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Important Conversations: Exploring Parental Experiences in Providing Sexuality Education for their Children with Intellectual Disabilities

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IMPORTANT CONVERSATIONS: EXPLORING PARENTAL EXPERIENCES IN PROVIDING SEXUALITY EDUCATION FOR THEIR CHILDREN WITH INTELLECTUAL DISABILITIES

by

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ABSTRACT OF DISSERTATION

IMPORTANT CONVERSATIONS: EXPLORING PARENTAL EXPERIENCES IN PROVIDING SEXUALITY EDUCATION FOR THEIR CHILDREN WITH INTELLECTUAL DISABILITIES

Parents typically serve as the primary sexuality educators for their children. This qualitative research explored the experiences of parents from Arkansas in providing sexuality education to their children with intellectual disabilities. Semi-structured interviews were used to obtain the perspective of parents, followed by transcription and coding of data. The analysis of the interview data resulted in several themes related to effective comprehensive sexuality education. Themes discussed in this paper include the individual and unique needs of each child and their family, parents needing collaborative support from other knowledgeable adults, and clear communication in relation to communication partners, communication mode, and regarding topics and skills deemed necessary by parents.

KEYWORDS*:* sexuality education, intellectual disabilities, parent experiences, qualitative interviews, self-determination, relationships

I would like to dedicate this work to Tammy Browne, Rashon Eyres, and Mirande Eyres. Thank you for the constant support provided by each of you throughout my doctoral program – we did this together!

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All students, regardless of their intellectual ability are sexual beings and deserve access to sexuality education (Treacy et al., 2018; Franco et al., 2012). In practice, however, most students with significant intellectual disabilities are denied access to sexuality education (Barnard-Brak, 2014; Schaafsma et al., 2015; Sinclair et al., 2015; Swango-Wilson, 2009) A majority of parents do believe that sexuality education is important for their children or young adults with intellectual disabilities, however, most feel unprepared to teach sexuality education concepts (Barnard-Bark et al., 2014; Swango-Wilson, 2009).

Access to sexuality education is often limited by multiple barriers, including parental and practitioner personal beliefs and stereotypes, lack of sexuality training opportunities, and/or unfounded fear that such education may lead to promiscuous behaviors by those they teach (Sinclair et al., 2015; Lafferty, et al., 2012; Wilkenfeld & Ballan, 2011; Healy et al., 2009; McConkey & Ryan, 2001). These barriers often prevent individuals with intellectual disabilities from receiving adequate, if any, instruction regarding sexuality (Wilkenfeld & Ballan, 2011).

Current literature identifies three main themes regarding sexuality education and individuals with intellectual disabilities. The themes include denial of sexuality education, existing barriers to sexuality education, and misconceptions and

unpreparedness of those in positions to provide sexuality education for individuals with intellectual disabilities.

Fear of not knowing what, or how, to teach concepts often results in many parents providing limited or even denying sexuality education to their children or young adults (Barnard-Bark et al., 2014; Rienzo et al., 2005; Aunos & Feldman, 2002). Review of previous research indicates that supporting parents or caregivers by providing sexuality education training has the potential to increase access to sexuality education for their children (Eyres et al., 2016). Providing comprehensive sexuality education to children can improve understanding of self, understanding of safety skills and increase capacity to make sexually related behavior decisions (Meaney-Travares & Gavidia-Payne, 2012; Wilkenfield & Ballan, 2011; Dukes & McGuire, 2009) such as consent, personal space, sexual health care, and safety skills.

Many parents feel that resources not being available to help guide them on teaching sexuality education topics presents a barrier in providing instruction to their children with intellectual disabilities (Pownall et al., 2012; Swango-Wilson, 2008). Parents are typically not aware of the resources available because many of the professionals and agencies that work with families and individuals with intellectual disabilities are not aware of the resources that do exist (Eyres et al., 2018). Many of the materials and resources advertising to meet the needs of children with intellectual disabilities, many do not include specific outcome goals and most have not been evaluated for effectiveness (Schaafsma et al., 2015).

According to the findings of Franco et al. (2012), parents, caregivers, and educators often hold misconceptions that teaching sexuality education should be primarily concerned with male and female sexual anatomy and the act of heterosexual sexual intercourse. In actuality, comprehensive sexuality education reaches well beyond the physical aspects of intercourse and encompasses many topics (Breuner & Mattson, 2016; Murphy & Elias, 2006) such as personal hygiene, understanding the concepts of public versus private places and behaviors, relationship skills, personal space, and sexual health.

Providing sexuality education to students who have intellectual disabilities is crucial (Ailey, 2003), however often not provided. Barnard-Bark et al. (National Longitudinal Transition Study-2, 2014) found that students with the most significant intellectual disabilities most often did not receive any formal sexuality education (Lafferty, et al., 2012; Wilkenfeld & Ballan, 2011; Healy et al., 2009; McConkey & Ryan, 2001). Treacy's et al. (2018) call to action included a need for further research into sexual health education for students with disabilities and information to help guide resource development to support families.

A majority of parents and of children and young adults with disabilities reported that they believed sexuality education was important, however it was also reported that most felt unprepared to implement instruction of sexuality education components (Barnard-Bark et al., 2014; Pownall et al., 2012; Swango-Wilson, 2009). Schaafsma et al. (2015) recommended

a need for sex education program for students with intellectual disabilities to not only address knowledge of important behaviors but also the generalization of skills into real life situations.

Eyres et al. (2016) indicated that professional development opportunities may increase the likelihood of sexuality education instruction provided to children with intellectual disabilities. Sexuality education skills instruction is shown to correlate with a positive impact on quality of life for individuals with intellectual disabilities (Lockhart et al., 2010).

Comprehensive Sexuality Education

Limited research exists in exploring comprehensive sexuality for children with intellectual disabilities, especially those with moderate to severe intellectual disabilities. The literature indicates that children with disabilities are systematically denied access to comprehensive sexuality education and opportunities to express themselves sexually (Treacy et al., 2018; Sinclair et al, 2015; Barnard-Bark et al, 2014; Winges-Yanez, 2014; Wilkenfeld et al, 2011; Ballan, 2011; Dukes et al, 2009; SIECUS, 2004; Ailey et al., 2003). The components of

comprehensive sexuality education may support parents as they navigate what and how to teach their children.

In the United States, guidelines for comprehensive sexuality education are set forth by the Sexuality Education and Information Center of the United States (SEICUS, 2004) and detailed in the Future of Sex Education's National Sexuality Education

Standards, K-12 (Future of Sex Education, 2012). In addressing the comprehensive sexuality education needs of people with intellectual disabilities, SEICUS asserts that all people have a right to education regarding sexuality, sexual health care, and opportunities for socializing and sexual expression. SEICUS also notes that all those in a position to provide comprehensive sexuality education (e.g., school staff, family members, caregivers) should receive training in understanding sexual development, behavior, and health care needs for individuals with disabilities

Purpose and Research Questions

The purpose of this qualitative study is to explore parent experiences in providing sexuality education to their children with moderate to severe disabilities. While extending the Treacy et al. (2018), Eyres et al. (2016), Schaafsma et al. (2015), Sinclair et al. (2017) and Pownall et al. (2010) studies, this study addresses two questions: First, what are parent experiences in providing sexuality education instruction to their children with intellectual disabilities? Second, how do components of comprehensive sexuality education relate to parent experiences in providing instruction to their children?

Methods

Qualitative interviews of nine parents from the United States living in Arkansas were conducted to explore their experiences related to providing sexuality education instruction to their children with moderate to severe disabilities. In-depth interviews were used in an effort to provide coherence and density to data collection, and to help the researcher understand better the lived experiences shared by parents (Weiss, 1994).

I am the mother of two children with disabilities. My fourteen-year-old daughter has multiple disabilities, including a moderate to severe intellectual disability. My younger adult sister has moderate to severe intellectual disabilities and I have twenty-three years' experience teaching students with moderate to severe disabilities. I feel a heavy burden to "get it right" so that parents feel more confident in teaching sexuality education topics in "just the right way" to help keep their children healthy, happy, and safe.

Participants

Purposeful sampling was used to recruit parents to participate in the in-depth interview process. Eligibility criteria for participants included having at least five years of experience being the parent of a child or young adult with a moderate to severe intellectual disability who was at least fourteen years old but not older than thirty years old. Recruitment included verbal invitations via local parent/caregiver support network groups and a call for participants flyer shared with interested participants.

Nine parents participated in the study. Of the nine participants, five were mothers

and four were fathers; six were parents of daughters and three had sons. Participants ranged in age from forty-one to sixty-four and their children or young adults spanned in ages from fifteen to twenty-nine. All participants were either African American or European American; two mothers and one father were African American and three mothers and three fathers were European American. All parents completed high school; three completed a college degree; and five completed at least one graduate degree. All participants reported being in the socio/economic status of middle or upper class; two mothers and two fathers in upper class and three mothers and two fathers in middle class. Included in the nine participants were three sets of heterosexual married couples. Two couples agreed to do separate interviews, but one couple requested to do the interview together meaning that the study includes nine participants and eight interviews. To help ensure the confidentiality of participants, pseudonyms were used. Table 1 displays participant demographics.

Procedure

Prior to scheduled interviews, a consent form was sent to each participant. Participants emailed their signed consent forms to the primary researcher indicating agreement to volunteer for the interview. Participants also received a copy of the interview guide and a copy of the SRE Child Checklist (Hartman, 2013) before their interview. The SRE checklist includes a list of comprehensive sexuality education learning concepts including gender, puberty, personal hygiene, public and private

concepts, safety skills, sexual health, sexual identities, contraception, pregnancy, birth, among other topics.

Providing the interview guide and the SRE checklist prior to the interviews served several purposes: First, it helped participants reflect on their experiences prior to the interview. Second, participants were able to review topics related to comprehensive sexuality education. Reviewing these topics increased likelihood that their shared experiences would produce data with substance. Third, access to the materials helped parents feel prepared for the interview.

A semi-structured interview guide used to explore the experiences of mothers who provided sexuality education to their children with autism spectrum disorders (Eyres, 2020) was adapted and updated to develop interview questions for this study. The semi-structured interview guide for this study included open-ended question prompts designed to elicit sharing from parents/caregivers about their lived experiences navigating sexuality education with their children/young adults. Situating more general questions at the beginning of the interview allowed for a natural conversational style process using comfortable transitions leading to discussion of more specific, and potentially, uncomfortable topics. Figure 1 provides a list of prompts included in the semi-structured interview guide.

Interviews were conducted via Zoom which included multiple layers of encryption. Zoom privacy settings were utilized to schedule the meeting with an encrypted passcode, which allowed only authenticated users to join the interview zoom

room. To ensure confidentiality, interviews were not recorded via the Zoom recording feature. The audio portion of each interview was recorded through the encrypted iPhone application called Voice Record Pro that allowed for multiple layers of encryption.

At the conclusion of each interview, participants were asked to pick a pseudonym. Seven of the participants requested a pseudonym be picked for them and two participants said it was okay to use their names. To meet confidentiality expectations of IRB, I selected pseudonyms for all participants.

Interview length varied between participants. The shortest interview session lasted forty-five minutes and the longest interview was one hour and fifty-one minutes.

Data Analysis

Following each interview, I manually transcribed each audio recordings. Initial transcription with initial coding took place within two days of each interview. Full transcription of all of the interviews took place over the duration of a month. I reviewed each transcription for accuracy by listening to the audio recording on a slow speed and checking to ensure that what was said matched the transcription.

Data were analyzed and interpreted using open coding to categorize and conceptualize it into themes (Bloomberg & Volpe, 2012). Clusters of meaning displayed themselves in each created theme. Multiple readings of the transcripts and listening to the audio recordings were utilized to become familiar with the data. While statements of similarity and data that aligned with research questions were highlighted, categories started to emerge. Memo writing allowed for reflection on what was being learned from

the data. Regular reflexive journaling aided in interpreting data and developing concepts. Both journaling and memo writing added to the trustworthiness of the data analyses process.

Using an iterative process of analysis, developing concepts and emerging categories were reexamined regularly. The primary researcher wrote about her own experiences throughout the study that also directly influenced theme development. The analysis created several themes related to parent/caregiver experiences in providing sexuality education to their children/young adults. Themes also emerged related to providing effective comprehensive sexuality education. Created themes include the individual and unique needs of each child and family, parents need collaborative support from other knowledgeable adults, and clear communication in relation to communication partners, communication mode, and in regards to topics and skills deemed necessary by parents.

Results

Individual and Unique Needs

All parents in the study shared information about the need for sexuality education to address the individual needs of their children. .The overarching message communicated by parents is that sexuality education instruction cannot be a one size fits all approach. Families' cultures and values play crucial roles in how they feel and/or approach topics related to sexuality education. The age of the child or young adult is necessary to consider, along with their developmental stages, when planning and implementing instruction. As Edward's says, "She is uniquely [child's name]. "She is the one who will direct where we put our focus. Experts do not know my kid. I know my kid," indicates the importance of involving parents/caregivers in the development of sexuality related instruction for children/young adults with intellectual disabilities.

Similarly, Lisa said, "What my big concern is for him is knowing what's appropriate, knowing when it's appropriate, and knowing where it's appropriate." With her son having a tendency to mimic behaviors he sees, she noted that educating him on appropriate behaviors means sometimes modifying behaviors of other family members. For example, after seeing his father put his opposite hand on someone's shoulder while shaking hands, Lisa's son mimicked this but ended up pulling the other person in so close it was perceived that he was trying to force a hug. In order for him to unlearn this, his father had to stop the behavior himself to help his son learn to only shake hands.

Parents in this study consistently expressed that they are open to advice,

suggestions, and supports about instructing their children or young adults in sexuality education topics. However, parents indicated the necessity that any resources, trainings, or other supports consider the individual need of their child or young adult. As one parent shared, "Take advice, take suggestions, look for support, but do not, do not, just accept something as a tactic and apply to your child without identifying what may be difficult for your specific child and what may be easier for your specific child in regard to how you handle sexuality education. That's what makes it so incredibly difficult to offer advice because it is so personal, it is so individual, there are so many factors…it is dependent on [the] characteristics and personality of the child and their parent, and the relationship they have."

Ivan describes his daughter's learning needs as "her most successful learning is between watching and doing. If she watched a video and then practices a skill, she does better." Ivan and his wife Sally work together to meet their daughter where she is at and structure sexuality education from an educational standpoint rather than avoiding it out of fear. Several parents agreed that approaching sexuality education based on their child's individual and unique needs removed initial feelings of fear and replaced them with empowerment. Parents described feeling empowered and successful in teaching their children necessary sexuality education skills including menstruation management, appropriate private spaces for masturbation, keeping clothing on in public places, keeping the door shut while using the bathroom, making clothing choices, teaching their child they can say, "no," and how to more independently complete personal hygiene tasks.

Sally explains, “I’m all down for all the education out there to help make it [sexuality education] less awkward. I just think that the parents have to be involved in the conversation. We cannot just have it as somebody else teaching our child. We need to all be at the same table talking about how we are going to do this together.” Her feelings speak to the importance of individual and unique needs for each child and their family and parent need for collaboration.

Parents Need for Collaborative Support

Participants shared the benefit of collaborative support from other knowledgeable adults. Seven of the parents shared that at least some sexuality education instruction was implemented to their children from school staff. This instruction included the topics of routine hygiene, personal boundaries, social skills, consent, body part identification, public and private touching rules, communication, and choice making.

Several parents felt that their children or young adult might respond with more engagement to sexuality education provided by someone other than themselves. As Xaiyla commented,“ I think most of the students might benefit from school and us teaching. Since they are teenagers, they may respond to some things better from school staff than parents.” Andrew felt collaboration is important when he shared, “I never know how much he is listening to me as the parent because I’m giving him information he needs or he is pretending to listen to me…because he’s a teenager and as the parent he believes I don’t know anything.”

School team members such as teachers, related service providers (occupational

therapists, speech therapists, vision specialists), caregiver staff, and family members were mentioned as individuals who might provide instruction related to sexuality education topics. Edward, Andrew, and Lisa all access parent support networks (both informal and formal) to help them locate helpful resources. They also indicated that support groups including other parents/caregivers who care for children or young adults with disabilities help them not feel alone.

Ula, Travis, and Yvette all shared concerns about what will happen once they are no longer able to care for their children or young adults. Each wondered during the interview what they could do so that the strategies they use in teaching sexuality related topics now or in the future would continue for their children or young adults. All but one parent expressed a need for collaboration with others to help their children or young adults learn to socialize in order to make friends and develop relationships with peers.

Andrew and Edward both felt it was important to seek out information from adults with disabilities similar to their children or young adults. Co-existing with intellectual disabilities, Andrew's son also has Down syndrome and Edward's daughter has autism spectrum disorder. They acknowledged that they are fathers of children or young adults with intellectual disabilities but do not know understand what it is personally like to live their children's or young adults' lives.

Clear Communication

Clear communication in relation to communication partners, communication mode, and about topics and skills deemed necessary by parents were important to all

parents in the study. The challenges of communicating clearly with their child was indicated as crucial by parents, noting the fear that they did not want to mistakenly communicate unintended messages about sexuality related topics. Recognizing that sexuality education topics are traditionally uncomfortable for many, Andrew shared that he does not "always know what to say or how to say it to my teenage son" to ensure he receives my intended message.

Sally shared that clear communication is important between her and her child's school team and caregivers. She stated, "We don't use baby words for body parts, we call it what it is. I have to communicate the expectation to others about the words they use around my child." She also said, "I never say you need to go give them a hug or you need to go give them a kiss." The words she uses to communicate expectations regarding boundaries and consent for her daughter guide others on behavior expectations.

Contextualizing "change" through language and instruction for children or young adults with moderate to severe intellectual disabilities was noted in at least a small way by all parents. Edward said, "Teaching change is important. If the concept of change is taught and infused from a young age into our children's lives, then puberty changes won't be as scary or traumatic."

Sally, Edward, Ula, Andrew, Lisa, Travis, and Yvette shared concerns that sometimes others did not understand what their children or young adults said due to a variety of communication challenges, including being nonverbal. Due to the importance of clear communication when discussing sexuality related topics to avoid

misunderstandings, they indicated the value of using communication supports their children or young adults were familiar with and used during other instruction. Communication supports used by the children or young adults of participants in this study included visuals, objects, communication devices, and peer supports

All parents in the study shared that boundaries, safety, personal space, communication, personal hygiene, and puberty were topics they deemed important for their children/young adults. Parents of female children or young adults all mentioned menstruation and gynecological health as important. Sally and Ula indicated that choosing clothing was something that helped their children or young adults express themselves. Ula, Travis, and Yvette said they do not ever expect their children or young adults to be without caregiver supervision but put safety expectations in place. Xaiyla and Andrew have teenage sons. Each of them shared experiences of teaching appropriate private spaces for masturbation. Consent was a topic of importance for Andrew, Lisa, Sally, Ivan, and Xaiyla. All of these parents shared teaching consent at early ages with instruction in personal space and touching rules and expectations.

Edward explained that he would advise other parents and other caregivers to consider that "Just because children have special needs doesn't mean they don't have sexuality." He also describes how he "feels almost wrong" talking "about sexuality in a specific box, as if you can separate it from anything. It's impossible to separate it from growth, it's impossible to separate it from life experience, it's impossible to separate it from how to interact with other people, it's impossible to separate it from relationships."

Similarly, to Edward, parents mentioned change as crucial skill, which overlaps many concepts in sexuality education including puberty, sexual health, and relationships. Using change as a lens was also mentioned as a way to help puberty

Sally's most important "The way I think of it is how can I protect her? I want her to be able to protect herself, to know what is important, what people should do and not do and where she should not go with other people."

Comprehensive Sexuality Education and Instructional Strategies

Parents mentioned many concepts that are typically included in evidence informed sexuality education training. Topics included boundaries, safety, menstruation, clothing choices, gynecological health care (pap smear, birth control), private versus public concepts (behavior, places, people, discussions), understanding the meaning of "no, "privacy, self-determination and self-advocacy, touching, masturbation, personal space, consent, body parts, erections, wet dreams, communication, personal hygiene, self-awareness, puberty and changes (Tanner stages of development), values and culture, relationships, pregnancy, and respecting self and others When discussing topics they taught Parents/caregivers described instructional strategies they either used at home or knew were utilized at school with their children or young adults for skills instruction in sexuality education related topics. The strategies parents reported as effective include positive reinforcement, prompting (gestures, verbal, physical, modeling, video modeling, role-play, task analysis, cues, routines, visual supports (schedules, cues, checklists, illustrations, prompts), repetition, and generalization.

Resources

Parents shared resources helpful to them in supporting the sexuality education needs of their children or young adults. A list of these resources can be requested by contacting the corresponding author.

Discussion

Each of the parents or caregivers in this study were a valuable part of a collaborative research process. This collaborative research process helped both the researcher and the participants develop recommendations for actions or next steps Creswell (2007) that may influence access to sexuality education for children or young adults with moderate to severe intellectual disabilities along with their parents, caregivers, family members and others.

Although sexuality education is important for all children, little information exists to explore the needs of those with moderate to severe intellectual disabilities. The themes emerging from this study provide insight into helpful supports for families, educators or other professionals who seek information about providing instruction to children or young adults in sexuality related topics.

Parent and caregiver input supports the need for comprehensive sexuality education training and resources to meet their children's or young adults' needs on an individual basis by considering their developmental and chronological learning needs. Existing resources, such as the National Sexuality Education Standards (2020) and the SIECUS Guidelines (2016), provide guidance on the essential components and topics to design comprehensive sexuality education programs and instruction. Then, assessment of individual students' knowledge and skills can guide what they need to learn and what they are ready to learn in regard to sexuality education. Individual student need would also guide which resources, instructional modifications, adaptations, and supports are

necessary successful understanding of content and skill development.

The importance of collaboration along with clear communication between parents/caregivers and others involved in their children's care and/or education contributes to the consistency of sexuality education instruction provided, both in terms of content and strategies utilized in implementation. Schools and agencies that support individuals with intellectual disabilities and their families can collaborate with parents in several ways. Sexuality education topics can be considered during individualized education planning meetings with goals written specifically outlining what the student will learn, how instruction will be implemented, and how assessment will measure skills learned and inform future instruction. Schools and agencies can find out about possible existing resources and/or trainings in their area or online to support students and their families. Schools and agencies can work to develop resources and/or trainings in collaboration with parents such as hosting parent groups to discuss topics and instruction, putting together a library of existing resources to help limit time it takes to search and find accurate information that is also applicable to individuals with intellectual disabilities and their families.

In addition to clear communication needed for collaboration, clearly communicating messages related to sexuality education topics to all children is crucial. Clear communication can be enhanced by using visual supports, repetition, and consistency in implementation of instruction between all family members, staff, and educators who provide sexuality education.

Effective instructional strategies for sexuality education implementation parallel with evidenced based instructional strategies used to teach academic and life skills to children or youth with moderate to severe disabilities. The realization that learning new instructional strategies is not necessary (assuming evidence informed strategies are being used by parents and educators) to begin instructing sexuality education might alleviate concerns about infusing new curricula into educational programming. As the parents in the study shared, the biggest challenge for many in this mid-south state is becoming comfortable with some of the language (i.e., penis and vagina) and topics (e, g., sexual safety) commonly seen as impolite to discuss.

More and varied resources, curricula, and training are needed to support the sexuality education for children or young adults with moderate to severe disabilities. Limited resources are available that include strategies for engaging students with complex learning needs that often exist for children/youth with intellectual disabilities. Visual supports, including easy to interpret illustrations and video modeling representing children or youth with disabilities would expand a resource and/or curriculum's reach to be inclusive of children or youth with intellectual disabilities. Adapting materials addressing sexuality education topics appropriate for high school students into formats using elementary reading levels would also benefit many children or young adults. Similarly, adapting books and other materials designed for younger children but making them available in age respective versions to use with older children would increase access to pre-made resources to help parents and educators.

Ultimately, understanding sexuality education as a right for all persons helps shape the conversation about why children/young adults with moderate to severe intellectual disabilities deserve access to instruction that helps them develop into happy and healthy adults. Andrew shared his son's desire to learn about relationships with his questions being, "What do I have to do to get a girlfriend? How do I be a boyfriend? How do I be a good boyfriend to a girlfriend? Andrew notes that his son's questions align with many other teenage boys who do not have intellectual disabilities.

Limitations and Future Research

This study includes multiple limitations. Data were limited to responses from only nine parents/caregivers from the same mid-south, mostly rural state. All participants in the study identified as a parent, either a mother or a father. Gathering data from other family members in future studies (i.e., siblings serving as guardians or caregivers) may provide additional insights and perspectives. All parents reported to be in either the middle or upper class socioeconomically and most completed graduate degrees.

Data gathered and analyzed only represents perspectives from parent. Information from this study does not represent the thoughts, feelings, or understandings of children in their own words. Although many parents shared experiences specific to their children, it was filtered through their parental views, expectations, fears, hopes, and understandings. Exploring the perspectives of children with moderate to severe intellectual disabilities through interviews, observations, and other data gathering methods would be powerful. Positioning children as the experts in their own lives from which others can learn not

only provides them a voice, but offers opportunities to collect rich data from which we all can learn.

Participants in this study included both mothers and fathers. Data analysis did not include comparison of similarities or differences between mothers' and fathers' responses. Some of the parents also had children who did not have intellectual disabilities. Interview questions were not designed to explore the differences in parent and caregiver experiences in providing sexuality education to their children with and without intellectual disabilities. Some of the participants had sons and some had daughters. Gender of their children or young adults may influence perspectives. Data analysis did not explore these potential differences. It would be helpful for future studies to explore the phenomena of mothers and fathers, children with and without intellectual disabilities, sons and daughters.

Future studies including parents with more diverse backgrounds and education levels would expand the perspectives and inform existing research. Just by volunteering to be interviewed, the parents most likely were already, at least somewhat, comfortable with discussing sexuality education in terms of their child or young adult. This limits the data gathered to only include experiences from families who already considered and/or provided sexuality instruction to their children.

Implications for Research and Practice

Experiences shared by parents have beneficial implications for future research and the development and/or adaptation of comprehensive sexuality education resources and

curricula for children with moderate to severe intellectual disabilities. Extending this study with an expanded number of participants, including participants from other regions of the country, would add more perspectives to the data and offer additional context from which data can then be analyzed. Results can then be utilized to respond to needs expressed by parents/caregivers.

The information may also help educators and professional agencies to support families and other caregivers who provide services for persons with intellectual disabilities. Care should be taken to realize that all families have their own cultural background, religious beliefs, and experiences that inform their views on sexuality education. However, it is helpful to understand how results of this study might work to reduce the barriers in accessing comprehensive sexuality education for children with moderate to severe intellectual disabilities.

The primary researcher is using information learned from this study in several ways. She is working with several disability specific local non-profit agencies, the state's subdivision for autism and developmental disabilities (DADD), and the state's parent training and information center to share information and resources supporting provision of comprehensive sexuality education for children and youth and their parents. Additionally, an introductory webinar was developed which will be shared online and freely accessible to anyone with an interest in providing sexuality education to children/youth with intellectual disabilities. The webinar includes links to researcher created short, instructional videos covering the topics of personal space, public versus

private spaces and behaviors, consent and body parts. Information is also being used in working with a national advocacy group working which is working to eliminate barriers to young people receiving high quality sexuality education. Suggested adaptations and modifications for lesson plans will be added to their free and accessible K-12 comprehensive sexuality education curriculum. Sharing information in these ways was recommended by parents in the study.

Parents also recommended the following as potential ways to help share information: YouTube channel, podcast, topic flyers, parent groups, zoom group, trainings for educators and families together, resources already modified/adapted, library of instructional videos, virtual training that can be accessed at any time, resource website, shared “what works” stories from parents/caregivers, video modeling library, and case study vignettes with messages from parents.

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Table 1

Interview Participant Demographics

Participant #	1	2	3	4	5	6	7	8	9
Pseudonym	Sally	Edward	Xaiyla	Ula	Andrew	Lisa	Ivan	Travis	Yvette
Gender	F	M	F	F	M	F	M	M	F
Age	41	42	58	64	54	58	45	46	46
Child Gender	F	F	M	F	M	M	F	F	F
Child Age	16	15	19	29	18	18	16	16	16
Race/Ethnicity	EA	EA	AA	EA	EA	EA	EA	AA	AA
Education	C	G	H	C	G	C	G	G	G
SES	U	M	M	M	U	U	U	M	M

Note. F = Female, M = Male, EA = European American, AA = African American, H = high school graduate, C = college graduate, G = at least one graduate degree, SES = Socio-Economic Status, M = middle class, U = upper class

Figure 1

Semi-Structured Interview Guide.

- Tell me how you define sexuality education.
- Tell me about how you were taught sexuality education. What is memorable?
- When thinking about sexuality education topics, what is most important for your child/young adult? Your family?
- You mentioned the sexuality education topics_____. Please share about how your child/young adult learned about this.
- What people/resources/agencies/etc. support providing sexuality education to your child/young adult and what does that support look like.
- Think of an experience in regards to sexuality education with your child/young adult that you felt was successful/progress making/skills learned, etc…..please tell me about it.
- Think of an experience in regards to sexuality education with your child/young adult during which you felt fear/unsure of what to say/unprepared, etc……please tell me about it.
- Tell me what you have noticed about strategies/resources used to teach sexuality education to your child/young adult.
- What stands out to you in respect to what your child/young adult expresses they want to learn in regards to sexuality education?
- What would you like to see as a result of this research-what ACTION should come from this research?
- How would you like to see the data from this research study represented?
- As a participant in this study, how would you identify (parent, caregiver, family member, etc)?
- What are your suggestions on how I could reach out to those who aren't comfortable talking about this topic (parents who would not have wanted to be interviewed)?

Follow Up Question Starters to gather more information:

- You mentioned ____, could you please describe an example of how that worked?
- You talked about _____, what usually happens then…
- You shared ____, can you share more examples of how your child understood_____?