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KEY COMPONENTS OF SUCCESSFUL SEXUALITY EDUCATION FOR HIGH
FUNCTIONING STUDENTS WITH AUTISM SPECTRUM DISORDER

A Dissertation

Presented to

the Faculty of the Morgridge College of Education

University of Denver

In Partial Fulfillment

of the Requirements for the Degree

Doctor of Philosophy

by

Brittany Sovran Greiert

June 2016

Advisor: Cynthia Hazel, Ph.D., NCSP

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Author: Brittany Sovran Greiert
Title: KEY COMPONENTS OF SUCCESSFUL SEXUALITY EDUCATION FOR
HIGH FUNCTIONING STUDENTS WITH AUTISM SPECTRUM DISORDER
Advisor: Cynthia Hazel, Ph.D., NCSP
Degree Date: June 2016

Abstract

To date, there is very little existing research on the sexuality education of high functioning adolescents with Autism Spectrum Disorder (ASD) even though current research suggests that 1 in 68 children are diagnosed with ASD (CDC, 2014). Through group consensus of experts in ASD representing families, school-based professionals, and researchers, this study aimed to reach an agreed upon understanding of the essential components necessary in teaching high functioning students with ASD about sexuality. Using the Delphi method, expert participants responded to three iterative questionnaires and provided their opinions and recommendations on the content, delivery, and responsibilities of schools and families regarding sexuality education curricula designed specifically for high functioning adolescents with ASD. Based on participant responses, the *Guidelines for Developing Sexuality Education Curricula for High Functioning Adolescent Students with Autism Spectrum Disorder* were developed.

These guidelines are intended to be used as a tool to guide future sexuality education curriculum development that address the specific needs of high functioning students with ASD and to provide suggestions to modify existing curricula so that the needs of high functioning adolescents students are met. Additionally, families, school psychologists, and researchers are advised to utilize these Guidelines as an advocacy tool to increase awareness of the unique needs of high functioning students with ASD regarding their sexuality education and to initiate conversations and action.

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Chapter One: Introduction

Think back to your adolescence...to your first crush, your first kiss, and to your first relationship. Think back to the nervousness that accompanied trying to read whether or not your romantic feelings were reciprocated and to the evenings spent replaying a date over and over again, trying for the life of you to understand what happened that made him or her not want to call you back. Think back to when you first started noticing your body change and trying to make sense of the experience of the new sensations and emotions that were completely foreign to you. For many individuals, navigating the waters of adolescence is a difficult task. Managing the physical changes that accompany puberty and learning to initiate, foster, and engage in romantic relationships is confusing. The popularity of dating websites and apps used by adults today indicates that effective romantic interactions and sustaining successful relationships are not easily mastered skills.

Puberty is a challenging developmental period of biological, cognitive, and social changes that impacts long-term developmental trajectories (Biro & Dorn, 2006; Peper & Dahl, 2013). Transitioning from childhood into adulthood is often an awkward time for everyone, and it is not uncommon for a shudder to run down a person's spine when thinking back to adolescent years. During puberty our bodies rapidly change and our brains are flooded with hormones (Biro & Dorn, 2006; Peper & Dahl, 2013). Navigating the physical, emotional, and social changes that come along with sexual development is

difficult for most adolescents – but navigating those changes with the social reciprocity and communication deficits associated with Autism Spectrum Disorder (ASD) makes sexual development even more difficult to navigate for adolescents with an ASD diagnosis (Davies & Dubie, 2012). It is imperative that students with ASD receive comprehensive sexuality education during adolescence to help them prepare for the complex emotional, social, and physical changes that accompany sexual maturity; however, a paucity of research and resources exist for the ASD population.

Autism Spectrum Disorder

ASD is a neurodevelopmental disability characterized by deficits in social communication and social interaction across multiple contexts as well as restricted, repetitive patterns of behavior, interests, or activities (American Psychiatric Association, 2013). A person with ASD may have a difficult time recognizing social cues and understanding the point of view of others; they typically view the world monotropically (Lawson, 2005). ASD is a spectrum disorder, with variances in functioning occurring between person to person. Typically, individuals with ASD are referred to as either high functioning, with average to above average intelligence, or low functioning, with below average intelligence.

ASD is a disorder that has captured America's attention in recent years. Media focus on the quickly rising prevalence rate and the growing influence of national organizations such as Autism Speaks, coupled with characters with ASD highlighted in popular television shows such as *Parenthood* and *Sesame Street* , has resulted in an increased awareness and understanding of ASD in the general population. With one in

every 68 children being diagnosed with ASD (CDC, 2014), it is now more important than ever to dedicate time, resources, and finances towards research in the arena of ASD.

ASD and Sexuality Education

As recently as the 1990s, it was widely accepted that individuals with ASD were asexual beings with social deficits so severe that long-lasting, romantic relationships were unrealistic (Koller, 2000). Current research (Attwood, Henault, & Dubin, 2014; Holmes & Himle, 2014) and autobiographical accounts written by adults with ASD (Attwood et al., 2014; Lawson, 2005) indicate that not only are individuals with ASD sexual beings with explicit desire for romantic relationships but that adolescents with ASD as young as 13 have the ability to, and the experience of, falling in love, achieving orgasm, and having shared sexual experiences (Dewinter, Vermeiren, Vanwesenbeeck, Lobbestael, & Van Nieuwenhuizen, 2015). There is a need for current and future research to address the needs of high functioning adolescents with ASD regarding their sexuality and to develop effective sexuality instruction specific to students with ASD in concert with families and professionals (Travers & Tincani, 2010).

Despite the rapidly increasing prevalence rate of ASD diagnoses, there is still little research that has been conducted on how to effectively teach adolescents with ASD about sexuality (Koller, 2000). Of the limited materials that do exist, few can be considered evidence based. In recent years, more experts in ASD have moved towards researching and/or creating materials for use in the sexuality education of students with ASD; however, many of these materials are not created in collaboration with families of children with ASD and school-based professionals (such as school psychologists, school

social workers, school nurses, special education teachers, and school counselors), who work with students with ASD and are responsible for providing the majority of their interventions.

Like their typically developing peers, adolescents with ASD experience puberty, emotional changes, and sexual feelings. But, unlike their typically developing peers, adolescents with ASD lack appropriate educational resources and a peer group from whom to obtain sexual knowledge (Nichols & Blakeley-Smith, 2010). Even more so than typically developing children, it may be difficult for children with ASD to reach out to trustworthy adults with questions pertaining to sexuality and/or relationships due to deficits with social reciprocity and communication associated with their diagnosis. Adolescents with ASD often have difficulty reading social cues, making sense of and adhering to social norms, and engaging in socially appropriate and reciprocal conversations without explicit instruction.

Adolescents with ASD have an increased risk for exploitation due to difficulty recognizing dangerous situations and interpreting the thoughts, feelings, intentions, and behaviors of others (Nichols & Blakeley-Smith, 2010). Moreover, adolescents with ASD often rely more heavily on adults for day-to-day functioning, and therefore may be more trusting and susceptible to sex abuse as opposed to children without ASD. To date, little research has been conducted on sexual abuse or sexual offending in ASD populations, so it is difficult to know how individuals with ASD respond to sexual abuse or how to successfully work with individuals with ASD who have been labeled as sexual offenders (Sevlever, Roth, & Gillis, 2013). Ultimately, research has indicated that individuals with

special needs are left dangerously in the dark in regards to sexuality, and are highly susceptible to abuse, disease, and unplanned pregnancy due to lack of basic sexual education (Kijak, 2011).

In general, adolescents with ASD have deficits in social communication and social interaction, and repetitive behaviors that occur on a spectrum of severity. These deficits often result in a lack of a peer group. Additionally, adolescents with ASD often have difficulty navigating the increasingly complex social interactions that occur in middle and high school. Adolescents with ASD experience the emotional and sexual changes that accompany puberty; however, due to their social reciprocity and repetitive behavior deficits, they are often at an increased risk for exploitation and abuse and require explicit instruction on how to engage in appropriate social interactions.

Sexuality Education in Schools

Education pertaining to sexuality is a contentious, yet important, component of the educational process. States, school districts, and individual schools differ on how they approach sexuality education with the typically developing population. Currently, only 22 states and the District of Columbia require sexuality education in schools (Guttmacher Institute, 2015), even though research indicates that the public is generally in favor of sexuality education in the schools (Bleakley, Hennessy, & Fishbein, 2006; Kaiser, 2000). Even more concerning, only 13 states require that sexuality education be medically accurate when provided, and only 26 states and the District of Columbia insist on sexuality education being age appropriate when provided (Guttmacher Institute, 2015).

Deciding whether or not to teach sexuality education in the U.S. public school system has been widely debated. Those arguing for sexuality education to be integrated into school curricula see sexuality education as a critical part of the global development of successful and appropriate interpersonal relations and social well-being. Those arguing against sexuality education within the schools purport that education about sex, sexuality, and relationships encourages precocious sexual activity, may encourage sexual experimentation before marriage (Aggleton & Crewe, 2005), and that abstinence is the only 100% effective way to prevent sexually transmitted infections (STIs) and teen pregnancy.

Especially prominent in the school-based sexuality education discussion are the merits of comprehensive sexuality education versus abstinence only sexuality education curricula. The supporters of abstinence only education are in the minority in America, with the public overwhelmingly in support of comprehensive sexuality education in the schools (Bleakley et al., 2006; Kaiser, 2000). Indeed, Bleakley et al. (2006) found in a cross-sectional survey that 82% of US adults support programs that include both abstinence education as well as other methods of preventing pregnancy and sexually transmitted diseases. The overwhelming majority of the data indicate that comprehensive sexuality education leads to a significant decrease in teenage pregnancy and a reduction in sexually transmitted diseases (Kohler, Manhart, & Lafferty, 2008), whereas abstinence only education is often to have no effect on either variable (Kirby, 2008). Most researchers agree that a comprehensive sexuality education curriculum, which may or

may not include an abstinence component, leads to improved academic, social, and physical outcomes for teenage students (Kirby, 2008).

Comprehensive sexuality education should include more than just the physical changes that occur during sexual development because healthy sexuality involves understanding more than just the anatomical aspects of sex. A comprehensive sexuality education program should include medically accurate and age-appropriate physical, mental, emotional, and social dimensions of human sexuality and should be provided by trained teachers (Future of Sex Education, n.d.). The Sexuality Information and Education Council of the United States (SIECUS) defines sexuality as follows:

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

As evidenced by the *National Sexuality Education Standards* (Future of Sex Education, 2012) sexuality education does not merely encompass sexual intercourse and physical changes. Identity, healthy relationships, and personal safety are all part of the construct of sexual education that impact development (Sciaraffa & Randolph, 2011) and should be incorporated into sexuality education programming within schools.

Families and Sexuality Education

American parents support comprehensive sexuality education in schools (Kaiser, 2000). In telephone interviews with a nationally-representative sample of parents of middle, junior, or senior public high school students ($n=1501$), the majority of

respondents endorsed that it was “very important” that schools teach adolescents about: how to deal with the emotional issues and consequences of being sexually active (84%); how to get tested for HIV/AIDS and other Sexually Transmitted Diseases (STDs) (76%); how to talk to a partner about birth control and STDs (77%); how to use condoms (68%); where to get and how to use other birth control methods (61%); and abortion (59%) (Kaiser, 2000). Additionally, 74% of parents reported that sensitive topics like abortion and homosexuality should be discussed in sex education in a way that provides a fair and balanced presentation of the facts and different views in society (Kaiser, 2000).

In the general population, less than half of adolescents and parents report talking with one another about sex and birth control (Robert & Sonenstein, 2010). To foster family-child communication surrounding sexuality, research has indicated the use of family homework activities (Grossman, Frye, Charmaraman, & Erkut, 2013; Grossman, Tracy, Charmaraman, Ceder, & Erkut, 2014). Family homework activities that are designed to provide a clear context in which to begin a conversation about sexuality as well as provide information and strategies to support parents in the initiation of conversations about sex with their children can delay sex among early adolescents and complement school-based sex education programs (Grossman et al., 2013).

Purpose of Study

The goal of this study was to develop guidelines for the sexuality education of high functioning adolescents with ASD. By obtaining the consensus of experts in ASD representing families, school-based professionals, and researchers, this study was successful in achieving an agreed upon understanding of the essential components that

are necessary to effectively teach high functioning students with ASD about sexuality. Through an iterative process of asking participants to answer questions about what content should be delivered, how content should be delivered, how knowledge acquisition should be measured, and what roles professionals and families should have in delivering the information, I developed guidelines that highlight the key components of a comprehensive sexuality education curriculum for high functioning students with ASD.

Significance of Study

This study involved the collaboration of family, school-based, and research experts in the areas of ASD and sexuality education to determine the essential elements and strategies needed to teach high functioning adolescents with ASD about sexuality. The result of this study was the development of the *Guidelines for Developing Sexuality Education Curricula for High Functioning Adolescent Students with Autism Spectrum Disorder*. These guidelines, as developed by experts, are intended for use by school-based professionals and families, and can assist researchers in the future development of sexuality education curricula for high functioning adolescent students with ASD.

School psychologists, in particular, can benefit from these guidelines by parsing out stand-alone strategies to use with high functioning students with ASD who require intervention, support, or education surrounding the broad topic of sexuality. Additionally, school psychologists can use these guidelines in a consultative role when working with school professionals and families to develop or modify sexuality education curricula that meets the needs of high functioning students with ASD.

This study adds to the dearth of research in the realm of ASD and sexuality, and is the first of its kind that brings together families and experts in order to reach a shared understanding of what an ideal sexuality education curriculum rooted in family-school partnering for high functioning adolescents with ASD looks like. Researchers, families, and school psychologists can use these guidelines to advocate for the sexuality education needs of high functioning adolescent students with ASD.

Statement of the Problem

There are too few resources that provide current information on how parents, teachers, school psychologists, and other school-based professionals should talk to students with ASD about the physical, social, and emotional aspects of sexuality. A rapidly changing public opinion as to the sexual rights and experiences of individuals with ASD combined with a growing prevalence rate of ASD diagnoses in children establishes a dire need for resources and supports for educating adolescents with ASD about the changes that accompany sexual development. Instead of in collaboration between school professionals, researchers, and families to determine how best to address the sexuality education needs of students with ASD, curricula and resources have typically been developed reactively out of necessity for use in specific, ungeneralizable populations. In order to address the need for comprehensive sexuality education for students with ASD, an invitation must be extended to all key stakeholders to have a seat at the table. In this study, I invited families, school-based professionals who work with students with ASD, and ASD researchers to share their opinions and come to a consensus

on the essential components necessary in developing a sexuality education curriculum for high functioning students with ASD.

Research Questions

The research questions for this study were as follows:

1. What do experts in the field of ASD and sexuality, school-based mental health services, and family-school partnering believe to be essential content in comprehensive sexuality education for high functioning adolescents with ASD?
2. What learning strategies should be considered when teaching high functioning adolescents with ASD about sexuality?
3. What type(s) of family-school collaboration could best support high functioning adolescents with ASD in their sexuality education?

Definition of Terms

Asperger's Disorder

Asperger's disorder was considered a Pervasive Developmental Disorder diagnosis in the *Diagnostic and Statistical Manual of Mental Disorders, 4th ed., text rev.* (DSM-IV-TR; American Psychiatric Association, 2000) that described individuals with "severe and sustained impairment in social interaction" and "the development of restricted, repetitive patterns of behaviors, interests, and activities." In the DSM-IV-TR, Asperger's Disorder differed from Autistic Disorder in the lack of a "clinically significant delays or deviances in language acquisition" (American Psychiatric Association, 2000). The *Diagnostic and Statistical Manual of Mental Disorders, 5th ed.* (DSM-5; American Psychiatric Association, 2013) no longer includes the diagnosis of Asperger's disorder; it

is subsumed within the diagnosis of ASD. Colloquially, many high functioning individuals with ASD still refer to themselves as having “Asperger’s,” and resources that have been developed for individuals with Asperger’s disorder are often still appropriate for use with individuals with a *DSM-5* diagnosis of ASD. Under the current *DSM-5* definition of ASD, *DSM-IV-TR* diagnoses of autistic disorder, Asperger’s disorder, childhood disintegrative disorder, and pervasive developmental disability not otherwise specified are included (American Psychiatric Association, 2013). In this dissertation, the term “Asperger’s” will be used when discussing publications and prior research that used or referenced the Asperger’s disorder diagnosis. The *DSM-IV-TR* diagnostic criteria for Asperger’s disorder is provided in Appendix C.

Autism Spectrum Disorder (ASD)

Autism Spectrum Disorder (ASD) is defined as a neurodevelopmental disability characterized by persistent deficits in social communication and social interaction across multiple contexts as well as restricted, repetitive patterns of behavior, interests, or activities (American Psychiatric Association, 2013). The symptoms of ASD must be present early in a child’s development, result in significant impairment in functioning, and not be better explained by intellectual disability or developmental delay. The *DSM-5* definition of ASD is provided in Appendix A.

High Functioning Individual with Autism Spectrum Disorder

When referring to individuals with ASD, it is common to use qualifiers such as high or low functioning to indicate where on the spectrum the individual falls. For the purposes of this research, high functioning will refer to individuals with an ASD

diagnosis, an intelligence score in the average to above average range, and verbal communication ability that allows the individual to speak in full sentences. The term High Functioning Autism (HFA) is frequently used in the extant literature to describe persons with the aforementioned characteristics; however, this research will use the term High Functioning to refer to the person with the ASD diagnosis and not the ASD diagnosis itself. Therefore, the phrase, “high functioning individual with ASD” will replace HFA in this research. The term “adolescent” or “student” may be substituted for the term “individual” in the phrase “high functioning individual with ASD.”

Low Functioning

For the purposes of this research, the term low functioning will be used to identify individuals who have an ASD diagnosis, are unable to engage in verbal communication, and/or have an intelligence score that falls in the below average range. As with the term High Functioning, Low Functioning is intended to refer to the individual and not the disability.

Neurotypical

Neurotypical is a term commonly used in the ASD community to refer to individuals who are not on the Autism spectrum. For the purposes of this research, neurotypical will refer to a person who has not been identified on the autism spectrum and who is not identified with a disability that has resulted in cognitive deficits.

Sexual Intercourse

Unless otherwise specified, sexual intercourse is intended to include vaginal intercourse, anal intercourse, fellatio, or cunnilingus between two persons.

Sexuality

This research will adopt the SIECUS definition of sexuality, which states that,

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

Sexuality Education

Although sexuality education curricula can differ dramatically in content and approach, for the purposes of this research sexuality education encompasses comprehensive education regarding all aspects of human sexuality. Current programs and literature often use the term “sex education” when referring to a sexuality education that meets this definition. For the purposes of this research, all comprehensive sex education programs will be referred to as sexuality education. If a program explicitly teaches abstinence only, then the qualifier of “abstinence only” will be added to sexuality education (i.e., abstinence only sexuality education).

Chapter Two: Review of the Literature

The purpose of this chapter is to provide an overview of five aspects of the literature: (1) Autism Spectrum Disorder; (2) ASD and sexuality; (3) sexuality education in the United States of America; (4) sexuality education for individuals with disabilities; and (5) sexuality education curricula and related resources for high functioning adolescents with ASD.

Autism Spectrum Disorder

ASD is a neurodevelopmental disorder that involves difficulties with social reciprocity, communication, and repetitive behaviors (Hyman & Levy, 2013).

Prevalence. The Autism and Developmental Disabilities Monitoring (ADDM) Network is a surveillance system funded by the Center for Disease Control (CDC) that is tasked with providing an estimation of the current prevalence of ASD in children aged eight-years-old based on data collected in 11 U.S. states. Their most recent report on the 2010 data indicates that 1 in 68 children have been identified with ASD and that a diagnosis of ASD is five times more common in males than in females (CDC, 2014). This is an increase of 123% since the CDC Autism and Developmental Disabilities Monitoring Network 2002 report. The most recent report indicates that White children are 30% more likely to be identified with ASD than Black children, and almost 50% more likely to be identified with ASD than Hispanic children (CDC, 2014).

Diagnosis. In 2013, the definition and criteria for Autism changed with the publication of the *DSM-5* (American Psychiatric Association, 2013). The differences between the *DSM-IV-TR* and the *DSM-5* included drastic changes in the diagnosis of ASD, Asperger's Syndrome, and Pervasive Developmental Disorder Not Otherwise Specific (PDD NOS). In the *DSM-IV-TR*, individuals could receive a diagnosis of either autistic disorder, Asperger's Syndrome, childhood disintegrative disorder, or Pervasive Developmental Disabilities Not Otherwise Specified (American Psychiatric Association, 2000); however, in the *DSM-5* individuals with any of the four aforementioned diagnoses should now either meet the criteria for ASD or another *DSM-5* diagnosis (American Psychiatric Association, 2013).

According to the *DSM-5*, the diagnostic criteria that must be met in order to obtain a diagnosis of ASD includes: persistent deficits in social communication and social interaction across multiple contexts; restricted, repetitive patterns of behavior, interests, or activities; symptoms that are present in the early developmental period; and clinically significant impairment in social, occupational, or other important areas of current functioning (American Psychiatric Association, 2013).

Social communication deficits can manifest in different ways. The American Psychological Association (2013) identifies the following three social communication deficits to be the most commonly seen in persons with ASD: (1) deficits in social-emotional reciprocity, (2) deficits in nonverbal communicative behaviors used for social interaction, and (3) deficits in developing, maintaining, and understanding relationships.

The deficits in social-emotional reciprocity can range from awkward social approach and an inability to sustain normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions (American Psychological Association, 2013). Deficits in nonverbal communicative behaviors used for social interaction can range from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication (American Psychological Association, 2013). Deficits in developing, maintaining, and understanding relationships can range from difficulties adjusting one's behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to the absence of interest in peers (American Psychological Association, 2013).

Common examples of restricted, repetitive patterns of behavior include (1) stereotyped or repetitive motor movements, use of objects, or speech, (2) insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior, (3) highly restricted, fixated interests that are abnormal in intensity or focus, and (4) hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (American Psychiatric Association, 2013).

A complete description of the *DSM-IV-TR* diagnostic criteria for Autism Disorder, Asperger's Disorder, and PDD NOS and the current *DSM-5* diagnostic criteria for ASD can be found in Appendices A, B, C, and D.

Special education criteria. An individual who has received a *DSM-5* diagnosis of ASD may not necessarily be eligible to receive special education services within the school unless the student also meets the special education criteria outlined in Part 300.8 of the reauthorized 2004 Individuals with Disabilities Education (IDEA) Act. The 2004 reauthorization of IDEA is federal legislation that ensures that all students receive a free and appropriate public education (FAPE) regardless of disability. To provide each child with FAPE, the school will need to develop an individualized education plan (IEP) to ensure that students with disabilities are able to access their education. Under IDEA 2004, a child with a disability includes:

having mental retardation, a hearing impairment (including deafness), a speech or language impairment, a visual impairment (including blindness), a serious emotional disturbance, orthopedic impairment, autism, traumatic brain injury, an other health impairment, a specific learning disability, deaf-blindness, or multiple disabilities, and who, by reason thereof, needs special education and related services. (IDEA Regulations, 34 C.F.R. § 300.8)

Furthermore, the 2004 Reauthorization of IDEA defines Autism to be:

a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child's education performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. Autism does not apply if a child's educational performance is affected primarily because the child has an emotional disturbance. (IDEA Regulations, 34 C.F.R. § 300.8)

IDEA states that a student who otherwise meets the criteria for ASD but whose academic performance is not negatively impacted by the communication and social interaction deficits commonly associated with ASD would not be eligible to receive an IEP (IDEA Regulations, 34 C.F.R. § 300.8). A *DSM-5* diagnosis of ASD does not necessarily

indicate that a child will qualify for special education services under IDEA, and a student who meets criteria for special education services under an Autism disability category in a public school may not necessarily meet the criteria for a *DSM-5* diagnosis.

If a referral is made for a student who is suspected to have ASD, a comprehensive, multidisciplinary assessment is typically conducted within the school. Although there are no diagnostic assessments or medical tests that can definitively diagnose ASD, a school psychologist or a district assessment team with experience in evaluating individuals with ASD may utilize a variety of diagnostic tools to determine whether or not the student qualifies for special education under the Autism category. The comprehensive assessment may include the use of screening tools such as the Modified Checklist of Autism in Toddlers (M-CHAT); or diagnostic tools which may include the Autism Diagnostic Observation Schedule (ADOS), the Autism Diagnostic Interview, - Revised (ADI-R), Social Responsiveness Scale (SRS), Social Communication Questionnaire (SCQ), or the Childhood Autism Rating Scale (CARS). A cognitive assessment such as the Wechsler Intelligence Scale for Children, Fifth Edition (WISC-V), Differential Ability Scales, 2nd Edition (DAS-2), Kaufman Assessment Battery for Children, Second Edition (KABC-II) or the Stanford Binet Intelligence Scale, Fifth Edition (SB5); and an adaptive assessment such as the Vineland Adaptive Behavior Scales, Second Edition or the Scales of Independent Behavior – Revised (SIB-R) may also be administered to determine the severity of ASD.

Severity. Because ASD is a spectrum disorder, individuals with ASD fall along a continuum of severity. A current issue in the field is that there is not a universally

accepted, standardized indicator of severity for ASD (CDC, 2014). The *DSM-5* uses the severity specifiers of: Level 1, requiring support; Level 2, requiring substantial support; and Level 3, requiring very substantial support (American Psychiatric Association, 2013). Other organizations choose to use the phrasing of low functioning, moderate functioning, and high functioning. Within the literature, individuals with Level 1 or High Functioning Autism are frequently defined as having average or above average intelligence and individuals with Low Functioning Autism are defined as having below average intelligence (Dewinter et al., 2015; Holmes & Himle, 2014). The *DSM-5* description of severity indicators is provided in Appendix E.

Comorbidity. Individuals who have received a diagnosis of ASD may also receive other diagnoses as well. Intellectual disability is commonly diagnosed comorbid with ASD (American Psychiatric Association, 2013; Matson & Cervantes, 2013). The CDC has reported in a large sample of 8-year-old students with ASD, 31% had an IQ of less than 70, which classified them in the range of intellectual disability, and 23% were in the borderline range with an IQ between 71-85 (CDC, 2014). Anxiety disorders are also commonly diagnosed comorbid with ASD (Simonoff et al., 2008)

The *DSM-5* now allows clinicians to make an ADHD diagnosis in the context of ASD (American Psychiatric Association, 2013), and research has established comorbidity between ASD and ADHD (Antshel, Zhang-James, & Faraone, 2013; Simonoff et al., 2008). Additionally, structural language disorder, specific learning disabilities, and developmental coordination disorder are often found to be comorbid with ASD, as is avoidant-restrictive food intake disorder (American Psychiatric Association, 2013).

Evidence-based interventions. High functioning adolescents with ASD often require evidence-based interventions across multi-tiered systems of support (MTSS) in order to effectively access their education in accordance with IDEA 2004. Due to the social deficits associated with ASD, improved social skills are often a goal listed on IEPs of high functioning adolescents with ASD. To meet these goals, school-based mental health professionals often utilize evidence based social skill curricula such as the *Program for the Education and Enrichment of Relational Skills (PEERS®)* program (Laugeson, Ellingsen, Sanderson, Tucci, & Bates, 2014) or *Superflex...A Superhero Social Thinking Curriculum* (Madrigal & Winner, 2008). Often, school-based mental health providers will choose to include students with ASD into existing social skills groups within the school.

Applied Behavior Analysis (ABA) is a systematic behavior modification process that is commonly used to address behavior concerns for persons with ASD. Baer, Wolf, and Risley (1968) describe ABA as, “the process of applying sometimes tentative principles of behavior to the improvement of specific behaviors, and simultaneously evaluating whether or not any changes noted are indeed attributable to the process of application.” ABA involves the use of reinforcement to increase desirable behaviors and decrease undesirable behaviors, and utilizes data collection and analysis to determine whether or not ABA interventions are effective. ABA was famously proven effective for use with ASD populations by Lovaas (1987), and continues to be a frequently referenced, researched, and utilized strategy in working with students with ASD.

Components of Cognitive Behavior Therapy (CBT) have been successfully utilized in working with children with ASD. CBT is a therapeutic technique that integrates information-processing, learning therapies, reciprocal relationships, cognitive processes, physiology, and behavior (Roth, Eng & Heimberg, 2002). CBT involves a client, with the help of a therapist, considering their own thinking process, evaluating their core beliefs, cognitively re-framing events, and responding to feedback (Kroncke, Willard & Huckabee, 2016). Bolton, Christner, and McPoyle-Callahan (2011) suggest the use of CBT to enhance the social experience of students with ASD, and Ordetx (2012) utilizes CBT in her Teaching Theory of Mind curriculum to address social challenges. Of note, the efficacy of CBT is directly correlated to the cognitive level of the client; that is, the therapeutic outcome of using CBT with individuals with ASD is more likely to be positive if the client has higher cognitive functioning (Kroncke et al., 2016).

ASD and Sexuality

Historically, the public and academic perception of individuals with ASD was that they were uninterested in relationships, sexuality, or intimacy. This misconception that individuals with ASD are not sexual has been disproven in the literature (Brown-Lavoie, Viecili, & Weiss, 2014; Dewinter et al., 2015; Dewinter, Vermeiren, Vanwesenbeeck, & van Nieuwenhuizen, 2013; Gougeon, 2010; Hellemans, Colson, Verbraeken, Vermeiren, & Deboutte, 2007; Holmes & Himle, 2014; Koller, 2000). In addition to the growing body of research that demonstrates individuals with ASD are sexual beings, several high functioning adults with ASD have published books on their experience of sexual

development, identifying their sexual orientation, and how ASD impacted their experience of sexuality development (Attwood et al., 2014; Lawson, 2005; Newport & Newport, 2002). It is well documented that high functioning individuals with ASD can engage in healthy, happy romantic relationships that involve sexual intimacy.

Multiple studies have found that the vast majority of people with ASD display some kind of sexual behavior and most masturbate (Haracopos & Pederson, 1992; Hellemans et al., 2007; Mehzabin & Stokes, 2011). In their narrative review of 26 empirical studies and 29 case studies on ASD and sexuality, Dewinter et al. (2013) found that the literature has suggested that most males with ASD masturbate and that most high functioning adults and adolescents with ASD have demonstrated sexual behavior towards others or expressed the desire for being in a relationship. The literature reports very different findings for sexually intimate experiences such as hugging, kissing, mutual masturbation, oral sex, and penile-vaginal or anal intercourse (Dewinter et al., 2013), perhaps because very few studies obtain their data via self-report. Typically, research has relied on caregiver report to discern the sexual behaviors of individuals with ASD although recent reports indicate that parents generally underestimate the lifetime sexual experiences of their children (Dewinter, Vermeiren, Vanwesenbeeck, & Nieuwenhuizen, 2016).

There are very few studies that have been conducted that specifically look at the sexual behavior of adolescents with ASD. Hellemans et al. (2007) found via caregiver report that, of the 14 institutionalized, high functioning male adolescents with ASD included in their study, one third had problematic sexual development that required

intervention, 80% masturbated, half expressed desire for an intimate sexual relationship, half had experienced a physical relationship, and that none of the sample below age 18 had coital experience. Also reported was that, even though the adolescent participants were high functioning, they often did not learn how to appropriately masturbate which resulted in stress and hypermasturbation (Hellemans et al., 2007). Recently, a study was published that investigated the sexual behaviors and attitudes of high functioning adolescent males with a diagnosis of autistic disorder or Asperger's disorder in comparison to the male general education population (Dewinter et al., 2015). This study is unique in that results were obtained via self-report, whereas the majority of other studies that report on the sexual behavior of adolescents with ASD obtain their data via parent or caregiver interview or survey. It is questionable whether or not parent report can accurately capture the lived sexual experiences of an adolescent with ASD – or any adolescent for that matter. Indeed, Dewinter et al. (2016), have found that parents generally underestimate the sexual experiences of their sons. Further, DeWinter et al. (2015) have indicated that adolescent males with ASD experience no differences in lifetime sexual experience compared to their peers in the general population.

In sum, a growing body of research indicates that individuals with ASD are sexual beings capable of engaging in solo and partnered physically intimate experiences such as sexual intercourse and masturbation. In adolescence, individuals with ASD have sexual thoughts and engage in sexual experiences.

Sexuality Education in America

Sexuality is part of what makes us human. The ability to engage in romantic relationships is a celebrated part of humanity that can and should be enjoyed by everyone. Sexuality education in the United States, simply put, is inadequate. The US has the highest teen pregnancy rate of any country in the industrialized world (Kearney & Levine, 2012). A recent study analyzing the pregnancy rates and outcomes among 21 countries indicated that the pregnancy rate among 15 to 19 year old teenagers was the highest in the United States, at 57 pregnancies per 1000 females (Sedgh, Finer, Bankole, Eilers, & Singh, 2015). In a study of 14 developed countries in Europe, the United States, and Canada, it was found that the U.S. has substantially higher syphilis, gonorrhea, and chlamydia rates in adolescents than in most other developed countries (Panchaud, Singh, Feivelson, & Darroch, 2000).

High pregnancy rates are either a result of high rates of sexual activity or low rates of contraception usage. Santelli, Sandfort, and Orr (2008) report that, although teens in the U.S. and Europe engage in sexual activity at similar rates, European teens are more likely to use contraceptives as well as the most effective forms of contraception, thus resulting in a substantially lower pregnancy rate than U.S. teens.

Almost all Americans are in favor of sex education in schools. In a national telephone survey administered by National Public Radio (NPR), the Kaiser Family Foundation, and the Kennedy School of Harvard University in 2004, a nationally representative sample of respondents 18 years of age or older (n=1759), including parents (n=1001), considered unwanted pregnancy (73%) to be a greater problem facing teens

today than suicide (46%). This same survey reported that 90% of the general population stated that it is important to have sexuality education as part of the school curriculum, and 67% of the general population agreed that the federal government should fund more comprehensive sexuality education programs that include information on how to obtain and use condoms and other contraceptives (NPR et al., 2004). Additionally, 66% of the general population reported that sexuality education should be a requirement for students (NPR et al., 2004). Americans are in favor of sexuality education in public schools, but there is much dissention surrounding how sexuality education should be provided.

Abstinence only sexuality education. Historically, the United States federal government has allocated sizeable sums of money to fund abstinence only sexuality education curricula within the schools even though a preponderance of research has found that most abstinence only curricula are ineffective (Collins, Alagiri, & Summers, 2002; Kay & Jackson, 2008; Trenholm et al., 2007). The United States federal government began funding sexuality education in the form of abstinence only education in 1982 through the Adolescent Family Life Act (Howell, 2007). In 1996, the Title V, Section 510(b) abstinence-only program was introduced through welfare reform (P.L. 104-193) and \$50 million per year was allocated towards the funding of abstinence only education programs (Howell, 2007). In 2000, Congress created the Special Projects of Regional and National Significance Community-Based Abstinence Education Program (CBAE), which allotted grants to public and private community-based organizations to provide abstinence-only education in accordance with the federal government definition of abstinence education set forth in Title V, Section (§) 510 of the Social Security Act.

As of 2008, over \$1.5 billion has been allocated to States to provide abstinence only sexuality education in public schools (Kay & Jackson, 2008).

In 1996, Title V, Section (§) 510 of the Social Security Act stipulated that the states that receive abstinence education funds honor the government's definition of abstinence education. The federal government definition of abstinence sex education, as defined by Title V, Section (§) 510(b) of the Social Security Act, is as follows:

A) has as its exclusive purpose, teaching the social, psychological, and health gains to be realized by abstaining from sexual activity;

(B) teaches abstinence from sexual activity outside marriage as the expected standard for all school age children;

(C) teaches that abstinence from sexual activity is the only certain way to avoid out-of-wedlock pregnancy, sexually transmitted diseases, and other associated health problems;

(D) teaches that a mutually faithful monogamous relationship in context of marriage is the expected standard of human sexual activity;

(E) teaches that sexual activity outside of the context of marriage is likely to have harmful psychological and physical effects;

(F) teaches that bearing children out-of-wedlock is likely to have harmful consequences for the child, the child's parents, and society;

(G) teaches young people how to reject sexual advances and how alcohol and drug use increases vulnerability to sexual advances; and

(H) teaches the importance of attaining self-sufficiency before engaging in sexual activity (Separate Program for Abstinence Education, 42 U.S.C. § 710, § 510(b)(2))

Within the past decade, reports evaluating the efficacy of federally funded abstinence only programs have emerged. One such report, a 2007 government mandated multi-year, experimentally based evaluation of four Title V, Section 510 abstinence education programs (*My Choice, My Future!*; *ReCapturing the Vision*; *Families United to Prevent Teen Pregnancy*; and *Teens in Control*), found that abstinence only programs were ineffective at reducing the rate of teen sexual activity (Trenholm et al., 2007). The report did find that abstinence only programs did no harm, as participants were not more likely

to have unprotected sex than the control group (Trenholm et al., 2007). However, for the amount of money the United States is investing in abstinence only programming, the finding that these programs are not effective, but at least do no harm, is insufficient reason for their continued funding.

Although the majority of the literature is in support of comprehensive sexuality education programs and demonstrates that the majority of abstinence only curricula are ineffective, there are certain abstinence only curricula that have demonstrated positive outcomes. For example, a long-term follow-up to the *Sex Can Wait* curriculum found that there existed statistically significant differences at 18 months between the treatment and comparison groups at the elementary, middle school, and high school levels (Denny & Young, 2006).

Effective or not, Kay and Jackson (2008) found that many abstinence only curricula teach medically inaccurate and gender biased information. President Obama, for the first time in United States history, attempted to eliminate abstinence only funding through Title V (§ 510 of the Social Security Act; however, in April 2015, Congress voted for a two year extension of abstinence only funding.

Comprehensive sexuality education. An alternative to abstinence only education is comprehensive sexuality education. SIECUS is in support of comprehensive sexuality education in schools and defines comprehensive school-based sexuality education as follows:

SIECUS believes that comprehensive school-based sexuality education that is appropriate to students' age, developmental level, and cultural background is an important part of the school curriculum at every grade. A comprehensive sexuality program will provide medically accurate information, recognize the

diversity of values and beliefs represented in the community, and complement and augment the sexuality education children receive from their families, religious and community groups, and healthcare professionals. (SIECUS, School Based Sexuality Education section, para 1)

The overwhelming majority of research supports the use of comprehensive sexuality education curricula in reducing teen pregnancy and STD rates (Collins et al., 2002; Guerra, 2015; Kirby, 2008). In addition to research supporting their use, the majority of Americans (67%) are in favor of comprehensive sexuality education (NPR et al., 2004).

Comprehensive sexuality education curricula can differ; however, experts in the field have reached a general agreement of the minimum content that should be covered in a comprehensive sexuality education curriculum. In 2012, a collaboration between the American Association of Health Education, the American School Health Association, the National Education Association – Health Education Network, the Society of State Leaders of Health and Physical Education, and the Future of Sex Education (FoSE) Initiative resulted in the development and dissemination of the *National Sexuality Education Standards: Content and Skills, K-12*. The goal of these standards was to, “provide clear, consistent, and straightforward guidance on the essential minimum core content for sexuality education that is developmentally and age-appropriate for students in grades K-12” (Future of Sex Education, 2012). The *National Sexuality Education Standards: Content and Skills, K-12* was developed based on extant research, expert opinion, and were heavily influenced by the National Health Education Standards (NHES); they are organized by topic and grade level. The *National Sexuality Education Standards: Content and Skills, K-12* by grade level are provided in Appendix F.

The *National Sexuality Education Standards: Content and Skills, K-12* utilize the following seven topics as the essential minimum, core content and skills for K-12 sexuality education (Future of Sex Education, 2012):

- Anatomy and Physiology: should provide a foundation for understanding basic human functioning
- Puberty and Adolescent Development: should address a pivotal milestone for every person that has an impact on physical, social and emotional development
- Identity: should address several fundamental aspects of people's understanding of who they are
- Pregnancy and Reproduction: should address information about how pregnancy happens and decision-making to avoid a pregnancy
- Sexually Transmitted Diseases and HIV: should provide both content and skills for understanding and avoiding STDs and HIV, including how they are transmitted, their signs and symptoms, and testing and treatment
- Healthy Relationships: should offer guidance to students on how to successfully navigate the changing relationships among family, peers and partners. Special emphasis on increasing the use and impact of technology within relationships
- Personal Safety: should emphasize the need for a growing awareness, creation and maintenance of safe school environments for all students

These seven topics are organized by the following eight *National Health Education Standards* (American Cancer Society, 2007):

- Core Concepts: Students will comprehend concepts related to health promotion and disease prevention to enhance health.
- Analyzing Influences: Students will analyze the influence of family, peers, culture, media, technology, and other factors on health behaviors.
- Accessing Information: Students will demonstrate the ability to access valid information and products and services to enhance health.
- Interpersonal Communication: Students will demonstrate the ability to use interpersonal communication skills to enhance health and avoid or reduce health risks.
- Decision-Making: Students will demonstrate the ability to use decision-making skills to enhance health.
- Goal-Setting: Students will demonstrate the use of goal-setting skills to enhance health.
- Self Management: Students will demonstrate the ability to practice health enhancing behaviors and avoid or reduce health risks.
- Advocacy: Students will demonstrate the ability to advocate for personal, family and community health.

In addition to the *National Sexuality Education Standards*, since 1991 SIECUS has published *Guidelines for Comprehensive Sexuality Education, Kindergarten through 12th grade*. The primary difference between these two publications is that the *National Sexuality Education Standards* are considered to be a criteria set intended for national compliance that reflects the minimum essential core content that should be taught in a

sexuality education curriculum whereas the *Guidelines for Comprehensive Sexuality Education* is considered to be recommendations for best practice that includes any and all topics that could be a part of a sexuality education curriculum. The most recent version of the *Guidelines for Comprehensive Sexuality Education* is organized into six key concept areas: human development, relationships, personal skills, sexual behavior, sexual health, and society and culture (SIECUS, 2004). The SIECUS' position statement on sexuality education states that,

Sexuality education should address the biological, sociocultural, psychological, and spiritual dimensions of sexuality within the cognitive learning domain (information), the affective learning domain (feelings, values, and attitudes), and the behavioral learning domain (communication, decision-making, and other skills). (SIECUS, Sexuality Education section, para 2)

Within the last five years there has been a gradual shift towards the use of evidence-based comprehensive sexuality education programs. The year of 2010 saw the first allocation of federal dollars towards comprehensive sexuality education via the State Personal Responsibility Education Program (PREP) and The President's Teen Pregnancy Prevention Initiative (TPPI). TPPI is implemented by the Office of Adolescent Health (OAH) and was funded at \$110 million to provide grants to public and private entities for use in providing comprehensive sexuality education programs (SIECUS, 2012). PREP was enacted to award grants to state agencies to comprehensively educate young people, with an emphasis on homeless, rural, or racial minority youth, on sexuality (Family & Youth Services Bureau, 2015). TPPI awarded \$75 million in grants to 32 states and the District of Columbia for up to \$400,000 for five years of funding in 2010 (U.S. Department of Health & Human Services, 2015). As of 2014, the State Personal

Responsibility Education Program (PREP) awarded \$41.1 million to 49 public or private grantees for use in educating young people in comprehensive sexuality education (Family & Youth Services Bureau, 2015). Some examples of comprehensive sexuality education programs funded by the federal government include *Teen Outreach Program TM*, *¡Cuidate! and Be Proud! Be Responsible!*, and *It's Your Game: Keep it Real* (U.S. Department of Health & Human Services, 2015). In April of 2015, Congress also passed an extension to PREP, which will continue to allocate federal funds towards comprehensive sexuality education programs.

Overall, comprehensive sexuality education addresses all aspects of sexuality including anatomy and physiology, puberty and adolescent development, identity, pregnancy and reproduction, sexually transmitted diseases and HIV, healthy relationships and personal safety and includes cognitive, affective, and behavioral learning. The majority of the American public is in favor of comprehensive sexuality education and federal funding has gradually been shifting towards funding comprehensive sexuality education. Table 1 provides an overview of the history of federal funding of sexuality education in the United States of America.

Differences in sexuality education by state. Sex education in the United States varies dramatically by state. Currently, 24 states and the District of Columbia mandate sex education, 33 states mandate HIV education, and 37 states require that information on abstinence be covered (Guttmacher Institute, 2016). Thirteen states currently require discussion of sexual orientation, with four of those states requiring only negative discussion on sexual orientation as opposed to inclusive discussion (Guttmacher Institute,

2016). Only 13 states require that sex and HIV education programs be medically accurate, only 26 states and the District of Columbia require that sex and HIV education programs provide instruction that is age appropriate, and only 8 states require that the

Table 1

U.S. Federal Funding of Sexuality Education

Funding Source	Type of Allowed Funds	Year Initiated	Year Eliminated	Amount/year ^a	Current Amount/year ^b
Adolescent Family Life Act (AFLA) Prevention Program	Abstinence Only	1981	2010	\$13-30	Not funded
Title V, Section 510(b)	Abstinence Only	1996	Still Funded	\$50 -\$75	\$75
Community-Based Abstinence Education (CBAE)	Abstinence Only	2000	2010	\$20-113	Not funded
Personal Responsibility Education Program (PREP)	Comprehensive Sexuality Education	2010	Still Funded	\$75	\$75
The President's Teen Pregnancy Prevention Initiative (TPPI)	Comprehensive Sexuality Education	2010	Still Funded	\$101-\$110	\$101

Note. Additional federal funding may have been/be provided through earmarks dollar amount refers to millions.

^a Dollar amount in millions

^b Dollar amount in millions

program provide instruction that is appropriate for a student's cultural background and not be biased against any race, sex, or ethnicity (Guttmacher Institute, 2016).

Student perceptions of sexuality education. According to the Kaiser Foundation (2000), 61% of teens aged 13-18 get information about how to talk about sexual health issues from their friends, compared to 44% who receive the information from a sexuality education class. Additionally, 89% of public school students in the United States take sexuality education sometime between 7th and 12th grades, and one out of every three schools utilize an abstinence only sexuality education curriculum (Kaiser, 2000). In America today, there is a movement towards utilizing evidence based sexuality education programs proven to reduce pregnancy rates in U.S. teenagers.

Family child communication and sexuality education. Research indicates that parents are typically the initial sexuality educators of children (Martin, Luke, and Verduzco-Baker, 2007); however, they are often not perceived as the primary sexuality educators by the child (Angera, Brookins-Fisher & Inungu, 2008). In a study of undergraduate college students ($n=192$) investigating the perception of past communication about sexuality with their parents, Angera et al. (2008) found that only 17% of the respondents identified their parents as the primary source of sexuality information and that mothers are more likely to engage in conversation about sexuality than fathers.

Teenagers between the ages of 13-18 rated parents (32%) below friends (61%), sex ed class (42%), TV/Movies (40%), and magazines (35%) in regards to where they get information about how to talk about sexual health issues (Kaiser, 2000). Additionally,

43% of students who have had sex education in the schools reported wanting more information about how to talk with their parents about sex and relationships (Kaiser, 2000).

Parents also want more information on how to discuss sexuality with their children. Often, parents rely on a mix of resources such as the Internet, other parents, or books to aid in their conversations about sexuality with their child(ren) rather than a formal approach; Ballard and Gross (2009) have found that there is an interest amongst parents for the development of a formal parent-child sexual communication program. Kaiser (2000) found that 89% of a nationally-representative sample of parents endorsed that it was very important that sex education programs teach their child about how to talk with their parents about sex and relationship issues. Further, the National Campaign to Prevent Teen Pregnancy (1997) has advocated for the inclusion of families in sexuality education programming.

Programs such as the Parent-Adolescent Relationship Education (PARE) program, which integrates “interactive parent-child activities into an after-school prevention education curriculum for middle-school students and their parents” using social learning and cognitive behavioral concepts do exist (Lederman & Mian, 2003). Research supports the use of social interactive activities and parent-child discussions as being more effective at strengthening social and self controls and reducing the risk of pregnancy and sexually transmitted diseases than a more didactic approach (Lederman, Wenyaw & Roberts-Gray, 2008). Additionally, research has demonstrated that the use of parent-child homework assignments, such as “reviewing and discussing advertisement

portrayals and men and women, and how these advertisements directly or indirectly promote sexual activity,” in sexuality education curricula can impact the sexual behavior of middle school students and have an additive effect on school-based prevention curricula (Blake, Simkin, Ledsky, Perkins & Calbrese, 2001). It is important that future sexuality education curricula purposefully involve families in their design as research supports that parental involvement can increase contraception use (Frisco, 2005).

Sexuality Education in Special Needs Populations

There is burgeoning interest in understanding sexuality in disabled populations. Entire academic journals, such as the *Journal of Sexuality and Disability*, exist to disseminate research on the psychological and medical aspects of sexuality in rehabilitation and community settings. Within the field of sexuality education, there is agreement that persons with disabilities have the right to comprehensive and medically accurate sexuality education. The position statement of SIECUS regarding the sexuality of persons with disabilities states:

SIECUS believes that individuals with physical, cognitive, or emotional disabilities have a right to education about sexuality, sexual health care, and opportunities for socializing and sexual expression. Healthcare workers and other caregivers must receive comprehensive sexuality education, as well as training in understanding and supporting sexual development, behavior, and related healthcare for individuals with disabilities. The policies and procedures of social agencies and healthcare delivery systems should ensure that services and benefits are provided to all persons without discrimination because of disability. (SIECUS, Sexuality of Persons with Disabilities section, para. 1)

Although it is clear that students with disabilities have the right to and need for sexuality education, the sexuality education needs of individuals with disabilities are often ignored. For example, the *National Sexuality Education Standards: Content and Skills, K-12*

standards provide guidance on what students should be able to do and know by the end of certain grade levels, but do not provide guidance on how a topic area should be taught or modified to meet the needs of diverse student learners or students with exceptionalities (Future of Sex Education, 2012). Gougeon (2009) argues that sexuality education for individuals with Intellectual Disability is profoundly inadequate, coining the term “ignored curriculum of sexuality” in reference to sexuality education of individuals with Intellectual Disability. She further states that sexuality education for children with special needs is so inadequate that the majority of their education is derived from incidentally learned aspects of sex and sexuality by neurotypical peers rather than in a comprehensive, school-based sex education program (Gougeon, 2009).

Kijak’s (2011) analysis of the available literature on sexuality found that although men and women with intellectual disability reach sexual maturity on average two years later than their peers without intellectual disability they still reach biological sexual maturity similarly to their peers. Though individuals with intellectual disability are aware of the changes occurring within their bodies as they move through puberty, they are often unaware of what the changes mean and are unsure of how to handle emotions that are associated with sexual development. Furthermore, Kijak found that only 37% of examined youth with intellectual disability are able to correctly define the changes in the opposite sex occurring during adolescence; in particular, they had difficulty explaining the reasons for menstruation and wet dreams, and about 22% did not know what an erection was. More concerning, only 10% of them knew what contraception was and

only 2% could name at least two sexually transmitted diseases and explain their meaning (Kijak, 2011).

The current literature available on sexuality education for special needs populations often lacks full descriptions of methodological tools and includes only vague explanations of the research methods and techniques used to conduct the studies (Kijak, 2011), perhaps due to the sensitive nature of the subject matter. For instance, although researchers have attempted to compare and contrast existing sexuality education materials for special needs populations, there are few data available on the effectiveness of sex education programs targeting special needs populations. Additionally, sample sizes in studies surrounding sexuality and disability are often small and difficult to generalize to larger populations. Historically, special needs populations have been neglected in scientific research surrounding sexuality and sexuality education.

Sexuality Education for Adolescents with ASD

There is a need for more resources to be developed that address the sexuality education of high functioning adolescents with ASD. Mehzabin & Stokes (2011) found that high functioning young adults with Autism (n=24) reported that they felt they would benefit from more sex education. Although there are existing resources, curricula, and books on sexuality education created for use with high functioning individuals with ASD, lack of empirical validation, a control group, sample sizes large enough to be considered generalizable, and replication raise questions as to their appropriateness and efficacy (Sevlever et al., 2013). Additionally, few studies to date has actually asked adolescent students with ASD about their sexual behavior and sexuality (Dewinter et al., 2015).

Difficulties in obtaining approval from an Institutional Review Board to discuss sexuality with adolescents with ASD has resulted in the majority of the available data on the sexual behavior, desires, and knowledge of adolescents with ASD to be derived from parent or caregiver report, which can be inaccurate (Dewinter et al., 2016). The field is currently presented with the problem of how to obtain an accurate benchmark of where high functioning students with ASD are in regards to their sexual behavior and knowledge when methodological limitations often prevent obtaining such data.

Family involvement. Research has indicated that family involvement is a critical component of sexuality education for neurotypical students as well as students with ASD (Grossman et al., 2013; Holmes & Himle, 2014; Ruble & Dalrymple, 2002). However, the majority of resources designed to provide strategies or curricula on teaching sexuality education to students with ASD have not included parental input. Additionally, few curricula or resources in existence provide activities for parents and their children with ASD to do together.

In an ethnographic research study, Ballan (2011) found that parents of children with ASD strongly wish to communicate with their children and professionals about sexuality but felt unsure about whether or not their child understood the information being shared. Of the 18 parents interviewed for her study, Ballan (2011) found that the majority of parents ($n=16$) had a strong desire to communicate with both their children and professionals about sexuality and that all parents discussed sexual abuse with their child. Parents were concerned about their child(ren) being able to appropriately generalize information about sexuality into everyday environments (Ballan, 2011). Some

parents ($n=7$) felt that there was a shared responsibility between parents, medical professionals, and educators to provide sexuality education to children with ASD; in contrast some parents ($n=6$) were not interested in professionals providing sexuality education to their child(ren) (Ballan, 2011). Holmes and Himle (2014) found that most parents of high functioning children with ASD provide sex education to their children surrounding topics such as privacy, sexual abuse prevention, puberty and hygiene, and basic relationship and sexual health topics but did not discuss more complex relationship and sexual health topics, sexual health and prevention, or general sexuality.

Some sexuality education programs for adolescents with ASD integrate parent-child communication. For example, the Tackling Teenage Training (TTT) program utilizes numerous strategies that involve parents including: weekly parent contact reports with information on the content of the session, take-home assignments of the child, and trainers sharing strengths and difficulties of the child after each session (Visser et al., 2015).

For a sex education curriculum to be truly successful, it is crucial that parents have a seat at the table when designing guidelines and activities. Fidelity is essential in any intervention; therefore, building a curriculum that parents will support and implement at home may increase fidelity and improve outcomes for students.

Teacher perspectives. In Kalyva's (2010) study asking teachers' perspectives on the sexuality of children with ASD, it was found that teachers' express more concerns specific to sexuality for high functioning children with ASD than low functioning children with ASD. Additionally, the majority of teachers of students with ASD did not

feel confident in providing sex education to their students with ASD and had not received training in how to teach sexuality education concepts to children with ASD (Kalyva, 2010).

In the schools. Of the limited ASD sexuality curricula in existence, few provide explicit instruction as to how to adapt the curriculum to a school setting versus a home setting versus an alternative education environment. Some resources, such as Hartman's (2014) book *Sexuality and Relationship Education for Children and Adolescents with Autism Spectrum Disorders*, state that both parents and professionals can benefit from the strategies included in the book, and provide tools for individually designing curricula, but do not explicitly discuss how family-school partnering is established and fostered throughout the sexuality education curricula or intervention and what activities are best suited for each environment. School psychologists, special education teachers, and school nurses have frequent interactions with high functioning students with ASD in the public school system, and gleaning their insights as to what would and would not work in a public school setting is important in the design of a comprehensive sexuality education curriculum.

Some researchers have suggested adapting existing sexuality education curricula designed for neurotypical populations for use with ASD populations, or developing an ASD sexuality education curricula based on the existing literature on sexuality education for individuals with an Intellectual Disability (Tullis & Zangrillo, 2013). These approaches prove problematic because individuals with ASD often have social deficits

that require individualized or explicit instruction of certain aspects of sexuality education, whereas individuals with Intellectual Disability may not.

Sexuality education for high functioning students with ASD would provide the most benefit if approached from a public health approach that focused on prevention, as well as intervention. Because data indicates in the neurotypical middle school population alone that 5-20% of sixth graders and 14-42% of eighth graders have engaged in sexual intercourse (Moore, Barr, & Johnson, 2013), and because of the lack of representative data examining the sexual behavior of adolescents with ASD, it is critical to initiate conversations about appropriate sexual behavior and relationships prior to the age of first sex. In her review of the extant literature, Gougeon (2010) found that although parents and caregivers are concerned and aware of the sexuality education needs of students with ASD, they are unsure of how to go about explicitly teaching the skills and subject matter effectively. Ideally, age-appropriate and medically accurate sexuality education should start in kindergarten, continue through the 12th grade, and build upon the knowledge and skills that were taught in previous stages (Future of Sex Education, 2012).

Legal concerns. Individuals diagnosed with ASD are at an increased risk of experiencing sexual victimization than their neurotypical peers (Sevlever et al., 2013). A recent self-report study revealed that adults with ASD experience higher rates of sexual victimization than neurotypical peers, and that perceived sexual knowledge can partially mediate the risk of victimization (Brown-Lavoie et al., 2014). Students with ASD who do not receive intentional sexuality education are at an increased risk for being victims of sexual crimes as well as being arrested for unintentionally committing a sexual crime.

Cases of stalking, viewing of child pornography, voyeurism, and inappropriate sexual behaviors have all resulted in criminal pursuits of individuals with an ASD diagnosis (Attwood et al., 2014).

Collaborative consultation. Consultation is becoming an increasingly important skill to be utilized by school-based professionals who work with students with ASD. The benefits of consultation include skill development for the consultee, improved outcomes for the client, and time management for the consultant. When thinking about addressing the sexuality education needs of high functioning students with ASD, utilizing consultation to foster skill development of pro-social relational behavior can prove valuable. Additionally, successfully utilizing interventions to address sexually inappropriate behavior as well as fostering family-child communication surrounding sexuality for school-based professionals, families of high functioning students with ASD, and high functioning students with ASD can prove beneficial. There are multiple consultation models utilized within the school setting including solution-focused consultation (Kahn, 2000), problem-solving consultation (Hazel, Laviolette, & Lineman, 2010; Kratochwill, 2008), behavioral consultation (Watson & Sterling-Turner, 2008), conjoint behavioral consultation (Sheridan, 1997), and instructional consultation (Rosenfield, 2002).

Because of the importance of including families, educators, and community partners in sexuality education, discussion, and intervention strategies a collaborative consultation model is suggested. Ruble and Dalrymple (2002) propose the use of the Collaborative Model for Promoting Competence and Success (COMPASS) to provide

indirect intervention to help students with autism achieve competence. The COMPASS assumes that competence can operate as a protective factor to protect children with ASD against circumstances that contribute to failure (Ruble & Dalrymple, 2002).

Curricula. Few of the curricula available on sexuality education for high functioning adolescents with ASD have been supported empirically. Koller (2000) outlines three different sexuality education methods that have met success in teaching sexuality skills to individuals with ASD: (1) the Devereux Centers for children and adults with autism in Massachusetts, New York, New Jersey, Pennsylvania, Florida, Texas, and California; (2) the Benhaven day and residential school community in New Haven, CT; and (3) the general policies for addressing sexuality in children and young adults with autism in Denmark. The Devereux Centers maintain that parents are the best sex educators, and that teachers and staff should attempt to fill this role only if parents are unable to educate their children with ASD about sexuality, and that it is normal for every person with a body to express their sexuality (Koller, 2000). Benhaven created their sexuality training in the 1980's based on policy decisions that can be considered regressive and out-of-date in comparison to the current research in the field. Policy decisions such as "there is to be no disapproval of masturbation, since it is probably the only kind of sexual satisfaction that will be available to our students during their lifetime" and "romance must be put aside for more realistic social encounters geared to expectations of friendly sharing of activities" (Melone & Lettick, 1985) indicate an assumption that people with an ASD diagnosis will never experience love and intimacy with a partner. Finally, Koller (2000) discusses Haracopos and Pederson's (1992) outline

of the general policies for addressing sexuality for children and young adults with autism in Denmark. Although included in a section entitled “curriculum,” Denmark’s general policies are just that – general, and lack specific resources or instruction as to how to develop a sexuality education program.

Since Koller’s (2000) article, additional resources and curricula for the sexuality education of individuals with ASD have been published. The *Healthy Relationships & Autism* (HR) curriculum (Sutton & Wesley Spectrum Services, 2013) addresses hygiene, biological sex education, and relationships. Recent studies has proven that Module 2 (basic biological sex education) been proven effective at increasing basic biological sex education knowledge acquisition (Pask, 2015).

The Tackling Teenage Training (TTT) program has been found to be successful in significantly increasing psychosexual knowledge in a sample of thirty 11-19 year old adolescents with ASD (Dekker et al., 2014). Additionally, most parents of the adolescent participants in the study reported a perceived transfer of the learned psychosexual knowledge to everyday life (Dekker et al., 2014). The TTT program involves 18 one-on-one sessions in which adolescents receive information and complete exercises surrounding several psycho-education topics. Recently, the Tackling Teenage Training (TTT) program for the psychosexual development of adolescents with ASD published a protocol that will be used to assess the program efficacy on adolescent participants ($n=150$) with a DSM-IV diagnosis of ASD using a randomized controlled trial research design (Visser et al., 2015). The results of this study are not yet available.

Henault (2006) created a sexuality education program for adults with Asperger's disorder; however, it is designed for use with ages 16 and up, leaving out the critical middle school ages. Her book, *Asperger Syndrome and Sexuality: From Adolescence through Adulthood*, can be a useful resource for parents and educators of students with ASD; however, some of the diagnostic criteria in regards to Asperger disorder and high functioning autism are out of date.

One of the more comprehensive sex education curriculum for high functioning adolescents with ASD is *Intimate Relationships and Sexual Health: A Curriculum for Teaching Adolescents/Adults with High-Functioning Autism Spectrum Disorders and Other Social Challenges* (Davies & Dubie, 2012). This curriculum was created by educational consultants and covers topics such as sexual responses and partnered sex, sexual anatomy; reproductive health; contraception and sexually transmitted infections; dating; stages of relationships; attitudes, values, and differences; and sexual harassment, aggression, and abuse. The curriculum includes handouts and resources and is intended to be used by parents or professionals who work with high functioning students with ASD.

The book *Sexuality and Relationship Education for Children and Adolescents with Autism Spectrum Disorders: A professional's guide to understanding, preventing issues, supporting sexuality and responding to inappropriate behavior* is a comprehensive guide to relevant topics on sexuality education for students with ASD and provides useful resources for parents, schools, and professionals who are in need of strategies to talk to high functioning students with ASD about different aspects of

sexuality (Hartman, 2014). Examples of social stories with pictures surrounding topics such as masturbation are included in the book, as well as a checklist and guide for creating an individualized sexuality education curriculum for high functioning student(s) with ASD across a wide age range. This book is useful as an à la carte method of selecting resources and materials for sexuality education, but does not provide clear guidelines as to how to implement some of the strategies suggested. Additionally, although this book is intended for youth across a wide age range, it is not clear what and what is not appropriate for each age range or grade level. Finally, while the book encourages parent participation in developing curricula with professionals and engagement in sexuality education conversations, explicit tools for parents to use that build on school-based instruction are not included.

Strategies. The literature has supported the use of several strategies when educating high functioning adolescents with ASD about sexuality. One of the most frequently cited strategies is Social Stories™. Developed by Gray and Garand (1993), social stories are defined as “short stories that describe social situations in terms of relevant social cues and often define appropriate responses.” Social stories are particularly well suited for use in sexuality education for high functioning students with ASD due to the stringent social and legal parameters to healthy sexuality. Using a social story, a high functioning student with ASD can be provided with relevant, succinct responses to personal or partnered sexual experiences or thoughts.

In addition to Social Stories™, the literature also supports the use of Applied Behavior Analysis (ABA). Wolfe, Condo, and Hardaway (2009) suggest the use of the

ABA-based strategies of video modeling, visual cues or stimuli, social stories, and social script reading for teaching sociosexual content pertaining to biology and reproduction, health and hygiene, relationships, and self-protection/self-advocacy to persons with ASD.

Resources. *Sex, Sexuality, and the Autism Spectrum* is a book authored by an adult with ASD and takes a strengths based approach to talking about sexual experiences (Lawson, 2005). Lawson discusses her own sexuality, and her journey to identifying as a homosexual autistic adult. This is one of the few resources that discusses transgender issues, and is a first-person account of how a person with ASD experiences sex and sexuality. *Autism-Asperger's and Sexuality: Puberty and Beyond* is a book written by a married couple who both have ASD and is written from the perspective of the authors speaking directly to adolescents (Newport & Newport, 2002).

Additionally, *Sex, Sexuality, and the Law*, co-authored by Nick Dubin who has ASD, is a powerful book for parents and mental health professionals to read as it highlights many of the issues, sometimes legal issues, that can arise in regards to sexuality for people with ASD (Attwood et al., 2014). Dubin tells his personal story of the lessons he learned on his journey towards understanding his own sexual identity and the legal ramifications and unintended consequences that resulted from some of his actions.

Making Sense of Sex: A Forthright Guide to Puberty, Sex and Relationships for People with Asperger's Syndrome (Attwood, 2008) is a book written for “young people” with Asperger’s Syndrome and uses teen-friendly language and the use of pictures to explain sexual relationships, anatomy, sexual health, reproduction and other sexuality

topics. The information provided in this book is accessible to youth and an introductory note at the beginning provides advice to caregivers on how to talk to children with Asperger's disorder about sex.

In addition to books, there are various websites that provide information for caregivers or individuals with ASD on sexuality. Hartman, author of the book *Sexuality and Relationship Education for Children and Adolescents with Autism Spectrum Disorders: A professional's guide to understanding, preventing issues, supporting sexuality and responding to inappropriate behavior*, maintains the website <http://www.autismsexeducation.com/> and provides links to information resources, books, and multimedia pertinent to the sexuality education of individuals with ASD. The website for Autism Speaks, the leading Autism science and advocacy organization, offers articles and suggestions for ASD sexuality education but only if the web visitor explicitly searches for "sexuality" in the search bar.

Summary

In sum, high functioning adolescents with ASD develop sexually similarly to their neurotypical peers, but often lack explicit sexuality education. This is particularly problematic considering that individuals with ASD are at an increased risk for sexual abuse. Individuals with ASD are often undereducated about sexuality, even though sexuality knowledge is a moderating factor to sexual abuse (Brown-Lavoie et al., 2014). In addition to safety concerns, individuals with ASD have a right to experience healthy romantic relationships but due to the social deficits associated with their diagnosis,

specific education strategies that differ from the general education sexuality education curricula may be necessary.

The road towards comprehensive sexuality education for students with ASD is a difficult one. Sexuality education for the general education population in the United States has been and still is a contentious topic. Historically, the majority of federal funding has gone towards abstinence only education even though research suggests that comprehensive sexuality education is more effective and the general public prefers comprehensive sexuality education to abstinence only sexuality education. A uniform approach to sexuality education will likely not be seen in the United States for many decades to come.

Amidst the controversy surrounding sexuality education within public schools, persons with disabilities are often left out of the discussion. Within the literature surrounding sexuality education for persons with disabilities, there is a dearth of research specific to the ASD population. High functioning individuals with ASD such as Dubin (2014), Lawson (2005), and the Newports (2002) have felt so passionately about the need for sexuality education information appropriate for persons with ASD that they wrote books on the topic from an ASD perspective.

Over the past 30 years more research and resources have become available on how to address sexuality with high functioning adolescents with ASD; however, key stakeholders in the field have yet to come together to discuss how best to educate high functioning students with ASD on sexuality. There are currently too few resources available that provide explicit instruction on how to teach sexuality education to high

functioning students with ASD, and very few were developed collaboratively with parents and educators of high functioning students with ASD. Currently, there is a gap in the literature surrounding comprehensive sexuality education strategies, guidelines, and resources for high functioning adolescents with ASD. It is critical to bring key stakeholders together to begin the discussion of what constitutes quality sexuality education for high functioning persons with ASD.

Chapter Three: Method

Purpose of Study

The goal of this study was to identify the key components that experts agree are necessary to include in a comprehensive sexuality education curriculum for high functioning adolescent students with ASD. To date, there is a paucity of information on sexuality education for adolescents with ASD. Currently, many of the existing sexuality education resources for high functioning adolescents with ASD were created out of reactive necessity by individuals with expertise in ASD. Further, many existing resources were not designed according to specific guidelines or collaboratively with families of students with ASD or school-based professionals who work with students with ASD. Sexuality is the intersection of emotion, biology, and social interactions; educating students with ASD about sexuality requires knowledge from experts in multiple arenas and who work with students in a variety of settings (e.g., school, home, center-based programs, etc). Expertise in only one area is not sufficient when developing a sexuality education curriculum for high functioning students with ASD. In order to develop a more comprehensive sexuality education curriculum for students with ASD, it is necessary to integrate best practices in sexuality education, ASD intervention strategies, education of students with ASD, and family-school-community partnering.

The Delphi method was the methodology chosen for this study so as to utilize a structured communication approach to reach group consensus amongst a panel of experts

on the complex issue of educating high functioning students with ASD about sexuality. Utilizing the Delphi method allowed for the consensus of group opinion of a panel of experts in the specialties of ASD and sexuality research, families of high functioning adolescents with ASD, and school psychologists. By achieving consensus amongst a panel of experts representing differing but equally important fields, a more effective and comprehensive sexuality education curriculum may be able to be created based on the educational guidelines that were established from this study. The final outcome of this study was the creation of curriculum guidelines including the agreed upon best practices as determined by the panel of experts. The primary research questions for this study included:

1. What do experts in the field of ASD and sexuality, school-based mental health services, and family-school partnering believe to be essential content in comprehensive sexuality education for high functioning students with ASD?
2. What learning strategies should be considered when teaching high functioning adolescents with ASD about sexuality?
3. What type(s) of family-school collaboration could best support high functioning adolescents with ASD in their sexuality education?

The Delphi Method

The Delphi method is a well-established research method that utilizes iterative questionnaires in order to establish consensus amongst a group of experts. Created over 50 years ago by the RAND Corporation as a means of improving group decision making (Dalkey, 1969; Dalkey & Helmer, 1963), the Delphi method has since been used in fields

including nursing (Powell, 2002), social sciences (Landeta, 2006; Laviolette, 2011), education (Skutsch & Hall, 1973), gynecology (Thangaratinam & Redman, 2005), tourism (Donahoe & Needham, 2009), and the military (Dalkey, 1969). According to Skutsch and Hall (1973), the distinguishing feature of the Delphi method in comparison to other group decision-making mechanisms is the iterative structure. Within the social sciences, the Delphi method is typically considered a qualitative methodology (Jones & Hunter, 1995), although Delphi involves a mix of quantitative and qualitative processes (Skulmoski, Hartman, & Krahn, 2007). The Delphi method is considered a valid research methodology and the extent of its use in research has maintained since its development over 50 years ago (Landeta, 2006).

Skutsch and Hall (1973) state that the Delphi technique is an appropriate method to use for gaining judgment on complex matters where precise information is unavailable and lends itself well to educational planning. Sexuality education for high functioning adolescent students with ASD is a complex matter, particularly because the social communication and social interaction deficits and repetitive behaviors and/or restricted interests inherent in an ASD diagnosis require special consideration regarding what content should be delivered, how content should be delivered, how knowledge acquisition should be measured, and what roles should professionals and families have in delivering the information. Additionally, precise information on the sexuality education of high functioning students with ASD is unavailable. The United States only recently developed comprehensive sexuality education standards for general education students in 2012; there is very little information available as to what types of strategies, topics, and

family-school partnering best benefits high functioning students with ASD in their sexuality education. Joining together the views and thoughts of multiple experts in research, school psychology, and parenting children with ASD via the Delphi method created a rich and broad array of ideas and allowed a team of experts to develop the *Guidelines for Developing Sexuality Education Curricula for High functioning Adolescent Students with Autism Spectrum Disorder* that are inclusive of research, school-based, and familial perspectives.

The synergistic nature of small group decision making inherent in the Delphi research methodology lends itself well to developing sexuality education guidelines, particularly when applying small group psychology theory which posits that, “group judgements are superior to individual ones” (Skutsch & Hall, 1973). When this “two heads are better than one” mentality is applied to the development of sexuality education guidelines using a cadre of experts rather than the opinion of a single researcher the final outcome is the consensus of multiple individuals that becomes greater than merely the sum of its parts.

According to Pfeiffer (1968), the Delphi method is comprised of three rounds of questionnaires. In the first round, a questionnaire is distributed to a panel of experts. In the second round, the results from the first questionnaire is sent to each expert in the study and each expert is then asked to rate or evaluate each item by some criterion of importance. In the third round, a questionnaire consisting of the list of items, ratings by the panel, and consensus is distributed to the participants. The experts are then asked to

either revise their opinions or discuss their reasons for not coming to consensus with the group (Pfeiffer, 1968).

The Delphi method is a structured, repetitive process and the findings represent the synthesis of expert opinion rather than statistically significant results (Donohoe & Needham, 2009). One of the benefits of the Delphi method is that it allows for the generation of a large quantity of high quality ideas (Donohoe & Needham, 2009). The anonymity of respondents allows for participants to share their opinion without worry of the group's reaction.

Study Design

This study utilized the Delphi research methodology to obtain group consensus amongst a group of ASD experts regarding the key components of successful sexuality education for high functioning adolescent students with ASD. I recruited experts with experience in conducting research and/or developing resources concerning the sexuality education of high functioning adolescents with ASD, raising high functioning adolescent children with ASD, and working with high functioning adolescents with ASD in the schools to ensure that the input of key stakeholders in research, families, and schools were given an opportunity to voice their opinions. Over the course of three months, respondents had the opportunity to complete three rounds of iterative questionnaires regarding their opinions on key components of sexuality education curricula for high functioning students with ASD. To ensure question clarity and quality, a pilot of the Round 1 Questionnaire was administered to three individuals representing each of the respondent groups and with familiarity of ASD. The final outcome of this research was

the development of the *Guidelines for Developing Sexuality Education Curricula for High Functioning Adolescent Students with Autism Spectrum Disorder*, as defined by experts. The Round 1 Questionnaire is provided in Appendix G.

Respondents

I recruited expert participants in ASD sexuality research, school psychology, and parenting high functioning adolescents with ASD. The literature states that it is not necessary to obtain representative samples of participants for statistical purposes (Powell, 2002); therefore, I discontinued recruitment once I reached a minimum of 15 expert participants with at least one participant in each respondent group.

The participants were separated into respondent groups based on area of expertise. The respondent groups included: (a) ASD and sexuality authors, (b) school psychologists who work with high functioning adolescents with ASD, (c) caregivers of high functioning adolescents with ASD, and (d) other. Due to the specific nature of expertise required for this study, and the lack of a national listserv comprised of individuals with such expertise, recruitment strategies differed per respondent group. As an incentive to encourage participation, I offered each participant a copy of the final product of sexuality education guidelines for high functioning adolescents with ASD.

When recruiting participants, I provided in my email or recruitment letter the needs for sexuality education in the ASD population, my definition of high functioning adolescents with ASD, and the purpose of the study. I described the iterative nature of the Delphi method and informed potential participants that they would be contacted three or more times, or until saturation of responses is reached. A copy of the recruitment

letter is provided in Appendix H. Participants had between one week to one month to respond to each iteration of the questionnaire.

Table 2 highlights the respondent groups, inclusionary and exclusionary criteria, and recruitment methods that were used to obtain participants for this study.

Table 2

Respondent Participation Criteria and Recruitment

Respondent Group	Inclusionary Criteria	Exclusionary Criteria	Recruitment Method
ASD and Sexuality Authors	<ul style="list-style-type: none"> - Published a peer reviewed journal article, dissertation, or book on the subject of ASD and sexuality OR created a sexuality education curriculum for high functioning students with ASD OR developed sexuality education materials for high functioning students with ASD - Live in the USA 	<ul style="list-style-type: none"> - Publications more than 15 years old - Live outside of the USA 	<ul style="list-style-type: none"> - Created a list of authors in the field of sexuality and ASD - Send recruitment email to authors requesting participation - 7 ASD and Sexuality Authors were recruited, $n=7$
School Psychologists	<ul style="list-style-type: none"> - Currently work with high functioning students who are receiving special education services for ASD in a public school - Licensed with their State Department of Education 	<ul style="list-style-type: none"> - Less than 3 years of experience as a school psychologist - Does not work with adolescent students with ASD 	<ul style="list-style-type: none"> - Recruited via state school psychologist listservs - Emailed statewide school psychology organizations of all 50 U.S. states for permission to recruit via their listserv

	- Work in the USA	- Is not licensed with their State Department of Education	- Obtained permission to recruit from 14 states
		- Do not work in the USA	- 6 school psychologists participants were recruited, <i>n</i> =6
Families	- Be the primary caregiver of an adolescent with an ASD diagnosis	- Child with ASD is not an adolescent	- Snowball sampling initially
	- Child has average or above average intelligence	- Child does not have an ASD diagnosis	- Solicited participation via email
	- Child is able to communicate verbally	- Child has below average intelligence	- Email survey link posted on the Autism Speaks Families Participate in Research webpage, Autism Society of Colorado Facebook page, and the Autism Resource Network of Indiana website
			- 2 family participants were recruited, <i>n</i> =2
Other	- May qualify as an expert in more than one group		- <i>n</i> =2

ASD and sexuality authors. Within the ASD and sexuality authors respondent group, I sought to include experts who had published research in peer-reviewed journals or conducted dissertations on the topic of ASD and sexuality; had created a sexuality education curriculum or program; or had authored books and/or created resources for professionals who work with students with ASD, families of children with ASD, and/or individuals with ASD. Authors whose most recent publication was more than 15 years

old were not recruited for participation in this study. Due to the differing sexuality education standards and differing cultural perspectives on sexuality in countries outside of the United States, only participants who reside in the United States of America were recruited for participation in this study.

Recruitment. To recruit participants for the ASD and sexuality authors respondent group, I developed a list of 27 potential participants and contacted them directly via email to request their participation. The list of potential participants was created by compiling the names and emails of researchers with publications in the area of ASD and sexuality. Participants were sought out by searching for keywords such as “Asperger’s” “Autism” “high functioning” “sexuality” “sex education” and “adolescent” in the PsychInfo and ERIC research databases and contacting the authors of peer reviewed journals that were found. I also specifically searched for the aforementioned keywords in the peer-reviewed journals *Sexuality and Disability* and *Journal of Autism and Developmental Disorders*. Finally, I contacted the authors of existing curricula and books on the topic of ASD or Asperger’s Syndrome and sexuality. Recruitment efforts resulted in seven participants in the ASD and sexuality authors respondent group ($n=7$).

School psychologists. The school-based professionals who work with high functioning students with ASD respondent group was limited to school psychologists who work with high functioning adolescent students with ASD. Although there are a variety of school-based professionals who work with students with ASD in the schools, including but not limited to school social workers, school counselors, speech language pathologists, school nurses, and special education teachers, school psychologists are

comprehensively trained in child development, students with exceptionalities, family-school partnering, consultation, problem solving, interventions, and data collection and analysis. Because of their training, school psychologists are uniquely situated to provide sexuality education curricula and or/interventions to high functioning students with ASD. The school psychologists included in this respondent group were currently working with high functioning students with ASD within the schools, had at least three years of experience working with students with ASD, and were licensed as school psychologists through their State Department of Education.

Recruitment. To recruit school psychologists, I solicited the state school psychology organizations of all 50 U.S. states for permission to recruit via their listserv. States that provided permission, but required a fee to access their listservs for research participant recruitment, were not further pursued. Of the 50 states that were contacted, 14 states (Alaska, Arkansas, Colorado, Connecticut, Delaware, Idaho, Kansas, Kentucky, Michigan, New Jersey, North Dakota, Ohio, Tennessee, Wisconsin) approved my request to send out the electronic recruitment letter via their listerv for no fee or to post the study recruitment verbiage to their state association website. The school psychologists that were chosen to be included in the study worked with high functioning students with ASD, were licensed through their State Department of Education, and had been working as a school psychologist for at least three years. Recruitment efforts resulted in six participants in the School Psychologist respondent group ($n=6$).

Families. The families of high functioning adolescents with ASD respondent group consisted of primary caregivers of children who had a diagnosis of ASD and were

considered high functioning. Each participant included in this respondent group was a primary caregiver to an adolescent who had received a diagnosis (educational versus clinical not specified) of ASD. The criteria for their child to be considered an adolescent included being between the ages of 11 to 21 and being currently enrolled in the sixth grade or above. For their child to be considered high functioning, they must possess verbal communication ability and have intelligence that falls within the average or above average range.

Recruitment. To recruit family experts I initially proposed utilizing the snowball method. I anticipated using my personal network of parent advocates to be referred to individuals who met inclusionary criteria and were interested in participating in this research. Recruitment of family-school partnering experts proved challenging and resulted in the need to expand upon my initial recruitment strategy in order to obtain responses from parents of high functioning adolescent students with ASD.

My recruitment efforts to recruit family participants were extensive. I obtained permission to post the study description and Round 1 Questionnaire link on the Autism Resource Network of Indiana website, the Families Participate in Research webpage of Autism Speaks, and the Facebook page of the Autism Society of Colorado. I directly contacted parent authors of ASD blogs, articles, books, and newsletters nationwide. The New Jersey Parent Advocate network distributed my study recruitment email via their listerv. My survey link was distributed to parents of high functioning adolescent students with ASD through special education teachers in schools in Alaska, Colorado, Michigan, and Washington. A private neuropsychological clinic specializing in ASD sent out a link

of this study to the parents of high functioning adolescent clients with ASD. I contacted The Arc of King County, Autism Intervention Bay Area, and Moms on the Spectrum parent Autism support groups and did not receive a reply back. I also asked my personal network to distribute my research study to their friends and family members who met criteria for participation. These efforts, which took place over a period of three months, resulted in two parent respondents. Hypotheses of why parent recruitment proved more difficult than anticipated is presented in the discussion chapter of this dissertation.

Other. The “Other” respondent group was intended to capture experts who either had multiple areas of expertise or whose expertise was not encapsulated in the other groups. Two respondents identified themselves in the “Other” respondent group in addition to one of the aforementioned respondent groups. One respondent identified themselves only in the “Other” respondent group, but was categorized into the ASD and Sexuality Author group due to her dissertation research being completed on the topic of sexuality education for students with Asperger’s disorder. Table 3 provides an overview of the respondent groups for this study.

Participant Demographics

A total of 26 individuals began the Round 1 Questionnaire and 15 individuals completed it in its entirety. Table 4 provides an overview of participants, by group, who initiated Round 1 and completed it. The 15 respondents who completed Round 1 were utilized for the remainder of this study. These participants ranged from 29 to 50 years of age and between three and 28 years of experience in their identified group. Participants were predominately females (87%). Approximately 93% of participants identified as

Table 3

Overview of Respondent Groups

Respondent Group	Total Participants	Percentage
ASD and Sexuality Authors	<i>n</i> =7	47%
School Psychologists	<i>n</i> =6	40%
Families	<i>n</i> =2	13%
Other	<i>n</i> =3	20%
Total	<i>n</i> =15	100%

Note. Respondents were able to identify themselves in more than one respondent group

Table 4

Round 1 Recruitment Attrition

Respondent Group	Started Round 1	Completed Round 1	Attrition
ASD and Sexuality Authors	9	7	22%
School Psychologists	10	6	40%
Families	5	2	60%
Unknown	2	0	100%
Total	26	15	42%

Note. Respondents who began the Round 1 questionnaire but did not identify a respondent group were categorized as Unknown

White and 7% identified as Hispanic/Latino. Participants were geographically diverse, representing 11 states across America. Degrees earned by participants in this study included Bachelors, Masters, Specialist, and Doctoral degrees. Tables 5 through 9 provide an overview of participant demographic information both as a whole and separated out by groups.

Table 5

Participant Gender

Group	Male	Female
ASD and Sexuality Authors	1	6
School Psychologists	1	5
Families	0	2
Total	2	13

Table 6

Participant Age and Experience

Respondent Group	Demographic Category	Minimum	Maximum	Mean
ASD and Sexuality Authors	Age	30	50	39.7
	Experience	3	25	9
School Psychologists	Age	29	51	38.3
	Experience	3.5	28	12
	Age	47	50	48.5
Families	Experience	16	18	17
Total	Age	29	50	40.3
	Experience	3	28	12.33

Note. Experience is reported in years.

Instrument Development

The first questionnaire consisted of open-ended responses designed to determine various subject areas that should be included in a sexuality education curriculum for high functioning students with ASD. A review of the literature, federal and state public health and sexuality standards, and existing sexuality education materials for students with disabilities was consulted in the creation of Questionnaire 1. All questionnaires were developed using Qualtrics online survey software.

Table 7

Regional Diversity of Participants

State	Number of Participants	Percentage
Arkansas	1	7%
Colorado	3	20%
Idaho	1	7%
Illinois	1	7%
Indiana	2	13%
New York	2	13%
Ohio	1	7%
Tennessee	1	7%
Utah	1	7%
Washington	1	7%
Wisconsin	1	7%
Total	15	100%

Note. Percentages were rounded up to the nearest whole percentage

Table 8

Participant Ethnicity

Group	White	Hispanic/Latino
ASD and Sexuality Authors	7	0
School Psychologists	6	0
Families	1	1
Total	14	1

Table 9

Participant Education

Group	Bachelor's Degree	Master's Degree	Specialists Degree	Doctorate Degree
ASD and Sexuality Authors	0	3	0	4
School Psychologists	0	1	4	1
Families	2	0	0	0
Total	2	4	4	5

Pilot. To determine the face validity, length of time to complete, and question readability, a pilot of Questionnaire 1 was sent to three pilot respondents with expertise in one of the respondent group areas. Because I did not want to limit my respondent pool by using potential respondents for the pilot rather than the study, the pilot participants did not require as stringent inclusionary and exclusionary criteria. The pilot respondent representing the ASD and sexuality authors group had presented on the topic of ASD and sexuality to adults with ASD and was a contributing author on a book in press about ASD. The pilot respondent representing the school psychologist group was licensed but had only been practicing for one year. The pilot respondent representing the families group had a high functioning son with ASD who was an adult.

Pilot participants were asked to take the survey, provide feedback on question clarity and content, note any grammatical or technological errors, and comment on their overall experience. Feedback received from pilot respondents included correcting a technical glitch that prohibited forwards and backwards clicking and correcting minor spelling and grammatical errors. These suggestions were integrated into the final draft of the Round 1 Questionnaire. The Round 1 Questionnaire is provided in Appendix G.

Data Collection

Before collecting data, approval from the University of Denver IRB board was obtained with exempt status. Upon obtaining IRB approval, the pilot of the Round 1 Questionnaire was sent to three people with expertise in ASD to ensure face validity and clarity of questions. Feedback from the pilot questionnaire was incorporated into the first questionnaire. In total, three rounds of questionnaires were administered to the

participants of this study. All questionnaires were distributed via email and included a description of the study, informed consent for each round, and a Qualtrics link that took them directly to the survey.

Round 1: Initial data collection. The first questionnaire, henceforth referred to as Round 1, elicited open-ended responses from the participants. Questions were specific to the content that should be included in a sexuality education curriculum for high functioning adolescents with ADS, the appropriate method of sexuality education delivery for this population, and the responsibilities of families and schools in educating high functioning adolescent students about sexuality. Round 1 also collected demographic information including role, gender, race, years of experience in their field, highest degree earned, email address, and location. The recruitment period was intended to last two months but was extended to three months in order to ensure a minimum of 15 participants were recruited. Because of this recruitment extension, Round 1 respondents had between three days to one month to participate in the survey depending on when in the recruitment phase they were contacted. In total, 26 respondents began Round 1 and 15 respondents (58%) completed Round 1. Responses from Round 1 were coded and analyzed for emergent themes. The themes that emerged from the open-ended responses from participants in Round 1 were utilized to develop the Round 2 Questionnaire. The Round 1 Questionnaire is provided in Appendix G.

Round 2: Consensus. The second questionnaire, henceforth referred to as Round 2, was emailed directly to participants via a Qualtrics link. Participants had nine days to respond to the survey. As the response deadline neared, participants were emailed

reminders to complete the Round 2 Questionnaire. In Round 2, participants were asked to agree or disagree with the themes that emerged from Round 1 analysis. Participants had the opportunity to provide feedback, additional thoughts, and critiques in a comments section beneath each cluster of items. At the end of the survey, participants had the opportunity to add additional suggestions or comments.

There was 0% attrition in Round 2; all 15 participants completed the Round 2 Questionnaire. Round 2 responses of disagree and agree were analyzed for consensus. Round 2 items that had below 80% consensus were not utilized to develop Round 3 items. Hsu and Sandford (2007) state that the primary researcher has the flexibility to define and determine consensus in a Delphi study. The criterion established for Round 2 was an 80% agreement. Miller (2006) states that if a certain percentage of responses fall within a desired range, consensus can be determined. The Round 2 responses from the comments section were coded and analyzed for additional themes. From these data, a draft of sexuality education guidelines for high functioning adolescent students with ASD was developed.

Round 3: Finalization. The third questionnaire, henceforth referred to as Round 3, was emailed directly to participants via a Qualtrics link. Round 3 consisted of statements that were developed from Round 2 responses and comments. Participants had two weeks to respond to this survey. In Round 3, participants were asked to review a draft of the *Guidelines for Developing Sexuality Education Curricula for High Functioning Adolescent Students with Autism Spectrum Disorder*. Participants were able to read through statements that were developed from items with 100% consensus in

Round 2 but not comment. Participants were asked to either agree with or edit statements that were developed from Round 2 items that did not have 100% consensus.

Analysis

Data analysis began after the Round 1 responses were collected from 15 participants representing three primary respondent groups. The open-ended questions from Round 1 were coded according to the coding strategy outlined by Stringer (2007): for each question I first sorted data units into related groups, next I labeled each group, then I revised the groups by either collapsing two or more groups into one or expanding one group into multiple groups, and finally I developed headings that described each group. This process is further outlined in the Results chapter. The codes extracted from these data were then reviewed by an expert reviewer in order to ensure that primary researcher bias was not influencing the coding process. All emergent themes from the Round 1 Questionnaire were used to develop items for the Round 2 Questionnaire. The reasoning behind including all emergent themes was to allow participants to be exposed to all of the ideas that were generated and to not penalize participants for unique ideas that were divergent from the norm. Including all emergent themes was especially important due to only having two parent voices represented in this study.

In Round 2, data analysis involved analyzing consensus amongst participants on whether or not they agreed with ideas developed from the Round 1 Questionnaire. Items in which 80% or more of participants agreed were used to develop Round 3 Questionnaire statements.

Round 3 data analysis involved having each participant review a draft of the sexuality education guidelines, state whether or not they agree with the statement, and rewrite statements that they disagreed with. The final guidelines were developed by reviewing each statement for agreeableness and then integrating participant rewrites of statements into a final version of the *Guidelines for Developing Sexuality Education Curricula for High Functioning Students with Autism Spectrum Disorder*.

Addressing bias. In any qualitative study it is imperative to take into account the impact that researcher bias may have on the interpretation of results. As the primary researcher, it is important for me to disclose any personal biases that I have which could impact my interpretation of the data that were collected. To quote Peshkin (1988), it was essential to take the time in the process of conducting this qualitative research to “actively seek out my subjectivity,” to “be aware of it in process,” and to be “mindful of its enabling and disabling potential” while collecting data.

I have worked for a reproductive health focused nonprofit organization and on contraceptive clinical trials. Additionally, my personal values support comprehensive sexuality education in schools, access to reproductive health care as a civil right, and the importance of collaboration between schools and families in the sexuality education of all students. I have worked directly with high functioning students with ASD as a clinical extern in a Los Angeles based private psychology practice as well as during practicum and internship experiences at high schools, middle schools, and elementary schools. Additionally, I currently provide one-on-one cognitive behavior therapy to moderate and

high functioning adolescents with ASD and am involved in the assessment and diagnosis of ASD at a neuropsychological clinic.

My own personal biases were addressed in two ways. Firstly, the codes and themes from Round 1 were sent to an outside qualitative researcher for review. The outside researcher that was selected had a Master of Science in Research Methods and Statistics and was a second year doctoral student in a Research Methods and Statistics Ph.D. program. She has participated in qualitative research on large-scale research grants and has presented her findings at national and international conferences. A Ph.D. student with expertise in family-school partnering and a licensed school psychologist in private practice who has presented on the topic of ASD and sexuality at local ASD organizations reviewed the Round 2 Questionnaire codes.

The second way that my personal biases were addressed was by including all emergent themes proposed by participants in Round 1. This ensured that I was not only selecting themes that supported my own personal beliefs.

I also was careful in my analytic process to ensure that I did not develop biases towards a particular group or respondent. For my initial coding, I analyzed participant responses separately from demographic information to ensure that I was not unintentionally biasing myself towards a particular response group. I analyzed separate group responses only after my initial coding and analysis was complete.

Limitations. There were foreseeable limitations to using the Delphi method for this study including the quality of experts, attrition, and researcher bias. These potential limitations were taken into consideration and addressed so as to minimize their impact.

Quality of experts. Firstly, the quality of the expert panel directly impacts the credibility and generalizability of the results in Delphi studies. To address this limitation, stringent inclusionary and exclusionary factors were developed to ensure that a high caliber of experts were recruited for participation. Refer to Table 2 for group inclusionary and exclusionary criteria.

Attrition. Another possible limitation addressed prior to recruitment was participant dropout. The Delphi method is an iterative process that requires participants to answer several rounds of questionnaires. To protect against attrition, care was taken to ensure that each round of questionnaires took less than 30 minutes to complete. Additionally, it was initially proposed that more than 20 experts would be recruited to participate in Round 1 so that even with a 50% dropout rate, 10 expert responses in Round 3 would still be collected. Taylor-Powell (2002) states that 10 responses is an acceptable number for a Delphi study. After approximately two months of extensive recruitment, a total of 15 experts participated in Round 1. Due to time limitations and difficulty recruiting respondents, recruitment was discontinued after 15 participants responded to the Round 1 Questionnaire. This allowed for a 33% attrition rate in order to maintain the 10 response minimum during Round 3.

Initial recruitment of participants was challenging. Of the 26 respondents who began the Round 1 Questionnaire, 15 completed it (58%). Of the three respondent groups, families had the highest attrition in the Round 1 recruitment phase with 60% ($n=3$) of potential respondents beginning, but not completing, the initial survey. The school psychologist group had 40% ($n=4$) of potential respondents begin, but not

complete, Round 1 and the ASD and sexuality author group had 22% ($n=2$) of potential respondents begin, but not complete, Round 1. Additionally, two unknown individuals began the initial survey, did not provide any demographic information, and did not complete Round 1. Initial recruitment resulted in a total of 42% ($n=11$) of potential respondents beginning, but not completing, the initial Round 1 survey and 58% ($n=15$) of respondents completing Round 1 and participating in this study.

The steps taken to limit attrition of respondents who participated in this study were successful; all 15 participants completed Rounds 1 and 2 and only one participant dropped out of the Round 3 survey resulting in a 7% attrition rate and a 93% response rate.

Bias. In any qualitative study, researcher bias can impact the interpretation of study results. It is impossible for a researcher to truly be unbiased. There are differing opinions in the field as to the values or limitations that the researcher brings to qualitative research. Borman, LeCompte, and Goetz (1984) suggest that personal and analytic discipline, including triangulation of data and consultation with outside researchers, prevent researchers from “speaking exclusively from their own subjective perceptions.” I maintain that my own expertise in ASD and sexuality education as well as my personal history of working in the reproductive and sexuality education field was a strength, rather than a limitation, in this study. There are few individuals who are willing or able to identify as experts in the area of sexuality education for high functioning adolescents with ASD; my background has established me as an expert in an under researched field. When coding participant responses, developing survey items, and extracting themes from

the data I was able to use my expertise in the field to compare, contrast, and assimilate data generated in this study to existing research, standards, and resources. By purposefully setting aside time for detachment, recruiting third parties to review codes and interpretation, and triangulating my data per the recommendations of Borman, LeCompte, and Goetz (1984) I took care to address any deleterious impact that my personal biases might have had on data analysis.

Sexuality Education for Students with ASD Guidelines

Based on the results of the three iterative rounds of questionnaires, key components necessary for a comprehensive sexuality education curriculum for high functioning adolescents with ASD were extracted and compiled as guidelines. These guidelines will serve to inform the future development of sexuality education curricula for high functioning students with ASD and also function as standalone strategies for use by parents of professionals who work with high functioning students with ASD.

Chapter Four: Results

The results of this study ultimately resulted in the creation of the *Guidelines for Developing Sexuality Education Curricula for High Functioning Adolescent Students with Autism Spectrum Disorder*. In this section, results of the Round 1, Round 2, and Round 3 Questionnaires will be discussed individually. Next, the final outcome of the study, the *Guidelines for Developing Sexuality Education Curricula for High Functioning Adolescent Students with Autism Spectrum Disorder* will be presented. Finally, individual group analysis will be explored to determine significant differences between the ASD and sexuality authors, school psychologist, and caregiver groups.

Round 1 Results

In Round 1 participants were asked to provide as many suggestions as possible for a list of questions that were developed from extant research, existing sexuality standards for typically developing students, and the research questions for this study. Recruitment efforts resulted in 26 respondents who began the Round 1 Questionnaire and 15 respondents (58%) who completed the Round 1 Questionnaire in its entirety. The Round 1 Questionnaire is provided in Appendix G.

The Round 1 items were categorized in three categories: content, delivery, and responsibilities. The content category consisted of questions specific to what material and subjects should be covered in a sexuality education curriculum for high functioning adolescents with ASD. The delivery category consisted of questions specific to what

types of environments, teaching and learning strategies, and methods to measure mastery of knowledge and skill would be best suited for use in a sexuality education curriculum for high functioning adolescents with ASD. The responsibilities category consisted of questions specific to who should be providing this curriculum and the roles of families and schools in the delivery of sexuality education to high functioning students with ASD. The Round 1 Questionnaire was designed to generate ideas from the expert participants; therefore, participants were asked to type in a text response to each question or prompt.

Round 1 Content Results. The content portion of the Round 1 Questionnaire first provided participants with the following statement that included the seven core topic areas suggested for inclusion in neurotypical sexuality education curricula by the *National Sexuality Education Standards* (Future of Sex Education, 2012):

It is suggested that comprehensive sexuality education curricula for general education students include the following seven topics: anatomy and physiology; puberty and adolescent development; identity; pregnancy and reproduction; sexually transmitted diseases and HIV; healthy relationships; and personal safety. Within each of these topic areas are educational goals. For example, an educational goal in the pregnancy and reproduction topic is that a student knows how to describe the signs of pregnancy by the end of 12th grade.

Participants were then asked to provide responses to the questions: are there additional topics that should be included in sexuality education curricula for high functioning students with ASD; if so, what topics should be added; and, what specific educational goals should be included in a sexuality education curriculum for high functioning adolescents with ASD within the topic areas of anatomy and physiology, puberty and adolescent development, identity, pregnancy and reproduction, sexually transmitted diseases and HIV, healthy relationships, personal safety, and other. Participants were

asked to provide suggestions for additional topics that should be included in the content of a sexuality education curriculum for high functioning students with ASD.

Additionally, participants were asked to agree or disagree and provide their reasoning to the question “should a sexuality education curriculum designed for high functioning adolescents with ASD differ from sexuality education curricula designed for general education students?”

Differences for students with ASD. Of the 15 participants that responded to the question regarding whether or not sexuality education curricula for students with ASD should differ from the general education sexuality education curricula, 100% agreed that there should be a difference. Participant responses were coded into five themes on how sexuality education for high functioning students with ASD and sexuality education for general education students should differ: social learning, addressing sensory differences, legal issues, individualized needs specific to ASD, and greater depth.

Social learning. Fifty percent of participants provided statements that were coded under the theme of social learning. The social learning theme encompasses statements that indicate students with ASD require explicit instruction on perspective taking, appropriate interpersonal skills, social communication, and social thinking when learning about sexuality. Coded data units in this theme also indicate comparative deficits in social learning and skills in comparison to their peers. One participant succinctly stated, “More instruction needed in social aspects. They aren't learning from peers.”

Individualized needs specific to ASD. Fifty percent of participants provided statements that were coded under the theme of individualized needs specific to ASD.

This theme addresses the learning differences associated with an ASD diagnosis such as anxiety related to change, the need for concrete instruction due to difficulty making inferences, a tendency towards a visual learning style, and individual differences that comprise the entire spectrum of ASD.

Address sensory differences. Twenty-one percent of participants provided statements that were coded under the theme of address sensory differences. This theme acknowledges that students with ASD might have sensory differences and respond best to multisensory teaching, and that sexuality education curricula for students with ASD should specifically address how to prepare for how the sensory components of sex and sexuality might impact an individual or their partner.

Greater depth. Twenty-one percent of participants provided statements that were coded under the theme of greater depth, which was explained as a need for more time spent fostering a deeper understanding of the material provided to students with ASD.

Legal issues. Seven percent of participants provided statements that were coded under the theme of legal issues. One participant stated that explicit “education in law and legal consequences” is needed for students with ASD and provided the example that students with ASD “may not fundamentally understand what child pornography is, why it is unethical, and why child pornography is illegal.”

Additional topics. Fifty-seven percent of participants believed that there should be additional topics included in sexuality education curricula for high functioning students with ASD. Participant responses were coded and four themes emerged from these data as topics to include in sexuality education curricula for high functioning

students with ASD: legal issues, social aspects, knowledge of different sex acts and use of common slang, and sensory needs.

Social aspects. Fifty-seven percent of participants provided statements that were coded under the theme of “social aspects.” The social aspect theme addresses communication, how to appropriately initiate a responsible romantic relationship, and the social aspects of sexuality education topics such as sexual decision-making. Coded data units in this theme include statements such as,

How to initiate a responsible relationship with a romantic partner. Many students with ASD may be interested in pursuing a relationship but lack the social skills to do so in an appropriate way. Students may come across as blunt to others and may need direct instruction on how to pursue an appropriate romantic relationship without getting into trouble.

Legal issues. Fifty percent of participants provided statements that were coded under the theme of “legal issues.” The legal issues theme includes addressing consent, privacy, stalking, legal consequences, and criminal behavior such as coercion, illegal sexual images, and inappropriate public behavior from both an offender and victim perspective. Coded data units that fall within this theme include “students need to be made aware of what ‘illegal’ means, as well as be taught what is legal and what is not” and “Criminal behavior- illegal sexual images, coercion, consent, stalking. These things may fall into ‘safety’ but are not typically addressed in the thoroughness needed for kids with ASD.”

Sensory needs. Fourteen percent of participants provided statements that were coded under the theme of “sensory needs.” The sensory needs theme addresses “management of sensory sensitivities” as well as “identifying and coping with sensory sensitivities in relationships.”

Knowledge of different sex acts and use of common slang. Seven percent of participants provided statements that were coded under the theme of “knowledge of different sex acts and use of common slang.” Only one statement was coded under this theme, and it was included so that in the Round 2 Questionnaire other expert participants could provide feedback on whether or not it should be included as an additional sexuality education topic. The participant who provided this statement stated that “details of the sexual acts themselves not just reproduction” and “rules about sexual behaviors such as masturbation (privacy etc.) as this is a 'hidden curriculum' for those with ASD” should be included in sexuality education curricula for students with ASD.

Round 1 Delivery Results. The delivery portion of the Round 1 Questionnaire began with the statement “due to the nature of their diagnoses, high functioning adolescents with ASD often learn best when certain strategies, environments, and needs are taken into consideration.” Participants were asked to provide responses to the following questions: what would an ideal school environment for teaching high functioning adolescent students with ASD look like, what types of strategies would be most useful in teaching students with high functioning ASD about sexuality, and what would be an appropriate way to measure the mastery of a skill taught in a sexuality

education curriculum for high functioning adolescents with ASD. Responses to each question were analyzed and themes were developed based on coded responses.

School environment. This question asked, “What would an ideal school environment for teaching high functioning adolescent students with ASD look like?” Five themes emerged from this question prompting experts to describe an ideal school environment for teaching high functioning students with ASD. These themes are: small group, a mixture of students with ASD and neurotypical peers, supportive classroom

Table 10

Round 1 Delivery: School Environment Themes

Theme	Percentage	Description
Small group	40%	An ideal school environment would utilize small groups
Supportive classroom culture	33%	An ideal school environment would have a small student to teacher ration; be open, accepting, and understanding of students; and have supportive individuals present to discuss topics with
Modified environment	33%	An ideal school environment will limit environmental distractions and address sensory needs of students
Mixture of students with ASD and neurotypical peers	20%	An ideal school environment would integrate high functioning students with ASD with their neurotypical peers when teaching sexuality education
Delivery recognizes individual needs	20%	An ideal school environment will deliver content to meet the individualized needs of high functioning students with ASD (e.g., using visuals, movies, slower pacing)

Note. Themes derived from participant responses to the question, “What would an ideal school environment for teaching high functioning adolescent students with ASD look like?”

culture, modified environment, and delivery that recognizes individual needs. A summary of the codes for this question is provided in Table 10.

Strategies. This question asked, “What types of strategies would be most useful in teaching students with high functioning ASD about sexuality?” Sixteen themes emerged from participant responses: examples; role play; use of visuals; discussion; direct, detailed, honest explanations; parent involvement; break down information into steps; practice; memorization; student led research; projects; use of breaks; establish

Table 11

Round 1 Delivery: Strategies Themes

Theme	Percentage	Description
Direct, detailed, honest explanations	40%	Presenting factual information in an honest, detailed, concrete, and specific way and answering all student questions honestly
Role play	33%	Role play (e.g., practicing interactions such as asking someone on a date)
Use of visuals	33%	Use of visuals such as videos, video games, and virtual reality
Examples	21%	Using many examples including real life examples and nonexamples
Discussion	20%	Allowing time for discussions on complex topics
Projects	13%	Hands on learning

Repetition	13%	Repetition of concepts
Teach from multisensory perspective	13%	Teachers should address student needs by modifying the environment to address specific sensory needs
Parent Involvement	7%	Parents should be involved in the curriculum when appropriate
Break down information into steps	7%	Information should be broken down into steps; ensure mastery before moving on to the next step
Practice	7%	Opportunities for students to practice and be provided with feedback
Memorization	7%	Students should memorize basic, rote information
Student led research	7%	Students should research information
Use of breaks	7%	Give students regular breaks
Establish boundaries	7%	Address the rules and boundaries of the class
Multiple modes of learning	7%	Students should be taught through multiple modes of instruction

Note. Themes derived from participant responses to the question, “What types of strategies would be most useful in teaching students with high functioning ASD about sexuality?”

boundaries; repetition; teach from multisensory perspective; and, multiple modes of learning. A summary of the codes for this question is provided in Table 11.

Measuring mastery. This question asked, “What would be an appropriate way to measure the mastery of a skill taught in a sexuality education curriculum for high functioning adolescents with ASD?” Eight themes emerged from participant responses to this question: quiz/test; project; role play; practical assignments; class discussion; parent/teacher report of life events; oral/written observations; and, increase of desired behaviors/decrease of problem behaviors. A summary of the codes for this question is provided in Table 12.

Round 1 Responsibilities Results. The responsibilities portion of the Round 1 Questionnaire began with the statement,

Children learn about sexuality from a variety of places and people. Ideally, the majority of what students learn about sexuality would come from a combination of their family and their school. Sometimes sexuality education curricula are intentional in how they involve the school, student, and family. For example, some curricula use family homework activities that require the student and their caregiver to complete an assignment together addressing what was covered in sexuality education class that day.

Participants were asked to provide responses to the following questions: what should the role of the school be in the sexuality education of high functioning adolescent students with ASD, what people within the school should be responsible for the sexuality education of high functioning adolescent students with ASD, what should the role of the

family be in the sexuality education of high functioning adolescent students with ASD, and how can schools and families partner to provide effective sexuality education for high functioning adolescent students with ASD. Responses to each question were analyzed and themes were developed based on coded responses.

Table 12

Round 1 Delivery: Measuring Mastery Themes

Theme	Percentage	Description
Quiz/Test	47%	Accurately answering questions via a typical quiz or test format or nonverbal assessment
Practical assignments	27%	Assignments requiring action such as practicing putting on a condom or completing steps to make a new friend
Role play	20%	Performance based measures through role play (e.g., role playing social skills, conversations)
Project	13%	Completion of an end project (e.g., presentation, paper, hands on activity) that is measured by a rubric
Class discussion	7%	Measuring mastery by class discussion
Parent/teacher report of life events	7%	Teacher and parent report of real life events experienced by the student
Oral/written explanations	7%	The student is able to provide oral or written explanations on a specific topic as measured by a rubric
Increase of desired behaviors/ decrease of problem behaviors	7%	An observed increase in target desired behaviors and a reduction of problematic behavior in real life

Note. Themes derived from participant responses to the question, “What would be an appropriate way to measure mastery of a skill taught in a sexuality education curriculum for high functioning adolescents with ASD?”

Role of school. This question asked, “What should the role of the school be in the sexuality education of high functioning adolescent students with ASD?” Five themes emerged from participant responses to this question: teach sex ed; parent school collaboration; adapt curriculum to meet student needs; address specific sex ed needs in IEP; and, provide a safe environment for learning. A summary of the codes for this question is provided in Table 13.

Table 13

Round 1 Responsibilities: Role of School Themes

Theme	Percentage	Description
Teach sex ed	79%	Schools should teach comprehensive sexuality education to students with ASD
Parent school collaboration	33%	The school should have a collaborative relationship with families where family needs are identified and the school provides information and support
Adapt curriculum to meet student needs	33%	The school should present sexuality education information to students with ASD in the most appropriate manner which may involve modification
Address specific sex ed needs in IEP	7%	If testing done by the school, or if IEP goals, indicate that a student has weaknesses in social skills, understanding non-verbal communication, pragmatic language and/or perspective taking then the student will need further supports to understand and access sexuality education
Provide a safe environment for learning	7%	Schools should provide a safe space for students to express their thoughts, ideas, and discomforts surrounding sexuality.

Note. Themes derived from participant responses to the question “What should the role of the school be in the sexuality education of high functioning adolescent students with ASD?”

School providers. This question asked, “What people within the school should be responsible for the sexuality education of high functioning students with ASD?”

Participants identified ten school-based professional roles that should be responsible for the sexuality education of high functioning students with ASD: health teacher; special education teacher; school psychologist; school nurse; general education teacher; school counselor; school social worker; principal; speech language pathologist; and, case manager. A summary of the percentage of participants who identified each role is provided in Table 14.

Table 14

Round 1 Responsibilities: School Providers

Provider	Percentage
Special Education Teacher	60%
Health Teacher	53%
School Psychologist	47%
School Nurse	33%
General Education Teacher	27%
School Counselor	27%
School Social Worker	13%
Principal	7%
Speech Language Pathologist	7%
Case Manager	7%

Note. Themes derived from participant responses to the question, “What people within the school should be responsible for the sexuality education of high functioning students with ASD?”

Role of family. This question asked, “What should the role of the family be in the sexuality education of high functioning adolescent students with ASD?” Nine themes emerged from participant responses to this question: reinforcing school curriculum; teach family values/personal beliefs; facilitate/foster sex ed discussions with child; primary sex

Table 15

Round 1 Responsibilities: Role of Family

Theme	Percentage	Description
Reinforce school curriculum	47%	Families should reinforce, build on, and/or supplement the sexuality education content is taught in the schools
Teach family values/ Personal beliefs	27%	Families should share their family beliefs regarding sexuality with their child; how their family values, culture, and religion help shape those beliefs; and aid in their child's development of their personal beliefs
Facilitate/ Foster sex ed discussions with child	33%	Families should be open to discussion with their children about sexuality, relationships, and any questions the child has regarding these topics
Primary sex ed role	20%	Families should be the primary sexuality educators of their children
Awareness of school curriculum	20%	Families should be aware of what their child is learning about sexuality education from the school
Provide consent	13%	Families should be able to opt out of their child receiving sexuality education from the school
Share child's needs with school	7%	Families should inform the school of their child's sexuality education needs
Team with school	7%	Families should be a part of a team with the school
Complete assignments	7%	Families should be actively involved in their child's sexuality education curriculum by completing assignments

Note. Themes derived from participant responses to the question, "What should the role of the family be in the sexuality education of high functioning adolescent students with ASD?"

ed role; awareness of school curriculum; provide consent; and share child’s needs with school. A summary of the codes for this question is provided in Table 15.

Family school partnering strategies. This question asked, “How can schools and families partner to provide effective sexuality education for high functioning adolescent students with ASD?” Nine themes emerged from participant responses to this question: two-way communication; allow parents to preview/discuss curriculum; involvement on
Table 16

Round 1 Responsibilities: Family School Partnering Strategies

Theme	Percentage	Description
Two-way communication	53%	Schools and families should have an open, active dialogue that encourages questions and discussion
Allow parents to preview/discuss curriculum	33%	Schools should inform families of the sexuality education curriculum that will be utilized (e.g., introduction at parent-school meeting, send home sample lessons, permit families to preview)
Provide parent education	13%	School should educate families about the sexuality education needs of students with ASD (e.g., bring in a speaker, specific parent component to the curriculum)
Involvement on sex education projects	7%	Families should be involved in school sexuality education projects
Share resources	7%	Schools should share resources such as handouts and community/online resources with families
Teaming	7%	Teaming should occur between the families and the school-based team involved in the sexuality education of the student

Reinforce what is learned at home	7%	Families should reinforce what is learned in the school-based curriculum at home
Include in IEPs	7%	Sexuality education needs for students with ASD should be included in a student's Individualized Education Programs (IEP)
Co-develop goals	7%	Families and schools should partner to discuss the baseline of understanding, agree on goals, and collaborate to accomplish those goals

Note. Themes derived from participant responses to the question, “How can schools and families partner to provide effective sexuality education for high functioning adolescent students with ASD?”

sex education projects; share resources; provide parent education; teaming; reinforce what is learned at home; include in IEPs; and co-develop goals. A summary of the codes for this question is provided in Table 16.

Round 2 Results

The Round 2 Questionnaire was developed based on the responses from the Round 1 Questionnaire. All themes that were extracted from Round 1 Questionnaire data were presented in a question or statement format in Round 2. In some instances, multiple themes from Round 1 were combined into one statement in order to reduce the length of the Round 2 Questionnaire.

There was 0% attrition in Round 2; all 15 expert participants responded. The themes that were developed in Round 1 were used to develop all items in Round 2. Participants were asked to either agree or disagree with the themes that emerged from Round 1. Participants were also able to add their comments and feedback in the questionnaire. The Round 2 Questionnaire is provided in Appendix J.

The Round 2 Questionnaire was analyzed by assessing the agreeableness for each item. Items that had over 80% of participants select “Agree” were used in the development of Round 3 Questionnaire. Items that had less than 80% of participants select “Agree” were not used in the development of the Round 3 Questionnaire or in the final version of the *Guidelines for Developing Sexuality Education Curricula for High Functioning Adolescent Students with Autism Spectrum Disorder*. Participant comments and feedback were reviewed and utilized in the development of the Round 3 Questionnaire. Table 17 shows the percentage of agreeableness for each item on the Round 2 Questionnaire.

Table 17

Round 2: Item Agreeability

Item	Item text	Agree	Disagree
Content			
1.	Sexuality education curriculum designed for high functioning adolescents with ASD should differ from sexuality education curricula designed for general education students by addressing sensory differences including aspects of social learning, emphasizing legal issues, going into greater depth within each topic, and discussing the impact that Autism Spectrum Disorder can have on sexuality and romantic relationships.	93%	7%
<i>Sexuality education curricula for high functioning students with ASD should include the following comprehensive sexuality education topics that are taught in general education curricula:</i>			
2.	Anatomy and Physiology: this topic provides a foundation for understanding basic human functioning and specifically should include understanding the functions and names of internal and external reproductive anatomy, stages of human sexual response, genital health, and preventative health strategies (e.g., breast exams, testicular exams).	100%	0%

3.	Puberty and Adolescent Development: this topic addresses the impact puberty has on physical, social, and emotional development and should specifically include physiological, hormonal, and emotional changes, neurodevelopment, and common experiences of adolescents.	100%	0%
4.	Identity: this topic addresses developing an awareness and understanding of one's self and should specifically include gender identity, sexual orientation, awareness of discrimination based on sexual or gender identity, knowledge of local resources to support gender identity or sexual orientation differences, and socio-political current events/rights.	100%	0%
5.	Pregnancy and Reproduction: this topic addresses how pregnancy happens and should specifically include understanding the signs of pregnancy, awareness of the stages of pregnancy, what to do if you think you or your partner might be pregnant, how to prevent pregnancy, and the responsibilities that come with having a child.	100%	0%
6.	Sexually Transmitted Diseases (STDs) and HIV: this topic addresses knowledge of what STDs/HIV are, how they are transmitted, and how to prevent them and should also include developing awareness of the symptoms and signs of STDs/HIV, social stigmas surrounding STDs/HIV, how to get tested for an STD/HIV, and community resources available for assistance in the testing, treatment, and prevention of STDs/HIV.	100%	0%
7.	Healthy Relationships: this topic addresses how to successfully navigate relationships among family, peers, and partners and should specifically include an understanding of different types of relationships, what constitutes a healthy and unhealthy relationship, how to identify a relationship that is unhealthy, qualities to look for in relationship partners, acknowledging that it is ok to not want a romantic relationship, and understanding different components of intimacy.	100%	0%
8.	Personal Safety: this topic should address self-advocacy, establishing and respecting boundaries, assertiveness, prevention of abuse, and dangers specific to the Internet.	100%	0%

In addition to the seven sexuality topics taught in general education curricula, sexuality education curricula for high functioning students with ASD should also include the following topics:

9.	Legal Issues: This topic includes educating students about consent, appropriate versus inappropriate behavior, defining “illegal”, and criminal behavior including illegal sexual images, coercion, rape, molestation, and stalking.	100%	0%
10.	Social Aspects of Sexuality and Romantic Relationships: This topic includes social norms, communication, dating/establishing a romantic relationship, sexual decision making, boundaries, and abuse awareness.	100%	0%
11.	Knowledge of Different Sex Acts and Use of Common Slang: This topic includes developing awareness of common colloquialisms and slang terms for sexual acts as well as an understanding of what various sexual acts involve (e.g., anal sex, masturbation, oral sex).	100%	0%
12.	Sensory Needs: This topic includes identifying, coping with, and discussing sensory sensitivities within the context of a romantic relationship.	100%	0%

Delivery

The ideal school environment for teaching high functioning adolescent students with ASD would include the following elements:

13.	Small group instruction	93%	7%
14.	A mixture of students with ASD and neurotypical peers	80%	20%
15.	A supportive classroom culture including a small student teacher ration, supportive individuals to discuss topics with, open and accepting teacher-student and peer-to-peer relationships, and respect for individual learning styles	100%	0%
16.	A modified environment that limits distractions, addresses sensory needs, and incorporates breaks	93%	7%

Strategies that would be useful in teaching high functioning students with ASD about sexuality include the use of:

17.	Visuals (e.g., video, pictures, charts, graphs)	100%	0%
18.	Examples	100%	0%
19.	Role Play	87%	13%
20.	Class Discussion	100%	0%

21.	Direct, detailed, and honest explanations	100%	0%
22.	Parent Involvement	100%	0%
23.	Breaking down information into measurable steps	100%	0%
24.	Practice	87%	13%
25.	Rote Memorization	47%	53%
26.	Repetition	100%	0%
27.	Student led research	80%	20%
28.	Project based learning	80%	20%
<hr/>			
<i>The best ways to measure mastery of skills taught in a sexuality education curriculum for high functioning adolescents with ASD include the following:</i>			
29.	Quizzes/Tests	40%	60%
30.	Completion of projects	80%	20%
31.	Role Play	80%	20%
32.	Practical Assignments (e.g., how to put on a condom)	93%	7%
33.	Class discussion	87%	13%
34.	Parent/teacher report of life events	87%	13%
35.	Oral/written explanations following a rubric (e.g., answering questions about specific scenarios)	80%	20%
36.	Increase of desired behaviors/decrease of problem behaviors	100%	0%
<hr/>			
Responsibilities			
<hr/>			
<i>What should the role of the school be in the sexuality education of high functioning adolescent students with ASD?</i>			
37.	Schools should teach sexuality education to high functioning adolescent students with ASD	100%	0%
38.	Schools should engage in parent collaboration when educating high functioning adolescent students with ASD about sexuality	100%	0%
39.	Schools should adapt sexuality education curricula to meet the needs of students with ASD	93%	7%
40.	Schools should provide a safe environment for learning about sexuality	100%	0%
<hr/>			
<i>Please check the box for each school-based professional who you believe should be responsible for the sexuality education of high functioning students with ASD.</i>			

41.	Health Teacher	87%	
42.	School Nurse	67%	
43.	Special Education Teacher	87%	
44.	School Psychologist	87%	
45.	General Education Teacher	7%	
46.	School Counselor	60%	
47.	Principal	0%	
48.	School Social Worker	80%	
49.	Speech Language Pathologist	33%	
50.	Case Manager	47%	
<hr/>			
<i>Families should have the following roles in the sexuality education of their high functioning children with ASD:</i>			
51.	Reinforce at home what is being taught in the school curriculum	100%	0%
52.	Teach family values and personal beliefs surrounding sexuality	87%	13%
53.	Be the primary sexuality educators of their children	67%	33%
54.	Facilitate/foster sexuality education discussions with their child	100%	0%
55.	Be aware of the school sexuality education curriculum (or lack of one)	100%	0%
56.	Provide consent for their children to participate in sexuality education	80%	20%
57.	Share their child's specific needs surrounding sexuality education with the school	100%	0%
58.	Team with the school	100%	0%
59.	Complete assignments from the sexuality education curriculum being taught in the school	80%	20%
<hr/>			
<i>Families and schools can partner to provide effective sexuality education for high functioning adolescent students with ASD by:</i>			
60.	Having effective two-way communication	100%	0%
61.	Allowing parents to preview and/or discuss the sexuality education curriculum that will be taught	93%	7%
62.	Encouraging family involvement on sexuality education projects	100%	0%
63.	Sharing of resources	100%	0%

64.	The school can provide parent education on the topic of the sexuality education needs of students with ASD	100%	0%
65.	Families and the school can co-develop goals for the sexuality education of high functioning adolescent students with ASD	93%	7%

Note. Items in italics refer to the questions or statements shown to participants in the Round 2 Questionnaire.

Results from Round 2 indicated that out of 65 items the expert participants reached 100% agreeability consensus on 32 (59%) of the items. Of the 32 of items that did not have 100% consensus amongst participants, only nine items were met with less than 80% consensus. In total, experts reached 80% or more agreement on 56 of 65 items (86%) and did not reach at least 80% agreement on 14% of items. The items with less than 80% agreeability included using rote memorization as a strategy for teaching high functioning adolescent students with ASD about sexuality (47% of participants agreed), the use of quizzes and tests as a way to measure mastery (40% of participants agreed), and that families should be the primary sexuality educators of their high functioning adolescent with ASD (67% of participants agreed). Additionally, regarding school professionals' best suited for providing sexuality education to high functioning students with ASD, only 7% of participants selected "general education teacher," 33% selected "speech language pathologist," 47% selected "case manager," 60% selected "school counselor," and 67% selected "school nurse."

Round 3 Results

The Round 3 Questionnaire required the expert participants to read statements developed from items in the Round 2 Questionnaire that had 100% consensus and to either agree or rewrite statements developed from items from the Round 2 Questionnaire

that had less than 100% but more than 80% consensus. The Round 3 Questionnaire is provided in Appendix K.

There was 7% attrition in Round 3; one member of the parent group did not complete the Round 3 Questionnaire. A total of 14 participants completed the Round 3 Questionnaire: 7 ASD and sexuality authors, 6 school psychologists, and 1 parent.

Round 3 Content Results. There were 11 statements developed for the Content section of the Round 3 Questionnaire that were created from items with 100% consensus in Round 2. Participants were permitted to review, but not provide feedback on, all of these 11 Content statements. One statement was developed for the Round 3 Content section based on items with less than 100% but more than 80% consensus in the Content section of Round 2. In Round 3, participants were asked to either agree with or rewrite this one Content statement.

Round 3 content statements for participant review. Statements that were developed from Round 2 items with 100% consensus were provided for participants review. Participants were not able to provide feedback or comments on these statements:

Sexuality education curricula for high functioning students with ASD should include the following topics.

1. **Anatomy and Physiology:** this topic provides a foundation for understanding basic human functioning and specifically should include understanding the functions and names of internal and external reproductive anatomy, stages of human sexual response, genital health, and preventative health strategies (e.g., breast exams, testicular exams).

2. Puberty and Adolescent Development: this topic addresses the impact puberty has on physical, social, and emotional development and should specifically include physiological, hormonal, and emotional changes, neurodevelopment, and common experiences of adolescents.
3. Identity: this topic addresses developing an awareness and understanding of one's self and should specifically include gender identity, sexual orientation, awareness of discrimination based on sexual or gender identity, knowledge of local resources to support gender identity or sexual orientation differences, and socio-political current events/rights.
4. Pregnancy and reproduction: this topic addresses how pregnancy happens and should specifically include understanding the signs of pregnancy, awareness of the stages of pregnancy, what to do if you think you or your partner might be pregnant, how to prevent pregnancy, and the responsibilities that come with having a child.
5. Sexually Transmitted Infections (STIs) and HIV: this topic addresses knowledge of what STIs/HIV are, how they are transmitted, and how to prevent them and should also include developing awareness of the symptoms and signs of STIs/HIV, social stigmas surrounding STIs/HIV, how to get tested for an STIs/HIV, and community resources available for assistance in the testing, treatment, and prevention of STIs/HIV.
6. Healthy relationships: this topic addresses how to successfully define and navigate relationships among family, peers, and partners and should specifically

include an understanding of different types of relationships, what constitutes a healthy and unhealthy relationship, how to identify a relationship that is unhealthy, qualities to look for in relationship partners, acknowledgement that it is ok to not want a romantic relationship, and understanding different components of intimacy.

7. Personal safety: this topic should address self-advocacy, establishing and respecting boundaries, assertiveness, prevention of abuse, and dangers specific to the Internet.
8. Legal Issues: This topic includes educating students about consent, appropriate versus inappropriate behavior, defining “illegal”, and criminal behavior including illegal sexual images, coercion, rape, molestation, and stalking.
9. Social Aspects of Sexuality and Romantic Relationships: This topic includes social norms, communication, dating/establishing a romantic relationship, sexual decision-making, boundaries, and abuse awareness.
10. Knowledge of Different Sex Acts and Use of Common Slang: This topic includes developing awareness of common colloquialisms and slang terms for sexual acts, developing an understanding that slang terms change over time, identifying appropriate resources to utilize to get more information, and developing an understanding of what various sexual acts involve (e.g., anal sex, masturbation, oral sex).
11. Sensory Needs: This topic includes identifying, coping with, and discussing sensory sensitivities; developing an awareness that sensory needs vary from

person to person; and understanding how sensory needs can impact a romantic relationship.

Round 3 content statements for participant feedback. Statements that were developed from Round 2 items with less than 100% consensus but more than 80% consensus were provided to participants for feedback. In the content section, there was one statement that required further participant feedback. Participant feedback in Round 2 was utilized and integrated when developing the Round 3 content statement. Participants were asked to either agree or disagree with the statement. If participants disagreed with the statement, they were asked to rewrite the statement as they believe it should be written by copying and pasting the text into a text box and directly editing it. The Round 3 content statement presented to participants to be rewritten and the percentage of participants that agreed or disagreed is provided in Table 18.

Table 18

Round 3 Content: Statements for Participant Feedback

Statement	Agree	Rewrite Required	Participant Responses
Sexuality education curricula designed for high functioning adolescents with ASD should differ from sexuality education curricula designed for general education students by: including aspects of social learning; emphasizing legal issues; addressing sensory differences in one’s self and in others; going into greater depth within each topic area; and discussing the impact that an Autism Spectrum Disorder, including cognitive and social differences, may have on sexuality and romantic relationships	50%	50%	14

Round 3 Delivery Results. There were three statements developed for the Delivery section of the Round 3 Questionnaire that were developed from items with

100% consensus in Round 2. Participants were permitted to review, but not provide feedback on, all of these three Delivery statements. Six statements were developed for the Round 3 Delivery section based on items with less than 100% but more than 80% consensus in the Delivery section of Round 2. In Round 3, participants were asked to either agree or rewrite these six Delivery statements.

Round 3 delivery statements for participant review. Statements that were developed from Round 2 Delivery items with 100% consensus were provided for participants' review. Participants were not able to provide feedback or comments on these statements:

1. Although every student has unique needs, some general guidelines for developing a supportive classroom environment for implementing a sexuality education curriculum for high functioning students with ASD include: a small student teacher ratio, supportive individuals to discuss topics with, open and accepting teacher-student and peer-to-peer relationships, and respect for individual learning styles.
2. Some strategies that would be useful in teaching high functioning students with ASD about sexuality include the use of visuals (e.g., video, pictures); using real-world examples; class discussion; repetition; direct, detailed and honest explanations; parent involvement; and breaking down information into measurable steps.
3. An effective way to measure the mastery of skills taught in a sexuality education curriculum for high functioning adolescents with ASD is family or school-based

professional observation of an increase in desired behaviors and a decrease of problem behaviors.

Round 3 delivery statements for participant feedback. Statements that were developed from Round 2 delivery items with less than 100% consensus but more than 80% consensus were provided to participants for feedback. In the delivery section, there were six statements that required further participant feedback. Participant feedback in Round 2 was utilized and integrated when developing the Round 3 delivery statements. Participants were asked to either agree or disagree with each statement. If participants disagreed with a statement, they were asked to rewrite the statement as they believe it should be written by copying and pasting the text into a text box and directly editing it. The Round 3 delivery statements presented to participants to be rewritten and the percentage of participants that agreed or disagreed is provided in Table 19.

Table 19

Round 3 Delivery: Statements for Participant Feedback

Item	Statement	Agree	Rewrite Required	Participant responses
1.	It is important to recognize individual student needs when providing a sexuality education curriculum to high functioning students with ASD. Individualized supports and differentiated instruction should be utilized whenever possible.	92%	8%	13
2.	Sexuality education curricula for high functioning students with ASD should be implemented in an environment that limits distractions, addresses sensory needs, incorporates breaks, and utilizes small group instruction when appropriate.	77%	23%	13
3.	In schools, a team of school-based professionals who understand ASD and who have positive relationships with the students	71%	29%	14

who they will be teaching should ideally provide a sexuality education curriculum for high functioning students with ASD.

School-based professionals who are particularly well suited for the delivery of sexuality education curriculum for high functioning students with ASD include health teachers, school psychologists, school social workers, and special education teachers.

4.	Additional strategies that can be useful in teaching high functioning students with ASD about sexuality include the use of role-play, student led research, project based learning, and practice.	71%	29%	14
5.	Including neurotypical peers in the sexuality education of high functioning students with ASD can be beneficial if done thoughtfully. It may not be appropriate to include neurotypical peers in every aspect of the curriculum as the delivery, pacing, and depth will be modified for students with ASD. Families and schools should discuss if, how, and when it might be appropriate to integrate high functioning students with ASD and their neurotypical peers in the context of a sexuality education curriculum.	86%	14%	14
6.	Measuring mastery of skills in a sexuality education curriculum for high functioning students with ASD can be difficult. There are a variety of strategies that can be appropriate for use in measuring skill acquisition such as role play, completion of projects, practical assignments (e.g., how to put on a condom), class discussion, parent/teacher report of life events; and oral/written explanations following a rubric. These strategies should be implemented with a highly structured plan and with plenty of guidance and support for the students. Ultimately, the goal is to have students be able to generalize what is learned in the curriculum to the real world.	93%	7%	14

Some participants did not provide a response to certain Round 3 Delivery items; that is, on items #1 and #2 one participant neither selected “agree” nor rewrote the statement as listed. This is reflected in the “Participant Responses” column in Table 20. The percentage of participants who agreed with each statement was calculated by dividing the number of “agree” responses with the total number of participants who provided an answer to that statement.

Round 3 Responsibilities Results. There were three statements developed for the Responsibilities section of the Round 3 Questionnaire that were developed from items with 100% consensus in Round 2. Participants were permitted to review, but not provide feedback on, all of these three Responsibilities statements. Five statements were developed for the Round 3 Responsibilities section based on items with less than 100% but more than 80% consensus in the Responsibilities section of Round 2. In Round 3, participants were asked to either agree or rewrite these five Responsibilities statements.

Round 3 responsibilities statements for participant review. Statements that were developed from Round 2 Responsibilities items with 100% consensus were provided for participants review. Participants were not able to provide feedback or comments on these statements:

1. Schools and families both have significant roles in the sexuality education of high functioning adolescent students with ASD. The sexuality education of high functioning adolescent students with ASD is most successful when schools and families partner and work together as a team. Examples of ways that schools and families can partner include engaging in effective two-way communication,

sharing resources (e.g., providers within the community who can provide additional support), and providing parent education trainings on the topic of the sexuality education needs of students with ASD.

2. Family involvement is a critical component of successful sexuality education curricula for high functioning students with ASD. Ideally, families should be aware of the school-based sexuality education curriculum (or lack of one), be able to reinforce what is being taught by the schools, facilitate/foster sexuality education discussions with their child, and share their child's specific needs surrounding sexuality education with the school.
3. Schools have a responsibility to teach sexuality education to high functioning adolescent students with ASD in a safe and effective learning environment.

Round 3 responsibilities statements for participant feedback. Statements that were developed from Round 2 responsibilities items with less than 100% consensus but more than 80% consensus were provided to participants for feedback. In the responsibilities section, there were five statements that required further participant feedback. Participant feedback in Round 2 was utilized and integrated when developing the Round 3 responsibilities statements. Participants were asked to either agree or disagree with each statement. If participants disagreed with a statement, they were asked to rewrite the statement as they believe it should be written by copying and pasting the text into a text box and directly editing it. The Round 3 responsibilities statements presented to participants to be rewritten and the percentage of participants that agreed or disagreed is provided in Table 20.

Table 20

Round 3 Responsibilities: Statements for Participant Feedback

Item	Statement	Agree	Rewrite Required	Participant Responses
1.	Schools should adapt sexuality education curricula to meet the needs of students with ASD.	86%	14%	14
2.	Allowing parents to preview and/or discuss the sexuality education curriculum that will be taught in the school and encouraging family involvement on sexuality education assignments that may occur during the curriculum are effective ways to develop a family-school partnership surrounding the sexuality education of high functioning students with ASD.	100%	0%	14
3.	Members of a student's individualized education plan (IEP) team, including the student's family, should specifically address the sexuality education needs of the student and, if appropriate, develop and include sexuality education goals within the Individualized Education Plan (IEP).	71%	29%	14
4.	Families are often the primary sexuality educators of their children. Sometimes, family values and personal beliefs surrounding sexuality may differ from what is being taught in a school-based curriculum. Regardless of what is being taught in the home, schools still have a responsibility to teach high functioning adolescents students with ASD about sexuality.	64%	36%	14
5.	Families may choose to withdraw consent for their child to participate in a sexuality education curriculum provided by the schools.	79%	21%	14

Final Outcome

The final outcome of this study was the creation of the *Guidelines for Developing Sexuality Education Curricula for High Functioning Adolescent Students with Autism Spectrum Disorder*. Miller (2006) states that if a certain percentage of responses fall within a desired range, consensus can be determined; Hsu and Stanford (2007) state that ultimately, the primary researcher has the ability to determine the criterion by which consensus will be measured. Due to the unique structure of Round 3 and the variability in the amount and significance of editing done to each Round 3 statement, it was determined that statements in which less than 70% consensus was obtained were either removed from the final guidelines or dramatically altered if participant comments suggested a common flaw. All Round 3 statements except for two, one in the Content section and one in the Responsibilities section, had at least 70% consensus amongst participants. The statement in the Content section that did not obtain at least 70% consensus was,

Sexuality education curricula designed for high functioning adolescents with ASD should differ from sexuality education curricula designed for general education students by: including aspects of social learning; emphasizing legal issues; addressing sensory differences in one's self and in others; going into greater depth within each topic area; and discussing the impact that an Autism Spectrum Disorder, including cognitive and social differences, may have on sexuality and romantic relationships.

The statement in the Responsibilities section that did not obtain at least 70% consensus was,

Families are often the primary sexuality educators of their children. Sometimes, family values and personal beliefs surrounding sexuality may differ from what is being taught in a school-based curriculum. Regardless of what is being taught in

the home, schools still have a responsibility to teach high functioning adolescents students with ASD about sexuality.

Items with more than 70% consensus were included in the final guidelines; participant rewritten statements were reviewed and integrated if appropriate in the final statements included in the final guidelines. Items with less than 70% consensus were not included in the final guidelines. A handout of the *Guidelines for Developing Sexuality Education Curricula for High Functioning Adolescent Students with Autism Spectrum Disorder* is provided in Appendix L.

Guidelines for Developing Sexuality Education Curricula for High Functioning Adolescent Students with Autism Spectrum Disorder (ASD). The following guidelines were developed by expert participants including researchers, authors, school psychologists, and parents of high functioning adolescent children with ASD. Most experts agreed that sexuality education curricula designed for high functioning adolescent students with ASD should be enhanced from sexuality education curricula designed for general education students. These guidelines are organized into three sections: content, delivery, and responsibilities. They are intended to help guide the development of sexuality education curriculum specifically designed for high functioning students with ASD and/or to aid in the modification of existing general education sexuality education curriculum to better address the individual needs of high functioning students with ASD.

Content. Sexuality education curricula for high functioning students with ASD should include the following topics.

- **Anatomy and Physiology:** this topic provides a foundation for understanding basic human functioning and specifically should include understanding the

functions and names of internal and external reproductive anatomy, stages of human sexual response, genital health, and preventative health strategies (e.g., breast exams, testicular exams).

- **Puberty and Adolescent Development:** this topic addresses the impact puberty has on physical, social, and emotional development and should specifically include physiological, hormonal, and emotional changes, neurodevelopment, and common experiences of adolescents.
- **Identity:** this topic addresses developing an awareness and understanding of one's self and should specifically include gender identity, sexual orientation, awareness of discrimination based on sexual or gender identity, knowledge of local resources to support gender identity or sexual orientation differences, and socio-political current events/rights.
- **Pregnancy and reproduction:** this topic addresses how pregnancy happens and should specifically include understanding the signs of pregnancy, awareness of the stages of pregnancy, what to do if you think you or your partner might be pregnant, how to prevent pregnancy, and the responsibilities that come with having a child.
- **Sexually Transmitted Infections (STIs) and HIV:** this topic addresses knowledge of what STIs/HIV are, how they are transmitted, and how to prevent them and should also include developing awareness of the symptoms and signs of STIs/HIV, social stigmas surrounding STIs/HIV, how to get tested for an

STIs/HIV, and community resources available for assistance in the testing, treatment, and prevention of STIs/HIV.

- **Healthy relationships:** this topic addresses how to successfully define and navigate relationships among family, peers, and partners and should specifically include an understanding of different types of relationships, what constitutes a healthy and unhealthy relationship, how to identify a relationship that is unhealthy, qualities to look for in relationship partners, acknowledgement that it is ok to not want a romantic relationship, and understanding different components of intimacy.
- **Personal safety:** this topic should address self-advocacy, establishing and respecting boundaries, assertiveness, prevention of abuse, and dangers specific to the Internet.
- **Legal Issues:** This topic includes educating students about consent, appropriate versus inappropriate behavior, defining “illegal”, and criminal behavior including illegal sexual images, coercion, rape, molestation, and stalking.
- **Social Aspects of Sexuality and Romantic Relationships:** This topic includes social norms, communication, dating/establishing a romantic relationship, sexual decision-making, boundaries, and abuse awareness.
- **Knowledge of Different Sex Acts and Use of Common Slang:** This topic includes developing awareness of common colloquialisms and slang terms for sexual acts, developing an understanding that slang terms change over time, identifying appropriate resources to utilize to get more information, and

developing an understanding of what various sexual acts involve (e.g., anal sex, masturbation, oral sex).

- **Sensory Needs:** This topic includes identifying, coping with, and discussing sensory sensitivities; developing an awareness that sensory needs vary from person to person; and understanding how sensory needs can impact a romantic relationship.

Delivery. It is important to recognize individual student needs when providing a sexuality education curriculum to high functioning students with ASD. Individualized supports and differentiated instruction should be utilized whenever possible.

Sexuality education curricula for high functioning students with ASD should be implemented in the least restrictive environment that limits distractions, addresses sensory needs, incorporates breaks, and utilizes both small group and individual instruction when appropriate.

In schools, ideally a team of school-based professionals who understand ASD and who have positive relationships with the students who they will be teaching should provide a sexuality education curriculum for high functioning students with ASD. School-based professionals who are particularly well suited for the delivery of sexuality education curriculum for high functioning students with ASD include health teachers, school psychologists, school social workers, and special education teachers. Other professionals such as school nurses, autism consultants, occupational therapists, and speech language pathologists who also have knowledge and experience working with

students with ASD may also be appropriate to deliver a sexuality education curriculum for students with ASD.

Although every student has unique needs, some general guidelines for developing a supportive classroom environment for implementing a sexuality education curriculum for high functioning students with ASD include:

- A small student to teacher ratio
- Supportive individuals to discuss topics with
- Open and accepting teacher-student and peer-to-peer relationships
- Respect for individual learning styles.

Some strategies that would be useful in teaching high functioning students with ASD about sexuality include:

- The use of visuals (e.g., video, pictures, graphs, charts)
- Using real-world examples
- Class discussion
- Repetition
- Direct, detailed and honest explanations
- Parent involvement
- Breaking down information into measurable steps (e.g., using video prompting to break down target skills into steps)
- Structured project based learning
- Student led research that is overseen by instructors
- Appropriate role-play for building relationship skills

Measuring mastery of skills in a sexuality education curriculum for high functioning students with ASD can be difficult. Ultimately, the goal is to have students be able to generalize what is learned in the curriculum to the real world. There are a variety of strategies that can be appropriate for use in measuring skill acquisition. These strategies should be implemented with a highly structured plan and with plenty of guidance and support for the students. Strategies to measure mastery of skill include:

- Role play
- Completion of projects
- Practical assignments (e.g., how to put on a condom)
- Class discussion
- Parent/teacher report of life events
- Oral/written explanations following a rubric
- Family or school-based professional observation of an increase in desired behaviors and a decrease of problem behaviors

Including neurotypical peers in the sexuality education of high functioning students with ASD can be beneficial if done thoughtfully. It may not be appropriate to include neurotypical peers in every aspect of the curriculum as the delivery, pacing, and depth will be modified for students with ASD. Families and schools should discuss if, how, and when it might be appropriate to integrate high functioning students with ASD and their neurotypical peers in the context of a sexuality education curriculum.

Responsibilities. Schools and families both have significant roles in the sexuality education of high functioning adolescent students with ASD. The sexuality education of

high functioning adolescent students with ASD is most successful when schools and families partner and work together as a team. Examples of ways that schools and families can partner include engaging in effective two-way communication, sharing resources (e.g., providers within the community who can provide additional support), and providing parent education trainings on the topic of the sexuality education needs of students with ASD. Allowing parents to preview and/or discuss the sexuality education curriculum that will be taught in the school and encouraging family involvement on sexuality education assignments that may occur during the curriculum are effective ways to develop a family-school partnership surrounding the sexuality education of high functioning students with ASD.

Schools have a responsibility to teach sexuality education to high functioning adolescent students with ASD in a safe and effective learning environment. Additionally, schools should adapt sexuality education curricula to meet the individual needs of students with ASD. Many students with ASD receive services through an Individualized Education Plan (IEP). If necessary, members of a student's IEP team, including the student and his or her family, should specifically address the sexuality education needs of the student and, if appropriate, develop and include sexuality education goals within the IEP.

Family involvement is a critical component of successful sexuality education curricula for high functioning students with ASD. Ideally, families should:

- Be aware of the school-based sexuality education curriculum (or lack of one)
- Be able to reinforce what is being taught by the schools,

- Facilitate/foster sexuality education discussions with their child
- Share their child's specific needs surrounding sexuality education with the school

Once the families are informed of the sexuality education curriculum that will be taught, families may choose to withdraw consent for their child to participate in the sexuality education curriculum provided by the schools. The school should communicate with the family about the potential risks involved in withdrawing consent.

Analysis by Group

This study was comprised of three separate groups: ASD and sexuality authors/researchers, school psychologists, and families with students with ASD. Each group was analyzed separately to determine if any significant between group differences emerged from the analysis. Significant findings for each group are discussed.

ASD and sexuality authors and researchers. This group was comprised of six female participants and one male participant ranging in ages from 30 to 50 and an average of nine years' experience in their field. The experts in the ASD and sexuality authors and researchers group were of high caliber; participants within this group had published a sexuality education curriculum for high functioning adolescents with ASD, written a book about ASD and sexuality, published more than six peer-reviewed journal articles on the topic of ASD and sexuality, written a dissertation on sexuality education and ASD, presented nationally on ASD and sexuality, and gained personal experience providing sexuality and relationship education to high functioning adolescents with ASD as a certified sexuality educator, Board Certified Behavior Analyst® (BCBA), and/or

licensed psychologist. This group was regionally diverse with participants located in Illinois, Indiana, New York, Tennessee, and Utah. All participants in this group completed Rounds 1, 2, and 3 of this study; there was 0% attrition within this group.

The ASD and sexuality researchers and authors group was the only group to not obtain 100% consensus on all Round 2 Content items. One participant disagreed with the statement,

Sexuality education curriculum designed for high functioning students with ASD should differ from sexuality education curricula designed for general education students by addressing sensory differences including aspects of social learning, emphasizing legal issues, going into greater depth within each topic, and discussing the impact that Autism Spectrum Disorder can have on sexuality and romantic relationships.

The participant who disagreed with this statement stated that “sexuality education for general education students should cover these things as well.” This participant echoed these sentiments on later Round 2 and Round 3 Questionnaire items.

The ASD and sexuality researchers and authors group were unable to obtain 100% consensus on one Round 2 Content item, 10 Round 2 Delivery items, and three Round 2 Delivery items. In regards to the endorsement of specific school-based professionals best suited for the delivery of sexuality education curricula to high functioning students with ASD, the ASD and sexuality researchers and authors group was the only group to obtain 100% consensus on the endorsement of school psychologists and school social workers.

Of note, the ASD and sexuality researchers and authors group were the only group to obtain 100% consensus in Round 2 on the use of “role play” as a strategy that would be useful in teaching high functioning students with ASD about sexuality. In contrast, they were the only group to not obtain 100% consensus in Round 2 on the use of “class discussion” as one of the best ways to measure mastery. The ASD and sexuality researchers and authors group was also the only group who did not obtain 100% consensus on the Round 2 statement, “schools should adapt sexuality curricula to meet the needs of students with ASD.” The one participant who did not agree with the statement commented that, “most schools are not equipped to modify curricula to meet the needs of students with ASD.” No themes emerged from the types of statements that the ASD and sexuality researchers and authors group tended to agree or disagree with.

In Round 3, participants in the ASD and sexuality researchers and authors group obtained 100% consensus for “agree” with two of the 12 statements that were provided for review and revision, obtained more than 70% but less than 100% consensus on nine of the 12 statements, and obtained less than 70% consensus on one of the 12 statements.

The participants in the ASD and sexuality researchers and authors group, in general, offered more comments and feedback than the other two groups. In Round 2, every single participant in the ASD and sexuality researchers and authors group offered comments and/or feedback. Many of the comments were thoughtful and tended to further explain their opinion beyond simply “agree” or “disagree” to a specific item. For example, one participant provided the following comment in regards to an item asking for a response of “agree” or “disagree” to whether or not “an increase in desired

behaviors/decrease of problem behaviors” is one of the best ways to measure mastery of skills taught,

Translation of knowledge into observable behavior is so important in measuring skill acquisition. Whereas quizzes/tests have some preliminary role, naturalistic assessment is critical in multiple settings, by multiple observers/rates. This is much harder to design but so much more meaningful in evaluating whether students have truly learned concepts and skills taught.

School Psychologists. This group was comprised of five female participants and one male participant ranging in ages from 29 to 51 with an average of 12 years of experience in the field. This group was regionally diverse with participants located in Arkansas, Colorado, Idaho, Ohio, and Wisconsin. All participants in this group completed Rounds 1, 2, and 3 of this study; there was 0% attrition within this group.

The school psychologist respondent group achieved 100% consensus to all items in the Content section of the Round 2 Questionnaire. Of note, the school psychologist respondent group was the only group to achieve 100% agreement in Round 2 that “A mixture of students with ASD and neurotypical peers” would be a useful strategy in teaching high functioning students with ASD about sexuality in comparison to 50% agreement to this item within the parent/caregiver group and 71% agreement to this item within the ASD and sexuality authors and researchers group.

The school psychologist respondent group did not obtain 100% consensus on 10 items from the Round 2 Delivery section and six items in the Round 2 Responsibilities section – omitting the item asking respondents to endorse which school-based

professional they think are best suited to deliver sexuality education curricula to high functioning students with ASD. On that item, it is significant to note that the only professional that all school psychologist respondents endorsed was Health Teacher; School Psychologist was met with only 87% agreement.

In comparison to the other two respondent groups, the school psychologist group had the least amount of consensus within the Round 2 Responsibilities section. The school psychologist respondent group was the only group not to obtain 100% consensus on the following statements regarding the prompt, “families should have the following roles in the sexuality education of their high functioning children with ASD,” “teach family values and personal beliefs surrounding sexuality,” and “complete assignments from the sexuality education curricula being taught in school.” The school psychologist group was also the only group not to obtain 100% consensus that “allowing parents to preview and/or discuss the sexuality education curriculum that will be taught” and “families and the school can co-develop goals or the sexuality education of high functioning adolescent students with ASD” are ways that schools and families can partner to provide effective sexuality education for high functioning adolescent students with ASD. In contrast, the school psychologist group was the only group to obtain 100% consensus that “practice” is a strategy that would be useful in teaching high functioning students with ASD about sexuality.

In Round 3, the school psychologist group achieved 100% consensus for “agree” with four of the 12 statements that were provided for review and revision, obtained more than 70% but less than 100% consensus with four of the 12 statements, and obtained less

than 70% consensus on three of the 12 statements. In general, the school psychologist participants tended to offer less comments when provided the opportunity than the ASD and sexuality researchers and authors group and the families group. No themes emerged from the types of statements that the ASD and sexuality researchers and authors group tended to agree or disagree with.

Families. This group was comprised of two female participants, one from the state of Colorado and one from the state of Washington. One family participant was 50 years old and the other was 47 years old. Both participants completed Rounds 1 and 2, and one participant completed Round 3; there was 50% attrition in this group for Round 3. The participant that dropped out of the study in Round 3 responded to many Round 1 Questionnaire items with answers such as “I don’t know.”

Overall, the two family participants agreed on 89% of the Round 2 items. When broken out by content area, the two family participants had 100% consensus on the Round 2 Responsibilities items and the Round 2 Content items with the exception of their identification of which specific professionals they feel are best suited to deliver sexuality education curricula to high functioning students with ASD in the schools. The only school professionals that the two parent participants disagreed on were school psychologists, school social workers, and speech language pathologists. Additionally, the participants in the parent group were the only two participants in Round 2 to not endorse a health teacher as being well suited to deliver sexuality education curricula to high functioning students with ASD. It is significant to note that, other than their differing endorsement of which school-based professionals they felt were best suited to deliver a

sexuality curriculum to students with ASD, the parent/caregiver group was the only group to obtain 100% consensus in the Responsibilities section on the Round 2 Questionnaire.

The two family participants disagreed on a total of seven Round 2 Delivery items including the use of small group instruction, role-play, practice, quizzes/tests, practical assignments, and whether or not students with high functioning ASD should receive sexuality education separately from neurotypical peers. In regards to students with ASD receiving sexuality education with a mixture of neurotypical peers, one of the parent participants stated,

I wouldn't mix ASD students with neurotypical peers. While I think it's always good to mix students, I don't think it would be for this topic. There are too many main ideas that neurotypical students know and understand that ASD students don't. The "catching up" for students on the spectrum may not be something that neurotypicals have patience for.

Both parents in the families group agreed that parents should be the primary sexuality educators of their children. This differs from the ASD and sexuality researchers and authors group and the school psychologists group where consensus on this item was not obtained in Round 2. Both family participants also agree that schools have a responsibility to educate students with ASD about sexuality. One participant eloquently stated,

Schools most definitely have a role to play. They're already teaching sexuality education in middle school. Adapting/modifying content to meet the needs of

their special ed population isn't asking them to do anything different from what they are already doing with academic content.

Overall, the participants in the families group were in agreement regarding the content that should be taught and who should be responsible for the sexuality education for high functioning students with ASD. The participants in the families group disagreed on certain strategies that should be used to teach high functioning students with ASD about sexuality. The caregiver respondent group was the smallest of the three expert groups and the only group in which a participant dropped out of the study.

Summary

Using the iterative Delphi research methodology, expert participants representing families, ASD and sexuality researchers and authors, and school psychologists who work with high functioning students with ASD in schools were able to come to a consensus on the content necessary for inclusion in a sexuality education curriculum designed for high functioning students with ASD, strategies that are useful in teaching and measuring mastery of sexuality education material to high functioning students with ASD, and the responsibilities of schools and families in educating high functioning students with ASD about sexuality. The final outcome of this study was the development of the *Guidelines for Developing Sexuality Education Curricula for High Functioning Adolescent Students with Autism Spectrum Disorder*.

Chapter Five: Discussion

The purpose of this research was to address the following research questions:

1. What do experts in the field of ASD and sexuality, school-based mental health services, and family-school partnering believe to be essential content in comprehensive sexuality education for high functioning students with ASD?
2. What learning strategies should be considered when teaching high functioning adolescents with ASD about sexuality?
3. What type(s) of family-school collaboration could best support high functioning adolescents with ASD in their sexuality education?

The final outcome of this study was the development of the *Guidelines for Developing Sexuality Education Curricula for High Functioning Adolescent Students with Autism Spectrum Disorder*. These Guidelines are organized into three sections: Content, Delivery, and Responsibilities. Each section represents strategies and statements that were generated based on the consensus of expert participants representing school psychologists, caregivers of high functioning adolescents with ASD, and ASD and sexuality researchers and authors. All statements and strategies included in the Guidelines achieved between 70% - 100% consensus amongst expert participants. The research questions for this study are addressed within each section of the final guidelines; research question 1 is addressed in the Content section of the Guidelines, research

question 2 is addressed in the Delivery section of the Guidelines, and research question 3 is addressed in the Responsibilities section of the Guidelines.

The following sections provide a discussion of each section of the *Guidelines for Developing Sexuality Education Curricula for High Functioning Adolescent Students with Autism Spectrum Disorder*, general findings, the limitations and implications of this study, and future research that is required.

Findings

The final outcome of this study was the development of the *Guidelines for Developing Sexuality Education Curricula for High Functioning Adolescent Students with Autism Spectrum Disorder*, hereafter referred to as the Guidelines, which is organized into three sections: content, delivery, and responsibilities. The Guidelines that were developed in this study are intended for use by researchers, school psychologists, and families of high functioning students with ASD as well as any other school or community based professionals with an interest in providing sexuality education to high functioning adolescents with ASD. These Guidelines are intended to be used as a tool to guide future sexuality education curriculum development that address the unique needs of high functioning students with ASD and to provide suggestions to modify existing curricula so that the needs of high functioning adolescents students are met.

It was repeatedly stated throughout each survey iteration of this study that general education students would also benefit from the content, delivery, and responsibility strategies and recommendations included in the Guidelines. Existing research acknowledges that sex education in the United States is inadequate (Bay-Cheng, 2010)

and even though the participants in this study were asked to focus their responses to the explicit sexuality education needs of high functioning adolescents with ASD, they could not help but recognize the insufficient sexuality education being provided to general education students.

Specific topics, learning strategies, and responsibilities of schools and families for educating high functioning adolescent students about sexuality are included within the Guidelines and can be useful in the modification of existing sexuality education curricula for general education students to meet the needs of high functioning students with ASD or for targeted interventions. Additionally, families, school psychologists, and researchers are advised to utilize these Guidelines as an advocacy tool to increase awareness of the unique needs of high functioning students with ASD regarding their sexuality education and to initiate conversations and action. In the following sections, each section of the Guidelines will be discussed regarding its utility, alignment or divergence from the literature, and significance.

Content. The content section of the Guidelines provides specific topic areas, and their descriptions, that should be included in sexuality education curricula for high functioning adolescent students with ASD. Seven of the 11 content topics in the Guidelines mirror the content topics suggested for inclusion in comprehensive sexuality education curricula for neurotypical students in general education by the *National Sexuality Education Standards*: anatomy and physiology; puberty and adolescent development; identity; pregnancy and reproduction; sexually transmitted infections (STIs) and HIV; healthy relationships; and, personal safety (Future of Sex Education,

2012). The topic descriptions for these 7 topic were catered in the Guidelines to meet the needs of students with ASD and therefore differ from the descriptions provided in the *National Sexuality Education Standards*.

In addition to modifying the descriptions of the seven shared topic areas within the *National Sexuality Education Standards*, four additional topic areas specific to sexuality education curricula designed for high functioning students with ASD were developed: legal issues; social aspects of sexuality and romantic relationships; knowledge of different sex acts and use of common slang; and, sensory needs. Although these four additional topic areas may enhance existing comprehensive sexuality education intended for neurotypical students, it is important to acknowledge that the Guidelines recognize each content area as a requirement, and not a suggestion, for inclusion in sexuality education curricula for students with ASD. Because of the vulnerability of ASD populations (Attwood et al., 2014; Brown-Lavoie et al., 2014; Kroncke et al., 2016; Sevlever et al., 2013;), the sensory sensitivities that commonly accompany an ASD diagnosis (Kroncke et al., 2016), and the social communication deficits associated with ASD (American Psychiatric Association, 2013; Kroncke et al., 2016) it is crucial to address each topic area provided in the guidelines when developing, modifying, or utilizing a sexuality education curriculum for high functioning students with ASD. In the following sections, each topic area that was included in the Guidelines will be discussed.

Anatomy and physiology. Anatomy and physiology is one of the essential topic areas included in the *National Sexuality Education Standards* for use in K-12 sexuality education and is also included in the Guidelines. In the *National Sexuality Education*

Standards, the anatomy and physiology topic is intended to “provide a foundation for understanding basic human functioning” (Future of Sex Education, 2012). In the

Guidelines, the anatomy and physiology topic,

provides a foundation for understanding basic human functioning and specifically should include understanding the functions and names of internal and external reproductive anatomy, the names of internal and external reproductive anatomy, stages of human sexual response, genital health, and preventative health strategies (e.g., breast exams, testicular exams).

The description of the anatomy and physiology content area in the Guidelines is closely aligned with, although expanded from, the description provided in the *National Sexuality Education Standards*. The *National Sexuality Education Standards* begins addressing the names for body parts, including male and female anatomy, in kindergarten; addresses male and female reproductive systems including body parts and their functions between 3rd and 5th grade; and addresses the human sexual response cycle between 9th and 12th grade (Future of Sex Education, 2012). The *National Sexuality Education Standards* do not include genital health or preventative health strategies, such as breast exams or testicular exams.

Many of the existing comprehensive sexuality education curricula for both neurotypical students as well as students with ASD already include understanding and naming internal and external reproductive anatomy, stages of human sexual response, genital health, and preventative health strategies (Davies & Dubie, 2012; Hartman, 2014; Sutton & Wesley Spectrum Services, 2013;). The *National Sexuality Education Standards* and the Guidelines are closely aligned in their description of the anatomy and

physiology content area because both neurotypical students and students with ASD require functional knowledge of how their bodies work.

Puberty and adolescent development. Puberty and adolescent development is one of the essential topic areas included in the *National Sexuality Education Standards* for use in K-12 sexuality education and is also included in the Guidelines. In the *National Sexuality Education Standards*, the puberty and adolescent development topic is intended to “addresses a pivotal milestone for every person that has an impact on physical, social and emotional development” (Future of Sex Education, 2012). In the Guidelines, the puberty and adolescent development topic, “addresses the impact puberty has on physical, social, and emotional development and should specifically include physiological, hormonal, and emotional changes, neurodevelopment, and common experiences of adolescents.”

The experts in this study agreed to keep the idea of puberty impacting physical, social and emotional development from the *National Sexuality Education Standards* and then expanded upon that description by explicitly including physiological, hormonal, and emotional changes, neurodevelopment, and common experiences of adolescents. It is particularly significant that the experts recognized that students with ASD will require explicit instruction on common, or “normal” adolescent experiences due to students with ASD often having less robust peer group from which to acquire information regarding puberty (Nichols & Blakeley-Smith, 2010). Puberty is a topic that has been included in existing sexuality education curricula intended high functioning students with ASD (Davies & Dubie, 2012; Hartman, 2014; Sutton & Wesley Spectrum Services, 2013),

however, it is significant to note that the Guidelines call for explicit instruction as to how puberty effects social and emotional development as well as neurodevelopmental changes that occur during puberty. Tying puberty to social-emotional and neuro development has not always been intentionally included in sexuality education curricula for high functioning students with ASD; future curricula should take care to purposefully integrate these aspects of puberty.

Identity. Identity is one of the essential topic areas included in the *National Sexuality Education Standards* for use in K-12 sexuality education and is also included in the Guidelines. In the *National Sexuality Education Standards*, the identity topic is intended to “addresses several fundamental aspects of people’s understanding of who they are” (Future of Sex Education, 2012). In the Guidelines, the identity topic,

Addresses developing an awareness and understanding of one’s self and should specifically include gender identity, sexual orientation, awareness of discrimination based on sexual or gender identity, knowledge of local resources to support gender identity or sexual orientation differences, and socio-political current events/rights.

The Guidelines identity topic description greatly expands on the *National Sexuality Education Standards* identity topic description. The *National Sexuality Education Standards* does address gender identity, sexual orientation, and the influence of the media on the expression of gender, sexual orientation, and identity across the core concepts and analyzing influences standards. Also, the *National Sexuality Education Standards* identify the ability to “differentiate between biological sex, sexual orientation, and gender identity and expression” as a core concept standard for grades 9-12 (Future of Sex Education, 2012); however, there is little stated in the *National Sexuality Education*

Standards about one's personal role in such differentiation or what resources are available for support in the community. Additionally, although the *National Sexuality Education Standards* provide advocacy and self-management standards surrounding treating others with dignity and respect, and advocating for the promotion of the dignity and respect of all people, the concept of discrimination based on gender expression and sexual orientation is not explicitly mentioned. The Guidelines recommend that high functioning students with ASD receive instruction on their own personal role in understanding their identity, be provided with knowledge of local resources that support gender identity or sexual orientation differences, and understand the concept of discrimination and how it relates to individuals who have gender expression and/or sexual orientation differences.

Currently, only nine states have a sexuality education content requirement that includes an inclusive discussion of sexual orientation; shockingly, four states require that only negative information on sexual orientation be discussed when sexuality education is taught (Guttmacher, 2016). Although gender identity and sexual orientation are not universally included in a positive way in existing comprehensive sexuality education curricula for neurotypical students or students with ASD, several prominent figures in the ASD community have written books about their own sexual identity journey, the unique challenges they faced in their struggle to define their identity due to their ASD diagnosis, and what type of impact this journey had on their lives (Attwood et al., 2014; Lawson, 2005). Indeed, a significant finding in this study is the universal agreement amongst experts that students with ASD require targeted, inclusive lessons on sexual and gender

orientation and identity, should be provided with information regarding available support resources, and be knowledgeable of current events related to these topics.

School-based professionals, researchers, and families of children with ASD should be encouraged to include conversations and lessons about gender identity and sexual orientation in sexuality education curricula provided to high functioning students with ASD. Additionally, although certainly not true for all individuals with ASD, some literature does support the notion that individuals with ASD have a higher likelihood to identify as asexual; therefore, it is important to explicitly present asexuality as an acceptable sexual identity (Gilmour & Schalomon, 2011).

Pregnancy and reproduction. Pregnancy and reproduction is one of the essential topic areas included in the *National Sexuality Education Standards* for use in K-12 sexuality education and is also included in the Guidelines. In the *National Sexuality Education Standards*, the pregnancy and reproduction topic is intended to “address information about how pregnancy happens and decision-making to avoid a pregnancy” (Future of Sex Education, 2012). In the *Guidelines for Developing Sexuality Education Curricula for High Functioning Adolescent Students with Autism Spectrum Disorder*, the pregnancy and reproduction topic addresses,

how pregnancy happens and should specifically include understanding the signs of pregnancy, awareness of the stages of pregnancy, what to do if you think you or your partner might be pregnant, how to prevent pregnancy, and the responsibilities that come with having a child.

The pregnancy and reproduction topic in the Guidelines includes the description from the *National Sexuality Education Standards* and expands upon it. For high functioning adolescents with ASD not only should information about how pregnancy occurs and can

be prevented be included in a sexuality education curriculum, but also information on how to tell if a woman is pregnant, what happens throughout a pregnancy, what to do if a person thinks that they might be pregnant, and details surrounding what type of responsibilities accompany parenting.

Because adolescents with ASD often lack a peer group from whom to obtain sexuality and relationship information (Brown-Lavoie et al., 2014; Nichols & Blakeley-Smith, 2010), there is an increased responsibility on the school, community, and family to provide medically accurate information regarding reproduction and pregnancy. Additionally, due to theory of mind (i.e., the ability to understand the perspective of others) deficits present in individuals with ASD (Happé, 1997; Kroncke et al., 2016), it is especially important that adolescents with ASD understand how to recognize the symptoms of pregnancy in others, especially male students recognizing if a female partner may be pregnant and how that will directly affect their own life.

Sexually transmitted infections (STIs) and HIV. STIs and HIV is one of the essential topic areas included in the *National Sexuality Education Standards* for use in K-12 sexuality education and is also included in the Guidelines. In the National Sexuality Education Standards, the topic is labeled “sexually transmitted diseases (STDs) and HIV” and is intended to “provide both content and skills for understanding and avoiding STDs and HIV, including how they are transmitted, their signs, and symptoms and testing and treatment” (Future of Sex Education, 2012). In the Guidelines, the STIs and HIV topic,

Addresses knowledge of what STIs/HIV are, how they are transmitted, and how to prevent them and should also include developing awareness of the symptoms and signs of STIs/HIV, social stigmas surrounding STIs/HIV, how to get tested

for an STI/HIV, and community resources available for assistance in the testing, treatment, and prevention of STIs/HIV.

One notable change between the *National Sexuality Education Standards* description and the Guidelines is the shift from using STD to using STI in reference to sexually transmitted infections. This reflects the cultural shift in America from using the term “disease” to using the term “infection.” Reasons for this shift in terminology include less stigma with the term “infection” versus “disease” (Crain, 2015). Overall, the Guidelines content area topic definition of STIs and HIV is very closely aligned with the *National Sexuality Education Standards* topic definition. This is not unexpected, as reducing pregnancy and STIs/HIV is one of the commonly stated goals of sexuality education programming in general; students with ASD should receive similar information as their neurotypical peers regarding STI/HIV prevention and treatment. One notable difference is that the Guidelines recommends providing high functioning adolescents with ASD information about the social stigmas that surround STIs and HIV due to the social reciprocity deficits associated with ASD (American Psychiatric Association, 2013; Kroncke et al., 2016).

Healthy relationships. Healthy relationships is one of the essential topic areas included in the *National Sexuality Education Standards* for use in K-12 sexuality education and is also included in the Guidelines. In the *National Sexuality Education Standards*, the healthy relationships topic is intended to “offers guidance to students on how to successfully navigate changing relationships among family, peers and partners. Special emphasis is given in the *National Sexuality Education Standards* to the increasing

use and impact of technology within relationships” (Future of Sex Education, 2012). In the Guidelines, the healthy relationships topic,

Addresses how to successfully define and navigate relationships among family, peers, and partners and should specifically include an understanding of different types of relationships, what constitutes a healthy and unhealthy relationship, how to identify a relationship partners, acknowledge that it is ok to not want a romantic relationship, and understanding different components of intimacy.

The healthy relationships content area in the Guidelines emphasizes defining different kinds of relationships and parsing out the varied elements of an intimate relationship more so than the healthy relationships topic in the *National Sexuality Education Standards*. Because individuals with ASD struggle with social communication and often fail to share enjoyment, interests, and emotional experiences with others (Kroncke et al., 2016), it is important for sexuality education curricula to provide instruction as to the value of friendships and romantic relationships.

One component of the Guidelines definition of the healthy relationships content topic area, “what constitutes a healthy and unhealthy relationship,” aligns with the *National Sexuality Education Standards* healthy relationship topic core concept expectations by neurotypical students by the end of 12th grade (Future of Sex Education, 2012). The other components of the Guidelines healthy relationships definition, which include defining relationships, identifying potential partners, understanding different components of intimacy, and acknowledging that it is ok to not want to have a romantic partner, are not referenced in the *National Sexuality Education Standards*. Neurotypical students have social reciprocity, awareness of social norms, and learn from social interactions and typically do not need the components of different types of relationships

explicitly stated; however, students with ASD who lack social reciprocity do need to be overtly taught the social norms surrounding healthy relationships that come easily to their neurotypical peers. High functioning adolescents with ASD will benefit from specific examples of what defines a healthy and unhealthy relationship and what are common emotional and physical expectations in intimate relationships. As eloquently stated by a participant in this study, sexuality education curricula for high functioning students with ASD must make the “implicit explicit.”

Another noteworthy difference between the descriptions of the healthy relationships topic in the Guidelines versus the Standards is that the *National Sexuality Education Standards* explicitly reference the role that the technology plays in relationships. The experts in this study did not include technology in their healthy relationships topic definition and instead identified the appropriate place to discuss technology as within the personal safety topic area.

Personal safety. Personal safety is one of the essential topic areas included in the *National Sexuality Education Standards* for use in K-12 sexuality education and is also included in the Guidelines. In the *National Sexuality Education Standards*, the personal safety topic is intended to “emphasize the need for a growing awareness, creation and maintenance of safe school environments for all students” (Future of Sex Education, 2012). In the Guidelines, the personal safety topic should address “self-advocacy, establishing and respecting boundaries, assertiveness, prevention of abuse, and dangers specific to the Internet.”

The Guidelines description of personal safety significantly differs from the description put forth by the *National Sexuality Education Standards* in that it expands the idea of personal safety from merely a school based perspective focused on a safe school environment. The Guidelines description of personal safety includes the development of skills such as self-advocacy and assertiveness that can lead to positive and safe sexual and relationship experiences throughout a student's life. Specifically, skills like self-advocacy, establishing and respecting boundaries, and assertiveness are often skills that schools, community providers, and families work on with their students with ASD - it makes sense to meaningfully include these skills in a sexuality education curricula, particularly because students with ASD often have difficulty generalizing learned concepts to other situations or scenarios (Kroncke et al., 2016). For example, a student who learns self-advocacy skills in the classroom to ask for help may not intuitively generalize this skill to telling a partner that he or she is uncomfortable in a romantic situation.

Other significant statements that were included in the personal safety Guidelines topic description were "prevention of abuse" and "dangers specific to the Internet." The inclusion of abuse prevention within the Guidelines is significant due to high functioning adolescents with ASD having a higher risk of sexual abuse (Nichols & Blakeley-Smith, 2010). Also, it is significant to note that experts in this study agreed that teaching high functioning students with ASD about dangers specific to the internet should be included in their sexuality education curricula. In the *National Sexuality Education Standards*, the role of the Internet is recommended to be discussed in standards within the healthy

relationships topic by the end of 8th grade (Future of Sex Education, 2012). The experts in ASD, however, perceived Internet usage as being more fitting in the personal safety content area of the Guidelines. Perhaps this was because of the vulnerability individuals with ASD have on the internet due to their difficulty in understanding appropriate social norms and understanding social cues and contexts. Indeed, Dubin, a man with ASD, shared his own harrowing story of the significant ramifications he suffered from unintentionally using the Internet in an unsafe way when searching for information to help him better understand his own sexual identity (Attwood et al., 2014). Overall, the personal safety content area in the Guidelines was conceptualized by the experts to represent skills that are necessary to maintain safety whereas the *National Sexuality Education Standards* conceptualized personal safety as being able to recognize and identify physically unsafe scenarios such as bullying, harassment, assault, and abuse.

Legal issues. The legal issues topic was generated from participant responses in this study and was not one of the topic areas included in the *National Sexuality Education Standards*. Although the Personal Safety topic in the *National Sexuality Education Standards* addresses some legal elements (e.g., by the end of 12th grade general education students are able to analyze the laws related to bullying, sexual harassment, sexual abuse, sexual assault, incest, rape, and dating violence), the Guidelines differentiated between topics of personal safety and legal issues. The description of the legal issues topic in the Guidelines reads, “this topic includes educating students about consent, appropriate versus inappropriate behavior, defining “illegal”, and criminal behavior including illegal sexual images, coercion, rape, molestation, and stalking.”

The inclusion of an explicit legal issues content area in a sexuality education curriculum designed for high functioning adolescent students with ASD separate from personal safety is logical; research supports that children with ASD have a greater likelihood of being victims of sex abuse or unknowingly breaking the law when exhibiting, engaging in, or acting upon a sexual behavior or desire (Attwood et al., 2014; Brown-Lavoie, 2014; Kroncke et al., 2016; Nichols & Blakeley-Smith, 2010). Interestingly, the description of the legal issues topic in the Guidelines can be read from both the perspective of educating students with ASD about their own legal rights as survivors of illegal sexual interactions (e.g., rape, molestation, stalking, consent, appropriate versus inappropriate behaviors) as well as from the perspective of teaching students with ASD about the legal ramifications of their own actions in sexually inappropriate and/or illegal behavior.

Existing curricula that have been designed explicitly for use with students with ASD have already begun including lessons on legal issues; it is encouraging that this research supports the need to explicitly educate students with ASD about illegal behaviors. For example, Davies and Dubie (2012) include an entire lesson in their sexuality education curriculum for high functioning students with ASD on “sexual intimidation: harassment, aggression, and abuse” and Hartman (2014) includes a chapter on “responding to ‘inappropriate’ sexual behaviours in the area of sexuality and relationships” in her sexuality education guide for children and adolescents with ASD. Additionally, it is significant to recognize that the Guidelines recommend that families, school-based staff, and researchers explicitly define what “illegal” means and discuss the

various ramifications a person's actions can have on themselves and on others. It is critical that individuals with ASD recognize their personal rights in sexual and romantic situations (e.g., the right to say no, the right to privacy) and understand when their legal rights are being infringed upon by others. Also, because individuals with ASD have theory of mind deficits, it is essential that, within the context of sexuality, individuals with ASD recognize how their actions may be perceived by others and the damage that can be caused to others by acting on sexual impulses or curiosities in an illegal way.

Social aspects of sexuality and romantic relationships. The social aspects of sexuality and romantic relationships topic was generated from participant responses in this study and was not one of the topic areas included in the *National Sexuality Education Standards*. The Guidelines definition of the social aspects of sexuality and romantic relationships topic addresses, “social norms, communication, dating/establishing romantic relationship, sexual decision-making, boundaries, and abuse awareness.”

The importance of teaching explicit social aspects of sexuality and romantic relationships to adolescents with ASD cannot be understated. Arguably, the most significant symptom of ASD is the lack of social reciprocity, that is, a tendency to “lack the understanding of the give-and-take nature of conversation and relationships” (Kroncke et al., 2016). Understanding the concept of friendship and relationships can be difficult for adolescents with ASD. Because individuals with ASD have theory of mind deficits (Happé, 1997; Kroncke et al., 2016), which is the ability to understand another person's perspective, comprehension difficulties may arise in social relationships. Therefore, the Guidelines recommendation to discuss social norms, communication,

dating/establishing romantic relationships, and boundaries in sexuality education curricula for high functioning students with ASD is of the utmost importance. It is particularly important in a sexuality education curriculum for high functioning adolescents with ASD to parse out socially appropriate and inappropriate behaviors because misreading social cues of a romantic or sexual nature can result in severe social and/or legal consequences. Sexual decision-making and dating/establishing romantic relationships often requires sophisticated social communication techniques such as being able to read tone, behavior, body language, and innuendos; this can prove particularly challenging to individuals with ASD due to their social reciprocity and communication deficits.

Many of the available resources that provide sexuality and relationship education targeting individuals with ASD include social aspects such as dating, identifying different types of relationships, and social boundaries (Davies & Dubie, 2012; Harman, 2015; Sutton & Wesley Spectrum Services, 2013). Indeed, it would be inappropriate to not address the social aspects of sexuality and romantic relationships when teaching adolescents with high functioning ASD about sexuality because social deficits is the hallmark of an ASD diagnosis.

Knowledge of different sex acts and use of common slang. The knowledge of different sex acts and use of common slang topic was generated from participant responses in this study and was not one of the topic areas included in the *National Sexuality Education Standards*. The Guidelines definition of the knowledge of different sex acts and use of common slang content topic area includes,

Developing awareness of common colloquialisms and slang terms for sexual acts, developing an understanding that slang terms change over time, identifying appropriate resources to utilize to get more information, and developing an understanding of what various sexual acts involve (e.g., anal sex, masturbation, oral sex).

Because adolescents with ASD often do not have a robust peer group from which to obtain sexual knowledge (Nichols & Blakeley-Smith, 2010), adolescents with ASD are often unaware of the myriad of terms that are used medically and casually. For example, sexual intercourse can be scientifically referred to as coitus, casually referred to as sex, and referred to in slang as making love, screwing, or countless other colloquialisms. Social comprehension can be difficult for high functioning adolescents with ASD (Kroncke et al., 2016), therefore it is important to educate individuals with ASD about the terminology that is used for various sexual acts and what social parameters surround each term.

For individuals with ASD, unfamiliarity with slang terms for sexual acts, and a lack of an understanding of what a specific sex act entails, may result in confusion (e.g., an adolescent with ASD might not understand that “balls” is common slang for “testicles” and misunderstand a peer conversation), negative social consequences (e.g., unintentionally offending a potential partner by referring to a sexual act as a slang term that is considered derogatory or rude), or unsafe behaviors (e.g., using the internet to search for a slang term and being provided inaccurate information or taken to illegal sites). Additionally, it is important that adolescents with ASD know where to safely seek out information on an unfamiliar term or sex act that they may have heard.

Inclusion of sexual colloquialisms in sexuality education resources for high functioning adolescents with ASD is not uncommon; Attwood (2008) and Davies and Dubie (2012) include slang terms for body parts and sex acts in their sexuality education resources. Ideally, a parent, sexuality education professional, or one of the “common slang” chapters or handouts provided in existing sexuality education resources (Attwood 2008; Davies & Dubie, 2012) can be utilized as a resource for high functioning ASD to get information on the meaning of specific slang terms or sexual acts. It is the recommendation of the Guidelines that high functioning adolescents with ASD be educated about common slang and different sex acts and that future resources developed for the sexuality education of high functioning students with ASD include content on the use of common slang and knowledge of different sex acts.

Sensory needs. The sensory needs topic was generated from participant responses in this study and was not one of the topic areas included in the *National Sexuality Education Standards*. The Guidelines definition of the sensory needs content topic area includes, “identifying, coping with, and discussing sensory sensitivities; developing an awareness that sensory needs vary from person to person; and understanding how sensory needs can impact a romantic relationship.”

Kroncke et al. (2016) state that the autism phenotype includes repetitive sensory and motor behavior. Individuals with ASD often have heightened sensory needs (Cermak, Curtin & Bandini, 2010) such as being highly sensitive to sights, smells, tastes and touch and/or becoming overwhelmed by mild sensory input (Kroncke et al., 2016). The powerful sensations that accompany sexual arousal, individual or shared touch,

masturbation, and sexual acts may be aversive to some individuals with ASD. For example, for some individuals with ASD the sensation of wearing a condom may be unpleasant. Oppositely, individuals with ASD may enjoy the sensation of sexual behaviors (e.g., masturbation) so much that it becomes a restricted and repetitive activity that is socially maladaptive. Indeed, Newport and Newport (2002) wrote a book about ASD and sexuality from their personal perspective as married partners with ASD and included an entire chapter entitled “sensory issues in sex!”

When dating or initiating romantic relationships for the first time, high functioning adolescents with ASD may not expect the various sensations that are involved in romantic relationships. Additionally, due to theory of mind deficits (Kroncke et al., 2016) individuals with ASD may have a difficult time understanding the sensory needs of their partner. The social communication deficits associated with ASD may make it difficult for an individual with ASD to communicate their sensory needs to a partner. It is the recommendation of the Guidelines that sexuality education curricula for high functioning students with ASD: addresses the role that sensation plays in intimate relationships, fosters an awareness of individual sensory needs and how they may differ from the sensory needs of a partner, and provides strategies for how to communicate and manage sensory differences. Newport and Newport (2002) recommend slowing down, sensually enjoying and engaging in the world involving all five senses, exercise, and meditation as strategies that can help individuals with ASD manage their sensory needs in sexually intimate relationships.

Delivery. The delivery section of the Guidelines provides statements regarding individual student needs, strategies to create the ideal learning environment, suggestions of appropriate school-based professionals to deliver sexuality education curricula to high functioning students with ASD, specific strategies that would be useful in teaching high functioning students with ASD about sexuality, suggestions of how to measure mastery of skill, and a statement regarding including neurotypical peers in a sexuality education curriculum designed for high functioning students with ASD. In the following sections, the delivery section of the Guidelines will be discussed regarding its utility, alignment or divergence from the literature, and significance.

Individual needs. Because Autism is a spectrum disorder, it is expressed differently in each individual; each person with ASD is unique. For example, whereas some students with ASD may benefit from proprioceptive input to help regulate sensory needs, other students with ASD may not. The Guidelines state that “it is important to recognize individual student needs when providing a sexuality education curriculum to high functioning students with ASD. Individualized supports and differentiated instruction should be utilized whenever possible.” The importance of catering sexuality curricula for high functioning students with ASD to meet the distinctive needs of the students in the classroom is imperative. Differentiated teaching is an intervention that should be available to all students universally (Kroncke et al., 2016). Individualized supports such as antecedent procedures (i.e., manipulating some aspect of the environment to generate a desired response or decrease an undesired response), delayed contingencies (unpredictable contingencies that increase the maintenance of behavior in

the absence of direct supervision), self-management strategies (e.g., student selection of goals, self-observation, student administering their own reinforcement), and peer-mediated interventions (i.e., involving neurotypical peers as socially competent facilitators to promote appropriate social communication and behaviors) have been proven to be effective in supporting children with ASD in general education classrooms (Crosland & Dunlap, 2012; Harrower & Dunlap, 2001). The Guidelines recommend that individual student needs be considered when implementing a sexuality education curriculum for high functioning students with ASD.

Environment. The Guidelines state that “sexuality education curricula for high functioning students with ASD should be implemented in the least restrictive environment that limits distractions, addresses sensory needs, incorporates breaks, and utilizes both small group and individual instruction when appropriate.” This aligns with federal legislation that requires that schools provide each student with a free and appropriate public education in the least restrictive environment (IDEA Regulations, 34 § C.F.R. 300.8). Additionally, because sensory sensitivities are common in individuals with ASD, providing proactive sensory breaks that are preferably developed by an occupational therapist and do not inadvertently serve to reinforce off-task or otherwise disruptive classroom behaviors may prove beneficial (Kroncke et al., 2016). Similarly, “many individuals with ASD frequently need movement breaks to enable them to optimally focus their attention when working” (Kroncke et al., 2016), therefore, providing proactive and frequent breaks within a sexuality education curriculum designed for high functioning students with ASD would be to the benefit of the student(s). Small

group instruction is often provided to students who are identified as “at-risk” in areas of need so that they are provided with increased opportunities to practice and learn skills (Fuchs, Fuchs, & Compton, 2012); because students with ASD have deficits in social reciprocity and communication and also are at an increased risk for victimization it is appropriate to provide a sexuality education program to high functioning students with ASD in a small group setting. If a particular student warrants more intensive intervention, then one-on-one support may be warranted (Fuchs et al., 2012).

The Guidelines also state that,

although every student has unique needs, some general guidelines for developing a supportive classroom environment for implementing a sexuality education curriculum for high functioning students with ASD include: a small student teacher ratio; supportive individuals to discuss topics with; open and accepting teacher-student and peer-to-peer relationships; and, respect for individual learning styles.

In general, research suggests that a small student to teacher ratio has been shown to be effective in teaching new communication or other skills to students with ASD and generalization skills can be targeted in larger groups or a full class of 20 or more students (Kroncke et al., 2016). Because sexuality education typically involves teaching new topics and skills to students with ASD, a small student-teacher ratio would be beneficial to the student in learning various aspects of the curriculum. Further, a supportive, open, and accepting classroom environment is essential in order for both adults and adolescents to feel comfortable and safe discussing sensitive subject matter such as sexuality and intimate relationships. Dubie and Davies (2012) recommend that being honest, having a sense of humor, and maintaining appropriate boundaries are all central strategies for providing a sexuality education curriculum to high functioning students with ASD.

Providers of school-based sexuality education curricula. Sexuality education providers often vary by school, district, and state. When identifying school-based professionals who are well suited to teach a sexuality education curriculum to high functioning students with ASD, it is important to first consider who within the school has already fostered a positive relationship with the students who will be in receiving the curriculum and what school-based professionals have familiarity with ASD. The Guidelines state,

In schools, a team of school-based professionals who understand ASD and who have positive relationships with the students who they will be teaching should ideally provide a sexuality education curriculum for high functioning students with ASD. School-based professionals who are particularly well suited for the delivery of a sexuality education curriculum for high functioning students with ASD include health teachers, school psychologists, school social workers, and special education teachers. Other professionals such as school nurses, autism consultants, occupational therapists, and speech language pathologists who also have knowledge and experience working with students with ASD may also be appropriate to deliver a sexuality education curriculum for students with ASD.

The most important portion of this statement is the first line that states it is best to involve a team of school-based professionals who understand ASD and who have positive relationships with the students. For example, school-based professionals with advanced training in ASD such as a school psychologist may be able to provide indirect consultation services that support delivery of the sexuality education curriculum to a health teacher or special education teacher who has fostered strong relationships with the student(s) and will be the one providing direct instruction. The list of professionals in the Guidelines who may be well suited for delivering sexuality education curricula to high functioning adolescent students with ASD is not intended to be absolute; it is intended to be used as a starting point for researchers and school districts who are interested in

providing sexuality education to high functioning students with ASD and are building their sexuality education team.

Teaching strategies. There are several strategies recommended in the Guidelines that would be useful in teaching high functioning students with ASD about sexuality. These strategies include: the use of visuals (e.g., video, pictures, graphs, charts); using real-world examples; class discussion; repetition; direct, detailed and honest explanations; parent involvement; breaking down information into measurable steps (e.g., using video prompting to break down target skills into steps); structured project based learning; student led research which is overseen by instructors; and appropriate role-play for building relationships skills. All of these strategies overlap with evidence-based strategies that have been used to teach students with ASD about social skills.

There is a plethora of research that supports the use of visuals when educating students with ASD (Dettmer, Simpson, Myles & Gantz, 2000) so it is logical to assume that sexuality education also should rely heavily on visual supports. Davies and Dubie (2012), Hartman (2014), and Visser et al., (2015) all include visual components to their sexuality education programming resources for high functioning students with ASD such as social stories, diagrams, and pictures. Similarly, the strategies of direct, detailed, and honest explanations (Davies & Dubie, 2012), parent involvement (National Campaign to Prevent Teen Pregnancy, 1997), breaking down information into measurable steps through supports such as video prompting (Domire & Wolfe, 2014), project based learning and student led research (e.g., utilizing an inquiry-based methodology to help students identify and research issues) (McManmon, 2015), and role-play for building

relationship skills (Tse, Strulovitch, Tagalakis, Meng & Fombonne, 2007) have been shown to be effective for use with students with ASD. A sexuality education curriculum for high functioning students with ASD does not necessarily have to incorporate each teaching strategy listed in the Guidelines. The teaching strategies provided are intended to help support parents, educators, and researchers in effectively catering sexuality education to the needs of high functioning students with ASD.

Measuring mastery. Because of the content included in a sexuality education curriculum, measuring mastery or skill acquisition can be difficult. Although some existing sexuality education curricula for high functioning students with ASD encourage the use of quizzes and tests to measure mastery, the experts in this study strongly disagreed that testing would adequately measure whether or not students understand the complex social, emotional, physical, and legal components of sexuality and relationships. Wiggins and McTighe (2005) posit that “if students can understand, then they can provide evidence of that understanding by showing that they know and can do certain specific things.” This rings true in sexuality education where knowledge of facts will do students little good if they do not understand how to utilize that knowledge in an appropriate way. The Guidelines state that

Measuring mastery of skills in a sexuality education curriculum for high functioning students with ASD can be difficult. Ultimately, the goal is to have students be able to generalize what is learned in the curriculum to the real world. There are a variety of strategies that can be appropriate for use in measuring skills acquisition. These strategies should be implemented with a highly structured plan and plenty of guidance and support for the students. Strategies to measure mastery of skill include: role play; completion of projects; practical assignments (e.g., how to put on a condom); class discussion; parent/teacher report of life events; oral/written explanations following a rubric; family or school based

professional observation of an increase in desired behaviors and a decrease of problem behaviors.

Many of the strategies suggested in the Guidelines follow Wiggins and McTighe's (2005) recommendation of "getting evidence of understanding by crafting assessments to evoke transferability: finding out if students can take their learning and use it wisely, flexibly, creatively" (Wiggins & McTighe, 2005, pg. 48). As stated in Guidelines, the ultimate goal is to have students be able to generalize what is learned in the curriculum to the real world. Many of the recommendations included in the Guidelines allow students to demonstrate a deeper understanding of the sexuality education concepts that they learn rather than merely reciting learned facts.

The use of appropriate role play would allow students to practice social skills such as initiating a conversation with a romantic interest or identifying the differences between a healthy versus unhealthy relationship. Oral/written explanations following a rubric allow educators or researchers to develop an individualized writing prompt that requires a student to explain their thinking and reasoning and can be targeted to the specific needs of a student. Parent/teacher report of life events and observation of increases in desired behaviors and reductions in undesired behaviors demonstrate gains made in daily functioning across multiple environments. Completing projects (e.g., put together a presentation about how a woman becomes pregnant; in a small group, write and perform a short skit about how to ask out a romantic interest) involves applied learning and provides opportunities to work collaboratively with peers, teachers, and parents. Practical assignments, such as how to put on a condom, allow students to practice behaviors and demonstrate skill acquisition in a safe, supportive learning

environment. Indeed, rather than merely relying on rote memorization and testing to demonstrate learned skills the Guidelines recommend strategies that demonstrate an understanding of acquired knowledge to achieve the goal of generalization to the real world.

Including neurotypical peers. The experts in this study were unable to reach consensus on whether or not a sexuality education curriculum for high functioning adolescents with ASD should be provided in an environment that includes neurotypical peers or in an environment that is solely comprised of students with ASD. What the experts were able to agree upon was that,

Including neurotypical peers in the sexuality education of high functioning students with ASD can be beneficial if done thoughtfully. It may not be appropriate to include neurotypical peers in every aspect of the curriculum as the delivery, pacing, and depth will be modified for students with ASD. Families and schools should discuss if, how, and when it might be appropriate to integrate high functioning students with ASD and their neurotypical peers in the context of a sexuality education curriculum.

Essentially, experts were able to agree that the decision to integrate high functioning adolescent students with their neurotypical peers should be considered on a case-by-case basis. There are valid arguments to including and excluding neurotypical peers from a sexuality education curriculum intended for high functioning students with ASD. For example, a parent participant shared concerns that students with ASD may be teased or victimized by certain neurotypical peers in a classroom where sexuality education was being taught; this is a reasonable concern as the literature supports that individuals with ASD are more susceptible to bullying (Kroncke et al., 2016). The opposing argument was that an inclusionary model of sexual education curriculum delivery is best practice;

this stance is also supported by research and federal legislation that supports an inclusionary model for education students with disabilities. Additionally, peer mediated strategies involving the involvement of neurotypical peers as “socially competent facilitators to promote appropriate communicative and social behaviors” (Strain, Kohler & Goldstein, 1996) have been found to be effective in providing social learning opportunities via peer interaction, peer modeling, and peer reinforcing (Crosland & Dunlap, 2012).

Ultimately, the findings of this study suggest that it is not appropriate to make a blanket statement that sexuality education for high functioning students with ASD should only occur in an inclusionary classroom model or only with other students with ASD. Rather, researchers, school psychologists, and families using the Guidelines are advised to engage in meaningful conversation taking into account the individual needs of the student(s) with ASD who will be participating in a sexuality education curriculum and rely on a body of evidence to guide their decision as to whether or not it is appropriate and beneficial to include neurotypical peers in their sexuality education.

Responsibilities. The responsibilities section of the Guidelines provides specific family-school partnering strategies that should be included in existing and future sexuality education curricula for high functioning adolescent students with ASD as well as statements regarding the role of families and the role of the school in providing sexuality education to high functioning adolescents with ASD. In the following sections, the Responsibilities section of the Guidelines will be discussed regarding its utility, alignment or divergence from the literature, and significance.

Family-school partnering strategies. Family-school partnering (FSP) is a framework that involves sharing responsibility for a student's school success (Lines, Miller & Arthur-Stanley, 2011). Research demonstrates that families have a significant influence on student achievement in school and that when schools, families, and community groups partner students tend to be more successful in school, stay in school longer, and like school more (Henderson & Mopp, 2002, pg 7). Because of the significant impact that FSP has on student success, it is essential to purposefully facilitate FSP within a sexuality education curricula for high functioning students with ASD. The Guidelines state that,

Schools and families both have significant roles in the sexuality education of high functioning adolescent students with ASD. The sexuality education of high functioning adolescent students with ASD is most successful when schools and families partner and work together as a team. Examples of ways that schools and families can partner include engaging in effective two-way communication, sharing resources (e.g., providers within the community who can provide additional support), and providing parent education trainings on the topic of the sexuality education needs of students with ASD. Allowing parents to preview and/or discuss the sexuality education curriculum that will be taught in the school and encouraging family involvement on the sexuality education assignments that may occur during the curriculum are effective ways to develop a family-school partnership surrounding the sexuality education of high functioning students with ASD.

When this statement is deconstructed, it is evident that the suggestions are all aligned with existing FSP and sexuality education research. Firstly, the opening statement that “schools and families both have significant roles in the sexuality education of high functioning students with ASD” is supported by FSP tenets (Lines et al., 2011) and sexuality education research (Grossman et al., 2013; Holmes & Himle, 2014; Ruble & Dalrymple, 2002). Further, the Guidelines state that “the sexuality education of high

functioning adolescent students with ASD is most successful when schools and families partner and work together as a team.” The recognition by the expert participants of the importance of family involvement and FSP surrounding the sexuality education of high functioning students with ASD is echoed in the following portion of the SIECUS position statement on parents and caregivers as sexuality educators,

SIECUS believes that parents and caregivers are – and ought to be – their children’s primary sexuality educators. SIECUS recognizes that a number of factors, including lack of knowledge, skills, or comfort, may impede a parent’s or caregiver’s successful fulfillment of that role. SIECUS believes that communities, schools, faith-based institutions, the media, and professional sexuality educators should help parents by providing training, resources, understanding, and encouragement (SIECUS, Parents as Sexuality Educators, para. 1).

It is noteworthy to highlight that SIECUS explicitly acknowledges the role of parents and caregivers in the sexuality education of their children as well as the role that schools have in “providing training, resources, understanding, and encouragement.”

The specific FSP strategies that support the sexuality education of high functioning adolescent students with ASD that are included in the Guidelines are: effective two-way communication, sharing resources (e.g., providers within the community who can provide additional support), providing parent education trainings on the topic of sexuality education needs of students with ASD, allowing parents to preview and/or discuss the sexuality education curriculum that will be taught in the school, and encouraging family involvement on sexuality education homework assignments that may occur in the curriculum. Each of these strategies (two-way communication, sharing resources, parent education, access to curricula, and encouraging family involvement) are supported in the FSP literature as effective (Lines et al., 2011). Meaningfully engaging

families in sexuality education curricula for high functioning adolescents with ASD is critical; future curricula should provide specific strategies and recommendations on how to engage families in the curriculum.

The role of families. This research purposefully sought to include a parent perspective and asked research, school psychologist, and family experts about the ideal role of families in a sexuality education curriculum intended for high functioning students with ASD. Many of the existing sexuality education resources do not intentionally engage families in the sexuality education of their child. That said, some recently developed sexuality education materials designed for high functioning students with ASD have explicitly acknowledged family roles such as partnering with a school-based team (Hartman, 2014) or engaging in sexuality education homework assignments with their child (Visser et al., 2015).

The Guidelines state that “family involvement is a critical component of successful sexuality education curricula for high functioning students with ASD.” This is aligned with the National Campaign to Prevent Teen Pregnancy (1997) advocacy efforts to include families in sexuality education programming. Specifically, the Guidelines recommend that families should: be aware of the school based sexuality education curriculum (or lack of one); be able to reinforce what is being taught by the schools; facilitate/foster sexuality education discussions with their child; and, share their child’s specific needs surrounding sexuality education with the school. The Guidelines recommendations for family involvement mirror many of the Colorado Department of Education recommendations for family, school, and community partnering within a

multi-tiered systems of support framework such as: sharing power by having families and staff partner in decisions that affect children and families and working together to create programs; supporting student success by supporting students' learning at home; communicating effectively by engaging in regular, two-way communication; and speaking up for every child by being advocates for their own and other children (Colorado Department of Education, 2015).

It is significant to note that experts in this study were unable to reach consensus on who bears the primary responsibility for educating high functioning adolescent students with ASD about sexuality. This is in contrast with the SIECUS position statement that identifies parents and caregivers as their children's primary sexuality educators (SIECUS, Parents as Sexuality Educators, para 1). Other research indicates that parents are typically the initial sexuality educators of children (Martin, Luke, & Verduzco-Baker, 2007); however, they are often not perceived as the primary sexuality educators by the child (Angera et al., 2008). Considering how controversial the topic of sexuality education in America is, it is not surprising that consensus was not met regarding whether schools or families should be the primary sexuality educators of students with ASD. Regardless of who should be the primary educator, the Guidelines unequivocally state that both parents and schools have a role in the sexuality education of high functioning students with ASD.

Currently, 35 states and the District of Columbia allow parents to opt-out of school-based sexuality education on behalf of their children (National Conference of State Legislatures, 2016). The Guidelines align with this stance, and state that,

Once the families are informed of the sexuality education curriculum that will be taught, families may choose to withdraw their consent for their child to participate in the sexuality education curriculum provided by the school. The school should communicate with the family about the potential risks involved in withdrawing consent.

It is significant to note that experts recommend that the school bears a responsibility to communicate with families about the risks involved in withdrawing consent from allowing their child with ASD to participate in school-based sexuality education.

Research suggests that adolescents with ASD are sexual beings (Dewinter et al., 2015) who experience puberty similarly to same-aged peers and are especially vulnerable to abuse (Brown-Lavoie et al. 2014, Nichols & Blakeley-Smith, 2010). It is to the benefit of the child that they are educated about sexuality and relationships, however, the Guidelines acknowledge that parents reserve the ultimate right to determine how their children is educated about sexuality, if at all.

The role of schools. The role of the school in providing sexuality education to students has been controversial in the United States for many years. Moral and religious values sometimes differ from the content that is taught in sexuality education curricula. This study added to the body of research that supports schools providing sexuality education curricula to students, specifically, high functioning students with ASD.

Indeed, the Guidelines state that,

Schools have a responsibility to teach sexuality education to high functioning adolescent students with ASD in a safe and effective learning environment. Additionally, schools should adapt sexuality education curricula to meet the individual needs of students with ASD. Many students with ASD receive services through an Individualized Education Plan (IEP). If necessary, members of a student's IEP team, including the student and his or her family, should specifically address the sexuality education needs of the student and, if appropriate, develop and include sexuality education goals within the IEP.

This statement is powerful in that it unwaveringly purports that schools have a responsibility to educate high functioning students with ASD about sexuality in a safe and effective environment. This statement also echoes recommendations put forth in Hartman's (2014) sexuality education resource for high functioning students with ASD regarding including sexuality education goals in a student's IEP. By including sexuality education goals in an IEP, the school has a legal obligation to educate adolescents with ASD about sexuality. Parents, school psychologists, or other school-based professionals who have concerns about maladaptive behaviors a student with ASD is demonstrating in school (e.g., frequent in-school masturbation) that may be mitigated via sexuality education programming should advocate for a specific goal to be written into a student's IEP regarding the reduction of the maladaptive behavior that is impacting the student's ability to obtain a free and appropriate public education via comprehensive sexuality education.

Implications

The final outcome of this study, the *Guidelines for Developing Sexuality Education Curricula for High Functioning Adolescent Students with Autism Spectrum Disorder*, represent the culmination of ideas from a diverse group of experts with experience working with, researching, or raising high functioning adolescents with ASD and an interest in how to best address sexuality and relationship development. The voices echoed through these guidelines are those of parents, developers of existing sexuality education resources for adolescents with ASD, and school psychologists who work with adolescent students with ASD on a daily basis. It is my hope that these

guidelines will be useful in the development of future sexuality education resources and curricula for students with high functioning ASD; they are a proactive step towards developing resources that have typically been developed reactively out of acute need.

There is a significant need in the field for more sexuality education resources to be developed for use with students with ASD, and for those resources to be evaluated for efficacy. This study confirms that there are specific content, strategies, and responsibilities of schools and parents that are well suited for high functioning students with ASD but not often incorporated into general education sexuality education curricula. Due to the social reciprocity deficits associated with ASD (American Psychological Association, 2013; Kroncke et al., 2016), it can be difficult for students with ASD navigate through the components of sexuality and relationship education in general education curricula. One participant in this study said it very well,

I believe that it is critical for all students to receive sexuality education. However, it is even more critical for students with Autism Spectrum Disorders. Most youth learn about sex informally through social situations and peers. Since youth with Autism Spectrum Disorders are less likely to be involved in peer groups, they have less opportunity to learn about sex. Sexuality education is very important for these students.

ASD and sexuality is an under researched topic and considered by some to be taboo. Many individuals are reticent to self-identify as an expert on this topic, even individuals who have published research on sexuality and ASD, worked with children with ASD, or raised high functioning children with ASD. By consuming research and utilizing

resources such as the Guidelines developed in this study, families and professionals advance their expertise. We should not be ashamed to acknowledge what we do not know, but we also should not be ashamed to share what we do know. In order for high quality resources and curricula to be developed that address sexuality education for students with ASD, individuals who have an interest, have knowledge, or who see a need must become active participants and staunch advocates for the continued expansion of this research area. Sexuality and ASD research is in need of pioneers who are willing to further this area of research by contributing to and/or participating in the development of resources.

In the context of sexuality education in general, it is significant to note that it was repeatedly stated by the experts in each questionnaire iteration that general education students would also benefit from much of the added content, specific strategies, and family-school partnering suggestions that were developed specifically for use in sexuality education curricula for students with ASD. This study adds to the body of research that supports the need for the enrichment of general education comprehensive sexuality education curricula and emphasizes that there is more that should be done to enhance the sexuality education guidelines for all students.

Finally, researchers must continue to collaborate with schools and teachers in addressing the issue of how best to educate students with ASD about sexuality. Especially because of the sensitivity of the subject matter, initiating and sustaining meaningful collaboration is crucial to creating effective programming that results in

positive outcomes for students with ASD. In the words of one of the participants in this study,

Schools and caregivers/parents need to be a collaborative team with respect to sexuality education. There is an equally important role for both, and teaching practices would ideally be comparable across settings to assist with learning, maintenance, and generalization.

School Psychologists, ASD, and Sexuality Education

The voices of school psychologists were included in this research due to their advanced training in consultation, interventions, and behavior. Additionally, school psychologists work with students with disabilities such as ASD in schools; they are often called upon in schools to provide services such as social skills training or behavior management. Sometimes, because of their expertise in behavior management, school psychologists may be asked to modify sexually inappropriate behaviors of high functioning students with ASD or to teach social skills surrounding dating and/or sexuality. McClung and Perfect (2012) argue that school psychologists should be involved in school-based sexual health education due to 1) their expertise in evidence-based interventions, data-based decision making, and research, 2) their training and involvement in primary, or tier 1, interventions involving risk-reduction strategies on a school-wide basis, and 3) their expertise in consultation. Indeed, school psychologists are well-equipped for involvement in the sexuality education of high functioning adolescent students with ASD in either a direct or indirect role.

School psychologists are encouraged to use the Guidelines as a resource to guide the modification or development of sexuality education curricula that meet the needs of high functioning adolescent students with ASD in schools. Using the specific family-school partnering strategies provided within the guidelines, school psychologists can advocate for the importance of sexuality education within a school setting, particularly for high functioning students with ASD, and foster positive conversations and collaboration between families and school staff surrounding this sexuality education. Additionally, school psychologists can utilize the learning strategies within the Guidelines to guide intervention and consultation. Finally, school psychologists are encouraged to use this resource as an advocacy tool in their communities to highlight the importance of providing sexuality education to the vulnerable high functioning students with ASD population.

Limitations

Perhaps blinded by my own passion for this research, I went into this study overzealous in my assuredness that individuals would be readily willing to participate. After all, I intended to recruit expert respondents with a vested interest in this population; either they had researched or developed sexuality education for high functioning adolescents with ASD, worked with high functioning adolescents with ASD, or were raising a high functioning adolescent with ASD. An unforeseen limitation to this study was participant resistance to self-identifying as an expert in sexuality education for high functioning adolescents with ASD. Another limitation was the small total sample size ($n=15$) and how few caregivers of adolescents with ASD participated in this study ($n=2$).

Parent voices were underrepresented in this research even though recruitment efforts were extensive. Finally, a small sample size limits the generalizability and voices that could contribute to this research.

Not identifying as an expert. Particularly surprising was that during the recruitment phase many potential participants replied that they did not identify as an expert. Five ASD and sexuality authors who had published peer-reviewed articles on topics related to ASD and sexuality declined participation. Four of the five stated that the reason for their refusal was that they did not self-identify as experts on this topic and one of the five stated that they did not have time. Two of the five who refused to participate based on a perceived lack of expertise provided me with the names of colleagues who they felt would be a better fit for this particular study.

Responses received from recruitment emails sent to expert participants for the ASD and sexuality author group included “I am not an expert in this area, but my colleague is,” “Although this is definitely an area of interest, I think there may be some others that would have the expertise you are looking for,” and “I am sorry my article on this subject was not prompted through any personal experience with this population.” One respondent politely replied,

I appreciate the invitation, but I don’t think I count as an expert in this field. I did a single paper in this area early in my graduate training, but haven’t even dabbled here since. Good luck with your research.

Another respondent began the Round 1 Questionnaire and then emailed me stating,

I consented to do your research project, but then when going through the questions I found they are far too detailed for my level of expertise. It's probably not the best use of my time or yours for me to continue. Please withdraw me from participation. Best of luck to you.

The fact that ASD researchers with publications on the topic of ASD and sexuality did not self-identify as experts in this field speaks volumes. Not only is sexuality and ASD an under-researched area, but some of the few individuals who have completed research in this area feel that they are under qualified to lend their expertise to future research.

In addition to researchers and authors not wanting to identify as experts, school psychologist and families were reticent to participate as well. The study recruitment email was sent out to state school psychologist organization listservs or posted on national ASD organization websites to recruit school psychologist and caregiver expert participants and often no responses were obtained from these endeavors. Even when an individual's interest was piqued, of the 26 individuals who started the Round 1 Questionnaire, only 15 (58%) completed it. The majority (73%) of individuals who did not complete the Round 1 Questionnaire discontinued after answering only the demographic items.

Amongst the three respondent groups, the highest attrition rate during Round 1 recruitment was the families group (60%), followed by the school psychologist group (40%) and then the ASD and sexuality author group (22%). It is significant that the majority of caregivers of an adolescent with ASD did not complete the initial Round 1 questionnaire after clicking on the link and answering the demographic questions. The

school psychologist group had the highest number ($n=4$) of potential respondents who began Round 1 but did not complete it. One possible hypothesis as to why 42% of Round 1 respondents did not complete the survey is that the open-ended questions proved too time consuming and involved. Additionally, the school psychologist and families group may have had a much larger proportion of potential respondents discontinue the Round 1 questionnaire than the ASD and sexuality author group because they most likely have not written about or studied this topic previously.

It is possible that more individuals would have been willing to participate in this study had the term “expert” not been used in the recruitment verbiage. I hypothesize that the term “expert” connoted a significantly advanced understanding of this subject area that few individuals possess and was intimidating to potential participants. In future research, using a term or phrase less extreme than “expert” to indicate exposure to, interest in, or awareness of the topic of sexuality education for high functioning adolescents with ASD may encourage more individuals to share their perspectives and experiences.

Limited family perspective. Perhaps one of the biggest limitations in this study is the underrepresentation of parent voices. To that end, the difficulty recruiting parent participants to lend their expertise as caregivers of high functioning adolescents with ASD is also one of the most significant findings that resulted from this research. It was unexpectedly difficult to recruit and retain caregivers of high functioning adolescents with ASD as participants in this research. I went into this study assuming that caregivers of children with ASD would welcome the chance to have their voices be a part of

research, and I was surprised and contemplative about their reticence to participate. Of the two parents that I was able to recruit for the study after months of solicitation, one dropped out in Round 3.

One hypothesis as to why so few parents wished to participate is subject matter. Sexuality is still a taboo subject for many individuals, and it might have been perceived as an uncomfortable task to discuss sexuality education via iterative questionnaires over the course of three months. Another hypothesis is that parents truly were unsure as to how to best develop sexuality education for high functioning adolescents with ASD; there are very few resources available and little discussion on how parents can address sexuality with children who have special needs. Finally, the research method used for this study may have intimidated parents from participating due to the time commitment involved; the open-ended and iterative response style; and the use of the term “expert.” It is possible that more parents would have been willing to provide their opinions on the sexuality education of high functioning adolescents with ASD if their responses were solicited via the single administration of a Likert style survey or through an in-person interview or focus group. Future research must address how to meaningfully engage families in the development of sexuality education resources for high functioning adolescents with ASD.

Lack of diversity. The majority of respondents who participated in this study were white females (87%). Fourteen of the 15 participants identified as white and one participant identified as Hispanic/Latino. Although the 15 participants represented 11 geographically diverse states within the United States of America, there was an

overrepresentation of white, female perspectives. Culture can have a significant impact on how an individual views sexuality, relationships, and sexuality education.

Additionally, male and females may differ on their perspectives on sexuality education for high functioning adolescent students with ASD. Future research would benefit from the inclusion of diverse voices.

Generalizability. As with any qualitative study, the ability to replicate findings is difficult if not impossible. The Delphi research method can be conceptualized as a pseudo-qualitative methodology; although I took a structured approach to analyzing data and relied on a percentage of consensus to create items, I still prompted respondents with open ended items to generate the vast majority of content used in the final version of the Guidelines. A different set of expert participants may have potentially generated different results. Care was taken to develop stringent inclusionary and exclusionary criteria so that the expert participants who participated in this study were of the highest caliber; participants were researchers, authors, practicing school psychologists, and parents of children with ASD. Even with a high caliber expert respondent group, it cannot be assumed that these results are reflective of all experts in ASD and sexuality. It is possible that the participants who did choose to participate in this research did so because of a personal belief in the value of sexuality education for students with ASD.

Subject matter. Americans in general are uncomfortable discussing sexuality. During the recruitment phase of this study I received responses from individuals and organizations either championing the importance of this topic, acknowledging the lack of sexuality education taking place in schools, or insisting that this topic would be better

addressed with other individuals. For example, one school psychologist who did not meet criteria for inclusion in the study sent an email stating,

The only sexuality education that our students get is in 5th grade, a single 1 hours [sic] presentation on adolescent development. There is no mention of sexual orientation, gender identity, or sexual activity. It is limited to human growth and development. I don't think I have much to offer you in your study...but I did want to let you know.

Regardless of how uncomfortable it may make some individuals, students with ASD are sexual beings. As educators, caregivers, and researchers it is our responsibility to help high functioning students with ASD navigate sexuality and relationship development in a healthy and successful way. Unfortunately, sexuality education is still not being addressed with the general education population in some school districts across the country, or, the information being taught is inaccurate or the curriculum being used is evidenced to be ineffective. If the general education population is not receiving sexuality education curricula in many school districts across the country, it is safe to assume that students with ASD are not receiving sexuality education curricula either even though they are a vulnerable population with social reciprocity deficits that make explicit sexuality education of the utmost importance. It is a great disservice to all students, and particularly students with high functioning ASD, to omit sexuality education curricula, provide insufficient information, or misinformation.

Future Research

This research resulted in the development of the *Guidelines for Developing Sexuality Education Curricula for High Functioning Adolescent Students with Autism Spectrum Disorder*. There is now a need for a sexuality education curriculum for high functioning students with ASD to be developed that follows the content, delivery, and responsibilities recommendations that are outlined within these Guidelines. Further, there is a need for the efficacy of future sexuality education curricula designed for students with ASD to be evaluated via experimental research designs and with large, generalizable sample sizes. Sexuality education curricula for high functioning students with ASD should be evaluated with the same rigor that has become standard in measuring the efficacy of academic or social emotional curricula. It is only through the proactive, thoughtful development and evaluation of sexuality education curricula and resources for students with ASD that we can achieve true evidence-based interventions and resources.

More research on the sexuality education of high functioning students with ASD is needed that brings together families, professionals who work with students day to day, and researchers. Sexuality can be a difficult subject to research and discuss; therefore, it is especially important to not leave out the voices of individuals (e.g., parents, teachers) who will often be responsible for the sexuality education of these students. Specifically, it will be important for future research to meaningfully engage families in the development of sexuality education resources for students with ASD. Families may be more willing to participate in research that is less labor intensive and does not require extended participation over several months. Families have a critical role in the sexuality

education of their children, and especially children with ASD; future research must provide a conduit for the thoughts, opinions, and needs of families. One participant in this study acknowledged that it would “probably be wise to conduct research with parents to find out what they want and what is feasible for the majority.” Additionally, it would be ideal to include the voices of adolescents with ASD in future research.

The expert participants in this study were unable to reach consensus regarding whether or not sexuality education curricula for high functioning adolescent students with ASD should be delivered in a classroom with a mixture of neurotypical students and students with ASD. Future research should specifically address the efficacy of sexuality education curricula that are delivered to classrooms with a mixture of neurotypical students and students with ASD compared to sexuality education curricula that are delivered to classrooms of solely high functioning students with ASD.

Conclusion

In conclusion, too often resources have been developed in this field out of reactive necessity rather than careful, proactive planning. I deeply commend the good work of my colleagues who have developed resources to aid in the sexuality education of high functioning students with ASD thus far in order to meet an unanswered need for resources in the field. My hope is that the Guidelines developed from this research will be a useful, proactive step in developing evidence based sexuality education curricula and resources for students with ASD. These guidelines can support future research and the development of sexuality education resources for students with ASD, and can be utilized by school-based professionals, community stakeholders, and families to modify existing

curricula to meet the sexuality education needs of high functioning adolescents with ASD.

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Appendices

- Appendix A – *DSM-5* Diagnostic Criteria for Autism Spectrum Disorder
- Appendix B – *DSM-IV-TR* Diagnostic Criteria for Autistic Disorder
- Appendix C – *DSM-IV-TR* Diagnostic Criteria for Asperger’s Disorder
- Appendix D – *DSM-IV-TR* Diagnostic Criteria for PDD NOS
- Appendix E – *DSM-5* ASD Severity Indicators
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Appendix A

Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5) Diagnostic Criteria for Autism Spectrum Disorder p. 50-51

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Neurodevelopmental Disorders

Autism Spectrum Disorder

Autism Spectrum Disorder

Diagnostic Criteria

299.00 (F84.0)

- A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive; see text):
1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
 2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
 3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.
- Specify current severity:*
Severity is based on social communication impairments and restricted, repetitive patterns of behavior (see Table 2).
- B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):
1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
 2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
 3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
 4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).
- Specify current severity:*
Severity is based on social communication impairments and restricted, repetitive patterns of behavior (see Table 2).
- C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).
- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

- E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Specify if:

With or without accompanying intellectual impairment

With or without accompanying language impairment

Associated with a known medical or genetic condition or environmental factor
(**Coding note:** Use additional code to identify the associated medical or genetic condition.)

Associated with another neurodevelopmental, mental, or behavioral disorder
(**Coding note:** Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)

With catatonia (refer to the criteria for catatonia associated with another mental disorder, pp. 119–120, for definition) (**Coding note:** Use additional code 293.89 [F06.1] catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia.)

Appendix B

Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revised (DSM-IV-TR) Diagnostic criteria for Autistic Disorder p. 75

299.00 Autistic Disorder 75 |

Diagnostic criteria for 299.00 Autistic Disorder

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

- (1) qualitative impairment in social interaction, as manifested by at least two of the following:
 - (a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - (b) failure to develop peer relationships appropriate to developmental level
 - (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
 - (d) lack of social or emotional reciprocity
- (2) qualitative impairments in communication as manifested by at least one of the following:
 - (a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
 - (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
 - (c) stereotyped and repetitive use of language or idiosyncratic language
 - (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
- (3) restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
 - (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - (b) apparently inflexible adherence to specific, nonfunctional routines or rituals
 - (c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
 - (d) persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Appendix C

Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revised (*DSM-IV-TR*)

Diagnostic criteria for Asperger's Disorder p. 84

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Disorders Usually First Diagnosed in Infancy,
Childhood, or Adolescence

Diagnostic criteria for 299.80 Asperger's Disorder

- A. Qualitative impairment in social interaction, as manifested by at least two of the following:
 - (1) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - (2) failure to develop peer relationships appropriate to developmental level
 - (3) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
 - (4) lack of social or emotional reciprocity
- B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
 - (1) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - (2) apparently inflexible adherence to specific, nonfunctional routines or rituals
 - (3) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
 - (4) persistent preoccupation with parts of objects
- C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
- D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).
- E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.
- F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

Appendix D

Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revised
(*DSM-IV-TR*)
Diagnostic criteria for Asperger's Disorder p. 84

299.80 Pervasive Developmental Disorder Not Otherwise Specified (Including Atypical Autism)

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behavior, interests, and activities, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder. For example, this category includes "atypical autism"—presentations that do not meet the criteria for Autistic Disorder because of late age at onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

Appendix E

Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5) Severity Levels for Autism Spectrum Disorder p.52

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Neurodevelopmental Disorders

TABLE 2 Severity levels for autism spectrum disorder

Severity level	Social communication	Restricted, repetitive behaviors
<p>Level 3 "Requiring very substantial support"</p>	<p>Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches.</p>	<p>Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.</p>
<p>Level 2 "Requiring substantial support"</p>	<p>Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and who has markedly odd nonverbal communication.</p>	<p>Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.</p>
<p>Level 1 "Requiring support"</p>	<p>Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to-and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.</p>	<p>Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.</p>

Appendix F

National Sexuality Education Standards by Grade Level p.12-23

National Sexuality Education Standards

Standards by Grade Level

GRADE K-2	Core Concepts CC	Analyzing Influences INF	Accessing Information AI	Interpersonal Communication IC	Decision-Making DM	Goal Setting GS	Self-Management SM	Advocacy/ADV
ANATOMY & PHYSIOLOGY								
By the end of the 2 nd grade, students should be able to:	Use proper names for body parts, including male and female anatomy AP.2.CC.1							
PUBERTY AND ADOLESCENT DEVELOPMENT								
	No items							
IDENTITY								
By the end of the 2 nd grade, students should be able to:	Describe differences and similarities in how boys and girls may be expected to act ID.2.CC.1	Provide examples of how friends, family, media, society and culture influence ways in which boys and girls think they should act ID.2.INF.1						
PREGNANCY AND REPRODUCTION								
By the end of the 2 nd grade, students should be able to:	Explain that all living things reproduce PR.2.CC.1							
SEXUALLY TRANSMITTED DISEASES AND HIV								
	No items							
HEALTHY RELATIONSHIPS								
By the end of the 2 nd grade, students should be able to:	Identify different kinds of family structures HR.2.CC.1			Demonstrate ways to show respect for different types of families HR.2.IC.1				
	Describe the characteristics of a friend HR.2.CC.2			Identify healthy ways for friends to express feelings to each other HR.2.IC.2				

Core Concepts CC	Analyzing Influences INF	Accessing Information AI	Interpersonal Communication IC	Decision-Making DM	Goal Setting GS	Self-Management SM	Advocacy ADV
PERSONAL SAFETY							
By the end of the 2 nd grade, students should be able to:	Explain that all people, including children, have the right to tell others not to touch their body when they do not want to be touched PS.2.CC.1	Identify parents and other trusted adults they can tell if they are feeling uncomfortable about being touched PS.2.AI.1	Demonstrate how to respond if someone is touching them in a way that makes them feel uncomfortable PS.2.IC.1			Demonstrate how to clearly say no, how to leave an uncomfortable situation, and how to identify and talk with a trusted adult if someone is touching them in a way that makes them feel uncomfortable PS.2.SM.1	
	Explain what bullying and teasing are PS.2.CC.2						
	Explain why bullying and teasing are wrong PS.2.CC.3	Identify parents and other trusted adults they can tell if they are being bullied or teased PS.2.AI.2	Demonstrate how to respond if someone is bullying or teasing them PS.2.IC.2				

GRADE 3-5							
Core Concepts CC	Analyzing Influences INF	Accessing Information AI	Interpersonal Communication IC	Decision-Making DM	Goal Setting GS	Self-Management SM	Advocacy ADV
ANATOMY & PHYSIOLOGY							
By the end of the 5 th grade, students should be able to:	Describe male and female reproductive systems including body parts and their functions AP.5.CC.1	Identify medically-accurate information about female and male reproductive anatomy AP.5.AI.1					
PUBERTY AND ADOLESCENT DEVELOPMENT							
By the end of the 5 th grade, students should be able to:	Explain the physical, social and emotional changes that occur during puberty and adolescence PD.5.CC.1	Describe how friends, family, media, society and culture can influence ideas about body image PD.5.INF.1	Identify medically-accurate information and resources about puberty and personal hygiene PD.5.AI.1			Explain ways to manage the physical and emotional changes associated with puberty PD.5.SM.1	
	Explain how the timing of puberty and adolescent development varies considerably and can still be healthy PD.5.CC.2	Identify parents or other trusted adults of whom students can ask questions about puberty and adolescent health issues PD.5.AI.2					
	Describe how puberty prepares human bodies for the potential to reproduce PAD.5.CC.3						
IDENTITY							
By the end of the 5 th grade, students should be able to:	Define sexual orientation as the romantic attraction of an individual to someone of the same gender or a different gender ID.5.CC.1	Identify parents or other trusted adults of whom students can ask questions about sexual orientation ID.5.AI.1				Demonstrate ways to treat others with dignity and respect ID.5.SM.1	Demonstrate ways students can work together to promote dignity and respect for all people ID.5.ADV.1

Core Concepts CC	Analyzing Influences INF	Accessing Information AI	Interpersonal Communication IC	Decision-Making DM	Goal Setting GS	Self-Management SM	Advocacy ADV
PREGNANCY AND REPRODUCTION							
By the end of the 5 th grade, students should be able to:	Describe the process of human reproduction PR.5.CC.1						
SEXUALLY TRANSMITTED DISEASES AND HIV							
By the end of the 5 th grade, students should be able to:	Define HIV and identify some age appropriate methods of transmission, as well as ways to prevent transmission SH.5.CC.1						
HEALTHY RELATIONSHIPS							
By the end of the 5 th grade, students should be able to:	Describe the characteristics of healthy relationships HR.5.CC.1	Identify parents and other trusted adults they can talk to about relationships HR.5.AI.1	Demonstrate positive ways to communicate differences of opinion while maintaining relationships HR.5.IC.1			Demonstrate ways to treat others with dignity and respect HR.5.SM.1	
PERSONAL SAFETY							
By the end of the 5 th grade, students should be able to:	Define teasing, harassment and bullying and explain why they are wrong PS.5.CC.1	Explain why people tease, harass or bully others PS.5.INF.1	Identify parents and other trusted adults they can tell if they are being teased, harassed or bullied PS.5.AI.1	Demonstrate ways to communicate about how one is being treated PS.5.IC.1		Discuss effective ways in which students could respond when they are or someone else is being teased, harassed or bullied PS.5.SM.1	Persuade others to take action when someone else is being teased, harassed or bullied PS.5.ADV.1
Define sexual harassment and sexual abuse PS.5.CC.2		Identify parents or other trusted adults they can tell if they are being sexually harassed or abused PS.5.AI.2	Demonstrate refusal skills (e.g. clear "no" statement, walk away, repeat refusal) PS.5.IC.2				

GRADES 6-8							
Core Concepts CC	Analyzing Influences INF	Accessing Information AI	Interpersonal Communication IC	Decision-Making DM	Goal Setting GS	Self-Management SM	Advocacy ADV
ANATOMY AND PHYSIOLOGY							
By the end of the 8 th grade, students should be able to:	Describe male and female sexual systems including body parts and their functions AP.8.CC.1	Identify accurate and credible sources of information about sexual health AP.8.AI.1					
PUBERTY AND ADOLESCENT DEVELOPMENT							
By the end of the 8 th grade, students should be able to:	Describe the physical, social, cognitive and emotional changes of adolescence PD.8.CC.1	Identify medically-accurate sources of information about puberty, adolescent development and sexuality PD.8.AI.1		Demonstrate the use of a decision-making model and evaluate possible outcomes of decisions adolescents might make PD.8.DM.1			
IDENTITY							
By the end of the 8 th grade, students should be able to:	Differentiate between gender identity, gender expression and sexual orientation ID.8.CC.1	Access accurate information about gender identity, gender expression and sexual orientation ID.8.AI.1	Communicate respectfully with and about people of all gender identities, gender expressions and sexual orientations ID.8.IC.1				Develop a plan to promote dignity and respect for all people in the school community ID.8.ADV.1
	Explain the range of gender roles ID.8.CC.2						
PREGNANCY AND REPRODUCTION							
By the end of the 8 th grade, students should be able to:	Define sexual intercourse and its relationship to human reproduction PR.8.CC.1						
	Define sexual abstinence as it relates to pregnancy prevention PR.8.CC.2		Demonstrate the use of effective communication skills to support one's decision to abstain from sexual behaviors PR.8.IC.1				
	Examine how alcohol and other substances, friends, family, media, society and culture influence decisions about engaging in sexual behaviors PR.8.INF.1						

Core Concepts CC	Analyzing Influences INF	Accessing Information AI	Interpersonal Communication IC	Decision-Making DM	Goal Setting GS	Self-Management SM	Advocacy ADV
PREGNANCY AND REPRODUCTION (CONTINUED)							
By the end of the 8 th grade, students should be able to:	Explain the health benefits, risks and effectiveness rates of various methods of contraception, including abstinence and condoms PR.8.CC.3	Identify medically-accurate resources about pregnancy prevention and reproductive health care PR.8.AI.1	Demonstrate the use of effective communication and negotiation skills about the use of contraception including abstinence and condoms PR.8.IC.2	Apply a decision-making model to various sexual health decisions PR.8.DM.1		Describe the steps to using a condom correctly PR.8.SM.1	
Define emergency contraception and its use PR.8.CC.4	Identify medically-accurate information about emergency contraception PR.8.AI.2						
Describe the signs and symptoms of a pregnancy PR.8.CC.5	Identify medically-accurate sources of pregnancy-related information and support including pregnancy options, safe surrender policies and prenatal care PR.8.AI.3						
Identify prenatal practices that can contribute to a healthy pregnancy PR.8.CC.6							
SEXUALLY TRANSMITTED DISEASES AND HIV							
By the end of the 8 th grade, students should be able to:	Define STDs, including HIV, and how they are and are not transmitted SH.8.CC.1	Identify medically-accurate information about STDs, including HIV SH.8.AI.1					
Compare and contrast behaviors, including abstinence, to determine the potential risk of STD/HIV transmission from each SH.8.CC.2	Analyze the impact of alcohol and other drugs on safer sexual decision-making and sexual behaviors SH.8.INF.1		Demonstrate the use of effective communication skills to reduce or eliminate risk for STDs, including HIV SH.8.IC.1		Develop a plan to eliminate or reduce risk for STDs, including HIV SH.8.GS.1	Describe the steps to using a condom correctly SH.8.SM.1	

GRADES 6-8 (CONTINUED)							
Core Concepts CC	Analyzing Influences INF	Accessing Information AI	Interpersonal Communication IC	Decision-Making DM	Goal Setting GS	Self-Management SM	Advocacy ADV
SEXUALLY TRANSMITTED DISEASES AND HIV (CONTINUED)							
By the end of the 8 th grade, students should be able to:		Identify local STD and HIV testing and treatment resources SH.8.AI.2					
HEALTHY RELATIONSHIPS							
By the end of the 8 th grade, students should be able to:	Compare and contrast the characteristics of healthy and unhealthy relationships HR.8.CC.1	Analyze the ways in which friends, family, media, society, and culture can influence relationships HR.8.INF.1				Explain the criteria for evaluating the health of a relationship HR.8.SM.1	
	Describe the potential impacts of power differences such as age, status or position within relationships HR.8.CC.2						
	Analyze the similarities and differences between friendships and romantic relationships HR.8.CC.3		Demonstrate communication skills that foster healthy relationships HR.8.IC.1				
	Describe a range of ways people express affection within various types of relationships HR.8.CC.4		Demonstrate effective ways to communicate personal boundaries and show respect for the boundaries of others HR.8.IC.2				
	Describe the advantages and disadvantages of communicating using technology and social media HR.8.CC.5	Analyze the impact of technology and social media on friendships and relationships HR.8.INF.2	Demonstrate effective skills to negotiate agreements about the use of technology in relationships HR.8.IC.3		Develop a plan to stay safe when using social media HR.8.GS.1	Describe strategies to use social media safely, legally and respectfully HR.8.SM.2	

Core Concepts CC	Analyzing Influences INF	Accessing Information AI	Interpersonal Communication IC	Decision-Making DM	Goal Setting GS	Self-Management SM	Advocacy ADV
PERSONAL SAFETY							
By the end of the 8 th grade, students should be able to:	Describe situations and behaviors that constitute bullying, sexual harassment, sexual abuse, sexual assault, incest, rape and dating violence PS.8.CC.1	Identify sources of support such as parents or other trusted adults that they can go to if they are or someone they know is being bullied, harassed, abused or assaulted PS.8.AI.1	Demonstrate ways to communicate with trusted adults about bullying, harassment, abuse or assault PS.8.IC.1			Describe ways to treat others with dignity and respect PS.8.SM.1	Advocate for safe environments that encourage dignified and respectful treatment of everyone PS.8.ADV.1
	Discuss the impacts of bullying, sexual harassment, sexual abuse, sexual assault, incest, rape and dating violence and why they are wrong PS.8.CC.2					Demonstrate ways they can respond when someone is being bullied or harassed PS.8.SM.2	
	Explain that no one has the right to touch anyone else in a sexual manner if they do not want to be touched PS.8.CC.3						
	Explain why a person who has been raped or sexually assaulted is not at fault PS.8.CC.4						

GRADES 9-12							
Core Concepts CC	Analyzing Influences INF	Accessing Information AI	Interpersonal Communication IC	Decision-Making DM	Goal Setting GS	Self-Management SM	Advocacy ADV
ANATOMY AND PHYSIOLOGY							
By the end of the 12 th grade, students should be able to:	Describe the human sexual response cycle, including the role hormones play AP.12.CC.1						
PUBERTY AND ADOLESCENT DEVELOPMENT							
By the end of the 12 th grade, students should be able to:	Analyze how brain development has an impact on cognitive, social and emotional changes of adolescence and early adulthood PD.12.CC.1	Analyze how friends, family, media, society and culture can influence self-concept and body image PD.12.INF.1		Apply a decision-making model to various situations relating to sexual health PD.12.DM.1			
IDENTITY							
By the end of the 12 th grade, students should be able to:	Differentiate between biological sex, sexual orientation, and gender identity and expression ID.12.CC.1	Analyze the influence of friends, family, media, society and culture on the expression of gender, sexual orientation and identity ID.12.INF.1				Explain how to promote safety, respect, awareness and acceptance ID.12.SM.1	Advocate for school policies and programs that promote dignity and respect for all ID.12.ADV.1
	Distinguish between sexual orientation, sexual behavior and sexual identity ID.12.CC.2						
PREGNANCY AND REPRODUCTION							
By the end of the 12 th grade, students should be able to:	Compare and contrast the advantages and disadvantages of abstinence and other contraceptive methods, including condoms PR.12.CC.1	Analyze influences that may have an impact on deciding whether or when to engage in sexual behaviors PR.12.INF.1	Access medically-accurate information about contraceptive methods, including abstinence and condoms PR.12.AI.1	Demonstrate ways to communicate decisions about whether or when to engage in sexual behaviors PR.12.IC.1		Apply a decision-making model to choices about contraception, including abstinence and condoms PR.12.DM.1	Describe the steps to using a condom correctly PR.12.SM.1

Core Concepts CC	Analyzing Influences INF	Accessing Information AI	Interpersonal Communication IC	Decision-Making DM	Goal Setting GS	Self-Management SM	Advocacy ADV
PREGNANCY AND REPRODUCTION (CONTINUED)							
By the end of the 12 th grade, students should be able to:		Access medically-accurate information and resources about emergency contraception PR.12.AI.2					
PR.12.CC.2							
Identify the laws related to reproductive and sexual health care services (i.e., contraception, pregnancy options, safe surrender policies, prenatal care) PR.12.CC.3							
Describe the signs of pregnancy PR.12.CC.4	Analyze internal and external influences on decisions about pregnancy options PR.12.INF.2	Access medically-accurate information about pregnancy and pregnancy options PR.12.AI.3					
Describe prenatal practices that can contribute to or threaten a healthy pregnancy PR.12.CC.5	Analyze factors that influence decisions about whether and when to become a parent PR.12.INF.3	Access medically-accurate information about prenatal care services PR.12.AI.4		Assess the skills and resources needed to become a parent PR.12.DM.2			
Compare and contrast the laws relating to pregnancy, adoption, abortion and parenting PR.12.CC.6							

GRADES 9-12 (CONTINUED)

Core Concepts CC	Analyzing Influences INF	Accessing Information AI	Interpersonal Communication IC	Decision-Making DM	Goal Setting GS	Self-Management SM	Advocacy ADV
SEXUALLY TRANSMITTED DISEASES AND HIV							
By the end of the 12 th grade, students should be able to:	Describe common symptoms of and treatments for STDs, including HIV SH.12.CC.1	Explain how to access local STD and HIV testing and treatment services SH.12.AI.1	Demonstrate skills to communicate with a partner about STD and HIV prevention and testing SH.12.IC.1	Apply a decision-making model to choices about safer sex practices, including abstinence and condoms SH.12.DM.1		Analyze individual responsibility about testing for and informing partners about STDs and HIV status SH.12.SM.1	
	Evaluate the effectiveness of abstinence, condoms and other safer sex methods in preventing the spread of STDs, including HIV SH.12.CC.2	Analyze factors that may influence condom use and other safer sex decisions SH.12.INF.1	Access medically-accurate prevention information about STDs, including HIV SH.12.AI.2		Develop a plan to eliminate or reduce risk for STDs, including HIV SH.12.GS.1	Describe the steps to using a condom correctly SH.12.SM.2	Advocate for sexually active youth to get STD/HIV testing and treatment SH.12.ADV.1
	Describe the laws related to sexual health care services, including STD and HIV testing and treatment SH.12.CC.3						
HEALTHY RELATIONSHIPS							
By the end of the 12 th grade, students should be able to:	Describe characteristics of healthy and unhealthy romantic and/or sexual relationships HR.12.CC.1	Explain how media can influence one's beliefs about what constitutes a healthy sexual relationship HR.12.INF.1	Demonstrate effective strategies to avoid or end an unhealthy relationship HR.12.IC.1				
	Describe a range of ways to express affection within healthy relationships HR.12.CC.2						
	Define sexual consent and explain its implications for sexual decision-making HR.12.CC.3	Analyze factors, including alcohol and other substances, that can affect the ability to give or perceive the provision of consent to sexual activity HR.12.INF.2	Demonstrate effective ways to communicate personal boundaries as they relate to intimacy and sexual behavior HR.12.IC.2				Demonstrate respect for the boundaries of others as they relate to intimacy and sexual behavior HR.12.SM.1

Core Concepts CC	Analyzing Influences INF	Accessing Information AI	Interpersonal Communication IC	Decision-Making DM	Goal Setting GS	Self-Management SM	Advocacy ADV
HEALTHY RELATIONSHIPS							
By the end of the 12 th grade, students should be able to:	Evaluate the potentially positive and negative roles of technology and social media in relationships HR.12.CC.4					Describe strategies to use social media safely, legally and respectfully HR.12.SM.2	
PERSONAL SAFETY							
By the end of the 12 th grade, students should be able to:	Compare and contrast situations and behaviors that may constitute bullying, sexual harassment, sexual abuse, sexual assault, incest, rape and dating violence PS.12.CC.1	Access valid resources for help if they or someone they know are being bullied or harassed, or have been sexually abused or assaulted PS.12.AI.1	Demonstrate effective ways to communicate with trusted adults about bullying, harassment, abuse or assault PS.12.IC.1				Advocate for safe environments that encourage dignified and respectful treatment of everyone PS.12.ADV.1
	Analyze the laws related to bullying, sexual harassment, sexual abuse, sexual assault, incest, rape and dating violence PS.12.CC.2	Describe potential impacts of power differences (e.g., age, status or position) within sexual relationships PS.12.INF.1	Demonstrate ways to access accurate information and resources for survivors of sexual abuse, incest, rape, sexual harassment, sexual assault and dating violence PS.12.AI.2	Identify ways in which they could respond when someone else is being bullied or harassed PS.12.IC.2			
	Explain why using tricks, threats or coercion in relationships is wrong PS.12.CC.3	Analyze the external influences and societal messages that impact attitudes about bullying, sexual harassment, sexual abuse, sexual assault, incest, rape and dating violence PS.12.INF.2					
	Explain why a person who has been raped or sexually assaulted is not at fault PS.12.CC.4						

Appendix G

Delphi Method Round 1 Questionnaire

Demographic Questions:

(This information will not be linked with your responses to ensure confidentiality)

I identify myself as: (please circle all that apply)

- a. A researcher with expertise in ASD and sexuality
- b. An author who has published a book and/or curriculum and/or resources for and/or about individuals with ASD and sexuality
- c. A school psychologist who works with students with ASD
- d. A caregiver to a high functioning child with ASD who is currently between the ages of 11-21 and enrolled in 6th-12th grade
- e. Other _____

Number of years you have been in the above position:

Gender:

- a. Male
- b. Female
- c. Other: _____

How do you identify racially?

- a. Hispanic or Latino
- b. American Indian or Alaska Native
- c. Asian
- d. Black or African American
- e. Native Hawaiian or Other Pacific Islander
- f. White

Age: _____

Email address: (you will be contacted at least three times for your input via email for this study)

Location: (City, State)

Highest Degree Earned:

I would like a final copy of the study results: (please circle one) Yes No

Please provide as many suggestions as you can for each of the below questions pertaining to the sexuality education of high functioning adolescent students with Autism Spectrum Disorder.

Content:

It is suggested that comprehensive sexuality education curricula for general education students include the following seven topics: anatomy and physiology, puberty and adolescent development; identity; pregnancy and reproduction; sexually transmitted diseases and HIV; healthy relationships; and personal safety. Within each of these topic areas are educational goals. For example, an educational goal in the pregnancy and reproduction topic is that a student knows how to describe the signs of pregnancy by the end of 12th grade.

- Are there additional topics that should be included in sexuality education curricula for high functioning adolescents with ASD? Please explain your reasoning.
 - If yes, what topics should be added?
- What specific educational goals should be included in a sexuality education curriculum for high functioning adolescent students with ASD within the following topic areas?
 - Anatomy and Physiology
 - Puberty and Adolescent Development
 - Identity
 - Pregnancy and Reproduction
 - Sexually transmitted diseases and HIV
 - Healthy Relationships
 - Personal Safety
 - Other
- Should a sexuality education curriculum designed for high functioning adolescents with ASD differ from sexuality education curricula designed for general education students? Explain your reasoning.
 - If so, how?

Delivery

Due to the nature of their diagnosis, high functioning students with ASD often learn best when certain strategies, environments, and needs are taken into consideration.

- What would an ideal school environment for teaching high functioning adolescent students with ASD about sexuality look like?
- What types of strategies would be most useful in teaching students with high functioning ASD about sexuality?
- What would be an appropriate way to measure the mastery of a skill taught in a sexuality education curriculum for high functioning adolescents with ASD?

Responsibilities

Children learn about sexuality from a variety of places and people. Ideally, the majority of what students learn about sexuality would come from a combination of their family and their school. Sometimes sexuality education curricula are intentional in how they involve the school, student, and family. For example, some curricula use family homework activities that require the student and their caregiver to complete an assignment together addressing what was covered in sexuality education class that day.

- What should the role of the school be in the sexuality education of high functioning adolescent students with ASD?
- What people within the school should be responsible for the sexuality education of high functioning adolescent students with ASD? Please explain your reasoning for each position you list.

- What should the role of the family be in the sexuality education of high functioning adolescent students with ASD?
- How can schools and families partner to provide effective sexuality education for high functioning adolescent students with ASD?

Other

Please share any additional thoughts.

Appendix H

Respondent recruitment email

Dear _____,

I am a doctoral student in the Child, Family, and School Psychology program at the University of Denver and am currently conducting my dissertation research on the sexuality education of high functioning adolescent students with Autism Spectrum Disorder (ASD). I am reaching out to you because I have identified you as an expert in this field. I would like to request your participation in my study.

The purpose of this research is to develop guidelines for the sexuality education of high functioning adolescent students with ASD. To date, there are few resources available that provide guidance on the sexuality education of students with ASD. Through your expertise and the joint effort of other experts, I hope to identify the key components of successful sexuality education of high functioning adolescent students with ASD. The experts in this study include caregivers of high functioning adolescent students with ASD, researchers and/or authors of sexuality education and ASD materials, and school psychologists who work with high functioning adolescents with ASD in a public school.

For the purposes of this research, an adolescent is considered a student between the ages of 11-21 who is currently enrolled as a student between grades 6-12. High functioning refers to students who have average to above average intelligence and verbal communication abilities.

I would like to learn from you about your experiences surrounding the sexuality education of high functioning adolescent students with ASD. Your opinion is valuable to developing guidelines for an important, but under-researched area of ASD.

Study participation involves three or more rounds of questionnaires through Qualtrics. Your answers will be anonymous throughout the life of the study. To thank you for your participation, you will be provided with the final outcomes of the study. If you are interested in participating, please sign the informed consent and contact me at bsovran@gmail.com.

Thank you, and I look forward to your participation.

Regards,

Brittany Sovran, MA

Appendix I

Informed Consent

TITLE: Key Components of Successful Sexuality Education for High Functioning Students with Autism Spectrum Disorder

Principal Investigator: Brittany Sovran, MA

Protocol #: 775819-1

Approval Date:

You are being asked to be in a research study. This form provides you with information about the study. Please read the information below before deciding whether or not to take part.

You are invited to participate in a research study about the sexuality education of high functioning adolescents with Autism Spectrum Disorder (ASD). In addition, this study is being conducted to fulfill the dissertation requirements of the primary investigator. The goal of this study is to understand your experience and opinions of the sexuality education of high functioning adolescents with ASD. Your participation is completely voluntary, but it is very important. Your participation will help me identify the key components of a successful sexuality education curriculum for high functioning students with ASD and develop curricula guidelines as part of my dissertation research.

If you agree to be a part of this research study, you will be asked to complete a series of questionnaires. As a researcher, I will be sending you three or more rounds of questionnaires via email. You may choose not to participate in the study and are free to withdraw from the study at any time. Refusal to participate or withdrawal from participation involves no penalty. This study will take approximately three months, with each questionnaire taking between 15-45 minutes to complete.

As the researcher, I will treat all information gathered for this study as confidential. This means that only I will have access to the information you provide. Your name or any identifiable information will not be included in any publications generated from this research.

There are two exceptions to the promise of confidentiality. Any information you reveal concerning suicide, homicide, or child abuse and neglect is required by law to be reported to the proper authorities. In addition, should any information contained in this study be the subject of a court order, the University of Denver might not be able to avoid compliance with the order or subpoena.

Your participation as an expert in this study will provide me with key insights as to the key components of a successful sexuality education curriculum for high functioning adolescents students with ASD. The benefits of being involved in this study include

being able to contribute to the body of research surrounding sexuality education of persons with ASD. You might also enjoy the opportunity to share your expertise in an area of interest. If you would like a copy of the findings of this study, I will be happy to provide one for you. Potential risks of being involved include the possibility of discussing certain issues about topics that may be upsetting. If this occurs, I will provide a list of appropriate professional resources in your area that can provide you with supportive care. You will not receive any payment for being in the study.

If you have any questions at all about this study on sexuality education of high functioning adolescents with ASD, please feel free to contact me, Brittany Sovran, at bsovran@gmail.com or my faculty sponsor, Dr. Cynthia Hazel at Cynthia.Hazel@du.edu. If you have any concerns or complaints about how you were treated during the research participation, you may contact the Chair of the Institutional Review Board for the Protection of Human Subjects, at 303-871-4015 or by emailing IRBChair@du.edu, or you may contact the Office of Research Compliance by emailing IRBAdmin@du.edu, calling 303-871-4050 or write to the University of Denver, Office of Research and Sponsored Programs, 2199 S. University Blvd., Denver, CO 80208-2121.

The University of Denver Institutional Review Board has determined that this study qualifies as exempt from full IRB oversight.

You may print a copy of this form for your records. Please type your name in the space provided if you understand and agree to the above. If you do not understand any part of the above statement, please ask the researcher any questions you have.

“I have read this paper about the study or it was read to me. I understand the possible risks and benefits of this study. I know that being in this study is voluntary. If I choose to be in this study I may print a copy of this consent form.”

Signature

Date

By continuing with this research, you are consenting to participate in this study.

Appendix J

Key Components of Successful Sexuality Education for High Functioning Students with Autism Spectrum Disorder: Round 2 Questionnaire

TITLE: Key Components of Successful Sexuality Education for High Functioning Students with Autism Spectrum Disorder

Principal Investigator: Brittany Sovran, MA

Protocol #: 775819-1

DU IRB Exemption Granted: 08/10/15

Dear Participant,

Welcome to Round Two of the Key Components of Successful Sexuality Education for High Functioning Students with Autism Spectrum Disorder research study. Thank you for your participation in Round One of this study. You are now invited to participate in Round 2, which should take approximately 15-20 minutes of your time.

This form provides you with information about the study. Please read the information below before deciding whether or not to take part.

You are invited to participate in Round Two of a research study about the sexuality education of high functioning adolescents with Autism Spectrum Disorder (ASD). In addition, this study is being conducted to fulfill the dissertation requirements of the primary investigator. The goal of this study is to understand your experience and opinions of the sexuality education of high functioning adolescents with ASD. Your participation is completely voluntary, but it is very important. Your participation will help me identify the key components of a successful sexuality education curriculum for high functioning students with ASD and develop curricula guidelines as part of my dissertation research.

You may choose not to participate in the study and are free to withdraw from the study at any time. Refusal to participate or withdrawal from participation involves no penalty.

As the researcher, I will treat all information gathered for this study as confidential. This means that only I will have access to the information you provide. Your name or any identifiable information will not be included in any publications generated from this research.

There are two exceptions to the promise of confidentiality. Any information you reveal concerning suicide, homicide, or child abuse and neglect is required by law to be reported to the proper authorities. In addition, should any information contained in this study be the subject of a court order, the University of Denver might not be able to avoid compliance with the order or subpoena.

Your participation as an expert in this study will provide me with key insights as to the key components of a successful sexuality education curriculum for high functioning adolescents students with ASD. The benefits of being involved in this study include being able to contribute to the body of research surrounding sexuality education of persons with ASD. You might also enjoy the opportunity to share your expertise in an area of interest. If you would like a copy of the findings of this study, I will be happy to provide one for you. Potential risks of being involved include the possibility of discussing certain issues about topics that may be upsetting. If this occurs, I will provide a list of appropriate professional resources in your area that can provide you with supportive care. You will not receive any payment for being in the study.

If you have any questions at all about this study on sexuality education of high functioning adolescents with ASD, please feel free to contact me, Brittany Sovran, at bsovrان@gmail.com or my faculty sponsor, Dr. Cynthia Hazel at Cynthia.Hazel@du.edu. If you have any concerns or complaints about how you were treated during the research participation, you may contact the Chair of the Institutional Review Board for the Protection of Human Subjects, at 303-871-4015 or by emailing IRBChair@du.edu, or you may contact the Office of Research Compliance by emailing IRBAdmin@du.edu, calling 303-871-4050 or write to the University of Denver, Office of Research and Sponsored Programs, 2199 S. University Blvd., Denver, CO 80208-2121.

The University of Denver Institutional Review Board has determined that this study qualifies as exempt from full IRB oversight.

You may print a copy of this form for your records. Please type your name in the space provided if you understand and agree to the above. If you do not understand any part of the above statement, please ask the researcher any questions you have.

“I have read this paper about the study or it was read to me. I understand the possible risks and benefits of this study. I know that being in this study is voluntary. If I choose to be in this study I may print a copy of this consent form.”

By continuing with this research, you are consenting to participate in this study.

Please type your name and date in the space provided below.

Key Components of Successful Sexuality Education for High Functioning Students with Autism Spectrum Disorder: Round 2 Questionnaire

The information in this section is a synthesis of the data collected from Round One of this study. Each Round One question was analyzed for emergent themes. Here you will be asked to determine whether or not you agree with themes that have emerged from data analysis. You will have the opportunity to add comments and/or suggestions on the data synthesis.

Content:

1. Sexuality education curriculum designed for high functioning adolescents with ASD should differ from sexuality education curricula designed for general education students by addressing sensory differences including aspects of social learning, emphasizing legal issues, going into greater depth within each topic, and discussing the impact that Autism Spectrum Disorder can have on sexuality and romantic relationships.
 - a. Agree
 - b. Disagree

Please add comments/suggestions you may have to the above statement

2. Sexuality education curricula for high functioning students with ASD should include the following comprehensive sexuality education topics that are taught in general education curricula:
 - a. Anatomy and Physiology:
 - i. Agree
 - ii. Disagree
 - b. Puberty and adolescent development:
 - i. Agree
 - ii. Disagree
 - c. Identity:
 - i. Agree
 - ii. Disagree
 - d. Pregnancy and reproduction:
 - i. Agree
 - ii. Disagree
 - e. Sexually Transmitted Diseases (STDs) and HIV:
 - i. Agree
 - ii. Disagree
 - f. Healthy relationships:
 - i. Agree
 - ii. Disagree
 - g. Personal safety:
 - i. Agree
 - ii. Disagree

Please add comments/suggestions you may have regarding the aforementioned sexuality education topics

3. In addition to the seven sexuality topics taught in general education curricula, sexuality education curricula for high functioning students with ASD should also include the following topics:
 - h. **Legal Issues:** This topic includes educating students about consent, appropriate versus inappropriate behavior, defining “illegal”, and criminal

behavior including illegal sexual images, coercion, rape, molestation, and stalking.

- i. Agree
 - ii. Disagree
- i. **Social Aspects of Sexuality and Romantic Relationships:** This topic includes social norms, communication, dating/establishing a romantic relationship, sexual decision making, boundaries, and abuse awareness
 - i. Agree
 - ii. Disagree
- j. **Knowledge of Different Sex Acts and Use of Common Slang:** This topic includes developing awareness of common colloquialisms and slang terms for sexual acts as well as an understanding of what various sexual acts involve (e.g., anal sex, masturbation, oral sex)
 - i. Agree
 - ii. Disagree
- k. **Sensory Needs:** This topic includes identifying, coping with, and discussing sensory sensitivities within the context of a romantic relationship.
 - i. Agree
 - ii. Disagree

Please add comments/suggestions you may have

Delivery

1. The ideal school environment for teaching high functioning adolescent students with ASD would include the following elements:
 - a. Small group instruction
 - i. Agree
 - ii. Disagree
 - b. A mixture of students with ASD and neurotypical peers
 - i. Agree
 - ii. Disagree
 - c. A supportive classroom culture including a small student teacher ratio, supportive individuals to discuss topics with, open and accepting teacher – student and peer-to-peer relationships, and respect for individual learning styles.
 - i. Agree
 - ii. Disagree
 - d. A modified environment that limits distractions, addresses sensory needs, and incorporates breaks.
 - i. Agree
 - ii. Disagree
 - e. The use of visuals, individualized supports, and differentiated instruction.
 - i. Agree
 - ii. Disagree

Please add comments/suggestions you may have regarding an ideal school environment.

2. Strategies that would be useful in teaching high functioning students with ASD about sexuality include the use of:
 - a. Visuals (e.g., video, pictures, charts, graphs)
 - i. Agree
 - ii. Disagree
 - b. Examples
 - i. Agree
 - ii. Disagree
 - c. Repetition
 - i. Agree
 - ii. Disagree
 - d. Role Play
 - i. Agree
 - ii. Disagree
 - e. Class Discussion
 - i. Agree
 - ii. Disagree
 - f. Direct, detailed, and honest explanations
 - i. Agree
 - ii. Disagree
 - g. Parent involvement
 - i. Agree
 - ii. Disagree
 - h. Breaking down information into measurable steps
 - i. Agree
 - ii. Disagree
 - i. Practice
 - i. Agree
 - ii. Disagree
 - j. Rote Memorization
 - i. Agree
 - ii. Disagree
 - k. Student led research
 - i. Agree
 - ii. Disagree
 - l. Project Based Learning
 - i. Agree
 - ii. Disagree

Please provide your comments/suggestions regarding strategies for teaching sexuality to high functioning students with ASD

3. The best ways to measure mastery of skills taught in a sexuality education curriculum for high functioning adolescents with ASD include the following:
 - a. Quizzes/Tests
 - i. Agree
 - ii. Disagree
 - b. Completion of projects
 - i. Agree
 - ii. Disagree
 - c. Role Play
 - i. Agree
 - ii. Disagree
 - d. Practical Assignments (e.g., how to put on a condom)
 - i. Agree
 - ii. Disagree
 - e. Class discussion
 - i. Agree
 - ii. Disagree
 - f. Parent/Teacher report of life events
 - i. Agree
 - ii. Disagree
 - g. Oral/Written Explanations following a rubric (e.g., answering questions about specific scenarios)
 - i. Agree
 - ii. Disagree
 - h. Increase of desired behaviors/decrease of problem behaviors
 - i. Agree
 - ii. Disagree

Please provide any comments/suggestions you may have

Responsibilities

1. Schools should teach sexuality education to high functioning adolescent students with ASD.
 - a. Agree
 - b. Disagree
2. Schools should engage in parent collaboration when educating high functioning adolescent students with ASD about sexuality.
 - a. Agree
 - b. Disagree
3. Schools should adapt sexuality education curricula to meet the needs of students with ASD.
 - a. Agree
 - b. Disagree

4. Schools should provide a safe environment for learning about sexuality.
 - a. Agree
 - b. Disagree

Please provide any comments/suggestions you may have

Professionals

The majority of responses from Round 1 indicated that school-based professionals selected to provide sexuality education to high functioning students with ASD should be based on the needs of the students and the expertise of the staff. Which specific professionals do you feel are best suited to deliver sexuality education curricula to high functioning students with ASD in the schools? Please select all that you believe apply.

- a. Health Teacher
- b. School Nurse
- c. Special Education Teacher
- d. School Psychologist
- e. General Education Teacher
- f. School Counselor
- g. Principal
- h. School Social Worker
- i. Speech Language Pathologist
- j. Case Manager

Please provide your comments/suggestions

Role of families

4. Families should have the following roles in the sexuality education of their high functioning children with ASD:
 - a. Reinforce at home what is being taught in the school curriculum
 - i. Agree
 - ii. Disagree
 - b. Teach family values and personal beliefs surrounding sexuality
 - i. Agree
 - ii. Disagree
 - c. Be the primary sexuality educators of their children
 - i. Agree
 - ii. Disagree
 - d. Facilitate/foster sexuality education discussions with their child
 - i. Agree
 - ii. Disagree
 - e. Be aware of the school sexuality education curriculum (or lack of one)
 - i. Agree
 - ii. Disagree
 - f. Provide consent for their children to participate in sexuality education
 - i. Agree
 - ii. Disagree

- g. Share their child's specific needs surrounding sexuality education with the school
 - i. Agree
 - ii. Disagree
- h. Team with the school
 - i. Agree
 - ii. Disagree
- i. Complete assignments from the sexuality education curricula being taught in school
 - i. Agree
 - ii. Disagree

Please provide any comments suggestions you may have

- 5. Families and schools can partner to provide effective sexuality education for high functioning adolescent students with ASD by:
 - a. Having effective two-way communication
 - i. Agree
 - ii. Disagree
 - b. Allowing parents to preview and/or discuss the sexuality education curriculum that will be taught
 - i. Agree
 - ii. Disagree
 - c. Encouraging family involvement on sexuality education projects
 - i. Agree
 - ii. Disagree
 - d. Sharing of resources
 - i. Agree
 - ii. Disagree
 - iii. Please add comments/suggestions you may have
 - e. The school can provide parent education on the topic of the sexuality education needs of students with ASD
 - i. Agree
 - ii. Disagree
 - f. Families and the school can co-develop goals for the sexuality education of high functioning adolescent students with ASD
 - i. Agree
 - ii. Disagree

Please add any comments/suggestions you may have

Please provide any additional comments or suggestions

Appendix K

Key Components of Successful Sexuality Education for High Functioning Students with Autism Spectrum Disorder: Round 3 Questionnaire

TITLE: Key Components of Successful Sexuality Education for High Functioning Students with Autism Spectrum Disorder

Principal Investigator: Brittany Sovran, MA

Protocol #: 775819-1

DU IRB Exemption Granted: 08/10/15

Dear Participant,

Welcome to the third and final round of the Key Components of Successful Sexuality Education for High Functioning Students with Autism Spectrum Disorder research study. Thank you for your participation in Rounds One and Two of this study. You are now invited to participate in Round Three, which should take approximately 30 minutes of your time.

This form provides you with information about the study. Please read the information below before deciding whether or not to take part.

You are invited to participate in Round Three of a research study about the sexuality education of high functioning adolescents with Autism Spectrum Disorder (ASD). In addition, this study is being conducted to fulfill the dissertation requirements of the primary investigator. The goal of this study is to understand your experience and opinions of the sexuality education of high functioning adolescents with ASD. Your participation is completely voluntary, but it is very important. Your participation will help me identify the key components of a successful sexuality education curriculum for high functioning students with ASD and develop curricula guidelines as part of my dissertation research.

You may choose not to participate in the study and are free to withdraw from the study at any time. Refusal to participate or withdrawal from participation involves no penalty.

As the researcher, I will treat all information gathered for this study as confidential. This means that only I will have access to the information you provide. Your name or any identifiable information will not be included in any publications generated from this research.

There are two exceptions to the promise of confidentiality. Any information you reveal concerning suicide, homicide, or child abuse and neglect is required by law to be reported to the proper authorities. In addition, should any information contained in this study be the subject of a court order, the University of Denver might not be able to avoid compliance with the order or subpoena.

Your participation as an expert in this study will provide me with key insights as to the key components of a successful sexuality education curriculum for high functioning adolescents students with ASD. The benefits of being involved in this study include being able to contribute to the body of research surrounding sexuality education of persons with ASD. You might also enjoy the opportunity to share your expertise in an area of interest. If you would like a copy of the findings of this study, I will be happy to provide one for you. Potential risks of being involved include the possibility of discussing certain issues about topics that may be upsetting. If this occurs, I will provide a list of appropriate professional resources in your area that can provide you with supportive care. You will not receive any payment for being in the study.

If you have any questions at all about this study on sexuality education of high functioning adolescents with ASD, please feel free to contact me, Brittany Sovran Greiert, at bsovran@gmail.com or my faculty sponsor, Dr. Cynthia Hazel at Cynthia.Hazel@du.edu. If you have any concerns or complaints about how you were treated during the research participation, you may contact the Chair of the Institutional Review Board for the Protection of Human Subjects, at 303-871-4015 or by emailing IRBChair@du.edu, or you may contact the Office of Research Compliance by emailing IRBAdmin@du.edu, calling 303-871-4050 or write to the University of Denver, Office of Research and Sponsored Programs, 2199 S. University Blvd., Denver, CO 80208-2121.

The University of Denver Institutional Review Board has determined that this study qualifies as exempt from full IRB oversight.

You may print a copy of this form for your records. Please type your name in the space provided if you understand and agree to the above. If you do not understand any part of the above statement, please ask the researcher any questions you have.

“I have read this paper about the study or it was read to me. I understand the possible risks and benefits of this study. I know that being in this study is voluntary. If I choose to be in this study I may print a copy of this consent form.”

By continuing with this research, you are consenting to participate in this study.

Please type your name and date in the space provided below.

Key Components of Successful Sexuality Education for High Functioning Students with Autism Spectrum Disorder: Round 3 Questionnaire

The information in this questionnaire is a synthesis of the data collected from Round Two of this study. Each Round Two question was analyzed for agreeableness amongst participants. Statements in which 80% or more of participants agreed were used in the development of the following statements.

The following statements are intended as a draft of guidelines for the sexuality education of high functioning adolescent students with Autism Spectrum Disorders. These guidelines were developed based on your and your fellow participants opinions, ideas, and comments. The guidelines are comprised of three sections: Content, Delivery, and Responsibilities. In each section, you will first read statements created from Round 2 questions that had complete consensus. Next, you will be asked to edit statements that did not have 100% consensus amongst participants; please rewrite these statements as you believe they should be written.

Please keep in mind that the following information is specific to the development of a sexuality education curriculum for high functioning adolescent students with Autism Spectrum Disorders. Although many of the suggestions and strategies below can be useful in educating students with ASD in other areas, for the purposes of this research please only think about their usefulness specifically in sexuality and relationship education.

Content:

The following statements were developed from items in the Content section of the Round 2 survey that had 100% consensus amongst all participants. These statements are provided below for your review.

1. Sexuality education curricula for high functioning students with ASD should include the following topics.
 - l. **Anatomy and Physiology:** this topic provides a foundation for understanding basic human functioning and specifically should include understanding the functions and names of internal and external reproductive anatomy, stages of human sexual response, genital health, and preventative health strategies (e.g., breast exams, testicular exams).
 - m. **Puberty and Adolescent Development:** this topic addresses the impact puberty has on physical, social, and emotional development and should specifically include physiological, hormonal, and emotional changes, neurodevelopment, and common experiences of adolescents.
 - n. **Identity:** this topic addresses developing an awareness and understanding of one's self and should specifically include gender identity, sexual orientation, awareness of discrimination based on sexual or gender identity, knowledge of local resources to support gender identity or sexual orientation differences, and socio-political current events/rights.
 - o. **Pregnancy and reproduction:** this topic addresses how pregnancy happens and should specifically include understanding the signs of pregnancy, awareness of the stages of pregnancy, what to do if you think you or your partner might be pregnancy, how to prevent pregnancy, and the responsibilities that come with having a child.
 - p. **Sexually Transmitted Infections (STIs) and HIV:** this topic addresses knowledge of what STIs/HIV are, how they are transmitted, and how to prevent them and should also include developing awareness of the symptoms and signs of STIs/HIV, social stigmas surrounding STIs/HIV, how to get tested for an STD/HIV, and community resources available for assistance in the testing, treatment, and prevention of STIs/HIV.

- q. **Healthy relationships:** this topic addresses how to successfully define and navigate relationships among family, peers, and partners and should specifically include an understanding of different types of relationships, what constitutes a healthy and unhealthy relationship, how to identify a relationship that is unhealthy, qualities to look for in relationship partners, acknowledgement that it is ok to not want a romantic relationship, and understanding different components of intimacy.
- r. **Personal safety:** this topic should address self-advocacy, establishing and respecting boundaries, assertiveness, prevention of abuse, and dangers specific to the Internet.
- s. **Legal Issues:** This topic includes educating students about consent, appropriate versus inappropriate behavior, defining “illegal”, and criminal behavior including illegal sexual images, coercion, rape, molestation, and stalking.
- t. **Social Aspects of Sexuality and Romantic Relationships:** This topic includes social norms, communication, dating/establishing a romantic relationship, sexual decision-making, boundaries, and abuse awareness.
- u. **Knowledge of Different Sex Acts and Use of Common Slang:** This topic includes developing awareness of common colloquialisms and slang terms for sexual acts, developing an understanding that slang terms change over time, identifying appropriate resources to utilize to get more information, and developing an understanding of what various sexual acts involve (e.g., anal sex, masturbation, oral sex).
- v. **Sensory Needs:** This topic includes identifying, coping with, and discussing sensory sensitivities; developing an awareness that sensory needs vary from person to person; and understanding how sensory needs can impact a romantic relationship.

The following statement was developed with items from the Content section of the Round 2 survey that did not have 100% consensus. Please read the following statement carefully. If you feel that changes are needed, please rewrite the statement as you believe it should be written. That is; copy and paste the text into the comment box and edit it as you feel it should read. If you feel no changes are warranted, you may leave the comment box empty and select “Agree”.

- 2. “Sexuality education curricula designed for high functioning adolescents with ASD should differ from sexuality education curricula designed for general education students by: including aspects of social learning; emphasizing legal issues; addressing sensory differences in one’s self and in others; going into greater depth within each topic area; and discussing the impact that an Autism Spectrum Disorder, including cognitive and social differences, may have on sexuality and romantic relationships.”
 - a. If you feel that no changes are needed for the above statement, please leave the comment box blank and select "Agree" below. If you feel that changes are needed, please rewrite the statement as you believe it should be written. That is; copy and paste the text into the comment box and edit it as you feel it should read.

- i. Text box
- ii. No changes need to be made to this statement
 - 1. Agree

Delivery

The following statements were developed from items in the Delivery section of the Round 2 survey that had 100% consensus amongst all participants. These statements are provided below for your review.

- 4. Although every student has unique needs, some general guidelines for developing a supportive classroom environment for implementing a sexuality education curriculum for high functioning students with ASD include: a small student teacher ratio, supportive individuals to discuss topics with, open and accepting teacher-student and peer-to-peer relationships, and respect for individual learning styles.
- 5. Some strategies that would be useful in teaching high functioning students with ASD about sexuality include the use of visuals (e.g., video, pictures); using real-world examples; class discussion; repetition; direct, detailed and honest explanations; parent involvement; and breaking down information into measurable steps.
- 6. An effective way to measure the mastery of skills taught in a sexuality education curriculum for high functioning adolescents with ASD is family or school-based professional observation of an increase in desired behaviors and a decrease of problem behaviors.

The following statements were developed with items from the Delivery section of the Round 2 survey that did not have 100% consensus. Please read the following statements carefully. If you feel that changes are needed, please rewrite the statement as you believe it should be written. That is; copy and paste the text into the comment box and edit it as you feel it should read. If you feel no changes are warranted, you may leave the comment box empty and select "Agree".

- 1. "It is important to recognize individual student needs when providing a sexuality education curriculum to high functioning students with ASD. Individualized supports and differentiated instruction should be utilized whenever possible."
 - a. If you feel that no changes are needed for the above statement, please leave the comment box blank and select "Agree" below. If you feel that changes are needed, please rewrite the statement as you believe it should be written. That is; copy and paste the text into the comment box and edit it as you feel it should read.
 - i. Text box
 - ii. No changes need to be made to this statement
 - 1. Agree

2. “Sexuality education curricula for high functioning students with ASD should be implemented in an environment that limits distractions, addresses sensory needs, incorporates breaks, and utilizes small group instruction when appropriate.”
 - a. If you feel that no changes are needed for the above statement, please leave the comment box blank and select "Agree" below. If you feel that changes are needed, please rewrite the statement as you believe it should be written. That is; copy and paste the text into the comment box and edit it as you feel it should read.
 - i. Text box
 - ii. No changes need to be made to this statement
 1. Agree
3. “In schools, a team of school-based professionals who understand ASD and who have positive relationships with the students who they will be teaching should ideally provide a sexuality education curriculum for high functioning students with ASD. School-based professionals who are particularly well suited for the delivery of sexuality education curriculum for high functioning students with ASD include health teachers, school psychologists, school social workers, and special education teachers.”
 - a. If you feel that no changes are needed for the above statement, please leave the comment box blank and select "Agree" below. If you feel that changes are needed, please rewrite the statement as you believe it should be written. That is; copy and paste the text into the comment box and edit it as you feel it should read.
 - i. Text box
 - ii. No changes need to be made to this statement
 1. Agree
4. “Additional strategies that can be useful in teaching high functioning students with ASD about sexuality include the use of role-play, student led research, project based learning, and practice.”
 - a. If you feel that no changes are needed for the above statement, please leave the comment box blank and select "Agree" below. If you feel that changes are needed, please rewrite the statement as you believe it should be written. That is; copy and paste the text into the comment box and edit it as you feel it should read.
 - i. Text box
 - ii. No changes need to be made to this statement
 1. Agree
5. “Including neurotypical peers in the sexuality education of high functioning students with ASD can be beneficial if done thoughtfully. It may not be appropriate to include neurotypical peers in every aspect of the curriculum as the delivery, pacing, and depth will be modified for students with ASD. Families and schools should discuss if, how, and when it might be appropriate to integrate high functioning students with ASD and their neurotypical peers in the context of a sexuality education curriculum.”

- a. If you feel that no changes are needed for the above statement, please leave the comment box blank and select "Agree" below. If you feel that changes are needed, please rewrite the statement as you believe it should be written. That is; copy and paste the text into the comment box and edit it as you feel it should read.
 - i. Text box
 - ii. No changes need to be made to this statement
 - 1. Agree

- 6. “Measuring mastery of skills in a sexuality education curriculum for high functioning students with ASD can be difficult. There are a variety of strategies that can be appropriate for use in measuring skill acquisition such as role play, completion of projects, practical assignments (e.g., how to put on a condom), class discussion, parent/teacher report of life events; and oral/written explanations following a rubric. These strategies should be implemented with a highly structured plan and with plenty of guidance and support for the students. Ultimately, the goal is to have students be able to generalize what is learned in the curriculum to the real world.”
 - a. If you feel that no changes are needed for the above statement, please leave the comment box blank and select "Agree" below. If you feel that changes are needed, please rewrite the statement as you believe it should be written. That is; copy and paste the text into the comment box and edit it as you feel it should read.
 - i. Text box
 - ii. No changes need to be made to this statement
 - 1. Agree

Responsibilities

The following statements were developed from items in the Responsibilities section of the Round 2 survey that had 100% consensus amongst all participants. These statements are provided below for your review.

- 7. Schools and families both have significant roles in the sexuality education of high functioning adolescents students with ASD. The sexuality education of high functioning adolescent students with ASD is most successful when schools and families partner and work together as a team. Examples of ways that schools and families can partner include engaging in effective two-way communication, sharing resources (e.g., providers within the community who can provide additional support), and providing parent education trainings on the topic of the sexuality education needs of students with ASD.

- 8. Family involvement is a critical component of successful sexuality education curricula for high functioning students with ASD. Ideally, families should be aware of the school-based sexuality education curriculum (or lack of one), be able to reinforce what is being taught by the schools, facilitate/foster sexuality education discussions with their child, and share their child’s specific needs surrounding sexuality education with the school.

9. Schools have a responsibility to teach sexuality education to high functioning adolescent students with ASD in a safe and effective learning environment.

The following statements were developed with items from the Delivery section of the Round 2 survey that did not have 100% consensus. Please read the following statements carefully. If you feel that changes are needed, please rewrite the statement as you believe it should be written. That is; copy and paste the text into the comment box and edit it as you feel it should read. If you feel no changes are warranted, you may leave the comment box empty and select "Agree".

10. "Schools should adapt sexuality education curricula to meet the needs of students with ASD."
 - a. If you feel that no changes are needed for the above statement, please leave the comment box blank and select "Agree" below. If you feel that changes are needed, please rewrite the statement as you believe it should be written. That is; copy and paste the text into the comment box and edit it as you feel it should read.
 - i. Text box
 - ii. No changes need to be made to this statement
 1. Agree
11. "Allowing parents to preview and/or discuss the sexuality education curriculum that will be taught in the school and encouraging family involvement on sexuality education assignments that may occur during the curriculum are effective ways to develop a family-school partnership surrounding the sexuality education of high functioning students with ASD."
 - a. If you feel that no changes are needed for the above statement, please leave the comment box blank and select "Agree" below. If you feel that changes are needed, please rewrite the statement as you believe it should be written. That is; copy and paste the text into the comment box and edit it as you feel it should read.
 - i. Text box
 - ii. No changes need to be made to this statement
 1. Agree
12. "Members of a student's individualized education plan (IEP) team, including the student's family, should specifically address the sexuality education needs of the student and, if appropriate, develop and include sexuality education goals within the Individualized Education Plan (IEP)."
 - a. If you feel that no changes are needed for the above statement, please leave the comment box blank and select "Agree" below. If you feel that changes are needed, please rewrite the statement as you believe it should be written. That is; copy and paste the text into the comment box and edit it as you feel it should read.
 - i. Text box

- ii. No changes need to be made to this statement
 - 1. Agree

13. “Families are often the primary sexuality educators of their children. Sometimes, family values and personal beliefs surrounding sexuality may differ from what is being taught in a school-based curriculum. Regardless of what is being taught in the home, schools still have a responsibility to teach high functioning adolescents students with ASD about sexuality.”

- a. If you feel that no changes are needed for the above statement, please leave the comment box blank and select "Agree" below. If you feel that changes are needed, please rewrite the statement as you believe it should be written. That is; copy and paste the text into the comment box and edit it as you feel it should read.
 - i. Text box
 - ii. No changes need to be made to this statement
 - 1. Agree

14. “Families may choose to withdraw consent for their child to participate in a sexuality education curriculum provided by the schools.”

- a. If you feel that no changes are needed for the above statement, please leave the comment box blank and select "Agree" below. If you feel that changes are needed, please rewrite the statement as you believe it should be written. That is; copy and paste the text into the comment box and edit it as you feel it should read.
 - i. Text box
 - ii. No changes need to be made to this statement
 - 1. Agree

Appendix L

Guidelines for Developing Sexuality Education Curricula for High Functioning Adolescent Students with Autism Spectrum Disorder (ASD)

The following guidelines were developed by expert participants including researchers, authors, school psychologists, and parents of high functioning adolescent children with ASD. Most experts agreed that sexuality education curricula designed for high functioning adolescent students with ASD should be enhanced from sexuality education curricula designed for general education students. These guidelines are organized into three sections: content, delivery, and responsibilities. They are intended to help guide the development of sexuality education curriculum specifically designed for high functioning students with ASD and/or to aid in the modification of existing general education sexuality education curriculum to better address the individual needs of high functioning students with ASD.

Content

Sexuality education curricula for high functioning students with ASD should include the following topics.

- *Anatomy and Physiology*: this topic provides a foundation for understanding basic human functioning and specifically should include understanding the functions and names of internal and external reproductive anatomy, stages of human sexual response, genital health, and preventative health strategies (e.g., breast exams, testicular exams).
- *Puberty and Adolescent Development*: this topic addresses the impact puberty has on physical, social, and emotional development and should specifically include physiological, hormonal, and emotional changes; neurodevelopment; and common experiences of adolescents.
- *Identity*: this topic addresses developing an awareness and understanding of one's self and should specifically include gender identity, sexual orientation, awareness of discrimination based on sexual or gender identity, knowledge of local resources to support gender identity or sexual orientation differences, and socio-political current events/rights.
- *Pregnancy and reproduction*: this topic addresses how pregnancy happens and should specifically include understanding the signs of pregnancy, awareness of the stages of pregnancy, what to do if you think you or your partner might be pregnant, how to prevent pregnancy, and the responsibilities that come with having a child.
- *Sexually Transmitted Infections (STIs) and HIV*: this topic addresses knowledge of what STIs/HIV are, how they are transmitted, and how to prevent them and should also include developing awareness of the symptoms and signs of STIs/HIV, social stigmas surrounding STIs/HIV, how to get tested for an STI/HIV, and community resources available for assistance in the testing, treatment, and prevention of STIs/HIV.

- *Healthy relationships*: this topic addresses how to successfully define and navigate relationships among family, peers, and partners and should specifically include an understanding of different types of relationships, what constitutes a healthy and unhealthy relationship, how to identify a relationship that is unhealthy, qualities to look for in relationship partners, acknowledgement that it is ok to not want a romantic relationship, and understanding different components of intimacy.
- *Personal safety*: this topic should address self-advocacy, establishing and respecting boundaries, assertiveness, prevention of abuse, and dangers specific to the Internet.
- *Legal Issues*: This topic includes educating students about consent, appropriate versus inappropriate behavior, defining “illegal”, and criminal behavior including illegal sexual images, coercion, rape, molestation, and stalking.
- *Social Aspects of Sexuality and Romantic Relationships*: This topic includes social norms, communication, dating/establishing a romantic relationship, sexual decision-making, boundaries, and abuse awareness.
- *Knowledge of Different Sex Acts and Use of Common Slang*: This topic includes developing awareness of common colloquialisms and slang terms for sexual acts, developing an understanding that slang terms change over time, identifying appropriate resources to utilize to get more information, and developing an understanding of what various sexual acts involve (e.g., anal sex, masturbation, oral sex).
- *Sensory Needs*: This topic includes identifying, coping with, and discussing sensory sensitivities; developing an awareness that sensory needs vary from person to person; and understanding how sensory needs can impact a romantic relationship.

Delivery

It is important to recognize individual student needs when providing a sexuality education curriculum to high functioning students with ASD. Individualized supports and differentiated instruction should be utilized whenever possible.

Sexuality education curricula for high functioning students with ASD should be implemented in the least restrictive environment that limits distractions, addresses sensory needs, incorporates breaks, and utilizes both small group and individual instruction when appropriate.

In schools, a team of school-based professionals who understand ASD and who have positive relationships with the students who they will be teaching should ideally provide a sexuality education curriculum for high functioning students with ASD. School-based professionals who are particularly well suited for the delivery of sexuality education curriculum for high functioning students with ASD include health teachers, school psychologists, school social workers, and special education teachers. Other professionals such as school nurses, autism consultants, occupational therapists, and speech language

pathologists who also have knowledge and experience working with students with ASD may also be appropriate to deliver a sexuality education curriculum for students with ASD.

Although every student has unique needs, some general guidelines for developing a supportive classroom environment for implementing a sexuality education curriculum for high functioning students with ASD include

- A small student teacher ratio
- Supportive individuals to discuss topics with
- Open and accepting teacher-student and peer-to-peer relationships
- Respect for individual learning styles.

Some strategies that would be useful in teaching high functioning students with ASD about sexuality include:

- The use of visuals (e.g., video, pictures, graphs, charts)
- Using real-world examples
- Class discussion
- Repetition
- Direct, detailed and honest explanations
- Parent involvement
- Breaking down information into measurable steps (e.g., using video prompting to break down target skills into steps)
- Structured project based learning
- Student led research which is overseen by instructors
- Appropriate role-play for building relationship skills

Measuring mastery of skills in a sexuality education curriculum for high functioning students with ASD can be difficult. Ultimately, the goal is to have students be able to generalize what is learned in the curriculum to the real world. There are a variety of strategies that can be appropriate for use in measuring skill acquisition. These strategies should be implemented with a highly structured plan and with plenty of guidance and support for the students. Strategies to measure mastery of skill include:

- Role play
- Completion of projects
- Practical assignments (e.g., how to put on a condom)
- Class discussion
- Parent/teacher report of life events
- Oral/written explanations following a rubric
- Family or school-based professional observation of an increase in desired behaviors and a decrease of problem behaviors

Including neurotypical peers in the sexuality education of high functioning students with ASD can be beneficial if done thoughtfully. It may not be appropriate to include

neurotypical peers in every aspect of the curriculum as the delivery, pacing, and depth will be modified for students with ASD. Families and schools should discuss if, how, and when it might be appropriate to integrate high functioning students with ASD and their neurotypical peers in the context of a sexuality education curriculum.

Responsibilities

Schools and families both have significant roles in the sexuality education of high functioning adolescent students with ASD. The sexuality education of high functioning adolescent students with ASD is most successful when schools and families partner and work together as a team. Examples of ways that schools and families can partner include engaging in effective two-way communication, sharing resources (e.g., providers within the community who can provide additional support), and providing parent education trainings on the topic of the sexuality education needs of students with ASD. Allowing parents to preview and/or discuss the sexuality education curriculum that will be taught in the school and encouraging family involvement on sexuality education assignments that may occur during the curriculum are effective ways to develop a family-school partnership surrounding the sexuality education of high functioning students with ASD.

Schools have a responsibility to teach sexuality education to high functioning adolescent students with ASD in a safe and effective learning environment. Additionally, schools should adapt sexuality education curricula to meet the individual needs of students with ASD. Many students with ASD receive services through an Individualized Education Plan (IEP). If necessary, members of a student's IEP team, including the student and his or her family, should specifically address the sexuality education needs of the student and, if appropriate, develop and include sexuality education goals within the IEP.

Family involvement is a critical component of successful sexuality education curricula for high functioning students with ASD. Ideally, families should:

- Be aware of the school-based sexuality education curriculum (or lack of one)
- Be able to reinforce what is being taught by the schools,
- Facilitate/foster sexuality education discussions with their child
- Share their child's specific needs surrounding sexuality education with the school

Once the families are informed of the sexuality education curriculum that will be taught, families may choose to withdraw consent for their child to participate in the sexuality education curriculum provided by the schools. The school should communicate with the family about the potential risks involved in withdrawing consent.