

Sexual Socialization and Agency for People with Intellectual and Developmental  
Disabilities

by

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*Certificate of Approval*

This is to certify that the accompanying thesis by Ella R. Manashil has been accepted in partial fulfillment of the requirements for graduation with Honors in Sociology.

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## ABSTRACT

People with intellectual and developmental disabilities (IDD) are generally not included in mainstream discussions of sexuality (Schaafsma et al. 2014, Shah 2017) and have largely been excluded from research on the subject. However, sexuality research among this population is hugely important because people with IDD are still sexual beings and typically experience higher rates of sexual abuse (Schaafsma et al. 2014). Therefore, I set out to investigate sexual socialization processes and their impact on sexual agency among individuals with IDD. My research took two major forms, the first being interviews with four participants with IDD and one special education professional. However, because of various difficulties experienced throughout the research process, I had a very small, localized sample, which limited the generalizability of my findings. Therefore, the second part of this thesis consists of a reevaluation of my methods choices and experience, as well as propositions for future research in this area.

Keywords: Sexual Socialization, Sexual Agency, Intellectual and Developmental Disability

## INTRODUCTION

People with intellectual and developmental disabilities (IDD) are sexual beings. They have romantic relationships and casual sex, masturbate, and engage with the same sexual media that most people do (Schaafsma et al. 2014). However, these individuals are largely excluded from mainstream discussions of sexuality (Schaafsma et al. 2014). In my six years of studying and working with issues of sexuality, people with IDD were never explicitly considered in conversations surrounding sexual topics. Issues surrounding inclusion in this area were not brought to my attention until this last year, and a lack of discussion surrounding sexuality for this population has persisted throughout my exploration of the issue. The more I researched, the clearer it became that sexuality for individuals with IDD is not regularly addressed in academic literature or everyday conversations, which made me begin to consider the potential physical and emotional implications for such silence. Thus, my research questions are as follows. First, what does sexual socialization look like for people with IDD? If not included in normative discussions about sexuality, then I would like to know how individuals with IDD are learning about and forming opinions on the topic. Second, what does sexual agency look like for this population? Given the lack of inclusion in discussions of sexuality, I want to know if people with IDD are able to have full control over their sex lives. Third, what aspects of such sexual socialization are impacting sexual agency for people with IDD? Here, I am curious about which specific aspects of sexual learning for this population influence their ability to control various aspects of their sexuality.

These research questions are sociologically important for a number of reasons. First, sexual socialization and agency both have significant implications for the mental

and physical wellbeing of all individuals (Shah 2017). Additionally, these issues are particularly important for people with IDD because this population experiences higher rates of sexual abuse and generally holds less sexual knowledge than neurotypical people (Schaafsma et al. 2014). Therefore, understanding these concepts among individuals with IDD could have serious implications for improving their overall wellbeing. Additionally, sexual socialization and agency have been explored in many different populations, but research has failed to explore the ways in which these concepts differ for people with IDD. Experts in the area of healthy relationships for this population have expressed the need for significant changes to their current sexual socialization, especially in terms of formal school-based sex education (Theresa Fears and Giselle Gudino, phone conversation, November 11, 2019). Not only could this research be generally beneficial for sexual expression and inclusion, but could also potentially be used to improve standards of sex education and mitigate rates of sexual misconduct among this population. Therefore, I think it is incredibly important that we break the silence and begin to explore and address issues of sexual socialization and agency for individuals with IDD.

Although important work, my exploration of this new research area proved to be much more difficult than expected. Difficulties obtaining and securing interview participants resulted in a sample size of five people from the same geographic location. So, although interesting and an important micro level view of sexual socialization for people with IDD, my findings are not largely generalizable. Some of the difficulties I experienced throughout my research process were circumstantial given the limited time, resources, and social context. However, many of the difficulties I ran into during data

collection directly reflect the issues of silence surrounding sexuality for people with IDD. Therefore, my thesis will proceed with the following. In the first section I will outline existing theory and literature in sociology, sexuality studies, and disability studies that have impacted my research questions. I will also describe my initial data collection procedures and analyze the limited themes that emerged from that research. In section II I will analyze some of the difficulties that I experienced during my research process and discuss how they indirectly illustrate my own findings and support prior research in the fields of disability and sexuality studies. Despite the challenges experienced during my research, an analysis of these struggles has given me insight into the problem and potentially more effective procedures for conducting this type of research in the future. Research like this is still hugely important, so I will also propose changes that could be made to improve future research endeavors in this area.

## THEORY AND LITERATURE REVIEW

### *Intellectual and Developmental Disability (IDD)*

To begin my investigation of sexual socialization and agency among people with IDD, I must first define and explain “intellectual and developmental disability.” There is a wide variety of terms used to label people with mental and intellectual impairments. These labels include, but are not limited to “mental disability,” “psychiatric disability,” “cognitive disability,” “neuroatypical,” “mental retardation,” “mental illness,” and “psychosocial disability” (Price 2014). It is important to be aware of the power that these labels hold and use them with caution. For the purposes of this paper I will mainly be using the term “intellectual and developmental disability” (IDD), which is the official term used by the American Association on Intellectual and Developmental Disabilities (AAIDD 2019). On the other hand, I will use the term “neurotypical” when referring to individuals without intellectual and developmental disabilities, as this was the label most commonly employed professionals in the disability community with whom I spoke throughout the research process. However, my language will shift necessarily to address the wide variety of terms used in the history of disability research.

AAIDD defines intellectual disability as “significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18” (AAIDD, as cited in Carulla et al. 2011:4). “Intellectual functioning” refers to general mental capacity, which includes learning, problem-solving, and reasoning. “Adaptive behavior” refers to social, cognitive, and practical skills. Social skills include interpersonal relations, social responsibility, self-esteem, and rule following. Conceptual skills include language,

literacy, money, and time. Practical skills refer to activities used in everyday life such as personal care, healthcare, travel, safety, and occupational skills. These terms summarize the “impairments” that people with IDD must manage in their everyday lives (AAIDD 2019). However, it is important to note that there are many different types of intellectual and developmental disabilities, and along with that, a wide spectrum of impairment severity across individuals with IDD. As we will see later, these impairments and their level of severity have some important implications for conducting research with this population, especially when dealing with a sensitive subject such as sexuality.

The Social Model of Disability, which was originally a model of physical disability, but has since been expanded to include IDD, makes a distinction between impairment and disability (Shakespeare 2013). This model defines disability as the following:

the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities (UPIAS 1975).

This particular model states that impairment is a personal limitation, whereas disability is more closely related to social exclusion. In other words, disability is dependent on social and historical context, whereas impairment is individually specific (Shakespeare 2013). According to this model, people with IDD experience intellectual and developmental impairments, but are disabled by structural barriers to social inclusion.

Education provides a great example for this model. Although integration and inclusion have been at the forefront of the disability rights movement for several decades (Connor and Ferri 2005), many people with IDD are removed from general education curricula and put into alternative or “special education” classrooms (Lalvani 2015).

Supporters of the social model would say that this separation and exclusion, not intellectual impairment, puts individuals with IDD at a disadvantage. However, critiques of this model suggest that its deemphasis of one's experience with an impairment is problematic. One critique suggests that impairment can actually become disability through the means of oppression (Owens 2014). Additionally, many dislike that the social model does not account for the large variety in experiences of impairment among people with disabilities (Owens 2014). As discussed later, these propositions are important when considering how best to conduct research among individuals with IDD.

### *Stigmatization and Othering*

People with intellectual and developmental disabilities (IDD) have been stigmatized and othered within our society in many senses. We can begin to understand their sexual socialization and agency by unpacking the stigmas surrounding this population. First, we must define stigma, which Goffman (1963) describes as “undesired differentness” that relies on a social relationship of comparison. To stigmatize is to label certain people in order to make them appear different and separate from others (Goffman 1963). This type of social comparison and rejection helps to reinforce the superiority of individuals who have desired traits that the stigmatized group lacks. In this sense, stigmatization works to maintain an existing social hierarchy and mark stigmatized people as being inferior within that hierarchy. Such social rejection typically leads to internalization of stigma and lower self-esteem among stigmatized populations (Brown 2013). Brown (2013) altered Goffman's (1963) definition of stigma to account for these social consequences. She stated the following:

Stigmatization only occurs when the social control component is imposed, or when the undesired differentness leads to some restriction in physical and social

mobility and access to opportunities that allow an individual to develop his or her potential” (Brown 2013:157).

This definition of stigma aligns well with the Social Model of Disability in that they both emphasize the social consequences of otherness.

Such stigmatization seems to originate and gain power from fear, which is a learned response to the differences of stigmatized groups. This fear is passed down through generations by mechanisms of socialization including, but not limited to, educational institutions, family, peers, and media (Brown 2013). There are a number of theories that explore the potential origins of such fear. One explanation is that fear of stigmatized groups stems from worries of stigmatization by association (Goffman 1963). Another theory states that fear emerges from the perception that stigmatized groups threaten the availability of limited resources such as jobs, water, food, and land (Brown 2013). However, theories pertaining to the stigmatization of mental problems tend to focus on the lack of knowledge about the etiology, predictability, and course of those conditions (Brown 2013). These theories would suggest that individuals with IDD are stigmatized mostly because of misconceptions about their conditions being unpredictable and uncontrollable.

Another important mechanism of stigmatization is the labeling of stigmatized groups. Labels work to reinforce stigma by emphasizing otherness through the terms used to describe stigmatized populations (Brown 2013). Take the label of “disabled” for example. Through labeling, people with IDD have been marked as lacking “normal” ability or differing from the “normal” intellectual and developmental level of others. The labels of “disabled” or “impaired” carry with them extreme amounts of stigma and negativity (Lalvani 2015). Such labels stigmatize people with IDD by identifying them as

differing from the norm in a negative way. Price (2014) argues that “terms used to label persons with mental disability have explicitly foreclosed our status *as* persons” (Price 2014:298). In this sense, disability labels can be incredibly dehumanizing. As discussed previously, stigmatized labels are not simply words, but instead have serious social and physical consequences for stigmatized individuals (Brown 2013). However, Price (2014) also recognizes that some, including herself, prefer the stigmatized term of “disabled” because “claiming disability is a journey of community, power, and love” (Price 2014:305). In this sense, there seems to be a possibility of empowerment through “reclaiming” stigmatized labels. Additionally, there seems to be a subjective spectrum of approval for different labels for individuals with IDD. For example, “mentally disabled” seems to be more acceptable than “mental retardation” among many, but not all parents of children with IDD (Lalvani 2015).

People with intellectual and developmental disabilities experience a wide variety of social and physical consequences that reinforce othering. For example, many students with IDD are removed from general education curricula and moved to an alternative or “special education” program (Lalvani 2015). Removal from general education physically separates individuals with IDD from their neurotypical peers and provides them with an entirely different education. Such processes likely reinforce stigmatization, as this separation is a constant reminder of their “undesired differentness.” This process is resisted by many parents of children with IDD for this very reason (Lalvani 2015). Additionally, although some students are integrated into general education classrooms, they are not always academically and socially included with neurotypical students (Connor and Ferri 2005). Here, it is important to make a distinction between integration:

the physical inclusion of students with disabilities in general education curricula, and inclusion: a process through which students with disabilities are able to benefit academically and socially from general education curricula (Connor and Ferri 2005). In this sense, exclusion and stigmatization can be present at various social and academic levels within schooling.

People with IDD are also othered sexually. Theory suggests that people tend to stigmatize the sexuality of individuals with IDD because they fear the reproduction of children with IDD (Brown 2013). As a result of sexual stigmatization, there is very little sexual representation of individuals with IDD in the media (Shah 2017). Additionally, people with IDD rarely have access to formal school-based sex education (Schaafsma et al. 2014). Despite the fact that many people with IDD engage in sexual behavior, cultural scripts regarding sexuality generally portray individuals with IDD as asexual (Payne et al. 2016). In this way, people with IDD are not included in mainstream discussions of sexuality or given the same opportunities to learn about their sexuality, which others them further in society. Such differences in sexual norms bring up questions about how their sexual socialization might differ from that of neurotypical individuals and impact their physical and emotional wellbeing.

#### *Sex Education and Sexual Socialization*

Young adulthood is often marked as a major time for sexual exploration and development (Morgan 2011). Therefore, most U.S. states require some form of school-based sex education for adolescents. However, formal sex education in the United States varies widely by state, district, and even school. School programs focus on different sexual health issues, use diverse teaching techniques, and are taught by those with varied

levels of training (Hall et al. 2016). For example, many states mandate abstinence only sex education, which considerably limits students' access to accurate sexual knowledge and their ability to develop healthy sexual relationship skills (Santelli et al. 2006). It is common for adolescents to be unsatisfied with their formal sex education, as they often learn from teachers who are unequipped to successfully educate students on issues of sexuality. Therefore, students often seek out informal sources of sexual knowledge such as parents, friends, magazines, and the internet (Edwards 2015).

Most individuals with IDD do not receive school-based sex education (Schaafsma et al. 2014). There are some alternative programs such as the Arc of Spokane's Healthy Relationships curriculum, which provide sex and relationship education to people with IDD (Arc of Spokane 2019), but these opportunities are few and far between (Theresa Fears and Giselle Gudino, phone conversation, November 11, 2019). Despite such rare access to sex education, individuals with IDD are still sexual beings (Shah 2017), so it is likely that they follow similar patterns of behavior to gain sexual knowledge when formal sex education is inadequate. Additionally, it is important to recognize that sex education needs might differ for people with IDD compared to neurotypical individuals. For example, people with IDD often have lower baseline levels of sexual knowledge, more difficulty forming healthy relationships, do not typically associate sex with pleasure, and struggle to understand the appropriate situations to engage in sexual behavior such as masturbation (Schaafsma et al. 2014). Therefore certain issues may need to be emphasized more for individuals with IDD compared to those addressed in general sex education.

These sources of sexual information contribute to individuals' sexual socialization, or the multi-dimensional "process by which knowledge, attitudes, and values about sexuality are acquired" (Ward 2003:348). This theoretical perspective points to typical sources of socialization such as peers, family, media, educational institutions, and religious organizations (Ward 2003). However, there are competing views about which interactions and relationships have the most significant impact on sexual socialization. Some identify parents as the primary source of children's sexual socialization (Christensen et al. 2016), whereas others argue that people learn the most concrete sexual information from same-sex peers (Ward 2003). Ward (2003) also identifies media as a major source of sexual socialization. The author states that sexual content is pervasive in the media and teens typically rank it as one of their main sources of sexual knowledge and expectations. Additionally it is likely that media representations of sexuality impact parent and peer knowledge, which make its way back to teens through interactions (Ward 2003). Additionally, although heavily relied upon by many individuals, informal sources of sexual information often present the risk of obtaining misinformation (Allen et al. 2008), which puts them at a higher risk for accidental pregnancy and sexually transmitted infection (STI) (Santelli et al. 2006).

Access to accurate sexual information is essential for forming a sense of sexual agency (Klein, Becker, and Štulhofer 2018). Although there are numerous definitions of sexual agency, it is generally defined as the ability to make decisions and assertions related to one's own sexuality. Such decisions include enacting one's sexual desires and preferences, communicating sexual boundaries and expectations, and feeling deserving of sexual pleasure (Klein et al. 2018). Such agency has important implications for the

physical and emotional wellbeing of sexually active people. In particular, higher sexual agency is connected to lower rates of STIs, more condom use, better consent practices, improved self-confidence, and more pleasure during sexual experiences (Averett et al. 2008). Sexual agency is impacted by the social expectations surrounding sexuality for a given population, often referred to as sexual scripts (Klein et al., 2018). Therefore this topic is typically explored among women, given frequent expectations of sexual passivity for this population (Klein et al., 2018). In this sense, men should generally have higher sexual agency than women. I will be employing the term to speak about people of all genders' ability to control their own sex lives, but these gendered differences in sexual agency will come into play in Findings and Discussion Part I.

When thinking about sexual agency for individuals with IDD, it is important to consider their everyday agency. People with IDD often depend on non-disabled adults for various aspects of personal care and everyday life (Shah 2017). This dependence limits their general agency in terms of being able to make their own choices about various aspects of their lives. Considering that parenting plays a significant role in the development of sexual agency (Klein et al. 2018), in combination with such dependence, I think it is likely that their sexual agency is limited as well. For example, sexual experience is often limited for individuals with IDD, in part because relatives discourage sexual expression (Schaafsma et al. 2014). When relatives limit sexual expression they remove one's ability to make decisions and assertions about his or her own sexuality. I would also expect that such agency is impacted by the general conception that people with IDD are asexual beings (Payne et al. 2016). There is a significant gap in existing literature about sexual agency for people with intellectual and developmental disabilities.

Therefore, in my thesis I hope to bridge the literature surrounding sexual agency and IDD described in this section.

## METHODS PART I

To investigate the research questions posed in this paper, I conducted in-person semi-structured interviews with adults with intellectual and developmental disabilities (IDD), as well as stakeholders in the issue of sex education for individuals with IDD. Although my research questions could be explored using other methods such as an online survey, I chose to conduct in-person interviews for several reasons. First, although the anonymity of an online survey could have been helpful, this method brings up issues of accessibility for my population, especially in terms of literacy and ability to use technology. Additionally, interviews allowed for more unstructured conversation and gave participants greater agency in how and how much they chose to talk about their sexual socialization. Along similar lines, these in-person interviews allowed for important topics to emerge in conversation that I had not considered to include in my interview questions.

My interview questions focused on two main ideas. First, how have people with IDD been receiving sexual information throughout their sexual development (ex. school-based sex education, alternative programs, peers, family, media, etc.) and what are the impacts of the information from those sources? Second, to what extent do people with IDD have agency and control over their sex lives? My interview questions allowed for reflection on both past and current experiences. For example, my participants were all adults over the age of 18, so when speaking about school-based sex education many of them reflected on adolescence. Reflection should not be a limitation in this research because it allowed for discussion of the experiences that have stuck with participants the most. Additionally, sexual socialization is an ongoing process that does not stop when

one reaches adulthood. Therefore, both reflection and description of current experiences provided valuable information. A copy of my interview questions is included in Appendix 1: Interview Questions and Materials.

Participants in my study were recruited through my own and my thesis advisor's personal and professional networks. In particular, I worked closely with the Area Director of Special Olympics, Tracy Gaines, who helped put me in contact with potential participants and others who are well connected in the local disability community. Once potential participants were identified with the help of Tracy and others, I contacted these individuals through phone and/or email to set up the interview logistics. Some of the participants with IDD have a legal or informal guardian that helps them make decisions. Therefore, I was in contact with both potential participants and their guardians (when applicable) during the recruiting process.

Initially, I scheduled interviews with five participants with IDD and three stakeholder participants. However, due to scheduling and timing difficulties, I was only able to meet with and interview five individuals (four adults with IDD and one stakeholder participant). Participants were able to choose the location of their interviews. I conducted two interviews in the sociology workroom on Whitman's campus, one in Reid campus center, one at a participant's home, and one at a participant's office. The interviews varied in length, ranging from seven to thirty five minutes. Before starting the interviews, participants read and signed an informed consent document. If the participant was not able to read through the document on their own, I went over it with them out loud. A copy of the consent form is included in Appendix 2: Informed Consent Document. All participants were compensated with a \$10 Safeway gift card upon

completion of the consent form. Interviews were transcribed by myself and the recordings were deleted once transcription was complete.

I identified two main forms of risk for participants in my study. First, there was some emotional risk, in that talking about experiences with sexuality may be traumatizing for some individuals depending on their personal history and values. This may be particularly salient for my participants with IDD because this population typically has less experience with sexual topics (Schaafsma et al. 2014). Discussing sexual subjects can be a very sensitive issue for many people, therefore all participants were given the option to skip any question with which they were uncomfortable and stop their participation in the study at any time. This was made very clear in both the informed consent document and verbally throughout the interview. There was also some reputation and stigmatization risk due to the often taboo nature of my research topic. Connecting participants' identities to personal sexual information could put their reputations at risk, which is why confidentiality was my top priority during the data collection and synthesis process. The disability community that I recruited from is relatively small, so I have been very careful to remove identifiable characteristics of participants in my writing. Additionally, interview participants were assigned pseudonyms before the interviews began and their real names were never connected to their interview recordings and transcriptions. The only record of their participation is located on the hard copies of the informed consent documents, which were kept in a locked binder until they were destroyed upon completing my research.

Due to the small number of interviews and their relatively short durations, I decided to code by hand instead of using a coding software such as NVivo or Dedoose.

Initially, I planned and coded for several main themes that my interview questions were meant to investigate. A list of these original codes has been included in Appendix 3: Codes. Additionally, further coding is outlined in Methods part II.

## FINDINGS AND DISCUSSION PART I

In the following sections I discuss the initial findings from my original coding and analysis. As mentioned earlier, these findings are limited due to my small, localized sample and logistical difficulties interviewing participants with IDD. However, the themes identified in my initial analysis still provide important insight into various aspects of sexual socialization for people with IDD.

### *Interest in and Prior Knowledge of Sexuality*

One of the first issues I assessed during my interviews was the extent to which people with IDD are interested in talking and learning about sexuality. This investigation was not limited to one question in particular, and instead became clear through participants' answers to many of my prompts. In an interview with local special education professional Julia, she expressed her strong belief that people with IDD are interested in sex to the same extent that neurotypical people are interested in the subject. In our interview, she stated the following:

Just because your child has an intellectual disability doesn't mean they're not going to have the same urges as any other child their age. Like middle school it hits, and you know I've taught high school and I've taught all levels of special ed within the high school, and you know they're boyfriend/girlfriend, I mean everybody wants to have one. It's not that I have a disability therefore I'm never going to want a boyfriend or a girlfriend. It's there, that's normal.

I think Julia's wording is important here. She frames the exploration of romantic relationships and sexuality as a normal process for people with IDD, which directly challenges typical presumptions that these individuals are asexual (Payne et al. 2016). Further, when asked if students express discomfort with discussing sexuality Julia's response was:

You know it's funny that you ask that because I was talking with our school psych, and no they're pretty curious, they come up with really good thoughts and discussions.

Julia makes it clear that in her experience, people with IDD are interested in sex in the same way that most people are. However, she then went on to clarify that such interest does not always equate to accurate knowledge. She said:

Sometimes you know it's what they're thinking is not true because they've heard it from somewhere, but [the school psychologist has] been able to dispel those myths and it's been really good and she's loved teaching it actually. Yeah she said 'you've gotta come and hear the discussions, they're so great.'

Although Julia's experience suggests that people with IDD are interested in sex, but are not necessarily knowledgeable about the topic, this combination was not directly supported in my interviews with participants with IDD. Three of my four participants with IDD described little engagement in sexuality discussions. Emily and Max received school-based health education in which sexuality was discussed, whereas Kate participates in an alternative "healthy relationships" class, which covers issues related to sexuality that are more applicable to individuals with IDD. However, none of them discuss the topic frequently outside of those classes. Additionally, none of them recall receiving sexual information through the media and do not talk about sexual topics with their friends. In this sense, their sexual socialization is seemingly much different than that of neurotypical individuals (Ward 2003). However, all three identified infrequent and short sexuality discussions with their parents and other close relatives. It is also important to note that Kate does not seem to know what sex is, whereas Max and Emily both seemed to have a basic understanding of the behavior. Although interest in an issue does not necessarily translate to understanding of or comfort talking about that issue, these are

the best measures that I have for interest at the moment. The validity of such measures will be discussed further in Findings and Discussion Part II.

Max also mentioned that he sometimes talks about sex with his girlfriend. However, these conversations with family and romantic partners seem to stem from necessity. When speaking about his conversations with family, Max said that “first they need to tell me get married before we have sex and plus condom, protect it our body.” He then reiterated this abstinence until marriage sentiment when speaking about his conversations with his girlfriend. Similarly, Kate described talking with her parents about “good touch, bad touch” and that nobody has the right to touch her<sup>1</sup>. In this sense, most of my participants with IDD did not seem interested in talking about sexuality unless it was a necessary conversation to help mitigate sexual risk. This sentiment was echoed by Julia when she said, “I would say there is few parents that actually talk about [sexuality] unless they’re faced with something that happened”. Here, it seems that sexuality is only discussed when it becomes a problem.

Only one of my participants described engaging in frequent conversations about sexuality. Like Max and Emily, Ben received health education in school, has not participated in an alternative sex education program, does not recall obtaining sexual information through the media, and talked to his parents about sexuality infrequently while growing up. However unlike the other participants, he described engaging in casual discussions about sexuality with his friends “almost every day”. Ben stated that:

The friends I have now are so raunchy it’s ridiculous. I used to work construction so all the guys are pretty- I mean there’s none of us that aren’t sick-minded by any stretch of the imagination.

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<sup>1</sup> Kate nonverbally communicated through her guardian for a majority of the interview. This is the phrasing of her guardian.

In this sense, Ben seemed to have significantly more interest in discussing sexuality with others, compared to my other participants with IDD. An important point to note in relation to this greater interest is that Ben has a large amount of independence in his everyday life, which also seems to translate to his sexuality. Ben is the oldest participant among my sample of people with IDD and lives an independent lifestyle with his girlfriend of many years. Therefore, he clearly has less barriers to his sexual expression than the other participants with IDD, all of whom still live with a parent(s) or guardian(s). Another factor that may be impacting Ben's greater interest in sexuality is his gender. As discussed in the literature review, baseline sexual agency is typically higher among men than women (Klein et al. 2018). Therefore, Ben's higher interest may be related to sexual scripts that expect men to be more sexually expressive in general. However, despite his gender and greater independence, Ben still provided short and hesitant responses to my interview questions, much like the other participants with IDD. In this way, there was clearly some level of discomfort talking about sexuality across all of my participants with IDD.

#### *Sexual Information Source Preference*

Another important idea that I investigated in my interviews was sexual information source preference. In other words, I wanted to know where my participants with IDD would go if they wanted to learn new sexual information. Answers to this question were widely distributed. Emily identified her step-mother and other family members generally as the ideal sources, Max spoke about people generally and later clarified that he talks most with his parents and girlfriend, Ben spoke about his friends, and Kate did not answer the question. The one common theme here seems to be people.

My participants were less likely to seek out information online or in books, and more likely to talk to other people about the topic of sexuality. Interestingly, the people identified as the sexual information source preferences were often the people already engaging in sexuality discussions with the participants. For example, Ben identified his friends as the source preference and most frequently talks with them about sex.

Additionally, Max identified his family, with whom he also talks most frequently about sex. In line with this, my stakeholder participant, Julia, emphasized parents as the main sexual socializer for her students. She also mentioned peers, the internet, and formal sex education as major influences, but feels that parents play the most important role in learning about sexuality. The responses from my participants help to clarify some of the debates in existing literature regarding the most prominent influences throughout sexual socialization (Christensen et al. 2016, Ward 2003).

Another interesting theme to note in these discussions is that conversations with parents and family were often regarded as more informative than those with friends. Max, Ben, and Emily all said they felt “informed” after discussing sexuality issues with their family and described these conversations as largely educational. On the other hand, Ben said that his discussions with friends were not informative, and instead more focused on banter and jokes. In particular, he said that these conversations were “more randomness than anything.” In this sense, conversations with family and relatives seem to serve a very different purpose than those with friends. Additionally, when asked if any of these conversations made them feel more confident about their sexuality, all of my participants said no. So although conversations with family were seen as more informative, there was not a clear connection to sexual agency.

### *Access to Formal Sex Education*

Aligning with existing literature, Julia is under the impression that most teenagers with IDD do not have access to formal sex education. In particular, she said that she has had many direct experiences with students who did not receive any type of sex education. She described personally working in the fight for inclusion on many fronts, including school-based sex education programs. Julia feels that this lack of access is very problematic, especially considering that the population is extremely vulnerable. She stated that:

The percentage of people with significant disabilities that are sexually abused and raped and all of those things is so high, you know it's just super high and we just have to spread that news to parents so that kids and adults are safe.

However, all of the individuals with IDD that participated in my study have received some type of formal sex education in school or through an alternative program. This finding contradicts Julia's experience and the existing literature on sex education for individuals with IDD (Schaafsma et al. 2014).

Although many of my participants were integrated into a general education health program, this may not be the most effective method of education. In her interview Julia argued that an alternative program for students with IDD is the most ideal form of sex education. When speaking about the healthy relationships curriculum she implemented at the local high school and 18-21 year old learning program, Julia stated the following:

It covers your body and boundaries and it covers things that a regular curriculum would not cover, such as 'if you pay people, they're not your friends' and those kinds of things... so it really covers a huge gamut of the- I think the area where a lot of adults with disabilities can have issues, like people taking advantage of them.

Again this conversation seems to come back to risk and vulnerability. Julia argues that a specialized sex education program is important for mitigating risk for individuals with IDD. Although this focus on risk makes sense given the high rates of abuse among this population, it also might be unintentionally damaging sexual agency for people with IDD. As discussed earlier, when sexuality is only discussed as a necessary function to mitigate risk, it is often not discussed until a problem emerges in that area. Such a focus does not allow much room for positive discussions surrounding sexuality for this population. Sexual agency is inherently connected to sex positivity (Klein et al. 2018), so an emphasis on risk might limit the potential of sexual agency for people with IDD, much like the ways in which an abstinence-based sex education curriculum is limiting (Santelli et al. 2006).

#### *Barriers to Sex Education and Sexual Agency*

In my interviews I also wanted to investigate whether there are any clear barriers to people with IDD learning about sexuality and developing sexual agency. However, the responses from my participants with IDD were not very fruitful, as most of them did not identify anyone or anything as limiting their control over their sexuality. One of my participants, Emily, very hesitantly identified her step-mother as a barrier, but did not feel comfortable expanding further. Here is an important contradiction for Emily, in that her step-mother is identified both as a sexual information source preference and a barrier to control over her sexuality. This sentiment that parents and relatives may be a barrier to sexual agency is supported by existing literature (Schaafsma et al. 2014) and my conversation with stakeholder, Julia. When asked if she gets pushback against her sex education inclusion efforts, she said:

It's not everybody. I think for a lot of parents they don't think about it. Like they're in the world of 'my child has a disability and how am I going to get my child to be able to do what other kids do' and that aspect of going through puberty and wanting to have a boyfriend and girlfriend, masturbation, all those things is something that isn't at the forefront of their thoughts because there's so much more when you have a child with a significant disability.

In this sense, Julia identifies parents as a barrier, not because they do not want their children to have sexual agency, but because they do not seem to regularly think about this issue. Additionally, the taboo nature of the subject likely adds yet another reason for parents not to engage with this topic, especially given all of the other challenges they face raising a person with IDD.

Julia also identifies another barrier that seems to be impacted by the taboo nature of sexuality. She says that:

I think a big thing is teachers and adults- how comfortable they are with discussing those kinds of things. I think it's super-duper important, but you know we don't get any of this in our teaching programs... I'm hoping that as our culture has gotten more open about it that eventually it will just become the norm. But we're not there yet, so I think that is a barrier and I- you know, to give a teacher a curriculum and say here you go you're going to teach this and it has some things in it that they don't feel comfortable with, then it's really difficult.

So, in Julia's opinion, not only are parents not thinking about this issue, but teachers that are supposed to formally educate their children about sexuality are not well equipped to do so. Throughout her experience in education over the last few decades Julia has found that teachers do not typically receive training on how to discuss sexuality with neurotypical students, let alone students with IDD, and they are often not comfortable engaging in such discussions. In this way, Julia believes that teachers are a huge barrier to sexual education and agency for this population, which is supported by existing literature on issues with sex education more generally (Edwards 2015). Additionally, the stigma surrounding sexuality for individuals with IDD only seems to add more

discomfort to an already uncomfortable experience for many teachers, further limiting sexual exploration for this population.

To compliment the investigation of barriers, I also asked my participants with IDD if there is anyone or anything that helps them gain control of their sexuality, but all of them answered ‘no’. However, despite this seeming lack of direct support and the various barriers to sexual agency discussed in this section, all of my participants who answered my question said that they feel they have full control over their sexuality and sexual expression. This finding seems contradictory and does not align with my predictions based on existing literature (Payne et al. 2016, Schaafsma et al. 2014). However, when asked if she thinks people with IDD are able to make their own decisions regarding their sexuality Julia said, “I think some are, but I think that a lot aren’t.” Therefore, it is very possible that my limited sample is an inaccurate assessment of the general population of individuals with IDD.

### *Concluding Remarks*

Despite the limited nature of this research, some interesting themes emerged in my findings. First, individuals with IDD receive sexual information outside of formal sex education, but discussions are generally infrequent and mostly emerge as a necessity for risk mitigation. Sexuality does not otherwise appear not to be explored. Next, people with IDD seem to prefer discussing the subject with those that have already instigated sexuality discussions with them in the past. Additionally, conversations with family were described as much more informative than those with friends. Last, a sense of sexual agency was common across my participants and few barriers to such agency were identified.

However, it is important to note that the sexual socialization and agency experiences discussed in this section are not homogenous. In this sense, there does not seem to be one common lived experience for individuals with IDD when engaging with sexual topics. However, this research does provide some insight into why certain peoples' experiences might differ from others' when dealing with sexuality. For example, gender and level of independence might play a role in the extent of interest in sexuality for people with IDD. Additionally, the perspective of a stakeholder often provided significantly different information than the perspectives of the participants with IDD. For example, all of my participants with IDD have received some form of sex education, but Julia's experience as a special education professional has revealed that most students with IDD do not have such access. Such discrepancies bring up important questions regarding methodological choices when conducting research among people with IDD that will be discussed further in the next section.

## METHODS PART II

As discussed in Methods Part I, I planned and completed a set of original methods that attempted to investigate sexual socialization and agency for people with IDD. This exploration relied on participants' direct responses to interview questions meant to understand how individuals with IDD get sexual information and the extent to which they have control over their sex lives. Although my original methods provided some important insight into these issues, various limitations and difficulties that I experienced throughout the research process have prompted me to reevaluate my methods choices and assumptions. In the following section I will demonstrate how the difficulties I faced actually reaffirm some of the conclusions I made in Findings and Discussion Part I, as well as provide further insight into the issues at hand. Similar to the coding procedures for my original findings, I re-coded all of my data by hand, but this time with a focus on limitations and difficulties, or what I refer to as negative space. However, here I engaged in inductive coding (Thomas 2006) through which I did not analyze the data with pre-planned codes. Instead, I completed a close reading of my interview data and looked for limitation themes in my methods and data collection experiences that might provide insight into my research questions. A list of these themes is provided in Appendix 3: Codes along with my original codes. I also did some thinking about the meaning of these categories and how they might be linked to other themes in the data. Finally, I investigated Oliver (1997)'s work on the concept of emancipatory research to help fuel new ideas for future research regarding sexuality for people with IDD.

## FINDINGS AND DISCUSSION PART II

### *Recruiting Difficulties*

As discussed in Methods part I, this study has an extremely small sample size of 5 participants. This limited sample is in part due to time constraints on the data collection period and limited resources. However, more pertinent to this discussion is the fact that I had significant difficulty finding and securing participants for the study. Although I worked with various people who are highly involved in the local disability community to help spread word about my study to those who might be interested, these efforts did not yield as many participants as I had hoped.

I think there are some important sociological issues at play here. Sexuality is already a taboo topic in our mainstream society, and is especially stigmatized for people with IDD (Payne et al. 2016, Schaafsma et al. 2014). Therefore, many of the people I spoke with were apprehensive of a stranger talking to them about sex. However, many of the parents and administrators I talked to were also extremely supportive of my thesis topic and recognized its importance. However, this acknowledgement did not usually translate to allowing their children to participate in my study or wanting to put me in contact with others that might like to participate. This dissonance is reflective of the issue discussed in my Findings and Discussion Part I that many parents acknowledge sexuality education as important, but often do not act upon it unless a problem emerges. The need for guardian approval for participation is also reflective of the agency of people with IDD when it comes to making their own decisions to engage with this topic. Many potential participants did not have their own say in deciding to participate in my study, which suggests they may have limited sexual agency. In this sense, many guardians seem to

serve as gatekeepers to their ward's sexual agency. However, this relationship needs to be explored further.

### *Impairment, Accessibility, and Elaboration*

I had to make a few methodological choices to accommodate IDD impairments throughout my research process. For example, I chose to conduct in-person interviews instead of an online survey to mitigate literacy and technology accessibility difficulties. When reevaluating my methods choices I began to wonder if that choice hindered my ability to obtain completely open and truthful answers to my interview questions. My participants with IDD all had significant agency in how they chose to talk about their sexuality and how much to say when answering my questions. Therefore, many of their answers to my interview questions were short and hesitant, which made the interviews quite short in length overall. I was very cautious not to push my participants to expand further because I was fearful of making them uncomfortable. During this reevaluation I began to wonder if this choice was a mistake, but the more I have thought about it the more I have realized that this lack of interference from me provided important insight into their sexual agency.

Although comfort talking about sexuality does not directly translate to sexual agency, it plays an important role in one's ability to make decisions and assertions related to one's sexuality (the general definition of sexual agency, Klein et al. 2018). To be able to make decisions and assertions about one's sexuality, one has to be reasonably comfortable discussing such sexuality. In this way, the comfort of my participants with IDD talking about and expanding on responses about sexuality may reflect a lack of sexual agency among this population. Additionally, I do not think that their hesitation and

lack of elaboration is a function of their impairments because my initial “warm up” interview questions (Appendix 1: Interview Questions and Materials, questions for participants with IDD 1-4) warranted much more expansive and direct answers. However, it is important to note that this discomfort could also be related to my role in the conversation as a relative stranger.

Another potentially limiting factor to consider here is that one of my participants, Kate, had her guardian present during the interview. Her guardian did not think it would be possible for Kate to speak with me on her own and she mostly communicated nonverbally through her guardian during the interview. Given that sexuality is an especially taboo subject for people with IDD (Payne et al. 2016, Schaafsma et al. 2014) and relatives often play a major role in limiting sexual expression for this population (Schaafsma et al. 2014), I think it is likely that Kate’s responses to my questions about sexuality were hindered by her guardian’s presence. In this sense, her ability to communicate by herself was potentially a limitation to my research and her agency during our conversation. Such lack of agency during our interview might also be a reflection of her everyday sexual agency. Again, if sexual agency is dependent on one’s ability to make decisions and assertions about their sexuality, some ability to talk about sexuality is necessary for sexual agency. However, researchers may also need to reevaluate the current definition of sexual agency when considering populations that are not able to communicate in the same way that neurotypical people do. In this sense, I wonder if sexual agency is possible without verbal communication.

Another methodological limitation regarding intellectual impairment was internal inconsistency in responses during my interviews with participants with IDD. Although I

checked in frequently for understanding, such inconsistency made it unclear if participants always fully grasped the meaning of my interview questions. For example, in my interview with Max, he first said that his school-based health education program did cover sex, but later said the opposite. Such inconsistency potentially limited my ability to obtain an accurate depiction of sexual socialization and agency for people with IDD. However, to a certain extent researchers should expect inconsistency in a neurotypical population as well. No participant has a perfect memory and I would argue that a huge part of qualitative research is reporting back on the lived experiences of participants, regardless of their factual “truth”. This belief aligns with emancipatory methodology, in that it rejects a positivist view of research and the pursuit of absolute knowledge (Oliver 1997).

Although many of the issues brought up in this methods reevaluation are exploratory and need to be researched further, I think it is important to recognize that they point to the same general phenomenon. When you take a stigmatized group and add a stigmatized topic, the major result appears to be silence. This silence puts huge limits on research in this area, but those challenges have some meaningful implications for the sexual socialization and agency issues discussed in this thesis.

### *Implications for Future Research*

Some would use the information presented in this section to critique the social model of disability. If methodological difficulties related to impairments hindered the research process, then those impairments are arguably disabling. In this argument, flaws in the research structure would be considered less restraining than the impairments of participants with IDD. However, I believe that such a critique only reinforces the point

that the model makes. Although impairments make this research more challenging, I think that many of these difficulties stem from our expectations of individuals with IDD to work within normative research processes. In this sense, the methodology structures researchers use to study this population are more limiting than the impairments themselves. Therefore, rather than putting the burden on people with IDD, I believe it is much more important for researchers to develop more creative methodology in order to deal with methodological issues such as accessibility and inconsistency. The following are some of my ideas for improving research on sexual subjects among individuals with IDD.

1. Following an emancipatory methodology model, which focuses on “placing of control in the hands of the researched, not the researcher” (Oliver 1997:3), I think it would first be important to ask people with IDD who have participated in social research what they would change about the methodology. For example, finding out what measures were most effective and what aspects of the research they found most uncomfortable or limiting. Here, we would be able to prioritize the needs and wants of the participants instead of relying solely on the thought experimentation of neurotypical researchers like myself.
2. Next, I think that research with people with IDD needs to utilize multiple accessible measures that help mitigate some of the accessibility issues I ran into during data collection. For example, developing a survey that has both audio and written forms of the questions to allow for accessibility while still maintaining anonymity. Such would hopefully allow for more uninhibited responses and a more accurate reflection of these issues. Similarly, one could develop a nonverbal

response measure using pictures or writing to allow for more response accessibility and hopefully eliminate the need for a guardian presence during data collection.

3. I would also consider sampling from a variety of populations who have a stake in the issue of interest for people with IDD. For example, not only interviewing and/or surveying people with IDD, but also talking to parents, teachers, and other stakeholders that might have valuable information to contribute to the study. Such a diverse sample would hopefully allow for a more holistic understanding of the topic of interest and help to mitigate accuracy issues potentially related to impairment such as response inconsistency.
4. Along with sampling from several populations, I would suggest utilizing a multi-method approach to this research. Although surveys and interviews can provide valuable information, these measures primarily investigate the direct responses of participants. Self-reported behavior is not always an accurate reflection of practiced behavior for that sample (Pryor et al. 1977). Therefore, I think it would be helpful to also conduct observation in order for researchers to see these practices for themselves. For example, for my research I could have spent time observing the Healthy Relationships course Julia and Kate described in their interviews. Additionally, I think that longitudinal research would aid in making participants more comfortable with the researcher's presence, which would hopefully increase elaboration in interviews and prevent social desirability bias during observation. Such research should also assist in gaining a more complete understanding of the issues of interest over time. In this sense, I think an

ethnographic research model would be ideal for studying sexuality among people with IDD, as it would allow for longitudinal observation and interaction for study participants.

5. Additionally, although more of a prediction than a suggestion, I think the more researchers study and discuss issues of sexuality among people with IDD, the more normalized such research will become. This prediction aligns with Julia's sentiment in Findings and Discussion Part II that teaching sex education to people with IDD should become easier as our "society becomes more open" about sexuality for this population. As research in this area becomes more common, I think it is likely that recruiting will get easier and participants will be less hesitant in their responses. So here my suggestion is to simply keep conducting research on sexuality for individuals with IDD. Do not let the challenges of working with a sensitive topic and population stop you from investigating these issues.

I learned a lot from my experiences over the last year, and I am hoping that these suggestions will help to mitigate many of the issues I ran into throughout my research on sexuality with individuals with IDD. However, I also think it is important to note that the extensive measures I have proposed may be difficult to achieve considering the often limited funding for disability studies (Oliver 1997). Macro-level logistical issues such as funding need to be addressed in tandem with the suggestions listed above. Additionally, I think that many of these suggestions are not only applicable to the specific issue of sexuality among people with IDD. Issues of inconsistency, elaboration, and measure validity are not limited to this subject and population, and often emerge in various types of research. Therefore, these methodological suggestions may also be useful for

sociological study more generally, especially when working with other stigmatized topics and populations.

### *Conclusion*

Although I expected this research to be difficult, I did not realize the full extent of stigma and discomfort surrounding sexuality for people with IDD. Although I engaged in extensive theoretical preparation for my project, such preparation only took me so far. Conducting this research first-hand was the only true way to gain an understanding of the challenges surrounding sexuality for individuals with IDD and research on these issues. Not only did my initial findings reflect such stigmatization, but I was able to observe such processes and consequences in practice throughout the research process. In this sense, my research experience was just as valuable as my direct interview data. This thesis process has been far from easy, but it has become increasingly clear to me that it would be more surprising if the research had been simple. My lived experience conducting this study has given me invaluable insight that will hopefully improve future research endeavors on sexuality for people with IDD, as well as sociological study more generally.

## APPENDIX 1: INTERVIEW QUESTIONS AND MATERIALS

Interview questions for stakeholder participants:

- Can you tell me about your professional role?
  - How long have you been in your position?
  - How does your work impact individuals with IDD?
  - Why are you interested in this work?
- Do you feel that access to sex education is important for individuals with IDD?
  - Why or why not?
- How do you think people with IDD are getting sexual information? Are they getting sexual information?
- What do you know about the current state of school-based sex/health education for individuals with IDD?
  - What do you know about the availability of existing alternative sex education programs?
- What do you think are the major barriers to sex education for individuals with IDD?
  - Do you see any solutions to these barriers? Are there specific problems you would like to see addressed?
- Do you think people with IDD are generally informed about the topic of sexuality?
  - Do you think individuals with IDD have enough knowledge to be confident in their own sexuality?
- Do you think that individuals with IDD typically have full control over their sexuality/sexual expression?

Interview Questions for participants with IDD:

1. What are some of your favorite activities and hobbies?
2. Can you tell me about your family? Do you have any siblings?
3. Can you tell me about your home and living situation? Who do you live with?
4. Do you have a romantic partner?
5. Where do you look and/or who do you go to when you want to gain new sexual information?
6. Did you ever receive any type of sex education in school? For example, health education about your body and sexuality, or learning about sex in other classes.
  1. If so, what was it? Do you remember what topics were discussed (can provide checklist)? When did it take place?
  2. If not, why? Was it not offered? Were you removed from the program? Did your peers receive sex education?
7. Did you ever learn about sexual health topics through alternative programs outside of school? For example, church groups or afterschool programs about healthy relationships.

1. If so, what was the program? Do you remember what topics were discussed (can provide checklist)? When did it take place? How and why did you attend the program(s)?
8. Have you ever received sexual information through the media (i.e. social media, television, movies, pornography)?
  1. If so, what did you learn? Did you feel informed about the topic of sexuality after receiving this information? Did this information make you feel confident about your own sexuality?
9. Have you ever received sexual information from peers or friends?
  1. If so, what did you learn and/or discuss? Did these conversations make you feel informed about the topic of sexuality? Did they make you feel confident in your own sexuality/sexual expression?
10. Have you ever received sexual information from your parents or other relatives?
  1. If so, what did you discuss/learn? Did these discussions make you feel informed about the topic of sexuality? Did they make you feel confident about your own sexuality/sexual expression?
11. Do you feel that you have full control over your sexuality and sexual expression? Are you able to make your own decisions regarding your sexuality (ex. desires, boundaries, expectations, etc.)?
  1. Does anyone/anything limit your control over your sexuality? If so, who/what?
  2. Does anyone/anything help you gain control of your sexuality? If so, who/what?

Sexuality and sex education sheet:

Below is a definition of sexuality and a checklist of sex education topics. This page was printed and given to participants with IDD to help in answering interview questions 5 and 6.

Sexuality Definition: The way people experience and express themselves sexually. This includes sexual feelings, attraction, sexual relationships, sexual behavior, and the body.

Sexual Health Education Topics:

- Reproduction
- Puberty
- Sexual orientation
- Gender identity
- Family relationships
- Friendships
- Romantic relationships and dating
- Communication
- Decision making
- Consent
- Abstinence

- Pregnancy
- Abortion
- Sexually transmitted infection
- Contraception (birth control pills, condoms, diaphragms, IUDs, etc.)
- Gender roles
- Diversity
- Other \_\_\_\_\_

## APPENDIX 2: INFORMED CONSENT DOCUMENT

### **RESEARCH CONSENT FORM:**

#### **Sexual Socialization and Agency for People with Intellectual and Developmental Disabilities**

Ella Manashil, a student at Whitman College, is conducting this study for her Senior Thesis in Sociology. You are being asked to participate in my research study. This form provides you with information about the study. Please read through the entire document and sign at the indicated location.

**Overview of Study:** The purpose of this study is to gain a better understanding of how people with intellectual and developmental disabilities obtain sexual information and how such knowledge relates to their sexual agency. If you agree to participate in this study, I will ask you a series of questions about your experiences with sexual agency and obtaining sexual information. The interview is estimated to last between 30 minutes to 1 hour. Your participation in this study is entirely voluntary and you can stop participation at any time. To do so, simply tell the researcher that you would like to end the interview and your responses will not be recorded. Halting or refusing your participation will not affect current or future relationships with Whitman College or the researcher. All participants will be compensated with a \$10 gift card.

**Risks of participation:** You may feel uncomfortable with answering certain interview questions. Therefore, you may skip any questions you do not want to answer and can stop your participation in the interview at any time by alerting the researcher. Additionally, we will be discussing sensitive topics surrounding your experiences with sexuality. Therefore, all information collected in this study will be kept completely confidential.

**Privacy Protection:** Any information that is obtained in connection with this study will remain completely confidential. You have been assigned a pseudonym and your real name will never be connected to your interview. Additionally, all data collected will be kept on my personal computer in a password protected file. I will use the data strictly for my research with the possibility of presenting the findings to organizations or at conferences. Again, all identifying information will be kept confidential in these findings. Additionally, the researcher is not a mandatory reporter, which means that no information regarding sexual misconduct will be reported or shared outside of the interview. However, if a guardian is present for the interview, he or she will have access to the information shared.

**Contacts and Questions:** If you have any questions about the study or your rights, please contact the researcher, Ella Manashil (manasher@whitman.edu) or faculty sponsor, Michelle Janning (janninmy@whitman.edu). If you have any concerns about this research you may contact the Whitman College IRB (irb@whitman.edu).

**My signature below indicates that I am at least 18 years old, have read the information provided above and am consenting to participate in the study. I**

**understand that I may discontinue my participation at any time with no adverse consequences.**

Participant Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Guardian Signature (if applicable): \_\_\_\_\_

Date: \_\_\_\_\_

- Check here if you will be present for the interview
- Check here if you opt out of being present during the interview

## APPENDIX 3: CODES

### Part I:

- Interest in sexuality
- Sexuality knowledge
- Sexual information source preference
- Receipt of school-based sex education
- Receipt of alternative sex education
- Sources of sexual information
  - Media
  - Family
  - Friends
- Control of sexuality
- Barriers
- Supporters

### Part II:

- Recruiting difficulty
- Guardian approval
- Accessibility
- Hesitancy
- Elaboration
- Inconsistency

## APPENDIX 4: GLOSSARY

**Inclusion** - a process through which students with disabilities are able to benefit academically and socially from the general education curriculum (Connor and Ferri 2005).

**Integration** - the physical inclusion of students with disabilities in general education curricula (Connor and Ferri 2005).

**Intellectual and developmental disability (IDD)** - “significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18” (AAIDD, as cited in Carulla et al. 2011:4).

**Neurotypical** - without intellectual and developmental disability (Theresa Fears and Giselle Gudino, phone conversation, November 11, 2019).

**Sexual Agency** - the ability to make decisions and assertions related to one’s own sexuality (Klein et al. 2018).

**Sexual Socialization** - the multi-dimensional “process by which knowledge, attitudes, and values about sexuality are acquired” (Ward 2003:348).

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