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Jessica Welson Markowitz  
*Smith College*

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Jessica W. Markowitz  
Figuring out the Birds and  
the Bees: Parents'  
Experiences Navigating  
Issues of Sex and Sexuality  
with Their Teenage and  
Young Adult Children with  
Intellectual Disabilities

### **Abstract**

This interpretative phenomenological analysis explores parents' experiences navigating issues of sex and sexuality with their teenage and young adult children with intellectual disabilities. The purpose of the study was to examine parents' perceptions of the sexual knowledge and sexual identity development of their children, as well as provide a glimpse into their experiences as parents navigating these issues. Six parents of individuals ages 16-25 with an intellectual disability diagnosis were interviewed via semi-structured interviews. Parents were asked to speak about their children's sexual development as well as the role they have played as parents in fostering that development. Parents shared diverse stories about their children, revealing that they perceive their children as having varying levels of sexual knowledge, interest, and experience. Parents also spoke to their personal worries, hopes, struggles, and triumphs in supporting their children and themselves. Though each story was unique, common themes emerged across interviews around issues of their children's sexual interest and disinterest, sexual knowledge and lack of knowledge, and the level of sexual experience in their children. Emergent themes among parents' roles in navigating these issues included concerns about their children's safety in sexual situations, the need to take an

active and realistic stance around supporting their children, and the use of other parents of children with intellectual disabilities as support networks.

**FIGURING OUT THE BIRDS AND THE BEES: PARENTS' EXPERIENCES  
NAVIGATING ISSUES OF SEX AND SEXUALITY WITH THEIR TEENAGE  
AND YOUNG ADULT CHILDREN WITH INTELLECTUAL DISABILITIES**

A project based upon an independent investigation  
submitted in partial fulfillment of the requirements for the  
degree of Master of Social Work

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2011

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To my family, who has supported me through this year-long endeavor and through my entire Smith journey, I love you all.

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## CHAPTER ONE

### Introduction

Human sexuality encompasses the sexual knowledge, beliefs, attitudes, values, and behaviors of individuals. Its various dimensions involve the anatomy, physiology, and biochemistry of the sexual response system; identity, orientation, roles, and personality; and thoughts, feelings, and relationships. Sexuality is influenced by ethical, spiritual, cultural, and moral concerns. All persons are sexual, in the broadest sense of the word. (Sexuality Information and Education Council of the United States, n.d., "Human Sexuality," para. 1)

Though sexuality is an essential component of being human, it is just recently that people with intellectual disabilities (ID) have begun to be appreciated as sexual beings.

The National Center on Birth Defects and Developmental Disabilities (2005) defines intellectual disability as

characterized both by a significantly below-average score on a test of mental ability or intelligence and by limitations in the ability to function in areas of daily life, such as communication, self-care, and getting along in social situations and school activities. (para. 1)

(Intellectual disability has historically been referred to as mental retardation.)

Given these limitations, through history people with ID have been seen as asexual, childlike, or incapable of having sexual identities. Since the deinstitutionalization of people with disabilities in the 1960's, the sexual needs and rights of this population have slowly begun to gain appreciation (DiGiulio, 2003; McCabe, 1999). Unfortunately, a full appreciation of the sexuality of people with intellectual disabilities is still lacking.

With this neglect comes often-inadequate sex education, which is particularly important for individuals with ID, given their vulnerable status, and increased risk of sexual exploitation, unwanted pregnancies, sexual abuse/assault, and sexually transmitted diseases

(Walker-Hirsch, 2007). It is essential that attention be paid toward the sexualities of people with ID, so to provide opportunities to understand their bodies, learn appropriate decision-making skills, express themselves sexually, and become more personally independent (Carter, 1999).

For teenagers and young adults with ID who may be living with their parents or maintain close connections, the process of learning about sexuality and discovering their sexual identity may create additional challenges for parents. While the task of supporting one's child as he or she explores this aspect of his or her identity may be daunting for any parent, parents of individuals with ID face additional unique challenges that go along with raising a child with cognitive limitations (Isler, Beytut, Tas, & Conk, 2009; Resch et al., 2010).

This study aims to gather information about parents' experiences navigating issues of sex and sexuality with their teenage and young adult children with intellectual disabilities. It will explore parents' perceptions of the sexual knowledge and experience of their children, as well as provide a glimpse into their lived experiences navigating these issues. Through semi-structured interviews, parents will discuss where they think their child lies in terms of sexual development, experience, and knowledge, and speak to the role they have played as parents.

While individuals with ID are often a neglected group, so are their parents. This study will open a door to raising awareness about both groups, and provide implications for future research and direction.



## **CHAPTER TWO**

### **Literature Review**

#### **Sexual Knowledge and Identity Development in Individuals with Intellectual Disabilities**

Until recently, our society abounded with many myths surrounding the sexuality of individuals with intellectual disabilities (ID). For some, people with ID were considered asexual and incapable of sexual expression (O’Callaghan & Murphy, 2006). For others, individuals with ID were considered “degenerate beings” and thought “to be a threat to society” (O’Callaghan & Murphy, 2006, p. 197). The fear that women with ID would “reproduce disproportionately” (O’Callaghan & Murphy, 2006, p. 197) led to the sterilization of many women with ID during the eugenics movement. Even as recently as a 1988 study, roughly 48% of parents responded “yes,” when asked if they would consider sterilization or other forms of birth control for their children with Down syndrome (Pueschel & Scola, 1988).

In recent years, there has been increased attention given to the sexual interests and needs of the ID population. Consequently, there has also been increased examination into the sexual knowledge and sexual identity development of people with ID. The research done thus far generally shows a significant lack of sexual knowledge in this population. Galea, Butler, Iacono, and Leighton (2004) tested the sexual knowledge of a group of adults with intellectual disabilities using the Assessment of Sexual Knowledge (ASK) tool (Butler, Leighton, & Galea, 2003), and found their knowledge to be “limited” (p.

362). This was true in regard to information on safe sex, sexually transmitted diseases, contraception, and sexual health screenings (Galea, Butler, Iacono, & Leighton, 2004). Similarly, in a study on sexuality with adolescents with ID, Isler, Tas, Beytut, and Conk (2009) found that many of the adolescents lacked sexual knowledge or had incorrect knowledge. This included information in areas such as anatomy, menstruation, masturbation, and sexual intercourse. Galea, Butler, Iacono, and Leighton (2004) offered minimal interpretations of their findings, while Isler, Tas, Beytut, and Conk (2009) attributed the inadequacy of sexual knowledge to the lack of formal sex education for many of the participants.

The limited sexual knowledge of individuals with ID as well as the isolation faced by many was also assessed by McCabe (1999), who conducted a study in which she interviewed people with intellectual disabilities, people with physical disabilities, and people without disabilities using the Sex Knowledge, Experience and Needs Scale (McCabe, 1998) appropriately adapted for each population. Her results indicated that the people with intellectual disabilities had the lowest levels of knowledge across all areas of sexuality. McCabe (1999) suggests that the sexual experiences of people with ID are less likely to be normalized and found “less discussion of sexual issues among people with disability with family (parents or siblings) or friends” (p. 167).

Like McCabe’s (1999) findings, in a study by Swango-Wilson (2009), participants demonstrated a limited understanding of appropriate sexual relationships and practices through questions such as, “What’s the difference between sex and rape?” (Swango-Wilson, 2009, p. 226). In a study by Healy, McGuire, Evans, and Carley (2009), “rudimentary” knowledge was found among their 13-17 year-old participants.

Knowledge of “condoms and contraception” as well as of “both STD’s and male/female sexual anatomy” was poor, and incorrect knowledge was prevalent (Healy, McGuire, Evans, & Carley, 2009, p. 909).

This inadequacy of sexual knowledge is often compounded by limited privacy and sexual opportunities for people with intellectual disabilities. In 2002, Lesseliers and Van Hove interviewed people with developmental disabilities and found that despite often strong feelings of love and sexual attraction, they had experienced limited opportunities to talk about sex and relationships. There was a sense of isolation and fear among participants, many of whom were not given privacy, did not know how to communicate effectively with their partners, had experienced abuse, or felt guilt or shame around sex and sexuality (Lesseliers & Van Hove, 2002). In one study, it was found that “secrecy and deception were sometimes necessary to exercise their sexual rights” (Healy, McGuire, Evans, & Carley, 2009, p. 910). This may be particularly true when it comes to expressing same-sex desires, as Healy, McGuire, Evans, and Carley (2009) found among their participants a “relatively low tolerance of...homosexual activity” (p. 910).

Teachers, who are common resources in examining the sexual knowledge of the ID population, have also observed this lack of opportunity. Lamorey and Leigh (1996) found among teachers “strong concerns that their students possessed neither an adequate knowledge base in terms of understanding various contemporary issues nor an appropriate experiential background in terms of their awareness of their own or others’ social, moral, sexual, or civic behaviors” (p. 124).

This inadequate knowledge base is concerning, given that research has shown individuals with disabilities to be “at increased risk for every known risk factor for

HIV/AIDS” (Groce, 2003, p. 1401), and that without knowledge around sexuality and sexual relationships, people with disabilities may not understand appropriate sexual interactions and may not have enough information to know if they are being taken advantage of (Walker-Hirsch, 2007). In a research review by Bowman, Scotti, and Morris (2010), it was found that individuals with ID are more likely to experience maltreatment in their lifetime than individuals without disabilities.

However, this often inadequate knowledge base does not mean that people with ID are uninterested in relationships, sex and/or sexuality. It is often quite the opposite. Individuals, regardless of whether or not they’ve received formal sex education, learn about “the supposed meanings of their bodies from the world around them, their peers, and their lives in school, and this shapes their identity, their sexuality, and their sense of self-worth” (Diorio & Munro, 2003, p. 122).

Socialization also contributes to sexual curiosity and sexual interest, and this applies to individuals with ID as well. In one study, participants with ID expressed aspirations to marry, have families, and experience the benefits of intimate relationships, including increased self-esteem, “companionship and security,” and trust in a partner (Healy, McGuire, Evans, & Carley, 2009, p. 908). Many also supported the idea of a dating agency specially geared toward people with ID (Healy, McGuire, Evans, & Carley, 2009). Because of these interests, many people with ID are eager for more practical information about sex, sexual relationships, and sexuality (Isler, Tas, Beytut, & Conk, 2009; Swango-Wilson, 2009).

## **Parental Experiences**

The gap between the sexual knowledge and sexual desires among people with ID is of particular concern to parents raising or maintaining close relationships to their children with ID, given the unique challenges and responsibilities already inherent in their roles. First, it need not be overlooked that many parents of children with ID experience genuine joy and satisfaction in their lives. In a study by Boström, Broberg, and Hwang (2010), narratives from parents of young children recently diagnosed with an intellectual disability included both positive and negative themes, and researchers suggest that “stories of joy, love and other positive emotions could counterbalance the difficulties experienced by parents” (p. 98). Recent research has found much resiliency in families of children with developmental disabilities (Maul & Singer, 2009), and parents have reported that having children with intellectual disabilities has made them better people and given their lives meaning (Durà-Vilà, Dein, & Hodes, 2010). Similarly, Turnbull, Behr, and Tollefson note that “Parents of children with disabilities identified their children as reasons for strengthened family ties,” and reported “greater pride and sense of accomplishment, greater knowledge about disabilities, less likelihood to take things for granted, and greater tolerance, sensitivity, and patience” (as cited in Paster, Brandwein, & Walsh, 2009, p. 1338).

Despite these positives, raising a child with cognitive limitations may also have negative mental health implications for parents. Research has shown that stress levels of parents of children with disabilities are generally higher than those of parents of children without disabilities (Lessenberry & Rehfeldt, 2004), and may particularly rise upon initial diagnosis and during major life events (Bailey & Smith, 2000). These parents may

experience “loss of friendships, feelings of isolation, anger, resentment, shock, and sadness,” (Paster, Brandwein, & Walsh, 2009, p. 1337), and may be at an increased risk for depression and anxiety (Feldman et al., 2007; Gallagher, Phillips, Oliver, & Carroll, 2008).

In a study by Feldman et al. (2007), primary family caregivers of young children with or at risk for developmental disabilities were administered the Beck Depression Inventory II (Beck, Steer, & Brown, 1996). Researchers found that 40% of the participants experienced mild to severe depressive symptoms, with 20% scoring above the clinical cut-off for depression – percentages significantly higher than those of the general population (Feldman et al., 2007). Similarly, in their study on psychological morbidity in parents caring for children with intellectual disabilities, Gallagher, Phillips, Oliver, and Carroll (2008) found high levels of depression and anxiety among parents, and found caregiver guilt to be the “strongest and most consistent predictor of psychological morbidity” (p. 1133). Grief has also been found to be an ongoing feature of raising a child with ID (Bruce & Shultz, 1994).

When examining attitudes about sex and sexuality among parents of children with ID, it is perhaps not surprising to find that this issue in particular creates additional parental stress and concern. In a study by Isler, Beytut, Tas, and Conk (2009), concerns around how to protect their children from abuse resonated with 42.5% of parents, and 72.5% of the parents expressed concern around their child’s future given the inadequate knowledge and sex education. Additionally, in a study by Swango-Wilson (2009), safety was identified as the primary sex-related concern among caregivers. In another study, the majority of parents reported worrying that their child might be taken advantage of

sexually (Pueschel & Scola, 1988). The findings from studies like these indicate how important issues of sex and sexuality are for individuals with ID.

Yet, despite this importance, families and other individuals who work with young people with intellectual disabilities often describe feelings of ambivalence around issues of sex and sexuality (Löfgren-Mårtenson, 2004). In the aforementioned study by Pueschel and Scola (1988), 16 parents reported feeling “uncomfortable or embarrassed discussing the subject of sexual development” with their child with Down syndrome (p. 217). Isler, Tas, Beytut, and Conk (2009) also note that,

Many parents are afraid of talking to their children (disabled or not) about sex. Parents often fear that (1) Talking about sex will encourage sexual experimentation; (2) The parents do not know enough to handle questions appropriately; and (3) Their children already know too much or too little. (p. 230)

Concerns about sex education increasing the likelihood of sexual behaviors, as in the second point noted above, are common (Isler, Tas, Beytut & Conk, 2009; Page, 1991), and in some cases, family members may also discourage caretakers from providing sex education or talking about issues of sexuality with children with ID (Irvine, 2005). However, research has shown that sex education for individuals with ID is *not* correlated with an increase in inappropriate sexual behavior, as measured by the Inappropriate Sexual Behavior Scale (Dukes & McGuire, 2009). Instead, sex education interventions have been shown to lead to “improved decision-making ability” around sex and sexuality (Dukes & McGuire, 2009, p.732).

Yet even those interested in supporting their children with sex education remain affected by the lack of resources or the inaccessibility of resources that exist (Resch et al., 2010). Some relatives or staff members of individuals with intellectual disabilities may

acknowledge the right to fulfilling sexual lives, but lack direction as to how to navigate emerging issues around sex and sexuality (Löfgren-Mårtenson, 2004). In a review of the literature, Aunos and Feldman (2002) note that, “even though many teachers were in favour of sexual education programmes, few have actually taught a course on sexuality because of lack of personal knowledge, fear of community reactions, and lack of administration support” (p. 287). Wolfe and Blanchett (1997) acknowledge that many educators have difficulty finding appropriate materials and curricula for their students with disabilities, and knowing when and how to use the materials that are available. Thus, sex education is often neglected, and individuals with disabilities are left to figure out sex and sexuality on their own (Boehning, 2006).

Consequentially, parents often become default sex educators for their children, especially during adolescence and young adulthood, when sexual development and curiosity often emerge in more salient ways, and when hormonal changes and subsequent increases in sex drive (Diorio & Munro, 2003) may lead to new concerns. This may be particularly true for girls, who tend to have an earlier age of pubertal onset (Dick, Rose, Pulkkinen, & Kaprio, 2001), and whose parents may develop worries around risk of pregnancies as a result of sexual exploration. And given that many adolescents and parents generally underestimate “pubertal stage” (Dorn, Susman, Nottelmann, Inoff-Germain, & Chrousos, 1990, p. 324), parents and children themselves may not recognize the ways in which they are developing sexually and may, therefore, not consider the ways in which their development may be impacting their emotional wellbeing, their relationships with others, or their safety.



There has been extensive research done on parents' experiences raising children with intellectual disabilities, and research done on issues related to sex education for this population, but less attention has been paid to the experiences of parents as they navigate the two. At times during more general interviews, parents will offer tangential thoughts or stories about experiences with their children around these issues (Durà-Vilà, Dein, & Hodes, 2010), but research is lacking in having this topic be the study focus. The current study provides a targeted look into these experiences.

The narratives explored in this study will provide more information on the sexual knowledge and development of teenagers and young adults with ID, and also on what life is like as a parent of these children. Through sharing stories of struggle and triumph, stress and resilience, and success and failure, parents were given the opportunity to provide narrative data on this topic so that others will begin to understand their experiences. This research opens the door to exploring the ways in which parents are affected by the sexual development and sexual identity development of their children with ID, and the information gathered will allow for a greater appreciation of both the parents and their children, and provide implications for the ways in which the needs of this unique population can be best addressed.

## **CHAPTER THREE**

### **Methodology**

This study examined parents' experiences raising their teenage and young adult children with intellectual disabilities through their sexual and sexual identity development. Through semi-structured interviews, parents were asked to share their perceptions of their child's stage of development and sexual knowledge, and also their experiences as parents navigating these issues. Although past research has shown that the sexual knowledge of people with ID is limited and inadequate, systematic qualitative studies of parental experiences have yet to be conducted. This investigation is an attempt to examine the phenomenological experiences of managing issues of sex and sexual identity from the parents' points of view. Parents were asked to provide information about their experiences broadly, so that the phenomenology of their individual lives emerged. The interview allowed parents to discuss the successes and struggles that may have occurred on both an emotional and practical level in the parents' lives. Parents were also asked about what resources have been helpful (and what has not been helpful) in navigating these issues with their children. The goal of the current study is to explore in as much detail, without a priori expectations, the nature of the lived experiences of these parents.

### **Procedures**

This study used a descriptive qualitative design. Participants were interviewed in-person or on the phone for an average of 40 minutes. Interview methodology was chosen

to allow for the richest collection of in-depth, personalized information. Using a qualitative method allowed the nuances and complexity that accompany issues of sex and sexuality to emerge. Each parent had unique stories to tell and this method allowed for the richest and most complete representation of each lived experience.

Semi-structured interviews were used to allow for flexibility in talking with participants, and to cultivate a more collaborative conversation. I was able to develop rapport with each participant, probe relevant areas that arose, and follow my participants as they shared their personal experiences (Smith & Osborn, 2003).

### **Sample**

Six parents were interviewed for this study. Eligibility required that all parents be English-speaking and have raised the child since infancy. This criterion was chosen so that parents could reflect on the overall development of their child as it may relate to their sexual development. It also decreased the likelihood of confounding factors, such as having experienced multiple transitions through childhood. Eligibility criteria required that the children be between the ages of 13-25 and have a diagnosed intellectual disability, as reported by parents.

Participants were gathered using the “snowball” technique. Information about the study was dispersed via informal contacts and word-of-mouth. Recruitment letters and fliers were distributed to individuals, families, and agencies that work with individuals with intellectual disabilities or have connections in the field. Participants initiated contact with me via email or phone to determine eligibility. For phone interviews, participants were mailed an Informed Consent form and the interview was set up once the form was

returned. For in-person interviews, the Informed Consent form was signed at the start of the interview.

### **Demographics**

Demographic information was gathered from each of the six participants via open ended questions. Participants were asked to report their gender, age, race, ethnicity, occupation, marital status, number of children, religion, and sexual orientation. Participants were also asked to report their child's gender, age, race, ethnicity, occupation, religion, sexual orientation, and intellectual disability diagnosis. Participants were given the option of passing on any question and were not required to offer an explanation when passing.

#### **Participant demographics.**

All six of the parents identified as female, with ages ranging from 49-58. All participants identified as either White or Caucasian. Four individuals reported their ethnicities; one identified as American, one as British, one as Italian/Slovic, and one as German/Irish. The occupations of the parents differed greatly and included retail manager, teacher, clinical coordinator, credit analyst, administrator, and gallery manager. Five participants reported being married and one reported being divorced. All of the parents had multiple children, ranging between 2-4. Half of the participants (N=3) identified as Catholic, with the others identifying as Angelican, Methodist, and Jewish. All parents identified as heterosexual or straight.

#### **Child demographics.**

Five of the children discussed in the study were female and one was male. The ages ranged from 16-25. All children were identified as White or Caucasian. Four of the

participants reported the ethnicity of their child; one was identified as American, one as British, one as Italian/Slovic/English/Irish, and one as German/Irish/Welsh. Occupations were indicated for five of the children, with three identified as students, one as a coffee shed worker, and one as “various.” Half (N=3) were identified as Catholic, one as Methodist, one as Angelican, and one as Jewish. Five of the children were identified as straight or heterosexual, and one’s sexual orientation was not indicated. The reasons behind each omission of information was not indicated. Four of the children were identified as having Down Syndrome, one as Down syndrome/Mental Retardation, and one as Mental Retardation/Angelman-like syndrome.

Down syndrome is a genetic condition most commonly involving an extra copy of the 21<sup>st</sup> chromosome that leads to cognitive delays and an increased risk for certain medical conditions (National Down Syndrome Society, 2011). Angelman syndrome is a neuro-genetic disorder often characterized by “developmental delay, lack of speech, seizures, and walking and balance disorders” (Angelman Syndrome Foundation, Inc., 2011, para. 1).

### **Data Collection**

Parents were required to read and sign an Informed Consent document prior to their interviews. They were given the option of meeting in-person or conducting the interview via phone or video-chat. One interview was done in-person; the rest were done via phone. All interviews were digitally recorded and later transcribed. Parents were informed that given the nature of the study, anonymity was not possible, but that confidentiality would be maintained and no identifying information put into the final

study. Parents were told that they could decline to answer any questions, or opt out of the interview at any time.

As outlined above, demographic information was collected prior to the start of the interview. The parents were asked to contribute this demographic information voluntarily and told that they could refuse to answer any question. The only information that was required was the age of the child and the relationship status of the participant to the child, as to determine eligibility.

The semi-structured interview was divided into 3 sections. However, as the interviews began, it became clear that there was more overlap between sections than originally considered. For example, as section 2 began and parents spoke about the sexual knowledge of their children, they often answered questions I had anticipated asking during section 3. Thus, the structure was adapted for each participant and the following simply outlines the general format.

All interviews opened by asking participants to tell me about their relationship with their child. The parents could take this question in any direction they chose, thus allowing them to gain some initial comfort in the interview process and in talking about their children.

The second section involved questions related to the sexual knowledge and experiences of the children. The questions began broad and funneled down to be more specific. The first question asked parents about their impression of what their child knows about sex and sexuality. More specific questions were then asked about issues such as sex education, relationships, and boundaries. This section ended by asking parents they

thought I had left anything out or if there was additional information they would like to share.

The third and final section involved questions about the parents' own experiences. It began by broadly asking the participants about their experiences navigating issues of sex and sexuality with their children. More specific prompts were then given to address issues such as hopes and concerns for their children, and resources they have found helpful in navigating these issues. The interview ended by asking participants if they thought I had left anything out or if there was additional information they would like to share. I also offered time for the interviewee to ask me questions.

Through the interview, I attempted to get a well-rounded picture of each parent and child. To accomplish this, I asked questions about both strengths and weaknesses, and was mindful to not ascribe causality where unwarranted.

### **Data Analysis**

All of the interviews were recorded digitally and then transcribed into an electronic document. All participants were informed of the recording procedure.

The transcripts were open-coded for common themes and variables, and analyzed using Interpretative Phenomenological Analysis, as described by Smith & Osborn (2003). This "bottom-up" approach allowed me to develop themes as I analyzed each interview. In reviewing the interviews, I made note of common and unique themes that emerged through use of a Microsoft Excel spreadsheet. The first column listed emergent themes. Each interview was then designated a column and the grid was used to indicate whether or not the theme was present in the interview. I began this process by completely coding the first interview for emergent themes. The second interview was then coded for themes,

paying attention to the themes that had already been identified through the first interview, as well as new themes that emerged. This pattern continued with subsequent interviews, thereby developing a list of themes that emerged through each interview as well as those that emerged across interviews. Sections of each transcription were also cut and pasted by sections into the file, to organize examples and vignettes.



## **CHAPTER FOUR**

### **Findings**

This study examined parents' experiences navigating issues of sex and sexuality with their teenage and young adult children with intellectual disabilities. Demographic data were collected first, and participants were then asked to talk about their understanding of where their child lies in his/her sexual and sexual identity development. Participants also spoke to the ways in which their child's sex and sexuality impacts them, and how they manage issues that arise. This section will discuss the themes that emerged in the interviews.

#### **Sexual Interest and Sexual Experience**

Through the interviews, each parent had much to offer in discussing both the sexual experiences of their children, as well as their experiences navigating issues of sex and sexuality. It quickly became clear that this was not the first time these parents had considered these issues.

Most (N=5) of the parents said that their child has indicated an interest in romantic/intimate relationships. All parents said that their child has been in past relationships or is currently in a relationship. All relationships were with members of the opposite sex. Worth noting is that though relationships were common, the levels of the children's understanding and intimacy within these relationships varied. This will be discussed further below.

All of the parents indicated noticing some sexual interest, or behaviors that would suggest sexual interest, in their child. Half (N=3) said that their child has expressed interest in hand-holding, getting married, and kissing; and two in masturbation. This interest was noted through conversation with their child or observation of their child's behavior.

She really, for a girl that – she's a big flirt. I mean, she just bats her little eyes. She's very cute and very petite...She's a very happy girl, and she seems content having a boyfriend – a boyfriend that she can tickle and, you know, hold hands and give a kiss to once in a while.

In several (N=3) of the interviews, parents noted that along with interest came areas of disinterest. One parent noted that her daughter had expressed discomfort when her boyfriend wanted to touch her breasts, and two made references to sex as being of disinterest or as not on their child's "radar."

I mean, some of the TV shows she watches, there's always somebody pregnant on there. So, she talks about... She knows that that means that they have a baby in their tummy. And then, you know, we've talked about how the baby comes out. She's like, 'No! No!' So, there, again, that's another... I mean, she doesn't seem to be real curious about sex itself. She seems to be, you know, as she's having the boyfriend, and kissing and holding hands or whatever, but as far as actual sexual intercourse, it doesn't really seem to be... I mean, it's not a hot topic of conversation with her.

I'm not sure that – I – she can be a little funny, though. Because there was one boy that she kind of liked a little bit and he didn't necessarily like her back kind of thing. And she – I tried to talk to her about it. And she was just kind of like, 'Oh, Mom.' Like, brushing me off. And I'm not quite sure how much she, you know – how curious she is or if that's something that's really entered her radar yet.

### **Sexual Knowledge**

As noted above, each parent made note of some sexual interest in their child. Accompanying stories of interest, however, were varying thoughts around their child's

sexual knowledge, and concerns about the ways in which their child's interests and areas of knowledge may be misaligned.

All of the participants (N=6) spoke about their children as possessing some sexual knowledge, whether it be in regard to physical development, relationships, or sex itself. Speaking about her daughter, one parent noted, "I think she knows some of the mechanics of sex." Another parent said that her daughter understands the concept of loving, perhaps because of this mother's recent remarriage.

But also I think she was thinking very much about relationships because I remarried just a short time ago, and it was a significant and happy change for me, and she did a lot of thinking about that... And even though I'm like, you know, older, I think that really made her think about relationships and marriage and happiness and that kind of thing as well.

Two parents noted their daughters' understanding of their menstrual cycles, with one parent saying that her daughter has been to the gynecologist and noting that, "She knows about her period. She hates it. But she handles it all by herself."

Along with the sexual knowledge, all parents spoke about their children as lacking knowledge in certain areas. One parent said that her child has some understanding of where babies come from, but more common were references to lack of knowledge in this area. When asked about sex, one mother said that her daughter and her daughter's boyfriend have "some level of comprehension about it, but they don't really know what it is." When then asked whether or not her daughter has an understanding of the relationship between sex and babies, she responded with, "No. None whatsoever... She has no concept of sex. Neither does her boyfriend."

One mother spoke about her daughter as having an "immature" level of understanding of sexuality. Another mother remarked that, "I think that even though

we've talked tons about sexuality and sex and stuff, I think he still tends to be pretty naïve.”

### **Sex Education**

Four of the parents reported that their child had received formal sex education, but coupled it with expressing that the information received was not always understood or retained. One parent noted her perturbation around her child being intentionally excluded from sex education, saying, “They took these kids that they felt were a little on the lower functioning side and they didn't do sex ed.”

Another parent spoke about her struggle around her child being taught things in sex education with which she and her family do not agree. This child’s sex education program taught against having sex before marriage, while this family felt comfortable with sex in the context of any “ongoing relationship.”

### **Boundaries**

Another way in which the parents observed their child’s knowledge and understanding of sex and sexuality was through their ability to maintain and enforce appropriate boundaries. All of the parents addressed both strengths and weaknesses around their child’s boundaries.

Many of the parents (N=4) spoke about appropriate boundaries they have seen enforced by their children, both personally and interpersonally. Accompanying these stories were feelings of pride and relief. One parent spoke about how her teenage daughter was able to enforce boundaries after a breakup.

And then they broke up because he moved on to another girl. But I was really proud of her because she was very clear. Like, he was kind of saying to her, ‘Well, I could go out with this girl and then I could go out with you.’ And she's

kind of like, ‘Look, either I’m your girlfriend or I’ll see you later!’ So, I said, ‘That’s good, Emma.’<sup>1</sup> And it kind of hurt her feelings but she moved on from it.

Another noted the ways in which her daughter was able to maintain boundaries and resist inappropriate touching with her boyfriend.

Every so often, his hand will, like, move somewhere where, like – and I think it’s an accident, honestly. I think he’s, like, tickling her, like he’s trying to tickle her but he’s too close to her breast and... she’s very protective. She’ll be like, ‘No!’ You know? And will put his hand right back on his lap... Or if he all of the sudden – one time she rolled the window down and she was sort of flirting with him and he gave her this big kiss on the lips, and she just said, ‘No!’ Because it wasn’t comfortable within her personal space.

Accompanying these prideful stories were those that spoke to the children’s struggles with boundaries. Two parents said that their child has had difficulty modulating displays of affection in public, and both spoke about needing to talk with their child about behaviors that need to be kept private. Regarding her daughter’s relationship, one parent said, “I don’t want to squash any forms of affection between them – I want it to be able to take place. It’s just, I want her to understand that, you know, you can’t kiss Teddy in school.”

Along with the interpersonal boundaries, one parent also spoke about her struggles with teaching her daughter that masturbation is an activity to keep private.

And, so, yeah, you know, that’s something that I have to remind her. ‘You just can’t do that. You can only do that in the privacy of your *own bedroom*. Because it’s *private*. It’s okay but it’s *private*.’ So, it doesn’t always stick. It’s almost like, she gets very relaxed where she is sometimes and she starts watching TV and she just kind of forgets where she is. So that’s kind of something I’ve been dealing with...since she was 11 or so. That’s one of the normal parts of development. It’s just, with our kids, they need to be reminded that, you know, it is okay, it’s just a private thing. And with her, it doesn’t seem to stick.

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<sup>1</sup> All personally identifying information has been disguised to protect the confidentiality of the participants.

## Comprehension/Readiness Concerns

As referenced by the last mother's mention of the information not "sticking," a common concern among parents was around their child's ability to understand the sexual knowledge which with they have been imparted. As one mother said,

I think the hardest aspect is... they want to be like their peers and all their peers at that age have girlfriends or boyfriends and they see them interacting, you know, in girlfriend and boyfriend ways, and they want that. They deserve that. But cognitively, they're either 8-year-olds or 9-year-olds, and hormonally their like 16- and 18-year-olds. It's a very scary situation and it's difficult to manage.

Another mother spoke about her concerns around her son's retention of knowledge and how it could affect his relationships and real-life experiences.

I think as much as he would like to have a real intimate relationship, I don't think that he has any idea what that's really like or that he would be ready for it.

I think it's like anything else or with any kid with a cognitive disability; you know, you can read a book, you can look at pictures, you can talk all you want, and until it's happening and there's a relationship, it's hard to transfer what you're reading to real life situations.

Given these concerns around comprehension and the varying levels of cognitive abilities, each of the parents reported being mindful of how they share information and what information they share. One mother spoke about not wanting to share more information than her child may be able to cognitively handle.

It's like, I haven't really explained sex...because I don't know if I really have to. And at a stage if I do have to, I will. I mean, I basically – I got some book and I showed her, this is a boy, this is a girl. And, you know, I didn't really want to explain how things work because I don't think she's cognitively there. And I think that might confuse her, you know?

Related to the ability to understand some of the mechanics of sex, one parent also shared concerns around her daughter understanding the emotional component of being in

a relationship or being sexually active. She expressed worry around how her child might manage the emotional connection that often accompanies physical connection.

It's like, the emotional maturity is kind of a big part of it... Like I said, emotionally, she's – it's a tough thing, because, you know, I don't know if emotionally she's at the point where she could actually understand feelings that go along with sexuality with another person.

### **Involvement in Relationships and Sex Education**

Given these worries around boundaries, comprehension, and readiness, all parents noted that one way in which they've provided support is through an involvement in their child's relationships and sex education. Parents spoke of teaching their children about appropriate boundaries, helping navigate breakups and new relationships, and providing support in pursuing sexual interests.

One woman spoke about helping her daughter understand why her boyfriend asked to touch her breasts, and teaching appropriate ways to respond to such requests. Another mother spoke about helping her daughter understand a breakup, and when it is and is not appropriate to try to initiate a new relationship. One mother described helping initiate hand-holding in her daughter's relationship.

When Dan wanted to hold her hand, she told me. She said, 'Dan wants to hold my hand at the movies, Mom.' And I said, 'Okay.' ... And Dan and I have a very good relationship and he's telling me that, 'We're going to hold hands at the movies.' And I said, 'Okay, great.' And they're at the movies and I'm getting text messages from the two of them. 'She's not doing it!' ... 'Mom, he's not holding my hand.' ... The texts were flying back and forth and then finally I was like, 'Guys. Just watch the movie. We'll talk about this later.' So they came out and I'm like, 'Okay, you didn't get the hand holding done.' ... And we – my husband and I – actually sat down and we showed Kendall, you know, 'This is how it can happen. It doesn't have to be anything elaborate, you just kind of reach over and you hold hands.' So they go to the movies... and I went and picked them up and they came out and got in the car and I said, 'Well? Did you hold hands?' And they both looked at me and they said, 'Yes, we did!' And I said, 'Fantastic!'

## **Safety Concerns**

Considering the lack of sexual knowledge, the varying types of sexual exploration, and the observations parents have made while helping their children through their development and relationships, concerns around safety was another major theme.

Five parents spoke to this, with statements like, “I think there's people out there that could take advantage of her if she's put in a wrong situation,” and, “I'm a little concerned about that because I want her to feel in control of her own body and to not feel pressured into having any type of relationship that she doesn't want.”

One parent spoke about how sending her daughter to camp elicits worries.

It's always a concern. She goes out to a camp on the weekends once in a while... and I'm like, you know, they have male camp counselors and there's male clients, you know? But, Carrie's fortunate enough to have a one-to-one. So, she always has a girl assigned to her. So, but, things can happen. Things can happen. Yeah, I worry about that.

Three parents also made specific mention of the prevalence of sexual abuse and exploitation, and the risks faced by their children, with one mother acknowledging her belief that, “it would be easier for somebody to take advantage of her.”

One parent shared a specific incident in which her child's safety had been compromised. This incident – in which her daughter met a man (who did not have an intellectual disability) in public, invited him back to her place, followed instructions to expose parts of her body, and later told others that he was her boyfriend – produced understandable feelings of concern and horror. She shared, “We were simply surprised. It was complete surprise and shock. It was out of the blue. And we were horrified how close she had come to being hurt – allowing herself to be hurt.”



## **Being Realistic**

In order to effectively support their children in learning appropriate boundaries, having healthy and safe relationships, and exploring other aspects of their sexuality, every parent expressed a need to be realistic. While thoughts to the contrary arose from time to time, each parent was able to note that sex and sexuality cannot be avoided.

Despite anxieties around confrontation, two of the mothers spoke about how it is increasingly necessary and relevant, saying, “You know, we're kind of getting to that point where we're gonna have to deal with it. They're really not little kids anymore,” and, “It’s inevitable that she’s going to be interested in relationships.”

Another shared her frustrations in some other parents she’s come across who deny the existence of sexuality in their children.

I find that when I bring up questions about sexuality, parents like, they go into this, like, ‘Oh, we don't really talk about that.’ And it's pretty much, the common thing, you know, is, ‘We don't really plan on our daughter having sex.’ Well, sexuality is a lot more than that. But, you know, it's breaking down those barriers of why [you] don't you see your daughter having sex as a normal progression of a healthy nurturing relationship where they get married and live in your house or their house or someplace else in the community or something, and have safe sex if you don't want grandchildren kind of thing!... Like, if the son gets an erection or something, that would be the end of the world, you know? Responding normally to being stimulated or happy or something.

While parents’ comfort with different sexual behaviors varied, the acknowledgment of their normalcy existed across all conversations. As one parent remarked, “Sexuality is part of everybody, whether or not you have a relationship... You know, having those feelings is normal and expressing them is normal.”

### **Same as Raising Other Children**

For half of the participants (N=3), comparing their experiences with their child with special needs to their experiences with their children without special needs seemed to help them stay grounded and realistic.

I think it's the same kind of feeling that I had when my second kid, you know, developed a really serious relationship with another girl. It was like, you know, they're old, they're growing up and they're moving out, and that kind of thing.

No. I don't know that it's been any harder or easier or different than with the other two girls.

Another mother laughed as she said, "Hey, it's part of life, and, you know, I have a 13 year old boy coming behind her, and he scares me more than her!"

### **Being Proactive**

Given the acknowledgement of sex and sexuality as being "here to stay," parents spoke about the importance of taking a proactive stance in addressing these issues.

Most of the participants (N=5) said that they tend to initiate conversations about sex and sexuality more than does their child.

It's such an incredibly important part for our kids because my other kids kind of learned the ins and outs by listening to other kids talking and watching, kind of thing. I mean, Dean doesn't have that opportunity. He doesn't hang out with a bunch of typically developing kids that he can listen to stories or share their experiences even vicariously, because it's just not the way his social network is set up. So, somebody's got to do it.

You know, to me it's like you don't wait for stuff to happen. I'm more like the antecedent to the behavior than, like, let's see what happens and then pedal backwards kind of thing.

Three parents noted that they work to weave these conversations into their everyday life. Some parents described finding segues in current events or daily activities, so that the task feels less daunting.

You take care of it when it happens. It's not like, 'Oh my god! I have to sit down and have a conversation with her!' When I see it happen, I stop it right then and there if it's not appropriate. And she hopefully learns from it. I mean, she does. I know she does.... It's everyday life!

### **Strategies for Teaching/Support**

Despite the common themes of staying realistic and being proactive, parents differed in the ways in which these values manifested. Each, however, was creative in the tools they used and developed to assist in supporting their child, and each cited personal ideas and strategies.

To help with boundaries, one mother spoke about teaching her daughter to keep her hands in her pockets to resist being affectionate in the workplace. This mother also got a puppy for her daughter to care for, after she had expressed an interest in babies, but was (emotionally and cognitively) not able to have her own.

Three parents said that educational books have been helpful supports through sex education and their child's development. One mother provided several book suggestions as well (see Appendix A).

Another helpful resource cited was the website for the National Down Syndrome Society (NDSS). In particular, this parent noted the "Sexuality" section (in the "Education, Development & Community Life" section under "Transition and Adulthood"), in which NDSS offers information on a variety of topics, such as bodily changes, birth control, and healthy sexuality, as being particularly helpful (Walker-Hirsch, n.d.).

Related to these educational materials were mentions of courses and workshops. One parent shared her positive experiences attending workshops/courses targeted at

parents, and sending her child to those targeted at people with special needs. Similarly, another parent noted support both she and her child have received from the social skills and vocational groups in which her daughter has participated. She not only felt as if her daughter was “in good hands,” but also that she was in a safe environment to learn different styles of interacting and exploring.

After the aforementioned incident with one woman’s daughter being taken advantage of by a man she met on the subway, this mother said that holding a meeting with the daughter’s staff and housemates, and providing the daughter with a cellphone were useful in reducing anxiety. Another mother spoke about the relief she feels knowing that her daughter will always need to be with staff, and will therefore have a form of protection.

One woman told me about creating a book of her own to help teach her daughter about sex and sexuality.

I more or less developed my little book myself and – I tend to customize things...and put it in a book form and make it almost like a storybook sometimes. And if it's about her and if it's customized for her, she gets it... It's easier for me to just do it myself. And she also needs reinforcement. So, she can walk around with her little healthy relationship boyfriend book. And she could look at it whenever she wanted and it's like a visual reminder for her. Because with our kids, nothing really sticks. So having things that are really constant reminders. You know? And especially storybooks about her.

This mother described the book as being particularly helpful, which illustrates the effectiveness of adapting resources to the individual.

### **Other Parents as Supports**

On top of the individual strategies, across all interviews parents spoke about other parents as allies. Referring to support she’s received in navigating issues of sex and

sexuality, one parent shared, “It's people that you can call up and say, ‘Wow, this is what happened and this is great,’ or, ‘This is what happened and I'm horrified,’ and we all get it, we've all been there and done that kind of thing.” One parent said that talking with other parents about her child’s masturbation was especially helpful.

I mean, I've caught her masturbating. You know, she was young, and it was like, ‘Oh my gosh!’ But I have enough other parents of kids with special needs, you know, so I've talked to them, and they've all said, ‘Oh yeah! Been there, done that!’

When the question of parental supports came up with one of the parents, she laughed and shared,

I remember when Malia was younger...and the doctors and everybody would always say, ‘Now, you need to get into a support group.’ And I'm like, ‘I don't need a support group!’ Because we would always somehow connect with other parents who had kids with some form of disability.... They would tell their stories, and you'd tell your stories, and they'd tell how they handled the situation, how you handled the situation. It was a learning experience. It was like our own little support group.

## **Hopes**

Through the conversations, parents also wove in their personal hopes.

Emphasizing the importance of these hopes, one parent aptly put it, “To not have the dream, I think really limits more kids than anything else.”

Most parents (N=5) shared hopes that their child will have satisfying relationships in his/her life, whether or not the relationship is sexual. “I would love for her to be able to have a full-blown relationship sometime,” one mother noted, “So, would I like her to enjoy a sexual relationship? Yeah.” Another expressed hope for her son, saying,

I want him to have that. I want him to have, you know, a person that he's really attracted to for the right reasons and that he sees himself spending his life with kind of thing. But, you know, knowing that there's definitely going to need to be supports there.

Only one parent reported having no hopes, responding to the question with, “No, just, no, actually I don't. I'm not sure what form that will take.”

Many (N=4) parents anticipated challenges in supporting their child in having a sexual relationship, but also noted that they would not deprive their child of such experiences. One parent did playfully remark, in reference to her daughter's hand-holding and casual kissing, “I hope she continues to enjoy the boundaries that she has.”

### **Minimization**

One mother in particular seemed to minimize her worries, through comparisons to her other children. This mother followed many of the concerns she shared with comments such as, “But then again, I think, well, that could happen to [other daughters] wherever they are,” or “Well, [other daughter] does that everyday and I don't think about that with her.”

### **References to “Others”**

Through our conversations, three of the parents made references to “other” parents or individuals in the field and their beliefs and/or practices.

As referenced above, one parent spoke about her frustrations in witnessing other parents' discomfort around acknowledging sexuality in their children with ID. Another spoke about not being “one of those parents” who might respond with, “Oh my god,” to their child expressing an interest in sex.

Another spoke of the fears that other parents might possess, saying that sexuality is “an area that probably is scary for a lot of parents,” and that, “I think it's maybe somewhat more scary for some people that – you know, not want to lose control because all the issues of abuse and thinking about protecting your kid when they're vulnerable.”

Three of the parents also noted that their child's partner has expressed more sexual curiosity than their child. One spoke about her son's girlfriend pressuring him to kiss her breasts; another spoke about the way in which her daughter's boyfriend's older age and typically-developing twin brother has contributed to his increased sexual interest.

So, they haven't kissed. They talk about it but they haven't done it. But, Dan on the other hand – Dan is 18. My daughter is 16. He is an identical twin and his brother is typical. So, he, unfortunately, has been exposed to a lot more than Kendall has because she's my oldest. So he has seen his brother with his girlfriends so he really aspires to have a typical boy-girl relationship.

### **Control**

Another way in which parents seemed to both protect their child and perhaps maintain their own comfort around these issues was through maintaining some control over their child's sexual lives.

One parent spoke of needing to “keep our eyes on them” when her daughter and daughter's boyfriend express affection. Another spoke about secretly monitoring her child's activities, admitting that, “I'm a sneaky mom - I check her cellphone as often as I can get to it and read through the texts that have gone back and forth.”

Another parent spoke about teaching her daughter about boundaries by framing it as what she, as the parent, approves of.

I mean, I've been very explicit to her about what my expectation is about what they can do and can't do. I've said, you know, I'm okay with you holding hands. I'm okay with a little hug, and a little kiss. And we kind of talk romantic kisses or just kisses and I keep telling them, "Not big romantic kisses." And, "Oh, I know, Ma!"

### **Humor**

While the concerns and worries were very real, through each interview parents were able to incorporate a balance of lightheartedness and humor, and take an “it is what

it is” stance. Whether laughing at personal interactions with other parents, or while retelling their own failed attempts to incorporate sex education into daily interactions, many (N=3) of the parents communicated that not everything can be taken too seriously.

Two of the parents used humor in discussing different sex education programs. One talked about an unsuccessful attempt to find an appropriate sex education class, while the other shared her opinions around traditional sex education and how her son might be able to apply his sexual knowledge in real-life situations.

I did go to this class that offers sexuality for everybody...I went for an overview of what the kids would actually be exposed to...And the woman encouraged me to send Carrie and I honestly didn't think it was appropriate for Carrie. And she said, 'Well, everybody benefits. You may think that she isn't going through things, but she is. And everybody benefits at some level.' But, this was a pretty hardcore class. (Laughs.) I mean – it was really...like... blow-up dolls. (Laughs.)

I'm sure that when he's in a relationship and, you know, something like putting on a condom becomes a lot more realistic, I'm not quite sure how I'd do that. I think the banana thing is kind of stupid. I can't see myself sitting there and going, 'Okay, now that you have an erection, let's open up the package!'

Upon ending our interview, one woman laughed and exclaimed, “That's the way it is! Conversations I never had with my mother!”

### **Comfort/Discomfort**

Three parents explicitly noted being comfortable talking about sex. One parent in particular spoke about her ease in using proper terminology, relating it to her job as a nurse.

Two parents seemed to express some discomfort through the interview. One mother in particular seemed uncomfortable speaking about her child’s sexuality, using euphemisms and hesitating with her language.



So, she's seen quite a bit of sexual, um, activity on TV and she knows the whole idea of, um, loving couples and sexuality and boyfriends and kissing. And I think she knows some of the mechanics of sex. She understands loving... but the full import of what a boyfriend would be, I don't think for her, is very clear. I think it's still a bit vague for her. Despite of the fact that she's had classes about, um, sex and about, you know, taking care of yourself, going to the, you know, doctor, and having appointments. She's never actually had one of those appointments where she's had an, um, exam or anything.

### **Generalizations**

As I spoke with the parents about sex, sexuality, relationships, development, etc., three of the parents spoke to concerns or experiences unrelated to sex and sexuality, or compared their experiences navigating these issues to other obstacles that have come up.

Speaking to frustrations with other parents, one mother noted,

But, you know, I can honestly say it's not always about sexuality either. It's about how a lot of parents view their kids' futures. Like, they don't see futures that can be anything close to a typical or what other kids are doing.

When talking about her efforts to provide her daughter with a sense of agency, another mother directed the conversation to a more general concern she has about her daughter.

And one thing that is in the back of my mind too is that a lot of kids at a certain point can tend to get depressed when they feel like they have limitations and they want to be able to do certain things that maybe they're not able to do. And that they're kind of coming to terms with their disability in a way that can be hard for some kids... I hope we can help her get through some of those feelings without feeling that she's, you know, less-than, or that there's lots of things that she can't do because, you know, there's lots of things she can do. And if she can focus on the positives in her life, then there's a lot she can do. Of course you want to protect your kids from feeling badly about themselves.

A third parent compared the way in which her daughter is receptive to her input on sex- and sexuality-related matters to the way in which she generally operates in the world.

You know, the thing with Malia – and I don't know if it's this way with everybody with a disability – but it's like, you just go, 'This is the way it is.' And she's like, 'Okay.' You know, whereas one of the other girls (daughters) could say, 'But, what if...?' And Malia is like, 'This is the way it is.' She's like, 'Okay.' Like, with anything else. 'Malia, when you take your clothes off, you either put them in the dirty clothes basket or you hang them up and put them away.' 'Okay.' Whereas [other daughters] would say, 'Yeah, but I like laying mine on the floor.' But with everything, that's just kind of the way it is with her, which is kind of nice.

## CHAPTER FIVE

### Discussion

This study examined parents' experiences navigating issues of sex and sexuality with their teenage and young adult children with intellectual disabilities (ID). Parents were asked to discuss their perceptions of their children's understanding of sex and sexuality, as well as the role that they play as parents as it relates to these issues.

#### Key Findings

The interview was formally structured to have separate sections. One section was for questions related to the children's knowledge and experience, and another section was for questions related to the parents' experiences.

#### **Parents' perceptions of their children's sexual knowledge and experience.**

Research has indicated that individuals with ID have significantly lower levels of knowledge and understanding of sex and sexuality than do those without ID (Galea, Butler, Iacono, & Leighton, 2004; Healy, McGuire, Evans, & Carley, 2009; Isler, Tas, Beytut, & Conk, 2009; Lamorey and Leigh, 1996; McCabe, 1999; Swango-Wilson, 2009; Walker-Hirsch, 2007). Not surprisingly, across all interviews in the current study, parents perceived their children as having a lack of sexual knowledge. Parents generally attributed this lack of knowledge to inadequate sex education, and/or cognitive limitations in their child. One child was intentionally excluded from formal sex education at her school, and, as might be expected given the research (Aunos & Feldman, 2002; Boehning, 2006; Löfgren-Mårtenson, 2004; Resch et al., 2010; Wolfe and Blanchett,

2003), all four of the parents who noted that their child had received formal sex education indicated that it was inadequate in some way.

The research is generally lacking in exploring the ways in which people with ID have *adequate* understandings of sex- and sexuality-related issues. The focus tends to be more on the absence of understanding. In this study, however, parents discussed the struggles and inadequacies in their children's understandings, while also focusing attention on the ways in which their child has demonstrated accurate knowledge of and interest in sex and sexuality. In fact, each parent incorporated stories of positive and healthy aspects of their child's sexuality.

Each parent described their child as having some sexual knowledge and sexual interest. The sources of knowledge were cited as formal sex education, informal sex education, observation, experience, and media influences – resources used by many to learn about sex and sexuality. Parents spoke to their children's knowledge around human anatomy, the menstrual cycle, or different sexual behaviors, such as “French kissing.”

The acknowledgment of each child as having an interest in sex and sexuality was a finding I expected, as sexuality is not tied to IQ, and each child is at an age where sexual interest is typical (Walker-Hirsch, 2010). A person with developmental disabilities has “the same requirements for love, affection, and fulfilling interpersonal relationships as does any other person” (Di Giulio, 2003, p. 58). Thus, recognition of sexual interest within the children was not surprising to me, nor to the parents in this study.

Each parent also discussed sexual experiences their child has had. All parents reported that their child has been involved in romantic relationships and several noted being aware of their child engaging in intimate behaviors such as kissing and hand-

holding. All of the parents said that their child has not had sexual intercourse. Most of the parents noted keeping open communication with their child around sex and sexuality, and spoke confidently about their perceptions of their child's knowledge and interest. Given the special needs of teenagers and young adults with ID, and given the close relationships between parents and children in the current study, it made sense that parents felt as though they had a pulse on their children's sex lives.

One parent, however, shared a story that revealed some uncertainty around what behaviors her daughter may be engaging in with her boyfriend.

Dan texts me a lot, and he texted me and he said, 'Did Kendall tell you we kissed today for the first time?' And I was like, 'Oh!' I said, 'No she didn't.' ... And when I asked Kendall about it, she said, 'No we didn't.' And she said, 'We did something else.' And I said, 'What do you mean you did something else?' And she said, 'Nothing.' I said, 'Well he said he gave you a kiss.' And she said, 'No, he didn't! We didn't do anything.' So, my suspicion is that something happened that day, but I still don't know what.

Thus, despite the seeming confidence exhibited by many of the parents, this story demonstrates that boundaries around disclosure may exist between parent and child. This story also emphasizes the fact that in studies such as this, the information on sexual knowledge and experience of the individuals with ID is second-hand, and serves as a reminder that we can only be experts of our own experiences.

Parents also noted some sexual disinterest in their children. It is difficult to know whether or not this is related to the child's intellectual disability. Only one parent made such a connection, referencing her daughter's sensory issues as contributing to her disinterest in touch. On one hand, one could argue that the sexual disinterest noted by these parents is likely unrelated to their disabilities, as the biological development (including hormone production) of individuals with ID is typically similar to those

without ID (Walker-Hirsch, 2010). Thus, there might not be a biological basis for the disinterest. However, for people with ID, “the social, emotional, intellectual and experiential maturity is most likely to lag behind that of typical children” (Walker-Hirsch, 2010, p. 4). Thus, it is possible that social factors could contribute to teenagers and young adults with ID having lower levels of sexual interest than same-aged individuals without ID.

In discussing boundaries, parents spoke to experiences of noticing appropriate and inappropriate personal or interpersonal boundaries held by their children. Parents were prideful when sharing stories of observing their children enforcing appropriate boundaries. One parent warmly shared a story about her daughter’s boyfriend asking if he could touch her daughter’s breasts, to which her daughter responded, “I’m a girl and you’re a boy, and that’s girl stuff.” Given the high incidences of abuse and vulnerability among people with ID (Bowman, Scotti, & Morris, 2010; Groce, 2003; Walker-Hirsch, 2007), this pride also seemed to be communicating relief and feelings of reassurance that their children had retained information around appropriate interactions.

There is evidence that at least a few of these children have encountered situations in which their safety was at risk. Despite stories around compromised safety being something I had anticipated hearing, the stories were sad and frightening, and reminders of the many factors that may be out of parents’ control when it comes to protecting their children. I was impressed by the parents’ ability to share such personal stories with me and allow themselves to be vulnerable.

**Parents' personal experiences managing issues related to their children's sexuality.**

Each parent was able to recognize their child as having some form of a sexual identity, consistent with the way people with disabilities are increasingly being appreciated as sexual beings. Worth noting, however, is the voluntary nature of this study. Participation in this study may have appealed more to parents who are able to appreciate their child's sexuality in the first place. Nonetheless, the confirmations were encouraging.

Parents' discussions of their children's sexual knowledge and experience, and their own experiences were often intertwined. When I asked my first participant the opening interview question ("What impression do you have about what your child knows about sex and sexuality?"), she responded by discussing her daughter's understanding of her menstrual cycle, which segued into a story about how she has used her daughter's cycle to initiate conversations about sexual intercourse with her daughter. The same pattern was noted through interviews, which made more and more sense as I got to know and understand these parents. Given the close relationship between child and parent, as was reported by each parent, it is not surprising that stories about their children almost always involved discussion of their own reactions, interventions, emotional responses, etc. In the end, these connections were what made the interviews so rich and powerful.

As I listened to these stories, I felt as though I was being welcomed into the lives of these parents. The undertones of pride and caring were unmistakable. As suggested in the study by Boström, Broberg, and Hwang (2010), the positive narratives and outlooks

seemed to support the parents in this study with maintaining a balanced stance and resilience around navigating these serious issues with their children.

Each parent spoke about providing sex education to their children, though they varied in the ways in which the education was provided. Across all interviews, parents seemed to be more cautious than liberal in information sharing. This may be related to common concerns that sex education will increase the likelihood of sexual behaviors (Isler, Tas, Beytut & Conk, 2009; Page, 1991), as each parent made some reference to being mindful of the information they share, and one in particular mentioned hoping her child stays satisfied with having “a boyfriend that she can tickle and, you know, hold hands and give a kiss to once in a while.”

In regard to education, parents also noted their child’s cognitive limitations as interfering with their ability to understand or absorb information about sex and relationships. To me, this indicated the participants’ ability to hold a balanced perspective; that is, they were able to appreciate what is the fault of the education system, and what expectations are realistic for their children in general.

Another common theme involved parents playing an active role in their children’s sexual identity development or explorations, whether it be in regard to teaching appropriate boundaries, helping to navigate breakups and new relationships, or providing support in pursuing sexual interests. One parent spoke about the lengths she went to to help her daughter and her boyfriend gain comfort holding hands; another spoke about intervening when her daughter was going to break up a friend’s relationship and teaching her that “it is okay to not have a boyfriend for a little while.” These stories demonstrated the parents’ commitments to supporting and protecting their children, and reinforced the



love and care they expressed as having for their children. The stories also revealed the level of need among the children. One mother made an interesting comment that illustrated this.

Like, they don't know what to do so it's, you know, it's such a different experience. And, I said, it's kind of weird because I'm sure all teens and adolescents go through this. You know, how do I do what? And, how does this all work? But they (children without ID's) don't express those things to their parents.

This mother seemed to be speaking to the way in which involvement is a necessity given her child's lack of knowledge and experience, and also to his special needs when it comes to navigating these issues.

As noted above, parents varied in the ways in which they supported their children, and the resources they accessed. Resources parents referenced included books, websites, and workshops. Parents also spoke about individualized strategies. One mother gave her daughter a puppy, as an alternate to caring for a baby; another spoke about providing her daughter with a cellphone for use in emergencies. I was particularly impressed by one mother's strategy to create an individualized book for her daughter. The book was sex educational, and used pictures and stories about her daughter to allow for the information to be relevant, and therefore better understood. Personalizing the teaching materials may be one way that parents of children with ID can better communicate complex and complicated topics such as sex and sexual relationships.

Across all interviews, parents spoke to adopting proactive and realistic stances in navigating issues of sex and sexuality with their children. The proactive stances seemed to tie into parents' desires to protect their children, help them develop their sexual identities, and maintain a sense of control over their children. Parents presented both

stances neutrally. That is, there was neither a sense of disappointment around needing to face these issues, nor a sense of celebration around supporting their child's explorations.

The need to be realistic may also be related to the more general experience of raising a child with a disability. Two of the parents described their reactions upon hearing their child's diagnosis. One mother noted that, "We definitely went through the grieving thing, and, um, weren't necessarily happy that he had the diagnosis, but, you know, he was our kid and it didn't matter."

Another mother described how her child's diagnosis has impacted her parenting goals.

And when I realized that she was going to be okay from a medical standpoint...I just was, like, so happy that she was alive. And from that point forward, I decided that, like, I.Q. really didn't matter that much in the big scheme of things. The goal is really to raise your child so they're happy. Happy, well-adjusted... we all want our children to live happy, productive lives. So that's my goal.

As noted above, safety concerns among parents emerged as a major theme. Again, this was not surprising, given the research (Isler, Beytut, Tas, & Conk, 2009; Pueschel & Scola, 1988; Swango-Wilson, 2009). For two parents, discussion of safety arose after I asked about worries around their child's sexual exploration. It is hard to know whether or not the topic would have come up unprompted, but both of these parents spent significant time talking about their safety concerns.

Another parent initiated discussion of safety issues early in the conversation by sharing the story about her daughter being taken advantage of. It seemed as though a desire to share this story may have fueled this mother's interest in the study.

One parent made several references to worries around her daughter exploring further than kissing with her boyfriend. When asked about her fears around this, she said

that her biggest concern is that “their natural urges take over.” The deeper reasons behind this worry were not expressed.

Only one mother did not express concerns about her child’s safety around sex-related issues. This parent was the mother of the only male child in the study. When asked about concerns, this mother responded by sharing her worries around how she might be able to support her son were he to decide to have sexual intercourse. She did not mention concerns of safety. Given how pervasive safety issues are in the research, I was surprised that it did not come up during our conversation. However, given that most reports of sexual abuse are from women, it is possible that fear of her child being victimized may be less present given her son’s gender (American Association on Intellectual and Developmental Disabilities, 2011).

Five of the parents shared having hopes for their children, as they relate to sex and relationships. One parent said she did not have hopes for her child. Looking at the larger picture, this was surprising. However, given that this was the mother who shared the story of her daughter being taken advantage of, it felt more understandable. This mother may have anxieties around the topic, may hope that her child does not end up in a relationship, or may feel uncertain as to her hopes after the incident – all of which might result in a denial of fantasy about her daughter’s future sexual relationships.

Minimization was observed in one parent. This mother seemed to minimize concerns around her daughter’s safety by arguing that she does not have such concerns for her other children who do not have an ID. This minimization seemed to serve several purposes. On one hand, it may be adaptive. As described by Rudy and Grusec (2006), “in most cases it would not be adaptive for parents to constantly ruminate about problems

with children that have occurred in the past, or may occur in the future” (p. 91). However, the minimization may also be maladaptive. Parents who minimize may have difficulty noticing their child’s emotions, affect, or perspective; and may be more strict to demand compliance and use “low-level reasoning (e.g. ‘Because I said so’) or normative statements (‘Good girls listen to their parents’) rather than reasoning that addresses their child’s perspective” (Rudy & Grusec, 2006, p. 92). During my interview with this mother, I sensed that her minimization was at times supporting her in staying realistic, and at other times, defending against her own anxiety.

Another pattern observed in my conversations with parents was the use of generalizations. In half of the interviews, when responding to questions or comments about sex or sexuality, parents made references to their experiences raising their other children, other obstacles (unrelated to sex and sexuality) that they have encountered raising their child, or the experiences of other parents of children with ID. Making generalizations or drawing such links is not unlike the way in which many people learn to manage and understand situations. Making comparisons to other obstacles or life experiences seemed to help these parents maintain perspective and may also be helpful in figuring out the best ways to support their children.

Parents generally seemed comfortable talking with me about sex and sexuality, though one mother seemed uncomfortable, as evidenced through her tone and word choice. This mother was also more conservative in the information she shared. Talking about sex is often considered taboo, and it is a topic that makes many uneasy. Combine this with talking about your children having sex, and it can certainly lead to anxiety. However, this discomfort surprised me, as I had expected that only parents comfortable

with talking about sex would choose to participate in the study. Nonetheless, this mother's participation indicated to me that despite her possible discomfort, she acknowledges the importance of confronting these issues.

Across all interviews, parents spoke about receiving informal support from other parents of children with disabilities. Past research has found "informal support" to be a significant and meaningful resource for parents of children with disabilities (Lindblad, Holritz-Rasmussen, & Sandman, 2007). In their study on informal supports used by parents of children with disabilities, Lindblad, Holritz-Rasmussen, and Sandman (2007) referenced interpersonal relationships, and described their value in providing parents with space for genuine expression of emotions.

Informal support also means to be provided a room for sorrow and joy and this is experienced as closely intertwined...Being provided a room for sorrow means an awareness of being enabled to share experiences of heavy feelings, which are too burdensome to carry alone. This implies being allowed to openly communicate current feelings of sorrow, sadness and worries connected to the child's disability and the strenuous situation of the family including worries for the siblings. Here, the parents feel, that they are taken seriously and encouraged to be honest about their feelings. (p. 243)

The parents in the current study similarly described the value of mutually supportive relationships with other parents. Participants spoke to how other parents "get it" and provide "our own little support group," one woman saying that, "we get through some trying times through the support of other parents." The experience of raising a child with special needs is unique, and utilizing the advice, experience, and support of other parents of children with special needs allowed these parents to both gain tools to help support their own children, as well as feel understood in their own experiences.

The humor that emerged as another theme across interviews can be understood as serving various purposes. In some instances, the lightheartedness seemed to come from an adaptive stance of needing to “pick your battles.” That is, parents did not feel a need to take everything seriously, and could instead laugh at themselves and their experiences. In other instances, humor seemed to be used as a way to deny or avoid the discomfort around the topic of sex and the worries and concerns it triggers in the parents. Laughing may be easier than facing the often-scary reality.

### **Limitations**

Interpretative phenomenological analysis (IPA) was used in this study to allow for a deeper understanding and exploration into these parents’ experiences. Unlike some other modes of analysis, the purpose of IPA is more on understanding individual experience, and less on making large generalizations (Smith & Osborn, 2003). Thus, it is important to note that the group of parents that I interviewed is not likely representative of the general population of parents of teenage and young adult children with ID, and therefore, their experiences may not be. Such representation would be impossible with such a small sample size collected in this manner.

The demographics of the parents in this study also limits this study’s representativeness and generalizability. Though IPA encourages homogenous samples (Smith & Osborn, 2003), I did not take any steps to intentionally limit the diversity of my sample. Nonetheless, the six parents in this study had similar demographics in relation to gender, age, race, religion, employment status, and marital status; and each child had similar demographics in relation to gender, age, race, religion, and intellectual disability diagnosis.

The representativeness of this study's participants is also limited by the fact that parents self-selected to be in this study. They may have been drawn to it for various reasons – individual interest in the topic area, strong opinions about sexuality, an eagerness to share stories with an objective listener, etc. Thus, the parents represented in this study may have particular views that limit this sample representativeness.

In addition, it is possible that parents may have withheld or inaccurately represented information to me during the interview. Discomfort around talking about sex, talking about their children, or social pressures may have led parents to share certain stories over others, or present themselves in a more desirable light.

Only one of the interviews was conducted in person, with the other five conducted over the phone. The different modes of communication may have impacted parents' comfort levels and/or information sharing, and the phone interviews did not allow for me to pick up on some of the nuances in facial expressions or affect that can be detected in person.

### **Implications**

This study provided an intimate look into the lives of parents as they have navigated issues of sex and sexuality with their teenage and young adult children with intellectual disabilities. Unlike studies done in the past, the nature of this study allowed parents the flexibility of sharing a variety of stories – positive, negative, humorous, scary, etc.

The information gathered in this study will allow for a greater appreciation of these parents' experiences and needs. Through sharing their stories and emotions, these parents have given voice to a topic that can be uncomfortable or taboo, and taken the

discussion in new directions. From these data, it is clear that there is a greater need for more proactive forms of sex education for people with ID. However, given the unique needs of this population, methods for *adequately* teaching and supporting these children and their families around issues of sex and sexuality may still need to be formulated. Special considerations, such as comprehension level of the child, child readiness, and finding ways to involve the family in the educational program, may be needed to allow for more effective teaching. Given safety concerns around sexual encounters and the likely variable levels of understanding and education around sexuality on the parents' part, a more standardized but sensitive educational program is warranted. Without such a program, the largest burden for sex education falls on the parents. The parents in this study revealed the great efforts that have gone into supporting their children through their sex education and sexual identity development, and demonstrated a dedication to their children. Yet even these parents, whose creativity and resourcefulness were plenty, also expressed their challenges around providing their children with adequate and effective support, thus highlighting the need for continued attention paid toward the sexual needs of people with intellectual disabilities.

For service workers, this study provides a well-rounded, honest look at the challenges, joys, fears, and needs of these parents. It opens the door to exploring the ways in which parents are impacted by their child's sexual and sexual identity development, and the ways in which they have navigated their roles. Issues of sex and sexuality are often overlooked, and this study highlights the importance of addressing them.

For other parents of children with ID, this study validates the uniqueness of each experience, while also showing the common threads. The emotional experiences shared



will help support parents who may be going through similar processes with their children, and the interventions, tools, and resources described will contribute to parents' ability to best care for their children and themselves.

### **Conclusion**

This study examined parents' experiences navigating issues of sex and sexuality with their teenage and young adult children with intellectual disabilities. Parents spoke to their children's areas of sexual interest and disinterest, varying levels of sexual knowledge, and sexual experiences. Parents also discussed their personal experiences supporting their children through their sexual development and exploration, sharing stories of pride, struggle, worry, and hope. This study highlights the importance of supporting teenagers and young adults with ID as well as their parents as they navigate issues of sex and sexuality and express themselves as sexual beings.

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## Appendix A

### Book Suggestions

Couwenhoven, T. (2007). *Teaching children with Down Syndrome about their bodies, boundaries, and sexuality*. Bethesda, MD: Woodbine House

McGuire, D. & Chicoine, B. (2006). *Mental wellness in adults with Down Syndrome: A guide to emotional and behavioral strengths and challenges*. Bethesda, MD: Woodbine House.

Walker-Hirsch, L. (2007). *The facts of life and more: Sexuality and intimacy for people with intellectual disabilities*. Baltimore, MD: Paul H Brookes Publishing Co.

## Appendix B

### Human Subjects Review Committee Approval Letter



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Smith College  
Northampton, Massachusetts 01063  
T (413) 585-7950  
F (413) 585-7994

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November 9, 2010

Jessica Markowitz

Dear Jessica,

Your second revision is fine and we are happy to give final approval to your study.

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*Please note the following requirements:*

**Consent Maintaining Data:** You must retain all data and other documents for at least three (3) years past completion of the research activity.

*In addition, these requirements may also be applicable:*

**Amendments:** If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

**Renewal:** You are required to apply for renewal of approval every year for as long as the study is active.

**Completion:** You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your interesting project. My guess would be that parents of these children are very fearful or concerned about poor judgment and sexual acting out. That's a guess (with a little experience with some parents dealing with this). It will be interesting to really find out.

Sincerely,

A handwritten signature in cursive script that reads 'Ann Hartman'.

Ann Hartman, D.S.W.  
Chair, Human Subjects Review Committee

CC: Jill Clemence, Research Advisor

## Appendix C

### Informed Consent Form

Dear Participant,

My name is Jessica Markowitz, and I am a graduate student at Smith College School for Social Work. I am conducting a research study in which I will explore parents' perceptions of the sexual knowledge and identity development of their teenage and young adult children with intellectual disabilities, as well as provide a look into the parents' experiences as they navigate these issues. This research will be used for my Master's thesis in clinical social work, and the findings may be presented in future papers and presentations.

As a participant, you will engage in one in-person, phone or video-chat interview. I will conduct the interview, which will run about one hour in length. In order to participate, you must be a biological or adoptive parent (or parent couple) of a child between the ages of 13-25 who has a diagnosis of an intellectual disability. You (or at least one member of a parent couple) must have raised your child since infancy.

The interview will involve discussion about how your child's sexual development has impacted you as a parent. You will also be asked to provide general demographic information about you and your child in regard to gender, age, race, ethnicity, occupation, marital status, number of children, your child's diagnosis, religion, sexual orientation, and for adoptive parents, the age of your child at the time of adoption. This information will allow me to characterize the diversity of my sample in the thesis report. The interviews will be recorded or video taped. This study is completely voluntary and you will only be asked to share information that you are willing to share. However, the topic itself may cause discomfort for some. You may withdraw at any time up until 7 days after the interview is completed, or decline to answer specific questions, and you will be provided with a list of referral sources in case additional support is needed. Although I am unable to offer financial compensation for participation, you may experience other benefits of volunteering. By participating in this study, you will provide valuable information about the experience of having a child with an intellectual disability who is navigating issues of sex and sexuality. You will be given an opportunity to share your personal stories about how these issues affect you as a parent and the ways in which you have managed them. These stories will add rich information to the field and provide implications for further research and better ways of supporting you and your child.

Confidentiality will be maintained, and no identifying information will be included in the final thesis. I will be the sole handler of the information you share during the interview, and my research advisor, who will assist me in my work, will only have access to the interview transcriptions once all identifying information has been removed or disguised. In publication or presentations, the data will be presented in aggregate form, and when any of your individual vignettes or quotes are used, they will be carefully



disguised. When interviewing a parent couple together, confidentiality will be limited by each parent hearing the other's responses; however, the same precautions will be taken to ensure confidentiality of the data collected after the interview. As required by Federal guidelines, all data (including interview recordings and transcriptions) will be kept in a secure and protected location for a period of 3 years and then destroyed. Should I need the materials beyond the 3-year period, they will continue to be kept in a secure location and destroyed when no longer needed.

Your participation in this study is entirely voluntary. You may refuse to answer any question and may withdraw from the study at any time up until 7 days after interview is concluded. If you choose to withdraw, all materials pertaining to you will be immediately destroyed. If you have any additional questions or wish to withdraw, please contact me via email at [jmarkowi@smith.edu](mailto:jmarkowi@smith.edu), or phone my cell at (*number removed for privacy*). Should you have any concerns about your rights or any additional aspect of the study, I encourage you to contact me at the email or phone number listed above, or contact the Chair of the Smith College School for Social Work Human Subjects Review Committee at (413) 585-7974.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

---

Participant Signature

---

Date

---

Researcher Signature

---

Date

Please keep the provided copy of this form for your records.

Thank you for your participation,  
Jessica Markowitz

**Appendix D**  
**Interview Guide**

I. Opening:

Tell me about the relationship you have with your child.

II. Sexual Knowledge and Identity Development of Child

- 1.) What impression do you have about what your child knows about sex and sexuality?

*Prompt:* Has your child ever shown signs of knowing things about sex?

*Prompt:* Not knowing?

- 2.) What impression do you have about whether or not your child is curious about sex?

*Prompt:* Has your child ever asked questions?

*Prompt:* Does your child seem curious?

*Prompt:* Shown any signs of an interest/disinterest?

- 3.) What is your understanding of your child's knowledge around safe sex?

*Prompt:* Understanding of what constitutes abuse or inappropriate touching?

*Prompt:* Understanding of what constitutes inappropriate language or verbal harassment??

*Prompt:* Protection?

- 4.) Has your child ever had any formal sex education?

- a. If so, in what form?

*Prompt:* Do you think it was effective?

- b. If not, have you ever provided informal sex education?

*Prompt:* What was that like?

*Prompt:* Do you think it was effective?

- 5.) Is there anything you think I left out or any other information you'd like to share?

### III. Experience as Parent

- 1.) What has it been like for you, navigating these issues of sex and sexuality as you raise your child?

*Prompt:* How does it impact you on a personal level?

*Prompt:* How does it impact you on an emotional level?

*Prompt:* How does it impact the way you view the world?

*Prompt:* How does it impact your daily life?

- 2.) Do you have concerns about your child in regard to sex and sexuality?

- 3.) Do you have hopes for your child in regard to sex and sexuality?

- 4.) What supports have you found for taking care of yourself?

*Prompt:* Have you been able to connect with others around these issues?

- 5.) Is there anything you think I left out or any other information you'd like to share?

- 6.) Do you have any questions for me?

## Appendix E

### Recruitment Flier

# Seeking Parents for Study on Raising Children with Intellectual Disabilities

My name is Jessica Markowitz, and I am a graduate student at Smith College School for Social Work. I am conducting **research on parents' experiences navigating issues of sex and sexuality with their teenage and adult children with intellectual disabilities.**

For individuals with intellectual disabilities, it is often crucial, yet difficult to develop appropriate and necessary sexual knowledge. For parents, helping to navigate these issues may be a daunting task; one that may even influence their own lives on a personal and emotional level

### What has the experience been like for you?

I am seeking biological or adoptive parents or parent couples of individuals ages 13-25 with an intellectual disability for in-person, phone, or video-chat interviews. This research will be used for my Master's thesis and steps will be taken to safeguard confidentiality.

Through sharing your stories, you will help others recognize, appreciate, and understand your experiences as parents, and help inform the ways in which the needs of both you and your teenage and adult children may be best addressed.

If you have any questions, would like more information, or are interested in participating, please contact me via email ([jmarkowi@smith.edu](mailto:jmarkowi@smith.edu)) or phone (*number removed for privacy*). If you know of others who may be interested or able to help in this recruitment process, please pass along this information.

### Thank you!

Jessica Markowitz  
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