Sex Education for All?

Exploring Parental Views on the Sex Education Needs of Children with Autism

Courtney Hansen

A Dissertation Submitted to the Faculty of

The Chicago School of Professional Psychology

In Partial Fulfillment of the Requirements

For the Degree of Doctor of Psychology

June 19, 2018

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2018

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Acknowledgements

I want to thank Dr. Braden Berkey for his reassurance, enthusiasm, and support of this project of passion. I want to thank Dr. Kim Dell'Angela for her critical eye and her encouragement. I want to thank my parents, Lisa and Davin, for listening to every frustration and pushing me through each moment of doubt and procrastination. I would also like to thank my two younger sisters, Megan and Taylor, for always being curious about my work and being the sounding boards I needed. I want to extend a thank you to Denise Lai-Caspi, the person who first told me I had what it takes to work with people with autism. Thank you to my friends and fellow doctoral students, this process was a lot less daunting because of you. Lastly, I want to thank the three remarkable women who gave me their precious time and trusted me enough to open up and discuss their experiences.

Abstract

Although there is a greater percentage of parents and professionals agreeing that individuals with Autism Spectrum Disorder (ASD) need more, and better, sex education, there remains a lack of comprehensive sex education targeting children with ASD. This study seeks to gain an understanding of how parents of children with ASD view their child's sex education needs and how parents want mental health professionals to support them and their child in terms of sex education. Parents with a child with ASD took part in 60- minute semi-structured qualitative interviews using a questionnaire created by the researcher with feedback from mental health professionals working with children with ASD. After transcription of the interviews, the researcher ascertained six major themes and three minor themes: 1) Knowledge and Comprehension; 2) Important Topics; 3) Seeing the Big Picture; 4) Safety Concerns; 5) Benefits of Intervention; 6) Looking for Guidance. The three minor themes were: 1) The "Talk"; 2) Masturbation and Privacy; 3) Romantic Relationships. The lived experiences of the participants' perspectives on the sex education needs of their children demonstrated a general interest in their child receiving sex education and a desire for mental health professionals to be proactive in providing support in this area. This study supports and validates the fact that parents are aware of their children's need to learn information and skills related to puberty, sexual activities, consent, and romantic relationships. Findings indicates that parents are looking for guidance and support from clinicians and therapists in addressing the sex education needs of their child with Autism Spectrum Disorder.

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Chapter One: Nature of the Study

Background

Despite changing societal views on the sexuality and sexual expression of those with developmental disabilities there is a prevailing lack of comprehensive sex education provided to individuals with autism (DiGiulio, 2003). A growing body of research exists concerning interventions and education for individuals with autism; however, this research has focused on decreasing maladaptive behavior, increasing social skills, and promoting special education coursework. (Travers & Tincani, 2010). Despite the increasing body of literature about individuals with autism, issues of sexuality and sex education have received minimal attention. The autism population is extremely varied, and individuals can have a wide range of functioning, cognitive abilities, language, and interpersonal skills. This large variation indicates that sex education needs will vary greatly, and the education will need to be highly individualized and comprehensive. However, Richards et al. (2006) states that myths, misconceptions, and parental overprotection still provide significant barriers against the sex education of individuals with autism. In fact, DiGiulio (2003) stated that less than 50% of adolescents with developmental disabilities, including those with autism, receive formal sex education and only 50% of those who did are satisfied with the quality and amount of information they received (p. 61). Most current sex education curriculum is vague and incomplete at best and inaccurate and denigrating at worst (Boehning, 2006). Even with improvement in societal views on the sexuality of those with developmental disabilities such as autism, there are still significant barriers to individuals receiving the necessary comprehensive and affirming sex education they need.

DiGiulio (2003) outlines several key issues that individuals with autism face in regard to sexual health and expression of their sexuality. They experience an overwhelming lack of

information or access to it, are often deliberately misinformed, and lack the privacy to explore and engage in sexual activities. Parents often do not provide any concrete information about sex and sexuality because of "fear of their child being sexually abused or behaving in socially and sexually inappropriate ways" (p. 141). Parental views on their children's sexuality ends up being a significant barrier to individuals with autism getting necessary information about sexual health and intimate relationships. Society views the sexuality of those with autism and other developmental disabilities in many extreme ways, from seeing them as completely asexual without any sexual drive to being consumed by biological urges and unable to control or channel them appropriately (Wilkenfeld & Ballan, 2011). Some misinformation stems from the belief in the asexuality of individuals with developmental disabilities, and that if they are indeed asexual then teaching them about sexuality will only plant ideas in their heads.

On the reverse side, the belief that individuals with developmental disabilities are overly sexual and unable to control themselves leads to deliberate misinformation designed to prevent socially inappropriate behavior and to dilute the assumed excessive sexuality (DiGiulio, 2003). This also leads to overprotection and a lack of the privacy that's necessary for socially appropriate exploration of sexuality. Many individuals with autism are constantly being watched and supervised to prevent misbehavior, which creates an ironic cycle. When those individuals are deprived of privacy in their home, they will look to other places, such as parks or public restrooms to engage in sexual activity and then "ironically, such people are, in many ways, pushed by conditions in which they live to engage in the 'inappropriate' sexual behavior that will then be used against them" as evidence of their misbehavior (p. 61). The lack of information, deliberate misinformation, and the limited private outlets prevent the healthy expression of sexuality among individuals with autism.

Problem Statement

Richards et al. (2006) propose that the attitudes of educators, parents, and direct care staff cause barriers to comprehensive and accurate sex education because they transmit misinformation and negative perspectives on sexuality that affect this population. Negative views about sexuality from parents, educators and others often impact the views of individuals with autism. Further, Richards et al. (2006) noted that people with developmental disabilities have higher percentages of fear, dislike, and disgust of sexual activities and expression of sexuality. These internalized negative reactions coupled with misinformation and lack of education lead to confusing feelings about their own sexuality and a higher level of frustration in romantic relationships and perceptions of self. Despite a greater majority of parents and professionals agreeing that individuals with autism need more and better sex education, there is disagreement and confusion about who is most appropriate to provide it (Ballan, 2011; Swango-Wilson, 2009).

Purpose of the Study

Due to the importance of parent involvement and support in providing sex education, this study explored the readiness of parents in participating in the sex education of their children with autism as well as what parents need from professionals in order to provide the most appropriate, tailored, and comprehensive sex education to their children.

Research Questions and Hypotheses

The overall question guiding this study was: What are the perceptions of parents regarding the sex education needs of their children with autism? The study was further grounded by two subquestions:

1. How do parents consider the sexuality of their children with autism?

2. In what ways have parents sought out or acquired sex education for their children with autism already?

Theoretical Framework

Through the use of a phenomenological approach and semi-structured interviews with parents of children with autism (where the child is at least 10 years old), the present study sought to understand and describe the lived experiences of these parents in relation to their child and sex education.

Scope of the Study

The current study was limited to ascertain the perceptions of parents given that research has demonstrated that parental views are a deciding factor in whether or not individuals with developmental disabilities access sex education (Richards et al., 2006). Different theoretical frameworks were considered including qualitative designs as well as a case study approach. Given that the purpose of the study was to ascertain the lived experiences of parents with children with developmental disabilities a phenomenological approach was determined to be the best framework.

Definition of Key Terms

Autism. Autism or Autism Spectrum Disorder (ASD), refers to a developmental disability categorized in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5). Autism is characterized by a broad range of challenges in social communication and the presence of restricted and repetitive behaviors (American Psychiatric Association, 2013).

Developmental Disabilities. Developmental Disabilities are a group of disorders that are considered to be neurodevelopmental in that they are present in early development and are

lifelong conditions that affect an individual's overall development. Autism is one developmental disability (American Psychiatric Association, 2013).

Significance of the Study

This study was conceived to provide a current understanding of parental views about the sexuality and sex education needs of their children with autism. Findings from this study are meant to inform and aid mental health professionals in understanding parents' readiness, concerns, and needs regarding sex education for their child with autism.

Summary

Historically there has been mistreatment and a lack of sex education options for individuals with developmental disabilities, including autism (DiGiulio, 2003). Individuals with autism continue to experience decreased access to sex education and are at higher risk for abuse and victimization (Richards et al., 2006). Parental views on the sexuality of their children with developmental disabilities continue to be a factor in how individuals with autism learn about sex and sexuality (Wilkenfeld & Ballan, 2011). The current study will explore the lived experiences of parents with children with autism in relation to their child's sexuality and perceived sex education needs. The following chapters will outline the Literature Review, Methods, Findings, and Discussion of the current study.

Chapter Two: Literature Review

Introduction

The current study sought to understand how parents of children with autism understand their child as a sexual person and what they believe their child needs in terms of sex education. Parental views are couched within the cultural beliefs and biases surrounding the sex education needs of those with autism and other developmental disabilities. Therefore, a review of the literature was conducted to ascertain the Historical Context, the Current Sex Education Programs available, the Attitudes, Misconceptions, Beliefs of individuals with developmental disabilities and those who have contact with them, and literature that has proposed ideas for the Development of Better Sex Education.

Research Strategy

A literature review was conducted using multiple journal and article databases including, ProQuest, EBSCO, PsychINFO, and SAGE. The following key terms were used to find literature: Autism, Developmental Disabilities, Parents, and Sex Education. Approximately 30 articles were found through these searches. All articles that were published within the last 30 years were included in the literature review.

Historical Context

Society's views on the sexuality of individuals with developmental disabilities has come a long a way despite the fact that there is still much greater improvement needed (Radford & Park, 1995). Beginning in the 1880's and continuing into the 1940's, the eugenics movement, based on the principles of social Darwinism, forced mass sterilization and segregation on people with developmental disabilities. Believing that developmental, cognitive impairment was purely genetic, supporters of the eugenics movement fought to involuntarily sterilize all individuals

with developmental disabilities to prevent the perceived disintegration of society. In 1927, the Supreme Court upheld the constitutionality of involuntary sterilization of those with developmental disabilities in *Buck v. Bell*, stating, "it is better for all the world if instead of waiting to execute degenerate offspring for crime or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind" (*Buck v. Bell*, 274 U.S. 2000(1927)). Society viewed those with developmental disabilities as criminal, socially unfit, and biologically promiscuous and believed sterilization and segregation to be the most appropriate solution (Radford & Park, 1995). Segregation of people with developmental disabilities continued for years to prevent those who weren't sterilized from having children with each other or with non-disabled people, keeping their disabilities out of the gene pool.

While the eugenics movement fell out of favor in the 1940s, it wasn't until 1971 that a major change occurred in the form of a United Nations declaration that the rights extended to one individual must be extended to all individuals regardless of ability status (Richards et al, 2006). In the 1970s, the so-called "normalization movement" was pushing for individuals with developmental disabilities to be able to live normal, free, and ordinary lives. Better residential services and education became available and attitudes evolved about the incorporation of people with developmental disabilities into mainstream communities. Further progress was made in 1997 at an international conference held by the World Congress of Sexology where nine sexual rights for those with disabilities were outlined, including "(1) freedom; (2) autonomy, integration, and safety of the body; (3) sexual equality; (4) sexual health; (5) wide, objective and factual information on human sexuality; (6) comprehensive sexuality education; (7) associate freely; (8) make free and responsible choices, and (9) privacy" (Richards et al., 2006). Despite the forward progress, involuntary sterilization is still legal in the United States in certain

jurisdictions upon proof that sterilization would be in the "best interest" of the individual; for example, to decrease the chances of sexual abuse, exploitation, and the spreading of sexually transmitted diseases (DiGiulio, 2003). The fact that there are still situations in which involuntary sterilization occurs, indicates the remaining problematic societal views about the sexuality of individuals with developmental disabilities.

Current Sex Education Programs

Sex education in the United States has undergone massive changes in the last four decades due to public health concerns around adolescent pregnancy as well as the HIV/AIDS pandemic (Hall, Sales, Komro, & Santelli, 2016). As part of the welfare reform on the late 1990's abstinence only until marriage (AOUM) sex education was adopted across the majority of states and was federally funded. Today, 37 states continue to require abstinence as a part of sex education with a decreasing number requiring AOUM sex education due to substantial and rigorous research documenting the lack of efficacy of AOUM in reducing sexually risky behaviors. Only 21 states and the District of Columbia mandate sex education with HIV and STD education and only 17 require sex education that provides information on contraception options. Implementation of sex education continues to vary greatly from school district to school district and many sex education programs continue to be incomprehensive and to lack use of evidence-based models. Research in medicine and public health indicate evidence that sex education continues to be insufficient in medical and scientifically sound information as well as for in providing sex education that addresses the diversity of sexual orientations and sexual relationships. Currently, only 8 states require sex education be inclusive of sexual orientations. Further, there is growing psycho-social research that indicates significant inequities sex education with girls receiving less than boys, with people of color receiving less than white

individuals, and people of lower socio-economic status (SES) receiving less than those of higher SES (Hall, Sales, Komro, & Santelli, 2016).

Given the general lack of comprehensive, evidence-based, and diverse sex education across the United States, it is unsurprising that sex education for individuals with ASD and developmental disabilities continues to be limited. Sullivan and Caterino (2008) stated that there has been greater consideration paid to sex education programs for individuals with intellectual and developmental disabilities, but less attention on the specific sex education needs of individuals with autism spectrum disorder (ASD). The authors completed a comprehensive review of existing sex education programs for individuals with ASD and found only three published curricula. The University of North Carolina's TEACCH Autism Program is a comprehensive education program that includes sex education and employs sequenced levels that target various levels of cognitive functioning. TEACCH's acronym represents their core values of teaching, expanding, appreciating, cooperating, collaborating, and using a holistic approach. Sullivan and Caterino argue that TEACCH is the most comprehensive public program, in large part because of its sequenced levels, but also because of the high levels of collaboration between parents, professionals, and educators. The sequenced levels begin with topics such as body parts and functions and privacy; this level includes behavior modification and focuses on developing appropriate behaviors and habits. The next levels move through issues of hygiene, sexual life-cycle, social functioning, and abuse awareness. TEACCH "emphasizes the point that a sexual education program must view sexual behaviors in the context of social skills, communication, cognitive ability, and other areas of strengths and weaknesses" (p. 387). While TEACCH emphasizes social skills, Sullivan and Caterino pointed out that TEACCH does not include any

concrete programming on building and maintaining long-term intimate relationships and has a heavy focus on behavior modification (Sullivan & Caterino, 2008).

The Devereux Centers, a large nonprofit behavioral healthcare provider, currently offers a multi-tiered sex education curriculum for individuals with ASD (Sullivan & Caterino, 2008). Topics covered in this program include "body parts and functioning, social/sexual behavior, sexual life-cycle, dating, marriage, parenting, establishing relationships, abuse awareness, boundary issues, assertiveness, and self-esteem" (p. 387). This inclusion of topics such as marriage and parenting is unique among sex education programs for anyone with developmental disabilities, particularly for those with ASD, as they are usually viewed as incapable of the social capacity required for marriage or parenting. Additionally, the Devereux Centers individualizes their curriculum and focuses on empowering parents to be the primary teachers in their child's sexual education, believing that the assertiveness and self-esteem pieces are of high importance and are best taught from parents and caregivers. The curriculum often includes multi-sensory tools and methods including situational instruction, audio-visual materials, and discussions (Sullivan and Caterino, 2008).

Sullivan and Caterino (2008) highlight one residential and day school program, the Benhaven School, which takes a firm stance that "relationships are considered beyond the scope of their clients because of their low social development" (p. 388). The curriculum at Benhaven focuses only on self-care and appropriate behaviors; for instance, masturbation is taught as an acceptable behavior in private, and individualized behavior modification programs are used to highlight privacy issues and prevent public masturbation. The authors note that the Benhaven School's approach is largely the norm when it comes to residential and educational programs for individuals with ASD; however, they point out that few programs have a published and concrete

sex education program, such as the one at the Benhaven School. The University of North Carolina's TEACCH program, the Devereux Centers' curriculum, and the Benhaven School's approach were the only three published sex education programs at the time of Sullivan and Caterino's search and demonstrated vastly different approaches to what and how sex education should be taught to the ASD population. Notably, none of these sex education programs address concepts of sexual orientation, gender identity, or sex outside of relationships and appear to have hetero-centric and cis-gender assumptions about this population. The programs do not explore the development or concept of sexual identity. The TEACCH, Devereux, and Benhaven programs also make an explicit connection between sexual activity and relationships (Sullivan & Caterino, 2008).

Attitudes, Misconceptions, Beliefs

Community and societal perspectives. Individuals with developmental disabilities have been stereotyped as asexual and childlike or, paradoxically, as sexual deviants without the ability to restrain their urges (Wilkenfeld & Ballan, 2011). While there has been gradual change toward more positive and open-minded views on the sexuality of individuals with developmental disabilities, misperceptions still persist. For instance, many view individuals with autism spectrum disorder (ASD) as sexually immature or asexual despite recent research, that has demonstrated that youth with ASD "display sexual interest and engage in sexual behaviors, not unlike their peers" (Ballan, 2011, p. 676). Although there is growing evidence that a significant proportion of individuals diagnosed with gender dysphoria (the psychological diagnostic term for transgender) have concurrent ASD, many people assume all individuals with autism are cisgender or are not aware of their own gender (Glidden, Bouman, Jones, & Arcelus, 2016). These negative beliefs and attitudes toward sexual activity and identity amongst individuals with

developmental disabilities sends the message that sex is bad or inappropriate for that population. (Swango-Wilson, 2008). One study conducted in Australia with 25 male adults with intellectual disabilities found that the majority of their subjects reported being sexually active and were aware that this was not approved of by others. (Cuskelly & Bryde, 2004). These individuals reported awareness of negative stereotypes about their own sexuality. Societal misconceptions and discomfort with sexuality amongst the developmentally disabled population negatively impacts the self-esteem and sexual expression of those with disabilities. Women with developmental disabilities often face additional challenges about body image and society's views of their "imperfect" disabled bodies. (Christian, Stinson, & Dotson, 2001). Women in this population experience the unrealistic and unhealthy ideals of female bodies in the media coupled with the negative societal images about disability.

Christian, Stinson, and Dotson (2001) have argued that negative views and attitudes about the sexuality of individuals with developmental disabilities not only leads to internalized negative self-image, but also causes barriers to accurate sex education and health care. Sex education for individuals with developmental disabilities has been largely neglected and adolescents with developmental disabilities tend to be less informed and display more sexually inappropriate behaviors than their non-disabled counterparts. Oftentimes women with developmental disabilities lack choices regarding reproductive issues and many are given very cursory or inaccurate information about menstruation, pregnancy, and sexually transmitted diseases. Further, women in this population are often prescribed and given birth control without being provided with sufficient education and autonomy over this choice. Negative attitudes and misconceptions about the sexuality of the developmentally disabled population has limited the access to education for these individuals and is tied with higher rates of sexual victimization.

Parental Perspectives. Ballan (2011) pointed out that parents are often considered primarily responsible for the sexuality and sex education for children with developmental disabilities. However, parents are often uncertain of the best way to educate their developmentally disabled children and many shy away from teaching sexual topics to their children. Individuals with developmental disabilities are "a vulnerable population at risk for victimization, pregnancy and sexually transmitted infections" (Wilkenfeld & Ballan, 2011, p. 351). Ballan (2011) has noted that parents of children with ASD share fears about their child's safety, and the sex education they attempt with their children often centers on sexual abuse prevention. Some parents in Ballan's study expressed concern that they have inadvertently given their child contradictory messages about sexual abuse; for many years parents will encourage their children to get help from everyone, such as help using the restroom or getting dressed, and then as their children age, they must try to communicate times when it is and when it isn't appropriate for others to interact with them in that way. Additionally, parents worry that their child lacks the requisite communication skills to report when sexual abuse has happened. These fears about sexual victimization have led parents to be more thorough about that aspect of sex education.

According to Ballan (2011), parents' concerns that their children's behaviors will be misinterpreted present a considerable barrier to more comprehensive sex education communication between parents and their developmentally disabled children. First, parents witness how often their children's non-sexual behaviors are interpreted as sexual and even deviant. Children with ASD and other developmental disabilities often have difficulties in understanding socially appropriate physical boundaries or misunderstand what is appropriate in public versus in private, and so their actions are often misconstrued as sexual when their

intention is not. Fixations and perseverations on sexual information or sexual activities were also reasons parents shied away from direct sex education. On the other hand, parents have expressed concern that their "children's normative sexual behaviors will be both stigmatized and feared…their sexual behavior was not viewed as a sign of 'normalcy' rather an aspect of development to further separate their child from nondisabled peers" (p. 679). Parents described instances of normal sexual development that were viewed by others, including mental health professionals, as troubling and another difficult area of development to be targeted and changed. In fact, parents found the professionals in their child's life to be particularly unhelpful in the area of sexuality; they tended to be reactive in addressing sexuality as opposed to taking initiative to communicate with the family or educate about what to expect in this area. Although parents expressed a desire for more professional involvement and guidance, some parents wanted professionals to play a background or indirect role by educating the parents and not educating the children themselves. Many parents felt that sexuality and sex education should be their responsibility and domain despite their fears about how to go about it.

Cuskelly and Bryde (2004) demonstrated that parental attitudes toward their developmentally disabled children's sexuality is largely positive; but that it tends to be more conservative on topics of intimate relationships, marriage, and parenthood. Parents doubted the possibility of their children to be involved in romantic and sexual relationships. In Ballan's (2011) study, none of the 16 parents of children ages 6 to 18 with ASD could foresee a future that included a partner and all the parents expressed the belief that sex education would be giving false hope to their children. Some parents felt strongly that sex with a partner was never going to be an option for their child due to the child's social difficulties. The majority of parents continue to assume or posit that sex will only occur for their child within long-term or monogamous

relationships and equate the lack of a long-term relationship as being sexually inactive. Contrary to parental assumptions, the majority of adults with developmental disabilities engage in sexual activities with partners throughout their lives even though this population experiences lower rates of long-term relationships. In fact, today many adults with and without developmental disabilities engage in sex without being in relationships and have many sexual partners over their lifetime. This discrepancy between parental views on the possibilities for sexual relationships and the actual sexual expression of individuals with developmental disabilities indicates that parents require more education on sexuality in this population in order to provide comprehensive sex education for their children.

Staff and educators' perspectives. Cuskelly and Bryde (2004) found staff and educators to have more liberal and progressive views about sexuality of individuals with developmental disabilities than parents. However, staff viewed parenthood amongst this population skeptically because of the potential needs for support and concerns about the level of care that would be provided to the children of people with developmental disabilities. Staff and educators expressed concern about pregnancy amongst women with developmental disabilities because of health concerns as well as the emotional complexities involved. However, in other areas of sexuality, such as sexual expression, masturbation, and partnered relationships, caregivers and educators were open-minded and had very positive perspectives.

Direct care staff or caregivers identified several barriers to free sexual expression, namely issues of consent, privacy, and facilitation (Wilkenfeld & Ballan, 2011). A major concern for staff in enabling their clients to have healthy and appropriate sexual or intimate relationships is the issue of consent. Caregivers expressed worries about their clients' fully understanding consent, both giving it and determining the level of consent of a partner. In relation to the topic

of consent, many staff desired to convey to their clients that sexual activity with a partner is both physical and emotional and staff hoped that they could prepare their clients for the consequences of engaging in sexual activity. Direct care staff argued that logistical considerations were the most significant barriers to those individuals who comprehend consent. Most adults with developmental disabilities who live in residential facilities have little access to privacy since most share rooms with roommates and are supervised by caregivers at all times. Finding a room to be alone with a partner requires prior communication with staff to ensure a roommate is elsewhere so that the individuals have privacy. Sexual activity is further complicated when individuals have disabilities that require some form of facilitation. Some individuals with developmental disabilities have physical disabilities as well or difficulties in motor coordination that makes sexual activity impossible without a staff member to help. Requiring a facilitator removes a sense of autonomy and also necessitates finding a staff who is trained, comfortable, and able to assist in a way that promotes as much autonomy for the clients as possible. Agencies often go without policy surrounding privacy and facilitation issues because they are sensitive areas, it is difficult to find employees who are capable and willing, and facilitation is time and money consuming because of the additional staff needed.

Swango-Wilson (2008) discovered that a majority of direct care staff for individuals with developmental disabilities were willing to provide or facilitate sex education despite having minimal training. Direct care staff indicated that there was a definite need for better sexuality and sex education for their clients and many felt comfortable providing the education. However, staff perceived their abilities to teach sex education as much higher than their limited training would indicate. Additionally, Christian, Stinson, and Dotson (2002) found that few residential facilities had any policy about sex education and that when agencies did have a policy, few staff

members were aware or ready to use it when given case scenarios. While it is heartening that staff are willing to provide education on personal matters like sexuality, there is an overwhelming need for in-depth training.

Conversely, Wilkenfeld and Ballan (2011) noted that educators were less willing to provide sex education and often indicated that nurses and family members should be primarily responsible. Educators felt similarly to caregivers about the need for more open sexual expression and greater comprehensive sex education, but they felt that sex education was not most appropriately taught by them. Parents expect the school to provide at least basic sex education; however, educators don't see sex education as their responsibility. This disagreement between who should be providing sex education for individuals with developmental disabilities creates service gaps, leaving many children and adolescents without comprehensive and accurate sex information, as well as skill development.

Development of Better Sex Education

Swango-Wilson (2010) argues for the use of systems theory in sex education and development of sexual identity for individuals with intellectual and developmental disorders. There is increasing awareness of the importance of sex education, but it often focuses on basic topics such as body functions, hygiene, and privacy and barely touches on issues of relationships, intimacy, and sexual identity. The author points out that people with intellectual or developmental disabilities are often separated from the mainstream either within their family or in institutional settings, which leads to the individual being "further disabled by denial of access to the flow of information and communication coon to the general public within the larger social system" (p. 161). The separation from the mainstream results in impoverished education and minimal chances for social learning from peers and the community. By working from a systems

approach, Swango-Wilson believes that individuals with developmental disabilities can feel a greater sense of inclusion and a stronger sense of self. A stronger sense of identity will lead to better outcomes in social relationships and is paramount to the development of a sexual identity, which Swango-Wilson argues should be the end goal in sex education for anyone, but especially those with developmental disabilities because of their high rates of sexual victimization. Incorporating parents, caregivers, educators, and community members would be a part of using systems theory, but Swango-Wilson argues that using a systems theory should start with the individual, and so those with developmental disabilities should be the first to give ideas about what is needed from sex education.

Swango-Wilson conducted two studies (2009) and (2011) in which she interviewed individuals with developmental disabilities about their experiences with sex education and what they'd like to get out of further education. In her 2009 study, Swango-Wilson interviewed four different cohorts; parents of children with developmentally disabilities, professionals who work directly with individuals with developmentally disabilities, health care providers who work with this population, and adults with developmental disabilities themselves. Each cohort was small, only 3 or 4 members, but Swango-Wilson was able to pull out distinct themes from each cohort about what the focus of sexuality and sex education should be. First, parents identified denial about the importance or even existence of sex in their adult children's lives; parents also expressed fear about sexual abuse and victimization. Second, the professionals, who were caregivers, teachers, and counselors, focused on safety and legal ramifications of sexual encounters. Third, the health care professionals emphasized sexual health issues, such as sexually transmitted diseases and prevention of pregnancy. The individuals with developmental disabilities had their own ideas about sex education; they desired more practical knowledge, such

as how to put on a condom or how to best ask for consent, and they wanted more relationship guidance, such as how to move from being friends to being in a romantic relationship. Swango-Wilson argues that these different areas of focus have negatively impacted the type of sex education this population receives because there is no consensus on what should be taught. This lack of consensus leaves out important topics; unfortunately, the area most often left out, intimate relationships, is one of the primary concerns of those with developmental disabilities (Swango-Wilson, 2009).

In 2011, Swango-Wilson interviewed only individuals with developmental disabilities with a larger focus on what types of relationship knowledge were desired and to look into what methods would be most helpful in sex education curriculum. When discussing relationship topics, the subjects highlighted three themes, which included friendships, lasting relationships and marriage, and safe intimacy. Issues of trust and the boundaries of friendship were of most concern, as subjects felt they lacked the knowledge or skills to navigate those finer details of relationships. Individuals with developmental disabilities brought up issues of marriage and lasting relationships, feeling they needed education on how to maintain a commitment and on how to make decisions about pregnancy and parenting. The theme of safe intimacy includes basic education about birth control, condoms, sexually transmitted diseases, but also issues of consent and boundaries. The subjects in this study reported not receiving any education on these topics and many stated that they'd never received any sex education at all (Swango-Wilson, 2011).

Swango-Wilson (2011) asked the same adults with developmental disabilities what types of sex education methods or tools they thought would be most beneficial. Suggestions included videos, role-plays, and homework to be completed with caregivers, and many highlighted the

need to have mixed gender classes. Individuals who suggested videos and role-plays felt that having specific demonstrations in videos and trying out skills with the instructor or with peers would help solidify their knowledge and provide a guide for what to do in various situations. All of the individuals stated, "the need to include caregivers in the development of the sex education programs…so that the caregiver had access to the information taught and could follow up factual knowledge with social situational learning opportunities" (p. 117). The caregivers would be able to generalize the knowledge learned in class by arranging opportunities in daily life for the individuals to try out their new skills. Additionally, caregivers tend to be closer and more trusted people and are often to whom the people individuals with developmental disabilities go with questions or concerns and, as such, should be fully informed of the curriculum. Lastly, the subjects identified the need for mixed gender classes because they had been given very little understanding of the anatomy of the opposite sex and feel that it would be easier to work on relationship skills and do role-plays with both genders present. Swango-Wilson argues that each of these suggestions have merit, could be incorporated into sex education programs, and need to be included to meet the needs of this population. Indeed, many of these suggestions directly address the unmet education on relationships and intimacy.

Hannah and Stagg (2016) interviewed young adults with and without ASD about their sexual knowledge, experiences, feelings, and needs. The individuals with ASD reported greater dissatisfaction with sex education in school in terms of content, but also the difficulties of learning the material in a practical or applicable way. Specifically, the individuals with ASD reported suffering from social anxiety around how to date, how to meet potential partners, and how to navigate moving from a platonic relationship to a sexual one. Hannah and Stagg argued that many of the difficulties the individuals with ASD described in relationships were connected

to their abilities to understand and interpret others' thoughts, feelings, or intentions when dating or pursuing sex. Additionally, two of the twenty young adults with ASD indicated non-heterosexual identities. These two participants reported having same-sex sexual experiences prior to a realization that they were not heterosexual. One individual with ASD indicated significant distress about exploring his sexual orientation due to his "black-and-white thinking" about orientation and his confusion about the concept of sexual identity. Overall the individuals with ASD had lower scores on a sexual consciousness scale which measured their attention to internal private sexual cues such as motivation, arousal, and reflection on sexuality. Hannah and Stagg's research indicates that individuals with ASD experience greater difficulty with exploring sexual identity and may experience higher levels of distress or confusion about being attracted to people of the same-sex. Sex education for this population will need to address issues of internal sexual identity as well as the diversity of sexual orientations (Hannah & Stagg, 2016).

Tarnai and Wolfe (2007) have argued for the incorporation of social stories into sex education programs for those with autism spectrum disorder and other developmental disabilities as a way to emphasize relationship knowledge and skills. Social stories are "scripts to teach appropriate social skills and behaviors to children and youth having autism or related disorders" (p. 30). Developed by Carol Gray in 1991, social stories have become widely used in Applied Behavior Analysis (ABA) programs for individuals with ASD and have garnered empirical support. The stories are often written in first person, include visual aids, are brief and concise, and are stated in positive terms to outline appropriate behavior in a specific situation. Tarnai and Wolfe conducted a comprehensive review and found no evidence of social stories being used in sexuality education despite their wide use as a tool for learning social skills. The authors postulate that social stories could be effectively used in areas of health and hygiene,

relationships, and self-advocacy in intimate encounters; they have included several examples and argue that collaboration between educators, parents and the individuals would increase the efficacy of the social stories.

Current Study

All individuals with developmental disabilities, regardless of severity, have a basic right to sex education, a sexual life, and intimate relationships (Sullivan & Caterino, 2008). Current sex education curriculum for those with developmental disabilities is often inaccurate and sometimes nonexistent. (Boehning, 2006). According to the World Congress of Sexology, individuals with disabilities have the right to sex education that provides wide, objective, comprehensive, and factual information on human sexuality, autonomy, safety of the body, sexual equality, and all aspects of sexual health (Richards et al., 2006). Myths, misconceptions, and negative attitudes about sexuality in this population still provide significant barriers against access to comprehensive sex education. Parents, staff, and educators are frequently untrained or uneducated about best ways to educate and promote healthy sexuality and sexual relationships for individuals with developmental disabilities. Current research indicates that sex education should incorporate multi-sensory tools and methods including situational instruction, audio-visual materials, and discussions (Sullivan & Caterino, 2008). Using a systems approach can help individuals with developmental disabilities feel a greater sense of inclusion and a stronger sense of self; additionally, a systems approach will promote more inclusion of parents, staff, and health professionals in sex education for this population (Swango-Wilson, 2010). Future research should focus on incorporating the voices and opinions of individuals with developmental disabilities (Swango-Wilson, 2011) as well as ways of empowering parents, staff, and educators to provide comprehensive sex education (Cuskelly & Bryde, 2004). The present

study sought to understand how parents of children with autism view the sexuality of their child as well as their child's sex education needs. In exploring parental views, concerns, and readiness, the current study is intended to inform mental health professionals about what families need regarding sex education for their child with autism. Despite the exploratory nature of this study, it was hypothesized that parents will see the value in sex education for their child with autism and will express interest in having mental health professionals involved in provided sex education to their child.

Chapter Three: Research Design and Method

Chapter Overview

The current study sought to ascertain an understanding of how parents today view the sexuality and sex education needs of their children with autism in order to provide mental health professionals with greater knowledge in how to work with these families. This chapter will review the research questions that guided the study and will explain why a phenomenological method was chosen. Furthermore, this chapter will outline what parents with autism were recruited to participate in the study and how they were recruited. Validity, data collection, and data processing will be described in addition to the assumptions, limitations, and ethical assurances that have affected the data.

Research Questions

As stated previously, the overarching question which guided this study was: What are the perceptions of parents regarding the sex education needs of their children with autism? In addition to ascertaining parents' perceptions the current study sought to answer two subquestions. How do parents consider the sexuality of their children with autism? In what ways have parents sought out or acquired sex education for their children with autism already? Learning how parents not only view sex education needs, but also their child's sex education is intended to provide a greater understanding of what parents are wanting mental professions to know and do.

Research Design

A phenomenological study has the ability to enhance mental health professionals' knowledge and understanding of how parents of children with autism address their child's sexuality and need for sex education. Because the intent of phenomenology is to understand the

commonality of experience (Donalek, 2004), this approach was meant to ascertain the universals amongst parents of children with autism. While a narrative study might have provided detailed information about one individual's experience or story (Creswell, 2012), it wouldn't be able to capture the essence of what and how these parents handle sexual topics in relation to their child. A phenomenological design was chosen to ensure that the participants' experience is the focus and that their own voices could be highlighted in determining what is common about sex education concerns amongst this population.

Population and Sample

Participants who are parents who have a child (or multiple children) with autism spectrum disorder were selected. This study sought to explore the experiences of parents of a child with autism in relation to sex education; given the scope and exploratory nature of this study only parents of a child with a medical diagnosis of autism were included. Parents of children who have received an educational diagnosis of autism without receiving a diagnosis from a qualified medical or mental health profession, were excluded from the present study. Individuals with autism spectrum disorder represent a wide variety in levels of functioning, skills, and deficits, all of which may affect how parents view sex education in relation to their child. However, given the difficulty in categorizing level of functioning amongst individuals with autism in a consistent and objective way, a medical diagnosis of autism was considered sufficient for inclusion.

For the purposes of this study, the child with autism was between the ages of 10 and 18, reflecting the ages when sex education is taught by the Illinois public school system (SEICUS, 2008). To be eligible for the study, parents were required to be legal guardians for the child with autism as they were asked questions in relation to decision making about sex education.

Individuals who did not speak English fluently were excluded from the present study as all interviews were conducted in English with the researcher. Because the interviews included questions addressing their child's participation in the American educational system's sex education, participants who immigrated to the United States within the last two years were excluded from the present study.

Procedures

Participants were recruited through snowball sampling beginning with professional contacts in Chicago, Illinois, including autism service providers, community agencies, and support groups. Recruitment was conducted electronically, by word of mouth from participants, and through the use of flyers or informational sheets that were disseminated through professional contacts in order to describe the purpose of the study and the eligibility requirements.

Instrumentation

Participants took part in individual qualitative and semi-structured interviews of approximately 60 minutes. Open-ended questions were crafted to create a semi-structured format that were intended to allow an exploration of the subjective and lived experience of the parents with children with autism. Questions addressed parents' readiness to engage in a conversation about their child's sexuality and sexual knowledge, parents' interest in sex education for their child, parents' thoughts on who should be involved in educating their child on this topic, and what parents' want or need from the professionals who work with them and their child. Parents whose child has already participated in some amount of sex education were asked questions in regard to the experience, the quality of the sex education their child received, and what if any further education they believe their child may need. The semi-structured interview was reviewed by mental health professionals who work with families of a child with autism in

order to gain feedback from these professionals about the types of questions asked. Parents were also asked to provide basic demographic information for themselves and their child including age, gender, ethnicity, and level of education (See Appendix A).

Data Processing

Analysis was targeted at finding the commonality and essence of parents concerns, beliefs, and needs in relation to their child's sex education (Donalek, 2004). Data analysis involved transcribing the interviews and reading through them to highlight significant statements before developing clusters of meaning into themes (Creswell, 2012). Codes were then chosen in order to highlight significant statements and quotes that demonstrated insight or understanding into the common experience (Creswell, 2012). At the beginning stages clusters and themes were gathered by detailed and repeated combing through the transcripts. After themes were discerned from the data, the themes were then used to write a description of the common experience of the participants. The description is meant to reflect the experience, but more so to convey the essence of the experience to the reader (Donalek, 2004).

Ethical Assurances

Participants were then informed of the voluntary nature of the study as well as how their confidentiality would be protected through de-identification of their personal information. Interviews were recorded in audio formats. Interviews took place in person in a comfortable and private setting to ensure both the comfort of the participant and privacy when discussing such personal and sensitive topics. Consent was gained for audio recordings, which were then transcribed and de-identified. Confidentiality was protected through assignment of identification numbers and pseudonyms to each participant, housing the interviews on a password protected computer, and encrypting transcripts (See Appendix B for Informed Consent).

Chapter Four: Findings

The purpose of this exploratory study was understanding the ways parents of children with autism view their child's sex education needs, providing a basis for future research in this area. Examining how parents view the importance and type of sex education their child needs is particularly important given the lack of comprehensive sex education among this population as well as the way parental views on the sexuality of their child with ASD have been barriers to sex education for this population in the past. (Boehning, 2006; Cuskelly & Bryde, 2004; Richards et al., 2006; Sullivan & Caterino, 2008). Exploring the views and concerns of parents will hopefully aid mental health professionals in understanding the sex education needs of families with a child with autism.

Three mothers with a child with autism within the ages of 10 and 18 were interviewed for this study. The semi-structured interviews lasted 50 to 70 minutes and utilized the interview questions created by the examiner with feedback from mental health professionals who work with this population. The questions addressed the sex education the child has received, what sex education the parent believes the child needs, what topics within sex education are viewed as important, and what parents want mental health professionals to know or do. The participants also provided basic demographic information about themselves and their child, including age, education level, and ethnicity (See Appendix A).

Participants ranged in age from early 40's to early 50's and their children ranged in age from 10 years to 17 years. All participants had a college education; their children ranged in the amount of sex education supportive services they have received. Two participants and their children identified as Caucasian and one participant and her child identified as Latinx. The participants reported a significant range in terms of how much sex education their child has had

previously, including school-based and therapy services. Brief descriptions of each participant and their child are provided below, followed by an examination of common themes found amongst the three participants.

Annie - Participant One

Annie (pseudonym) is a married woman in her early 40's who has a son with Autism Spectrum Disorder who is 12 years old and currently in 7th grade. She and her husband have two other children ages 11 and 9 years old, who do not have developmental disabilities. Annie is a college graduate and her son attends general education classes with some special education accommodations. She and her son identify as Latinx. Her son was diagnosed with ASD at the age of 3 years old and has received behavior therapy services as well as occupational and speech therapy services throughout his childhood. Annie indicated that her son has received sex education through the public schools since 5th grade and that he is currently on the waiting list for a therapy group that addresses puberty and sex education topics. She also noted that during 6th grade her son was reported to be touching his private area at school and, therefore, she sought help surrounding this issue from her son's behavior therapist. Annie found the therapist to be instrumental in changing her son's behavior and in helping her address the topic of masturbation with her son. She indicated a desire for her son to have more sex education and for her to be involved; however, she also indicated feeling unequipped and unsure of how to best teach her son.

Elise - Participant Two

Elise (pseudonym) is a married woman in her early 50's who has a daughter with Autism Spectrum Disorder who is 10 years old and currently in 5th grade. She does not have any other children. Her daughter identifies as transgender and has begun identifying as female since the

age of 6 years old. Elise's daughter was diagnosed with high-functioning ASD two years ago at 8 years of age. Her daughter has been attending mental health services since the age of 6 years old when she began identifying as transgender and began receiving behavior therapy services at the age of 8 years old when diagnosed with ASD. Elise is a college graduate; her daughter attends general education classes without special education accommodations. Elise and her daughter identify as Caucasian.

Elise reported that she and her husband have been very proactive in terms of seeking support and discussing topics of gender as her daughter began indicated gender-related concerns since the age of 3 years old. However, she stated being unsure of how to approach sex related topics with her daughter. She noted that her daughter has had crushes on other girls at school recently and that the family is currently discussing future hormone treatment and transitioning with their pediatrician. Elise's daughter has not yet received any formal sex education but has addressed issues of gender identity and puberty within therapy.

Brenda - Participant Three

Brenda (pseudonym) is a woman in her late 40's who has a son with Autism Spectrum Disorder who is 17 years old. Brenda is divorced and has another child who is 14 years old. Brenda and her son identify as Caucasian. Brenda is a college graduate. Her son is currently in 11th grade in a self-contained special education classroom with extensive supports. Brenda's son is non-verbal and uses a picture exchange system and a tablet to communicate with others. He has received therapy services since the age of 18 months and was diagnosed with ASD at the age of 3 years. He has not received any formal sex education outside of some school and therapy instruction around issues of privacy, personal boundaries, and puberty (e.g., body changes). Brenda reported that planning for the future is particularly difficult for her and her son given his

challenges with daily living skills. She indicated that he will likely live in a group home setting after leaving public school at the age of 22 years old. Brenda indicated significant concerns involving her son's lack of sex education and his ability to understand sex education information.

Themes Across Participants

Six major themes and three minor themes emerged from examination of the interviews of the three participants. Major themes were defined as themes that were addressed by all three participants while minor themes were defined as themes addressed by two participants. The six major themes, in no particular order, are: 1) Knowledge and Comprehension; 2) Important Topics; 3) Seeing the Big Picture; 4) Safety Concerns; 5) Benefits of Intervention; 6) Looking for Guidance. The three minor themes are: 1) The "Talk"; 2) Masturbation and Privacy; 3) Romantic Relationships (See Appendix C for a table of themes). Within each theme participants varied on their specific concerns or emphases depending on they and their child's unique life experience.

Major theme one: Knowledge and comprehension. All three participants thoroughly addressed concerns around their child's ability to understand sex education topics, to learn the necessary information, and to have enough skills to implement their knowledge. Two of the participants indicated concerns with determining when their child has adequately understood a topic. They each pointed out that their child struggles to verbalize or indicate when they comprehend something or when they do not. Brenda talked about how her son struggles with abstract concepts: "he is a concrete thinker…I've been told that's common with ASD to you know struggle with understanding concepts that can't be touched or modeled or attempted". All the participants indicated that concepts related to social skills were more challenging for their children to learn than other types of skills or knowledge. Given that the mechanics of sexual

activities and romantic relationships are a part of sex education, the participants expressed concern that their children would need repetition and practice before truly gaining knowledge in these areas.

Participants all mentioned that their child was a unique learner and that in connection with their ASD it can be hard to teach topics that relate to social interactions or situations. Annie talked about how her son "doesn't learn the same way as other kids—he can't just listen to you and get it especially if he can't see it or try it out for himself." Similarly, Elise was concerned that her daughter often understands basic concepts but doesn't understand how to apply it.

> She will get it. She's smart so she'll pick up on the information provided and she's able to tell you when she doesn't understand. But things that are harder for her like talking about emotions, joining conversations with friends, or navigating conflicts and arguments, these things she knows theoretically but doesn't realize that she doesn't do them well in practice. And for sex or just romantic relationships I assume it will be the same so how will she learn these skills in everyday life?

In terms of learning applicable knowledge, Brenda had specific concerns about her son given that he does not use language to communicate and needs intensive hands-on instruction to learn new skills or information. Two of the participants specifically mentioned social stories as a method their child has learned from, but that they were unsure if this method translates well into sex education topics.

Major theme two: Important topics. All of the participants indicated uncertainty about the topics their child would need to learn in regard to sex education. When asked what topics she believed would be most important for her son to learn, Annie stated, "you know I'm not even

sure. Like, should he learn about girls' bodies?" The three participants seemed to be overwhelmed about all the information that their child would need to have, considering the breadth of topics covered by sex education. Brenda talked about the vast array of topics: "I mean he needs to know everything I'm sure. From like body hair to safe sex. He has to know about puberty and consent and pregnancy and STD's and who knows what else."

Each of the participants indicated a priority for their child to learn concrete skills related to their everyday life. For instance, Annie expressed the importance of when her son learned about using deodorant during sex education at school while Brenda indicated that her son really needs to learn about how to clean up after masturbating. Elise also indicated a desire to address concrete skills:

> She's 10 now so if she were biologically female I'd be preparing her for her first period like how to use pads or tampons but learning about menstruation is probably not nearly as important as learning about what wet dreams are, how to conceal an erection if she's at school, or how to shave when she gets body hair. And then when she's older she'll need to learn about condoms like just how and when to use them. I mean aside from all the relationship stuff she has to learn these things these skills.

The three participants all mentioned relationship or social skills necessary to navigate sexual activities, but they all discussed these as being harder for their child to learn and not a priority at this time due to the more concrete needs that were occurring or were soon to arise. In fact, Annie pointed out that learning these skills has at times occurred when a problem has already arisen:

> Realistically? We didn't talk about a lot of puberty, sex education stuff until his teacher reported him touching himself at school and so we immediately brought that up to the therapist…it wasn't something we addressed all that much until therapy and then yeah there was a lot of educating him about when and where it is appropriate to you know masturbate.

Some of the participants also indicated being unsure of when a certain topic should be brought up given that their children have developed at different times than some of their typically developing peers. Brenda noted that her son has always been developmentally delayed and at age 17 he continues not to show interest in others sexually but does masturbate, which has left her wondering, "so when should he learn? Or should he at all if it's not important to his life right now?"

Major theme three: Seeing the Big Picture. Prioritizing concrete or daily living skills for each of the participants was partially due to the day-to-day challenges of having a child with ASD. The three participants expressed that there are typically larger problems in getting through the day that take precedence over focus on sex education and future planning. Annie noted, "honestly most of the time these topics don't seem that important…every day there are more important issues like school, friends, for him video games, that sort of thing." Similarly, Brenda indicated that anything that wasn't a pressing issue would have to wait:

> We're putting out fires as they happen you know? Because [my son] is so low functioning and is nonverbal there are just day-to-day problems that take up all our time and energy. You know just gaining independence in toileting was a battle and struggle for a few years and getting him able to prepare a simple meal like a sandwich has

> required intensive support in therapy, so we just don't have the time to be also thinking about what sex education topics should he learn unless it's a problem right this minute.

The participants have children who range in abilities, but they each reported having daily struggles that make it difficult to plan or think about sex education when it is not a pressing issue at the moment. Annie indicated that gender identity and puberty have been a focus, but other topics of sex education has not:

> Because she's been expressing gender identity concerns since being 4 years old or so we've really focused on that. And because she's 10 and will be hitting puberty soon we're constantly talking to her pediatrician about you know hormone treatment when to start transitioning, etc. These are all really important decisions…So yes, we focus on some of these topics related to sex education like puberty and body changes, but sex itself and safe sex or what have you? Just not currently on our radar, but it will be someday probably soon I'm sure.

Beyond the specific issues that arise, all the participants' children are also busy with daily life like school, extracurricular activities, family time, and a myriad of typical life events that are a larger priority than sex education and future planning.

Looking forward at what the future holds and what information their child will need later in life is a particularly challenging task. Annie described how difficult future planning in general has been for her son:

> You know when he first got diagnosed, I asked so much about what would his life be like later? And the therapists all told me we don't know because autism is so different for each individual and to focus on now and work on what's important now and yeah some

> days it's just day by day and that's all we can do. And other times I think about what's ahead…I have hopes for what his life will be like.

Annie described hopes about her son's independence, relationships, education, and career. Elise described wanting to plan for the future but feeling a little lost: "there are so many possibilities for what her life will look like and I want to be ready but it's hard to prepare for anything and everything." Conversely, Brenda indicated attempts specifically to not plan for the future: "I don't like thinking about more than a year or so ahead because we just can't know given all his challenges, we just can't plan for every possibility." She expressed having to grieve the loss of different futures and that planning for the now was the best way to stay positive about her son's progress.

Major theme four: Safety concerns. Concerns and worries for the safety of their children and others during sexual experiences was a theme expressed by all three participants. Each of the participants indicated being worried about their child's physical and emotional wellbeing if and when their child engaged in sexual activity. Elise noted that her daughter tended to be impulsive, which could be problematic during sexual relationships: "I just worry about her getting in over her head…thinking she's ready or old enough, but not realizing how sex can impact her emotionally." Elise highlighted the emotional and nuanced decision-making required in deciding when to engage in sex with someone as well as the emotional impact of being so intimate with someone. She stated, "I just don't want her to have sex with someone she cares about and then realize they don't care for her that same way or they are only looking for a one-night-stand kind of thing." Conversely, Annie and Brenda expressed more concerns with physical health and physical consequences of unsafe sex. Annie also had specific fears about pregnancy, sexually transmitted infections (STI's), and consent:

> How will he read a girl's interest? Will he know when and where to stop if he needs to? And be safe…my biggest fear is he comes home one day saying he got some girl pregnant…or you know not realizing he got an infection?

Similarly, Brenda emphasized concerns about pregnancy and STI's, highlighting the fact that her son is nonverbal and has difficulty informing others about his health. She also noted that her son "might not understand the consequences. I just don't think he'd be able to think through how serious the risks are." The three participants explicitly tied these concerns about potential harm with their child's unique learning style and ASD related challenges.

Only one participant used terms, such as abuse or assault, but all three indicated concerns about their child being a victim of sexual misconduct or even unable to voice discomfort or refusal during sexual activities. Annie wondered, "what if he didn't know any better when someone touches him, and he doesn't like it…does he know when to stop someone else?" Elise stated concerns about others taking advantage of her daughter: "people who are transgender are at higher risk of being sexually assaulted and given that she struggles with social cues, I'm worried she wouldn't know when someone was using her or hurting her." The three participants all had concerns about their child's ability to give consent though each participant emphasized different aspects of consent. Brenda specifically brought up her son's communication barriers as making consent difficult to provide while Annie indicated concerns about her son's ability to understand what he was consenting to. Elise reported having concerns about her daughter's ability to remove consent as actions escalate:

> She needs to know and understand that just because she said yes to one thing that doesn't mean yes to everything. I know that's hard for lots of people to understand, but [my daughter] is such a people pleaser…she does what others ask of her because she struggles

> to read social cues to begin with so will she fall prey to someone pressuring her to go further than she wants to?

Elise noted that consent is a particularly socially nuanced aspect of sexual activity and, therefore, was likely to be a difficult concept for her daughter. All of the participants saw consent as a crucial aspect in their child's safety in engaging in sexual activity.

Major theme five: Benefits of intervention. Although the amount of therapeutic and professional services in sex education varied greatly amongst the children, each participant reported finding intervention to be helpful for their child. Annie, whose son received therapy following being caught masturbating at school, indicated that "therapy was especially helpful, like he doesn't touch himself anymore at school and is slowly learning about privacy and boundaries that type of thing." Similarly, Brenda stated that

> His therapists have been instrumental in his life overall. They are the ones who have taught him about privacy when he masturbates. We just didn't know what to do about that when that became a problem at home and at school, but his therapists knew exactly how to help and how to teach us what we needed to do at school and home for him to learn all the rules about when he can't do that.

Annie and Brenda identified the ways therapists have helped their children learn specific rules, skills, or information. Annie's son will soon be in a therapy group addressing sex education topics and Annie expressed excitement about this opportunity for her son to have more therapeutic intervention in this area. Elise stated that her daughter has not received therapy services directly targeting sex education but has received services in regard to her gender

identity. She indicated that crushes and concerns about puberty have come up in therapy and that her daughter's therapist has been very helpful:

> The therapist is so good about talking to [my daughter] about these things and just making it all seem to normal and understandable…being able to talk about these things in therapy has been so important for [my daughter's] self-esteem and comfort with these things.

Annie and Brenda indicated that sex education through school has been positive, but that therapy and direct instruction proved to be more helpful. Annie stated, "The stuff at school…he seemed to learn the things he needed to I guess. I'm not sure though how much he understood…but he really didn't understand about privacy until the therapist worked with us more." Brenda also found therapy to be more helpful than school in teaching sex education:

> School has been helpful in teaching him vocational skills and some of the daily living things like cooking and they even taught him about laundry. But it has been his therapists who have helped us address the awkward stuff…the therapists are the ones I go to when sex education topics have come up.

Participants found therapy to be the best equipped setting to address sex education topics, especially when the participants felt unsure on how to teach their children themselves. Elise expressed that when sex related issues come up she would turn to her daughter's therapist first as "the therapist has made it clear that those kinds of topics are fair game in therapy and she's been open to addressing those, which makes me more comfortable turning to [the therapist]."

Major theme six: Looking for guidance. When asked what they would want mental health professionals to know about their child's sex education needs, all of the participants

reported wanting professionals to be more proactive in bringing up these topics. The participants indicated turning to therapists for help with sex and puberty related issues but hoping that in the future therapists would target these issues before they become problems. Annie stated that upon informing the therapist of her son masturbating at school:

> The therapist told us…that it's not uncommon, but I didn't know that! I mean I get it. How are you going to tell everyone, warn everyone? But if it's not uncommon than as a parent I want to know that that could happen…I guess knowing earlier might have helped…we would have been ready for that.

Annie also expressed feeling lucky that her son was recommended for a therapy group about sex education because she has spoken to other parents whose children never received that type of therapy service. Elise also expressed a desire for mental health professionals to publically discuss or inform parents about when and what to teach in terms of sex education. She hoped that therapists would "know what she needs to learn because I feel a little overwhelmed by the sheer amount of knowledge she should be equipped with."

Some of the participants reported hoping that therapists would better know how to teach sex education topics to their child given the ASD diagnosis. Annie discussed how therapists have helped address her son's unique learning style, stating that therapists perhaps will know how to teach sex education topics: "How should he learn? I mean are social stories going to work for every topic? Are there social stories for using a condom? I don't know." She hoped that therapists would be able to use their knowledge of ASD to translate learning techniques, such as social stories, to sex education topics. Similarly, Brenda reported wanting therapists to provide her with teaching tools, such as social stories, to use for her son's sex education needs outside of therapy. Elise voiced specific concerns about professionals outside of mental health being

unequipped to address sex education for her child given her diagnosis of ASD and her transgender identity:

> She just has different needs. I mean school isn't going to teach about how to tell a partner that you have genitals that do not match your outward gender appearance. And on top of that she struggles with social interactions and that has to be a very challenging situation. I just have to assume that therapy would be the best place for that as long as the therapist was knowledgeable about trans issues as well as ASD.

All of the participants have positive views about involving therapists in sex education and expressed a desire for mental health professionals to be more proactive in addressing these topics.

Minor theme one: The "talk". Annie and Elise both mentioned having conversations with their child about sex that were unprompted by anything specific and were meant as a general introduction to the topic. Annie noted that her husband had a sex talk with her son covering "the basic mechanics of what sex is, you know what body part goes where, and that he's too young for all that and that it's for adults…I'm not sure what he understood from that though." She noted that the talk from her husband was an attempt to introduce the topic of sex and that it was intended to be general and just an initial conversation rather than a comprehensive discussion. Elise also discussed having a sex talk with her daughter, which happened recently as she turned 10. Elise stated, "I sat her down and described what sex is and how it leads to pregnancy…it was mostly biological." She also indicated that one of the intentions of having this talk was to inform her daughter before she was misinformed by peers or her own assumptions. Both participants who discussed having a sex talk felt that it was helpful as a way to begin sex education, but not sufficient on its own. Elise mentioned:

> I feel like having the talk is how I am involved. How I can start her on a positive journey in learning these things. But at the same time, I think therapy and school and even her pediatrician will be important in her learning both concrete information but also you know the social stuff, the gray areas.

When asked about how they have been involved in their child's sex education, Annie and Elise both indicated that the talk was the primary way they have been involved. Additionally, Annie also pointed out how having a sex talk with one's child is a fairly modern concept:

> I'm realizing how times have changed…when I was a kid my mom handed me a pamphlet…and told me to ask her if I had any questions…. now there's so much more talk about discussing this stuff with your kids. I just don't know. There isn't a manual for this…especially about how to teach kids like [my son].

Minor theme two: Masturbation and privacy. Annie and Brenda reported having concerns about their son's masturbation and understanding of privacy and boundaries. The participants both noted that masturbation was the most pressing sex related concern they had and that it has been an area they have sought professional support around. Brenda indicated that when her son began masturbating it was the first indication that he was developing any sexual awareness as he has never indicated sexual interest in others

> He's nonverbal but even so he's never shown any interest in others that way. He's so social isolated as it is, so I am unsure at all if he'll want to or understand having sex with someone else, but he does understand sexual pleasure in some way I suppose since he does masturbate.

Annie and Brenda each expressed the challenge of teaching their son about when and where it is appropriate to masturbate as their son did not intuitively understand it was a private activity. Brenda stated, "he just didn't understand that it was socially unacceptable to do that, so we had to set up rules about it because he really didn't know."

Additionally, Annie indicated that having a child with ASD or other special needs leads to knowing or being more involved in personal issues than many parents are.

> A lot of my friends just assume that their son or daughter is masturbating, but I am intimately aware because [my son] doesn't have the same natural sense of privacy and social rules that other kids do. It makes for a different experience as a parent with this sex education piece.

Minor theme three: Romantic relationships. Annie and Elise both expressed concerns regarding their child's ability to navigate romantic or sexual relationships. Annie wondered about her son's interest in having that type of relationship:

> Will he ever fall in love? Is he you know capable of that? I don't know because so much of just friendship is hard for him. So, could he or would he want to date someone someday…I hope he's not always alone…but I don't know that that's realistic.

Conversely, Elise noted that her daughter has already had several crushes on girls at school and clearly has interest in romantic relationships of some kind. She indicated concerns about her daughter's ability to navigate a romantic relationship:

> She's had so much therapy and social skills groups that have helped her build the skills needed for her just to make friends, so I imagine she'll need a lot of support to build those dating or romantic relationship skills because they don't come naturally for her.

Annie stated that her son will need help learning things, such as “getting permission for a kiss…how to approach girls appropriately…how to ask for a date.” Elise also described a variety of skills her daughter would need to have, such as knowing when someone isn’t interested and how to maintain a relationship that is romantic in nature.

Chapter Five: Discussion

Three mothers of children with Autism Spectrum Disorder (ASD) participated in 50 to 70-minute semi-structured interviews in regard to their child's sex education needs. The study explored the lived experiences of parents with a child with ASD in considering, providing, and seeking sex education for their child. Although misconceptions about the sexuality and sexual interest of individuals with ASD have changed over recent years, individuals with ASD continue to lack comprehensive sex education that targets their specific learning needs. (Boehning, 2006; Cuskelly & Bryde, 2004; Richards et al., 2006; Sullivan & Caterino, 2008). Interview questions for this study were created by the researcher with feedback from mental health professionals who work with this population. The participants responded to questions addressing their child's previous experience with sex education, what areas of sex education they believed their child needed to learn about, and what they wanted mental health professionals to know about the sex education needs of their child. The participants were found through snow-ball sampling and had a child with a medical diagnosis of ASD between the ages of 10 and 18 years old.

Following transcription of the interviews, the researcher highlighted significant statements before developing clusters of meaning into themes that demonstrated common experiences between the participants. Major themes were found when all three participants expressed similar experiences and minor themes were found when two of the participants described similar experiences. Six major themes and three minor themes were found and described above in order to reflect and convey the lived experiences of the participants using their own words whenever possible. An organizational tool or structure was considered to contextualize the results of this study; however, attempts to fit the various themes within a structure proved to dilute the participants' lived experiences and narratives. The optimal way to

organize the findings of the interviews was thematically in order to offer a nuanced picture of the participants perspectives, concerns, and experiences in regard to their child's sex education needs. The following major themes were discovered: 1) Knowledge and Comprehension; 2) Important Topics; 3) Seeing the Big Picture; 4) Safety Concerns; 5) Benefits of Intervention; 6) Looking for Guidance. The following minor themes were ascertained: 1) The "Talk"; 2) Masturbation and Privacy; 3) Romantic Relationships. Participants indicated a general desire for their child to receive sex education, concerns about their child's ability to understand and apply sex education knowledge, and a need for mental health professionals to be proactive.

The findings of the interviews supported the hypothesis that parents perceive a need for their child with ASD to receive sex education. Not only did the participants report wanting their child to learn concepts related to puberty, sex, and consent, the parents all indicated having already sought out therapy services to address these topics. Multiple participants indicated having sought out sex education due to a previous issue having arisen, such as masturbation in public. Parents appear to be considering sex education primarily from a reactionary perspective followed by a desire to prevent future problems. This reactionary perspective is likely in part due to the fact that unforeseen issues arise when raising a child with ASD who develops social skills differently than many typically developing children, which can lead to issues understanding the difference between friendship and romantic relationships, privacy and boundaries, or the nuances of providing and gaining consent. Prior research indicated that parents often struggled with being proactive despite voicing a desire to plan ahead which may be because parents of a child with ASD often don't have the luxury of being future-oriented when there are daily struggles that take precedence (Ballan, 2011). This researcher posits that many parents of children with autism are interested in considering their child's sex education needs

from a more holistic or proactive perspective but get mired in the day-to-day challenges of raising a child with autism. In fact, when parents are considering what topics related to sex education are most important, they prioritize concrete skills that are applicable in the moment and view their child's learning of abstract information and abilities as long-term goals.

Further, the participants indicated feeling overwhelmed or uncertain about what topics their child would need to be informed of but believing that their child would need a range of knowledge including concrete and relationship skills. Results indicate that parents are uncertain about their child's ability to comprehend various sex education topics due to the unique learning style or their child or their child's intellectual abilities. Likely due to the variation in cognitive, emotional, social, and behavioral functioning amongst children with ASD, parents express a variety of concerns related to the sexual interest their child is likely to have and their child's ability to comprehend the abstract and social nature of sex related topics. Much of the parents' desire for sex education related to the safety risks they foresee if their child is left uninformed of some of the consequences of sexual activity, including pregnancy, sexually transmitted infections, and emotional intimacy. Fears surrounding potential abuse and harassment were among the fears parents had for their child. Contrary to earlier research in this area (Ballan, 2011; Cuskelly & Bryde, 2004; Swango-Wilson, 2009), the results of this study indicated that parents' worries and concerns were not preventing the parents from seeking out sex education for their child but rather motivating for greater sex education.

Notably, only one of the participants of this study explicitly expressed concerns about their child being the victim of sexual abuse or being a sexual offender, which contrasts with previous research in this area. This researcher conjectures that the parents of this study expressed fewer concerns about abuse because these topics are particularly sensitive and

intimidating to consider. The participants may have indicated further concerns in this area if directly asked. Parents in previous research have reported fears that their child's odd or socially inappropriate behavior would be misconstrued or seen as sexually deviant (Ballan, 2011; Cuskelly & Bryde, 2004; Swango-Wilson, 2009). Given that Annie's son has masturbated in a public place, it seems likely that she has at least considered the legal ramifications of such behavior. Elise noted concerns about someone taking advantage of her daughter without her daughter being aware but was vague about what that meant; however, the researcher speculates that Elise was indicating that her daughter could be a victim of sexual harassment or assault without realizing it. Further, the researcher is curious about the possibility that some of Brenda's concerns about her son's ability to communicate his needs may be similar to the previous research that highlighted parents' concerns that their child would not be able to voice when they had been mistreated in some way. The participants of this study may be implying concerns around abuse or sexual misconduct or perhaps not fully considering these issues as of yet.

Considering the concerns, the parents of this study and previous studies have reported around potential misconduct and abuse as well as the concerns about relationships and concrete sex education skills, it appears that there may be some universal fears and concerns amongst parents of a child with ASD. This researcher is interested in any similarities or differences in concerns and fears there may be between parents with typically developing children and parents who have a child with autism. The themes found from this research as well as evidence from previous research indicate that parents with a child with ASD are particularly concerned about their child's ability to learn necessary skills, to develop the abilities to navigate sexual and romantic relationships, and to provide and gain consent. Therefore, it appears that parents with a child with ASD have specific concerns related to their child's diagnosis. Indeed, the parents in

this study and in previous research have reported the same concerns, which may indicate a universality for parents with a child with ASD in regard to sex education. However, it is important to note that the parents of this study demonstrated a greater interest in sex education because of these concerns as opposed to previous research where parents' fears were a barrier to sex education (Ballan, 2011; Cuskelly & Bryde, 2004; Swango-Wilson, 2009). The majority of previous research in this area is 5 to 10 years or more out of date and, therefore, it is possible that there has been a shift in the motivational factor that these fears play in ascertaining sex education for children with ASD.

An area that doesn't seem to have changed over the time since prior research on parental attitudes is the assumption that individuals with ASD will only engage in sexual activity within a relationship. The parents in this study not only expressed the importance of romantic relationships but discussed the possibility of their child having sex as a consequence of if their child could make and maintain a romantic relationship of some kind. The parents differed in how much they emphasized a long-term relationship or if they used the word romantic or sexual, but each of the three parents in this study referenced sex and relationships as integrally connected. Previous research on parental attitudes revealed the same assumption, that their child with ASD would experience sex based on their ability to secure a sexual or romantic relationship of some kind (Ballan, 2011; Swango-Wilson, 2009). However, research has demonstrated that individuals with ASD engage in sexual activity at a rate similar to their non-ASD peers despite having fewer romantic relationships than their non-ASD peers (Wilkenfeld & Ballan, 2011). This researcher posits that parents continue to see their children with ASD as less interested in sex than their non-ASD peers or as incapable of engaging in sexual activity outside of a relationship. Perhaps parents of most children struggle with the concept of their child being a

sexual person who engages in sex outside of relationships. As the romantic and sexual cultural norms change over time, parental views are likely to change as well. This researcher wonders if subsequent generations of parents with a child with ASD will want their child to learn about dating applications and social media as a way for their child to explore sexual activities.

This researcher acknowledges that the topic of sex and sex education is intimately tied to values, beliefs, and moral systems. The assumption that a relationship must precede sexual activity is one such idea couched in moral systems and beliefs. Religion, specifically, has had a massive influence on societal beliefs and opinions surrounding sex. In the United States there continues to be a significant impact of conservative religious views on sex education as well as expectations for the nature of sexual relationships (Hall, Sales, Komro, & Santelli, 2016). The moral beliefs of the participants of this study were not assessed, but it appears that the three mothers continue to value the connection between romantic relationships and sexual engagement. Further, moral systems impact views on sexual orientation and gender identity that are of note in this study given that one participant's daughter is transgender and has demonstrated interest in girls. The other two participants never discussed gender identity or sexual orientation, and each made assumptions that their child was heterosexual. Parental assumptions of cisgender and heterosexuality are certainly not uncommon even today with changing societal views and it appears that many parents with a child with ASD also make these assumptions. Given the recent research suggesting high rates of transgender individuals with ASD, it is crucial to examine these assumptions and for parents to be informed (Glidden, Bouman, Jones, & Arcelus, 2016). As Elise mentioned, there are likely to be unique challenges when raising a child who has ASD and who is exploring non-traditional gender identities or sexual orientations.

An emerging theory about why there are higher rates of transgender people who have ASD than in the general population asserts that individuals with ASD are often unaware of or live outside of social norms and therefore are less impacted by social constructs of gender (Glidden, Bouman, Jones, & Arcelus, 2016). This theory implies that individuals with ASD might be more likely to express fluid gender identities while other research indicates that individuals with ASD experience greater confusion and decreased internal identity exploration (Hannah & Stagg, 2016). This researcher posits that this growing field of research into LGBT issues amongst the ASD population will be crucial in developing more comprehensive sex education and in directing mental health professionals in how to support these individuals and families. The majority of mental health support for individuals with ASD is behavior therapy, which is skills and behavior based. Behavior therapy for individuals with ASD is effective because it helps this population decrease socially inappropriate behaviors and increase skills necessary for functioning at home, school, and in the community (Sullivan & Caterino, 2008). However, most behavior therapy and skills-based therapy does not focus on concepts such as exploring identity, internal processes, and examining stereotypies. Because most mental health professionals working with this population teach foundational skills and social expectations, often young children with ASD are instructed about the typical gender expressions of boys and girls without thought given to organic exploration of gender identity. This researcher posits that families such as Elise's need more thorough and open engagement with mental health professionals to support the gender identity and sexual orientation exploration of individuals with ASD.

The participants reported having positive experiences with therapists who had addressed sex education issues with their child in the past. As hypothesized, participants expressed interest

in having mental health professionals involved in the sex education of their child with each participant voicing a desire for therapists to be proactive in bringing up these topics with them early and often. Previous research had indicated some confusion about the roles of parents, medical professionals, educators, and therapists in providing sex education for children with ASD (Swango-Wilson, 2008; Wilkenfeld & Ballan, 2011). This study did not seek to answer the question of who is best to provide sex education for this population, but results indicate that parents are looking for mental health professionals to be involved. Results suggest that parents are most looking for mental health professionals specifically to help parents learn techniques for how to teach sex education topics to their child given the unique learning profile of most children with ASD. Even amongst parents who have attempted to educate their children on their own, there were difficulties in determining how much their child was comprehending. Multiple parents indicated a desire for social stories and other known therapeutic methods for teaching skills to children with ASD. Further, parents are looking for therapists to be knowledgeable in this area as well as open to discussing personal topics such as puberty, masturbation, and sex.

Limitations

With three participants, the present study does not purport to express the views of the entire population of parents of a child with ASD. The intention of this research is to explore how parents of children with ASD are currently viewing the sex education needs of their children, providing mental health professionals insight regarding ways to support these families. The goal of this study was to begin to lay a foundation in understanding the experiences of these parents rather than to make generalizations about this population as a whole. Attaining a large sample size increased the risk of losing narrative depth and the personal detail possible with a smaller sample size given the scope of this study. Additionally, attaining a large sample size proved

difficult due to the personal nature of the topic and the busy lives of parents with a child with autism. As the participants themselves indicated, having a child with autism brings about day-to-day challenges must be prioritized over other events, activities, or plans. Several additional parents were interested in aiding this research but were unable to find the time in their schedule necessary to participate, which reflects the demanding schedules these parents manage. It appears that there is growing interest in the area of sex education, but as mentioned by the participants this area is often not thought of when families are living with the day-to-day challenges of raising a child with ASD.

With a smaller sample size, this research is limited in terms of deeper analysis with specific variables that arose, such as cognitive level of the child, access to therapeutic services, and likely many others. During analysis the researcher noted that some of the parents indicated concerns with their child's comprehension of sex education topics due to the cognitive abilities of their child. The impact of a child's cognitive level on how a parent perceives their sex education needs would be an important area to examine further. This researcher posits that individuals families with a child who is lower functioning will report even greater focus on concrete skills than families with a child who is higher functioning. Additionally, the three participants of this study had previously accessed therapeutic services targeting gender, puberty, and sex education issues, which likely impacted their view of the importance of having mental health professionals involved in their child's sex education. Participants for this study were self-selected in that they willingly volunteered to participate in research about sex education and, therefore, are likely more interested and willing to seek sex education for their children. This researcher posits that families who have not yet experienced challenges in this area (e.g., public masturbation) are less likely to explore the sex education needs of their child. Further, many

families with a child with ASD do not have abundant access to therapeutic resources in their local area or within their financial means and this would certainly be a factor in their ability to involve therapists and clinicians.

Other factors such as parent's gender, education level, race or ethnicity, or religion may impact the ways they perceive their child's sex education needs. Only mothers with bachelor's degrees were involved in this study, which may be a sampling bias and likely impacted the findings. This researcher speculates that individuals with higher education levels are more likely to be interested in sex education for their child and more open to discussing these issues with mental health professionals. Further, providing sex education to one's child is often tied to cultural beliefs and conventions as well as generational effects as noted by one participant who received a pamphlet from her mother growing up but is trying to have ongoing conversations with her child instead. Religious beliefs are likely to have a significant impact on the findings of studies similar to this one given the importance of moral systems on views about sex and sex education. The gender of the child may have an impact on the parents' perceived needs and the specific skills and education they feel would be most important for their child. The current study included parents of children who are male and transgender (biologically male) and, therefore, the impact of female gender was not examined. Additionally, the age of the child is likely to have a significant impact given that within the 10 to 18 year range covered by this study there is significant development in terms of puberty, sex, and social ability. Because participants were found through snowball sampling and were informed that the topic of this research was sex education, it is possible that this sample is particularly open to considering the sex education needs of their child. The parents who participated were all invested in giving their time to research addressing this issue and, therefore, may have unique experiences or interests in the sex

education needs of their children. This study was exploratory in nature and had sample limitations that further support the use of these findings as a basis for future research rather than as definitive or generalizable results.

Future Research

There is ample opportunity and need for future research in the area of sex education and ASD. Continued research on the needs of parents and their children in regard to sex education should focus on assessing the effectiveness of current sex education with this population. More and more children with ASD are receiving some form of sex education, such as informal conversations with parents, school-based learning, and therapeutic intervention. Research is needed to determine the effectiveness of these various formats for sex education in terms of knowledge gained and applicable skills learned. Research in the past has evaluated the impact of parental perspectives on access to sex education and given the results of this study examining the perspectives of clinicians could be beneficial in determining how prepared clinicians are to be involved in the sex education of this population.

As previously noted, the cognitive abilities of children with ASD likely has an impact on how parents and professionals view sex education with this population and would be an important new area for research. The majority of research has focused on individuals with high-functioning ASD, but as noted by the results of this study, lower functioning individuals with ASD also have sex education needs, which may be unique to their cognitive and communication abilities. Further, the majority of research on the topic of sex education for individuals with ASD has focused on the parents, caregivers, educators, and professionals rather than on the individuals with ASD themselves. Interviewing or surveying individuals with ASD has proven to be difficult because of the wide range of intellectual and communication abilities of this

population, but it would be invaluable to hear from the individuals themselves about their sex education needs and experiences. As mentioned above within the area of limitations, the effects of gender of the child and religious views of the parent are unknown and areas that ought to be explored further. Additionally, the impact of socio-economic status (SES), race/ethnicity, and region of the United States have been known to be influential in general views on sex education and, therefore, may be impactful on the results of future research within this population (Hall, Sales, Komro, & Santelli, 2016).

Clinical Implications

Education and Training. The findings of this study indicate a greater need for education in professional programs and post-graduate training of mental health professionals in regard to the sex education needs of individuals with ASD. As parents in this study noted, mental health professionals are not yet proactive in addressing topics of sexual health, identity, engagement, and orientation within the population of individuals with ASD. The initial step in ensuring therapists provide families with sufficient support is providing graduate-level students with sufficient education and post-graduate training in the needs of this population. Indeed, there is a need for greater education and training regarding the diversity of sexual orientation, gender identity, and sexual health of a variety of patients. Future research needs to be implemented into education and training programs to teach evidence-based methods of providing mental health support for individuals with ASD in regard to sex and sex education. As part of education and training, this researcher asserts that there must be a focus on the holistic life experience of those with ASD. The field of psychology must continue the efforts to view individuals with ASD whole people with all the complex experiences of life, including sexual needs, wants, and desires.

Direct Work with Clients. The results of this study highlight the importance of mental health professionals being involved in the sex education of children with ASD. Parents of children with ASD are looking for psychoeducation and support in teaching their children information and skills related to puberty, masturbation, safe sex, romantic relationships, and other sex education topics. When working with families in this population, it is particularly important to be proactive in asking about these areas of physical and sexual development to ensure that parents are thinking about their child's needs in these areas. The findings of this study demonstrate that parents often feel overwhelmed about what their children need to learn in regard to sex education and would benefit from direction and guidance. Because development is affected by ASD, many parents are unsure about when their child should be educated about these topics. Asking about these topics at younger ages will hopefully prevent parents from feeling unprepared and prevent problematic behaviors from arising, such as public masturbation.

Additionally, findings suggested that parents appreciated mental health professionals who opened up space within the therapy room for discussion of sex-related topics. When a therapist or clinician demonstrates an openness to talk about sex-related areas of development, they demonstrate to families that the therapy room is a place where these concerns can be brought. Mental health professionals should build comfort in initiating these conversations with clients and parents and consider these conversations to be a crucial aspect of intake sessions. Aside from bringing up these topics, mental health professionals should be prepared to address these sensitive issues or problematic behaviors within the therapy room with children with a wide range of cognitive functioning. This may include creative use of behavior management techniques, social stories, parent training, and consultation with educators and other service providers. Parents and their children with ASD will benefit from clinicians who are open,

knowledgeable, proactive, and sensitive to the challenges of providing sex education to this population.

Advocacy and Change. Significant progress over the last few decades has been made in the recognition of the sexuality and sex education needs of individuals with ASD. However, many individuals with ASD continue to lack access to comprehensive sex education (DiGiulio, 2003). Mental health professionals have made massive strides in the education and skill training of children with ASD and have a unique opportunity to change the way sex education is provided to this population. Clinicians and therapists can have an important role and impact as advocates for our clients. Advocacy on individual, microsystemic, or macrosystemic levels is needed to address the concerns of clients, to provide psychoeducation and outreach, and to consult with legislators and researchers as a way to promote the sex education of individuals with ASD. As this study highlights, clinicians are not the only professionals involved in sex education for those with special needs, such as ASD, but families are looking for the support, psychoeducation, and behavioral change that mental health professionals can help provide. Clinicians and therapists should educate others in this field about techniques and resources that are helpful in this area; keeping colleagues informed about the importance of addressing these topics with clients will benefit those we seek to support.

References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5*. Washington, D.C: American Psychiatric Association.

Ballan, M. S. (2011). Parental perspectives of communication about sexuality in families of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *42*(5), 676–84.

Boehning, A. (2006). Sex education for students with disabilities. *Law and Disorder*, 1, 59-66.

Buck v. Bell, 274 U.S. 200 (1927).

Christian, L., Stinson, J., & Dotson, L. A. (2002). Staff values regarding the sexual expression of women with developmental disabilities, *Sexuality and Disability, 19*(4), 283-291.

Creswell, J.W. (2012). *Qualitative inquiry and research design* (3rd Ed.). Thousand Oaks, CA: Sage Publications.

Cuskelly, M., & Bryde, R. (2004). Attitudes towards the sexuality of adults with an intellectual disability: parents, support staff, and a community sample. *Journal of Intellectual and Developmental Disability*, *29*(3), 255–264.

DiGuilio, G. (2003). Sexuality and people living with physical or developmental disabilities: a review of key issues. *Canadian Journal of Human Sexuality, 12*(1), 53-68.

Donalek, J. G. (2004). Phenomenology as a qualitative research method. *Urologic Nursing, 24*(6), 516-517.

Glidden, D., Bouman, W.P., Jones, B.A., & Arcelus, J. (2016). Gender dysphoria and autism spectrum disorder: A systematic review of the literature review. *Sexual Medicine Reviews, 4*(1), 3-14.

Hall, K.S., Sales, J.M., Komro, K.A., & Santelli, J. (2016). The state of sex education in the United States. *The Journal of Adolescent Health, 58*(6), 595-597.

Hannah, L. A., & Stagg, S. D. (2016). Experiences of sex education and sexual awareness in young adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 46*(12), 3678-3687.

Radford, J. P., & Park, D.C. (1995). The eugenic legacy. *Journal on Developmental Disabilities 4*(1), 63-74.

Richards, D., Miodrag, N., & Watson, S. L. (2006). Sexuality and developmental disability: obstacles to healthy sexuality throughout the lifespan, *Developmental Disabilities Bulletin, 34*(1), 137–155.

SEICUS: Sexuality Information and Education Council of the United States. (2008). *The status of sexuality education in Illinois.* Retrieved from http://www.siecus.org/index.cfm?fuseaction=Feature.showFeature&featureID=903.

Sullivan, A., & Caterino, L. C. (2008). Addressing the sexuality and sex education of individuals with autism spectrum disorders. *Education and Treatment of Children, 31*(1), 381-394.

Swango-Wilson, A. (2008). Caregiver perceptions and implications for sex education for individuals with intellectual and developmental disabilities. *Sexuality and Disability, 26*(3), 167–174.

Swango-Wilson, A. (2009). Perception of sex education for individuals with developmental and cognitive disability: A four cohort study. *Sexuality and Disability, 27*(4), 223–228.

Swango-Wilson, A. (2010). Systems theory and the development of sexual identity for individuals with intellectual/developmental disability. *Sexuality and Disability, 28*(3), 157–164.

Swango-Wilson, A. (2011). Meaningful sex education programs for individuals with intellectual/developmental disabilities. *Sexuality and Disability, 29*(2), 113–118.

Tarnai, B., & Wolfe, P. S. (2007). Social stories for sexuality education for persons with autism/pervasive developmental disorder. *Sexuality and Disability, 26*(1), 29–36.

Travers, J., & Tincani, M. (2010). Sexuality education for individuals with autism spectrum disorders: critical issues and decision-making guidelines, *Education and Training in Autism and Developmental Disabilities, 45*(2), 284–293.

Wilkenfeld, B. F., & Ballan, M. S. (2011). Educators' attitudes and beliefs towards the sexuality of individuals with developmental disabilities. *Sexuality and Disability, 29*(4), 351-361.

Appendix A

Demographic Questions

1.) How old is your child with autism?
2.) What gender is your child with autism?
3.) What is your child's ethnicity/racial identity?
4.) What grade in school is your child with autism?

5.) What is your age?
6.) What gender do you identify with?
7.) What is your ethnicity/racial identity?
8.) What is your education level?
9.) How many children do you have?

Interview Tool

1.) Has your child (with autism spectrum disorder) received any formal sexual education?

If yes,

Please explain the nature of the sex education your child has received. Were you involved in providing this sex education to your child? How so? Did you find this sex education to be helpful for your child? Why or why not?

If no,

Do you believe your child (with autism) would benefit from formal sex education? What has prevented or been a barrier to your child receiving formal sex education?

2.) Have you taught or discussed any sex education topics with your child (with autism)?

If yes,

What topics have you attempted to teach your child about? How have you attempted to teach your child these topics? Do you believe this has been helpful for your child? Why or why not?

If no,

Have you considered teaching or discussing sex education topics with your child (with autism)? Why or why not?

3.) What sex education topics do you believe are most important for your child to have (further) education about?

4.) What concerns do you have for your child if they do not understand these topics?

5.) Have you discussed sex education for your child (with autism) with any mental health or other professionals who work with you or your child?

6.) What would you want mental health or other professionals to know about the sex education needs of your child?

7.) What kind of support would you like from these professionals regarding sex education topics?

Appendix B

Informed Consent Script

Introduction: Hello, my name is Courtney Hansen. I am a student at The Chicago School of Professional Psychology. This study is being conducted as a part of my dissertation requirement for The Chicago School of Professional Psychology's Clinical PsyD Program. I will now review with you information about the purpose, procedures and confidentiality of this study prior to beginning the interview. If you consent to participating, I will begin the audio recording and you will be asked to state your consent to participate and to be audio recorded.

Purpose: The purpose of this study is to examine your experience as the parent of a child with autism in relation to sex education. This study seeks to gain an understanding of how you view your child's sex education needs and how you want mental health professionals to support you and your child in terms of sex education.

Procedures: Once you submit a request for participation on my website, https://cah5117.wixsite.com/dissertation, I will call you with a list of questions to see if you qualify for the study, and if you qualify I will tell you at the end of the phone call. If you qualify for the study, I will schedule a time to meet with you for an interview at The Chicago School of Professional Psychology in a secure room where confidentiality will be ensured. Alternatively, you will have the option of being interviewed over a secure online video calling platform, VSee. Interviews will take between 60 and 90 minutes. Interviews will be audio recorded on a secure recording device. Following the interview, I will transcribe the interview and any identifying information will be coded through the use of pseudonyms to protect your identity and retain anonymity. I will be the only person with access to the coded transcriptions of the interviews. After all data has been gathered and interpreted, the results of the study will be available on my website. I will be open to follow up questions about the study via phone or e-mail.

Benefits to Participants: Your participation in this study is voluntary and may ultimately increase psychologists' understanding of the sex education needs of families with a child with autism. While you might not directly benefit from participation in this study, your participation may benefit the autism community, as well as clinicians who work with this population.

Alternatives to Participation: Participation in this study is voluntary. You may withdraw from study participation at any time without any penalty.

Risks to Participation: The anticipated risks of completing the interview are minimal; however, it is possible that some interview questions that ask you to think about current or previous experiences may be uncomfortable or distressing to some individuals. Openness and honesty during interviews is encouraged as all information provided will be coded. At any point in time if you are feeling uncomfortable, you are allowed to discontinue your participation in the study. At the end of the interview, you will be invited to debrief with me about the interview and if you would like to process your emotional reactions to the interview further, you will be provided with referrals for counseling and support services. There is a risk of possible loss of confidentiality and the following measures will be taken to minimize this risk:

Confidentiality: During this study, your name, telephone number, email address, and demographic information, such as your age, gender, ethnicity, and education level will be collected for the purpose of this research. If you use identifying names for yourself, your child, or other persons during the interview, the names will be coded in the transcription so as to protect anonymity and confidentiality. I will be the only person with access to recordings of the interview. You will not be providing any written documentation. You will state your informed consent for participation and for audio recording at the beginning of the recording. Electronic copies of your name and contact information will be kept in a locked, password protected file of my password protected personal computer. Your demographic information will be stored with your coded randomly assigned participant number provided in the interview, so demographic information will not be identifiable. Upon completion of the study, all identifying contact information will be destroyed. Research materials will be kept for a minimum of five years after publication per American Psychological Association guidelines.

Your research records may be reviewed by federal agencies whose responsibility is to protect human subjects participating in research, including the Office of Human Research Protections (OHRP) and by representatives from The Chicago School of Professional Psychology Institutional Review Board, a committee that oversees research.

If you have any questions, please feel free to ask them now. If you have questions later, you may contact me, Courtney Hansen, or my dissertation chair, Dr. Braden Berkey.

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If you have questions concerning your rights in this research study you may contact the Institutional Review Board (IRB), which is concerned with the protection of subjects in research project. You may reach the IRB office Monday-Friday by calling 312.467.2343 or writing: Institutional Review Board, The Chicago School of Professional Psychology, 325 N. Wells, Chicago, Illinois, 60654. Consent to Participate in Research.

Appendix C

Themes Across Participants

Major Themes	Minor Themes
Knowledge and Comprehension	The “Talk”
Important Topics	Masturbation and Privacy
Seeing the Big Picture	Romantic Relationships
Safety Concerns	
Benefits of Intervention	
Looking for Guidance	