suspicion. This finding also supports a relational view of autonomy, whereby an individual's capacity to be autonomous cannot be separated from the social context (Sherwin & Winsby, 2010); in this case the influence of caregivers who wish to protect the adult with MID from potential harm.

Another significant study finding was the integral role of caregivers in mediating the inclusion of adults with MID in social and sexual life. Most of the adults with MID in the study reported that they do most of their socializing within the context of segregated, structured activities. these spaces offer opportunities to meet and spend time with others for the purposes of friendship and dating. Unless, however, the adults with MID can meet

outside of these activities in public or private, these adults must navigate their relationships within these supervised, structured contexts only. This does not allow much freedom to just "hang out" with friends or go on dates; two activities that are typically afforded to adults without MID. Additionally, these spaces do not allow privacy for intimacy between partners; this was unfortunate for a couple of participants who were also restricted in terms of privacy in their homes. If these adults were sexual citizens, they would have the freedom to participate in sexual activity (Weeks, 1998; Richardson, 2000).

Adults with MID in the study demonstrated the ability to actively negotiate the limits of their own participation. This is contrary to the assumption of adults with MID being solely passive and vulnerable to the research process. Additionally, some participants did not want to answer certain questions that caused discomfort, and they communicated this in order to protect their own interests. Even if the adult with MID was unable to express this verbally, I was able to respond appropriately to the non-verbal communication that took its place and did not probe further. Phelan and Kinsella contend that researchers can recognize and negotiate these moments of increased vulnerability by being reflexive (2013). Reflexivity can be described as the process of the researcher being critically reflective of their interpretations of what is going on in the research process (Guillemin & Gillam, 2004). In this case, reflexivity involved my reflections on my interpretations of the participant's behaviour as an expression of discomfort. Adults with MID shared insights regarding how they can be better supported to be included in social and sexual life; advice that will be shared with agencies and caregivers as an important part of dissemination. Adults with intellectual disability have stated that they

want their participation in research to go towards educating others on their needs and desires in order to improve their lives (McDonald, 2012).

Researchers wishing to include adults with mild intellectual disability in qualitative research should consider the power of agencies and caregivers to both facilitate and restrict their inclusion. Efforts should be made to emphasize the importance of including adults with MID in research that will inform the very policies and practices that will shape their lives. A commitment to inclusion for adults with MID in all facets of life requires researchers, agency gatekeepers, and caregivers to challenge assumptions of vulnerability and autonomy by viewing these adults as experts in their own lives; capable of speaking and advocating for themselves. Researchers can also support the participation of adults with MID by attending to relational autonomy, working with ongoing consent processes, taking extra time to educate people with MID on their rights as research participants, within research, and engaging in ongoing reflexivity with respect to issues arising in the research process. The contributions to current knowledge of the first-hand experiences of these adults will go towards shaping supports to be more in line with what adults with MID want for themselves, rather than what others think is best.

Chapter 3

3 "I'm just trying to talk to somebody…": Adults With Intellectual Disabilities Negotiate Intimacy, Relationships, and Sexual Health Within the Context of Care Environments

3.1 Introduction

For adults with intellectual disabilities, dependence on caregivers is often essential to their ability to live and thrive in various familial, social and community contexts. However, this dependence can present challenges to autonomy in developing intimate and/or sexual relationships (Seibers, 2008; Shildrick, 2012). Historically, adults with intellectual disabilities have been the target of what some have characterized as unjust regimes of control because of their sexuality, including forced institutionalization as well as sterilization (Harris-Zsovan, 2010; Kempton & Kahn, 1991; Simmons, 1982; Trent, 1994). Presently, there is greater acknowledgement that people with intellectual disabilities are entitled to the same freedoms as any other citizen, including the right to participate in their communities, and to make decisions according to their own needs and preferences (Bjiornsdottir, Stefansdottir & Stefansdottir, 2015). While improvements have been made in regard to supporting the participation of adults with intellectual disabilities in leisure and vocational pursuits, there remains reluctance on the part of many caregivers to support intimate relationships and the development of a sexual identity with these adults (Abbot & Horwath, 2007; Thomson, Ward, & Wishart, 1995). Parental and paid caregivers attribute this reluctance to a desire to protect their children

or clients with intellectual disability from sexual abuse and unplanned pregnancy (Foley, 2012). Paid caregivers also attribute this reluctance to inadequate training to address these topics with clients, and concerns about personal liability and potentially negative reactions from parents (Abbot & Horwath, 2007).

Compared to the perspectives of caregivers, there is relatively little known about how adults with intellectual disabilities experience relationships and sexuality within this context of dependence, and how these experiences inform their social and sexual health and wellbeing. Part of the reason for this is that parental and paid caregivers are often concerned with safety issues and frequently do not know how to approach the already taboo issue of sexuality with those with intellectual disabilities (Abbot & Horwath, 2007; Foley, 2012). Further, caregiver's frequently do not know how to support people with intellectual disabilities in the realm of sexuality; rather they tend to use their own experiences as a reference point for what may be considered normal or abnormal behaviour, and when deemed abnormal, caregivers are reported to take on controlling or restrictive approaches (Lofgren-Mateson, 2013). A non-restrictive approach is therefore only possible if the experiences of adults with disabilities are made visible by being included in discussions of sexuality. Furthermore, inclusion of the voices of adults with intellectual disability about sexuality, intimacy, and autonomy is vital to informing the very policies and practices that shape their day-to-day lives and interactions with caregivers.

3.1.1 Purpose and Objectives

This paper explores the experiences of adults with mild intellectual disability (MID) with negotiating relationships and sexuality within the context of dependence on caregivers. The following questions were crafted to achieve this aim:

1) What role does the issue of independence play in the development of sociosexual relationships among adults with mild intellectual disability?

2) To what (if any) extent do caregivers and others in the social/care environment create barriers in the development of these sociosexual relationships? And;

3) How do these experiences with and potential challenges related to relationship formation affect the social and sexual health of adults with mild intellectual disability?

3.2   Methods

This was a qualitative study informed by elements of critical action research. Critical action research is a cyclical process of analyzing environments, processes, and practices, with an aim of developing social changes that address social and structural inequalities (Crotty, 2012; Hinchey, 2008). The role of the researcher is to acquire knowledge from participants who are conceived of as experts in the topic of inquiry due to their unique experiences (Hall, 2013; Knox, Mok, & Parmenter, 2000).

3.2.1 Recruitment

Participants were recruited purposively through word of mouth among trusted gatekeepers at several local agencies that offer supports to people with intellectual disabilities and their families. The purpose of the study and what the study would entail were explained via email to the executive directors of different agencies, along with a copy of the letter of information. This information was passed on to support workers and other staff, who then explained the study to people with MID that they work with. People with MID who wanted more information recorded their name and preferred contact information on a sign-up sheet, which was then sent to the lead author.

I contacted each person who expressed interest and explained the purpose of the study as well as what would be involved. The amount of interaction between the myself and participants prior to the interviews varied, as some required more time and additional information. One example of additional information requested was regarding the anonymization of written and verbal presentations of the data. I explained the use of aliases for participants as well as anyone they reference during the interviews. Another example was a participant who wanted more information on the use of direct quotes, and how this would look in written presentations of the findings. In addition to using clear and lay language, I showed these participants a visual representation of how this information would ultimately be displayed in the form of a hard copy of a published journal article. Confidentiality was explained, along with what will be done to protect their identifying information outside of written presentations of the data; this included explanations of who would be able to access consent forms, audio files, and transcriptions of their interviews.

3.2.2 Data Collection

Fifteen participants with mild intellectual disability participated in the study and engaged in one individual, semi-structured interview with me at a location of their choosing. The interviews aimed to elicit participants' perspectives on their experiences of negotiating the development and maintenance of relationships and sexuality. Interviews were audio-recorded, apart from one, where this participant stated that they were not comfortable with being audio recorded. For this participant, short jot notes were taken throughout the interview to help remember key details, and detailed notes on the interaction and participant's answers were taken immediately after the interview.

I wrote descriptive and reflexive notes after each interview as well as at different points in the research process. These notes included details about the interview itself, including the setting and notes about participant behaviour. These insights provided additional context regarding the participants, the research process, and the data gathered.

3.2.3 Data Analysis

Data analysis involved multiple readings of each transcribed interview as they were completed and was an iterative process that occurred alongside ongoing data collection. (Braun & Clarke, 2006; Taylor, Bogdan, & DeVault, 2016). Throughout each reading, themes were developed both within and across interviews in relationship to the research questions (Baeil & Williams, 2014; Braun & Clarke; Taylor, Bogdan, & DeVault, 2016). A particular focus was paid to commonalities, nuance, and representativeness in the data to identify themes (Baeil & Williams, 2014: Braun & Clarke). Critical disability theory

and the theoretical concept of sexual citizenship were employed to analyze the data. This meant examining participants' experiences with an eye to the ways in which structural and social factors coalesce in the lives of the participants as they constructed and sought to understand their sexual experiences within a context of a largely ableist society and often protectionist families (Seibers, 2008; Shildrick, 2012).

3.2.4 Ethical Considerations and Approval

Ethical approval for the study, including guidelines for obtaining written consent for all participants, was granted by my institutional Research Ethics Review Board.

Three important aspects to consider before doing research with marginalized groups are vulnerability, risk, and capacity (Ramcharan, 2006). Generally, the more vulnerable to exploitation an individual is perceived to be, the more regulation is required to ensure that this risk is mitigated (Ramcharan, 2006). A person with an intellectual disability is deemed to be vulnerable to exploitation due to cognitive differences as well as being in a less powerful social position as opposed to those without intellectual disability (Iacono, 2006). It is this vulnerability that has led to people with intellectual disability being excluded from research pertaining to their lives (Hall, 2013). This is unfortunate, as people with intellectual disabilities have the right to express themselves regarding issues that will have a direct effect on their lives (Stalker, 2010).

I was committed to addressing ethical issues throughout the entire research process, so that adults with MID could participate with the least risk of harm. Care was taken to ensure that all participants understood the nature of the research as well as their right to participate or not and withdraw consent at any time. Prior to each interview,

participants with intellectual disabilities had multiple reviews of the letter of information, first by agency gatekeepers, and then with me over the phone and prior to the interview. People with intellectual disabilities may have difficulty comprehending the nature of the research and what consenting means for them (Nind, 2008). Previous studies that included participants with intellectual disabilities recommended being prepared to explain details of the study in multiple ways (Hall, 2013; Stalker, 2010). Therefore, I adjusted the language as needed while going through the letters of information with each participant. I also used visual aids in the form of qualitative research articles to demonstrate how the research will be shared and what was meant by unidentified quotes. The use of visual aids has been found to help people with intellectual disabilities understand their participation in research (Nind, 2008).

As with other elements of consent, great care was taken in explaining the voluntary nature of the study and I provided examples of what they could do or say if they chose not to participate at any time during the interview. Participants were also provided with my contact information should they choose to withdraw their data from the study after the interview. Participants were informed that they would face no negative repercussions from withdrawing from the study.

To ensure the greatest level of anonymity, a pseudonym for each participant has and will be used in all presentations of findings. The use of pseudonyms is an effective way to anonymize participants; however, there is still a risk that other identifiers can lead to participants being identified (Wiles et al., 2007). This is especially poignant for the participants in this study, as they are a relatively small community, and they utilize many of the same programs and agencies. Therefore, identifiers such as locations, other

people's names, and exact ages were removed from presentations of the data. Where participants reference other people, pseudonyms are always used.

3.3   Findings

3.3.1 Participant Profiles and Contextual Insights

Eight women and seven men with mild intellectual disability participated in the study. The average age of participants was 36, with an age range of approximately 24 to approximately 58. Eight participants lived in their parental homes, one lived in a senior's residence, one lived in a group home, and five lived in their own rented accommodation with varying levels of staff support. All participants reported receiving practical and emotional support from family, and participants living outside the parental home reported more frequent support from paid staff. Two participants were employed on a part time basis, one was employed full time, and the remainder spent most of their days attending agency-run leisure and/or vocational programs. All were financially dependent on government disability support programs to some degree.

Participants reflected on relationships, intimacy, sexual health, and autonomy while telling stories about their lives. Participants were asked about their most intimate relationships, including friends and partners, including how they met and what they did together, and the value they added to their lives. Most of the participants reported meeting their friends and partners within the context of structured, segregated activities such as day programs, and they tended to evaluate these spaces according to the connections they have there, with little regard to the actual program itself.

Participants described their day-to-day lives and activities and shared insights on how their days were structured and who decides what they do in a day and where they go. These reflections revealed a great deal about the relationship between autonomy, friendships, and socio-sexual relationships, which intersect with space and dependence in powerful ways. Those living in the parental home reported less control over their day-to-day lives and decision-making than those who lived independently with support; only one participant living with one or more parents said that they make their own schedule and decisions.

All but two participants described heterosexual experiences when discussing past relationships and hopes for future relationships. Two women, Kelly and Chantelle, discussed sexual encounters with other women in the past. Kelly self-identifies as "bi-curious", and Chantelle did not use any word to describe her sexual attractions, just saying that she is attracted to men and women but prefers men. While most participants described heterosexual experiences and attraction, this does not necessarily mean that most participants identified as heterosexual. Rather, it could reflect having little experience with discussing or learning about other kinds of sexual behaviors and preferences.

3.3.2 Challenges in Dating Relationships

Participants shared challenges that they have faced or currently face in their dating relationships. They expressed concerns about partners cheating, being too busy to spend time together, needing more attention from partners than partners are willing to give, and

heartbreak due to unreciprocated feelings. When discussing her relationship with her ex-boyfriend, Anne recounted his inattentiveness, and how this made her feel ignored:

When I was talking to him- like when I was talking to his face, it felt like I was talking to a wall. Because he wasn't listening to anything I was saying and he was paying more attention to his phone than me. Playing games on his phone and all that and that made me upset.

Another participant, Jeff, talked about struggling to find the time to spend with his ex-girlfriend, which may have hastened or caused their eventual break-up: "She had a pretty busy schedule, far busier than mine…I was concerned about that, I think that it ultimately led to the breakup six months later." Infidelity or cheating was another concern that participants raised, including Chantelle, who worried about her boyfriend cheating on her again because he had done so in the past. This had led to frequent arguments between them at the day program they attend, a situation that was not resolved at the time of the interview. Chantelle expressed that she tries to get help with her relationship concerns from staff at the day program, but that they don't seem interested in listening, and even express annoyance towards her talking about the issues:

The staff yelled at me, [she] yelled at me, I'm like, "I'm just trying to talk to somebody", and then after, [she's] like to me, "That's what you do, you come in, you just come in, you just talk Dylan-this, Dylan-that,

you just complain- you have your problems you always complain about

everything about Dylan, you never let me be- let me have my lunch in

peace.

Some participants expressed that finding someone to date was a significant challenge. Jeff stated that he wants a new girlfriend, but "Just a matter of where to find one, that's all. And who. Right now, my search is just general. Looking everywhere." Greg is primarily interested in women who do not have disabilities, and also struggled with finding a girlfriend. At the time of the study, he had not found a date on the Facebook singles group that he frequents. Greg also described the heartbreak of not having his feelings reciprocated when he tried to pursue a romantic relationship with a support worker:

It kept on hurting me. It was 2013 and the pain hasn't really- I mean

it's subsided, but since 2013 I don't- I was able to bounce back but I

don't think the pain has- part of the pain has left. The physical pain,

like the nerve pain has left. But, the feelings are kind of there.

Greg's struggles with finding a girlfriend were unique compared to other participants in that he expressed being unsure where he fits in due to his sensory impairment as well as not feeling like he can relate to many of his peers with and without MID; this presents a unique challenge in the search for a partner.

A number of participants shared that previous partners had engaged in abusive behaviours towards them. Kelly, for instance, described her ex-boyfriend as "a control freak," who would not let her talk to other men. Vicky's experience with her past boyfriend who she lived with was so terrible that she expressed never wanting to date again and did not want to talk about it. Miranda shared that her last boyfriend was "abusive and stuff." Jake experienced physical violence by his girlfriend: "I was dating somebody at [the day program] and it didn't work out, 'cause she kept hitting me."

Two participants were very vocal about how they struggle with a lack of opportunities for intimacy with their partners, due to near-constant surveillance and rules imposed by parents and agency staff. Chantelle has gotten into trouble and has been threatened with suspension for trying to be intimate with her boyfriend in the locker room at her day program and has also gotten in trouble for dancing suggestively with her boyfriend at an agency dance. Chantelle explained how she also faces restrictions and a lack of privacy at her house, which was exceedingly frustrating:

> *I can't have boyfriends over at my house either, my mom and dad*
>
> *doesn't let me because they think I'm gonna have sex in my bedroom*
>
> *that's what they say, "Oh you can't have Dylan, he's not your husband*
>
> *you can't have Dylan in your bedroom, he has to be in the kitchen or in*
>
> *the living room downstairs." But they always watch me like a hawk.*
>
> *Every single time that he's over, we can't even French kiss. We can't*
>
> *French kiss, we can't, I can't be in his lap, on top of his lap. They get*
>
> *really upset and this is when I start French kissing him in his lap, they*

say, "What are you doing, what are you doing? You guys shouldn't be

doing that!" That's why, I don't have any- how do I say, I don't have

any privacy in my house because whenever I want a guy over, they

always have to watch me and Dylan.

Nathan also experienced a lack of privacy at home and spoke of a time when he had a girlfriend in his room and his mother pushed the door open because she thought they were having sex. Both Chantelle and Nathan therefore must navigate their romantic relationships within strict parameters set by parents and staff.

3.3.3 Sexual Health

Participants reported varying degrees of understanding of sexual health topics such as sexually transmitted infections (STIs) and their prevention, reproduction, and consent. Knowledge of sex education came from a variety of sources: high school classes, classes at community agencies, family, friends, partners, and television shows. Participants between the ages of twenty-five and thirty-five demonstrated greater understanding of sexual health topics than those at the other two ends of the age spectrum. These participants also reported the most variety in sources of sexual education, while older and younger participants often only reported one source of sexual education, most often high school classes only, a female family member, or an agency-run sex education class.

Vince and Brittany demonstrated the greatest understanding of each sexual health topic. When asked about if he knew how to prevent STIs, Vince responded, "I believe it's condoms? Yeah, I know that's the main thing that I need if I go and have… that"

[Laughs]. Vince also knew about birth control pills for the prevention of pregnancy, stating, "There are actual pills that [girlfriend] can take." Brittany shared the story of how she insisted on condom use after learning about how they prevent STIs:

> *I: Do you and Rick use condoms?*
>
> *B: Yeah, definitely. Because I heard quite a bit from other sources- people saying that um, you can get AIDS, you can get HIV, you can get all kinds of diseases. And so Rick- when I found out I told Rick, "No, that's not going to happen, we're always gonna have one of those things because I'm not gonna have, um HIV or MTS or whatever else is out there, kind of thing? Because originally that was scaring me. A little bit. And he's like, "Yeah I agree!" Cause he had no idea what kind of disease was out there, too. And I'm like, "No, we're doing it the smart way" [Laughs] you know? Like we're too- I'm too young to die, right? If I got it, kind of thing. And I'm like, "No, I'm not doing it." And he even, he's like, "Yep. Sure, that's fine. We can do it the other way."*

In this excerpt, Brittany's partner was not familiar with the purpose of using condoms for preventing sexually transmitted infections, and Brittany shared what she knew about the topic in order to enlighten him as well as engage in safer sex.

Most participants expressed some degree of confusion about sexually transmitted infections and condoms, with some demonstrating a vague understanding and others

having no recollection of ever learning about them. Steve said he knew what STIs were but was unsure about the role of condoms in sex, "Some people told me it's only safe to have sex with a condom, and I go like, "is that true or is that not true?" [Laughs]. Linda confused preventing STIs with preventing pregnancy; when asked if she knew about how to prevent sexually transmitted infections, she replied, "Oh yeah! Um what was it… I took one of those pills you know? So you don't get pregnant?" Tom stated that he took sex education in high school, "but I don't remember them ever talking about that [STIs]."

All but one participant had some understanding of consent to sexual activity. Brittany explained what she has been told to do in a situation where someone is violating her consent:

> *If somebody pushes you into something that you're very uncomfortable with, you just tell them-say no, or tell them to stop. Um whatever they're doing kind of thing, and if they don't listen to you, you tell an authority. That's what we got taught.*

Tom also explained his understanding of consent, which was very similar to Brittany's: "I know my rights, um I guess sexual abuse, that-I know that it's not right for somebody to come up and say, 'OK, I wanna touch your private stuff' without my permission." Steve explained his role in respecting the rights of others when it comes to sexual activity and consent: "You can't force yourself to have sex with a girl if she doesn't want to. If it's no, it's no."

3.3.4 Sexual Violence

While participants were not asked outright about whether or not they had ever experienced sexual violence, a number of them disclosed these experiences when discussing other topics that involved their understanding of consent. Brittany spoke at length about being stalked, sexually assaulted, and tortured by two acquaintances:

> *They abused me, they sexually assaulted me, they um hit me, they punched me, I almost had two broken ribs… they kicked me… they almost took a cigarette butt and lit my whole arm up, they tried to cut me a few times…*

When asked about his understanding of sexual consent, Andy responded, "Uh huh. I've been abused once." He then proceeded to recount an experience of unwanted touching by an unknown man while outside waiting for his father to pick him up downtown. Vicky explained that a man attempted to sexually assault her downtown as well, but she managed to kick the perpetrator and a police officer intervened. Greg disclosed that he was sexually abused by staff at his boarding school when he was a teenager, stating that it was "hell" due to the abuse he faced there.

None of these instances of sexual violence were ever resolved in a legal sense, and the participants who experienced these situations described the effects of this violence on their lives as traumatic and enduring. Vicky said that she still feels scared when she is alone with men and avoids being alone with them, even adopting the strategy

of doing her laundry late at night as she believes this will decrease the chances that she will have to do her laundry in the same room as an unknown man. Brittany's two abusers spent a night in jail but did not face any long-term legal consequences, as she explained:

We tried to charge them, like my dad, cause my dad knows police officers on the force, and um, we tried to charge them, but it didn't do any good. They only were like there for one day, their- and then their dad took them out.

Brittany described feeling fearful when in public due to having seen her abusers downtown. In these situations, her partner provides a sense of safety and security, "Every time I see them I tuck behind [boyfriend]! [Laughs]"

3.3.5 Reproduction

Participants varied in their interest in having children with current or future partners, with five saying they wanted children at some point in the future, and the rest expressing that they did not want or could not have children. Brittany's fiancé has a daughter and she hopes to have a child with him one day, too. Jake wants to have children, "In the future. Definitely," as does Steve who said it would be "somewhere down the road." Kelly takes birth control now but wants to have children when she feels ready. Vince was adamant about never wanting children, citing disinterest in taking on the responsibility it would entail.

Four participants shared their personal stories of surgical sterilization when discussing whether or not they wanted children in the future. Two male participants (Nathan and Tom) had vasectomies and two female participants had either a partial hysterectomy (Miranda), or tubal ligation (Linda). When asked about the decision to get a vasectomy, Tom used a term to refer to the procedure that is typically heard in conversations about sterilizing animals, which is reflected in this statement: "Well we [referring to his wife] decided, you know, it was best for the- if I just get fixed. And so that's what we decided on." Linda indicated that the decision about her reproductive capacity was made by others, "[My sister] and my mom told me to get my tubes tied tight and then I don't have to worry about kids." Linda did not express regret about the procedure, indicating that she and her husband believe that if they had children, they would be removed from their care anyway.

In her experience, Miranda said that her partial hysterectomy was done as a way to control menstruation rather than to prevent pregnancy, saying, "I couldn't handle my periods." In the excerpt below, Nathan makes it clear that he was forced to have a vasectomy, and his feelings of this being unjust are made clear. The excerpt also illuminates a troubling coercive strategy employed by his mother, who provided misinformation in order to get him to agree to the procedure:

> *V: Say, how about in the future, do you ever want to get married and*
> *have kids-*
> *Nathan: [Interrupts] Oh I don't wanna have kids. I mean, I want to*
> *have kids but then my mom stopped me from having kids.*

V: Oh.

Nathan: My mom gave me- well wanted me to have this operation done? And I had it done since the first girlfriend I had.

V: Oh, OK, when was that?

Nathan: Maybe when I was twenty and graduated school?

V: Oh, OK.

Nathan: Yeah.

V: Were you a part of that decision at all too?

Nathan: No! I wasn't really. I mean, my mom just made that decision for me, she's like, "I don't want you to have kids because they're too much!" I kind of felt like, that they were forcing, well she was forcing me to not have kids.

V: Yeah.

Nathan: But she would let my sisters have kids… which kind of sucks, cause like, why can't I? And why can they?

V: So, you feel like that's not very fair?

Nathan: No. No it's not very fair [sigh]. But I- she said I could adopt.

3.4   Discussion

This study aimed to explore the experiences of adults with mild intellectual disability (MID) as they negotiate the development of intimate relationships and sexuality within a context of dependence on caregivers. Those with MID who took part in the study

revealed that most of their close relationships were formed in the context of segregated, highly structured places in the community; namely, day programs and segregated leisure or vocational classes. Participants highly valued these spaces, however they also shared examples of how reliance on these spaces to socialize can make it harder to find privacy for intimacy. Chantelle, for example, faced with a lack of privacy at home, tries to use the day program and agency-run dances as a space where she can be intimate with her boyfriend. The reprimands and threats from staff, however, indicate that she has very little say in what she can and cannot do in these spaces. Ultimately, this begs the question of whom these spaces are designed for and who determines the rules of behaviour within them? And should these spaces not meet her needs, what other options are there?

Participants demonstrated limited understanding of important sexual health topics, such as sexually transmitted infections (STIs) and the use of condoms. This is in line with previous research assessing sexual knowledge of adults with intellectual disabilities (Finlay et al., 2015; Healey et al., 2009; Kelly et al, 2009). Those with access to more sources of knowledge were able to demonstrate a greater understanding of sexual health issues than participants who only reported one source, such as a class in high school or a family member. This supports research suggesting that people with intellectual disabilities need more opportunities to learn about sexual health to gain a greater understanding (Baines, et al., 2018; McDaniels & Fleming, 2018; Schaafsma, Kok, Stoffelen, & Curfs, 2016). Brittany's example of how she used her new-found knowledge about condoms to inform her partner also demonstrates a potentially untapped source of knowledge in the form of peers and partners.

A high proportion of participants shared experiences of sexual violence, supporting research that indicates people with intellectual disabilities face higher rates of sexual abuse and assault than others (Mahoney & Poling, 2011). According to the literature, most instances of sexual violence against people with intellectual disabilities are perpetrated by family members, care workers, or acquaintances (Balogh et al., 2011; Mahoney & Poling, 2011). The experiences of the study participants reflected this, however, for two people, sexual violence was perpetrated by strangers in public settings. The lack of legal ramifications for perpetrators and the enduring effects of these experiences on participant's lives require more investigation on how sexual violence is dealt with by caregivers and the justice system.

Forced sterilization for the purpose of reproductive control is one of the often-talked about abuses of power inflicted on people with intellectual disabilities in the past (Harris-Zsovan, 2010; Kempton & Kahn, 1991; Simmons, 1991; Trent, 1994), however, the number of participants who discussed their own personal experiences with surgical sterilization indicate that this practice still occurs. Furthermore, it was clear that for one participant in particular, his rights were violated according to the numerous legislations against the practice (See: Canadian Charter of Rights and Freedoms, 1982; Canadian Human Rights Act, 1985; Ontario Human Rights Code, 1990; Ontario Health Care Consent Act, 1996; United Nations, 2007, UN Universal Declaration of Human Rights, 1948). Participants who shared that they had undergone a surgical sterilization procedure expressed it as being their choice while also making reference to negative societal attitudes towards their reproductive capacity. Tom used the word "fixed", a dehumanizing term, which also indicates that the vasectomy was a correction to

something that is inherently wrong with him. Linda and her husband were coerced by threats to their future children should they have any, and Nathan was coerced by assurances from his mother that he could always adopt if he wants children in the future. In their review of surgical sterilization and adults with intellectual disabilities, Recent studies have found that men and women are still being sterilized, however, the justifications of caregivers and health professionals have changed over time (Barton-Hanson, 2015; Li et al., 2018). For men with intellectual disabilities who have been encouraged to get vasectomies, greater sexual freedom is often cited as the reasoning behind it, and menstrual control is frequently the justification behind sterilization of women with intellectual disabilities (Barton-Hanson, 2015; Li et al., 2018).

3.5   Conclusion

Participants shared stories that drew attention to some of the complex issues they face while negotiating intimate relationships, sexuality, and autonomy within the contexts of varying degrees of dependence on caregivers. Some revealed how they must contend with serious affronts to their sexual wellbeing including a lack of privacy, restrictions of sexual expression, sexual violence, and violations of their reproductive autonomy. While these findings are not generalizable to all people with mild intellectual disability, they add to the growing body of literature that features their experiences regarding sexuality.

Chapter 4

4 "I'm the one that's still pulling the strings…": Exploring how Mothers Facilitate (In)Dependence, Access to Social Spaces, and Sexuality for Their Adult Children with Mild Intellectual Disability (MID)

4.1 Introduction

Parents of adults with mild intellectual disabilities are often depended on to support their children for an extended period into adulthood (Baumbusch et al., 2017; Namkung et al., 2018; Thackeray & Eatough, 2015). Independence has been identified as a key goal in adulthood generally and for people with MID (Salt et al., 2019). People with intellectual disabilities face significant barriers to doing things independently on account of the cognitive effects of their impairments as well as ableist practices and assumptions about their capacity to do things on their own at the societal level (Baumbusch et al., 2017; Namkung et al., 2018; Nelson-Goff et al, 2016; Thackeray & Eatough, 2015; Young-Southward et al., 2017). Discriminatory employment practices and insufficient supplemental income programs leave adults with intellectual disabilities with few options, resulting in many remaining dependent on parents for a protracted period (Namkung et al., 2018; Nelson-Goff et al., 2016; Thackeray & Eatough, 2015; Young-Southward et al., 2017).

Developing independence in adulthood often entails risk, as it involves the acquisition of new skills that require some trial and error alongside taking on new roles and responsibilities (Salt et al., 2019; Yidiz & Cavkaytar, 2020). Parents of adults with

MID grapple with encouraging independence while considering the risks involved in doing so (Codd & Hewitt, 2021; Kammes et al., 2020; Thackeray & Eatough, 2015). Parents report fears that their children with MID will experience abuse, violence, discrimination and financial exploitation (Codd & Hewitt, 2021; Kammes et al., 2020). Consequently, parents of adults with MID are less apt to encourage independence, instead choosing to engage in paternalistic practices of doing for and making choices on behalf of their children with MID in an effort to protect them from harm (Codd & Hewitt, 2021; Hollomotz, 2011; Thackeray & Eatough, 2015; Turner & Crane, 2016; Yidiz & Cavkatar, 2020). Adults with MID are therefore at risk of having their autonomy undermined should their parental caregivers engage in controlling practices in attempts to safeguard their children with MID.

Parents typically struggle with knowing how to support the development of relationships (friends and partners) as well as matters pertaining to sexuality (behaviors, desires, and identity) among their adult children with MID (Frank & Sandman, 2021; Kames et al., 2020; Tamas et al., 2019). Parents have been found to view their adult children with MID as inherently vulnerable, a view that they use to justify monitoring and restrictions on sexual expression (Hollomotz, 2011; Kammes et al., 2020). Furthermore, they report feeling unequipped and uncomfortable when it comes to addressing sexuality in supportive ways, which often leads to neglecting this aspect of development (Hollomotz, 2011; Kammes et al., 2020; Tamas et al., 2019). These parental fears and uncertainties about the social and sexual wellbeing of their children with MID can lead to a neglect of this important aspect of their lives, a lack of education on important sexual health topics, offering limited options for socializing, and excessive

surveillance (Hollomotz, 2011; Kammes et al., 2020; Tamas et al., 2019; Turner & Crane, 2016).

Research has focused more on understanding the caregiving experiences of parents of children with mild intellectual disabilities, including on the topic of sexuality, but far less is understood about the experiences of parents of adults with MID (Lam et al., 2019). Parents are in a powerful position whereby they can influence and support the social and sexual wellbeing of their adult children with MID, and the research shows that when given the support to do so, adults with MID are capable of finding satisfaction and autonomy in their social and sexual lives (Hollomotz, 2011; Kammes et al., 2020; Kramers-Olen, 2016; Lam et al., 2019). Current literature featuring the voices of people with MID as well as parents of people with MID reports that while attitudes towards sexuality and people with MID have become more liberal among parents, they still engage in restrictive practices in regard to sexuality (Kramers-Olen, 2016; Tamas et al., 2019). Exploring the experiences of parents in this aspect of life is important to uncovering the contextual factors influencing these behaviors and attitudes which have a negative effect on the social and sexual health of adults with MID (Kammes et al., 2020; Lam et al., 2019).

This paper discusses findings from a qualitative study that explored social and sexual wellbeing among people with MID from the perspectives of caregivers of people with MID and people with mild intellectual disabilities themselves. It focuses on parental experiences of navigating both dependence and independence, access to social spaces, and different aspects of sexuality for their adult children with MID. It focuses specifically

on mothers because they were the only parental group who consistently took part in the study.

4.2   Methods

Participants were recruited purposively through advertisements in local disability and support agency newsletters, as well as word of mouth from agency gatekeepers and other participants themselves. Inclusion criteria were that they had to be a parent of an adult (conceptualized as aged 19 or over) with mild intellectual disability who uses local services and is fluent in English. Six parents, all mothers, expressed interest by contacting the lead author for more information on the study and what their participation would entail.

Each participant engaged in a single, semi-structured interview with the researcher. Participants chose the locations of their interviews, including a café (n=2), their home (n=1), and my office at the University (n=3). The objective of each interview was to explore the issues of independence, social relationships, and sexuality of their adult children with mild intellectual disability. The interview questions included contextual information such as living arrangements and caregiving, and questions that explored their child's social and sexual lives, and their own roles therein. I used a conversational style during the interview, encouraging storytelling and elaboration of certain events as well as their feelings and reflections about them. All of the interviews were audio-recorded with the participants' consent for use in the transcription process. Descriptive and reflexive notes about the setting and feel of the interview and the participant were written out immediately after each one. Reflexive notes were also

written out periodically throughout the research process in the form of notes to my supervisory committee.

Data analysis began during the transcription of each interview, after which several iterative activities were undertaken to facilitate interpretation. This included actively reading each interview multiple times, writing out short jot notes, idea trees and reflexive insights that came to mind while reading. Then a master set of codes were developed, and during this process particular attention was paid to frequency of information and nuance within and between interviews, as well as data directly relevant to the research questions and underlying theoretical perspectives of the study. The codes were then organized into themes that fleshed out various elements of the participants' lived experiences and provided rich insights that furthered my understanding of the research aims. Each theme was then reviewed while I re-read the interviews to ensure the themes aligned with their respective codes.

The final stage involved placing each theme within the context of both the research questions and the pertinent literature and selecting the most compelling examples to use in writing up the data (Braun & Clarke, 2006). Sexual citizenship theory and critical disability theory were employed during the analysis, as two of the leading frameworks through which the forces of both systemic marginalization and individual resistance to structural and social exclusion among people with disabilities are conceptualized.

My institutional Research Ethics Review Board granted ethics approval for the study. All names, ages, and specific locations have been changed in order to respect participant anonymity.

4.3   Findings

The data presented in this paper are organized around the following themes deducted from the data: 1) Managing the day-to-day lives of their adult children with MID; 2) Facilitating their children's access to structured and supervised social spaces; 3) Navigating the dating world and managing expectations amid a different set of rules for their children with MID; and 4) Assessing their children's current and future sexualities and mitigating concerns about sexual activity.

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4.3.1 Managing the Day-to-Day Lives of Their Adult Children with Mild Intellectual Disabilities

All the participants who lived with their children with intellectual disability played a central role in organizing their daily activities, including managing the logistics of their participation in social activities that involve significant transportation and financial resources. The mothers described their child's schedules as being full of vocational and leisure programs through various community agencies and non-profit organizations, as well as volunteer work (three mothers) and for one, part time employment.

Some participants discussed the negative implications of not taking on a managerial role in organizing the day to day lives of their children with MID; namely, that their children would likely not be doing anything at all. Liz touched on this when referring to 'other' families who do not do things for their children, which she frames as being detrimental to the children. She also draws attention to the challenges of undertaking these activities beyond the structured timeline that being in school provides:

There's lots of families out there that aren't always on top of it, and their- the individual suffers, the individuals the one who's stuck at home not doing anything. When they're in school, like you're used to knowing like, OK from September through to June, you've got set things- things that are set for that time.

Liz also discussed the decision she and her husband made to ensure that Megan, their daughter, has a purpose. When talking about this she aligned having a purpose with the "utopian" goal of paid employment, something that may be beyond the purview of their daughter:

Both Megan's dad and I have always had on our mind that- she has to have a purpose, a reason to get out of bed every morning. So it doesn't have to be necessarily a paid job position, I mean that's the ultimate goal in a utopian world but there are few and far… out there.

Another participant, Lillian, echoes these sentiments when she reflected on the broader social importance of filling her son's schedule with activities: "You want them to be out and be a productive part of society, or at least- if they can't be productive at least be a participant in society, right?"

In addition to managing schedules and facilitating involvement in vocational and leisure activities, three of the mothers highlighted the importance of their financial

contributions to offset costs for their child because of the paltry amount provided to them through government funding. As Liz stated: "at the end of the day, if she wants to do that program and I have to subsidize it, as her parent, I will regardless of what her age is." Lillian also said that her son does not receive enough financial support, adding that the family was currently on a waitlist for more funding to hire a support worker, but until then, "it's gonna come out of my own pocket, right?" Pat is also on a waitlist for more funding for her son, and in the meantime her son's monthly disability payments, meant to be used to pay for basic needs, are used to pay for an independently contracted support worker.

Navigating their children's future living arrangements was a very common issue of concern among the participants and with the exception of Anna, all of the mothers hoped that their son or daughter would eventually move out of the parental home. Alexandra's son had already moved out and had been living in a group home for over ten years at the time of the interview. When asked about her experience with having her son move out, Alexandra compared it with her own living situation as an adult, stating, "I didn't live at home when I was 33, why on earth would he?" Pat's son was in transition, living half of each month in a group home. Although she laughed at his living situation and seemed to reduce it from "not even an apartment" to a living room with a bedroom, her son seems to be proud of his living situation as a rite of passage associated with adulthood:

> *He wanted to be a grown up. He looks at this as being- it's not even an*
>
> *apartment; it's a living room with a bedroom. And then he shares the*

bathroom and the kitchen with the group home. So… but he looks at it as

his apartment and he's so proud! Of his little apartment, you know?

[Laughs]. So I think that it's more of a um, for him it is a rite of passage

that most kids or most adults eventually go through.

Alexandra and Pat indicated that the decision to encourage and arrange for their sons to move out was driven by concerns for their future, specifically their eventual inability to care for their sons full time due to illness or death. As Alexandra shared: "[Husband] and I were thinking about- and this was really important; what happens when we die?" Pat also viewed moving out of the parental home as serving the purpose of preparing him for their eventual death: "I mean his father and I are gonna die one day… and to have him in the home, and have to see us carted off to the hospital or whatever… he would- he needs to have that transition way beforehand? So he'll be better prepared for that time."

With the exception of Susan, who plans to purchase a condo for her son to live in independently, all of the mothers who envisioned their children eventually moving out of the parental home were on a waitlist for government-funded supported housing through an agency at the time of the interviews. Liz placed Megan on the waitlist for supported housing when she was still in high school ten years prior to the interview, and she can expect to wait another five to ten years for her name to come up, saying, "It's uh, fifteen to twenty years. We're currently waiting for someone to die. That's basically what it is."

There are some situations that could warrant a faster move up the waitlist, but they typically involved very serious or life-threatening events happening to themselves or their partners. Liz gave an example, saying, "If, God forbid, [husband] and I were killed

in a car accident or something, then they might look at her and say, "Oh, well maybe we can do something…" Pat and Alexandra reported that their sons were moved up the list due to illness that affected their ability to care for their sons. Pat shared: "Originally, we had been told he'd be at least thirty before his name came up. But I think they're sort of- it's the family need more so than his."

Liz, Lillian, and Anna all envision highly dependent future living situations for their children, and these hopes were entangled with concerns for safety and concerns about their children's ability to care for themselves. Liz hoped to see Megan share accommodation and staff with roommates who also have disabilities who can help with meals, laundry, and other activities of daily living. Lillian wants her son to be in a living situation where he is supervised 24/7 by agency staff to ensure that he can access help:

My wish for him is that he would be in a supported living environment where there would be let's say three other people living in the house and there was always somebody I'd say 24/7 there with him… Like, let's say the furnace went off, right? Would he know- I don't think he'd be able to say, 'OK the furnace has gone off, I need to go over there and look to turn it up,' or, 'I'm really too hot' right? He'd say, I'm really too hot, well, I'm gonna take off my shirt' or whatever and I don't know if he'd be able to do that.

This excerpt reflects Lillian's assumption that her son's current adaptive living skills are what they will be in the future, which may not accurately reflect the arc of her child's

development. Anna shared this sentiment about her daughter's abilities to keep herself safe, and shared that this was the reason she felt her daughter would be best staying in the family home indefinitely: "Safety is an issue, she doesn't always react fast enough…" In contrast, Susan expressed a more dynamic assumption of her son's abilities, acknowledging that her son may not have the skills to live alone just yet, but he may be able to learn them in the future: "I'm just waiting for him to get back into a job and get some routine and maybe, you know, a little older. And let him, you know, teach him more cooking skills…"

4.3.2 Facilitating Access to Structured and Supervised Social Spaces for Their Children

All of the mothers reported that their children's social lives revolved around being involved in organized activities such as sports, leisure programs, employment classes, and day programs. Their accounts of accessing these social spaces also reflects their ideas about the kinds of relationships their children form, or do not form, within them. Liz has her daughter in Special Olympics, leisure programs at local agencies, and various activities at the local Down Syndrome Association. About the social impact of these activities, Liz says, " Megan's got a really great network of friends." Alexandra also regards programs as being a place for making connections and she and her son often run into people he has met through these activities: "We can't go anywhere with him where we don't at least meet someone that he knows. Whether it's from school, another program, [Agency]- whatever!"

Two of the mothers, Pat and Lillian, expressed that their son's friendships were limited to the context of the segregated programs they attend. Pat described her son as being unable to maintain a friendship outside of those spaces because he is lacking in what she describes as "social skills", an assessment that seems driven by very singular notions of what friendship should look like:

He has people he would call his friends? From Special Olympics and such but he doesn't have the skills necessary to maintain a proper friendship. He doesn't have um… he doesn't give back the way a friend would. Like he would- people send him Facebook messages or they'll follow him and talk to him, kids from camp and stuff…. and he'll kind of, yeah he'll talk to them- but he would never think to pick up the phone himself. And call.

Lillian also said that her son had a lot of friends in his programs, "But to actually have like somebody that he could just call up and say, 'Hey, do you wanna go to the movies?' He does not have that." Although Lillian attributes this lack of friendship to her son's need for supervision, it also seems to be connected to her deep fears of him socializing unsupervised with friends in public spaces. Her belief in her son's inherent vulnerability as a result of his impairment is reflected below, when she equates the presence of a non-intellectually disabled chaperone for social outings as the sole reason that he has never been exploited:

If he was gonna do any type of social interaction, he would need either myself, my husband or a support worker with him because he just wouldn't be able to just go by himself right? Also um even just figuring out how to connect with a person and then you know, let's say we were gonna go to the movies, right? So then they need somebody else to take them there or they have to have somebody with them. And um you know like what happens if something happens there, would they be able to be on their own? Maybe not. They would have to have somebody with them you know. So he relies on having somebody with him the majority of the time…. I don't feel comfortable putting him in a situation where he could be at harm or um that there's something weird can happen right it's better that he has somebody there with him. Also exploitation, right? Like exploitation if he was going to go out and he doesn't have a sense of money, right? So what if somebody came up and said, "OK give me your money" or whatever. I mean that's never happened because he hasn't been in a situation where he's on his own.

Both Anna and Liz, who calls herself her daughter's "social convener" given the role she plays in her daughter's social life, discuss their essential input in helping their daughters connect with friends outside of structured community activities. This includes planning informal get-togethers with friends in their homes or elsewhere in the community, as well as arranging transportation that may be involved. Liz's daughter frequently has sleepovers and movie nights with her best friend, and Anna's daughter

enjoys going to plays and out for dinner with her group of friends. Liz's daughter makes plans independently with her best friend, as they live near each other, but when Anna's daughter makes plans, she must rely on her mother's ability and willingness to support her due to distance. If Heather has not seen her friends in a while, she will approach Anna and say, "Okay, what can we plan so I can see them?" Anna explained that sometimes she is unable to accommodate Heather's desire to get together with friends, saying, "she's used to the yes's and she's used to the no's… I mean, I guess she wouldn't have as much of a social life if I didn't take her to everything, that's all there is to it, I guess." Liz compared the role she plays in her daughter's social life with that of adults who do not have an intellectual disability: "But, she's 29- so when you think of what a 29 or even a 24 or 25 -year- old is doing, in her life, I'm the one that's still pulling the strings and making things happen."

All of the mothers arranged for either a paid or unpaid relationship between a non-disabled volunteer or support worker and their children. Participants shared that these relationships served the purpose of giving them a friendship outside of their disabled peers:

> *Um she and [Support worker] get together once a week, and uh… just for*
>
> *a couple hours, usually Tuesday nights sometimes they go to Beth's house*
>
> *and they do some baking or make crafts, they go bowling… mini golf…*
>
> *[book store] is one of their favorite places to come hang out at [café]. Um*
>
> *so that's in all honesty that's basically what I use the [Passport] the 2000*
>
> *dollars a year for, it runs out in about the first 6 months um but we just*

continue to pay Beth because I think it's important for Megan to have some time without mom and dad and develop a friendship, you know… outside of her special needs peers. And Beth and her have been friends for…. Many years, I would say six, maybe seven years.

Like Liz, Lillian feels Oliver benefits from having a friend that does not have an intellectual disability because it enables him to do normative peer activities that supersede disability and are valued by every young person, including "hanging out" independently and away from parents:

I feel that you know he doesn't need to be with his parents all the time, he needs to be with other people who are at the same age as him right? I mean that are not developmentally challenged right? So hanging-I think just hanging out, I think that's quite important that he hangs out with other people other than his parents. Cause I'm sure you don't go hanging out with your parents all the time, right?

Lillian simultaneously attributes the importance of her son getting away from his parents all the time with normative notions of adulthood while also shining a light on the fact that the alternative to a worker is his parents.

4.3.3 Navigating the Dating World and Managing Expectations Amid a Different Set of Rules

Four of the mothers said that their child had some experience with dating relationships. Alexandra's son had had many girlfriends over the years, including a few long-term ones. Pat's son had gone on a couple of dates with someone he met at Special Olympics. Anna's daughter had been with her boyfriend for six years at the time of the interview. Liz explained that her daughter has had men show interest in dating her, but she has never shown an interest back. Susan's son had had a long-term relationship with his girlfriend from high school who was also her son's main friend, "They would hang out, come to dinner, do movies, you know- go bowling together and all sorts of stuff."

Lillian and Pat both indicated that their sons wanted girlfriends but lacked the skills that would be required to develop this type of relationship. Lillian stated, "I don't know whether he would even know how to go about to foster that relationship, I don't know if… he would be able to do that." Pat also talked about her son's skills in relation to dating, using the example of how her son's first dating relationship fizzled out due to a lack of effort:

> *She was so sweet and so nice, but he didn't make any efforts. You know?*
> *She would Facebook him and that's how they would stay in contact, and*
> *she- cause she wanted a- like a real dating situation, whereas he was just*
> *happy to think, 'I have a girlfriend. I'm done here now. I got that- check*
> *off that box' you know, sort of thing [Laughs].*

Pat's use of the phrase "real dating situation" suggests that her son does not see dating or having a girlfriend the same way she does.

Some participants expressed that their sons, in particular, need more opportunities to learn how to date instead of gleaning inaccurate insights about these things from classes and the places they socialize. Lillian's son wanted to find someone to date, but she is not sure how to help him and seems to imply that broaching these issues might even be considered inappropriate: "There's never been a program to say like 'Oh how would you go about if you wanted to have a girlfriend?' Like, how would you go about doing that? Right? He hasn't, like it's all been more, 'that's inappropriate' right?" Lillian and Pat both shared stories of instances where their sons had gotten into trouble in their day programs and sports activities for hugging or touching their friends. When describing how upsetting it was for her and her son when he was chastised by staff at his day program for doing this, Lillian drew on her own beliefs about what would be considered inappropriate: "I wouldn't consider a *hug* inappropriate touching. Like to me, when somebody says inappropriate touching it means in their private areas, right?"

Pat shared a story of her son getting into trouble for patting a teammate on the back during a game. She too felt that there is too much focus on inappropriate behaviours, to the point where all touch between men and women with intellectual disabilities are labeled as sexual when they are not. Pat reflected on how people tend to judge the behaviours of men with intellectual disabilities differently and pathologically, or as someone dangerous, compared to men who do not have MID:

I think that with young men with developmental disabilities it's much quicker to sort of slap that creep factor onto it? When it comes to sexual behaviour, even inadvertent flirty type of behaviour. It's labeled much quicker and sort of into a creep factor… than somebody who doesn't have a disability.

To spare her son from exhibiting behaviour that can be misconstrued as sexual or creepy, Pat said, "We're struggling to teach him not- just don't touch people." Pat added that her son tries to emulate the situations he sees on TV shows and movies in order to flirt and connect with women, which puts him at risk of getting into trouble and inadvertently violating someone's consent:

He has a tendency to- he tries to enact things, not the being in bed or the actual act of sex, but he'll try and, you know, walk up to a girl at Special Olympics and put his arms around them. And it's like you can't just do that. You can't- especially since we live in sort of that- we live in this consent age, where it even comes down to putting your arms around somebody- you don't do that. And he has a hard time because on TV they do that.

She went on to explain that she and her husband spend a lot of time correcting what he sees on TV, telling him, "That's on TV to look like this, this isn't necessarily the way

things happen." Further complicating the issue is that he sees his sibling and her friends interacting in ways that look like what he sees on TV:

> *But it's just difficult for him because he sees the life that his sister lives with all her buddies and friends and they do campouts in the back yard and they'll sit around the campfire [Laughs] and it kind of does to a certain extent look like something that's happening on one of these TV shows that he watches. And then he goes out and he has to live by a completely different set of rules.*

With respect to ideas about marriage, which some of the participants talked about, Pat and Anna had different expectations than their children did. Both of these participants seemed to assume that their children wanted to get married because they think it is what they should do, which to them as parents is an unrealistic goal. Anna said, "I mean her and her girlfriends talk about that kind of stuff, you know, but I mean that- I don't know sometimes it's what they see in the movies right? Like there is a little bit of that right? Cinderella movies…" Framing her daughter's desire to get married as a child-like fantasy illuminates how vulnerable and incapable she views her daughter in terms of her unique aspirations as well as her abilities to have a meaningful long-term relationship with a man.

Anna also shared that she has told her daughter and her boyfriend: "'Everybody doesn't have to get married to have a wonderful relationship", which is something she thinks her daughter's boyfriend agrees with. She shared: "I truly believe if Emmit was

thinking that way, he would talk to us [Anna and her husband] about it first. I do, he's smart. Yeah, but I think he's smart enough actually to know that it's fine the way it is." Pat also expressed paternalistic attitudes towards her son's hope to get married, stating that his view of the world and his desires are not in line with the plans and perspectives of those around him:

Yeah, I don't think he sees the world the way the rest of us see it for him… like just- it's just something that he's going to do, it's not something that he actually considers the consequences of, or you know that he would actually even have to make an effort for this to happen.

4.3.4 Assessing the Potential for and Mitigating Parental Concerns About Their Children's Sexual Activity

All of the mothers expressed near certainty that their sons and daughters with MID had never engaged in sexual activity with a partner beyond kissing, cuddling, and handholding. Anna stated, " I'm pretty much positive there hasn't been any of… that happening. I mean they kiss, they're cuddling all the time, they're on the couch cuddling and they kiss, I know that but beyond that I don't think so." When discussing her son's past relationship, Susan said, "No they weren't [sexually active]. I mean, but they hugged and kissed, but that- I think that's as far as it went." Pat's son went on a few dates that "ended with handholding and a kiss goodnight on the cheek."

Participants with daughters were more reserved in discussing the potential for their children to one day have a sexual relationship than participants with sons. Liz did

not speak about her daughter's future romantic and sexual relationships at all, other than to say that, "It has to be the right person, the right fit", while Anna expressed that she feels her daughter Heather does not need or desire sexual activity beyond kissing and cuddling in her relationship:

> So I- I think they just, Heather's happy to have that somebody, right, and she, oh my God, she like loves him, I mean there's no…. they love each other- that we know. You know you just have to say the word Emmit and it's like [Eyes wide] you know like it's just too cute. But they- in that way they're like teenagers, you know? It's that young love, it's cute. It's cute.

Anna's description of her daughter's relationship as "cute" denotes a sense of infantilization, which may be used to justify or rationalize her belief that her daughter and her boyfriend do not have sexual needs. This very limited interpretation of her daughter's sexual potential is likely also deeply bound up with Anna's fears of something untoward or inappropriate taking place in her daughter's life that is linked with sexuality, i.e., pregnancy, STIs, and abuse.

Participants with sons were far less reserved when discussing the prospects of their children having sexual relationships in the future. In fact, they seemed to position a sexual relationship or experience as something aspirational and very positive for their sons. Pat stated, "I think it would be very sad if he lived a whole life without some form of sexual relationship- it would be nice for him, I think, to have that." Susan wants her son to have a sexual relationship in the future, attributing this to how she sees her son as

having a desire for intimacy: "I would love that for him, because he's a very physical person, right?" While Alexandra also wanted her son to experience a sexual relationship at some point in the future, saying, "I'd like him to have what we all have." This stark gendered divide reflects the degree to which parental decisions and perceptions are shaped by standard, often very limited, models of not only female and male desire but also their children's abilities to occupy the 'right kind' of identity for an adult with MID.

While hopeful and open to the idea of their sons having sexual relationships in the future, they all had caveats that would have to be in place for it to be acceptable. Pat had concerns about sex, stating, "It would take a lot of- it would have to be managed to a certain extent." Pat then talked about the factors that would have to be in place for her to be fine with her son having a sexual relationship, placing herself in the role of ensuring the conditions are met: "You'd have to make sure the other person is also interested [Laughs]. You know… and um contraception would have to be dealt with, you know- all those things. But you know, the whole all-over concept of it, I have no problem with that." One of Susan's main considerations was the level of commitment between her son and a future partner, citing concern that they may be more heartbreak involved for her son should the relationship not last:

> *I guess it would depend on how long they'd been together and how long they were seriously thinking of marriage. Or yeah. Cause that- I think then that gets into a- cause then I saw how difficult it was with [Ex-girlfriend]… I think,, getting into a sexual relationship then raises that emotional factor just that much more. Right?*

Susan added that her son may not know how to engage in sexual activity and would therefore need to learn how: "It's [sex] not necessarily intuitive on what to do… the mechanics of it." Lillian added that the way sex is framed in negative ways makes her wonder if her son would be capable of having a sexual relationship at all: "I don't know if it's been too instilled in him as well like inappropriate touching and stuff, right? Like how does he perceive that?"

The mothers reported that their sons and daughters had received some form of sex education, either in school, through a community program, through a support worker, or themselves. Parents showed varied preferences for the breadth of sexual knowledge that their children obtain. Alexandra was pleased with the knowledge Randy had received through sex education classes at a community agency, which he has taken multiple times over the years. She stated, "He does know what, you know, condoms are, what they're for and yes about pregnancy and yes about anything else… so I hope he remembers what he was taught but since he's got a good memory, I'd say, he does."

Anna's daughter visited the health unit with her support worker for a few classes, and she thinks sex education may have been part of that but is unsure. Anna also states that her daughter attended a sex education course at a community agency that she thinks focused, "more in depth about things you have to- you know, safety issues." Pat has educated her son about procreation, but has refrained from talking about STIs, because she believes there is no need for it at this time, drawing on the highly supervised context of his life:

I just can't imagine that he would be somewhere where he would meet someone, be in a situation where he would be involved in a sexual relationship and we'd be unaware of it? So we haven't really addressed that, but he does know about it- like about condoms, he knows that by having sex that's how babies come about… you know somebody could get pregnant. He'd probably welcome that but I wouldn't [Laughs]. But STIs, that's something we haven't even approached, you know. But it is something that if he were living more on his own, then yeah- I definitely would talk to him about that.

Pat's concerns with preventing her son from procreating are reflected in the following statement, where she regards permanent sterilization measures as ideal for her son: "Ultimately, I would love a vasectomy! But that's not gonna happen because he would never consent to that and because of the laws, you know… he has the right to say no." Although she recognizes that forcing him to have a vasectomy would be ethically and legally questionable, Pat believes that a permanent method would be best for him because he would not be able to use other forms of contraception, saying that, "condoms are too sophisticated for him." Pat added that the inability to use condoms is often a reason for staff in group homes enforcing abstinence, so when she no longer has as much control over his life, a permanent method would give him more freedom to have sex in the future.

Pat then stated, "I know my son. I know his capabilities, and there's nowhere even ten years down the road that those- the capabilities required for parenting would be-

he would have." She adds that the skills necessary could not be taught: "I mean you can be taught to do dishes, you can be taught to walk a kid to school, but the emotional intelligence that you need in order to raise a child… I don't think he would have… I just- he would forget about them. He doesn't- he forgets, he just forgets, and he'd forget that they're there. [laughs] you know." Pat also stated that her son's desire for children in the future is simply due to him wanting to emulate normative expectations of adulthood, and not a real desire, stating "And again wanting children is just a matter of…. cause that's what he thinks he's supposed to have."

Like Pat, Anna expressed concern about her daughter's ability to be a parent as a result of her impairment and chose permanent contraception as a way to mitigate this concern. Anna recounted the experience of her daughter's tubal ligation as an opportunity that arose while she was prepping for a different surgical procedure. This powerful exchange reveals the degree to which leading examples of her daughter's inability to do the work of motherhood, which are tied to the hard work of taking care of herself, in the process of getting Heather sterilized. The intersection between parental concerns as well as deeply entrenched infantilization intersect with medical authority in the form of the nurse practitioner, who was essential in the 'conversations' with Heather about her reproductive future:

> *We did get her tubes tied. Just in case, you know… we have a new Nurse*
>
> *Practitioner and she's like, 'Heather, I know you're telling me you're not*
>
> *doing anything with Emmit sexually, but if- what if it happened? Would*
>
> *you want to look after a baby?' She was very forthright with her, you*
>
> *know? And uh we have, I have granddaughters now and Heather's with*

me a lot looking after these girls so I said, 'So Heather, so she's asking could you like look after [Granddaughter]? Feed her, change her diapers, do…' She's like [Shakes head], 'I can't do that'. [Laughs] as simple as that! So the Nurse Practitioner said to Heather, like, 'You would not want to have the chance of being pregnant right?' And she said, 'No. I don't- I can't look after a baby.' And I said, 'Because it's enough work to look after yourself, right?' And she goes, It is."

4.4   Discussion

The findings discussed in this chapter focus on the experiences of mothers of adults with mild intellectual disability (MID). The themes presented in this chapter are organized around the roles that mothers take on in the lives of their adult children with MID as they navigate the development of independence and socio-sexual relationships. The findings presented in this chapter both confirm and extend what is currently known about parent's experiences related to sexuality, independence, and autonomy among adults with MID. It adds to the scant but growing research on the caregiving dynamics between parents of adults with MID and their children (Baumbusch et al., 2017), particularly of mothers, as they tend to take on the majority of the caregiving role within the family (Thackeray & Eatough, 2015).

Participants who had their adult children living with them in the parental home discussed the essential roles they play in managing their children's day-to-day lives and routines. This included facilitating their involvement in activities outside the home, as well as organizing their schedules, finances, and transportation. These parents expressed

that without their influence, their children would not be doing anything at all. The participants drew on comparisons to the typical trajectory of adult life after high school, noting the lack of opportunities for employment and socializing as compared to their children's peers without intellectual disabilities. This is in line with the current research that parents of adults with MID continue to be heavily involved in their children's lives into adulthood (Baumbusch et al., 2017; Boehm & Carter, 2019; Foley, 2018; Forrester-Jones, 2021; Kammes et al., 2017; Nelson-Goff, 2016; Thackeray & Eatough, 2015; Young-Southward et al., 2017; Yidiz & Cavktar, 2020). Like previous research, some parents specifically discussed the difficulties they and their children faced as a result of exclusion from gainful employment and less opportunities to socialize after completing high school (Nelson-Goff 2016; Young- Southward, et al., 2017). By taking control of their child's routines and daily activities, the parents act as a buffer against this discrimination and exclusion, perhaps in attempts to protect their children from feeling the negative effects of their exclusion by creating routines that approximate norms in adulthood.

All of the mothers expressed concern for their child's future in regard to who will take their place in orchestrating the ins and outs of their children's lives when they are unable to do so as a result of advanced age, illness, or death. This is in line with previous studies that found parents have a lot of anxiety about the future (Baumbusch et al., 2017; Boehm & Carter, 2019; Codd & Hewitt, 2021; Forrester-Jones, 2021; Nelson-Goff et al., 2016). The future care needs of their children were highly intertwined with family needs as a whole, particularly in regard to the family's ability to fully support the adult with MID.

All but one of the mothers envisioned highly dependent futures for their children, characterized by living arrangements that support intensive care contexts. This is in line with previous studies, where parents were found to have significant difficulty imagining independent futures for their children (Kammes et al., 2020; Young-Southward et al., 2017). Like previous studies, the belief in their child's inherent vulnerability to harm on account of their impairments factored into these views (Baumbusch et al., 2017; Boehm & Carter, 2019; Kammes et al., 2020; Nelson-Goff et al., 2016; Thackeray & Eatough, 2015). The parents in this study also drew on their perceptions of their child's inherent capacity to obtain skills necessary to support independence in their futures, with most participants expressing a static view of their child's development.

Participants described two general contexts within which their children socialize; segregated vocational and leisure programs such as agency-run day programs and sports teams, and the less structured socializing characterized by hanging out with the sole purpose of spending time with friends. Participants credited themselves for supporting their children's access to both types of socializing. The participants expressed a preference for supervised socializing, drawing on perceptions of their children's vulnerability; This is in line with the literature on preference for supervised contexts when socializing on account of concerns for safety (Baumbusch 2017; Foley, 2018). The mothers in this study all facilitated a friendship with a support worker or non-MID volunteer to form a relationship with their child, citing the need for their children to have a friendship with non-disabled peers. The use of a support worker or volunteer seemed to coincide with hanging out, suggesting that the mothers perceive their child to be more

vulnerable in the presence of other people with MID, especially in unstructured environments.

Some of the mothers expressed that their children had to abide by a different set of rules when it came to socializing and dating, as their behaviour could more quickly be labeled as sexual and/or predatory when not meaning to be. Three mothers expressed that their sons had gotten into trouble to varying degrees in their day programs or sports teams for inappropriate touching, when they do not believe their sons meant to inflict any harm. This is in line with literature saying that people with MID face more intense monitoring against sexual behaviour (Codd & Hewitt, 2021; Foley, 2018; Kammes et al., 2020; Shakespeare & Richardson, 2018; Tamas et al., 2019). The adherence and acceptance by one of the mothers to enforcing strict rules of behaviour on her son could represent an effort on her part to protect him from a different form of vulnerability whereby her son is deemed at risk of legal and social repercussions as a result of societal attitudes and stereotypes towards men with MID.

Some mothers discussed the need to correct their children's expectations in regard to dating, marriage, and reproduction, drawing on the ways in which their children's expectations and hopes for the future are not realistic for them as a direct result of their impairments. This is in line with literature that posits that parents feel their adult children with MID are less likely to develop both sexual and romantic relationships (Kammes et al., 2020).

There was a stark contrast between the ways in which mothers of sons assessed the potential for sexual activity in the future and the ways mothers with daughters did (or did not). The mothers of sons all expressed that their sons had sexual needs, whereas the

one mother of a daughter who spoke about sexuality did not see her daughter as having any sexual needs and used infantilizing language when talking about her daughter's relationship. This supports previous research regarding parental attitudes to their children with MID's sexualities, whereby parents held more liberal attitudes towards the sexuality of their sons (Tamas et al., 2019). In a study by Foley (2018), parents were also found to have differing attitudes towards the sexuality of sons and daughters, where mothers of sons hoped their children would experience sexual relationships in the future but perceived their daughters as only needing loving relationships.

Chapter 5

5   Conclusion

5.1   Introduction

People with MID desire intimate relationships, just as their non-MID counterparts do (Healy, McGuire, Evans, & Crowley, 2009; Kelly, Crowley, & Hamilton, 2009; Walker-Hirsch, 2007). While many people with MID desire sexual expression, they experience multiple social, familial, and structural barriers in doing so. These barriers mean that people with MID have fewer opportunities to learn about relationships and sexuality than their non-intellectually disabled counterparts (Walker-Hirsch, 2007). Adults with MID experience a lack of privacy from professional and parental/familial caregivers' involvement in their lives (Healey et al., 2009; Kelly et al., 2009). For individuals with MID, their caregiver(s) place many restrictions on their lives due to fears of abuse or unwanted pregnancy (Foley, 2012; Shepperdson, 1995). Caregivers of adults with MID may also experience discomfort and not know how to address this domain in the lives of adults with MID (Abbot & Horwath, 2007; Foley, 2012).

These issues are embedded in a long history of exclusion from society on account of their impairments and their interactions with societal eugenicist concerns regarding reproduction (Kempton & Kahn, 1991; Simmons, 1991; Trent, 1994). These concerns led to unjust regimes of control including forced segregation via institutionalization as well as forced sterilization (Kempton & Kahn, 1991; Simmons, 1991; Trent, 1994). There are now policies that advocate for the right to equal participation in society for people with

MID including reproductive rights (See: Canadian Charter of Rights and Freedoms, 1982; Canadian Human Rights Act, 1985; Ontario Human Rights Code, 1990; Ontario Health Care Consent Act, 1996; The UN Universal Declaration of Human Rights, 1948; and the UN declaration on rights of disabled people, ratified by Canada in 2007). These commitments at the level of policy are not always enacted at the individual level, however, with people with MID still facing significant difficulties in accessing social and sexual relationships on an equitable basis as others (Abbot & Horwath, 2007; Crowley & Hamilton, 2009; Foley, 2012; Healy, McGuire, Evans, & Carley, 2009; Seibers, 2008; Shakespeare, Gillespie-Sells, & Davies, 1996; Shildrick, 2008; Walker-Hirsch, 2007).

The primary purpose of this critical qualitative study was to explore how adults with mild intellectual disability (MID) develop and maintain socio-sexual relationships within the context of dependence on care environments and caregivers. Three research questions that provided the framework for the study were as follows:

1) What role does the issue of independence play in the development of sociosexual relationships among adults with MID?

2) To what (if any) extent do caregivers and others in the social/care environment create barriers in the development of these sociosexual relationships? And;

3) How do these experiences with and potential challenges related to relationship formation affect the social and sexual health of adults with MID?

5.2   Dissertation Structure

The findings from my study are presented in Integrated Article format in three chapters. Chapter Two is published in *Research Involving Participants with Cognitive Disability and Difference: Ethics, Autonomy, Inclusion, and Innovation* (Casio & Racine, eds, 2019), with an expanded methodology section. The other two, comprising chapters Three and Four, are in in publishable format but have not yet been submitted for publication. It is my intention, after completing my doctoral degree, to adapt these articles for this purpose. Journals of interest for publication include *The Journal of Applied Research in Intellectual Disabilities, Disability & Society*, and *The Canadian Journal of Disability Studies*.

Chapter Two provided an overview of the methodology of the study, combined with findings and a discussion of the methodological challenges to including adults with MID in research. Specifically, I discussed how perceptions of vulnerability led to difficulties in gaining access to this population for recruitment and carrying out interviews with participants with MID. Findings from my study regarding dependence, vulnerability, and sexuality mirrored some aspects of the recruitment process; Specifically, the power of caregivers to mediate participation in both socio-sexual life and research via control over access to public and private spaces within which to engage with others.

Chapter Three presented and discussed key findings from the interviews with adults with MID as they discussed their lived experiences navigating independence, developing and maintaining sexual relationships, as well as hopes for future relationships.

The findings in chapter three are organized around four broad themes: 1) challenges in relationships, 2) sexual health, 3) sexual violence and abuse, and 4) reproduction.

Chapter Four presented findings from the interviews with parent participants who happened to all be mothers. The mothers discussed their roles in the lives of their adult children with MID, as well as their perceptions of their children's current and future capacities for independence. The findings are organized around four main themes in regard to their perceived roles in their children's lives: 1) a managerial role in which they manage the day-to-day activities of their children, 2) facilitators of access to structured and supervised social spaces, 3) supporting their children in navigating the dating world and managing their expectations, and 4) assessing and mitigating risk associated with current and future expressions of sexuality.

To accompany the following discussion, the table below outlines the thematic foci of each chapter, including identified themes and subthemes.

Table 1 Themes and subthemes as presented in the thesis

Chapter/Article	Themes	Subthemes
Chapter 2: Methodology and Mediators of Inclusion	Interconnectedness between caregiver and person/participant with MID	• Logistics (scheduling, transport, decision-making) • Safety concerns and perceptions of inherent vulnerability • Lack of privacy
	Control over public and private spaces	• Control over access • Control over rules of behavior • Lack of freedom
	Participants with	• Requesting additional information

	MID as active negotiators in the research process	• and clarification • Communicating non-consent to certain research activities • Identifying issues and proposing solutions
Chapter 3: "I'm just trying to talk to somebody…"	Challenges in relationships	• Establishing and maintaining emotional intimacy • Unhealthy relationship dynamics • Finding someone to date • Surveillance and rules influencing opportunities for intimacy
	Sexual health	• Variable but limited understanding of sexual health topics (STIs, condoms, pregnancy, consent) • Influence of age as well as variety of sources of sexual health information • Partners and friends as knowledge-sharers
	Sexual violence and abuse	• Instance of sexual abuse and violence shared when discussing understandings of consent • Lack of legal ramifications for perpetrators and enduring effects of on the lives of participants
	Reproduction	• Varied interest in having children in the future • Surgical sterilization normalized (e.g. use of the term, "fixed") • Lived experience of coerced surgical sterilization

Chapter 4: "I'm the one that's still pulling the strings…"	Managing the day-to-day lives of their adult children with MID	- Organizing, planning, scheduling activities - The necessity of the managerial role/lack of alternatives for their children - Concerns for the future due to ack of adequate government funding and options for housing - Envisioning dependent futures for their children
	Facilitating access to structured and supervised social spaces	- Preference for supervised, structured social activities - Dependence on parents to socialize is necessary- safety concerns, planning, transportation - Normative comparisons of their children's social lives
	Navigating the dating world and managing expectations	- Assessments of dating skills and capacities for relationships - More opportunities needed for their children to learn how to date and develop relationships - more opportunities needed for parents to support them in how to date and develop relationships - Different set of rules and expectations for present and future relationships

	Assessing current and future sexuality and mitigating risk	• The influence of gender on assessments of present and future sexual behavior • Caveats to sexual behavior • Perceptions of capacity and vulnerability as justifications for restrictions and surgical sterilization

5.3   Discussion of Study Findings

Issues of disability are not just questions of impairment, functional

limitations, or enfeeblement; they are issues of social values,

institutional priorities, and political will. They are questions of power:

of who and what gets valued, and who and what gets marginalized.

(Devlin & Pothier, 2006, pg. 9).

Challenges that people with MID continued to encounter include a lack of freedom to

socialize outside of segregated and supervised spaces, more strict rules regarding social

behavior, sexual behavior, and reproduction, not being provided adequate information on

relationships and sexual health, and sexual violence. These findings support what is

currently understood about issues facing people with MID as they navigate their social

and sexual lives in adulthood (See Baines et al., 2018; Finlay, et al., 2015; Healey et al.,

2009; Kelly et al., 2009; McDaniels & Fleming, 2018; Schaaffsma, Kok, Stoffelen, &

Curfs, 2016). The findings in this study contribute important insights to the literature

concerning independence, relationships, and sexual and reproductive autonomy as

experienced by people with MID and parental caregivers.

5.3.1 (In)Dependence and (Inherent) Vulnerability

Exploring the issue of dependence in relation to socio-sexual relationships was significant in this research study. A salient thread present in the findings was what I will term an *assumption of dependence*. I conceptualize this as the ways in which people with MID were unsupported, and in many ways were actively excluded from opportunities, to gain independence. Subsequently, their dependent status was at times weaponized against them in the form of justifications for caregivers to engage in paternalistic practices that undermined their autonomy. Participants with MID and caregivers provided implicit and explicit examples of how adults with MID are excluded from gainful employment and other vocational opportunities after high school, demonstrating a lack of options for them to participate in adult life in an equitable basis compared to their peers. This is in line with current literature that addresses challenges experienced by adults with MID as they transition out of high school (Nelson-Goff, 2016; Young- Southward et al., 2017). Furthermore, parent participants of adults with MID described insufficient governmental supplemental income programs for adults with MID, which ultimately contributes to their long-term dependence on others. This lack of funding also supports the experiences of parental caregivers maintaining a strong presence in their adult children's lives well into adulthood (Baumbusch et al., 2017; Boehm & Carter, 2019; Foley, 2018; Forrester-Jones, 2021; Kammes et al., 2017; Nelson- Goff, 2016; Thackeray & Eatough, 2015; Young-Southward et al., 2017; Yidiz & Cavktar, 2020).

In this study, the weaponizing of dependent status was heavily intertwined with assumptions of people with MID as inherently vulnerable, and thus in need of protection in the forms of segregation and near constant surveillance (Hollomotz, 2011; Kammes, et al., 2020). This perception of vulnerability represents an individualistic or deficit-based view of disability, whereby the problem, in this case, dependence and vulnerability, are located within the person with an impairment (Hollomotz, 2011; Kammes et al., 2020; Shildrick, 2012). Subsequently, a deficit-based view of impairment requires that the solution to the problem also lies within the person with MID, providing justification for restrictions on choices as well as near-constant surveillance.

The political and economic context within which this assumption of dependence is operating in reflects neoliberal values of independence, economic restraint, and reliance on government as a last resort (Krogh & Johnson, 2006; Russel, 2019). Budget cuts and fiscal restraint by governmental agencies that are responsible for providing support for people with intellectual disabilities negatively influence people with intellectual disabilities as well as their family caregivers (Forrester-Jones, et al., 2021). The assumption of dependence is reflected in the findings when participants discuss the lack of financial resources allocated towards supporting people with MID in adulthood, as well as the waitlists for funding and housing supports. These findings suggest that the government within which the participants are organized are highly dependent on parental caregivers to provide support to their children with MID until they are no longer able to.

5.3.2 Boundaries of Sexual Expression for Adults with MID

Participants with MID did not vary much in terms of where, when, with whom, and how they socialize. All participants described segregated and structured leisure and vocational programs and activities as being extremely beneficial to establishing social connections and finding partners. These spaces are extremely influential for the development of their social, romantic, and sexual relationships, as has been found in other qualitative studies on dating behaviour among people with intellectual disabilities (Bates et al., 2017). The rules of behavior, however, are restricted to the goals of these settings, which are largely determined by others. This can pose significant challenges to acting autonomously within these settings, and if, like many participants attested, they do not have control over accessing other spaces or have control over private spaces within their own homes, they are left with few options for developing their relationships autonomously and privately.

This lack of control over public and private spaces reflects the ways in which people with MID have historically been managed, and their sexualities governed, through supervision, segregation, and strict rules of behavior (Feely, 2016; Harris-Zsovan, 2010; Kempton & Kahn, 1991; Simmons, 1991; Trent, 1994) and is also a reflection of how these historical techniques of control are still active today, although in a more subtle way (Feely, 2016). Feely (2016) posits that day programs are an integral site of sexual surveillance and control for people with intellectual disabilities, and the people with disabilities who access them are subject to the same disciplinary techniques of segregation and surveillance within them as they were prior to de-institutionalization. He argues that the fears surrounding the sexual expression of people with MID within these spaces are no longer about preventing reproduction for eugenic purposes, but rather,

preventing abuse on account of perceptions of people with intellectual disabilities as inherently vulnerable (Feely, 2016). The result of this in day programs, he argues, is surveillance and strict rules of behavior that attempt to prevent and act on perceived sexual impropriety (Feely, 2016). In their research that included risk factors for abuse among people with intellectual disabilities, residential and day program settings were found to be a risk factor for abuse (Beadle-Brown et al., 2010; McCarthy et al., 2022), challenging the notion that day programs and residential settings are places where people with intellectual disabilities are most safe. Furthermore, surveillance, lack of privacy, and fears of disapproval by others can lead to behaviours that increase the risk of abuse in relationships and sexual violence due to the need to keep relationships secret (Hollomotz, 2011; McCarthy et al., 2022; Santinele, 2022).

The findings in this study have demonstrated instances where the boundaries of sexual expression differed according to sex for the adults with MID. Parental caregivers' views of their children's current and future potential for sexual relationships were embedded in highly gendered notions of masculine and feminine sexuality. While all parents had caveats to sexual activity that drew on their children's inherent vulnerabilities, mothers of sons were far more liberal in their attitudes than mothers of daughters. This is perhaps a reflection of historical notions of people with intellectual disabilities as being either hypersexual or asexual (Shakespeare, Gillespie-Sells & Davies, 1996; Shakespeare, 2003; Shepperdson, 1995; Walker-Hirsch, 2007).

5.3.3 Sexual Violence

Several participants with MID disclosed that they had experienced sexual violence at some point in their lives. This is in line with what is currently known about people with intellectual disabilities and their high rates of sexual violence and abuse as compared to the general population (Balogh et al., 2001; Beadle-Brown, et al., 2010 Eastgate et al., 2012; Fine, 2019; Mahoney & Poling, 2011; McCarthy & Thompson, 1997; Shakespeare, Gillespie-Sells, & Davies, 1996). In addition to the injustice of the sexual abuse encountered, some participants described how little was done to the perpetrators of these crimes. The standard for preventing sexual abuse and violence often involves educating people with intellectual disabilities on how to avoid, detect, and report sexual misconduct (Mahoney & Poling, 2011). This highly individualistic approach fails to focus the problem on the social, institutional, and structural factors involved in violence committed against people with MID (Fine, 2019). As the individualistic approach to preventing sexual violence places responsibility for the crime on the person with MID, it is also used as a justification by caregivers to engage in restrictive and autonomy-limiting practices in the name of protection (Codd & Hewitt, 2021; Eastgate et al., 2012; Hollomotz, 2011; Mahoney & Poling, 2011; Shakepeare, Gillespie-Sells, & Davies, 1996; Thackeray & Eatough, 2015; Turner & Crane, 2016; Yidiz & Cavktar, 2020).

While both men and women with MID in my study were represented in the group that disclosed having experienced sexual violence, like stated in the literature on sexual violence among people with intellectual disabilities (Balogh, et al., 2011; Beadle-Brown, et al., 2010; Mahoney & Poling, 2011; McCarthy & Thompson, 1997; Sampson, 2006) more women than men disclosed this in their interviews. In Sampson's (2006) research

analysis of sexual violence faced by women with intellectual disabilities in the legal system, she asserts that women with intellectual disabilities experience unequal treatment in the justice system and less legal protections than women without intellectual disabilities (Sampson, 2006). McCarthy and Thompson also found that abuse against women with intellectual disabilities was not taken as seriously as abuse against men with intellectual disabilities, with abuse against men being far more likely to be reported to law enforcement (1997). Sampson further draws on the historical and more current stereotypes of women with intellectual disabilities as either hypersexual or asexual; and more specifically, how these stereotypes allow the justice system to view women with MID as "bad" (p. 280) victims (2006). Her analyses of several cases involving women with intellectual disabilities as victims in sexual violence cases demonstrate how these biases influence how the legal system views them as deserving victims on account of promiscuity, or victims that invited the assault unwittingly (Sampson, 2006).

5.3.4 Reproduction

Participants with MID and parental participants discussed issues concerning reproductive autonomy of adults with MID. Some participants discussed how they or their partners could not have children because of invasive measures such as tubal ligation, partial hysterectomy, and vasectomies. These issues are embedded in the long history of eugenicist fears of people with intellectual disabilities reproducing (Harris-Zsovan, 2010; Kempton & Kahn, 1991; Simmons, 1991; Trent, 1994), which have been and are highly intertwined with assumptions of the value of people with intellectual disabilities. generally, in society; namely, an individualized assumption of disability as burden

(Hollomotz, 2011; Kammes et al., 2020; Shildrick, 2012). My research findings demonstrate that although moral and legal views of forced sterilization for eugenic purposes have dissipated, the practice of sterilization still occurs, albeit for different justifications. While all people should have the freedom to choose surgical measures to prevent pregnancy, including people with mild intellectual disabilities, the participants shared troubling stories involving overt or implicit coercion based on assumptions of their capacities to care for others, to care for themselves, and in two instances, their capacities to manage menstruation. This represents a deficit or individualized assumption of disability as burden (Hollomotz, 2011; Kammes et al., 2020; Shildrick, 2012). The lived experiences also demonstrate violations of human rights policy (See: Canadian Charter of Rights and Freedoms, 1982; Canadian Human Rights Act, 1985; Ontario Human Rights Code, 1990; Ontario Health Care Consent Act, 1996; The UN Universal Declaration of Human Rights, 1948; and the UN declaration on rights of disabled people).

The justifications for and experiences of surgical sterilization for participants were gendered, based on assumptions of not just capacity but also assumption of the sexualities of men and women with intellectual disabilities. Research on surgical sterilization suggests that for men with MID, the benefit is greater sexual freedom (Barton-Hanson, 2015, Li et al., 2018) as they can act on their inherent sexual desires without concern for pregnancy. The assumptions influencing the gendered notion of surgical sterilization are exemplified in two particularly salient examples from my findings. One parent of a son who preferred her son have a vasectomy because this would give him more freedom to engage in sexual activity in the future when she is no longer

around to monitor his sexual behavior; this assumption draws on the notion that men with intellectual disabilities are hypersexual or at least, have some innate desire to be sexual. A parent with a daughter provides a contrast to this, where she believed her daughter was asexual but still encouraged her to get a tubal ligation "in case something happened" between her and her daughter's boyfriend. This represents a distrust of her daughter's boyfriend's ability to contain his sexual desire, and her daughter's relative passivity in her own sexuality.

5.4   Conclusion

Supporting people with MID in developing relationships, including potentially sexual ones is an important aspect of affirming their humanity. This is an aspect of their lives that has historically been deemed irrelevant or dangerous, and this has contributed to their past and continued marginalized status today since citizenship is highly entwined with issues of sexuality and personhood (Fine, 2019; Richardson, 2018). When supported to do so, people with MID can and do have relationships that are fulfilling (Hollomotz, 2011; Kammes et al., 2020; Kramers-Olen, 2016; Lam et al., 2019; McCarthy et al., 2022). When an individual's humanity is not acknowledged and their equality and rights are not valued and affirmed, their marginalized status in their communities in society is further reified.

The findings from this study share the lived experiences of people with MID, offering valuable insight about how adults with MID navigate the development and maintenance of socio-sexual relationships within a context of dependence on caregivers. Their lived experiences are valuable sources of knowledge because they can be drawn on

to develop and amend policies that influence the social and sexual relationships of people with MID. Including the voices of people with MID in this study is commensurate with the slogan, "Nothing about us without us," a call adopted by disabled activists worldwide (Charlton, 1998, pg. 3), and as most recently adapted by Fine (2019), "No research on us, without us." (p. 980).

The findings from this study can also be drawn on to consider the underlying assumptions that guide the governance of people with MID. This is necessary for dismantling and challenging ableism as it requires dismantling underlying ideologies that sustain oppression of people with disabilities through policies that favor the non-disabled (Fine, 2019). The findings expose a deficit-based view of disability, as it directly places the issues within the context of greater societal influences that govern this population, particularly in the context of Ontario services and supports for adults with MID. This is extremely relevant, as the system of services and supports is undergoing major changes that will undoubtedly impact the day-to-day lives and opportunities of adults with MID in Ontario (See: Ministry of Children, Community and Social Services, [MCCSS], 2022). The findings of this study provide context and real-world examples of how policies influenced by fiscal restraint ultimately trickle down and influence people with MID in their daily lives, which includes their social and sexual health and wellbeing.

Prior to and throughout my graduate studies, I was also working and volunteering in a variety of contexts providing support for people with MID and their families. I have used the knowledge gained from these findings to expose and advance conversations in informal settings and conversations with coworkers, families, and people with MID, as well as formal settings including meetings with representatives from two support

agencies. I have also begun the process of taking on an advisor/listener role for a self-advocacy group comprised of people with MID in London, Ontario. It is my intention to continue to be involved in advocacy and to take what I have learned from this study and my lived experience to do more research in the field of health promotion, with a focus on issues facing people with MID.

5.4.1 Recommendations

Based on the findings of this study, the reviewed research and literature, and my own lived, embodied experience of working in this field, I offer the following recommendations to support the development of socio-sexual relationships and health among adults with MID:

> 1) Caregivers and others involved in the lives of people with MID should educate and discuss issues pertinent to healthy relationships and sexual health often and in a variety of ways. This means caregivers and others need to be open to learning about these topics themselves, including the potential negative impacts of not addressing them. They should refrain from shutting down or redirecting away from these conversations, even if it makes them uncomfortable. This recommendation is made with full recognition that taking on this task for family caregivers is not an easy feat without support from those who allocate resources to people with MID and their families in Ontario. The parents in this study expressed needing more support from the Ministry, as they are having to buffer the effects of insufficient support by engaging in a lot work, which, as Forrester-

Jones also found in her study on caregivers of adults with ID, has been described as frustrating and tiring for these caregivers (2021). Considering the work they are already doing, the additional tasks involved in learning about and educating their children on socio-sexual health and relationships is not easily done without Ministry support.

2) In line with the first recommendation, the governing bodies that decide how resources are allocated towards people with MID in Ontario need to understand and appreciate the negative implications of not providing people with MID with the financial support they require to live in their communities. They need to be aware of how austerity measures stray from the commitments found in the policies assuring that people with MID are worthy citizens that should have their rights respected on an equitable basis as others. One area that requires a stronger ministry response is to the issues of housing and poverty among people with intellectual disabilities. Although advocacy groups have called for increases in the Ontario Disability Support Plan (ODSP) for shelter and basic needs (Canadian Broadcasting Corporation [CBC], 2022), in July of 2023, the Ontario budget increased monthly payments by a mere 6.5 percent (MCCSS, 2023). The new maximum monthly amount an adult with an intellectual disability living independently in their own accommodation could receive is $1,308, which is $15,696 per year (Ministry of Children, Community, and Social Services, 2023). This is still below the Canadian Low-income cutoff (LICO) for 2022 which was $19,288, and would be expected to be higher in 2023 due to inflation (Stats

Canada). Devaluing people with intellectual disabilities through policies that essentially mandate poverty only serve to reify assumptions that they are burdens on society and their families and are not worthy of having their basic needs met.

3) People with MID should be actively involved in deciding how to use the spaces that are dedicated to supporting them, including day programs and other recreational activities. This includes the rules of behaviour within them; people with MID should be involved in all decisions regarding how these spaces are used. One way that this can be done was demonstrates by Chantelle, who wanted to talk to staff about her relationship issues in her day program. Research has shown that staff do not know how to approach these issues, and there are a lack of policies in place for how to do so (Bates et al., 2020). Supporting agency staff to address these issues proactively and as they arise could be one way to address this.

4) The lived experiences of abuse, sexual violence, and coerced sterilization mean that more research needs to be done in both of these areas if we are to support the sexual and bodily autonomy of people with intellectual disabilities. Specifically, more research on the responses of the justice system and caregivers is needed to identify gaps in areas where people with intellectual disabilities can be better supported in the event of sexual violence Additionally, more research is needed to understand how coerced sterilization is occurring, considering the laws in place that are meant to stop it, such as the Ontario Health Care Consent Act (1996).

5.4.2 Strengths and Limitations

The strengths of this critical, qualitative study include the rich, thick, triangulated nature of the data (Barringer, 2006). The findings were drawn from a variety of sources including contextual participant data, transcribed interviews, reflexive notes, descriptive notes, and observations of participants (Barringer, 2006). The findings support what is known, as previously described, but also add additional insights as included in this discussion that may be used to spark discussion on the influences on socio-sexual health and wellbeing for adults with MID. The inclusion of people with MIDs perspectives and lived experiences is a particular strength, as they have historically been excluded from research of this kind (Liamputong, 2007).

The limitations of this study include a relatively small sample, and only mothers being represented in the parental caregiver data. While this is in line with current literature on the gendered nature of caregiving (Thackeray & Eatough, 2015), the perspectives of fathers would have added richness and contributed additional nuance to consider. Another limitation is that there was a lack of cultural and racial diversity among the participants, as well as a lack diversity in terms of sexual preference and gender identities. Having more diversity in participants could have provided more nuance to consider; this is because race, culture, history, and sexuality intersect with these issues in unique ways (See Block, 2002). An additional limitation is that the data was collected pre-COVID and therefore some aspects of social life have undoubtedly shifted as a result of this.

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Appendices

Appendix A: Ethics Approval 1

Western Research

Research Ethics

Western University Health Science Research Ethics Board
HSREB Delegated Initial Approval Notice

Principal Investigator: Dr. Treena Orchard
Department & Institution: Health Sciences\Nursing,Western University

Review Type: Delegated
HSREB File Number: 108059
Study Title: Exploring the Development of Independence, Sexuality, and Social Relationships Among Adults with Mild Intellectual Disability in London, Ontario.

HSREB Initial Approval Date: August 15, 2016
HSREB Expiry Date: August 15, 2017

Documents Approved and/or Received for Information:

Document Name	Comments	Version Date
Letter of Information & Consent	Parents	2016/07/07
Letter of Information & Consent	Formal caregivers	2016/07/07
Letter of Information & Consent	Participant with Mild ID	2016/07/07
Western University Protocol	Received 2016/07/16	
Recruitment Items	E-mail	2016/07/07

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above named study, as of the HSREB Initial Approval Date noted above.

HSREB approval for this study remains valid until the HSREB Expiry Date noted above, conditional to timely submission and acceptance of HSREB Continuing Ethics Review.

The Western University HSREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use Guideline for Good Clinical Practice Practices (ICH E6 R1), the Ontario Personal Health Information Protection Act (PHIPA, 2004), Part 4 of the Natural Health Product Regulations, Health Canada Medical Device Regulations and Part C, Division 5, of the Food and Drug Regulations of Health Canada.

Members of the HSREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Ethics Officer, on behalf of Dr. Joseph Gilbert, HSREB Chair

Ethics Officer: Erika Basile ___ Nicole Kaniki ✓ Grace Kelly ___ Katelyn Harris___ Vikki Tran ___ Karen Gopaul ___

Western University, Research, Support Services Bldg. Rm. 5150
London, ON, Canada N6G 1G   www.uwo.ca/research/ethics

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Appendix C: Letter of Information: MID 1

Western

Project Title: Exploring the Development of Independence, Sexuality, and Social Relationships Among Adults with Mild Intellectual Disability in London, Ontario

Principal Investigator:

Dr. Treena Orchard, School of Health Studies, Western University
1151 Richmond St., London, ON

Student/Lead Researcher:

Vanessa Cox, School of Health and Rehabilitation Sciences, Western University

Letter of Information

1. Invitation to Participate:

- You are invited to participate in this research study about independence, sexuality, and social relationships. You are invited because you have been identified as one of the following:
    - You are an adult with a mild intellectual disability who uses services for people with intellectual disabilities in London, Ontario.

2. Purpose of the Letter:

- The purpose of this letter is to give you information about this study so that you can make an informed choice about whether or not you wish to participate.

3. Purpose of this Study:

- The purpose of this study is to explore how adults with intellectual disabilities exercise independence in the development and negotiation of friendships, romantic partnerships, and sexual partnerships.
- A total of 20 participants with mild intellectual disability are going to be recruited for this study, as well as 8 parents of an adult with mild intellectual disability and 8 paid caregivers of adults with mild intellectual disability.

1   Version Date: 07/07/2016   Participant Initials_____

Appendix C: Letter of Information: MID 2

Western

4. Inclusion Criteria: You may be included in this study if you fulfill the criteria below:

- You are an adult (19 years of age or older) who uses services for people with intellectual disabilities in London Ontario.
- You speak English, and communicate verbally.
- You are able to read this letter of information.

5. Exclusion Criteria: You may be excluded from this study if:

- You do not have a mild intellectual disability.
- You are not fluent in English, and do not communicate verbally.
- You under the age of 19
- You cannot read this letter of information.

6. Study Procedures:

- If you agree to participate, you will be asked to participate in an individual interview with the lead researcher (Vanessa Cox). It is anticipated that the entire interview will take approximately 60 minutes.
- Before the interview, you can decide where you want it to take place. You may choose to have the interview in your own home, at Western University, or in a private location somewhere else in the community. You may also choose whether you would like someone else present or nearby (a parent, caregiver, or someone else you trust) during the interview.
- You can decide whether or not you want the interview to be audio-recorded.
- During the interview, I will ask questions about your friendships, romantic and sexual attractions and experiences (including questions about sexual activities), as well as some general questions about your life, such as your living arrangements.

7. Possible Risks and Harms:

- Some questions (such as those about sexual activities) may make you feel uncomfortable. If you do not wish to answer a particular question, you do not have to- we will move on to the next question. You can also stop the interview completely at any time.
- If you need support for any issues that are brought up during the interview, there are options available to help you talk through what you are feeling. For example you may decide to speak to someone you trust (a friend, parent, support worker), or call the London Distress Centre ████████████
- There is a risk that in the final publication, someone who knows you may be able to identify you by something you said. This is a risk that I take very seriously, so I

Appendix C: Letter of Information: MID 3

Western 🛡️

will use a fake name in transcription and any further publications, as well as my thesis, and I will keep out identifying information, such as names of places, and other people mentioned during the interview.

8. Possible Benefits:

- You may or may not receive any direct benefit from participating in this study.
- The possible benefits to society may be the opportunity to contribute to policies that can have a direct affect on how adults with mild intellectual disabilities are supported to develop and maintain meaningful socio-sexual relationships and healthy sexuality.

9. Compensation:

- You will be given $40.00 for your participation in this study. If you do not complete the entire study (for example you wish to end the interview after only a few questions) you will still be compensated the full $40.00.

10. Voluntary Participation:

- Participation in this study is **voluntary**. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time with no effect on your future care as a service user.
- Audio-recording is your choice- you may decide that you do not wish to be audio-recorded, or you may ask that audio-recording be stopped during the interview.
- You do not waive any legal rights by signing this consent form.

11. Confidentiality:

- Your full name, initials, and **either** your telephone number or email will be collected for this study. None of this information will be used in any publications (and the transcription of the interview) about the results of this study- a fake name will be used in place of your actual name.
- All data collected will remain confidential and accessible only to the investigators of this study. If the results are published, your name will not be used. If you choose to withdraw from this study, your data will be removed and destroyed from our database.
- Consent forms will be stored in a locked desk at Western University, which only I (Vanessa Cox) have access to. All information from the interviews will be stored on my laptop and memory stick, both of which only I have access to.
- Confidentiality may be broken if, during the interview, something is shared that indicates you or another person is at risk of being harmed, or is currently being

Appendix C: Letter of Information: MID 4

Western

harmed. For example, if you are being abused by someone. In this case, police will be contacted and they will be required to follow up with you on the matter.

- Qualified representatives of the University of Western Ontario Health Sciences Research Ethics Board may look at your study records at the site where these records are held, for quality assurance (to check that the information collected for the study is correct and follows proper laws and guidelines).

12. Contacts for Further Information:

- If you have any questions about your rights as a research participant or the conduct of this study you may contact ██████████
- If you need any further information about this research study or your participation in the study you may contact one or both of the people below:
  - Dr. Treena orchard (Principal Investigator/Supervisor):
    - ██████████████████████████
    - ██████████████████████████
  - Vanessa Cox (Lead/Student researcher):
    - ██████████████████████

13. Publication:

- If the results of the study are published, your name will not be used. If you would like to receive a copy of any potential study results, please provide your name and contact number or email on a piece of paper separate from the Consent Form.

This letter is yours to keep for future reference.

Appendix D: Letter of Information Parent 1

Western

harmed. For example, if you are being abused by someone. In this case, police will be contacted and they will be required to follow up with you on the matter.

- Qualified representatives of the University of Western Ontario Health Sciences Research Ethics Board may look at your study records at the site where these records are held, for quality assurance (to check that the information collected for the study is correct and follows proper laws and guidelines).

12. Contacts for Further Information:

- If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Research Ethi
- If you need any further information about this research study or your participation in the study you may contact one or both of the people below:
  - Dr. Treena orchard (Principal Investigator/Supervisor):
  - Vanessa Cox (Lead/Student researcher):

13. Publication:

- If the results of the study are published, your name will not be used. If you would like to receive a copy of any potential study results, please provide your name and contact number or email on a piece of paper separate from the Consent Form.

This letter is yours to keep for future reference.

Appendix D: Letter of Information Parent 2

Western 🛡️

- You are an individual who is fluent in English and has a son or daughter over the age of 19 that has a mild intellectual disability who uses services in London, Ontario.

5. Exclusion Criteria:

- You are not a parent of an adult with mild intellectual disability.
- You are not fluent in English.

6. Study Procedures:

- If you agree to participate, you will be asked to participate in an individual interview with the lead researcher (Vanessa Cox). It is anticipated that the entire interview will take approximately 60 minutes.
- Before the interview, you can decide where you want it to take place. You may choose to have the interview in your own home, at Western University, or in a private location somewhere else in the community.
- You can decide whether or not you want the interview to be audio-recorded.
- During the interview, I will ask questions about your child's friendships, romantic and sexual attractions and experiences (including questions about sexual activities), as well as some general questions about yours and your child's lives, such as caregiving and living arrangements.

7. Possible Risks and Harms:

- Some questions (such as those about your child's sexual activities) may make you feel uncomfortable. If you do not wish to answer a particular question, you do not have to- we will move on to the next question. You can also stop the interview completely at any time.
- If you need support for any issues that are brought up, you can call the London Distress Center a███████ r talk to someone you trust about the feelings that have been brought up by the interview.
- There is a risk that in the final publication, someone who knows you may be able to identify you by something you said. This is a risk that I take very seriously, so I will use a fake name in transcription and any further publications, as well as my thesis, and I will keep out identifying information, such as names of places and other people.

8. Possible Benefits:

- You may not receive any direct benefit from participating in this study.
- The possible benefits to society may be the opportunity to contribute to policies that can have a direct affect on how adults with mild intellectual disabilities are supported to develop and maintain meaningful socio-sexual relationships and healthy sexuality.

2   Version Date: 07/07/2016   Participant Initials_____

Appendix D: Letter of Information Parent 3

Western

9. Compensation:

- You will not be paid any amount of money for participating in this study.

10. Voluntary Participation:

- Participation in this study is **voluntary**. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time.
- Audio-recording is your choice- you may decide that you do not wish to be audio-recorded, or you may ask that audio-recording be stopped during the interview.
- You do not waive any legal rights by signing this consent form.

11. Confidentiality:

- Your full name, initials, and **either** your telephone number or email will be collected for this study. None of this information will be used in any publications (and the transcription of the interview) about the results of this study- a fake name will be used in place of your actual name in the transcription, and in any publications or my final dissertation, if used at all.
- All data collected will remain confidential and accessible only to the investigators of this study. If the results are published, your name will not be used. If you choose to withdraw from this study, your data will be removed and destroyed from our database.
- Consent forms will be stored in a locked desk at Western University, which only I (Vanessa Cox) have access to. All information from the interviews will be stored on my laptop and memory stick (encrypted), both of which only I have access to.
- Confidentiality may be broken if, during the interview, something is shared that indicates you or another person is at risk of being harmed. For example, if something is brought up which indicates a vulnerable person in your care or someone else's is being abused, police will be contacted and they will be obligated to follow up on the matter as needed.
- Qualified representatives of the University of Western Ontario Health Sciences Research Ethics Board may look at your study records at the site where these records are held, for quality assurance (to check that the information collected for the study is correct and follows proper laws and guidelines).

12. Contacts for Further Information:

- If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Research Ethics at
- If you need any further information about this research study or your participation in the study you may contact one or both of the people below:
    - Dr. Treena orchard (Principal Investigator/Supervisor):

3   Version Date: 07/07/2016   Participant Initials_____

Appendix D: Letter of Information Parent 4

Western ████

- : ████████████████
- :
  - ○ Vanessa Cox (Lead/Student researcher):
    - : ████████████████

13. Publication:

- If the results of the study are published, your name will not be used. If you would like to receive a copy of any potential study results, please provide your name and contact number or email on a piece of paper separate from the Consent Form.

This letter is yours to keep for future reference.

Appendix E Consent Form 1

Western 🛡️

<u>Consent Form</u>

Project Title: Exploring the Development of Independence, Sexuality, and Social Relationships Among Adults with Mild Intellectual Disability in London, Ontario

Principal Investigator:
Dr. Treena Orchard

Student/Lead researcher:
Vanessa Cox, PhD (candidate)

I agree to be audio-recorded in this research (Circle one):

YES   **NO**

I consent to the use of unidentified quotes obtained during the study in the dissemination of this research (Circle one):

YES   **NO**

I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

Participant's Name (please print): _____

Participant's Signature: _____

Date: _____

Person Obtaining Informed Consent (please print): _____

Signature: _____

Date: _____

5   Version Date: 07/07/2016   Participant Initials_____

Appendix F: Interview Guide MID 1

Interview Guide: Adults with Mild Intellectual Disability

1. Socio-demographic information:
 a. How old are you?
 b. Where do you live and/or are from originally (i.e., London or elsewhere)?
 c. How do you identify culturally (i.e., White, Indigenous, Black, Mixed ancestry)?
 d. How do you identify in terms of gender (man, woman, gender queer or transgender)?
 e. How do you identify in terms of sexual and/or romantic preference (straight, gay, lesbian, bi-sexual, queer)?

2. Independence:
 a. Who do you live with?
 b. If lives with parents, do you ever want to live on your own?
  i. Probe questions: Why or why not?, What do you like about living with parents or others? Any challenges about living with parents?
 c. If lives on his or her own, for how long have you lived on your own?
 d. If lives on his or her own, how did that decision come about- to move out of your family home?
 e. If lives on his or her own, would you describe your living situation as independent or in a community context?
 f. How has independent or community living affected your daily life?
 g. How has independent or community living affected your relationship with parents, siblings, or other people?
  i. Probe question about having more say or control in these relationships
 h. What things do you like about living on your own or in community?
 i. Is there anything you don't like about living on your own or in the community?
 j. Has living on your own impacted your ability to form relationships with other people, in friendships or with people you are attracted to in a sexual or romantic way (boyfriend or girlfriend)?
 k. Who makes most of the decisions about your school, social activities, or other things you do/enjoy?
 l. Do you ever feel like other people (family, workers, siblings) make a lot of decisions for you?
  i. Probe questions: Is this Okay with you or would you like to make more decisions about your life on your own?
 m. Are there any particular kinds of decisions you would like to make on your own (i.e., what they eat, who they spend time with)?
 n. If others tend to make a lot of these decisions- why do you think others tend to make a lot of decisions for you?

3. Socio-sexual relationships:
 a. Can you tell me about some of the people who are your friends?
 b. How did you meet these people?
 c. What do you like about these people/friendships?

Appendix F: Interview Guide MID 2

  d. Have you ever had problems or challenges with these friendships?
    i. Probe question: Are any of these challenges related to the influence of parents or others in your life?
  e. Do you have a boyfriend or girlfriend or partner?
  f. If so: how did you meet that person?
  g. If so: is this relationship different from those you have with your friends?
  h. If so: can you tell me about your relationship, the things you do together, the things you like about that person?
  i. If so: are there things you can't do with that person that you would like to do?
    i. Probe questions: If so, who or what prevents you and why?
  j. If so: have you had sex with this person or is that something you want to do?
  k. If so: have you experienced a break-up or troubles with your girlfriends or boyfriends in the past?
    i. Probe question: What was that experience like?
  l. If not: can you tell me why you haven't had a boy or girlfriend yet?
    i. Has someone prevented you from having one?, What was that experience like?
  m. How do you learn about sexuality and sexual relationships (i.e., parents, school, friends, social media, caregivers)?
  n. Are there things about sex or sexuality that you would like to learn more about?
    i. Probe questions: What things?, From whom or where?, Why these things?

4. Sexual Health:
  a. Do you know what a sexually transmitted infection is?
  b. If yes, do you know how to prevent them when having sex?
  c. Do you know how pregnancy happens?
  d. If yes, do you know how to prevent it, if you are having sex and you wish to?
  e. If they have been/are sexually active: Do you use condoms regularly with your partner (or did you? Why or why not?)
  f. What do you know about your rights when it comes to sex (E.g. saying no, saying yes to some things, no to others, etc.)?
  g. Do you know what to do if someone does not respect your rights to say no? How would you respond/who would you tell?

Appendix G: Interview Guide Parents 1

Interview Guide: Parents of Adult with Mild Intellectual Disability

1. Independence of their adult son or daughter with mild intellectual disability
    a. Does your son or daughter live at home with you?
    b. If yes, do you ever envision a time when your son or daughter will live on his/her own?
        i. Probe question: What would you hope this looked like (e.g. group home, casual support through agency, supportive roommate, etc.)?
    c. If no, where do they live?
        i. Probe questions: Are you happy with this arrangement?, Do you know if your son or daughter happy with this?
    d. What level of support do they receive (e.g. support worker, day program, etc.)?

2. Social life of their adult son or daughter with mild intellectual disability
    a. Can you describe the friendships that your son/daughter currently has?
    b. How did these friendships form?
    c. What activities do they do together?
    d. Do they rely on you for meeting up with friends (e.g. transport, arranging social activities, etc.)?
    e. Do you feel satisfied with the quality of your son/daughter's social life?
    f. Do you feel as though your son/daughter is happy with his/her level of social activity and connections with friends?

3. Sexual life of their adult son or daughter with mild intellectual disability
    a. Has your son/daughter had a romantic relationship in the past or currently (ie., boyfriend or girlfriend)?
    b. If yes, do you know if they are engaging in sexual activity with each other?
        i. Probe question if yes: Is this something you are comfortable with? Why or why not?
    c. If no, is this something you would encourage?
    d. If no, do you know if your son or daughter is sexually active?
        i. Probe question if yes: Is this something you are comfortable with? Why or why not?
    e. Do you feel your son/daughter is prepared to engage in sexual activity with another person? By prepared, I mean understanding of the risks and how to mitigate them?
    f. What form of sexual education did your son/daughter receive (e.g. from you/other parent, sibling, at school, in program, etc.)?
    g. Do you/have you talked to your son/daughter about sexuality (ie., masturbation, sexual identity, healthy sexual relationships, STI and pregnancy prevention)?
        i. Probe question: Why or why not?

Curriculum Vitae

Name:	Vanessa Cox

Post-secondary Education and Degrees:

Mount Royal University
Calgary, Alberta, Canada
2007-2010 Diploma, Disability Studies

Western University
London, Ontario, Canada
Bachelor of Health Sciences (BHSc.) Honor's Specialization
Minor: Psychology

Western University
London, Ontario, Canada
PhD (c), Health and Rehabilitation Sciences (Health promotion)
2013-2023

Honours and Awards:

Jason Lang Academic Excellence Scholarship
2007

MPTA Alberta Scholarship Winner
2011

Deans List
2007, 2008, 2009, 2012

Annual Dr. Benjamin Goldberg Research Award, 2016
Developmental Disabilities Division (DDD)
Schulich School of Medicine and Dentistry

Received nominations for 2016 and 2017 TA Awards

Related Work Experience

Residential/Vocational Support Worker
Supported Lifestyles, Ltd
Calgary, Alberta, Canada
2007-2011

Teaching Assistant
Western University, Health Science
2013-2016

SOGS Health Plan Committee
Western University

2014-2018

Teaching Assistant, Disability Studies
Kings University College
2016-2017

Research Assistant, Disability Studies
Kings University College
2018-2019

Direct Support Professional
Alice Saddy Association
London, Ontario, Canada
2018-Present

Publications:

Cox, V., Orchard, T., Cushing, P., & Kinsella, E. A. (2019). Mediators of Inclusion:
Challenges to Including Adults with Mild Intellectual Disability in Qualitative Research.
In Cascio, A., & Racine, E.(Eds.),

HRS Graduate Research Conference, 2017, *Exploring the Development of Independence,
Sexuality, and Social Relationships Among Adults with Mild Intellectual Disability in
London, ON.*

Ontario Association on Developmental Disabilities Conference, 2016, *Exploring the
development of independence, Sexuality, and Social Relationships Among Adults with
Mild Intellectual Disability in London, ON*