

**“IT IS TOTALLY A POWER STRUGGLE”:
STRUGGLES OVER THE SEXUALITY OF SOME INTELLECTUALLY
DISABLED INDIVIDUALS IN SOUTHERN ALBERTA**

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Dedication

To my brother and best friend, Bruno Santinele Martino,
for his unconditional love and support.

Abstract

This study explores the attitudes and experiences of five individuals with intellectual disabilities regarding their sexual expression and practices, and inquires whether and how their direct care workers impact these expressions and practices. Additionally, the attitudes and experiences of six direct care workers were analyzed. Drawing from standpoint theory, I explore the participants' experiences as embedded in multifaceted social relations and power struggles. Intellectually disabled individuals discuss their struggles in developing sexual and romantic relationships, having privacy and control over their space, and dealing with workers and guardians who insist on speaking on their behalf. Conversely, direct care workers highlight their fear of discussing sexuality and getting in trouble with their organizations or the guardians or families of their clients. The experiences of these social actors indicate broader struggles that disempower them both, and reveal a culture commonly understands disability and sexuality as something that will land people in trouble.

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Chapter One

Introduction

The purpose of this exploratory study is primarily to examine the attitudes and experiences of a non-representative small sampling of individuals with intellectual disabilities in regards to their sexual expression and practices, and inquire whether and how these individuals' direct care workers had affected their expressions and practices. Additionally, this study explores some of the attitudes and experiences of a non-representative small sampling of direct care workers when dealing with the sexual expression and practices of their clients. Drawing from standpoint theory, and particularly the work of Dorothy Smith (1987; 2005; 2007), I have taken a position of inquiry that, instead of starting from the abstract, started from people's actual lived experiences. To accomplish that, I conducted in-depth interviews with a small number of individuals with intellectual disabilities, and direct care workers from non-profit organizations and service agencies in order to better understand their actual lived ongoing practices, challenges, and triumphs. In keeping with standpoint theory, I also started from the premise that "society is structured by [unequal] power relations that generate unequal social locations" and that have actual consequences on the possibilities and limitations for people's exercise of power (Wood, 2009, p.397). More importantly, standpoint theorists have claimed that research should begin from the lives of the most marginalized who are able to provide more compelling accounts, not only of their own marginalized social and political position, but also of those who occupy a more privileged position within these social relations (Harding, 1993). In other words, the experiences of those in more marginalized positions can serve as an important starting point to bring into view these various unequal power relations, and open them for analysis and critique. In addition to standpoint theory,

I have also drawn from Michel Foucault's (1977; 1978; 1980; 2003) model of power to discuss the power operations that seemed to be manifested in the narratives of my research participants.

As Goble (1999) has noted, even though the relationships between direct care workers and individuals with intellectual disabilities might "be more personalised and humanised than in older institutional settings [...] they are still profoundly unequal" (p.458). In terms of sexual expression and practices, in particular, direct care workers have historically held considerable cultural authority and legitimacy to exercise influence and control over the expressions and practices of the people they serve. In contrast, individuals with intellectual disabilities have often been deemed to be either childlike or hypersexual, and unable to make 'good' decisions on their own. These unbalanced power relations between individuals with intellectual disabilities and their direct care workers have sometimes served as a basis, and perhaps a justification, for the overprotection, infantilization, surveillance, and control over the lives of intellectually disabled people, who have various specific challenges in experiencing sexual expression and practices. I chose to begin from and highlight the voices of participants with intellectual disabilities because they often have less power in relations with their workers, and since their particular perspectives can assist scholars, caregivers, and care workers to better understand the ways that power imbalances embedded in those relationships may engender frustration, disempowerment, and resistance for this small sampling of intellectually disabled people. Nevertheless, I also chose to speak with direct care workers as a means of complicating oversimplified ideas in the literature that workers are

oppressors. Rather, I suspect that workers also operate within their own constraints with guardians and parents and employers, which will be shown in my analysis.

This thesis is divided into four chapters. Chapter One presents the research topic and questions, outlines the key conceptual and theoretical frameworks guiding this thesis, and presents some of the literature on the historical and present experiences of individuals with disabilities and direct care workers regarding sexual expression and practices. Chapter Two briefly discusses the paradigmatic, ontological, and epistemological approach taken, and focuses on the methodology that underpins the research. It touches on issues of recruitment, interviewing and ethical considerations and presents the analytic framework. It also clarifies my approach to reflexivity, exposes my subjectivity, and problematizes the idea of ‘giving a voice’ to marginalized groups. Chapters Three and Four synthesize the findings that emerged from the research, provide a discussion on the data, and draw together some conclusions. I also address some of the limitations of the research, talk about the challenges experienced, and suggest some possibilities for future research.

Terminology

For this particular project, instead of relying directly on medical or psychological truth claims that often construct intellectual disability through medical definitions, measurements, and diagnostic procedures, I chose to recruit community members who self-identify as intellectually disabled. My recruitment strategy, primarily through agencies and self-advocacy groups, helped to keep the sample contained.

When referring to direct care workers, I am referring to current employees of non-profit organizations and service agencies in Southern Alberta delivering front-line regular

personal supports to individuals with intellectual disabilities in residential and/or day programs. This research included permanent and relief workers currently delivering overnight assistance at group homes, respite services to parents and caregivers, and supports to individuals with intellectual disabilities in their various activities in the community.

Finally, sexuality, as a social construct, has a diverse set of meanings, but is often defined in three domains: desires, identities, and practices (Jackson, 1998). In this specific project, even though the first two were of passing interest, I focused particularly on the domain of practices, which encompasses, for instance, questions about love and care, barriers and facilitators, relationships, flirtation, access to privacy, casual sex or sex within a committed relationship, the consumption of pornography, and masturbation.

Theoretical Framework

Standpoint Theory

As I have mentioned, I draw from standpoint theory and, in particular, the work of Dorothy Smith (1987; 2005; 2007), as a theoretical and epistemological guide for this thesis. This is especially because feminist scholars have raised the important question of who can be a knower, and subsequently, where inquiry should start. With this in mind, it is important to note that, even though different feminist scholars including Nancy Hartsock, Sandra Harding, Dorothy Smith, Patricia Hill Collins, and Donna Haraway have often been simplistically grouped together as standpoint theorists, each one of them has constructed a distinct conceptualization of standpoint and standpoint theory.¹ As

¹ I acknowledge that I too started off with a somewhat simplistic understanding of standpoint theory. However, as I explored the literature more extensively through this project, I have got a much better grasp on the controversies, complexities, and potential

Smith (1997) has pointed out, these feminist scholars had been working somewhat independently based on their different assumptions and concerns before they were even grouped as standpoint theorists. Nonetheless, one can say that they have shared a common concern in “locating knowledge or inquiry in women’s standpoint or in women’s experience” (p.392). Harding (1987) stated that “studying them [women] from the perspective of their own experiences [...] can claim virtually no history at all” (p.8). In the same way, Smith (1987) examined the “historical silencing of women,” and proposed that women should “seize authority for [their] own voices so that [they] can both speak and be heard” (p.9). Standpoint theory can be similarly relevant to discussions about disability and sexual expression and practices because individuals with intellectual disabilities have also been commonly silenced in research endeavors, while their family members and care workers have spoken in their names and about their experiences. According to Barnes (2008), until the 1990s individuals with disabilities in general rarely had a voice in the research process, and often, the knowledge that was created in these inquiries “had little or no relevance to disabled people and their organizations” (p. 2-3). Building on that, it was particularly significant to this project to make space for some individuals with intellectual disabilities to speak on their own behalf about their experiences concerning sexual expression and practices, as they currently understand them. I suggest that, in starting from how this small number of individuals with intellectual disabilities make sense of their own situation, we can better understand the complexities in their relations with their direct care workers, the effects of particular

of standpoint theory. For insight into the diversity of perspectives among standpoint theorists, I would recommend Sandra Harding’s (2004) edited collection of influential essays.

forms of power on their “field of possibilities” concerning sexual expression and practices, and their responses to those forms of power.

I am also inspired by Smith’s (2007) work because she has suggested that inquiry should start from “the actualities of people’s everyday lives and experiences” with the aim to “discover the social as it extends beyond experience” (p.328). This is important because, as Smith has noted, certain “sociological discursive practices” have treated people as “*objects* of investigation and explanation” rather than “subjects” or “knowers” who can speak about their own *situated* experiences, practices, and relations with others (p.335). She importantly emphasizes that starting from people’s everyday lives “does not confine us to particular descriptions of local settings without possibility of generalization,” and this is because “the problematic of the everyday world arises precisely at the juncture of particular experience, with generalizing and abstracted forms of social relations” (ibid, p.339). That being the case, in-depth interviews with focus on individual experiences can serve as what Smith (2005) refers to as “point[s] of entry” that bring to view how people’s actual lived experiences are influenced by local and trans-local forms of social relations (p.10). It is important then to highlight the significance of social relations because this is not about individuals and individual experiences in a vacuum, but experiences that are embedded in, shaped by, and negotiated through various local and extra-local social relations. Individuals with intellectual disabilities and direct care workers are both implicated in various power relations and “extra-local determinations of experience,” some of which might not even “lie within the scope of [their] everyday practices,” but that still influence their possibilities, constraints and practices (Smith, 2007, p.340). That is to say that, one of the aims of this project was to

complicate some oversimplified accounts of power relations between individuals with intellectual disabilities and direct care workers, and examine whether and how there might be more to these power relations than what is evident in these individuals' everyday experiences and practices.

Literature Review

Experiences of Individuals with Intellectual Disabilities with Sexuality

Historically, individuals with intellectual disabilities have been seen as asexual or – worse – specifically targeted by eugenic groups in different parts of the world because their sexuality is seen as ‘dangerous’ (Servais, 2006). Currently, most people with intellectual disabilities are still commonly viewed as asexual,² child-like and innocent, or hypersexual, promiscuous, and unable to make decisions about sexual expression and practices (Ballan, 2001; Gomez, 2012; Hollomotz & The Speakup Committee, 2008; Servais, 2006; Szollos & McCabe, 1995). According to Lesseliers & Van Hove (2002) the general population generally has held negative attitudes towards the sexual expression and practices of people with intellectual disabilities. Even though some studies have suggested that these attitudes among the general population seem to have improved in the last decades (Murray & Minnes, 1994; Whitehouse & McCabe, 1997), according to Howard-Barr, Rienzo, Pigg and James (2005) most non-disabled people are still reluctant to consider sexuality as acceptable for people with intellectual disabilities. In their study with undergraduate students, seniors from community citizens, and direct care workers

² I should note that, even though the literature has commonly referred to asexuality as a stereotype that should be contested, I concur with Kim (2011) who has importantly noted that a “universalizing claim that all disabled people are sexual denies that asexuality can be positively experienced by subjects with a disability” (p.482). The experiences of disabled people who self-identify as asexual certainly need to be further explored.

from residential agencies in Midwestern United States, Oliver, Leimkuhl and Skillman's (2002) found that questions of marriage and reproduction in particular were still not viewed positively for intellectually disabled people.

Individuals with intellectual disabilities are commonly viewed as less desirable, both as sexual and romantic partners, than people without disabilities (Gomez, 2012). For men, this is because disabilities, as Fine and Asch (1988) noted, are frequently seen as "synonymous with being dependent, childlike, and helpless - an image fundamentally challenging all that is embodied in the ideal male" (p.3). Men with disabilities have reported feeling caught in a "dilemma of disabled masculinity" as disabilities, commonly associated with dependency and helplessness, come into conflict with dominant ideas of masculinity as associated with autonomy and power (Shuttleworth, Wedgwood & Wilson, 2012).

Sometimes individuals with intellectual disabilities are also seen as unable or unwilling to work which, in turn, makes them seem unfit to support a romantic partner and be good parents to their children (Booth & Booth, 1994). Additionally, some of these individuals are seen as 'dirty' and 'dangerous' sexually because they may pass on their 'disorders' and 'contaminate' the future generations of 'healthy people' (Grekul, 2002). That considered, it is understandable that some individuals with intellectual disabilities, who grow up with such negative messages, might develop negative beliefs and attitudes towards sexual expression and practices (Cuskelly & Bryde, 2004). In fact, this question of personal beliefs and attitudes will be further explored as I examine how a small sampling of individuals with intellectual disabilities make sense of and experience sexual expression and practices. Those dominant ideas of disabilities and sexuality, however, are

just one of the various challenges that individuals with intellectual disabilities face. For the purpose of this research, lack of access to information and sexual experiences, vulnerability, and the influence of family members and care workers are particularly salient challenges.

Access to Information about Sexuality

In a western context, educating people on sexuality is typically seen as a parents' and family members' responsibility, however, because most of them are hesitant to discuss it, and feel that they lack the appropriate information and skills, this responsibility is then passed on to education professionals (Wilkenfeld & Ballan, 2011). According to Smylie, Maticka-Tyndale, Boyd and the Adolescent Sexual Health Planning Committee (2008), schools tend to be considered the most "attractive and effective location" for sexual education because they are intrinsically dedicated to "increasing students' knowledge and to improving their skills" (p.26). However, some studies have suggested that when it comes to sex education for students with intellectual disabilities, some 'special education' teachers feel unprepared, and report discomfort over addressing sexuality (Howard-Barr et al., 2005), while others fear sex education might lead to what might be deemed to be 'inappropriate sexual behaviors' (Brantlinger, 1992).

Studies have consistently shown that individuals with disabilities are often less informed about sexuality and relationships than the general population; worse, they can even be purposely misinformed to reinforce fear and prevent sexual expression (Galea, Butler & Iacono, 2004; Murphy & O'Callaghan, 2004; Servais, 2006; Szollos & McCabe, 1995). The literature also suggests that most individuals with intellectual disabilities rarely have an opportunity to participate in sex education (Murphy, 2003; Murphy &

O’Callaghan, 2004), and when such education is available, it tends to be presented solely from a biological perspective rather than addressing questions about sexual practices and pleasure (Ballan, 2001; Howard-Barr et al., 2005). In their research, for instance, Healy, McGuire, Evans and Carley (2009) found that only half of their participants had received some form of sex education. Even when sex education is provided, it is not a guarantee that its pedagogy and content are either appropriate or helpful to people with intellectual disabilities. According to Gougeon (2009), sex education provided to people with intellectual disabilities tends to be ineffective because it is often “indirect, vague, and euphemistic (often referring to the ‘birds and the bees’) or [...] overly technical (describing sexuality as sex organ and sex functions from a scientific perspective” (p.283).

It has also been suggested that sometimes families and support workers purposely prevent access to information or provide misinformation to individuals with intellectual disabilities to discourage relationships and sexual expression, or protect the person from sexual abuse, or to prevent behaviors that are deemed inappropriate (Gomez, 2012; Hamilton, 2009; Swango-Wilson, 2008). This desire to protect disabled people from abuse or from getting in trouble can come from well-intentioned families and workers who care about and want the best for their loved ones or clients. It can be quite challenging for both families and workers to figure out ways to support individuals with intellectual disabilities in having the romantic and sexual lives that they desire while making sure that they do so safely. The problem, as studies have widely noted, is that preventing people with intellectual disabilities from having information and experience with sexual expression and practices tends to increase the frequency of instances

involving behaviors that are deemed inappropriate including public masturbation, inappropriate comments, or inappropriate touch (Franco, Cardoso & Neto, 2012; McCabe, 1999; Swango-Wilson, 2008). According to Grieve and McLaren (2008), these inappropriate behaviors often result in the punishment, restriction, and greater surveillance of individuals with intellectual disabilities. Thus, I asked participants what, if any, kinds of discussions take place concerning sexual expression and practices between direct care workers and their clients.

Perhaps some of these inappropriate behaviors are actually the only outlet available for some individuals with intellectual disabilities, who commonly lack privacy to explore or express their sexual desires. Living in group homes or with family members into adulthood can curtail privacy. Indeed, some studies have suggested that people with intellectual disabilities are subject to more invasion of personal space than are non-disabled people, partially because they are considered child-like and are hence disrespected in terms of space and autonomy (Hollomotz & The Speakup Committee, 2008; Lesseliers & Van Hove, 2002; Servais, 2006). Finally, Lesseliers and Van Hove (2002) have argued that some individuals with intellectual disabilities also face some difficulty exploring and expressing their sexuality because their family members and caregivers tend to, or perhaps attempt to, ignore their sexual feelings and desires.

Some scholars have suggested that the lack of information about sexual expression and practices hinders disabled people's ability to distinguish abusive relationships (Murphy & O'Callaghan, 2004), consequently increasing the risk of abuse (McCarthy & Thompson, 1997; Murphy, 2003). Also important to note is that sometimes people with intellectual disabilities are enforced or coerced into relationships of dependency, either

living in group homes or with family or support workers, and the power imbalances in these relationships might mean that perpetrators are able to withhold information about sexuality, to take advantage of the individual's lack of information, or that individuals with intellectual disabilities might fear to seek help (Hollomotz, 2011). There is also evidence that birth control has been given prophylactically to some women with intellectual disabilities in order to "conceal sexual violence, as an unwanted pregnancy could be a means of detecting that rape has taken place" (ibid, p.74). Finally, according to Cheng and Udry (2005) the lack of access to information also increases the probability of contracting STIs or having unplanned pregnancies, though as some studies have noted, only a few individuals with intellectual disabilities are even able to have an active sexual life (Löfgren-Mårtenson, 2004; Servais, 2006). In general, as Dukes and McGuire (2009) have noted, when provided with helpful and appropriate sex education, individuals with intellectual disabilities are better able to make well-informed decisions about sexual expression and practices.

Sexual Expression and Practices

It is normative for non-disabled people to be in relationships and sexually active. However, as Gomez (2012) points out, the same expectations do not seem to apply to individuals with intellectual disabilities. Despite common assumptions that intellectually disabled people are asexual, child-like, and lacking sexual or romantic desire, many studies have noted that most are interested in learning about approaching potential partners, dating, and having sexual experiences (Chivers & Mathieson, 2000; Goodley, 2003; Löfgren-Mårtenson, 2004; McCabe, 1999). These individuals, however, often face challenges accessing relationships and a desirable sexual life (Carlson, Taylor & Wilson,

2000; Hamilton, 2002; McCabe, 1999; McCarthy, 2000; Szollos & McCabe, 1995). McCabe's (1999) study, for instance, found that participants wanted to date and have sexual experiences but struggled due to a lack of opportunities and embarrassment resulting from their lack of sexual and relationship knowledge and skills.

It is difficult to know the level of sexual activity among individuals with intellectual disabilities, due to the inconsistencies in data sources, sample populations, living environments, sample size and conceptualizations of sexual experience that might or might not include non-consensual, coerced and abusive intercourse (Servais, 2006). However, some scholars have suggested that individuals with intellectual disabilities are less sexually active than individuals with other kinds of disabilities or without disabilities (Löfgren-Mårtenson, 2004; Servais, 2006), sometimes due to lack of privacy, perceived disapproval or prohibition by their caregivers, and negative personal beliefs towards sexuality (Lesseliers & Van Hove, 2002; Servais, 2006). Even though, as Frawley (2003) found in her study, a few individuals with intellectual disabilities are actually able to have an active sexual life, most studies still indicate some significant difficulty in experiencing sexual relations and intimacy, particularly due to the overprotection and prohibitions by authority figures including support workers and family members (Frawley, 2003; Löfgren-Mårtenson, 2004). Consequently, Szollos and McCabe (1995) have suggested, masturbation sometimes becomes the only outlet available for individuals with disabilities.

Housing arrangements also seems to affect one's sexual opportunities and experiences, as those who live in group homes, for instance, tend to live with other individuals with disabilities with whom they have not chosen to live (Löfgren-Mårtenson,

2004), sometimes with little privacy (Hollomotz & The Speakup Committee, 2008; Lesseliers & Van Hove, 2002; Servais, 2006) in small rooms with only single beds (Brown, Croft-White, Wilson & Stein, 2000) and no door locks (Hollomotz & The Speakup Committee, 2008). In Löfgren-Mårtenson's (2004) study, few people with intellectual disabilities believed they would have opportunities to eventually have children. This is understandable considering that there is some evidence that when people with intellectual disabilities do have children, they are more likely to experience challenges in maintaining custody (Booth & Booth, 1994; Booth, McConnell & Booth, 2006), in addition to being treated unfairly in family courts (Glaun & Brown, 1999; Mosoff, 1994). As I am particularly concerned with questions of access, rights and fulfilment in regards to sexual expression and practices of intellectually disabled people, I explored questions of values and beliefs, opportunities for flirtation and courtship, opportunities for obtaining sexual pleasure, access to privacy, and other barriers and facilitators especially in interviews with individuals with intellectual disabilities.

Vulnerability

Lack of information about sexuality can make individuals with intellectual disabilities vulnerable to sexual abuse. Studies have shown that people with intellectual disabilities are more likely to be victims of sexual predation, both in care and in the community (Murphy, 2003; Sequeira & Halstead, 2001). The estimations of cases of sexual abuse vary greatly, ranging from approximately 10% to 80% of individuals with intellectual disabilities experiencing sexual abuse at some point in their lives (Hollomotz, 2011). Studies have suggested that most cases are perpetrated by people who are known and trusted by people with disabilities (McCarthy & Thompson, 1997). Andrews and Veronen (1993), for example, have mentioned some of the reasons why individuals with

intellectual disabilities tend to be more vulnerable to sexual abuse. This includes dependency on other people for their care, lack of information, and the fact that individuals with disabilities, who are victims of abuse, will often not be believed. Additionally, support workers sometimes have inadequate preparation to deal with cases of sexual abuse when they occur (Brown & Turk, 1992; Brown, Hunt & Stein, 1994), and there is indication that some people who choose to work with people with intellectual disabilities do so because they think it will offer them easy targets (Hollomotz, 2011).

It is important to recognize that most studies regarding sexual abuse have focused their analysis on individuals with intellectual disabilities and their individual attributes and self-defence skills without considering social arrangements that help create vulnerability (Hollomotz, 2009). There is enough evidence to suggest that, when sexuality is discussed within families, individuals with intellectual disabilities are less likely to experience abuse (Murphy, 2003). A further important element in reducing the risk of sexual abuse, involves “refrain[ing] from individualistic conceptualizations of risk” that focus on individual attributes, self-defence skills and (over)protection of intellectually disabled people, and “aim[ing] to eliminate conditions that create risk [...] targeting social processes that are responsible for the creation of risk” (ibid, p.110).

In this research, I explore how and whether dominant discourses that tie disability and vulnerability together unproblematically might be reflected in the beliefs and practices of a small number of direct care workers. I will also problematize how workers’ good intentions in protecting their clients from potential abuse, or their assumptions about vulnerability might affect their clients’ access to fulfilling sexual expression and practices.

Parents, Guardians,³ and Sexuality

Studies done in the United States suggest that most individuals with intellectual disabilities live at home with family members, and in fact, this number seems to be growing (Davenport & Eidelman, 2008; Fujiura, 1998; Rizzolo, Hemp, Braddock & Schindler, 2009). Similar studies in countries such as Australia, Canada, England and Ireland have found similar trends, suggesting that at least half of individuals with intellectual disabilities live with family members into adulthood (McConkey, Mulvany & Barron, 2006; Braddock, Emerson, Felce & Stancliffe, 2001; Weeks, Nilsson, Bryanton & Kozma, 2009). According to Howard-Barr et al. (2005), many parents do not feel prepared to deal with the sexual expression and practices of their loved ones. Evans, McGuire, Healy and Carley (2009) similarly found that parents felt significantly less confident to engage in discussions around sexuality and relationships in comparison with workers, who seemed to talk more often about sexuality with individuals with intellectual disabilities. Ballan (2012) found that, even though parents showed a strong desire to engage in discussions about sexuality with their sons and daughters as well as support workers, there was still a great level of apprehension and concern about having such discussions. Conversely, as illustrated in different studies, support workers also tend to be careful about approaching family members with matters related to sexual expression and practices, and often wait for their clients and family members to ask for services and information in these areas (Abbott, Howarth & Glyde, 2005; Abbott & Howarth, 2007;

³ Guardianship arrangements often involve a private guardian, typically a family member or a friend of the disabled individual, or a public guardian assigned by the province, which is seen as a “last resort” (Alberta Human Services, 2014b). The decision-making scope of these guardians can vary from day-to-day to financial decisions in the name of those under guardianship orders.

Löfgren-Mårtenson, 2004; Murray & Mines, 1994). In their study with family carers and staff members, Evans et al. (2009) have suggested that family carers might be more hesitant to talk about sexuality with their loved ones because of their lack of training, higher average age, and more “traditional” views about even more general forms of sexual expression and practices. Yet, it is reasonable to speculate that, at least in this social and cultural context most parents, both of disabled and non-disabled individuals, show discomfort and avoid as much as possible having conversations about sexuality with their sons and daughters (Wilkenfeld & Ballan, 2011). In relation to this culture that often ties sexuality with shame and silence, I recall one of my previous interviews with a mother of a young disabled man who told me: “it is easy to think about it [sexuality], it is *easier* not to think about it.”

As illustrated in two studies conducted in the UK, parents, particularly older ones, tend to be more conservative than most support workers (Brown et al., 1994; Rose & Jones, 1994). Thus, as Cuskelly and Bryde (2004) notes, sexual expression and practices can become an area of conflict between family members and workers, placing individuals with intellectual disabilities in a difficult position. In her study, Ballan (2012) found that apprehensions about sexuality have motivated some parents to look for guidance in order to develop more knowledge and skills to better communicate with their sons and daughters about sexuality. These parents mentioned that support workers often lack the initiative and receptivity to address sexuality, not addressing it until a “behavioural problem” happens. Most parents in Ballan’s study then referenced other parents as the main source of information regarding sexuality. In my research, I attempt to explore the

complex relationships that may exist between family members and support workers concerning sexual issues.

According to Löfgren-Mårtenson (2004), workers and family members often struggle finding a balance in letting intellectually disabled people make their own decisions regarding sexual expression and practices. These social actors are usually worried about potential unwanted pregnancies, sexual abuse, and behaviors deemed as inappropriate (Ballan, 2001; Löfgren-Mårtenson, 2004). These concerns can sometimes result in lack of privacy and overprotection of people with intellectual disabilities as a result of surveillance (Hollomotz & The Speakup Committee, 2008; Löfgren-Mårtenson, 2004). This might also mean denying individuals with intellectual disabilities the right to take risks, make mistakes, and perhaps learn from them (Koller, 2000). In this study, I explored whether and how these concerns affect workers approaches to dealing with protection, prevention and surveillance concerning their clients' sexual expression and practices.

Direct Care Workers and the Sexuality of Their Clients

Direct care workers can play a significant role in the lives of people with disabilities and their families by sharing information, delivering services, and facilitating opportunities for social inclusion. As Ford and Honnor (2000) have noted, direct care workers often take on various roles and responsibilities when delivering care to individuals with intellectual disabilities, from providing “training, supervision, [and] opportunities for social inclusion,” to serving as “counsellor[s], advocate[s], friend[s], cook[s], and chauffeur[s]” to those under their care (p.344). Previous studies, however, have consistently shown that front-line care workers are often underpaid, face significant

work overloads, have limited promotion prospects, experience limited communication with administrative and supervisory workers, and thus, have minimal input into how care is even conceptualized (Ford & Honnor, 2000; Hatton et. al, 1999). Studies have also shown high rates of burn out and turnover among front-line workers, in part, due to the stress and intensive emotional labour involved in the position, as well as to the various constraints in organizational structures, hierarchies and opportunities for career development (Devereux, Hastings & Noone, 2009). In sum, even though direct care workers take on various roles and responsibilities and engage in intensive hands on and emotional labour with their clients, these workers also tend to be underpaid and undervalued, work with minimum support from their organizations, and have some limited input and decision-making power into the care work that they are expected to do.

A number of scholars have theorized the relationships between direct care workers and individuals with intellectual disabilities, particularly in relation to different models of service delivery. The person-centered approach to service delivery, which aims to shift decision-making power from professionals to individuals with disabilities, has become, at least in theory, the most common among non-profit organizations and service agencies in western societies (Parley, 2001). However, according to Goble (1999) even though the relationships between workers and their clients might “be more personalised and humanised than in older institutional settings [...] they are still profoundly unequal” (p.458). Servais (2006) has similarly suggested that negative attitudes among workers and family members towards the sexually and sexual expression of disabled people persist, and that the relationships between these various social actors remain quite unequal.

In his study with seven individuals with learning difficulties, Goble (1999) found that most of them considered their support workers to be “physically, emotionally and politically central in their worlds” (p.457). These participants had “little knowledge of the official designations of staff” or their “officially designated roles,” and even though workers were seen as “powerful and authoritative,” the participants did not understand “the source of and rationale for this power and authority” (ibid). Goble has suggested that these particular relations between workers and their clients demonstrate the disempowerment of individuals with intellectual disabilities who rarely have the opportunity to establish their own needs and wants. Lafferty, McConkey and Simpson (2012) have also suggested that most individuals with intellectual disabilities “remain dependent on others to identify and respond to their needs” (p.41). I thus examine how some direct care workers and individuals with intellectual disabilities perceive the power relations in which they are embedded. This reflects one of my main research questions, exploring the ways that power imbalances embedded in the relationships between direct care workers and people with disabilities may engender frustration, disempowerment, and resistance for this group of intellectually disabled people in relation to sexual expression and practices.

Institutional Policies and Training Concerning Sexual Expression and Practices

The presence of clear policies and guidelines⁴ at the agency level can influence and guide the practices of direct care workers. Many studies suggest that agencies

⁴ I recognize that these organizational texts are not neutral, and perhaps should be approached with caution as they serve not only to coordinate the practices of direct care workers, but also to contour the subject position of both direct care workers and their

commonly do not have policies that address clients' sexual expression and practices, which consequently allows workers to make their own decisions on how to address situations as they arise (Christian, Stinson & Dotson, 2001; Löfgren-Mårtenson, 2004, Ward, Trigler & Pfeiffer, 2001). The lack of policies and guidelines can cause anxiety and confusion among direct care workers and individuals with intellectual disabilities when dealing with situations related to sexual expression and practices. Evans et al. (2009) found that some workers were not sure about the sexual rights of their clients in regards to different issues including privacy. McConkey and Ryan (2001) found that 50% of the staff interviewed identified the need for clearer policy guidelines to feel more confident dealing with issues regarding sexuality, while Abbot and Howarth's (2007) similarly found that most staff members needed and wanted to have a sexuality policy to improve their practices. Building on Smith's (2005) theorizing on texts as well as the literature reviewed, I interrogate how the actual practices of this small sampling of direct care workers might be tied to organizational texts, including policies and guidelines concerning the sexual expression and practices of the people they serve.

Various studies have also highlighted that direct care workers may not follow whatever policies are in place because they do not seem to change their attitudes and practices in accordance to such policies (Bazzo, et al., 2007; Christian et al., 2001; Murray & Minnes, 1994; Murray, MacDonald, Brown & Levenson, 1999). Thus, as Murray et al. (1994) have noted, simply having a policy that addresses matters related to sexuality is not enough to ensure changes in practice. Rather, it is also important to look

clients as well as their 'appropriate conduct' within those relationships, and produce and reproduce particular discourses about sexual rights of intellectually disabled people.

at the actual practices of workers handling cases pertaining the sexual expression and practices of intellectually disabled people.

Finally, the literature has also suggested that it is important to provide adequate training for workers in order to generate discussions on sexual expression and practices, and improve practices not only in terms of addressing ‘incidents’ when they happen, but also taking a more proactive role in facilitating sexual and romantic opportunities for intellectually disabled people. Nonetheless, sexual expression and practices have been avoided or considered ‘unnecessary’ in training programs for workers even though such information can enhance services and improve agency practices. McConkey and Ryan (2001), for instance, found that only 25% of agency workers surveyed had received training concerning the sexual expression and practice of their clients, while Evans et al. (2009) found that only 12% of agency workers had received some form of training. It is thus reasonable to assume that some direct care workers might be unprepared, and even unwilling, to handle and facilitate their clients’ sexual expression and practices, and this is something that I explored in the interviews with direct care workers.

Attitudes and Beliefs Towards The Sexual Expression and Practices of Their Clients

There have been many studies on the experiences and attitudes of agency workers related to the sexual expression and practices of their clients. It seems that attitudes and values towards sexuality vary greatly among workers, depending on factors like age, job position, level of training and religious affiliation, which can then cause confusion to these workers’ clients (Brantlinger, 1983; McConkey & Ryan, 2001; Murray & Minnes, 1994). The data suggests that agency workers’ attitudes have become more liberal over time (Yool, Langdon & Garner, 2003), with young, male, well-educated, non-religious

workers across different studies showing more positive beliefs and attitudes towards sexuality (Brantlinger, 1983; Murray & Minnes, 1994; Trudel & Desjardins, 1992) in comparison with female and older paid workers delivering direct care or working in residential settings (Aunos & Feldman, 2002; Bazzo et al., 2007; Löfgren-Mårtenson, 2004). Most of these studies, however, have relied on surveys, which provide us with a limited understanding about the complexities in the attitudes, understandings, and experiences of these workers in regards to the sexual expression and practices of their clients. Thus, in using a qualitative approach, I hoped to delve into some of those complexities and picture a more complicated scenario. Some studies have suggested that direct care workers tend to act more conservatively in regards to the sexual expression and practices of their clients because of their fear of potential law suits and/or conflicts with the family members of their clients (Bazzo et al., 2007; Trudel & Desjardins, 1992). In Southern Alberta, some of the agencies that serve people with intellectual disabilities, as stated in their organizational texts available to the general public, have a strongly professed basis in Christianity, and it is fair to assume that those values will affect workers' capacity or willingness to support their clients' sexual expression and practices. The role of workers' beliefs and attitudes about sexuality, and their situations within value-based agencies, is a central aspect of my interviews with direct care workers.

Support workers have commonly reported fear regarding potential negative consequences to job security, or unwillingness to address the area of sexual expression and practices, which have often led them to avoid taking a proactive role. These workers often wait for their clients and their family members to ask first for services or assistance in the area of sexual expression and practices (Abbot, Howarth & Glyde, 2005; Abbot &

Howarth, 2007; Löfgren-Mårtenson, 2004; Murray & Minnes, 1994). Although I recognize the importance of having more open discussions about sexuality with individuals with intellectual disabilities, I think it is reasonable to say that most non-disabled people do not have others approach them and ask them in the middle of the day whether they would like to talk about or receive supports with their romantic and sexual lives. Rather, more informal conversations about relationships, sex and pleasure often happen within particular contexts and social relations. The problem is that for intellectually disabled people, who tend to be more socially isolated and sheltered (Abbott & McConkey, 2006), these opportunities to talk about sexuality might be more limited. According to Frawley, Johnson, Hilier and Harrison (2003), some workers also believe that facilitating or even dealing with their clients' sexual expression and practices is not a part of their job description. On a similar note, Christian et al. (2001) found that about 44.2% of agency workers felt that there were more important priorities than sexuality when it came to delivering services, in this case to women with developmental disabilities.

Support workers can be hesitant to talk about sexual expression and practices with their clients, fearing possible law suits (Evans et al., 2009; Löfgren-Mårtenson, 2004; Trudel & Desjardins, 1992), conflicts with their clients' family (Trudel & Desjardins, 1992), or invasion of clients' privacy (Abbott & Howarth, 2007). According to Sundram and Stavis (1994) some workers might acknowledge the right of their clients to sexual expression, and yet, might not provide privacy to them. At other times, as Hamilton (2009) has noted, workers might prohibit any form of sexual expression in organizational premises altogether. In some cases, workers themselves determine clients' sexual rights

based on their presumed intellectual ability (Christian et al., 2001), while some workers have used the question of legal consent as an excuse to restrict sexual expression (Cambridge & Mellan, 2000). In this research, I sought to better understand how the practices of this small number of direct care workers might be influenced by organizational policies and training (or perhaps lack thereof), and the workers' personal beliefs and values.

Conclusion

The thesis examines the attitudes and experiences of a small number of individuals with intellectual disabilities in regards to their sexual expression and practices, and inquires whether and how these individuals' direct care workers had affected their expressions and practices. In addition, this study explores some of the attitudes and experiences of a small sampling of direct care workers when dealing with the sexual expression and practices of their clients. This study is important because on the one hand, the perspective of individuals with disabilities can highlight potential power imbalances embedded in their relationships with their direct care workers, and illuminate their experiences of frustration, disempowerment, and resistance. Conversely, speaking with direct care workers can illuminate some of the values that workers bring to their involvement with clients' sexual expression and practices, and will also allow us to see the challenges and supports that facilitate workers in dealing with these issues.

In this chapter, I introduced the research topic and questions, outlined the key conceptual and theoretical frameworks guiding this thesis, and presented some of the literature on the experiences of individuals with disabilities and direct care workers regarding the challenges and possibilities relating to sexual expression and practice of intellectually disabled people. In the next chapter, I turn to methods, where I will

introduce my paradigmatic, ontological, and epistemological approach, discuss the methodology underpinning this specific project addressing issues of recruitment, interviewing and ethical considerations, and present my analytic framework.

Chapter Two

Paradigm, Ontology, and Epistemology

A qualitative research approach was the most suited for this specific project because it makes space for participants to talk about their realities and positions in the world “in their own words and [...] on their own conditions [as] they may express views, give words to their experiences and describe events and situations” (Boeije, 2010, p.32). As I was interested in understanding the actual experiences, challenges, and triumphs of the participants from their point of view, qualitative methods, in particular in-depth interviews, provided the most compelling tool for eliciting more contextualized narratives (Ramazanoğlu & Holland, 2002). In keeping with standpoint theory, I took into account the various social and power relations in which these participants were embedded, as well as some of the potential contradictions or conflicts that could exist within those relations. I conducted in-depth interviews to facilitate the research participants in discussing the topic of sexual expression and practices – a topic fraught with social, cultural and historical proscriptions and silence to better understand the complexities in their situated experiences, perspectives, and relations.

Formulating an appropriate research approach also involved assessing the paradigm that informed this research (Bloomberg & Volpe, 2012). Guba and Lincoln (1994) define paradigm as “the basic belief system or worldview that guides the investigator, not only in choice of method but in ontologically and epistemologically fundamental ways” (p.17). In other words, research endeavors are always situated in the researcher’s own worldview, and as Guba and Lincoln suggest, no researcher “ought to go about the business of inquiry without being clear about just what paradigm informs and guides his

or her approach” (ibid, p.36). I grounded this research on a critical-constructionist framework that, as its basic tenet, acknowledges that there are various versions of ‘truth,’ which are always partial, locally situated, and fluid (Bloomberg & Volpe, 2012; Guba & Lincoln, 1994). Similarly, a critical-constructionist framework suggests that ‘reality’ is always “multiple,” “intangible,” “experientially based,” and “situated” (Guba & Lincoln, 1994, p.110). In other words, in interviews, participants talked about their experiences as they understood them in that particular moment, and those experiences were true for them. It was my role to interact meaningfully with participants, actively listen to them, attempt to make sense of their reality, and provide an ethical representation and interpretation of their experiences. Moreover, a critical-constructionist framework recognizes how these ‘truths’ are indeed embedded in various power relations in which certain ‘truths’ are privileged over others, and I aimed to bring these power relations into view in order to better understand them and open them to question.

Reflexivity

Guillemin and Gillam (2004) point out that, ideally, a reflexive researcher does not report “facts” but in fact “actively constructs interpretations (what do I know?), while at the same time question[ing] how those interpretations came about (how do I know what I know?)” (p. 274). According to Pillow (2003), however, “most researchers use reflexivity without defining how they are using it, as if it is something we all commonly understand and accept as standard methodological practice for critical qualitative research” (p.176). Based on a critical-constructionist paradigm and a standpoint theory, I do not claim to be producing value-free research, and I acknowledge that my subjectivity, personal narratives, and values have shaped the research process and outcomes (Wylie, 2004).

Reflexivity, similarly to ethics, should be an ongoing process, present in every stage of research. This is because, when ongoing and critical, reflexivity can help us researchers work through our own subjectivity more productively, and better address important epistemological, ontological, methodological, and ethical questions that arise throughout the research. It helps us be more critical about our practices, stances, and goals regarding research.

As a part of being reflexive, I have purposely included a few personal pieces of writing within chapters two and five in order to share personal narratives that have had a deep influence on me as an individual, family member, community member, activist and scholar. These are pieces that should allow the readers to have an idea of who I am, and how I make sense of the research topic, and the research process. There are multiple ways of engaging with reflexivity at different moments in the research process. Ellis (2009), for instance, engaged in a dialogue with an “alter ego” that allowed her to think through the “ethical dilemmas and relational responsibilities” involved in her work (p.340). Even though Ellis might not have an answer for all the questions posed by the “alter ego,” the fact that she is thinking through those questions shows us that she is being reflexive about her work. The point is not to have an ‘answer’ for every question but to be able to raise those questions in the first place. I have found that engaging in a similar dialogue with an “alter ego” was valuable to my own research experience and I share excerpts of these dialogues throughout this thesis. I have also found that writing and talking to colleagues were useful reflexive tools. I believe that these different voices have enriched the research, helped me grow as a researcher, and showed my respect for the research participants.

Reflexive Statement of My Standpoint

As a part of reflexivity, qualitative researchers pay particular attention to how their subjectivity might affect their work, looking at questions of “how does who I am, who I have been, who I think I am, and how I feel affect data collection and analysis” (Pillow, 2003, p.176). Finlay (2002), who has written extensively about reflexivity, suggests that researchers should consider reflexivity “from the moment the research is being conceived” in order to scrutinize “their motivations, assumptions, and interests in the research as a precursor to identifying forces that might skew the research in particular directions” (p.536). Without a doubt, my personal narratives have influenced my interest and approach to the topic of disability and sexuality, how I chose to conduct this research, how I wanted to approach my relationship with participants, and what I hoped could come out of this research.

I became interested in researching disability and sexuality because of my personal experience serving as a volunteer in different non-profit organizations delivering services to people with disabilities, and growing up with an older brother with cerebral palsy. I was a volunteer in the arts program of a non-profit organization in New York State when one day, during an improvisation exercise, a young man with Down syndrome said “love is natural, we all love” and later, “S.E.X. that’s what we guys want.” People in the room, meaning agency workers and other ‘clients,’ reacted to those statements with some embarrassment and nervous laughter. At the end of the scene, nobody commented or even acknowledged those statements, and consequently, sexuality and sexual expression remained a taboo, an ‘elephant in the room’ that people chose to ignore. That experience made me interested in researching the organizational policies and practices of non-profit

organizations regarding sexuality. This is because I would hope that such instances, in fact, would serve as opportunities to discuss and encourage discussion about sex among individuals with disabilities rather than shut them down or reinforce norms about sex and disabilities as incompatible.

I also got interested in researching sexuality and sexual expression due to my experience growing up with an older brother, Bruno, who has cerebral palsy. My own family, like many others, has struggled to support a family member with a disability in regards to his sexuality and sexual expression. For a long time none of us have felt comfortable or confident enough to address this important area in my brother's life, which has resulted in an unformulated agreement that we should just "not go there." It hurt me to acknowledge that I had failed to support my brother in this area for so long. The guilt I have felt because of my experience with him has paralyzed me at different times during this research process. I would spend hours thinking about past experiences with my brother, feeling frustrated and somewhat ashamed for even doing this work. It is my true hope then that this research might help other families and their loved ones have a better experience dealing with sexuality, an area that is so important, and yet so silenced in our lives.

I often feel like I live in a strange position, as I consider myself a temporarily able-bodied person who has a particular form of experience with disability through my brother, who feels committed to supporting him as well as other individuals with disabilities. However, I am still trying to figure out my boundaries as a brother, community member, activist and researcher. For the moment, I cannot help but feel a bit stuck in the middle, not quite fitting into either side, sometimes feeling pushed or thrown

back and forth from all the edges of the circle. How can I, from this strange space, come in defense of my brother (as he does with me) without falling into the trap of speaking about or appropriating an experience that I do not embody myself? What should my role be? Where do I belong in this discussion? What particular vision, advantages, and disadvantages does this strange position grant me? These questions have puzzled me since I started doing research on disability and had to start forming my identity as an academic and researcher in relation to my other longstanding identities as a brother, family member, and activist.⁵

I am not claiming to be value-free because I know that my subjectivity and values have shaped the research process and outcomes. For scholars in Disability Studies, the idea of a value free research “has been dismissed as ‘politically naïve and methodologically problematic’” (Back & Solomos as cited in Barnes, 2008, p.7). I acknowledge my position of belief that individuals with intellectual disabilities have the right to sexual expression and that it is not possible to talk about social inclusion without considering what I would call *sexual-social inclusion*. This concept aims to highlight the importance of recognizing individuals with disabilities, not only as workers, students and citizens, but also as sexual beings within their communities, and facilitating opportunities for these individuals to have their desired sexual and romantic life.

⁵ I would like to thank Dr. Bill Ramp for his kind and encouraging feedback on the papers I wrote in his classes during my graduate coursework. His comments have guided me through the interrogation of these questions as well as the negotiation of my longstanding and newer identities.

The Problems with ‘Giving a Voice’

I see my role as a researcher who is studying the experiences of a group of people who have often been silenced, however, I do not consider that I am ‘giving voice’ to a silenced other in this research. Second wave feminist movements were central in the construction of the notion of giving a voice to women, which later on was also used by other marginalized groups (Ashby, 2011). Bogdan and Biklen (1998) describe the action of giving a voice as “empowering people to be heard who might otherwise remain silent” (p.204). Thus, optimistically, for some individuals with disabilities, participating in this research might serve as a much-needed opportunity to be able to talk about sexuality, relationships, and intimacy.

On the other hand, the notion of giving a voice can be problematic because “regardless of the intentions of the researcher, hierarchies of power are re-inscribed when the researcher presumes to give voice to someone else” (Ashby, 2011). There is indeed a paternalistic danger here, and assuming that one lacks agency can be quite problematic. According to Fine (1992), there is a tendency for scholars to use “voices to accomplish a subtler form of ventriloquism” which means that “researchers appear to let the Other speak, just under the covers of those marginal - if now ‘liberated’ voices” while remaining “hidden” and “unproblematical” (p.215). In other words, Fine is pointing out that some researchers use ventriloquism by selectively listening to and analyzing participants’ voices to have them say what the researcher wants them to say. She suggests that an “activist stance,” on the other hand, prompts researchers to “position themselves as political and interrogating, fully explicit about their original positions and where their research has taken them” (Ibid, p. 212). Thus, an activist stance opens up free speech to participants so that their original positions are clearly expressed without the researcher’s

interference. It is my belief that people hold truths that are true for them and my role as a researcher is to create space for these truths and attempt to uncover some of the “extralocal determinations of [...] experience” (Smith, 1987, p.161). Instead of giving a voice, I hope to facilitate those voices so their truths can become public. It is important to acknowledge that I bring my own perspectives and experiences into this research, and that the voices of participants are, after all, also being mediated and interpreted through my own worldview and experiences, and it is my responsibility as a researcher to make those interpretations evident (Fine, 1992).

The question of voice, interpretation, and representation raises various ethical issues. How do I ethically interpret and represent voices in two groups of research participants who are embedded in unbalanced power relations? Do I need to pick a side? Can I escape the dichotomy of the oppressor and the oppressed? The relations between individuals with disabilities and their direct care workers can involve experiences of disempowerment, frustration, alignment, and resistance. I recognize that most often the voices of workers are deemed as more legitimate than the voices of those with disabilities, however, it is important to go beyond binaries of oppressed vs. oppressor as well as powerful vs. powerless. I then concur with Grossberg (as cited in Newman, 2010, p.9) who has suggested that instead of relying on such dichotomies, it might be more productive to work on the construction of “historical agency” which, as Newman explains, creates space for “pluralities ... of subject position” and “disrupt[s] the logics which often privilege one side of a binary logic” (ibid). Although direct care workers tend to hold more authority, legitimacy and power in relation to their clients, workers act within and are affected by oppressive institutional structures. Similarly, while individuals

with intellectual disabilities might often be disempowered in various areas of their lives, they are not always passive or victims, and can exercise some agency. Thus, I approached the relationships and operations of power between direct care workers and their clients as highly complex. This, for me, meant that each party holds certain strategies and skills to engage in these relationships, and attempts to achieve what they want. Nevertheless, because individuals with intellectual disabilities are likely to have less power in those relations, I chose to deliberately highlight their voices in this research.

Choosing Interviewing

I chose to conduct semi-structured in-depth interviews to explore the actual lived experiences, challenges, and triumphs of this small number of individuals with intellectual disabilities and direct care workers. I started from the premise that people can be knowers of their own situated position and social relations (Smith, 2007). That being the case, semi-structured interviews fit well with standpoint theory framework as they allow us to “understand the world from the subject’s point of view, to unfold the meaning of the subject’s experiences, to uncover their lived world” (Kvale & Brinkmann, 2009, p.1). Semi-structured interviews also provided the flexibility to explore the individual and personal experiences of participants in detail, allowing interviewers to probe beyond pre-determined questions, and interviewees to raise new themes and questions not considered previously (Berg, 2009; Bernard, 2013; Hennink, Hutter & Bailey, 2011). Booth and Booth (1996) advise that participants in this group tend to present some “inarticulateness” when expressing themselves, which is not only due to “restricted language skills,” but also to “other factors including a lack of self-esteem, learned habits of compliance, social isolation or loneliness, and the experience of oppression” (p.56). In addition, they point

out that it is important to consider the most appropriate question formats for interviewing individuals with intellectual disabilities. This is because some studies have shown that interview questions that are more straightforward, grounded on concrete references, and presented as to create a narrative tend to show higher levels of responsiveness (ibid). As a result, I have taken this literature into consideration when developing the interview guides for this research.

Dealing with “Ethnophobia”

It is common for emerging researchers to experience what Jackson calls “ethnophobia” (as cited in Blee & Currier, 2011, p.404), or “the anxieties researchers can experience [as] they wade into unfamiliar research situations whose ineffability may heighten researchers’ nervousness about committing ethical transgressions” (p.405). I was initially planning to interview only direct care workers; however, a meeting with my supervisor led to a change in approach, when she asked me: “why not interview individuals with intellectual disabilities too?” That particular question made me wonder: Why was it that I did not want to interview individuals with disabilities? Why was I hesitant to do so? As I went back to a paper that I wrote as an undergraduate student I found, in the very last paragraph, my recommendation: “it is important to provide [...] individuals [with disabilities with] the opportunity to have a voice and be able to share their own perspectives, challenges and needs in this area” (Martino, 2010, p.14). Wasn’t it ironic that I was now considering not having their voices in my research? In time, inspired by Ellis’s (2009) work on reflexivity, I engaged in an important dialogue with my “alter ego”:

Alter Ego: Why was it that you did not want to interview individuals with disabilities for your thesis at first? Were you just ‘thinking pragmatically’?

Ego: I kind of was...

Alter Ego: What do you mean by “kind of was”? You can be honest with me.

Ego: I guess it was more than that. The reality, I guess, is that I was freaking scared of talking to these individuals and potentially causing them some sort of harm. I did not know how to talk to them about this topic without being able to guarantee that they would always leave the interviews feeling well. It would be extremely heartbreaking for me to see that my research had somehow hurt these individuals. Is it a risk worth taking? Perhaps the IRB can tell me that it is a risk worth taking but my deep personal commitment goes beyond a simple IRB decision. My feelings and the feelings of my participants go beyond IRB requirements. The relationship of trust and genuine care that I want to develop with them goes beyond those requirements.

Alter Ego: Apparently this is making you quite emotional, isn't it?

Ego: It is. It touches on so many things that are extremely important in my life. It is hard facing these questions, and yet, I can no longer stop doing that. It seriously fries my brain.

As it can be seen, I struggled with “ethnophobia,” finding myself somewhat paralyzed by the fear of potentially causing some form of emotional harm to the participants in my study. In part, that fear, or perhaps guilt, had its origins in my own historical personal narrative, yet, it reflected how “the potential for people to be adversely affected by their participation in sexuality research is an important ethical issue [that] requir[es] careful consideration” (Thomas & Kroese, 2005, p.144). Thomas and Kroese’s (2005) study, however, found that individuals with intellectual disabilities were more likely to be positively affected by their participation in research about sexuality. In fact, some researchers have argued that participants in general often find their participation in research to be therapeutic (Blackman, 2007; Dickson-Swift, James, Kippen &

Liamputtong, 2007). Patai, for instance, suggests that this is the case because “many people who participate in research do not have enough people in their lives who want [or perhaps feel comfortable enough] to listen to what they have to say” (as cited in Dickson-Swift et al., 2007, p.331).

While I acknowledge that writing this thesis should not be a therapy session for me, the research has offered me an opportunity to reflect on my own life and it has helped me disrupt some ongoing silences within my own family. Similarly, for some individuals, especially those with disabilities, participating in this research might have served as a much-needed opportunity to talk about their expression and practices. My goal in this project was to pose questions, provoke thoughts, and attempt to disrupt negative dominant ideas regarding disability and sexuality. However, instead of taking the role of the “transformative intellectual” which “tends to cast the inquirer in a more authoritative role,” I preferred to take the role of the “passionate participant” making space for some individuals with intellectual disabilities to share their own experiences and perspectives on sexual expression and practices (Guba & Lincoln, 1994, p.33-34). That said, I recognize that I am always present in the writing of this work, and I accept that “analysis does not end, but rather begins with the recognition of [my] own emotion” (DeVault, 1990, p.105). Because of my emotional connection to this research, it was important for me to work to keep my own narratives from interfering with my capacity to listen to the stories of others clearly.

Participant Recruitment

Once I obtained approval from the ethics board at the University of Lethbridge, I invited two groups of participants to participate in this research. The first group involved

community members who self-identified as intellectually disabled, were over 18 years of age, acted as their own guardians, and had had direct care workers in their lives. They were invited to share their experiences of sexual expression and practices, and their interactions with their direct care workers. This research excluded individuals with intellectual disabilities under guardianship orders because I understand that guardianship arrangements are not always congenial, and that access may not always be granted when dealing with guardians. As a result, the data and analysis relating to individuals with intellectual disabilities included in this study is limited.

The second group involved direct care workers from non-profit organizations and service agencies delivering regular personal supports to individuals with intellectual disabilities. They were asked to contribute their insights, beliefs and practices in regards to the sexual expression and practices of their clients, their interactions with their clients and their families, and the influence of institutional policies and training on their work. It was relevant to include direct care workers because they can play a significant role in the lives of some individuals with intellectual disabilities by sharing information, delivering services, and supporting or discouraging sexual expression and practices both at residential and community contexts.

My recruitment strategies included calls for participation posted in public places as well as online notice boards, individual conversations, referrals from interviewees (snowball sampling), and pre-existing contacts in self-advocacy groups and local agencies for individuals with disabilities. I was able to successfully recruit five community members with intellectual disabilities and six direct care workers for this study. Because posted calls for participation did not seem to be attracting potential

participants, the pre-existing contacts that I had developed throughout the community became central in the recruitment process for this research. Throughout my graduate program, I volunteered and participated in different programs and events involving individuals with disabilities and their family members, as well as involving direct care workers of local non-profit organizations and service agencies. These connections to self-advocates and direct care workers facilitated the recruitment process significantly, allowing me to access potential research participants. In addition, I used snowball sampling to recruit research participants who were somewhat “hidden” due to the sensitivity of the research topic. The main limitation of snowball sampling, however, is that selected participants might not be diverse (Esterberg, 2002, p.93-94), and this is reflected in the final sample of my research participants.

I considered my pre-existing relations with potential participants very carefully throughout the recruitment process. For instance, one self-advocate who I knew through my volunteering had previously shown to be uncomfortable talking about sexuality, and thus, I deliberately chose not to invite this person to this research to avoid causing some potential anxiety or embarrassment. In another instance, another self-advocate hesitantly told me that he “would think about it,” when I invited him to participate, and in the end I did not include this individual in the project. It was also the case that some direct care workers I had met were not willing to participate in the research due to their limited free time, or their hesitancy to speak about their organizations and their practices. I also respected their decisions not to partake in this research and instead kindly asked for potential referrals.

Given my recruiting methods, it was possible that some of these participants could have known each other either as colleagues, workers, friends, or as members of self-advocacy groups, and hence they could have independently discussed their research participation with each other. However, in terms of my involvement in the research process, I endeavored to protect all participants' identities within their communities by disguising details such as names, locations, and identifying features. I also ensured that the individuals or agencies that had referred potential participants would not receive any information from me as to the outcome of those referrals.

Research Participants

I conducted ten in-depth interviews with five community members with intellectual disabilities and six direct care workers in Southern Alberta⁶. In the first group, consisting of individuals with intellectual disabilities, I interviewed four men and one woman with ages ranging from 28 to 42 years. All participants identified as Canadians, White, and heterosexual. Their disabilities included cerebral palsy, ADD, ADHD, seizures, autism, depression, and other learning disabilities. At the time I conducted the interviews, Nicholas and Samantha had been married for over five years, and Jeremy, William and Anthony were single; one of them was divorced. In terms of religious background, one participant identified as agnostic [Jeremy], two reported not belonging to any religion [Samantha and Anthony], one identified as a Mormon [William], and another as a non-practicing Christian [Nicholas]. At the time of the interview, Nicholas and Samantha were living together independently in a family owned house, Jeremy was living with

⁶ The full demographic information of the participants is appended. I have used pseudonyms for all participants and have made every effort not to provide identifying information in reporting these data.

roommates, William was living with roommate companion, and Anthony was living in a rented house with the regular supports of a direct care worker. In terms of education level, with the exception of Anthony who was working on his bachelor's degree, all the other participants had concluded high school. Three participants [Nicholas, Samantha and Anthony] were self-employed, another participant [Jeremy] was employed, and one participant [William] was unemployed.

A key selection criteria for participants was that they wanted to share their experiences concerning how their direct care workers might have affected their sexual expression and practices. At the time of the interviews, Anthony was the only participant still receiving regular personal supports from a direct care worker, while the others had either decreased their interactions with direct care workers to monthly meetings to go over financial and service matters, or ended those interactions altogether. However, all these participants had had direct care workers in their lives within the last five years, and wanted to talk about their experiences regarding their sexual expression and practices and how workers have affected them either positively or negatively. This small sampling of participants thus enjoyed a somewhat privileged position because they were their own guardians, and enjoyed significantly independent community life. As will be seen, these participants have shown some significant decision-making scope, which might not be the case for some other community members with intellectual disabilities who, for instance, are not their own legal guardian.

In the second group, consisting of direct care workers, I interviewed 5 women and 1 man with ages ranging from 23 and 49 years.⁷ These individuals participated in this research because they had served as direct care workers in non-profit organizations and service agencies delivering regular personal supports to individuals with intellectual disabilities, and they were willing to discuss their experiences and practices concerning the sexual expression and practices of their clients. I have also used pseudonyms [Michael, Marina, Celine, Rose, Susan and Paola], and withhold some their characteristics to protect their identities. Michael, Marina, Celine and Rose identified as Canadians and White, while Susan identified as Southeast Asian and Paola as Latin American. Marina, Celine and Paola identified as heterosexual, Michael identified as gay, Susan as bisexual, and Rose as undeclared. When asked about their religious beliefs, Michael and Rose reported being agnostic, Marina identified as agnostic/atheist, Paola identified as Catholic, Celine as spiritually open-minded, and Susan mentioned not belonging to any religion. At the time of the interview, Marina, Rose and Paola had concluded their bachelor's degree, Celine and Susan were still undergraduate students, and Michael was working on his master's degree. Their degrees encompassed different fields of study such as General Humanities, Modern Languages, Nursing, Exercise Science, and Sociology. The selected participants included permanent and relief workers delivering overnight assistance at group homes [Michael, Marina, Rose, Susan and Paola], respite services to parents and caregivers [Celine and Rose], and supports to individuals with intellectual disabilities in their various activities in the community

⁷ Previous studies have examined how care work is a highly gendered form of labour and have inquired how gender might influence the everyday experiences and practices of both direct care workers and individuals with intellectual disabilities in multiple ways. See, for instance, Gilmore and Chambers, 2010; and Young, Gore and McCarthy, 2012.

[Celine and Susan]. These participants have worked as direct care workers in different agencies for different amounts of time; from two months [Paola] to 27 years [Marina]. I will discuss their relationships with their clients more thoroughly in the next couple chapters.

I also recognize that the groups of selected participants in this research were small. However, as Patton (2002) has noted, “there are no rules” in qualitative research in terms of sample size (p.244), and indeed most qualitative studies tend to involve smaller sample sets, and more in-depth analysis of the data (Braun & Clarke, 2013; Savin-Baden & Major, 2012). According to Braun and Clarke (2013), qualitative research is about “hav[ing] *enough* data to tell a rich story, but not too much that it precludes deep, complex engagement with the data in the time available” (p.56). Additionally, a critical-constructionist paradigm dismisses the notion of ‘data saturation’ because “there is always more to learn” (Savin-Baden & Major, 2012, p.317). My main interest was not to produce generalizable data per se, but to delve into the complexities in the actual lived experiences of a small sampling of individuals with intellectual disabilities and direct care workers, and create a compelling representation and interpretation of the ways in which these selected individuals make sense of the sexual expression and practices of intellectually disabled people. Instead of seeking to generalize findings from a specific small sample, I would suggest that the findings in this research “*may* be transferred and *may* have meaning or relevance if applied to other individuals, contexts and situations” (Finlay, 2006).

Interview Management

The interviews were conducted in a mutually agreeable location to allow participants to feel comfortable sharing their experiences. I interviewed direct care workers outside of their organizations to allow them to avoid concerns about possible employment consequences. The duration of these interviews ranged from 45 minutes to almost two hours. The interviews with individuals with intellectual disabilities involved some negotiation over the most appropriate location for participants to allay concerns over negative impacts on their relationships with family members and direct care workers. These interviews lasted from one and a half to two hours and 15 minutes. In one of the interviews, which took place at the participants' house, I considered it appropriate to put certain safeguards into place to also guarantee my own safety. I used a "buddy system," notifying a trustworthy colleague that I was going to a participant's home to conduct an interview. I kept certain details of the interview (e.g. name of participant, date, time, expected duration and location) in a small notebook, and in case I was not back within a few hours, my colleague would access that information (Braun & Clarke, 2013, p.65). However, in order to protect confidentiality, I made sure to return from the interview promptly, and notified my colleague immediately with a brief phone call so she did not need to access the information. All the interviews, with the exception of two, one which took place in a private office at a local agency and another at the participants' house, happened in an office on campus.

When interviewing, it was important to understand consent as an ongoing process that empowered participants to act on their right to decide whether they wanted to proceed in the research (Ellis, 2009). I informed participants at the time of reviewing the consent form that their participation was voluntary. I discussed with them that they could

refuse to answer any questions, or that they could terminate their involvement at any time during the interviewing process. I provided participants with consent forms with my name, address and email address in case they wanted to contact me with their questions or concerns pertinent to this research project. At the time of the interviews, I also told the participants that, following the interview, and any time prior to the conclusion of the project, they could withdraw their consent for any portion of the interview, or their participation in entirety, without any penalty. None of the participants chose to withdraw from the study.

I transcribed and assigned the interviews identification codes as soon as each one of them was done. The transcription of interviews, though sometimes taken for granted, is an important part of the research process, and requires some consideration regarding how to appropriately represent interviews on paper, as those representations can affect the research analysis (Bird, 2005; Dickson-Swift et al., 2007; Kvale, 1996). Certainly, transcripts, as “translations” of oral and body language into a written language, are “decontextualized conversations” (Kvale, 1996, p.165); and I addressed this to some extent by listening to the interviews even during the analysis process in order to recall some of the particular context and body language in different parts of the interviews. Also, I transcribed, to the best of my abilities, the exact words of participants and took note of some “nonverbal communication, such as pauses, laughter, or interruptions” for more contextualized representations of interviews (Bloomberg & Volpe, 2012, p.136). I included “um,” “mm-hm” and “you know” in the transcripts because I felt that these were “response tokens” which might not be “quite words [but] are nevertheless language [and] using certain mono- or bi-syllabic sounds, can relay both meaning and understanding to

the interlocutors” (Oliver, Serovich & Mason, 2005, p. 1284). Response tokens such as a “thoughtful Hm or wishful Mm” can, for instance, “serve as useful markers in speech, indicating participant discomfort or other affective states (e.g. distress, happiness, pride, etc.)” (ibid).

Ethical Considerations

I started conducting interviews once I obtained approval from the ethics board at the University of Lethbridge. When potential participants responded to the call for participation, I asked them whether they were in a guardianship arrangement, as this project only involved individuals with intellectual disabilities who have the right to consent. At the time of the interview, I provided the consent form (Appendix A) to the participants, and read it along with all of them to ensure that the form had been understood. I reaffirmed that their participation was voluntary, that they could refuse to answer any questions or that they could terminate their involvement at any time during the interview process without any form of penalty. I provided my name, address and email address on the consent form along with a statement inviting participants to contact me at any time with their questions or concerns, including withdrawal. As I have noted, none of the participants chose to withdraw from this study.

I audio-recorded the interviews with the participants’ permission, and after data collection I uploaded the recordings into a computer. I transcribed the interviews, and kept identifying information out of transcripts by applying pseudonyms to participants. I am the only person with access to the pseudonym/participant linkage information, and the interview data are reported using pseudonyms, changing place names, organization names and family details to protect the anonymity of participants. It was particularly

important to assure participants that identifying information would not be made available to any members of their community, including their peers, agencies, clients, guardians, and family members. The only exception to this would have been if participants revealed information about illegal activities, such as physical or sexual abuse; I explained the need of reporting illegal activity as part of obtaining informed consent from participants.

An ethical approach should involve not only procedural ethical guidelines, but also should engage in relational ethics (Blee & Currier, 2011; Ellis, 2009; Librett & Perrone, 2010). This is because, as Ellis (2009) points out, “relational situations will come up in the field and in the interviews that will make [...] heads spin and [...] hearts ache” (p.310). I was aware that some of the participants could get upset when sharing their experiences around sexual expression and practices, as some of these experiences can be painful to talk about. As Ellis notes, despite the fact that we hope that “in the best of all worlds, all of those involved in our studies will feel better [...] sometimes they won’t; you won’t” (p.316). As a part of my common practice, I provided all the participants with the name and telephone number of a local agency director who has both the tools and the sensitivity to be a positive resource for any additional debriefing participants might require. I even offered to facilitate the contact if necessary.

As part of my “ethics of care” (Lincoln as cited in Ellis, 2009, p.308), after interviews, I spent some time debriefing with all participants in order to check if they were feeling all right about the interview, or had any questions or concerns. This was particularly important in one of my interviews with a direct care worker who disclosed that he had been sexually abused as a child. We spent a significant amount of time debriefing at the end of his interview and I provided him with a list of resources in the

local community. As a general practice, I also followed-up with a phone call or email two weeks after the interviews to see how interviewees were feeling post-interview. In these follow-up contacts, none of the participants seemed to be upset by their participation in the research. I also took care of my own wellbeing by taking notes at the end of the interviews in order to de-compress and reflect on them, and by counting on the support of family members and university colleagues.

Self-Disclosure and Reciprocity

Interviews, as Kvale (1996) points out, are not a “reciprocal interaction of two equal partners,” because interviewers often “defin[e] the situation, introduc[e] the topics of the conversation, and through further questions stee[r] the course of the interview” (p. 126). Behar acknowledges this unequal exchange of experiences, and notes that “we ask for revelations from others, but we reveal little or nothing of ourselves, we make others vulnerable, but we ourselves remain invulnerable” (as cited in Ashby, 2011). Second wave feminist scholars have suggested that self-disclosure can sometimes help researchers establish rapport with participants, and challenge the hierarchy between researcher and participant (Oakley, 1981). Similarly, for Dickson-Swift et al. (2007), self-disclosure can “enhance rapport, show respect for the participants and validate the participants’ stories” (p.332). The frequency and amount of researcher self-disclosure can vary significantly depending on the research topic and its sensitivity level (ibid).

I started from the premise that, if participants were expected to reveal certain intimate aspects of their lives, I should also be willing to share some personal information that I felt comfortable sharing at the moment. I suspected that some direct care workers would ask me about my opinion in regards to the sexual expression and practices of

individuals with intellectual disabilities, or that individuals with intellectual disabilities would ask me questions about my romantic and sexual experiences, or my stance regarding their sexual rights. In the case of direct care workers, none of them asked me any questions about my personal experiences and perspectives. Conversely, the self-advocates who I interviewed, who were aware that I have an older brother with a disability, often asked me questions about my brother's experiences in regards to sexual expression. In that case, I shared little information because, even though I was willing to share some of my own experiences and perspectives with participants, I did not feel that it was right to share information about my brother's experiences.

As I look back and reflect on the interviewing process, I come to think about how my previous relationships with some of my participants influenced significantly my interactions with them before, during, and after the interviews. It was somewhat challenging at times for me to negotiate the intricate interactions of my different subjective positions (e.g. as a buddy, an ally, a researcher) in relation to my participants. That is to say that the interview encounter proved to be a significantly distinct form of interaction with those individuals who I had spent time with in different community activities, interactions which had been based on informality, humor, spontaneity and, perhaps, in a way, a more equalized power relation. Nonetheless, once I started the tape recorder and went over the consent form with my participants, we both seemed to adopt the roles of the interviewer and the interviewee. This time, I had the power to ask questions about their intimate lives, about aspects which we had never discussed openly before, and thus, at times, I feared that my questions about sex and pleasure would make some participants uncomfortable. I also recognize that such a hesitation to talking openly

about sex and pleasure also came from my own timidity in openly discussing those topics. Consequently, in some cases, I ended up asking more intimate questions either indirectly or more briefly. Nevertheless, my previous relationships with some of the participants not only shaped the questions I asked to my participants and how I asked those questions, but also involved some critical labor on both sides in terms of (re)establishing different ways of relating to one another. I say that because I spent a significant amount of time talking with my participants after the interviews and, as I look back, we did seem to both engage in a process of reestablishing our previous kind of relationship as buddies or allies. In this process, we would leave my research project and my role as a researcher almost completely aside, and would establish once again a different form of social relation by talking about different community activities, remembering past funny moments, and playing jokes on each other.

This is not to say that I do not embody certain privileges in relation to my participants. As Reinharz has noted, “we have to study who we are and who we are in relation to those we study” (as cited in Fine, 1992, p.215). Thus, through interviewing, I had entered a whole set of local and trans-local social relations and power dynamics, which required me to interrogate my own positionality and privileges in relation to my participants. I do know, for instance, that some participants looked up to me as an “educated scholar,” a significant privilege considering that the majority of the individuals with intellectual disabilities who I interviewed had not had a chance to attend university. My positionality as a scholar has allowed me, in the first place, to select a topic and conduct this research, gain some access into the lives of my participants, and have the opportunity to analyze, write, and then disseminate my work amongst other scholars.

Reciprocity, however, can help researchers challenge the hierarchy between researcher and participant (DeVault, 1990; Oakley, 1981). Some scholars have advocated for reciprocal relationships as a way to “enable researchers to acknowledge the value of what the participants have shared with them,” and this could take the shape of “some community action, a report, or some community service” (Dickson-Swift et al., 2007, p.334). McDonald, Kidney and Patka (2013) found that most individuals participate in research to help researchers better understand their experiences and opinions as well as to improve the lives of other people with disabilities. Participants hoped to benefit directly from the research by “learning new things related to achieving their goals or improving their lives, having new experiences, meeting new meeting, having something to do, and helping others learn about people like them” (p.4).

Ashby (2011) notes that it is important for qualitative researchers “to be very clear about the goals of the project and the reasonable potential outcomes.” In her case, particularly, she chose not to assume that the “research project can itself be the force that brings about change,” but to take her “role as standing with my participants and making space for their voices” (ibid). Moreover, as Madison has suggested, “*angst* and *guilt* about your benefits [from representing Others in your work] cannot eclipse or cloud your *responsibility* to do meaningful work” (as cited in Ellingson, 2002, p.103).

I was not naïve or pretentious to think that a one-hour interview would be a life-changing experience to participants. I also recognized the importance of articulating to my participants, right from the start, what might (or might not) realistically come out from this research. Even though there is often some pressure for us scholars to provide recommendations or ‘solutions’ at the end of our papers, I have considered that my role

in this specific project was to raise questions and provoke thoughts regarding the sexual rights and expression of individuals with intellectual disabilities. This is also because, inspired by the work of Michel Foucault, I recognize that instating a new proscription can be problematic.

Nevertheless, as a demonstration of reciprocity, the consent form I used in this study included a section where participants could let me know of their interest in receiving a brief research write-up, in plain language, once the project was completed. The majority of participants de facto asked for a summary of the research findings. I have committed to make the final thesis available in the University of Lethbridge library archive where participants can access the complete research study. I have also committed to send participants a copy of any future articles published from this research project. I would like to believe that my work might trigger some form of positive change, be it in the individual level as I interacted with participants, or in a larger scale influencing the experiences of some individuals with disabilities or the practices of some direct care workers.

Data Analysis

As Kvale (1996) suggests, we should not assume that our research will generate “knowledge claims that are so powerful and convincing in their own right [that] they [...] carry the validation with them, like a strong piece of art” (p.252). Thus, even though scholars such as Guba and Lincoln (1994) have acknowledged that “the issue of quality criteria [...] is [...] not well resolved and further critique is needed,” it still is important to hold on to some form of criteria to evaluate qualitative research (p.114). In this regard, Ballinger (2006) has suggested four main “considerations” for qualitative researchers.

The first consideration, “coherence,” refers to the coherent matching of the research purpose, the research methods, and the role taken by the researcher within that methodology (p.240-241). The second consideration, “systematic and careful research conduct,” which also “translate[s] differently, depending on the methodology adopted,” might involve some evidence that the researcher considered issues such as recruitment, self-disclosure, and participants’ representation carefully (p.241). The third consideration, “convincing and relevant interpretation,” refers to the construction of a “credible and compelling” account which might, for instance, involve the backing of our interpretations by a relevant theoretical framework (p.242). Finally, the last consideration refers to reflexivity, particularly in regards to the ways in which the researcher may have influenced the research process and outcomes. Above all, according to Madill, Jordan and Shirley (2000) it is important for qualitative researchers “to make their epistemological position clear, conduct their research in a manner consistent with that position, and present their findings in a way that allows them to be evaluated properly” (p.17). These considerations fit well with my research approach, and thus, I considered them throughout this project.

In terms of data analysis, I examined the data from a critical-constructionist and standpoint theory framework using thematic analysis. After I transcribed the interviews, I read the transcripts multiple times to further familiarize myself with the data and generate an initial list of codes. I also kept footnotes on the transcripts as well as side notes in order to tentatively identify some codes and themes. Nonetheless, I conducted the formal coding of my interviews using Atlas.ti, a qualitative data analysis program. My coding method started off with the open coding of the interview transcripts, meaning a line by

line reading of the transcripts which allowed me to translate the interview “data [in]to codes” and eventually establish broader themes and concepts (Boeije, 2010, p.108). I started with a basic code list based on the first few interviews, which was then used in the analysis of subsequent interviews. However, as I developed new themes throughout the coding process, I also went back to my first interviews to code them based on my updated code list. I should mention that the coding process was both “theory-driven,” approaching the data with specific questions and a theoretical framework in mind, as well as “data-driven” with codes “depend[ing] on the data” itself (Braun & Clarke, 2006, p.18).

The final stage of the coding process involved looking at the interviews for common themes and shared experiences among the participants. Thematic analysis, Braun and Clarke (2006) state, can be helpful in “identifying, analyzing, and reporting patterns (themes) within data” (p.6). Themes can vary greatly in recurrence, and “more instances do not *necessarily* mean the theme itself is more crucial,” but rather, “the ‘keyness’ of a theme” is more dependent on “whether it captures something important in relation to the overall research question” (ibid, p.10). It is important to note, as Braun and Clarke have cautioned, that it is problematic to speak about “emerging” or “discovered” themes, as they note that “it denies the *active* role the researcher always plays in identifying patterns/themes, selecting which are of interest and reporting them to the readers” (p.7). That considered, one of the aims of this study was to explore the hindrances and opportunities for a small number of intellectually disabled individuals to engage in sexual expression and practices and, with that in mind, I identified different themes that seemed to inform my inquiry. That included, for instance, the theme of housing arrangements and their effects on the sexual opportunities of this small number

of intellectually disabled individuals, which had been identified in the literature review and that was also expressed by the participants as a significant barrier for sexual expression and practices. As for the direct care workers, when exploring some of their attitudes and experiences when dealing with the sexuality of their clients, I also identified some key themes. That included, for example, the workers' own positions as sexual beings and their influence in their practices related to the sexuality of their clients, which was either mentioned or implied by most of the participants as relevant to their practices.

Participants' Experiences as Data

It has been noted by different scholars that researchers have somewhat of a central role in their research endeavors as they often occupy a privileged position, which allows them to interpret and construct a narrative for their data (Denzin 1998; Finlay, 2002; Kvale, 2006; Mantzoukas, 2004). Moreover, second wave feminist scholars have emphasized the importance of interrogating how the positionality and social relations of researchers are always implicated in the analysis and writing of their work (Finlay, 2002).

As Mantzoukas (2004) eloquently puts it:

The research text does not write itself, nor is there a hand as an object that mechanically dots down symbols or letters; instead, research texts are written by someone and by a hand that is attached to a greater body that is part of a whole person, which includes mind and soul (p.1001).

Thus, I acknowledge that even though the experiences of my participants served me as a foundation for my research, I was the one who ultimately chose which stories to tell as well as how to tell those stories. When selecting and writing the participants' stories, I wanted to provide not only a snapshot of their experiences as they understood them, but also to show some of the multiplicity and complexity in their accounts. It was particularly important for me to explore the complexity in the participants' narratives in order to

illuminate some of their practices and the ways in which these individuals, for various reasons, have struggled to move forward in regards to disability and sexuality. Nonetheless, this meant that, at multiple points, I had to deal with what my supervisor has referred to as an “internal voice,” one which made me consider various ethical, epistemological, and methodological questions when doing the analysis of my data. To begin with, as one can see in my analysis, I have privileged the voices of this small sampling of intellectually disabled individuals, and that had to do with my epistemological commitment for this particular project. My intention was not to take the complexities in the experiences of direct care workers for granted, as I have certainly acknowledged and hinted at certain potential areas for further exploration in regards to their particular experiences and challenges throughout my analysis. However, it was still important for me to highlight the voices of the individuals with intellectual disabilities especially because, historically, these voices have not been given the appropriate space and authority within social inquiry.

Another challenge that I faced during the analysis of my data had to do with the interrogation of how my positionality and privileges have affected how I made sense of the experiences of my participants. It was sometimes difficult for me to recognize the similarities and/or differences between my own experiences, challenges, aspirations with regards to my sexuality and sexual expression and those of my participants, especially those coming from young male participants around my age. On one hand, I figured that some of their experiences and challenges could have been more disability-related. For instance, I recognize that, as a non-disabled individual, I have been granted the opportunity to make mistakes in relation to my sexual and romantic life without having

other people question my ability to make what one may consider to be good decisions. In contrast, my participants spoke strongly about being able to make mistakes and learn from them as they strived to have the sexual and romantic life that they desired. On the other hand, I also noticed how my participants and I also had some dreams and hopes in common. As Jeremy spoke about waiting for the right person, almost as in a fairy tale, I realized that I too seemed to hold on to that dream, often asking myself when the right person would come my way. Thus, even though I know that Jeremy and I have had distinct challenges when trying to achieve that fairy tale, we did share some common dreams in regards to loving and being loved.

Finally, as I have tried to look at my data from different perspectives, throughout my analysis I also discussed my interpretation of certain participants' narratives with my colleagues who, at times, challenged me to look at my data in new ways. Moreover, I am reminded of a professor who once asked a colleague of mine in her thesis defence: "Is this an interpretation and representation of your participants that allows you to put your head onto your pillow and sleep well at night?" And for that question, I would confidently say yes.

Conclusion

In this chapter, I discussed the paradigmatic, ontological, and epistemological approach taken, and focused on the methodology that underpins this research. I looked at various methodological and ethical questions such as recruitment, interviewing strategy, ethical considerations, participants' representation, self-disclosure, and reciprocity. I also talked about the process of data collection, transcribing and coding, and presented the analysis framework. In the next couple chapters, I will synthesize the findings that

emerged from the research, provide a discussion on the data, and draw together some conclusions. I will also address some of the limitations of the research, talk about the challenges experienced, and suggest some possibilities for future research.

Chapter Three

Individuals with Intellectual Disabilities

This chapter explores the attitudes and experiences of a small number of individuals with intellectual disabilities in regards to their sexual expression and practices, and inquires whether and how these individuals' direct care workers had affected their expressions and practices. The five individuals with intellectual disabilities who I interviewed presented a diverse group in regards to their historical and current sexual practices and experiences. At the time I conducted the interviews, Jeremy, Anthony and William were single; William was divorced, and Nicholas and Samantha had been married for over five years. Altogether, their narratives seem to illuminate experiences of heartache, hope, pleasure, and resistance when exploring and expressing their sexual and romantic desires. The full demographic information of the participants including their living situation, religiosity, and relationship status has already been discussed and can also be located on the following page.

Table 1 - Demographic Information – Individuals with Intellectual Disabilities

Name	Age	Sexual Orientation	Relationship Status	Religiosity	Guardianship Status	Living Situation	Educational Attainment
Jeremy	28	Heterosexual	Single	Agnostic	Own Guardian	Living w/ Roommates	(Modified Curriculum) High School
William	35	Heterosexual	Single (Divorced)	Mormon	Own Guardian	Living w/ Roommate Companion	(Modified Curriculum) High School
Nicholas	42	Heterosexual	Married	Non- Practicing Christian	Own Guardian	Living in a Family- Owned House w/ Samantha	(Special Education) High School
Samantha	31	Heterosexual	Married	None	Own Guardian	Living in a Family- Owned House w/ Nicholas	(Special Education) High School
Anthony	28	Heterosexual	Single	None	Own Guardian	Living in a Rented House w/ Regular Support of a Direct Care Worker	2 nd year B.A.

Housing Arrangements and Sexual Opportunities

I often started the interviews asking participants about their current living arrangements and whether they had workers supporting them at home. This was because various studies have suggested that housing arrangements can significantly affect the sexual opportunities and experiences of individuals with intellectual disabilities (Hollomotz & The Speakup Committee, 2008; Lesseliers & Van Hove, 2002; Löfgren-Mårtenson, 2004). The interviewees reported a variety of past and current housing arrangements ranging from highly supervised and restrictive group homes to more independent and private living arrangements. At the time of the interview, Anthony lived at a house on his own with the supports of a personal assistant living next door. In the past, he had lived in a group home. As he talked about the group home and some of the “house rules” that had been in place, it became evident how these were significant barriers for him to have privacy, be able to maintain relationships, and have sex with his partners. For instance, Anthony was told that he had to be back at the group home by 10pm, the time that the doors of the house would be locked. That curfew limited his time out in the community as well as his chances to socialize and participate in nighttime events. Therefore, he had fewer opportunities to meet potential romantic and sexual partners, and to engage in flirtation, hook-ups,⁸ and courtship. Even when he did meet potential sexual partners, another restrictive rule was that he was not allowed to have any visitors. Anthony spoke about the reaction of one direct care worker when he had a woman over after a party:

⁸ The term hook-up has a variety of meanings but it is often associated with almost any type of sexual activity, from kissing fervently to having sex, done among people who are not in a committed relationship.

I had a worker who tried to kick a girl out of my house, they'd come there and be like, "No, you gotta go," and I am like, "What? This is my house. She doesn't have to go anywhere. You have to go ... I pay the rent. I decide who comes and goes."

Anthony was also not allowed to have a lock on his bedroom door because that was against the group home's rules, which effectively limited his access and control to a private space in which to engage in sexual practices and obtain sexual pleasure. Another direct care worker told him, "oh you can't have your girlfriend here," in a way that presumed that for him, this form of relationship would not require privacy. In response to that rule, he had his father actively come to his defense, as Anthony reported:

He drilled holes in the door and deadbolts, and said, "Stay out of here" like [laughs] so, but they made a big deal about that, they tried to go to some committee, "Oh no, he can't have a lock on his door, no, that's against the group home's rules." [laughs] My dad is like, "Rules? What rules?"

Due to these restrictive rules, Anthony decided to move out of the group home, and for over five years he has been living independently with the daily supports of a worker he has personally hired, based on his own needs and preferences. This was possible partly because Anthony has moved away from receiving services through agencies funded by the government to having a self-managed funding arrangement that allows him to directly employ his own direct care worker. Self-managed supports, also known as family-managed supports, is a funding option for individuals with disabilities and their families to receive funding directly from the government and "take a primary role" in arranging their own supports, managing their expenditures, and keeping records. This funding option allows people to select, hire and manage their own direct care workers (Darrell Cook Family Managed Supports Resource Centre, 2014).

Another participant, Jeremy, also reported experiencing a lack of privacy and control over his living space when sharing a house with paid roommate companions.⁹ He provided an example relating to a former roommate, a middle aged woman with whom he lived with for a short time: “She was the main one in the contract for the rental place and she said my room had to be like clean and stuff to the point that I had no privacy, like she would be in my room checking it out constantly.” One can imagine that having his roommate access his private space at her own discretion to make sure it was clean limited his sense of independence and privacy, and perhaps even his opportunities for sexual expression and practices. In his experiences living with roommate companions, he was allowed to bring people to his home. However, he did not have any visitors other than his family members because, as he noted, “it was just more awkward, and I guess it’s when you have that paid staff, things aren’t the same as when you don’t have those paid staff in your life constantly.” Jeremy noted that this is not a typical roommate relationship, but one with clearly defined roles, where “there’s certain things set from the agency level that they [workers] have to follow.” In the case of Jeremy, this particular kind of relationship, which is often mediated through a series of texts including policies, guidelines, and reports, seems to leave little room for equal, spontaneous, and common roommate relationships. Thus, Jeremy did not see discussing sexuality within this kind of relationship as the most appropriate option. Jeremy has realized that a roommate

⁹ The term roommate companion, also known as supportive roommate, refers to individuals or families renting rooms at their houses to individuals with intellectual disabilities. Their responsibilities include, for instance, providing companionship and personal care, helping with budgeting, and facilitating everyday household tasks. Roommate companions are often financially compensated through the rent paid by the individual with a disability as well as some government funding based on the level of care. Participants considered roommate companions to be direct care workers.

companion arrangement does not work for him, and since then, he has moved on to live in a house with three young men around his own age. In trying to describe how he felt about his current housing arrangement, he could only say:

I can't explain it. I can't put it into words. It's just like freedom, that's the best way to describe it ... Here, it's not awkward to have people over, yeah, it's like- it's like my place, not like the other people's place.

In regards to the influence of this new living situation on his sexual expression and practices, he has limited his use of this more private and independent space to consuming pornography and masturbating because, as he noted, he is "still waiting for the right person." Nevertheless, this represents a choice that in his former living situation was not available to him.

In William's case, since he moved from his parents' house, he has been living with a family with four children. He reported being mostly satisfied with his current arrangement, as he said: "I mean, compared to bigger issues, there's nothing issue- no issues, but I mean, you weigh the pros and cons, I really wouldn't want to move at this point." The only problem about this living situation, he said, was that his room was on the main floor, sharing the same hallway with the rest of the family. This is when he briefly mentioned a lack of privacy:

I just- like a little more priv- like, it'd be nice if they le- like, had a basement suite or something, but they don't, I mean, it's minor, I mean, it doesn't affect that- I mean, if you- for this, I don't think it affects the- like if I needed privacy I think I could get it...

On one hand, William certainly notes that he could have privacy if needed and that the family has even put a lock on his bedroom door to offer him more privacy. On the other hand, it is reasonable to say that such a living situation can be somewhat discouraging in terms of actually having potential sexual partners come over, engaging in sexual

practices, or holding open conversations about sex. Furthermore, certain social conventions view children as lacking sexual feelings and being innocent, and in need of being sheltered from anything sexual. Therefore, it is also reasonable to say that having small children living just two doors down the hallway might also make William hesitant to engage in openly sexual practices at the house. Nevertheless, William said that he was not interested in moving out of the house because, as he noted:

I don't really bring people over other than my brother but the point is I don't- I mean, I get people from church that come over for talk and do things, so it's not that, but, I mean, I just give them a heads up, so the basement can be clean.

It is worth noting that William, who self-identifies as a Mormon, is actually sworn to celibacy because pre-marital sex is commonly seen as a sin amongst devout Mormons. In William's case, particularly, his religious background has played a significant role in his sexual expression and practices, and this will be furthered explored on the forthcoming section about religiosity.

Lastly, Samantha and Nicholas talked about their experiences living independently as a couple for over a year, renting a house from Nicholas's parents. Their access to sexual autonomy and privacy became evident as they talked about their opportunities and experiences engaging in a variety of sexual practices, including a "swing lifestyle." In few words, as Serina et al. (2013) explain, "a couple who self identifies as 'swingers' are partners who agree to engage in sexual interactions with other couples who also engage in swinging" (p.349). Nicholas spoke about how they usually meet and get to know potential swing partners: "I usually wanna get the girl to have a drink or coffee first but- and the one gentleman I told you about, we did have success, he came over, he had coffee with us and that was it." As seen in other participants' narratives, one could say that this

level of sexual autonomy might not be available to other people with intellectual disabilities living in more restrictive and surveilled settings. Before living independently, Samantha and Nicholas both lived with roommate companions as a transitional step. As Samantha recalled:

I was living pretty much on my own with a roommate companion, like he had his place upstairs and I had my own place downstairs, so it helped me transition to be living independently quite well between in the two years that I was with him.

In regards to engaging in sexual practices, Samantha reported that she was allowed to have visitors: “as long as my roommate knew who the person was because it was his house that I was living in, as long as he knew who they were, then everything was ok.” Nevertheless, similarly to William, she rarely talked with her former roommate companion about sexuality:

We talked but we never got into any relationship talks or intimacy talks or anything like that considering he had two boys with him, two kids, and then it was like um... [laughs] how do you talk to your roomie when there are kids there and stuff like that?

In sum, participants talked about how a variety of former and current housing arrangements influenced (and sometimes limited) their opportunities to engage in sexual expression and practices. Even though most of these individuals started off living in more restrictive and surveilled living arrangements, they have managed to move into more independent and private settings that have provided them with more autonomy to engage in certain sexual practices.

Education and Its Effects on Relationships and Sexuality

In terms of educational attainment, with the exception of Anthony who was working on his bachelor’s degree, Samantha, Nicholas, William and Jeremy had all

concluded high school in ‘special’ education or modified programs. Studies have widely suggested that students with intellectual disabilities in special education as well as in mainstreamed programs tend to have fewer friends, be more socially isolated, and experience loneliness (Guralnick, 2006; Heiman, 2000; Mason et al., 2013). Indeed, in the cases of Samantha, Nicholas, William and Jeremy, their romantic and sexual experiences during their school years were often marked by isolation, loneliness, and heartache. For Samantha, special education involved being mostly in “a separate classroom,” while for Nicholas, it involved being in “a completely private and closed section of the school.” Their segregation and the exposure of their status as special education students contributed to their further stigmatization and isolation. As Nicholas remarked, “I was bullied to the fullest.” He added, “My time in school was a very lonesome period.” Samantha, who was included in some ‘regular’ classes throughout her education, was able to be in a few romantic relationships in school. However, when talking about those relationships, she remembered:

It was rough, I would be in and out of a relationship within like a week to two weeks ... I kept getting hurt, they- they- when they found out I had a disability it’s like, “OK, I’ll just use you and I’m off” ... up until I met Nicholas it was like, I can’t take it anymore, I can’t do this.

Adding to Samantha’s narrative, Nicholas immediately interjected, “we’re extremely vulnerable to abuse like that... they’ll use you right to the T when they know you have disabilities.” As noted in the literature, some individuals with intellectual disabilities experience difficulties grasping the subtleties of interpersonal interactions and relationships, and sometimes have a harder time recognizing abusive relationships because of their intellectual disability and/or their ill preparation for engaging in relationships (Hayashi et al., 2011; Murphy & O’Callaghan, 2004). For Nicholas and

Samantha, one way of dealing with that vulnerability was to selectively date other people with intellectual disabilities, as Nicholas briefly noted: “In my own lifetime, I had only two instances with normally functioning women.” This time, Samantha interjected saying that, deliberately choosing to date other intellectually disabled people was mostly because of “a comfort level” and a sense of shared struggles.

In the case of William, in addition to speaking about his experiences of loneliness during his time in school, he also reported a lack of sexual and romantic experiences. For him, though he was included in some regular classes, being included did not necessarily lead to opportunities to meet people and the ability to build romantic relationships. On one hand, William suggested that there needs to be more informal opportunities for people with intellectual disabilities to socialize and meet people, as well as potential romantic partners:

I think the inclusion that is needed in high school is more of that extracurricular- like, being included in the rallies, the football, the basketball, sporting events, having friends who will ask you to come to-doing things like that.

Nonetheless, as he also noted, sometimes participating in extracurricular activities does not necessarily result in inclusion, or perhaps more opportunities to meet different potential partners, or even the ability to flirt. He used the Special Olympics as an example to illustrate how even these more informal activities might not always be particularly helpful:

It’s not that I am saying that Special Olympics is bad, it is when you’re in a very tiny bubble that your dating experiences might not be so- or if you do go on a date you might have staff sitting in another booth across the way because you still have to have that supervision that most people don’t have to have, so, it makes it harder to have that relationship even.

William's statement illuminates two significant barriers to engaging in sexual expression and practices. First is how great levels of supervision by direct care workers can make it harder for individuals with intellectual disabilities to have privacy to be able to flirt, meet other people, and even hook-up. Secondly, William notes that, sometimes, extracurricular activities or day programs can be significantly sheltered and segregated, becoming what he calls "a tiny bubble" that limits disabled people's access to a more diverse pool of potential partners. As he added later on in his interview, some people with intellectual disabilities "don't get out of that little circle because that's all they know" and consequently, "you end up dating what you know," in this case other people with disabilities.

Jeremy spoke briefly about his one and only romantic relationship during his school years which, as he reported, lasted for about one year. That relationship, he noted, "was good. It was definitely a good experience, I learned a lot about myself, yeah." When I asked him about what he had learned about himself from that experience, Jeremy limited himself just to saying:

What I want out of a relationship. [laughs] I learned a lot in that way, and what type of person I would prefer so yeah, so, yeah, [laughs] the only way you're gonna figure that out is by trial and error. [laughs]

Jeremy's statement echoes those of the other participants who also spoke about learning about sexual expression and practices by a process of "trial and error," which I will discuss further in the upcoming section. Jeremy's only romantic relationship did not involve sex, as Jeremy had never had sex before because he was waiting for the "right person." It became evident in his account that he had not had a lot of sexual experiences, with the exception of consuming pornography and masturbating. Nonetheless, at the time

of the interview, he reported feeling more confident about approaching potential partners and taking the risk of rejection. He said that he was “actively looking” for a romantic relationship, and mentioned a recent experience to illustrate his active efforts to get a date:

Well, somebody I met through volunteering. I asked her on a date and she was already dating so, it was one of those- yeah, kind of, a bit embarrassing because like you just meet them once and you’re like, go on a limb, you don’t know if they’re dating somebody or not, so- ... We’re still good friends, so yeah, she’s like, “Yeah, I’ll have to turn you down because I am dating somebody.” I am like, “That’s OK.” [Laughs]

In contrast with some other participants, Anthony, who also has a visible physical disability, talked about his experiences of sexual expression and practices during his school years in more positive terms. He reported:

I am a normal kid, I partied in high school, I got in trouble in high school, I dated girls in high school um... I couldn’t keep them off me honestly um... this is my personality. People are really drawn to who I am. It has nothing to do with physically who I am, it’s me and that’s just it.

Even though his interview was characterized in some ways by bravado about the ease of dating, he also admitted – made a confession even – that disability does play a role in his opportunities. He acknowledged that it was tougher at times for him to get a date especially due to the various stereotypes that non-disabled people have about individuals with physical and intellectual disabilities:

It’s like tougher than the average, but I don’t find it super tough. I can get a date, it’s not a um... is it always the right person? No. Um... but yeah, I can get a date, I’ve dated some pretty hot women in my time so you know and it’s just the whole- the whole matter for me is just like explaining everything [about his disabilities].

Anthony’s statements seem to point to Shuttleworth et al.’s (2012) work on the “dilemma of disabled masculinity,” as Anthony attempts to reassert his masculinity, desirability,

and capability by emphasizing: “I can get a date, I’ve dated some pretty hot women.” He even went on to add at another point in the interview: “I’ve had them, like, I’ve dated like professional women, nurses, like, you know.” For him, one way of dealing with, and perhaps challenging, some of the dominant ideas about disability, sexuality, and perhaps masculinity, was to use humor because, as he noted, “if you’re willing to make a joke out of it [disability] then they’ll know that you’re comfortable with it, and they’re willing to go forward, that’s usually my [go to].” Anthony provided an example to illustrate his use of humor, and sometimes irony, to work through his interactions with women and to assert his masculinity and ability to engage in sexual practices:

Some girl will walk to me in a bar, and she doesn’t know, but she looks at me and she goes, “Can you, like, do it?” [laughs] I am like, “Honey, are you serious? Would I come to a bar full of beautiful women, if I couldn’t get me some of that?” [laughs]

Anthony was also the only participant currently attending college. One can say that having a college experience has allowed him to be in regular contact with other people his own age, and be in a setting that often facilitates opportunities for meeting new people and being sexually active. This was expanded upon in another interview when Nicholas, who has not had an opportunity to go to college, commented: “I never really had a college or a university sex life at all... that’s what we are trying to make up for now ... we wanna get a taste of what that was like, what we missed.” Samantha agreed with Nicholas and said that her sexual life had started later on in her life: “I never fully got a chance to experience most of that until later on in the years.” In her case, in addition to not having that university life sex she also reported being, at times, overprotected by their family members. She noted, for instance, that it’s hard to have relationships “when you’re the youngest of three and you got two older brothers that protect you.” To Jeremy and

William, who concluded their high school education through modified programs, the idea of attending college was seen as unattainable because of their lack of coursework required for college application and entrance. Thus, that opportunity to experience different forms of sexual expression and practices within a university context, which is sometimes considered to be a safe and ideal place for sexual exploration, was also not available to these young men, who themselves reported experiencing some isolation.

To summarize, when talking about their experiences with sexual expression and practices in their school years, most participants talked about feelings of loneliness, vulnerability, few romantic relationships, and lack of satisfying sexual experiences. In the following section, I will discuss how the lack of helpful information and discussions about sexual expression and practices has led the participants to learn about sexuality through trial and error.

Learning about Sexuality by Trial and Error

The literature has suggested that individuals with intellectual disabilities who receive appropriate and helpful information tend to be better prepared to make better-informed decisions in relation to sexual expression and practices. Nevertheless, studies have also noted that most intellectually disabled people rarely have an opportunity to participate in sex education (Murphy, 2003; Murphy and O'Callaghan, 2004). This was not the case with the five participants that I interviewed because they all reported having had some sex education at some point in their schooling. However, they also said that their sex education was significantly limited, addressing solely facts and information about biology and hygiene. In addition to that kind of information about sexuality, some participants reported a need for role models, more open discussions, and more

opportunities for actual sexual experiences. Jeremy, for instance, spoke about the need for role models to serve as references for what good relationships look like. He explained his need saying that it is about “watching and observing relationships and how a good relationship works ... people with disabilities aren’t around people who have good relationships to begin with, how are they supposed to build those relationships?” To further explain what he meant by people with disabilities not having role models, he referred to the relationship between individuals with intellectual disabilities and their direct care workers:

You can’t hug them [direct care workers], you can’t- like there are certain things around it that you can’t do. Now, some people need to learn when to hug and when not to hug, and I’ve had conversations with staff about this, and yeah, you need boundaries with certain individuals that overstep those steps, but that’s modeling a good relationship, when to hug, when not to and stuff.

Jeremy seems to suggest that, even more important than individuals with intellectual disabilities having access to information and discussions about sexuality, is having references, examples of appropriate ways of interacting in interpersonal relationships and engaging in sexual expression and practices, as well as examples that show the possibilities and contours of successful romantic and sexual relations. In addition, Jeremy seems to suggest that there needs to be more opportunities for individuals with intellectual disabilities to actually engage in and practice their social skills in order to be better prepared to build new relationships.

Participants also reported a lack of discussions about sexual expression and practices with their parents and direct care workers. Samantha and Nicholas had never discussed sexuality with their former direct care workers. Resonating with Jeremy’s claimed need for role models, Nicholas said:

Those with disabilities like... [makes sound of frustration]... like we discussed, right from the guardians and up, nobody wants to teach you what relationships are, so you go out and you have to learn for yourself, unfortunately that's what happens.

Anthony corroborated Nicholas's statement noting:

As far as agency workers that did everything by the book, no. There's no room for it [discussions about sexuality], they [agencies] would not allow it, they were not- you know, they [agencies] don't condone it.

Nonetheless, in some cases, participants did not see direct care workers as the most appropriate choice for discussing and asking questions related to sexual expression and practices. Jeremy, for example, said that he would feel "awkward" discussing sexual expression and practices with direct care workers, who "get paid to work." His statements seem to suggest that discussions about sexual expression and practices between direct care workers and their clients are inappropriate because that is not what these workers are supposedly paid to do. Jeremy would rather talk to a registered nurse in case he had any questions related to sexuality.

William also suggested that health professionals would be the best option for engaging in discussions about sexuality. In regards to having such conversations with the adults he was living with, he noted:

It depends on how it was brought up, but I don't think I would be like "Hey, you wanna talk about my love life?" Well, that's non-existent, I mean, that would be the shortest discussion.

The literature has certainly examined the question of who usually starts, or perhaps should start, discussions about sexuality with intellectual disabilities (Abbot, Howarth & Glyde, 2005; Abbot & Howarth, 2007; Löfgren-Mårtenson, 2004; Murray & Minnes, 1994). Again, although I recognize the importance of having more open discussions about sexuality with individuals with intellectual disabilities, William raises a reasonable

point as he complicates this idea of who initiates talks about sexuality by saying ironically: “hey, you wanna talk about my love life?”

The lack of role models, discussions and helpful information about sexual expression and practices has led the participants to learn about sexuality through a process of trial and error. This approach, however, can be problematic because, as the literature has suggested, a lack of information and guidance in regards to sexual expression and practices can sometimes lead to instances of inappropriate behavior, hinder disabled people’s ability to distinguish abusive relationships, and increase the probability of contracting STIs, or having unplanned pregnancies (Cheng & Udry, 2005; Grieve & McLaren, 2008; Murphy & O’Callaghan, 2004). In other words, for some individuals with intellectual disabilities, who already have difficulties engaging in interpersonal relationships because of their disability, also having inadequate preparation to engage in sexual and romantic relationships can get them into trouble. Even more importantly, the participants noted that learning by trial and error entails, quite frequently, making mistakes, but also reflecting and learning from those mistakes. As William noted, “it is hard to date,” but nevertheless, “there’s a lot that we learn” from those experiences. He then added, “a lot of people do make mistakes but everyone learns and moves on.” To further illustrate the importance of being able to make mistakes, he talked about his experience getting married without dedicating enough time to getting to know his former partner. As he reflected about the marriage, William concluded:

There are safety things that you’ve learned that you need to make sure that you iron out before you get married but if you don’t, this- I mean, to be fair, people who’ve been married for 40 plus years end up getting divorced but you’re more likely to stay married longer if you date a little longer without rushing into it, so, I think that’s half of my problem.... I honestly think that we should have dated more.

Anthony validated William's statement, explaining:

I think that's the same with everybody, like you learn from your experiences, but if you are not given those chances to learn, then you end up with a whole bunch of these sheltered people that know nothing about life.

To summarize, individuals with intellectual disabilities reported that a lack of discussion and helpful information relating to sexuality, as well as examples of role models of good relationships, has led them to learn by trial and error. It was evident in these participants' accounts that they were both able and willing to critically reflect on their previous sexual and romantic experiences in order to make sense of what may have gone right or wrong in their previous romantic relationships. Participants spoke about the importance of being able to make mistakes and learn from them, without having other people presume that they are incapable of having relationships. Though participants noted a lack of role models for good relationships, as well as open discussions about sexuality, some suggested that religion offered guidance in their pursuit of relationships, to which I will now turn.

Religiosity and Its Effects on Relationships and Sexuality

As Healy et al. (2009) have noted, the religious background of individuals with intellectual disabilities must be considered when examining their attitudes and experiences in regards to sexuality. This is because religious doctrines and beliefs can sometimes serve as a framework for people to make sense of and explain their experiences with sexual expression and practices. With that in mind, I also asked participants about their religious background in order to explore whether and how religion may have influenced their sexual and romantic experiences. At the time of the interviews, William self-identified as an active Mormon, Jeremy self-identified as an

agnostic and former Mormon, Nicholas self-identified as a non-practicing Christian, and Samantha and Anthony said they did not follow any particular religion.

William's and Jeremy's sexual expression and practices seemed to be greatly influenced by their religious backgrounds. As William reported, there was a lot of pressure from his parents and from his religious community for him to get married and have children, to the point that he "jumped into getting married to the first thing that moved." William briefly summarized how he met his former wife: "We met in a Mormon dating site and then she came over for a visit and we decided to get married and so I went over there [to Europe] for 6 weeks and we got married over there." Even though he provided a few more details about his story, it seemed that this was still a hurtful experience for him to talk about. He often limited himself just to saying, "whatever reason, it wasn't meant to work out." This became even more evident when he talked about romantic relationships as being something risky and leading to nothing but pain. As he stated:

I really didn't date much to start with anyways, and the whole situation with me was- it kind of- it's like cutting off the safety thing on an electric thing and then sticking it, you're opening yourself to electrocution.

At the time of the interview, William felt quite discouraged from getting into a new romantic relationship. Here, once again, he used a metaphor to describe how he felt:

Right now, I don't think- I am not trying [to have a romantic relationship], so, it's not gonna happen. It's like wanting to win the lottery without buying the ticket but if you want to buy the ticket you need to get out there and buy it and get into that, put yourself out there. I think that's half of the battle for me, it's that putting yourself out there and set yourself up for that.

William's narrative, nevertheless, demonstrates that he has reflected on and taken some control over his own sexual and romantic life, as he noted, sometimes this involves:

Not letting what people say about dating and how you should be dating or the fact that your mother wants grandchildren to play into it ... this is how you do it at the church level, this is what you should be doing, blah blah blah.

Therefore, his parents and church have expectations, but he chooses to ignore them at the moment because of the pain of having had a bad experience. Additionally, his narrative illuminates how William has difficulties developing and maintaining romantic relationships, and he had not received tools or support for learning how to do these things, which don't come 'naturally' to him. His hurt is in part also the result of failure that is disability-related.

Jeremy, who also grew up in a Mormon household, reported having some sex education in school, which was limited to information concerning biology and hygiene. In addition, his religious upbringing also served as a roadmap to figure out "what [he] shouldn't and should do" in terms of sexual expression and practices. In his interview, Jeremy self-identified as currently being an agnostic. However, it was evident in his narrative, as Jeremy himself recognized, that his religious upbringing was not something he has simply left behind but it actually continues to influence his understandings regarding sexuality. Jeremy was the only participant in the group who said he had never had sex. When I asked him how he felt about having sex sometime in the future, Jeremy provided a short answer before quickly changing the topic: "[4 secs silence] Um... eh- eh- definitely excited, yeah, and still waiting for the right person, to find the right person, but yeah." In short, Jeremy was quite hesitant to talk about sex, as he himself connected that hesitancy to his religious upbringing:

It's not so much- yeah, I don't- it's- [laughs] see? It's awkward talking about it [sex] now [laughs] so, yeah, it's almost like sex is a taboo in our society, to openly talk about it as a whole- so, I don't know if religion has a

part to play in that, I think it does, making it a taboo, not talking openly about it, so, yeah [laughs].

The influence of religion was also implicit in Nicholas's narrative. He self-identified as a Christian who occasionally goes to church on Sundays, but most often prefers to stay home and sleep in. Nevertheless, Nicholas made a clear reference to the Bible when he referred to his swinging lifestyle as "a forbidden fruit that you just want to eat." He seems to use that particular metaphor, drawing on notions of temptation and sin, to demonstrate how such a swinging lifestyle, though perhaps dangerous and sinful, is also tempting and exciting for him. Mirroring these tensions, the couple has kept this sexual practice a secret from their families, as Nicholas explained:

That's one thing with expanding our swinging lifestyle, we're keeping the family completely quiet from this because we'll get criticized right to the... [makes sound of frustration] ...They don't understand that that type of thing actually makes Samantha and I healthy in our marriage.

Religion seemed to play less of a role in Samantha's talk. She said that she was raised Catholic, but that she currently had no religion. All she said was that the only time she goes to church is during Christmas with the rest of her family. Even though she did not talk much about religion in her interview, it is reasonable to speculate that her enjoyment of a swinging lifestyle might indicate her disregard for certain religious conventions that might condemn such sexual practices.

Certainly, this couple enjoys a somewhat privileged position, being their own guardians and having a place of their own, which offers them more opportunities for sexual expression and practices. However, the fact that they are, as Nicholas said, "expanding [their] sexuality," regardless of religious and family expectations, can be seen as an exercise of their agency. Additionally, as they both noted, their more recent

experiences with sexuality in more pleasurable and bonding ways contrast greatly with those from their school years, which were marked mostly by heartaches, loneliness, and discouragement from engaging in sexual expression and practices, which have been discussed more fully in a previous section.

Lastly, when I asked Anthony whether he had any religious affiliations, he emphatically replied, “Hell, no.” He self-identified as not having any religious affiliation and spoke strongly and critically about people who have tried to impose their religious values and beliefs on him. As he clarified, “The way I look at that is ... if your religion puts you at peace, then that’s your business, I am all for that, but don’t bring it into my house.” Anthony drew from one of his experiences with a direct care worker to further explain his position towards religion:

I had some guy [a worker] of a particular religion tell me I was gonna burn in hell because I was friends with a lesbian or a gay person... I have nothing against religion, nothing, you know ... but this whole thing about bashing other people, no, it’s like if that person is gay, what does it have to do with you?

His narrative also illuminates how individuals with intellectual disabilities and their direct care workers may, at times, have conflicting beliefs and values regarding sexual expression and practices. For Anthony, it was particularly important to assert his control over his space by setting up boundaries, as he said “don’t bring it into my house.” Thus, Anthony attempts to manage what can be said and what values and beliefs are expressed in his space. Also, as a part of maintaining control of his space, it was important for Anthony to be able to determine who can access that space. When continuing his narrative, Anthony talked about how he reacted to the direct care worker who told him he was going to “burn in hell.”

I lost it, it was like, “Man, you gotta get out of my house or I am gonna bust your frigging legs,” seriously... this guy wouldn’t leave my house, I instructed him to leave, and I am like, “Dude you need to leave or you know I’ll make you leave,” so I picked up a baseball bat and I said- I didn’t even go towards him, I am like, “Dude you need to leave...”

According to Anthony, the worker considered pressing charges against him, but was later convinced by his sister not to pursue that avenue. The agency, however, defended the worker, demonizing Anthony by suggesting that he was both uncooperative and violent.

Anthony said,

I always had to reiterate that to agencies, “I am in control here and you need to realise that.” And they didn’t like it, “Oh no, he’s so uncooperative” ... and they just make it out to be other things, like, “He’s uncooperative, he’s violent, blah blah blah.”

In addition to being labelled uncooperative and violent, Anthony said that he was further stigmatized because of his previous experience dating one of his former direct care workers. He told:

I got a hell of a story man, like my ex-girlfriend was my worker [laughs] ... she had the same disability I did, but in like a lesser aspect, so we had so much in common that it just- I am like, this is crazy. I ended up dating her for 5 or 6 years. She quit her job to pursue things with me, and that’s it, and people were like, “What? You’re crazy man.” No, it’s not crazy. It’s called life. If someone spends enough time around you, it’s gonna happen...

After that experience, Anthony noted, he became known as “the guy who dated his worker:”

Even after that, like after we split up the whole- even after that, they were accusing me of different stuff like, years later, they were like, “That’s the guy who dated his worker so maybe he did this to-” or like you know they were like, “Oh my God, who would do that?”

It was evident in his account that he was demonized not only because he had dated a worker, but also because he represented a potential sexual threat to future workers supporting him. According to Anthony, some agency workers at the time warned other

workers about him, saying for instance, “oh you know? He messes with his workers.” One can suggest that Anthony’s narrative illuminates a historical stereotype and fear, that which Lambrick and Glaser (2004) refer to as the “menace of the feeble-minded” (p.381). Individuals with intellectual disabilities are sometimes viewed as being hypersexual, promiscuous, and unable to make good decisions about sexual expression and practices, supposedly making these individuals a menace to others (Ballan, 2001; Gomez, 2012; Hollomotz & The Speakup Committee, 2008; Servais, 2006; Szollos & McCabe, 1995). One of the problems, as Anthony said, is that “they [agency] write it on your file” and, according to him, it was noted on his file that he was violent, and that he had dated a worker in the past. As we can see in Anthony’s experience, in addition to being labelled and demonized, he also faced some significant backlash from his service provider, which affected the services that he was receiving for almost a year. As he remembered:

... and they [the agency] dismissed my services for me being religiously-um... persecuted for my sexual choices [laughs] ... I lost services for over a year for that and I had to go to the government and basically lobby my case and fight while I didn’t have services...

Nevertheless, Anthony counted himself lucky because, in that one year without receiving services from the agency, he was able to count on the social and financial support of his family and friends. He acknowledged, “My situation is obviously unique and I’ve been lucky with people that I have been able to get the supports.” He decided then to move into a self-managed funding arrangement, which removed his need to have an agency as a mediator.

To conclude, the five participants talked about different ways in which their own religious beliefs and moral values, as well as those of others around them, have influenced their attitudes and practices in regards to sexuality. In the case of William and

Jeremy, their religious background seemed to play a significant role in their sexual expression and practices shaping, for instance, their choice of potential partners and their decision to remain celibate until marriage. Conversely, for Anthony, Samantha and Nicholas, religion seemed to play less of a role in their understandings and practices of sexuality, as they spoke about their rejection of certain values and expectations coming from their current or historical religious backgrounds as well as those from people around them. As it can be seen, these individuals have engaged with intersections of religion and sexuality in various complex and diverse ways, and that seems to suggest the need for further exploration of the actual experiences of individuals with intellectual disabilities who are navigating such intricate intersections.

Parents, Family Members, and Sexuality

The five individuals with intellectual disabilities that I interviewed all acted as their own guardians. However, that did not mean that their parents and family members had not influenced their sexual expression and practices. Also, some participants spoke about how they had turned to their family members for guidance and had, at times, perceived them as role models as they navigated their own experiences with sexuality. One could say that most people without disabilities do not need to consult their families on sexual matters. In contrast, as Walker-Hirsch (2010) has noted, parents of individuals with intellectual disabilities may sometimes need to take a more active role in guiding and facilitating opportunities for the sexual expression and practices of their loved ones. For some individuals with intellectual disabilities, who often have difficulties forming interpersonal relationships, experience isolation, and a lack of information and practice with sexuality, family members can become an important source of information and

discussion, a role model for satisfying relationships, and an ally. However, as the literature has suggested, parents often feel unprepared or uncomfortable dealing with the sexual expression and practices of their loved ones, and avoid talking about sexuality until an incident happens (Howard-Barr et al., 2005). Nonetheless, participants reported that their parents and family members had been consistently encouraging and supportive of their experiences with sexual expression and practices.

William and Jeremy, who both had Mormon parents, had been encouraged to find eligible Mormon women with whom to have romantic relationships, marry and have children. In William's case, after a significant amount of time reflecting on his failed marriage, and the pressure he had received from both his parents and religious community to find a romantic partner, he decided to ignore the expectations and pressure from others around him and, instead, make his own path in regards to his sexual expression and practices. He said:

I think it just comes down to you as an individual, what you want, because it's you that has to be happy with it ... specific comes to not letting what people say about dating and how you should be dating or the fact that your mother wants grandchildren to play into it...

As for Jeremy, his way of dealing with the enthusiasm of his family every time he meets a potential partner was to keep his romantic life a secret from his family. He explained:

She's [his mother] so outgoing, I believe that it can be really hard to introduce her to people, from my standpoint, and knowing when in a relationship is a right time to do that as well for me, knowing that my mom is that way and stuff so it's been very interesting [laughs] I just feel like there's that component of enthusiasm that she brings to- where it's like oh... [makes sound of frustration]... Don't scare them off! [laughs]

One can say that people in general tend to be careful about how they bring their own parents and family members into their romantic lives. However, it can also be said that

some parents of intellectually disabled individuals, even if well-intentioned, can more often overstep their boundaries, and prevent their sons and daughters from making their own decisions, and conceptualizing and constructing their own relationships. This did not seem to be the case with the small number of individuals who I interviewed because they were indeed their own guardians, and they saw themselves as having the ability and decision-making power to make their own decisions about their relational lives. As for William and Jeremy, their statements seem to illuminate different strategies in dealing with the expectations of their families in regards to their experiences with relationships, marriage, and parenting, as well as taking control of their own sexual and romantic experiences. Either by disregarding their families' expectations, as in the case of William, or by controlling their families' knowledge about their romantic lives, as in Jeremy's case, these two young men seem to be trying to follow their own paths to achieve their desired sexual and romantic lives.

In the case of Nicholas and Samantha, family members, though hesitant at first, have been quite supportive of their marriage. As I discussed in a previous section, Samantha reported that she had had hurtful sexual and romantic experiences during her years in school and that, in response to those experiences, her family members sometimes attempted to protect her by keeping her sheltered. She had almost given up on finding a romantic partner when she finally met Nicholas through friends. The couple first met, as Nicholas humorously said, through "a blind date that never ended," as the couple had been together for over five years. According to Nicholas, after having dinner at a romantic local restaurant, "I tried to get her off to a relationship right off the bat but, we both talked and she said 'this is the way I wanna play it, let's be friends and then we'll go

from there.” The couple spent over 5 months getting to know each other before they actually started a committed relationship. In the beginning, Samantha was hesitant to talk to her family about her relationship with Nicholas because, as she said:

I noticed, every time I said to my parents, “I am seeing someone,” the relationship would sour two months later so I got- you know if I don’t say anything to my parents right away, maybe this relationship will work out... [it’s hard] when you’re the youngest of three and you got two older brothers that protect you.

As seen in her statement, Samantha seemed to imply that her family, while well-intentioned in trying to “protect” her from “getting hurt,” sometimes became a barrier for her to experience sexual expression and practices. The literature has widely noted the challenges that parents often face when trying to find a balance between protecting people with intellectual disabilities from heartaches or getting in trouble and allowing these individuals to make their own decision relating to sexuality (Löfgren-Mårtenson, 2004). Additionally, it has been suggested that, because women with intellectual disabilities tend to be seen as “in need of protection,” they can experience greater levels of both social isolation and dependency (Grabois, 2001; Becker, Stuifbergen & Tinkle, 1997). Samantha’s response to that (over)protection was to keep her relationship a secret from her family for some time. It was at a Thanksgiving dinner at Samantha’s house, months after she had started dating Nicholas, that she introduced him to her family. She noted, “It was a little nerve wracking at first ‘cause I didn’t know what my family would expect.” However, she also said that “it went quite well.” Nicholas agreed, attributing his good reception from Samantha’s family to one of his acts during the dinner: “I was the only one that got up and helped clean up the dishes. So, so right away, that impressed the whole entire family, and I still do that.” He added, “actually with my personality and my

sense of humor, they weren't up to me, I was up to them rather quite quickly actually.” According to Nicholas and Samantha, indeed, both of their families had been significantly supportive of their marriage. For instance, as Samantha mentioned, “my parents actually hosted our wedding at their house.” Nicholas added, “they [both families] all got together and they purchased this place [and even though] my parents own this house ... this house is in our inheritance so it will be ours.”

In contrast, their families seemed more hesitant when it came to discussions about Nicholas and Samantha having children sometime in the future. Nicholas talked about a conversation he had with his brother:

I talked to my brother about it [having children] and he said when he had our niece ... it caused him to evaluate his whole entire life, and he said um... that he and his wife give everything they got, to the point they're exhausted and they can't give anymore, so he- he suggested, “Don't have kids.” ‘Cause he says, “I don't think that physically, mentally, that you would be able to raise a child.”

Samantha interjected at this point saying that their financial situation has also discouraged them from considering having children someday. She explained:

Financially as well for us, because of us being- yeah, I see a lot of people who are on AISH¹⁰ have kids but they- but I feel like they just live off the system, the more kids we have, the more money we get from AISH because you get \$100 per kid when you are on AISH.

It is reasonable to say, first of all, that such a small amount of financial support is quite unrealistic in terms of being an amount that could actually support a child. Secondly, the offer of such a small stipend to support the child of disabled parents makes it seem as though the AISH policy does not prioritize support for family life. It may ever be said

¹⁰ AISH stands for Assured Income for the Severely Handicapped. It is a funding program in the province of Alberta that “provides financial and health-related assistance to eligible adults with a disability. The disability must be permanent and substantially limit the person's ability to earn a living” (Alberta Human Services, 2014a).

that such a monetarily insignificant amount discourages people from starting a family or creating the family they had hoped for. Nevertheless, Samantha's statement seems to point to dominant discourses of individuals with intellectual disabilities as being unwilling to work and, consequently, making them seem unfit to support their romantic partner and children economically, and be good parents to their children. Additionally, intellectually disabled people are sometimes discouraged from having children because some believe that that may place a burden on their families and on the system (Booth & Booth, 1994). Given these points, the couple has since then put their desire of having children on hold. As Samantha stated, "in terms of kids, she [their cat] is our kid [laughs]."

Finally, Anthony's family, and particularly his father, have also shown a significant level of involvement and support for him to engage in an autonomous sexual life. In a previous section, I discussed how Anthony's father intervened, at times, in Anthony's former group home, challenging some of the "house rules" in order to guarantee the privacy and autonomy of his son. In another instance, when Anthony spoke about his experience dating one of his former direct care workers, it became evident once again that his father was an important supporter of his sexual expression and practices. Anthony said:

He would say to me, "What are we supposed to do Anthony? You know, you fell in love with her, whatever man, just go with it, and if you have to be persecuted for something that you enjoy, then that's, you know, that's just it." But even he looks and me, and he's like, "Man, I couldn't do it."

His father has also intervened at different times to reassert his son's sexuality, masculinity, and capability to engage in sexual expression and practices. In one instance, Anthony explained:

They [his grandparents] said to my sister, “Oh, you’re gonna be the only person that’s gonna carry on the family name.” My dad turned around and was like, “Are you kidding? Like, he’s gonna make ‘a mistake’ and have kids one day.” [laughs]

To conclude, the narratives of these participants suggest that their parents and family members have influenced their experiences with sexual expression and practices in both limiting and facilitating ways. For the most part, their family members had encouraged them to engage in sexual expression and practices as long as they fit with their family values and expectations. I also noticed some ambivalence from participants in regards to having children at some point in the future, as some of them seemed discouraged from parenting due to their family members’ disincentive or their limited monthly income.

Chapter Four

Direct Care Workers

This chapter explores some of the attitudes and experiences of this small number of direct care workers when dealing with the sexual expression and practices of their clients. The six direct care workers who I interviewed presented as a diverse group in regards to their job position, type of agency, motivation for being in the position, and number of years of work experience. The selected group of participants included permanent and relief workers delivering overnight assistance at group homes, respite services to parents and caregivers, and supports to individuals with intellectual disabilities in their various activities in the community. These individuals are located at the front-line of disability service delivery, having around them other direct care workers, as well as team leaders that linked them with the agency administration. In accordance with the literature, the participants had had little, if any, direct interaction with higher up agency administrators, usually relying solely on their team leaders for guidance and feedback (Ford et al., 2000). They had served as direct care workers in different agencies for different amounts of time: from two months to 27 years. With the exception of Marina and Rose, who had been working in openly Christian-oriented organizations, the other participants reported working for ecumenical family-led organizations. The participants reported a variety of reasons for working as a direct care worker. These included: having family members or friends with a disability and feeling committed to supporting other disabled people, being attracted by the flexible work hours that allowed them to simultaneously proceed with their college education, or seeing the position as a good temporary job opportunity that could provide some training for their actual future careers in health professions.

It is important to keep in mind that the clients that these direct care workers serve are much more controlled than the individuals with intellectual disabilities that I actually interviewed for this project. The clients of these direct care workers were all under legal guardianship and had more constant and intensive interactions with direct care workers, and one could speculate that they might experience less autonomy, privacy, and decision-making power in comparison to the individuals with intellectual disabilities in my sample. As I have mentioned, I was not able to speak with people with intellectual disabilities who are in these kinds of power relationships due to protectionism and guardianship issues; however, I was fortunate to gain some insight into their situation from the direct care workers.

This group of direct care workers were also somewhat diverse in demographic terms, especially in regards to their age, sexual orientation, and religious background. As I have mentioned, I interviewed 5 women and 1 man with ages ranging from 23 and 49 years. When I asked about their sexual orientation, Marina, Celine and Paola identified as heterosexual, Michael identified as gay, Susan as bisexual, and Rose as undeclared. In terms of their religious beliefs, Michael and Rose reported being agnostic, Marina identified as agnostic/atheist, Paola identified as Catholic, Celine as spiritually open-minded, and Susan mentioned not belonging to any religion. The full demographic information of the participants has already been discussed and can also be found on the next page.

Table 2 - Demographic Information - Direct Care Workers

Name	Age	Sexual Orientation	Religiosity	Educational Attainment	Current Job Position	Years of Work Experience
Michael	25	Gay	Agnostic	1 st year M.A.	Permanent Overnight Support	1 year and a half
Marina	49	Heterosexual	Agnostic/Atheist	B.A. and B.Ed.	Permanent Overnight Support	27 years
Celine	25	Heterosexual	Spiritually Open Minded	2 nd year B.A.	Respite Support	6 years
Rose	28	Undeclared	Agnostic	B.A.	Respite and Residential Support	2 years
Susan	32	Bisexual	None	3 rd year B.A.	Relief Residential Support	1 year and 3 months
Paola	23	Heterosexual	Catholic	B.A.	Relief Residential Support	2 months

“I don’t know if I can talk about that [laughs]”

In this project, I also spoke with a small sampling of direct care workers as a means of complicating oversimplified accounts of power relations, and illuminating how these workers also operate within their own constraints with guardians and parents and employers. Direct care workers often take on various roles and responsibilities when delivering care to individuals with intellectual disabilities (Ford & Honnor, 2000), and one of those roles can involve dealing with the sexual practices and sexual expression of their clients, which I will explore in this section.

The literature has suggested that the presence of clear institutional policies and guidelines about sexuality can influence and guide the practices of these workers (Christian et al., 2001; Löfgren-Mårtenson, 2004, Ward et al., 2001). With this in mind, I asked participants about institutional policies and guidelines about sexuality at their organizations. Participants, however, were often hesitant about answering any questions related to institutional policies and training. Paola, for instance, whispered: “I don’t know if I can talk about that [laughs] ... I don’t wanna talk about it. [laughs]” This hesitation in discussing institutional policies and practices was not unique to Paola, as some other workers that I interviewed also chose not to talk about them. As I will discuss in the next chapter, both workers and disabled individuals spoke poignantly about power struggles in their interviews. The circumspect responses of my participants to seemingly straightforward questions about training indicate that power and a fear of getting into trouble colored their willingness to speak.

Most workers seemed to have little knowledge about the policies and guidelines in place at their organizations, and often had a hard time recalling what was written into

those policies. One can say that it might be the case that such organizational texts may not be as influential in the actual everyday practices of this small number of direct care workers as previously noted in the literature (Christian, Stinson & Dotson, 2001; Löfgren-Mårtenson, 2004, Ward, Trigler & Pfeiffer, 2001). For instance, when I asked Susan whether her organization had policies or guidelines related specifically to sexuality, she said: “well, first, I don’t think so, but secondly, I prefer not to discuss the company policy... yeah, and I don’t pay attention- pay too much attention to the policy.” Similarly, Rose reported, “sure, there was a policy [on sexuality], but it wasn’t nothing that has stayed in my brain to recall.”

This seems to suggest that some workers might perceive themselves as having at least some autonomy to make their own decisions when addressing some situations related to sexual expression and practices with their clients. The literature has suggested that a lack of clear institutional policies and guidelines can lead to workers making their own decisions, which can cause some confusion for their clients who may deal with varying attitudes and practices across different workers (Christian et al., 2001; Löfgren-Mårtenson, 2004, Ward et al., 2001). However, these workers also spoke about feeling disempowered and constrained within their own power struggles with organization administrators as well as family members and guardians of their clients, which I will further explore in the next chapter. It may have also been the case that some workers chose to respond in such a manner to avoid talking about institutional policies, practices, and getting in trouble with their organizations, even though their research participation was completely anonymous. Future studies could perhaps continue to interrogate whether and how the actual practices of direct care workers might be tied to organizational texts,

including policies and guidelines concerning the sexual expression and practices of the people they serve.

According to the literature, another way to equip workers to deal with the sexuality of disabled people is to provide adequate training for workers in order to generate discussions about sexuality, and improve workers' practices (Christian et al., 2001; Evans et al., 2009; McConkey & Ryan, 2001). It did seem that, amongst the workers I interviewed, education and training about sexual expression and practices were lacking. Of the six workers I interviewed, Rose, Celine, Michael and Susan reported that dealing with clients' sexual expression and practices had not been formally addressed in the training programs at their current organizations. Marina and Paola were the only ones who had received some formal, and yet quite limited, training related to sexuality. Marina's training had been limited to watching videos about sexual abuse and inappropriate behavior prevention every second year throughout her 27 years working at the organization. Paola reported that she had received a lecture from her organization about its policies and guidelines in regards to the sexual expression and practices of its clients or, to be more precise, information about abuse prevention and procedures to address inappropriate sexual behaviors. As I have noted, Paola was hesitant about discussing the details about institutional training and policies at her agency, nonetheless, she noted that, during that lecture on policies and practices in regards to the sexuality of their clients, there was no opportunity for actual open discussion on the topic. It was evident that such training, so focused on abuse prevention and inappropriateness, neglected to address the more positive aspects of sexuality including relationships, intimacy and pleasure. As Marina herself briefly acknowledged:

We participate in watching a video which is- needs to be changed- about abuse and prevention of sexual abuse. But in terms of their rights to be sexually active, we really don't have a lot of about that, they [the agency] kind of stay away from that subject.

Previous studies have suggested that workers tend to be particularly concerned about potential cases of sexual abuse and behaviors that are deemed inappropriate (Ballan, 2001; Löfgren-Mårtenson, 2004). That being the case, such focus on abuse prevention and inappropriateness can make sexual expression and practices seem dangerous or wrong, and lead to a lot of notes in the lives of individuals with intellectual disabilities. It is then understandable that some individuals with intellectual disabilities develop negative beliefs and attitudes towards sexuality themselves (Cuskelly & Bryde, 2004).

Conversely, when I asked Rose, Susan and Michael, who had not received training, about how they would feel if training related to sexual expression and practices was actually available at their organizations, they did not seem particularly enthusiastic about or receptive to the idea. Rose said that having some training would help her be "a little bit more informed," although she also mentioned that "not necessarily training, but just a conversation" among workers would be enough. As she further explained, it would be more relevant to have "just a conversation, just 'let's talk about this, let's understand it,' at least a conversation." When I asked Rose about what should be addressed in these conversations, she limited herself to saying: "I've never really thought about it."

Michael also seemed hesitant, as he mentioned: "I don't know. I don't- I don't know how that would look so until some- an outline is created with what would fall underneath that topic, it's hard to determine that." This hesitation was, in part, due to his personal discomfort with talking about sexuality, which was particularly evident when, before asking to stop the recorder, Michael disclosed:

That whole topic [sexuality]- it scares me, not that- not with the clients, but in today's society, the whole like- I don't know- it's like a taboo topic and- the topic kind of makes me uncomfortable...

Additionally, one can say that his lack of interest in receiving more training may also be tied to the way in which Michael perceives his job, as a temporary job until he finds another one that is more aligned to his long-term career plans. As he explained:

Since I started working for the government I don't need to work so intense at this occasion but when I am done with my government job, I'll probably hit that job [as an overnight staff] hard-, I'll probably get back to it hardcore and start working a variety of shifts until I find another job that is more impor- some more, more of my alley in regards to a future career.

As I have mentioned, it has been noted in the literature that agencies delivering services to disabled people commonly struggle with the retention of direct care workers (Devereux et al., 2009; Ford & Honnor, 2000). Nevertheless, the position has been well-known for being deskilled and low-paying, as well as for requiring minimum educational credentials and training. Some of these agencies recruit their direct care workers by holding booths at university campuses aiming for students who need a temporary and flexible job that will pay for a part of their education. According to the literature, one of the problems with this staff recruitment approach is that, as workers come and go, the relationships between individuals with disabilities and their direct care workers get easily discontinued, which can have negative effects on disabled people (Ford & Honnor, 2000).

Susan first learned about the position of direct care worker through a job fair at her university. As she told, "I wasn't particularly looking for a particular job with supporting people with disability, I wanted it to be more rehabilitation, but the opportunity came and I just took it." Among the workers that I interviewed, Susan was the least enthusiastic about potential training as she similarly mentioned that it would "depend on what aspects

[related to sexuality] we are approaching.” Additionally, Susan mentioned that, “For me, personally, I don’t know if I wanna spare more time with this company. That’s just me, I mean, it could be different if I am more involved in a certain way, like, if I am full time with this individual, absolutely.” One may argue that time is an issue for her here perhaps because, as a relief direct care worker who spends a very sparse and limited amount of time with her clients, she feels less attached to those she serves. It may also be the case that she is not interested in spending more time at her agency and receiving additional training because she also does not perceive this job as being in her long-term career plan. The motivations for workers to join the field of disability service could certainly be further explored in future studies in order to provide insights into their motivation, commitment, and practices when it comes to facilitating the sexual expression and practices of those they serve.

To summarize, participants were often hesitant to discuss the institutional policies at their organizations and sometimes implied that their actual practices were not really tied to such organizational texts. Direct care workers, who had sexual expression and practices addressed in their training programs, received some very limited information. Their training focused on questions of sexual abuse and appropriate behavior but completely disregarded other aspects of sexuality including dating, intimacy, pleasure, and reproduction. The accounts of workers who had not been trained seem to resonate with previous studies suggesting that sexual expression and practices have historically been avoided or considered unnecessary in training programs for workers (Evans et al., 2009; McConkey & Ryan, 2001; Robillard & Fitchen, 1983). Altogether, their accounts seem to indicate that these direct care workers may not have the skills to support their

clients to actually have a desirable sexual and romantic life. Even for those who had received some training about sexuality, the instructions that they received regarding how to handle situations related to the sexual expression and practices of their clients seemed, at times, confusing, conflicting, and highly problematic, which I discuss briefly in the following section.

“Oh, have you seen the weath- the sun today?”

To illustrate how workers had sometimes received some problematic instructions on how to deal with the sexual expression and practices of their clients, I would like to refer to the experiences of Marina and Paola, who had both received some training related to sexuality. Both reported that they had been instructed to avoid the question if possible. In other words, they were supposed to change the subject of the conversation, if a client ever brought up questions or made comments related to sexual expression and practices. Even though Marina did not agree with such an approach, she stated: “the message is that we [as an organization] prefer that individuals are asexual,” and consequently should “try to redirect as much as possible.” She noted that, even though she would feel somewhat comfortable engaging in discussions about sexual expression and practices with her clients, she had been instructed to redirect such discussions to the parents and guardians of her clients. She said:

I’d simply say, “You’re gonna have to talk to your guardian,” that would be my answer. “If you want to meet that person and have a relationship, if you want a boyfriend or a girlfriend, then you need to talk to your guardian about that”...

Paola, who has been working in the field for only two months, received similar instructions to redirect when dealing with instances of inappropriate behavior from her clients towards her or others:

Because the individual knows that you are a worker and he's not supposed to talk with you in certain ways ... we can say that it's not appropriate to do that ... if it's not directed to you, um... just change the topic, "Oh, have you seen the weath- the sun today?"

I would suggest that more than simply changing the subject of the conversation, redirecting is also about making someone else be the decision-maker, which reflects the tensions of who has the proper authority over this kind of issue. Thus, Paola's account illuminates how such practice should be considered a power issue, which I will talk about in the next chapter, but also indicates the level of discomfort by workers as multi-factored. For Paola, being able to redirect her clients' attention to other topics has been somewhat of a "relief" as she considers herself to be "too much insecure" to deal with the sexual expression and practices of her clients. She explained her insecurity by saying:

My insecurity of- of saying about that- I will be afraid of um... how can I explain? Um... for example, if an individual has an issue with sexuality I'd be afraid of replying to this, like to keep on this topic, so I'll redirect because I will not know like- because I don't know how to handle [laughs], that's why I say the agency is like responsible for the orientation because I think they should address this. [whispers] I am too much insecure. [laughs]

Evident in her statement is that a lack of helpful information and support from the organization can further discourage some workers from engaging in discussions with their clients and supporting them when it comes to sexuality, because the workers feel unprepared to do so. As for Paola, she seemed particularly apprehensive about where such discussions with her clients would take her, as she noted:

I am afraid of talking about that, like, um... replying or talking about that because I don't know if I will say like appropriately and the person will be like um... be willing to ask more and talk more about that.

It seems that some of her attitude has to do with her own personal discomfort with the topic of sexuality, her hushed voice and the coyness seem to indicate a certain

prudishness, which perhaps no institutional policy or training could actually influence or change. Nonetheless, it is reasonable to argue that this redirect approach is problematic for various reasons. Firstly, it infantilizes individuals with intellectual disabilities, treating them as children and presuming that these individuals cannot speak for themselves or make sense of their own sexuality. Secondly, it shuts down opportunities for individuals with intellectual disabilities to have more open and perhaps informative discussions about sexual expression and practices. Thirdly, it is problematic because it takes away the agency of intellectually disabled people at the same time that it places decision-making power into the hands of the worker, parents and family members who get to decide the scope of sexual expression that is permissible for individuals with intellectual disabilities.

In the next section, I will offer another example to show how some workers have also had to deal with some conflicting and unrealistic organizational expectations and understandings of what are held to be permissible sexual expression and practices for individuals with intellectual disabilities.

“This is not something God would want”

It is reasonable to speculate that organizational values can shape the practices of direct care workers in regards to the sexual expression and practices of their clients. This was particularly evident in the cases of Marina and Rose, who had both been working at Christian value-based organizations. These two talked about the influence of religious organizational values in their actual work practices related to sexuality, even though both self-identified as being agnostic. Marina, who has been working for a Christian organization for over 20 years, stated: “The policy is there. It’s not encouraged that individuals have relationships, sexual relationships with others.” Marina suggested that

this was the case because: “it’s a religious association and so I think they simply say ‘this is not something that God would want,’ yeah, because they’d need to be married.”

Rose also spoke about how, even though her organization allowed their clients to get married, clients were still discouraged or barred from actually dating, having hook-ups, or having pre-marital sex. As Rose noted, clients in her organization are allowed to “express these things, as long as you’re like married.” To further explain the expectations of her organization, she said it bluntly: “You say your vows. You’re celibate, celibate, celibate, married, family, sex.” There seems to be a clear disjuncture though between the time individuals with intellectual disabilities are single to the time that they are married. Excluded in these expectations are some common steps in building relationships such as flirtation, courtship and intimacy. As Rose acknowledged, such an approach is simply unrealistic. Nonetheless, she seemed to provide a justification for the practices of her organization, as she also said: “I don’t necessarily agree with Christian religions but I think that’s not something hidden from people, it’s open, like that understanding of the world.” Rose furthered explained that, because the agency was open about its religious values and clients had supposedly chosen deliberately to receive services from that particular organization, there was not much room for critiquing the policies and practices of the agency. Nevertheless, she acknowledged her privileged position as she noted, “I can say that because I can disagree to it, and I have the freedom to walk away from it but if I had a disability and my family liked these rules, I don’t have the right to walk away from it so that’s where the trouble is.” That is to say that, sometimes, individuals with intellectual disabilities might have little say in terms of selecting their service providers

while others around them, including their family members and guardians, might make such decisions for them.

These two narratives illuminate some clear inconsistencies in terms of what these workers have been told about allowing or discouraging sexual expression and practices in their clients. Marina and Rose both recognized that the directions they had received from their organizations were both disjunctured and unrealistic. However, Marina chose to follow the procedures in place, while Rose, in addition to following procedures, even seemed to provide a justification for her agency's practices. Nevertheless, it was evident in the accounts of direct care workers that they had faced difficulties when dealing with the sexual expression and practices of their clients, due to a lack of helpful information and support, as well as due to problematic directions that they had received from their organizations. Moreover, these workers' narratives expose how they see themselves within their own power struggles with family members, guardians, and employers, which I will turn to in the next chapter.

Chapter Five

When I first started conducting the interviews for this project, I had in mind some of the themes and questions that had been previously noted in the literature. As discussed in the previous chapter, these included questions about staff training and institutional policies on sexuality, as well as questions about intellectually disabled people's experiences with sexuality and whether and how support workers can influence those experiences. However, in the analysis of my data, I found a particularly critical and recurring overarching theme was that of power struggles. The participants' accounts, in explicit or implicit ways, all touched on questions about power relations, decision-making capacity, constraints, and resistance. Drawing from standpoint theory, I have a particular interest in examining power relations that can contribute to the further disempowerment and marginalization of disabled people. Hence, I am on the one hand inspired in part by Rolin's (2009) conceptualization of power as an "ability of an individual or a group to constrain the choices available to another individual or group" to make sense of these power struggles (p.219). On the other hand, as Rolin has also noted, power relations are not always about domination, although they can serve as "vehicles of domination ... in a way that is [constraining and] harmful for the individual or group" (ibid). In addition to domination, there is also a potential for power to be resisted or even to empower as individuals also have the "ability to act *in spite of* or *in response to* the power wielded ... by others" (p.220). The interviews with both groups of participants demonstrated both of these kinds of power – the power of domination and productive kinds of power used in response to and resistance against domination.

The notion of power struggles emerged most explicitly from the interviews with people with intellectual disabilities, as participants themselves used the term to describe

their experiences of frustration, (dis)empowerment, and resistance. These participants talked about their struggles in developing sexual and romantic relationships, having privacy and control over their space, and dealing with some workers and guardians who insisted on speaking in their names and attempted to control their decisions. Most importantly, this group of self-advocates talked about how being their own guardians has allowed them to make more decisions in their lives, be more independent, and assert their agency more strongly within their relations with others. As I noted in the literature review, guardianship arrangements can often involve a private guardian, typically a family member or a friend of the disabled individual, or a public guardian assigned by the province, which is seen as a “last resort” (Alberta Human Services, 2014b). The decision-making scope of these guardians can vary from day-to-day issues to financial decisions in the name of those under guardianship orders. In this particular research, participants normally talked about guardians in reference to parents and other family members who acted as their legal guardians. However, there were a few instances in which participants talked about guardians in reference to public guardians with some decision-making power over disabled people’s personal or financial decisions. The individuals I interviewed spoke passionately about their journeys as they attempt to assert their agency in their power relations with others, and as they strove to be in charge of their own lives.

As for the interviews with direct care workers, they were for the most part characterized by a fear of “getting in trouble,” either with their organizations or the guardians and family members of their clients, so that although they didn’t use the term power struggles, the idea was more implicit in most of these interviews. These participants’ struggles were spoken of in terms of having to navigate their own beliefs

and practices when it came to dealing with the sexual expression and practices of their clients. In addition they spoke about tensions between the policies and expectations of their organizations, the perceived beliefs and attitudes of guardians, and the expectations and desires of their clients.

In their own ways, both groups of participants talked about various constraints that seemed to limit their possibilities and actions, which will be analyzed in the next few pages. In sum, considering that the theme of power struggles was so central to the interviews, in this chapter I have deliberately chosen to focus on how participants made sense of and worked through these various power struggles.

“It is totally a power struggle.”

Even though the concept of power struggle was not one that I used in the interviews, the participants who self-identify as intellectually disabled often brought up the term as they discussed their challenges and triumphs in achieving more decision-making power in their lives and communities. The notion of power struggle was first introduced by Jeremy, a quite active and vocal self-advocate, who provided an example to illustrate what he meant by power struggle:

I’ve moved in with this one lady from where I used to work and she wasn’t paid staff but it kind of illustrates that power struggle like, she was the main one in the contract for the rental place and she said my room had to be like clean and stuff to the point that I had no privacy. Like she would be in my room checking it out constantly...

Jeremy’s statement resonates with previous studies suggesting that individuals with intellectual disabilities are throughout their lifetimes subject to more invasion of personal space than are non-disabled people. This is in part because they are often considered child-like, and similarly to children, they are also not respected in terms of space and

autonomy (Hollomotz & The Speakup Committee, 2008; Lesseliers & Van Hove, 2002; Servais, 2006). The infantilization of disabled people not only undermines their privacy, and by extension, their sexual autonomy, but can also be used to ‘justify’ the disregard to their privacy and spatial boundaries, lead to (over)protection, and reduce their independence (Gesser, Nuernberg & Toneli, 2014; Shakespeare, Gillespie-Sells & Davies, 1996). One could speculate that, for a man in his twenties, having a middle-aged woman enter his bedroom at her own discretion, can discourage him from engaging in certain sexual practices such as masturbation and using pornography. In Jeremy’s case, the lack of privacy was a significant barrier precisely because, for him, masturbation and consumption of pornography have been his main sexual outlets. In order to illustrate how power struggles were not only oppressive, but could also be resisted, Jeremy went on to note that:

...and I’m just like, “This is not a good situation at all to be in,” ... and I told her that “My room is my room, you can’t tell me what to do with my room, or else I am gonna leave.” She kept saying that, and I’m just like, “I’m done [laughs] I am outta there, this is not a good place for me,” and it’s that, where she thought she had authority over me, and it’s like, “No, you don’t, so I am outta here.”

As it can be seen, Jeremy’s story also illuminates his efforts at resistance, and his landlady’s further efforts to undermine his autonomy. Notably, Jeremy was adamant about asserting his control over his own private space, and setting up clear boundaries with his landlady. As he reasserted:

That’s the power struggle- where she thinks things need to be this way, where my room is my private room, and the rest that is shared, sure, you can tell me what to do, but my room is my room.

Jeremy then decided to move temporarily to his parents’ house until he found his current living arrangement, sharing a house with roommates his own age. At another point in his

interview, Jeremy provided another example to illustrate that the power struggles he experienced were not only with his landlady, but that these power struggles occurred at multiple points, in this case with his paid workers:

... like I don't mind getting support from paid staff but when you have to live with that paid staff it becomes awkward because they are above you all the time and stuff and it's not even the paid staff, it's the agency that sets these rules for the staff that you're living with.

Jeremy's story illuminates that for him, power struggles have unfolded on several fronts. First, he identifies the tensions between the need to receive services and the potential surveillance that comes with staff who "are above you all the time." Second, his story shows that in such situations, individuals with disabilities are often being 'served' by a number of paid and unpaid supporters, whose values may conflict with their own. Finally, Jeremy gives some insight into the multi-layered qualities of power relations in disabled people's and disability workers' lives, as workers often act as interpreters for policies with which, as we saw in the previous chapter, they may not be entirely comfortable or conversant. For Jeremy, the only way to make resolve these kinds of power struggles was to ensure that his living space was his own.

However, he noted that "a lot of people [with disabilities] don't even realize that that's what it is [a power struggle], because it's very hard to realize that it is that way and I'm just starting to realize that." Jeremy is telling us here that typical live-in care arrangements are often so multi-layered and complex that it is really difficult to even see that there are power struggles or that the power is inappropriate. For Jeremy, in fact, this realization only occurred years after those incidents.

William, Anthony, Samantha and Nicholas were also quite aware of and able to articulate different instances that illustrated these various power struggles around sexual

expression and practices. Jeremy and William, for example, spoke about other intellectually disabled people who had dealt with power struggles to keep custody of their children. Jeremy, for instance, told:

It's really, really sad, when you hear those stories of families that have- that both parents have a disability, saying that they can't keep their kids, and having the government say, "Take them away," and it's really sad because they're really not getting the supports they need to raise the kids because they can love their kids...

One could speculate that, for some individuals with intellectual disabilities, growing up with such negative messages about their sexuality, abilities, and reproduction might, at times, lead to a form of internalized oppression. As Pentzell (2010) explains, internalized oppression is "where individuals in a subordinate social group apply the cultural norms of the dominant group to themselves, devaluing themselves even though they do not believe in the external inequalities of the social system" (para.6). The literature has noted that individuals with intellectual disabilities are commonly seen as unfit to be good parents to their children (Booth & Booth, 1994). In contrast, both William and Jeremy perceived themselves as being capable of being good parents at some point in the future. For instance, when he was married, William and his partner were in fact considering having children:

We wanted children, I mean, anybody wants children, I mean, you might have a bit of a tougher time supporting it but there is family, friends, people who will support you- so I think that was our dream, and it didn't last long enough, I don't think it was meant to have children but, I honestly think there really is a lot of draw backs for people with disabilities, people think, "Oh, you can't have children."

However, William provided some insight into his power struggles when he talked about a paid worker who attempted to discourage him from being a parent:

This isn't my current worker but when I got married the worker, "So, we need to get you to the hospi- to the health unit and all that" ... because, "Oh, you can't have children, you don't know how to take- you're not capable of that."

His story illuminates a two-fold power struggle; one in terms of navigating his worker's attempt to control his and his partner's decision in regards to birth control, and another in terms of dealing with the worker's perception of him and his partner as not capable of parenting. His worker's reaction resonates with dominant ideas about intellectually disabled people as unfit to be good parents to their children. In his narrative, William is also telling us that his worker's idea of an appropriate or good parent is both limited and inappropriate, as he notes that with the right supports in place, he could perhaps be a good parent.

To conclude his narrative, William told that he and his wife refused to go to the clinic or get on birth control, which also illustrates a potential for resistance, as William asserted: "We just decided no, basically told her, and I think that's the luxury for me as I am my own guardian ... we ignored [the worker] and did our own thing." He added, "She didn't preclude us from ever having children but the fact that people were saying 'you shouldn't' or 'you should get on birth control' is really the- the issue."

In sum, this section illuminates how the five individuals with intellectual disabilities that I interviewed often saw themselves as embedded in a series of power struggles with different social actors. In the case of Jeremy, his struggle was in relation to controlling his space, setting boundaries and having access to privacy in order to engage in sexual expression and practices. For William, the power struggle was in relation to his ability to make his own decisions about birth control and reproduction, as well as to challenge dominant notions of good parenting. The two men have responded firmly

against such oppressive practices against them, and have often referred to their guardianship status to explain their sense of authority and empowerment when asserting their agency and refusing the intervention of others around them. Indeed, all five participants commonly referred to their guardianship status to explain the scope of their decision-making power, which I will now turn to.

“I’m my own guardian. It comes down to that.”

All five participants emphasized numerous times in their interviews that being their own guardians had granted them some unusual autonomy and decision-making power that was supposedly out of reach for most people under guardianship orders. For these participants, acting as their own guardians was not a status that had to be struggled for, as they commonly and humorously spoke about the efforts of their family members in encouraging their independence and decision-making power. William humorously said: “I was at a Family Conference and they did a break room session on the new guardianship rules and I said [to my mom] after that, ‘would you ever be my guardian?’ and my mom was like, ‘no’ [laughs].” Anthony even provided a clear example of how his father had encouraged, or even forced, him to be more independent, as he told: “as soon as I was eighteen, my dad kicked me out of the house, ‘yeah, get out of here, like, seriously’ [laughs].” These participants’ particular guardianship status has granted them with a strong sense of independence and empowerment, which has allowed them to challenge certain oppressive forms of power and make their own decisions in regards to their sexual expression and practices. This is no small accomplishment considering that people with intellectual disabilities are often told what to do and this can experience frustration and powerlessness (Goble, 1999).

It is important to note that being their own guardians has, in some ways, allowed these individuals to occupy a more privileged position in comparison with other intellectually disabled people who are under guardianship orders. As I have discussed in the last chapter, the individuals with intellectual disabilities that I interviewed had had more opportunities to engage in sexual expression and practices, and room to make mistakes, and learn from them. As William noted, “it’s a lot easier to make decisions” when disabled people are their own guardians and, indeed, William’s narrative illustrates how his sexual autonomy and opportunities were partly possible because of his guardianship status. For instance, being his own guardian allowed him to get a credit card, book a flight to another country to meet a woman he had met at a chat room, and eventually get married to her in Europe, all without needing to ask permission from his parents. In addition, William said, “if I wanted to, I could go on a date, if I want to- I can do whatever I want, whenever I want.” This might not be the case for some other intellectually disabled individuals who might be more highly supervised by family members and direct care workers and/or have less of a decision-making scope in regards to their sexual expression and practices.

Participants were indeed quite concerned with their ability to make their own decisions and be, as Anthony asserted, in “the driver’s seat.” This included, for example, the ability to select their support workers and service providers, as well as to terminate those relationships if their values and beliefs did not match. As Jeremy stated:

I am my own guardian. It comes down to that, they [workers] can’t disagree with me, if they do, they’re hit the road and they are no longer gonna work with me, that’s what it comes down to, and that’s the same with the agency.

That ability to terminate relationships with direct care workers was also seen in Anthony's narrative. He talked about his experience with a former direct care worker with whom he did not share similar values and beliefs in regards to sexuality, and how that led to the termination of the worker:

He'd [support worker] come there [my house] and my girlfriend was just leaving, right? And I bugged him, because I knew he was a religious guy, I'd like, "Yeah, you know what I was just doing in that chair right there?" [laughs] ... but telling me that I am gonna burn in hell 'cause my best friend is a lesbian, and all this stuff, no, that was like, "What?"

Anthony's statement illustrates his struggle when navigating conflicting beliefs and attitudes from his previous direct care worker in regards to his understandings of what counts as appropriate or permissible forms of sexual expression.

As I discuss later on in this chapter, direct care workers are also engaged in their own journeys as sexual beings, and they can bring those personal narratives to their everyday practices when delivering services to disabled people. Anthony, who had best friends who identified as gay or lesbian, chose to fire the worker right away and select one who was more compatible with his values, life-style and interests. When I asked him about his current worker, Anthony said that their relationship has "worked out good for both." On one hand, it was good for his worker because "he was working a crap job and people wouldn't employ him" because of his disability. On the other hand, it was also a good arrangement for Anthony because, as he said: "he is my friend, either he works for me or he doesn't, so, you know, a lot of people actually don't even know that I pay him." That, he added, had also helped eliminate the stigma of having clearly identified workers walking around with him. It cannot go unsaid, though, that not all individuals with intellectual disabilities can afford to fire and hire their workers that easily.

It is important to note that this small sampling of disabled people not only recognized their privileged position, but also showed a strong sense of responsibility in supporting other people with disabilities who were not their own guardians or had a more constant presence of workers in their lives. This commitment sometimes meant coming into the defense of the sexual rights of other individuals with intellectual disabilities around them. Anthony used an example to illustrate how he had had intervened in the past to defend the sexual rights of another disabled man:

Even the guy who I used to live with, he used to have urges and stuff and so they would say, “Oh, you know, we need give him a med to take that away.” I am like, “Are you nuts?” like [laughs] and I’m like- and so, you know, he got in trouble for like making a pass at this girl, I am like, “C’mon, he’s like a quadriplegic.” But she made a big deal out of it...

It is also worth noting that, according to these five participants, the question of funding has been commonly used by support workers and service providers to keep their clients “under control” as most clients and their caregivers fear losing that important resource. Jeremy pondered whether most disabled people can even question certain oppressive forms of power and advocate for their sexual rights when their funding might be at stake:

How to do it [assert agency] without fear of losing your funding? Because that’s what it comes down to ... and agencies use that all the time as a tool to get people to behave. I am sure that’s one of the fear tactics they use [laughs] I am sure of it, where me, like, I just laugh at them, I am like, “Yeah, right [laughs] I know you can’t do that.”

Despite all of this, people with intellectual disabilities are active in pushing for resistance, and they sometimes even succeed at doing so. As it can be seen, participants often drew from their guardianship status as a source of empowerment in order to assert their decision-making power to others around them. These participants recognized that their privileged position had offered them more opportunities and choices in regards to their

sexual expression and practices. Additionally, they spoke about how being their own guardians had also allowed them to select direct care workers who they deemed to be the best match for them. They reported feeling responsible for protecting the sexual rights of other individuals with disabilities who, for some reason, had had their voices discredited by family members or workers. At times, the struggles of individuals with intellectual disabilities are with their workers, but the workers themselves are also constrained by perceived workplace tensions or guardian issues, which I will discuss in the next section

“You don’t feel like you should have power over this other person.”

It has been suggested that direct care workers have typically held considerable cultural authority and legitimacy to exercise influence and control over the sexual expression and practices of the people they serve. In his study, Goble (1999) found that some intellectually disabled people often saw their direct care workers as being “powerful and authoritative” but did not understand “the source of and rationale for this power and authority” (p.457). Although I recognize the power imbalances embedded in the relationships between workers and clients, I have suggested in a previous chapter that it is important to go beyond binaries of oppressor vs. oppressed as well as powerful vs. powerless. The accounts of the direct care workers that I interviewed indeed indicate that views of workers as oppressors and clients as oppressed may be oversimplified and that instead, workers themselves seem to have been embedded in their own power struggles around disability, autonomy and sexuality. Some direct care workers were well-aware that they often occupied a more privileged position in relation to their clients. However, Celine, for example, did not believe that she “should have [that] power over” her clients. As she stated:

As a person, you don't feel like you should have power over this other person necessarily, but you're filling a role, you're filling this institutional yeah, role where like you represent the organization, you represent the guardian, you represent the policies, you represent the rules, you represent all this paperwork and red tape.

Throughout her interview, Celine gave various indications that she actually feels quite uncomfortable being in a more privileged position in relation to her clients, having to negotiate that privileged position, and sometimes having to exercise such power in ways that could be considered oppressive. As she explicitly noted, "We're working with people, like you spend a lot of time with people, you're gonna develop a relationship and it's uncomfortable to always be in a position of power." This discomfort with being in a position of power may be or may not be shared by other direct care workers, and that deserves further exploration in future studies. Furthermore, in a moment, I will talk about how some direct care workers may not even see themselves as occupying a more privileged position in relation to their clients. Additionally, one could say that Celine's statement illustrates how direct care workers sometimes may find it challenging to accommodate the various expectations, regulations, and values coming from different social actors and institutional texts. In fact, some workers feel significantly disempowered within their own power struggles with agency administrators and mid-management, as well as family members and guardians, which will become more evident in the upcoming sections. That is to say, it can be quite challenging at times for workers to support their clients in engaging in sexual expression and practices, when they might have different people with conflicting views telling them what to do. At least for this small sampling of direct care workers, the family members and guardians of their clients often had the final say in regards to the sexual expressions and practices that were either

encouraged or discouraged. I will elaborate on the position and influence of family members and guardians within these power struggles in an upcoming section in this chapter.

On the other hand, it was also evident in some interviews that a few direct care workers did not perceived their relationships with their clients as being unbalanced in terms of power. This was the case with Susan, Michael and Rose who did not perceive their relationships with their clients as power struggles but were instead consistent in referring to their clients as being their friends. For example, Susan asserted:

I don't believe that I have a power over her ... I believe that I am there to support her and I like to make sure that she can also feel good and valued and do things that she can enjoy and be happy, be herself, so that's- like, my role is to support her um... yeah, so that's that, that's why, like a friend you wanna be a supporter, you know, you don't wanna be like a boss to them or a staff...

One can say that such an approach might actually help equalize the relationships between direct care workers and their clients. However, I found it somewhat intriguing that, out of those three direct care workers that defined their clients as being their friends, only Rose actually talked about spending time with her clients outside her work hours. In her case, she said, "it was encouraged to have relationships outside the- just outside your hours, so I would go for dinner with some of the core members [individuals with intellectual disabilities] here and there." In contrast, Michael and Susan had never spent time with their clients outside their work shifts. Michael, for instance, explained:

For me, personally, I find it too hard- our- and- and if I don't work there anymore, I'd just feel awkward ... sometimes it almost feels like it's- that friendship- like it was in elementary school where a person- like where someone is paying someone to be your friend, that's how sometimes I feel because I wouldn't be here if I wasn't getting paid, I need a job 'cause I am

in school, but it kind of feels like that and that's- that's kind of sad, that's really sad.

As it can be seen in Michael's statement, the relationships between direct care workers and their clients sometimes resemble that of a work relationship, one that ends as soon as the shift is over. This is certainly not the case for all direct care workers. However, it is reasonable to say that such a relationship is not a typical friendship, one that perhaps involves more constant and intimate communication. Also, at the same time that it makes those relationships seem more equal and less artificial, calling such relationships friendships can also mask the power imbalances embedded in them. That said, even though some workers may say that they don't see themselves as having more power over their clients, they actually do have power, and can often choose not to see clients and have a private life when they want to, which is not something that can be said for most their clients.

Conversely, Marina, who had been working as a direct care worker for over 20 years, discussed her struggles with agency administrators:

There have been staff that said - and I am one of them - I believe that if individuals do have the ability to make decisions, and they are not a risk to anyone, there isn't volatility involved, they are not on anti-psychotics, for example, that they, you know, they have the right [to sexual expression and practices], but in a religious organization, you know, unfortunately there are limits to that.

Her statement illustrates a struggle when negotiating her own beliefs in regards to the sexual rights of her clients with those of the agency administrators. Marina spoke about different, and often unsuccessful, instances where she and her co-workers have tried to change some of the values and practices of their organization, a Christian value-based organization that discourages their clients from having relationships and being sexual before marriage. It might be the case then that some other direct care workers out there,

similarly to Marina and her colleagues, might indeed be attempting to create dialogues and change the practices in their agencies. However, as the literature has noted, direct care workers often have little communication with agency administrators and almost no input into organizational policies, guidelines, and decisions, and thus, commonly report feeling somewhat powerless in their work (Ford & Honnor, 2000). Thus, even though Marina believes that her clients should be able to engage in sexual expression and practices before marriage, her efforts to influence agency values and practices, as she said, have limits.

Celine was one of the workers who reported feeling powerless, which has discouraged her from continuing working in the field for much longer. As she stated:

I've never considered it career-wise because of the politics and because of the powerlessness ... it's very clicky and- and out of your control and your values- like my values did not mesh well with those coming from above so for me...

Nevertheless, she also noted that she would consider staying in the field if she was able to work in higher up positions with more decision-making power and influence to change institutional policies and practices:

I like doing the job but I'd rather- I mean, if I did get in it, it would probably eventually one day after being a different person, being administrative, trying to change things, not working from like- 'cause it's frustrating in the long run and tiring, yeah, to constantly deal with things that you disagree with [laughs] and then have to enforce things you disagree with...

As it can be seen, some workers, as Celine suggested, do not feel that they should have power over their clients, while others, as seen in the cases of Susan, Michael, and Rose, do not even perceive their relationships with their clients as being unbalanced in terms of power. Nonetheless, some workers spoke about their own power struggles with agency administrators and middle ranked employees and sometimes reported a feeling of

powerlessness. When dealing with that feeling, some workers seemed to be on verge of giving up, while others seemed to want to persist in generating discussions about sexuality with their agency administrators.

“It makes me wanna cry”

In addition to some of those constraints identified by the workers, it became evident to me that, when talking about their attitudes and practices, workers’ own positions as sexual beings could influence their work. As the literature has suggested, workers’ age and religious background can be influencing factors in their beliefs and attitudes when it comes to dealing with the sexuality of their clients. Marina’s quote below shows how our sexual identities and how we make sense of them are not fixed, and that indeed these are constantly shaped by our various experiences. This should be noted as we talk about the experiences and practices of direct care workers because these social actors are also engaged in an ongoing negotiation of their sexual identities and understandings of sexuality.

Marina talked about how getting older and more comfortable with her own sexuality had influenced her understanding about the sexual rights of her clients:

You know, as you get older, your own sexuality changes, right? You start to realize “oh ok, I was raised in a religious home but I don’t need to be ashamed of this, this is actually me and I have the right to this and nobody else has the right to take that away and it’s ok” ... so now I would advocate for the rights of others far more strongly than when I was 20, you know, I was kind of shy about the whole sexuality myself, right?

Paola, who was in her mid-20s, also made a clear reference to that ongoing personal negotiation, as she noted:

People put too much proscription against it and put fear in everybody, if it was me like a few years before [nervous laughter] I would not be doing this

interview with you [nervous laughter] but I am kind of like more open minded now so.

Paola is telling us here that her particular social, cultural and historical context, in which sexuality has been understood both in terms of ‘proscription’ and ‘fear,’ has shaped her own position as sexual being and made her hesitant to even openly talking about sexuality. Even though she said that she was ‘kind of like more open minded now,’ Paola’s statement and nervous laughter here indeed seem to further illuminate her historical personal discomfort with the topic of sexuality, as well as her willingness to follow the agency’s guidelines and avoid discussions about sexual expression and practices with her clients.

As a final example, Michael, who showed the most discomfort when talking about sexuality, disclosed towards the end of his interview that he had been sexually abused as a child. The following excerpt demonstrates how his historical personal narratives can intersect with his current attitudes and practices towards sexuality:

Michael: ... just like that whole topic [sexuality] - it scares me, not that- not with the clients, but in today’s society, the whole like- I don’t know- it’s like a taboo topic and- the topic kind of makes me uncomfortable, yeah.

Me: Can you tell me more about it?

Michael: like why it makes me uncomfortable?

Me: yeah.

Michael: I don’t know if it’s because of my past or- childhood- but- no- it makes me wanna cry, I don’t know, I don’t know, it makes me wanna cry, not that topic, I don’t know, it’s just the- like right now, I have a hard time thinking, I have a hard time breathing, it’s- yeah- I don’t know why I am uncomfortable but it’s the whole-

The interview discussion that preceded this exchange began with me asking about whether it was problematic to assume that disabled people could potentially get upset when sharing their experiences around sexuality and sexual expression and practices, as some of those experiences could indeed be painful to talk about. However, I did not

necessarily think that a worker could also get upset during the interview. In a way, this position reflects the literature that tends to focus on the broader social identities of workers and their influence on their attitudes and experiences rather than delving into the complexities of workers' own sexual identities. These complexities might involve pleasurable, hurtful, or challenging experiences with regards to sexuality.

The accounts of the workers that I interviewed indicate that there could be other factors and narratives that are embedded in their practices, even those seemingly oppressive ones. Also, they seem to suggest that, in addition to examining the sexual expression and practices of disabled people, it is important to look at the romantic and sexual narratives of workers, and how these might influence their approach to disability and sexuality. Additionally, it would be relevant to contextualize their experiences within a culture that commonly engenders fear and silence all around when it comes to sexuality, especially when it is about the sexual expression and practices of disabled people. Altogether, the accounts of direct care worker seem to illuminate a culture that commonly sees disability and sexuality as something that will land people in trouble.

Where do Family Members and Guardians Fit in These Power Struggles?

This research, mostly due to time constraints, did not include interviews with guardians or family members of individuals with intellectual disabilities. However, direct care workers talked at least to some extent about their perceptions of and experiences with parents, family members, and guardians. It has been widely noted in the literature that family members and guardians can have a significant influence on the sexual expression and practices of disabled people, and can be active participants in the relationship between direct care workers and their clients. The small sampling of direct

care workers that I interviewed saw the guardians as important social actors who had the ultimate power to make decisions relating to the sexual expression and practices of their clients. Marina, for example, noted that “guardians have a lot of power, a lot of power, and um... ultimately we only have a voice to the degree that we can offer suggestions, and if the guardian says no, it’s a no.” The other workers also reported that a common step in their procedures, when dealing with the sexuality of their clients, involved reporting what they perceived as problematic incidents and then talking to the guardians and family members of their clients. For example, when describing the procedures at her agency for dealing with instances of what are seen as inappropriate behaviors by their clients, Paola explained:

First, we use our own procedure that we learned and if it doesn’t work, like if the- for example, if the individual has some um... is saying something sexual to you, that is kind of offensive, or means something, that is an issue, and you redirect one, two or third time, if the person- if the individual is still continuing, we call the guardian so we can [have a conversation].

One could say that Paola’s statement does illuminate a particular (and perhaps gendered) concern in regards to potential cases of sexual harassment by clients with intellectual disabilities against their direct care workers.¹¹ However, I would suggest that, in Paola’s particular case, more than a question of self-protection against harassment, her interview seemed to point to a more general discomfort in regards to dealing with the sexual expression and practices of her clients, which meant that any kind of comments or questions related to sexuality coming from her clients were seen as being inappropriate

¹¹ This is certainly not a concern that should be taken for granted. The literature has indeed explored the experiences of workers within disability services, especially female workers who make the majority in the field, when it comes to harassment perpetrated by clients with intellectual disabilities (Martinello, 2014; Thompson, 1997; Thompson, 2000). I was not able to examine this aspect in this particular project. However, future studies should look at the experiences and vulnerabilities of direct care workers as well.

and in need to be redirected. Thus, Paola's statement also seems to expose how, at least at her organization, sexuality is not something to be addressed by direct care workers. Rather, statements or questions coming from their clients about sexual expression and practices should be redirected or, in other words, ignored and avoided as much as possible, and if they persist, the parents and family members of their clients should be contacted for resolution.

According to these workers, the attitudes of family members and guardians towards the sexual expression and practices of their clients varied greatly. Marina, who had the most contact with the parents and guardians, spoke about the mother of her current client and her attitudes in regard to the sexual expression of her son with an intellectual disability. She stated:

His mother is lovely, she's very self-aware, she um... really does want the best for him and she's smart as a whip so I've never had any conflict with her. I am not concerned about her, I think she really does the best for him um...

Nonetheless, as Marina proceeded in her account, it became evident that there was a shared understanding between her and her client's mother regarding the forms of sexual expression and practices that they considered as permissible for her client. On one hand, Marina spoke about the expressions and practices that were encouraged and allowed, which included:

If my client found someone that he's sexually interested in them, he would be encouraged and allowed to go for coffee and talk with them and visit them but um... he might even like them and you know touch their hair or you know play with their hair or hip check them like he does...

On the other hand, she also noted that certain expressions and practices were not encouraged or allowed, and these included:

... he wouldn't be encouraged, for example, to spend an hour alone with that individual. For one, he has volatile tendencies so, you know, we can't even leave him alone with someone.

For Marina, this limitation is in place because the greatest fear of her client's mother is that "he will be violent in the community and get arrested and that he would be in police custody and she would have no power. That terrifies her. Big fear, big fear." This is certainly a reasonable fear considering that studies examining the experiences of individuals with intellectual disabilities in the criminal justice system, particularly the ones charged with sex offences, have found that intellectually disabled people are "more likely to be arrested, convicted, sentenced to prison and victimized in prison" (Davis, 2009). It has also been suggested that a combination of disability-related factors, personal experiences and environmental factors actually make these individuals more susceptible to entering the criminal justice system as victims, or suspects, or offenders (Davis, 2009; Holland, Clare, & Mukhopadhyay, 2002). Marina seemed understanding and sympathetic to the mother as she agreed with her and consequently followed her instructions to keep the man from being alone with someone. Additionally, as Marina noted, "if the guardian says no, it's a no."

In another example of the influence of parents and guardians, Rose talked about two intellectually disabled individuals who lived in the same group home and got romantically involved. Rose told:

One of the living assistants [direct care worker] walked in on them and I don't know what they were doing, how much they were doing, I just know that it was in his bed. I think it was initiated more by her and the way the community responded was very quiet because not a lot of people knew. I found out through a friend who worked in the house and she's a little more chatty than she should have been.

The young man's family was supportive of his relationship. As Rose noted, for his parents, "that's what people do, that's like just what happens." The other disabled individuals living in the house were also supportive and willing to accommodate the couple. Rose said, "They decided that he would just move downstairs in the basement without the assistants, they made it "the men area," and then women just lived upstairs which was fine." However, Rose added, "her family- they removed her from the home ... because her family was so angry, they moved her out of the house." Before the young woman moved out of the house, Rose met her one more time, only to find out that she had been sterilized:

I remember when this young lady told me about this [hysterectomy]- when she explained to me, she seemed quite okay with it. Of course she would be, the way you know- I don't think she understood what that meant... [makes sound of frustration]...

It is worth noting that in Canada, as Rioux and Patton (2011) have noted, "people who have an intellectual disability cannot be required to undergo a non-therapeutic sterilization authorized by any third party including parents" (251). According to Eve's Law, the main piece of policy in Canada which guarantees the reproductive rights of disabled people, "In the absence of the affected person's consent, it can never be safely determined that it is for the benefit of that person" (The Supreme Court of Canada, 1986). That is to say that, parents' and guardians' convenience, wishes, or protection cannot overstep the bodily and reproductive autonomy of intellectually disabled people (Eugenics to Newgenics, 2014; Rioux & Patton, 2011).

Nonetheless, it has been noted in the literature that misinformation can be used as a tool to control the choices and experiences of women with intellectual disabilities in regards to their sexual expression and practices, as well as their reproductive and

parenting rights (Galea et al., 2004; Murphy & O'Callaghan, 2004; Servais, 2006; Szollos & McCabe, 1995; Waxman, 1994). It was evident in Rose's account that, throughout this particular situation, she had limited her role to that of an observer, which raises the question to why some workers might not take a more active role in such situations. Rose, for instance, limited herself to say: "she just left the group home, and they haven't really heard from her, and she does- she doesn't have anything to do with the organization." It might be the case that some workers, similarly to Rose, might feel disempowered to take a more active role, fearing potential negative consequences from their organizations or the family members and guardians of their clients. Additionally, an internal organizational culture of secrecy around instances involving the sexual expression and practices of their clients seems to indicate that such instances are dealt with "backstage" by agency administrators and family members and guardians, with little input from direct care workers themselves.

To conclude, it was evident in the accounts of both the direct care workers and the people with intellectual disabilities that these individuals perceived parents, family members and guardians as having a significant amount of power to influence the actual sexual expression and practices of intellectually disabled people. The direct care workers perceived family members and guardians to be the ultimate decision-makers when it came to deciding what forms of sexual expression and practices their clients were allowed to have and experience. Additionally, their accounts suggest a feeling of powerlessness, where workers become mere reporters of incidents, and then observers and enforcers of decision-making processes regarding their clients' sexual expression and practices. Yet, I must acknowledge that the clients that these direct care workers serve are

much more controlled than the individuals with intellectual disabilities that I actually interviewed for this project. The clients of these direct care workers were all under legal guardianship and had more constant and intensive interactions with direct care workers, and one could speculate that they might experience less autonomy, privacy, and decision-making power in comparison to the individuals with intellectual disabilities in my sample. Unfortunately, I was not able to speak with people with intellectual disabilities who are in these kinds of power relationships (as I discussed earlier) precisely because of protectionism and guardianship issues; however, I was fortunate to gain some insight into their situation from the direct care workers. Nonetheless, I should acknowledge that the direct care workers that I spoke with, though they mentioned a feeling of powerlessness, still remained a privileged group compared to many disabled people.

It is also reasonable to say that parents and guardians also struggle when dealing with the sexual expression and practices of individuals with intellectual disabilities. As it can be seen in participants' accounts, parents and guardians present a variety of attitudes and concerns towards sexuality, and they can both constrain and/or facilitate opportunities for sexual expression and practices of individuals with intellectual disabilities. Thus, both individuals with intellectual disabilities and direct care workers have pointed to how power struggles are much more complex than what might be visible in their everyday practices or even in the literature. These struggles involve and affect a variety of social actors, including parents, family members, guardians, agency administrators. In sum, this more complicated understanding of power relations and struggles suggest a broader struggle appears to disempower both workers and disabled individuals.

Chapter Six

Concluding Remarks

Drawing from in-depth interviews, this study primarily explored the experiences of a small number of individuals with intellectual disabilities in regards to their sexual expression and practices, and inquired whether and how these individuals' direct care workers had affected their expression and practices. The five individuals with intellectual disabilities who I interviewed presented as a diverse group in regards to their historical and current experiences with relationships and sexuality. At the time of the interviews, Nicholas and Samantha had been married for over five years, and Jeremy and Anthony were single; William was divorced. I started off by examining whether and how the housing arrangements of these individuals had affected their sexual lives. The participants talked about how a variety of former and current housing arrangements, ranging from highly supervised and restrictive group homes to more independent and private living arrangements, had influenced (and sometimes limited) their opportunities to engage in sexual expression and practices. Participants reported that, when living in more restrictive and surveilled housing arrangements, they had experienced a significant lack of privacy, control over their private space, and autonomy, which often limited their opportunities to maintain sexual relationships and obtain sexual pleasure. However, these individuals have managed to move into more independent and private settings within the last few years, which have provided them with more privacy and autonomy to engage in sexual expression and practices. At the time of the interviews, Nicholas and Samantha were living together independently in a family owned house, Jeremy was living with

roommates, William was living with a roommate companion, and Anthony was living in a rented house with the regular supports of a direct care worker.

I also asked participants about their experiences with sexual expression and practices in their school years because, as the literature has suggested, individuals with intellectual disabilities often experience isolation, stigmatization, and a lack of sexual and romantic relationships during their schooling years. I also inquired whether they had received sex education at some point in their schooling. Most of the participants talked about feelings of loneliness and vulnerability, and a lack of satisfying sexual and romantic experiences. Anthony was the only participant to talk about his sexual and romantic experiences during his school years in positive terms. He was able to have relationships and be sexually active, but he also acknowledged that he had faced difficulties pursuing potential hook-ups and dates because of the stereotypes that some non-disabled women have about men with physical and intellectual disabilities.

All five participants reported that they had received sex education in their school years. However, they also said that their sex education was significantly limited, addressing solely facts and information about biology and hygiene. Participants suggested that, in addition to that kind of information about sexuality, they would like to have role models of what good relationships look like, more open discussions, and more opportunities for actual sexual experiences.

These individuals reported that the lack of discussion and helpful information relating to sexuality, as well as role models of good relationships, had led them to learn about relationships and sexuality by trial and error. This approach, as I have noted, can be

problematic because a lack of information and guidance in regards to sexual expression and practices can sometimes lead to instances of inappropriate behavior, hinder disabled people's ability to detect abusive relationships, and increase the probability of contracting STIs, or having unplanned pregnancies. To put it differently, such a lack of information and support may put individuals with intellectually disabilities in a difficult position in which they might express their sexuality in problematic ways, or get into trouble, or have unsatisfying sexual and romantic lives. Nonetheless, when reflecting on their previous sexual and romantic experiences and making sense of what may have gone right or wrong in those experiences, the participants were clearly both able and willing to engage in some critical reflection. Furthermore, participants spoke about the importance of being able to make mistakes and learn from them, without having other people presume that they are incapable of having relationships and learning from them.

I also inquired whether and how the religious backgrounds of the individuals with intellectual disabilities had influenced their attitudes and experiences in regards to sexuality. The five participants talked about the different ways in which their own religious beliefs and moral values, as well as those of others around them, have influenced their attitudes and practices in regards to sexuality. Some participants suggested that religion had, at some point, offered them some guidance in their pursuit of relationships. However, they seemed to have moved away from that source of information and guidance, and decided to follow their own paths in regards to their sexual expression and practices. The influence of religion was also implicit in some other accounts but seemed to have less of an influence in the actual sexual practices of the interviewees. As a final example, one of the individuals with intellectual disability talked

about how the religious background of his direct care workers had affected his sexual and romantic experiences in the past. The influence of religion was also evident in the experiences of two direct care workers who had both been working at Christian value-based organizations. These workers talked about the influence of religious organizational values in their actual work practices related to sexuality, even though both self-identified as being agnostic. As I have noted, the fact that these individuals had engaged with intersections of religion and sexuality in various complex and diverse ways seems to suggest the need for further exploration of the actual experiences of individuals with intellectual disabilities who are navigating such intricate intersections.

I also explored whether and how the parents and family members of these individuals with intellectual disabilities had influenced their experiences with sexual expression and practices. For the most part, their family members had encouraged them to engage in sexual expression and practices as long as they fit with their family values and expectations. Some parents seemed encouraging in terms of their loved ones having relationships and even becoming parents, but they had not provided much support or guidance on how to manage or achieve those goals. In some cases, participants also talked about how their families had had a significant level of involvement and support to help them have a satisfactory and autonomous sexual life. When discussing about having children at some point in the future, I also noticed some ambivalence from the participants, as some of them seemed discouraged from the possibility of parenting due to a family member's discouragement, a fear of potentially losing custody of their child as they referred to previous cases involving other disabled parents, or their limited monthly income.

As for the small sampling of direct care workers that I interviewed, these participants were often hesitant to discuss the institutional policies at their organizations and sometimes implied that their actual practices were not really tied to such organizational texts. Direct care workers, who had sexual expression and practices addressed in their training programs, received some very limited information. Their training focused on questions of sexual abuse and appropriate behavior but completely disregarded other aspects of sexuality including dating, intimacy, pleasure, and reproduction. As for the workers who had not received training, they seemed ambivalent or not particularly receptive to the idea of receiving training related to sexuality. Overall, their accounts seem to indicate that these direct care workers may not have the skills to support their clients to actually have desirable sexual and romantic lives. Even the workers who had received some training received instructions regarding how to handle situations related to the sexual expression and practices of their clients that seemed, at times, confusing, conflicting, and highly problematic. In some cases, the workers had been instructed by their agencies that statements or questions coming from their clients about sexual expression and practices should be redirected or, in other words, ignored and avoided as much as possible. In other cases, the workers reported clear inconsistencies in terms of what they had been told about allowing or discouraging sexual expression and practices in their clients. Needless to say, most of these workers reported feeling hesitant and scared about dealing with, or assisting, the sexual needs and desires of their clients.

It was also evident to me that, when talking about their attitudes and practices, workers' own positions as sexual beings could influence their work. This seems to suggest that the experiences and values of direct care workers should also be examined as

these social actors are also engaged in an ongoing negotiation of their sexual identities and understandings of sexuality. I am certainly aware of various studies that have examined the attitudes of direct care workers in regards to the sexuality of their clients. However, as most of those studies have used surveys to gather their data, I would say that there needs to be more qualitative studies to examine workers' attitudes, especially if we hope to better understand the social position of direct care workers and its potential influence on their practices. Moreover, the narratives of the direct care worker seem to expose how they see themselves within their own power struggles with family members, guardians, and employers, and this also deserves further exploration in future research.

Similarly, individuals with intellectual disabilities often brought up the term "power struggle" as they discussed their challenges and triumphs in achieving more decision-making power in their lives. They spoke passionately about their attempts to assert their agency in those power struggles, and to be in charge of their own lives. Although their power struggles were sometimes with their direct care workers, the participants' accounts suggested that various other social actors such as parents, guardians, roommate companions, and agency administrators were also involved in those struggles, sometimes facilitating or containing their opportunities for sexual expression and practices. The direct care workers spoke about power struggles more implicitly, as their interviews were for the most part characterized by a fear of "getting in trouble," either with their organizations or the guardians and family members of their clients. As for these workers, they spoke about their challenges when navigating their own beliefs and practices and trying to accommodate the expectations and values of their agencies, as well as the guardians of their clients, when dealing with the sexual expression and practices of their

clients. They talked extensively about some of the tensions between the policies and expectations of their organizations, the perceived beliefs and attitudes of guardians, and the expectations and desires of their clients. Thus, I have suggested that, in their own ways, both groups of participants talked about various power struggles and constraints that seemed to limit their possibilities and actions.

One aim of this project was to complicate some oversimplified accounts of power relations between individuals with intellectual disabilities and direct care workers, and examine whether there might be more to these power relations than what is evident in these individuals' everyday experiences and practices, and if there is, how this plays out. This project focused on the various power relations in which both individuals with intellectual disabilities and direct care workers perceived themselves to be embedded. I chose to begin with and highlight the voices of participants with intellectual disabilities because they often have less power in relations with their workers; thus, their particular perspectives can illuminate unequal power relations, and open them for analysis and critique. However, in contrast with my initial characterization of participants with intellectual disabilities as marginalized, or oppressed, the accounts of this group of participants suggested that they actually perceived themselves as being significantly empowered. In part this may be because, as they described themselves, they were more privileged in comparison with some other individuals with intellectual disabilities. All five participants emphasized numerous times in their interviews that being their own guardians had granted them some unusual autonomy and decision-making power that was supposedly out of reach for most people under guardianship orders. For these participants, acting as their own guardians was not a status that had to be struggled for, as

they commonly and humorously spoke about the efforts of their family members in encouraging their independence and decision-making power. Being their own guardians has, in some ways, allowed these individuals to occupy a more privileged position in comparison with other intellectually disabled people who are under guardianship orders. As I have discussed in the last chapter, the individuals with intellectual disabilities that I interviewed had had more opportunities to engage in sexual expression and practices, and room to make mistakes, and learn from them. However, it was also clear that these participants actually had worked to change their living and support worker situations in ways that truly were empowered.

The accounts of the direct care workers that I interviewed indicate that views of workers as oppressors and clients as oppressed may be oversimplified and that, instead, workers themselves seem to have been embedded in their own power struggles around disability, autonomy and sexuality. Although I recognize the power imbalances embedded in the relationships between workers and clients, it is important to go beyond binaries of oppressor vs. oppressed as well as powerful vs. powerless. Certainly, at the same time that some of the direct care workers were well-aware that they often occupied a more privileged position in relation to their clients, a few others did not necessarily perceive their relationships with their clients as being unbalanced in terms of power. Nonetheless, all these workers spoke about their own power struggles with agency administrators and middle ranked employees and sometimes reported a feeling of powerlessness. When dealing with that feeling, some workers seemed to be on verge of giving up, while others seemed to want to persist in generating discussions about sexuality with their agency administrators.

The individuals with intellectual disabilities certainly spoke about experiences of oppression and disempowerment. They were quite well-aware of and able to articulate the various misconceptions and dominant ideas that some non-disabled people hold, especially in terms of their sexual expression, practices, and rights. Nevertheless, they also spoke passionately and proudly about their acts of resistance in the face of oppressive and constraining experiences. Standpoint theorists have noted how people embody multiple identities and that intricate intersections of these identities may grant people privileges or disadvantages at different contexts and times (Haraway, 1988; Wood, 2005). It was important for me then to avoid homogenizing the experiences of intellectually disabled people precisely by showing the great variations and complexities in the narratives of each participant. It was equally important to acknowledge some of the privileges that have allowed these particular individuals to have particular experiences when attempting to take control of own sexual and romantic lives.

Finally, I would like to briefly refer to the work of Michel Foucault (1977; 1978; 1980, 2003), whose model of power seemed to actually be manifested in the narratives of my research participants. I say that because, for Foucault (1980), power should be understood as something that is capillary and that affects everyone:

Something which circulates, or as something which only functions in the form of a chain [...] power is employed and exercised from a net-like organisation [...] individuals are the vehicle of power, not its points of application (p.98).

In my research, I found that both the individuals with intellectual disabilities as well as the direct care workers that I interviewed understood themselves to be a part of various local and trans-local social relations that commonly involved power struggles that created opportunities or limited their practices. Similarly, as Foucault (1978) has suggested,

power is not located within particular institutions nor is it simply top-down but, in fact, “power is everywhere” and “comes from everywhere” (p.93). According to Foucault (2003), power permeates all social relations and comes into existence precisely when it is “exercised” in social relations through which subjects come to “structure the possible field of actions of others” (p.138), controlling, limiting, or enabling certain actions (Peers, 2012).

This does not mean that power is always negative and repressive because, as Foucault (1977) noted, even though power can be repressive at times, it is also something that produces “reality, [...] domains of objects and rituals of truth” (p.194). In fact, even the most seemly constraining and oppressive operations of power can allow for new “forms of behaviour and events rather than simply curtailing freedom and constraining individuals” (Mills, 2003, p.36). For Foucault (1977), power, rather than ever negative and oppressive, can be productive and achieve unexpected results. That is to say that, power can be taken up and used, even by those who we think are vulnerable, like individuals with intellectual disabilities. Additionally, as Foucault (1978) has noted, “where there is power, there is resistance” (p.95). There is, for Foucault, a productive “field of possibilities in which several ways of behaving, several reactions and diverse compartments, may be realized” (as cited in Weberman, 2000, p.256), and individuals with disabilities can, for instance, resist through collective or individual, spontaneous or articulate, forms of action (Peers, 2012). Also, considering power as productive and always open for resistance allows us to see opportunities for people with disabilities and direct care workers to shift discourses and practices (Gilbert, 2003).

The work of Michel Foucault has been gaining more space within Disability Studies since the 1990s, with the increasing criticisms of the social model of disability from feminist and poststructuralist scholars (Hughes, 2005; Thomas, 2004; Tremain, 2005). I understand that an attempt to incorporate standpoint theory, and particularly the work of Dorothy Smith, into a Foucauldian framework might seem contentious to some scholars (Satka & Skehill, 2011). However, I would suggest that together, Foucault and Smith can provide what Satka and Skehill (2011) refer to as “two different viewpoints on the same scene,” or in other words, even though they might not be behind the same camera, having them both record the operations of power, subjectification, and actual subject conduct within relations between direct care workers and individuals with intellectual disabilities might provide important insights (p.199). Future studies should perhaps continue to build on the intersections of standpoint theory, which I would say, remains relevant as a theoretical, epistemological, and methodological tool, and a Foucauldian framework to further examine the topic of disability and sexuality.

This research has some limitations. The most noticeable one perhaps is that my research excluded individuals with intellectual disabilities who are under guardianship orders. As I have noted, this was the case because I understand that guardianship arrangements are not always congenial, and that access to interviewees may not always be granted when dealing with guardians. Due to time constraints, I intend instead to interview those under guardianship order in a future research project, which will allow me enough time to deal with such guardianship arrangements more appropriately and responsibly. I should also note that, although I sought out a diverse sample, especially in terms of race, ethnicity and sexual orientation, in the end I spoke only with individuals

with intellectual disabilities who were Canadians, Caucasian, and heterosexual. In the case of direct care workers, however, I was able to have a more diverse sample, particularly in terms of age, sexual orientation, and years of work experience. Yet, I should note that, due to time and monetary constraints, my recruitment strategy and pool of potential participants were limited to those living in Lethbridge and those who volunteered their participation. In future research, I might address this by becoming more deeply involved in community advocacy as an avenue for recruitment, or I might branch out into other communities, which proved difficult here because of transportation and isolation.

Nonetheless, I believe that this research not only offers a modest contribution to the literature on disability and sexuality, but also holds a potential to accomplish emancipatory knowledge and inspire changes in attitudes and practices. It is my sincere hope that my work has contributed to that effort in some way. Also, my intention in this project was to set the stage for future exploration on the experiences of sexual expression and practices of individuals with intellectual disabilities, and inspire skepticism in regards to what we know, or think we know, about the experiences of disabled people and their direct care workers. I acknowledge that the individuals that I interviewed were relatively independent, empowered, and vocal, which might not speak to the experiences of some other individuals with intellectual disabilities. However, the individuals with intellectual disabilities that I interviewed seemed to offer various instances that demonstrated a potential for empowerment and resistance within their different power struggles, which might speak to some other intellectually disabled people. Moreover, the narratives of individuals with intellectual disabilities seemed to illuminate some potential for

intellectually disabled people to have more fulfilling experiences with sexual expression and practices.

Future Research

This exploratory study points to various possibilities for future research. First and foremost, participants often referred to the need for more participatory research. These participants even offered me a whole range of ideas for future research projects. As the literature has noted, there has been an increasing body of both participatory and emancipatory research endeavors, which have allowed for more involvement of disabled people in research (Lewis et al., 2008; Swain & French, 2004). Thus, even though the challenges in conducting participatory research are well-known among qualitative researchers, I would suggest that such an approach could help us in continuing to change some of “the social relations of research [and knowledge] production” (Oliver, 1992, p.101).

Secondly, there are a variety of other social actors that should be included in future studies to provide further insights in regards to complexities in power struggles surrounding the experiences of individuals with intellectual disabilities with sexual expression and practices. These could include individuals with intellectual disabilities who do not act as their own guardians because it may be the case that these individuals may have less privacy, decision-making power, and sexual autonomy and control over their sexual and romantic lives. In the future, studies could also continue to examine the experiences of different family members of disabled people including, for instance, their older and younger siblings. This is because siblings, who may, at times, be the main carers of their disabled brothers and sisters, may also struggle when attempting to support

their siblings have in sexual and romantic life that they desire. It would also be worth pursuing further examination on the perceptions, priorities, and practices of government-level employees and policy makers when it comes to the sexual expression and practices of intellectually disabled people. This could allow us to better understand how they may have an influence on the actual practices of agencies serving disabled people, as well as on the experiences of people with intellectual disabilities and their family members. It would also allow us to further interrogate current policies and funding programs that can have actual implications on the opportunities for disabled people to be sexual, have relationships, and be parents if they desire. As I have briefly addressed in this thesis, the AISH funding program in Alberta, for instance, makes it seem that sexuality and parenting may not be a priority for disability services in the province.

Thirdly, it is also important for more individuals with intellectual disabilities to have the opportunity to speak about their experiences with sexual expression and practices on their own terms. This should include disabled people from their early teens to their later years, people who self-identify as both disabled and queer, people with intellectual disabilities across races, ethnicities, social classes and cultures, women with intellectual disabilities, people within and outside of guardian relationships, people in rural and urban settings, and perhaps other forms of intersectionality.

I also would like to point to the need to further examine how the social locations and personal narratives of direct care workers, in regards to their own sexual expression and practices, can shape their actual practices with their clients. As I have noted, the accounts of the workers that I interviewed seemed to indicate that there could be many more factors and narratives embedded in their practices, even those seemingly oppressive

ones, which might not have been particularly considered in previous studies. To accomplish this research, I would encourage more researchers to use qualitative research methods to delve into the complexities and develop more complicated accounts of the experiences of direct care workers. Future studies could perhaps use qualitative research methods to gain richer and thicker descriptions of how workers' personal narratives and social locations may influence their attitudes towards their own sexuality, as well as the sexuality of their disabled clients. Studies could also further examine the attitudes and experiences of team leaders and other staff members who are neither in the very front line of service-delivery nor in the administration body. This is because their middle position in the organizational hierarchy may provide some rich insights into what goes on from the management's policy and guidelines making process to the actual front-line practices of workers.

Finally, although I did not address the question of individuals with intellectual disabilities who have been served by sex workers, or sexual surrogates to deal with their sexual needs, the topic has received more public attention recently and has shown to be a relevant area for future research. Future studies could perhaps further explore the perceptions, experiences, and attitudes among individuals with intellectual disabilities in regards to sex work and sex surrogacy.

Final Reflections

As I have mentioned in my method chapter, I have decided to include a few reflexive pieces in this thesis to allow the readers to have an idea of who I am, and how I make sense of the research topic, and the research process. Therefore, I would like to conclude this project with some final reflections. In the initial stages of this project, I was

hesitant about interviewing people with intellectual disabilities because I feared that talking about their experiences with sexual expression and practices could be emotionally difficult for them. However, as I conclude this project, I see how important it was for me to create that space for people with intellectual disabilities to talk about their own experiences, struggles, and achievements in their own terms, and to acknowledge their position as *subjects*, as knowers of their situated position, instead of being merely “objects” of study. Also, I have come to realize how protectionism, even when coming from a genuine place of concern and care, can lead to the silencing of those we want to protect because we see them as being vulnerable. Without a doubt, this project would not have been the same without the insightful and passionate accounts of this small sampling of individuals with intellectual disabilities.

Secondly, it was noted by my supervisor and committee members earlier on that I seemed somewhat hesitant when talking more openly about sex and pleasure with my research participants in the interviews. For me, that was a reminder of how my own sexual identity and historical narratives were also implicated in my research work. As I look back and reflect on my own upbringing, I am reminded that sex and pleasure were not topics that were discussed at home, and that I had never shared details about my sexual and romantic life even with close friends. Growing up as someone who identifies as a bisexual man within a conservative culture that has often condoned violence against queer people made me want to keep my sexual orientation and sexual experiences a complete secret. Also, having close family members who did not approve of my sexual orientation also discouraged me from ever talking about my experiences with relationships and sex, to the point that I often felt that all those experiences had to be kept

hidden from everyone I knew. Now I find myself in a very different position in terms of understanding and experiencing my sexual expression and practices from when I started this project. This research was an important part of this journey of making sense of my sexuality and *finally* feeling more comfortable about speaking about experiences of sex and pleasure. In other words, this research was a significant transformative process for me.

Thirdly, I should acknowledge that I started off this research from a quite naïve position. The literature (and me, following that literature) has made certain pronouncements, for instance, that sex education will cure all, or that staff training will reduce power struggles. However, I have realized that, although people with intellectual disabilities and direct care workers did talk about these things in their interviews, these were really only aspects of broader struggles that actually disempowered them both, and a culture that commonly understands disability and sexuality as something that will land people in trouble. Both individuals with intellectual disabilities and direct care workers saw themselves as embedded in and constrained by various local and extra-local social relations and power struggles, which seemed to have kept them from moving forward in regards to this question of sexual expression and practices.

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Appendix A

How Individuals with Intellectual Disabilities and Direct Care Workers Make Sense of Sexuality and Sexual Expression.

Individuals with Intellectual Disabilities

Date

Dear Participant,

I invite you to take part in an interview for my master's thesis research project exploring how individuals with intellectual disabilities and direct care workers make sense of sexuality and sexual expression, and experience instances of agreement and/or disagreement regarding those areas.

This consent form, a copy of which has been given to you, should tell you what this research is about. Please ask me to explain anything you do not understand.

The study is about your experiences with relationships and intimacy, your interactions with direct care workers, and your potential experiences of agreement and/or disagreement with direct care workers regarding relationships and intimacy. The information gathered through this research project will be used to complete the thesis requirement of my Master of Arts degree.

If you agree, I will interview you and audio record the interview. It takes 1 to 2 hours and will take place at a location agreed to by both of us. I may briefly contact you for follow-up information. You do not have to answer any questions you are uncomfortable with. You can end the interview at any time you wish without consequences. If you choose to withdraw, it will not affect any services you are currently receiving. If you choose to withdraw from the study, the information gathered will be destroyed and it will not be included in any written thesis or publication resulting from this study.

This research is not being funded by any human services agency. The results of this research will be used in talks, reports, and journal articles about the research. Your name or any identifying information will not be used in any talk or article that may result from the interview.

I will transcribe the interviews. The information collected from interviews will be available only to me and my supervisor (Dr. Claudia Malacrida) who is bound by ethical protocols to maintain confidentiality and anonymity. I will only share anonymized interview transcripts with my supervisor. Tapes and copies of the typed interview will be kept in a locked cabinet in my office. The tapes and hand written observation notes will be destroyed after transcription, but the anonymized interview transcripts containing pseudonyms, and changes in place names, organization names and family details will be

kept for an indefinite period. The data may be used in future research completed by myself but I will protect your anonymity.

I will not lie to you about any part of this project, or trick you in any way. I want you to feel comfortable in this research, and if you do not, please tell me so I can change what I am doing.

The information you give in the interview will not be shared with agency workers, service providers, employers, family or friends. I will not use your real name or any identifying information in any talks, reports, or journal articles. Thus, you should not be at any risk by speaking with me about your experiences. You may even feel pleased or positive after telling me your story. However, you may also feel upset and need to talk with someone, and Anna Olson at the Southern Alberta Individualized Planning Association can help you. Her office telephone number is (403) 320-1515 and her email is anna.olson@saipa.info.

Although I will do my best to safeguard information from this interview, I may have to report information to authorities to protect your health or safety. If you tell me about illegal situations (for example, sexual abuse) I will be required to report the findings to an appropriate authority. I will do my best to make sure that you are not endangered because of my telling the authorities.

If you have questions about this study you can call me at any time. My telephone number is (403) 593-8997 and my email is a.santinelemartino@uleth.ca. If you want to ask about your rights in this research, the Office of Research Services at the University of Lethbridge can help you (Phone: 403-329-2747, email research.services@uleth.ca).

Following the completion of my program, a copy of my written thesis will be available in the University of Lethbridge library. If you wish to be contacted directly regarding the findings of this research, please provide an email address that I can send a summary of findings to (this may take an additional 18 months from the time of your interview).

I have read the above letter and have had it read to me, and I agree to participate. I am my own legal guardian.

Participant signature

Name (please print)

Date

Witness (if necessary)

I would like to know what you find out. Please send me a summary (takes 18 months)

Name: _____

Address: _____

How Individuals with Intellectual Disabilities and Direct Care Workers
Make Sense of Sexuality and Sexual Expression.

Direct Care Workers

Date

Dear Participant,

I invite you to take part in an interview for my master's thesis research project exploring how individuals with intellectual disabilities and direct care workers make sense of sexuality and sexual expression, and experience instances of agreement and/or disagreement regarding those areas.

This consent form, a copy of which has been given to you, should tell you what this research is about. Please ask me to explain anything you do not understand.

The purpose of this research project is to better understand your beliefs and practices in regards to the sexuality and sexual expression of your clients, your interactions with clients and their families, and the influence of institutional policies and training on your work. The information gathered through this research project will be used to complete the thesis requirement of my Master of Arts degree.

If you agree, I will interview you and audio record the interview. It takes 1 to 2 hours and will take place at a location agreed to by both of us. I may briefly contact you for follow-up information. You do not have to answer any questions you are uncomfortable with. You can end the interview at any time you wish without consequences. If you choose to withdraw from the study, the information gathered will be destroyed and it will not be included in any written thesis or publication resulting from this study.

This research is not being funded by any human services agency. The results of this research will be used in talks, reports, and journal articles about the research. Your name or any identifying information will not be used in any talk or article that may result from the interview.

I will transcribe the interviews. The information collected from interviews will be available only to me and my supervisor (Dr. Claudia Malacrida) who is bound by ethical protocols to maintain confidentiality and anonymity. I will only share anonymized interview transcripts with my supervisor. Tapes and copies of the typed interview will be kept in a locked cabinet in my office. The tapes and hand written observation notes will be destroyed after transcription, but the anonymized interview transcripts containing pseudonyms, and changes in place names, organization names and family details will be

kept for an indefinite period. The data may be used in future research completed by myself but I will protect your anonymity.

I will not lie to you about any part of this project, or trick you in any way. I want you to feel comfortable in this research, and if you do not, please tell me so I can change what I am doing.

The information you give in the interview will not be shared with agency workers, service providers, employers or your clients. I will not use your real name in any talks, reports, or journal articles. Thus, you should not be at any risk by speaking with me about your experiences. You may even feel pleased or positive after telling me your story. However, you may also feel upset and need to talk with someone, and Anna Olson at the Southern Alberta Individualized Planning Association can help you. Her office telephone number is (403) 320-1515 and her email is anna.olson@saipa.info.

Although I will do my best to safeguard information from this interview, I may have to report information to authorities to protect you or your clients' health or safety. If you tell me about illegal situations (for example, sexual abuse) I will be required to report the findings to an appropriate authority. I will do my best to make sure that you or your client will not be endangered because of my telling the authorities.

If you have questions about this study you can call me at any time. My telephone number in Lethbridge is (403) 593-8997 and my email is a.santinelemartino@uleth.ca. If you want to ask about your rights in this research, the Office of Research Services at the University of Lethbridge will help you (Phone: (403) 329-2747, email research.services@uleth.ca)

Following the completion of my program, a copy of my written thesis will be available in the University of Lethbridge library. If you wish to be contacted directly regarding the findings of this research, please provide an email address that I can send a summary of findings to (this may take an additional 18 months from the time of your interview).

I have read the above letter and have had it read to me, and I agree to participate. I am my own legal guardian.

Participant signature

Name (please print)

Date

Witness (if necessary)

I would like to know what you find out. Please send me a summary (takes 18 months)

Name: _____

Address: _____

Appendix B

Individuals with Intellectual Disabilities

Thank you for being willing to talk to me about your experiences. Today I would like us to focus on the ways that your experiences with sexuality and sexual expression have been affected by your direct care workers and how you have handled instances in which you may have not agreed with each other.

I would like to start by getting a sense of the direct care workers that you interact the most with. I think we could start with your home situation, and go from there. Would that be okay?

SECTION I

When you are at home, do you have direct care workers working with you?

If yes,

- Can you tell me about these workers?
- Gender? Age? Position? For how long? Agency affiliation?
- What kinds of services these workers provide?
- How did this person come to work with you?
- What part did you play in hiring/choosing them?
- How often are you together?
- What do you usually do together?
- What do you usually talk about?

Please describe for me your relationship with your worker(s).

- Tell me the best thing about your care worker.
- Tell me the thing that bothers you most about your care worker.
- How do you see these workers? Just workers? Friends?
- How do you think these workers see you? Client? Friend?
- Ideally, how would you like your relationship with your worker(s) to look like?

If not,

- Please tell me about your living arrangement?
- Tell me about the people you live with.
- If roommates, what part did you play in choosing them?
- Tell me what you like the most about the other people in the house.
- Tell me the thing that bothers you most about the other people in the house.
- What do you usually do together?
- Are there 'house rules' in the place you live?
- What are they?
- How do you feel about them?
- Are there any you dislike? Why?
- Do you have privacy?
- Do you have your own bedroom in the house?
- Are you allowed to lock the doors?

- Are you allowed to bring people into the house?
- What are the rules about that?

SECTION II

What about when you are at work or in community activities, are there direct care workers with you?

If yes,

- Can you tell me about these workers?
- Gender? Age? Position? For how long? Agency affiliation?
- What kinds of services these workers provide?
- How did this person come to work with you?
- What part did you play in hiring/choosing them?
- How often are you together?
- What do you usually do together?
- What do you usually talk about?

Please describe for me your relationship with your worker(s).

- Tell me what you like the most about your care worker.
- Tell me the thing that bothers you most about your care worker.
- How do you see these workers? Just workers? Friends?
- How do you think these workers see you? Client? Friend?
- Ideally, how would you like your relationship with your worker(s) to look like?

If not,

- Can you tell me about what you usually do outside the house?
- How do you feel about not having a support worker with you at that time?

SECTION III

Now, let's talk a bit about relationships and dating? I am interested in the ways in which your direct care workers may have affected your experiences with that.

Did you and your support workers ever talk about relationships?

If yes,

- Tell me about this time you talked about relationships with your support workers.
- Who did you talk to?
- What did you talk about?
- Where did this discussion happen?
- How did you feel about discussing it with them?
- Tell me how you feel about having a boyfriend or girlfriend.
- How would your support workers react to your desire to have a boyfriend or girlfriend?

- Would they be supportive or unsupportive?

If not,

- Why have you never discussed relationships with your workers?
- How would you feel about talking to your support workers about relationships?
- How do you think they would react?
- Tell me how you feel about having a boyfriend or girlfriend.
- How would your support workers react to your desire to be in a relationship?
- Would they be supportive or unsupportive?

Did you and your support workers ever talk about sex?

If yes,

- Tell me about this time you talked about sex with your support workers.
- Who did you talk to?
- What did you talk about?
- Where did this discussion happen?
- How did you feel about discussing it with them?
- Tell me how you feel about having sex.
- How would your support workers react to your desire to have sex?
- Would they be supportive or unsupportive?

If not,

- Why have you never discussed sex with your workers?
- How would you feel about talking to your support workers about sex?
- How do you think they would react?
- Tell me how you feel about having sex.
- How would your support workers react to your desire to have sex?
- Would they be supportive or unsupportive?

SECTION IV

Now, when it comes to relationships and sex, have you ever experienced some form of disagreement or conflict with your support workers?

If yes,

- Can you tell me about this experience?
- What happened?
- How did you handle the situation?
- Did you feel comfortable voicing your opinion?
- Did you feel that you were heard?
- What was the final result in this situation?
- Do you feel that you are usually able to make your own decisions about relationships and sex?
- Are you aware of other people's experiences with their direct care workers?

If not,

- Why do you think that is?
- Are you on the same page when it comes to relationships and sex?
- If necessary, though, how would you handle a situation in which you disagreed with your support worker?
- Would you feel comfortable voicing your opinion?
- Do you feel that you would be heard?
- Do you feel that you are usually able to make your own decisions about relationships and sex?
- Are you aware of other people's experiences with their direct care workers?

Please tell me about the kind of supports you think would be the most helpful to you in regards to relationships and sex.

- What should the role of support workers be?
- Should workers play an active role in helping you find a partner and start a relationship?
- From whom should information and support regarding sexuality come?

Is there anything else you would like to talk about?

Direct Care Workers

Thank you for being willing to talk to me. I would like to us focus on the ways that you have learned about or been trained about disabilities and sexuality as well as the challenges and successes you have experienced in your work relating to these issues.

SECTION I

I would like to start by getting a sense of your agency and your position in it. Can you please tell me a little bit about you agency and its mandate?

- What type of agency is it?
- What kinds of services does the agency provide?
- Tell me a little bit about the clients in the agency.
- Ages? Disabilities? Living Situation? Guardianship arrangements?

What is your position in the agency?

- Tell me about how you got started in this position.
- How long have you been doing this?
- What kinds of decision-making scope do you have in your work?
- How many client(s) do you currently work with?

SECTION II

Can you please tell me a little bit about your current client(s)?

- Age? Gender? Disability? Relationship status? Guardianship arrangement?
- What kinds of services do you provide your client(s)?
- How did you come to work with this client?
- How much time do you spend with your client(s)?
- What do you usually do together?
- What do you usually talk about?

Please describe for me your relationship with your client(s).

- Tell me the best thing about your relationship with your client(s).
- Tell me the thing that bothers you most in your relationship with your client(s).
- How do you see your client(s)? As Client(s)? Friends?
- How do you think your client(s) see you? As a support worker? A friend?
- Ideally, how would you like your relationship with your client(s) to look like?

SECTION III

Did you ever receive any training specifically on sexuality and sexual expression?

If yes,

- Please tell me about the training you received.
- Was it mandatory?
- How long was it?
- What kind of professional provided the training?
- What kinds of issues were addressed in the training?
- What kinds of issues were not addressed in the training?
- Was the training helpful when handling cases related to sexuality?
- How do you think other workers in your agency felt about it?
- Tell me about any discussions concerning education programs relating to relationships or intimacy occurred in your agency?

If not,

- Why do you think the agency does not provide training in this area?
- What kinds of challenges have you experienced by not having that training?
- How would you feel about having training on sexuality available to you?
- Do you think other workers in your agency would be interested in it?
- Have any discussions concerning education programs relating to relationships or intimacy occurred in your agency?
- Do you think it should be mandatory?
- What kinds of issues would you like to see addressed in such training?
- Why? Have you ever had any issues?
- Can you tell me about them, please?

Is there any agency policy in place that talks about sexuality and sexual expression?

If yes,

- What kinds of issues led your agency to decide to have one?
- What kinds of discussions have occurred in your agency concerning formal policies relating to relationships or sexuality?
- What kinds of issues are addressed in the policy?
- What kinds of issues are not addressed in policy?
- Tell me the best thing about this policy.
- Tell me the thing that bothers you most about this policy.

If not,

- Why do you think the agency does not have a policy in this area?
- What kinds of challenges have you experienced by not having a policy in place?
- How would you feel about having a policy on sexuality and sexual expression?
- What kinds of policies do you think would be useful?
- Do you think other workers in your agency would be interested in it?

SECTION IV

Are you aware of any incidents – negative or positive - concerning dating and/or intimacy that your clients have experienced?

If yes,

- Please tell me about that.
- How did you approach the situation?
- Did seek information and support for dealing with sexuality, relationship and parenting issues concerning your clients?
- Did you feel prepared to handle it?
- How often do you actually encounter issues related to sexuality?
- How do you feel about your clients being in a relationship and/or sexually active?
- How do you think other workers in your agency have dealt with sexuality?

If not,

- Would you feel prepared to address them if they come up?
- Where would you seek information and support for dealing with sexuality, relationship and parenting issues concerning your clients?
- How would you feel about your clients being in a relationship and/or sexually active?
- How do you think other direct care workers in your agency deal with sexuality?

Have any of your clients ever asked you/talked with you about relationships and intimacy?

If yes,

- Please tell me about that.
- How did you respond? Why?
- How often do you have discussions regarding sexuality with your clients?

- Who usually initiates these discussions? Clients? Support workers?
- What kinds of information, if any, have you provided to your client(s) about relationships and intimacy?
- What kinds of efforts, if any, have you made to facilitate relationships and intimacy, or conversely, to limit them? Why?
- Were you satisfied with the level of support or information you were able to provide? Why/not?
- What challenges have you experienced in providing these supports?
- How did you resolve them?

If not,

- Would you feel prepared to address those questions/discussions if they come up?
- Where would you seek information and support for dealing with those questions/discussions?

What issues concerning sexuality for your clients have I not covered here?

SECTION V

To what extent do you think the agency is responsible to provide information and support to the clients in regards to sexuality? And what those responsibilities are?

Please tell me about the kind of supports you think would be the most helpful to you when addressing issues related to sexuality and intimacy.

Is there anything else you would like to talk about?