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Sexual Health Education for Children with Neurodevelopmental Disorders: Genetic Counselor and Pediatrician Perspectives

Mary Catherine Smith

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Sexual Health Education for Children with Neurodevelopmental Disorders:
Genetic Counselor and Pediatrician Perspectives

by

Mary Catherine Smith

Bachelor of Science
Clemson University, 2019

Submitted in Partial Fulfillment of the Requirements

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Accepted by:

Jessica M. Fairey, Director of Thesis

Crystal R. Hill-Chapman, Reader

Michelle M. Macias, Reader

Tracey L. Weldon, Interim Vice Provost and Dean of the Graduate School

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Abstract

Many barriers prevent individuals with disabilities from receiving appropriate sexual health education (SHE), including deficits in social-communication skills and lack of resources and trained educators. There are few guidelines specifically addressing how to accommodate for providing SHE to individuals with disabilities. Healthcare professionals who are trained in working with adolescents with disabilities, such as pediatric genetic counselors, developmental-behavioral pediatricians (DBP), and neurodevelopmental disabilities (NDD) subspecialty pediatricians, could fill this gap. The purpose of the current study was to assess what informational items pediatric genetic counselors, DBP, and NDD subspecialty pediatricians felt were most essential to include in SHE for children and adolescents with autism spectrum disorder (ASD), intellectual disability (ID), or both diagnoses to help guide future recommendations for healthcare providers.

In the current investigation, we surveyed 18 genetic counselors and 23 pediatricians to assess what information is most important to include in SHE delivered during the pre-puberty and post-puberty time frames. The online questionnaire included 32 ranking questions for pre-puberty informational items and for post-puberty informational items. It also included questions regarding demographic information, frequency of contact with individuals with ASD or ID, and free response questions regarding their experiences providing SHE.

Four out of the top 10-ranked items for each group were deemed essential to include in SHE delivered pre-puberty and post-puberty, and four additional items were deemed essential to include in SHE delivered pre-puberty only. We also found statistically significant differences between average ratings of all four survey groups (pre-puberty and post-puberty item ratings for pediatricians and genetic counselors). Several themes emerged from the participants' free response answers, including sexual abuse prevention and the rights of those with ASD and those with ID to appropriate SHE.

Our findings may help define future professional guidelines regarding what is most important to include in SHE for individuals with ASD or ID, as well as graduate medical training curriculum. The results of this study also underscore the importance of interdisciplinary efforts to educate individuals with neurodevelopmental disorders by highlighting how pediatricians may act as the primary provider of SHE, while genetic counselors may play a role in patient advocacy.

Table of Contents

Acknowledgements.....	iii
Abstract.....	iv
List of Tables	viii
List of Figures	ix
List of Abbreviations.....	x
Chapter 1: Background	1
Chapter 1.1: Sexual Health Education for Individuals with Neurodevelopmental Disorders	1
Chapter 1.2: Role of Healthcare Providers in Providing SHE.....	9
Chapter 1.3: Rationale	14
Chapter 1.4: Purpose	15
Chapter 2: Sexual Health Education for Children with Neurodevelopmental Disorders: Genetic Counselor and Pediatrician Perspectives	17
Chapter 2.1: Abstract	18
Chapter 2.2: Introduction.....	19
Chapter 2.3: Methods.....	27
Chapter 2.4: Results	32
Chapter 2.5: Discussion	46
Chapter 3: Conclusion	59
References	63

Appendix A: Online Questionnaire for Healthcare Professionals	71
Appendix B: Invitational Emails.....	79
Appendix C: Genetic Counselor Free Response Section Results	82
Appendix D: Pediatrician Free Response Section Results	93
Appendix E: Informational Items in Rank Order	97
Appendix F: Breakdown of Item Ratings by Percentage of Total N	108
Appendix G: All Chi-Square Analysis Results	119

List of Tables

Table 2.1 Genetic Counselor Demographic Information	32
Table 2.2 Pediatrician Demographic Information	34
Table 2.3 Experiences Providing SHE	37
Table 2.4 Essential Informational Items to Include in SHE for Adolescents with ASD, ID, or Both Diagnoses.....	39
Table E.1 Genetic Counselor Rankings	97
Table E.2 Pediatrician Rankings	102
Table F.1 Percentage Breakdown of Informational Item Ratings	108
Table G.1 Chi-Square Analysis of Average Informational Item Ratings Per Group.....	119

List of Figures

Figure 2.1 Data Cleaning Flow Chart.....	30
Figure 2.2 Frequency of contact with individuals with ASD or ID in current area of practice.....	36
Figure 2.3 Resources Genetic Counselors Utilize.....	37
Figure 2.4 Resources Pediatricians Utilize	38
Figure 2.5 Thematic Analysis of Free-Response Answers	41

List of Abbreviations

AAP	American Academy of Pediatrics
ABP	American Board of Pediatrics
ABPN	American Board of Psychiatry and Neurology
ACGC	Accreditation Council for Genetic Counseling
ACGME	Accreditation Council for Graduate Medical Education
ACOG	American College of Obstetricians and Gynecologists
ADHD	Attention-Deficit/Hyperactivity Disorder
ASD	Autism Spectrum Disorder
CDC	Centers for Disease Control and Prevention
CSE	Comprehensive Sexuality Education
DBP	Developmental-Behavioral Pediatrician
DHHS	Department of Health and Human Services'
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, 5th edition
ID	Intellectual Disability
IDD	Intellectual Developmental Disorder
NDD	Neurodevelopmental Disabilities
NSGC	National Society of Genetic Counselors
OBGYN	Obstetrician-Gynecologist
SHE	Sexual Health Education
SIECUS	Sexual Information and Education Counsel of the United States

Chapter 1: Background

Chapter 1.1: Sexual Health Education for Individuals with Neurodevelopmental Disorders

1.1.1 Sexual Health Education Definition and Practice Guidelines

The Sexual Information and Education Council of the United States (SIECUS) defines comprehensive sexuality education (CSE) as programs that are taught from kindergarten through 12th grade and include “age, developmental, and culturally appropriate, science-based, and medically accurate information on a broad set of topics related to sexuality, including human development, relationships, personal skills, sexual behaviors, including abstinence, sexual health, and society and culture” (Harley, 2019, paragraph 9). The Centers for Disease Control and Prevention (CDC) defines sexual health education (SHE) as education equipping students with medically accurate and developmentally appropriate content to help them achieve sexual health and avoid sexually transmitted diseases and unintended pregnancy (Centers for Disease Control and Prevention, 2020). There have been multiple publications by professional healthcare organizations regarding SHE. For example, the American College of Obstetricians and Gynecologists (ACOG) Committee on Adolescent Health Care (2016b) published a committee opinion on this topic, stating that obstetrician-gynecologists (OBGYNs) are “an important resource for sexuality education programs.” They claim that “one key component of an effective

program is encouraging community-centered efforts” – this would include medical professionals, parents, and educators (Committee on Adolescent Health Care, 2016b, p. 1). Some of the topics ACOG suggests to include in CSE are the benefits of delaying sexual intercourse, contraception (for sexually transmitted infection protection and pregnancy prevention), forms of sexual expression (vaginal intercourse, oral sex, anal sex, mutual masturbation, texting/virtual sex), healthy sexual and nonsexual relationships, gender identity, and many more. They emphasize the importance of starting this education in childhood and continuing it throughout the patient’s lifespan. Regarding adolescents with disabilities, they suggest that the SHE provided should “be on par with their peers, and they should be included in sexuality programs through their schools and communities” (Committee on Adolescent Health Care, 2016b, p. 3). However, they do not describe how this education should be provided to adolescents with disabilities, only that these healthcare professionals should provide it.

The American Academy of Pediatrics (AAP) has published guidelines for SHE for children and adolescents. They suggest several topics that should be covered, such as healthy sexual development, gender identity, interpersonal relationships, affection, sexual development, intimacy, and body image (Breuner et al., 2016). Like the ACOG statement, the AAP states that conversations about sexual health can be initiated by the pediatrician “in early childhood and [the pediatrician can] continue discussions at ongoing health maintenance visits throughout school age, adolescence, and young adulthood” (Breuner et al., 2016,

p. e3). SHE is a teaching process that should evolve and be taught by multiple entities, such as pediatricians, parents, school staff members, and other professionals. They affirm that SHE should be provided to “all adolescents, including adolescents with disabilities, chronic health conditions, and other special needs” (Breuner et al., 2016, p. e2). A list of SHE resources for youth with disabilities is included in the report. Compared to the ACOG committee opinion, the AAP promotes pediatricians taking on a much more active role in SHE than ACOG proposes for OBGYNs. ACOG recommends that OBGYNs should be a resource to SHE programs. In contrast, the AAP recommends that pediatricians should both “provide and support longitudinal sexuality education to all children, adolescents, and young adults with and without chronic health conditions and disabilities” (Breuner et al., 2016, p. e2).

There are few guidelines addressing SHE for adolescents with disabilities. The AAP Committee on Children with Disabilities first addressed this issue in 1996 when they released a statement that said pediatricians “should provide guidance on sexuality education to parents of children with developmental disabilities, because few other professionals are consistently involved with both the family and the child” (p. 275). They also provided specific teaching objectives and topics, such as teaching children appropriate behaviors in public versus private settings. Ten years later, they published a clinical report addressing the issues of sexuality education that are specific to children and adolescents with disabilities and their families (Murphy & Elias, 2006). They reaffirm the belief that parents should be the principal educators of their children when it comes to

issues of sexual health. Still, they also include guidance for how pediatricians can teach children with disabilities about sexual health. Some of the suggestions they mention for pediatricians are as follows: discuss topics of sexual health starting in early childhood and continuing throughout adolescence, help parents understand how the cognitive abilities of their children could influence their behavior, and advocate for developmentally appropriate sexuality education in home, community, and school settings (Murphy & Elias, 2006). Other guidelines from the AAP and ACOG exist for menstrual management for adolescents with disabilities which list options for regulating menstruation, such as oral contraceptives or hormonal intrauterine devices (Committee on Adolescent Health Care, 2016a; Quint & O'Brian, 2016).

1.1.2 Defining Autism Spectrum Disorder and Intellectual Disability

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that varies in severity and most often affects an individual's social and communication skills. The latest Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5) updated ASD diagnostic criteria. There are now only two diagnoses listed: Autism Spectrum Disorder and Social Communication Disorder. According to Maenner et al. (2021), approximately 1 in 44 children are diagnosed with ASD, making this a highly prevalent condition. ASD is present in a male to female ratio of 4:1. Still, it is essential to note the reported diagnostic gender bias that may result in underdiagnosis of girls who meet ASD criteria (Loomes et al., 2017). The main clinical features of ASD are organized into two categories: persistent deficits in social communication and interactions and restricted, stereotyped, and

repetitive behavior patterns. Typically, individuals with ASD have impaired non-verbal behaviors, delayed peer interactions, few friendships, and delayed initiation of social interaction with others. People with ASD struggle with communication; this is seen through a delay in verbal language not accompanied by non-verbal communication compensation. They can have impaired expressive language (language used to express oneself) and exhibit impaired pragmatic language use (use of appropriate communication in social situations). In addition, their speech can be stereotyped, repetitive, or idiosyncratic. The restricted, stereotyped, and repetitive behavior patterns that individuals with ASD typically have are preoccupation with particular interests or topics, strict adherence to routines, repetitive motor mannerisms, self-stimulatory behavior, and sensory issues (American Psychiatric Association [APA], 2013). Several comorbid disorders are common in individuals with ASD, including intellectual delays (40-80%), attention-deficit/hyperactivity disorder (ADHD) (59%), obsessive-compulsive disorder (OCD) (37%), depression (2-30%), and anxiety (43-84%) (Levy et al., 2009).

Intellectual disability (ID), also called intellectual developmental disorder (IDD), is a heterogeneous condition that limits an individual's ability to learn, affecting their ability to do daily tasks. This condition has an onset during the developmental period, before the age of 18, and includes intellectual and adaptive functioning deficits in three categories: conceptual, social, and practical (American Association on Intellectual and Developmental Disabilities, n.d.; APA, 2013). The DSM-5 diagnostic criteria for ID includes the following:

- Deficits in intellectual functions confirmed by both clinical assessment and individualized, standardized intelligence testing,
- Deficits in adaptive functioning that result in failure to meet developmental and sociocultural standards for personal independence and social responsibility,
- And the onset of intellectual and adaptive deficits during the developmental period (APA, 2013, p.33).

The general population prevalence of ID is approximately 1%, and the prevalence of children aged 3-17 years diagnosed with ID in the US in 2016 was 1.14% (APA, 2013; Zablotsky et al., 2017). The same diagnostic gender bias seen in ASD is also seen in ID; however, some may be due to sex-linked genetic disorders, such as Fragile X syndrome and male vulnerability to brain insult. Males are more likely than females to be diagnosed with mild and severe forms of ID (APA, 2013). A National Center for Health Statistics study found that during 2014–2016, the prevalence of children diagnosed with ID in the US was 1.48% among boys and 0.90% among girls (Zablotsky et al., 2017).

Individuals with ID are categorized based on the level of the severity of their condition. The severity levels are mild, moderate, severe, and profound. These levels are based on IQ scores and adaptive functioning, which determines the level of support that an individual will require to complete daily tasks. For example, a person with mild ID will need extra support in school, be immature in social interactions when compared to their peers, and is at risk of being manipulated due to difficulty understanding the nuances of social situations. They

also may need some support in complex daily living tasks such as money management and grocery shopping. At the other end of the spectrum, a person with profound ID will have a limited understanding and use of symbolic language, such as speech or gestures, communicate mainly through nonverbal language, and depend on others for all aspects of their daily care. Some of the comorbidities that frequently occur in individuals with ID compared to the general population are mental/neurodevelopmental disorders (ADHD, ASD, and anxiety), epilepsy, and cerebral palsy (APA, 2013).

1.1.3 Barriers to SHE for Adolescents with ASD or ID

Many obstacles prevent adolescents with ASD or ID from receiving SHE. Few guidelines exist for providing SHE to children with disabilities, and these guidelines do not address how to combat issues specific to children with ASD or ID (Murphy & Elias, 2006). Due to these factors, children with developmental disabilities lack access to SHE in the public education system. The Federal Individuals with Disabilities Education Act (IDEA) requires that children with disabilities throughout the United States be provided appropriate access to public education and services (U.S. Department of Education, 2020). However, individuals with ASD and ID still lack access to comprehensive sexuality education provided by public schools. Those with more significant cognitive deficits are the most at risk for not receiving SHE. For example, one study found that a significantly lower percentage of individuals with moderate to profound ID (16%) received sex education when compared to individuals without ID (47.5%) (Barnard-Brak et al., 2014). Other barriers that prevent individuals with ASD or ID

from receiving SHE are their deficits in social and communication skills.

Individuals with neurodevelopmental disorders may struggle in forming relationships with their non-disabled peers due to their lack of communicative competence. This causes them to miss out on informal learning opportunities that their neurotypical peers participate in through talking within their social networks about sexual health and relationships. A study done by Jahoda and Pownall (2014) compared sexual understanding of adolescents with mild ID to that of their non-disabled peers, and they found that adolescents with ID had fewer sources of sexual health information and opportunities to learn informally from friends.

Individuals with ASD and other disabilities may be overlooked because of stereotypes that these individuals are asexual or not interested in relationships (Murphy & Elias, 2006; Sullivan & Caterino, 2008). Adolescents with ASD and ID have the same attitudes and perceived needs for sexuality, intimacy, and pursuing romantic relationships that neurotypical adolescents have. Therefore, they have the same need for SHE (Chianese et al., 2020; Kramers-Olen, 2016). For adolescents with neurodevelopmental disorders to safely participate in relationships, they need quality SHE, and a lack of this education could lead to an increased risk for abuse. The U.S. Department of Health and Human Services' (DHHS) Children's Bureau Report Child Maltreatment 2020 states that 9.4% of children in the U.S. are sexually abused (U.S. Department of Health & Human Services, 2022). It is well known that individuals with ASD and ID are at higher risk to be sexually victimized, with the prevalence rate of sexual abuse for children with ID being between 14-32% and the risk for coercive sexual

victimization in girls with ASD being 3x that of their peers (Byrne, 2018; Ohlsson Gotby et al., 2018). Adolescents with neurodevelopmental disorders need to receive adequate SHE to participate in healthy sexual relationships safely and to have a better quality of life.

Chapter 1.2: Role of Healthcare Providers in Providing SHE

1.2.1 The Genetic Counseling Profession

The roots of genetic counseling can be traced back to New York in 1971 when the first class of master's degree genetic counselors graduated from Sarah Lawrence College. A few years later, in 1979, the National Society of Genetic Counselors (NSGC) was formed (National Society of Genetic Counselors, n.d.). Now, 50 years later, the field of genetic counseling has grown exponentially. To become a certified genetic counselor, one must complete a master's degree in genetic counseling from an accredited program and obtain board certification from the American Board of Genetic Counseling (ABGC). Genetic counselors are prepared to work in three main clinical specialties through fieldwork training: prenatal, cancer, and medical genetics. In addition, genetic counselors who work in more specialized areas, such as neurogenetics or cardiology, receive on-the-job training. In 2003, the NSGC formed a task force that was dedicated to defining the genetic counseling profession; in 2006, this definition was updated by the task force. Their definition of genetic counseling is as follows:

Genetic counseling is the process of helping people understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease. This process integrates:

- Interpretation of family and medical histories to assess the chance of disease occurrence or recurrence.
- Education about inheritance, testing, management, prevention, resources and research.
- Counseling to promote informed choices and adaptation to the risk or condition (Resta et al., 2006, p. 77).

Genetic counselors work with many different patients in various clinical settings. According to the 2020 professional status survey published by NSGC, the top five areas of practice include cancer genetics, prenatal, pediatrics, preconception/reproductive screening, and general adult genetics (National Society of Genetic Counselors, 2020). Other practice areas include cardiology, neurology, psychiatric genetics, utilization management, laboratory, and research. In addition, counselors work closely with other health professionals such as medical geneticists, oncologists, and maternal-fetal medicine specialists in these settings. As a result, they serve a diverse patient population that spans from pregnant women at an increased risk of having a child with a genetic condition, to people who have familial pathogenic variants in a cancer predisposition gene, such as *BRCA1*, that increases their risk for developing cancer.

Typically, genetic counselors in the pediatric setting work with medical geneticists in a medical genetics clinic. Pediatric genetic counselors gather information about the patient's medical and family history, inform patients about diagnostic testing methodologies, and provide psychosocial support and

counseling. Geneticists perform a physical examination and, with the help of the genetic counselor, decide what diagnostic testing should be performed. Various indications could necessitate a pediatric genetics consultation, such as developmental delay, birth defects, dysmorphic features, growth problems, or family history of a genetic condition (Stein et al., 2018). ASD and ID diagnoses are also common indications for a genetics evaluation because they can be associated with genetic disorders diagnosed through genetic testing.

1.2.2 Developmental-Behavioral Pediatrics and Neurodevelopmental Disabilities Subspecialties

The AAP Committee on Pediatric Workforce (2015) defines pediatrics as “the specialty of medical science concerned with the physical, mental, and social health of children from birth to young adulthood” (p. 780). They define pediatricians as medical professionals who are “concerned primarily with the health, welfare, and development of children and [are] uniquely qualified for these endeavors by virtue of interest and initial training” (Committee on Pediatric Workforce, 2015, p. 780). The training to become a pediatrician involves four years of medical school and an additional three years of residency training, specifically in medical care for children from birth to young adulthood (The American Board of Pediatrics, 2018). Developmental-behavioral pediatricians (DBPs) must also undergo three additional years of fellowship training in developmental-behavioral pediatrics and pass a subspecialty examination to become certified by the American Board of Pediatrics (ABP) (The American Board of Pediatrics, 2016). Pediatricians can also become certified in

neurodevelopmental disabilities (NDD). The ABP and the American Board of Psychiatry and Neurology (ABPN) offer this certification. To receive it, a pediatrician must complete two years of pediatrics training with specified requirements and four years of neurology and neurodevelopmental disabilities training in an Accreditation Council for Graduate Medical Education (ACGME)-accredited neurodevelopmental disabilities program (The American Board of Pediatrics, 2013). Neurodevelopmental disorders include ID, communication disorders, ASD, neurodevelopmental motor disorders, and specific learning disorders. DBP and NDD are relatively newly certified subspecialties in the realm of pediatrics. The first board examinations for NDD and DBP certification were held in 2001 and 2002, respectively (Roizen et al., 2021).

The Society for Developmental and Behavioral Pediatrics defines the role of the DBP as a clinician who “evaluate[s], treat[s] and manage[s] infants, children, and adolescents with a wide range of developmental and behavioral concerns and conditions, as well as physical complaints that are best addressed via a biobehavioral approach” (Society for Developmental & Behavioral Pediatrics, n.d., paragraph 1). Some of the most common diagnoses treated by DBPs are ADHD, developmental delay, learning disorders, behavioral/conduct disorders, ID, and ASD (Roizen et al., 2021).

1.2.3 Role of Genetic Counselors and Pediatricians in Providing SHE

AAP guidelines state that pediatricians should act as a resource for SHE for adolescents with disabilities in combination with the education that is provided by other professionals, the school system, and parents (Breuner et al., 2016;

Murphy & Elias, 2006). However, limited professional guidelines address the genetic counselor's role in providing SHE. For example, a review article written by Levy and Packman (2004) provided recommendations for how genetic counselors can incorporate information about sex abuse prevention during counseling sessions for patients with ID. They state that, while genetic counselors may not be the primary providers of comprehensive SHE for their patients with ID, they must be familiar with the risk factors of sexual abuse and be able to address sexual health issues that come up during counseling sessions. They also assert that genetic counselors can assess the sexual health educational needs of patients with ID and make the appropriate referrals to other healthcare providers or organizations that can provide comprehensive sexuality/sexual abuse prevention education (Levy & Packman, 2004).

Although healthcare providers are expected to play a role in the SHE of their patients, many feel unprepared to facilitate these discussions due to several barriers. One major barrier is the lack of human sexuality education in healthcare provider training programs. Schmitt et al. (2021) conducted a study that interviewed healthcare professionals, including physicians, nurses, social workers, and rehabilitation therapists, and the results showed that the participants had a lack of knowledge of resources on the topic of sexual health for patients with intellectual and developmental disabilities, further emphasizing the need for more provider education. Another study conducted in 2003 that evaluated 141 schools of medicine across the United States and Canada found that most schools provided only 3-10 hours of sexuality education (Solursh et al.,

2003). The curricula in most genetic counseling training programs also lack information on how to address topics of sexual health in clinical settings. This is supported by the Murphy et al. (2016) study that surveyed pediatric genetic counselors and found that one of the most frequently reported barriers to providing sex education counseling to patients with ID was “a lack of training on how to provide sex education counseling.” Other barriers include lack of time during patient visits and lack of knowledge of available educational resources (Murphy et al., 2016, p. 557; Schmidt et al., 2021). Addressing the barriers that prevent healthcare providers from facilitating discussions about sexual health topics is necessary to improve access to appropriate SHE for adolescents with and without disabilities.

Chapter 1.3: Rationale

Healthcare providers who have training in working with adolescents with disabilities, such as pediatric genetic counselors and developmental-behavioral pediatricians, could play an essential role in supporting parents in teaching their children with ASD or ID about sexual health. Still, it has been reported that several barriers prevent healthcare professionals from providing these services, including lack of time during patient visits, limited provider education, and lack of knowledge of available educational resources (Murphy et al., 2016; Schmidt et al., 2021). There is a need for healthcare professionals to support families of adolescents with neurodevelopmental disorders in providing quality SHE that they may not receive through the education system or at home (Graham Holmes et al., 2020). According to the AAP Committee on Adolescence and the

Committee on Psychosocial Aspects of Child and Family Health, SHE helps prevent multiple health risks (e.g. HIV, sexually transmitted infections, and adolescent pregnancy) in all adolescents, including those with disabilities (Breuner et al., 2016). Therefore, at-risk adolescents with ID or ASD must receive appropriate SHE. Unfortunately, few guidelines exist for providing SHE to children with disabilities, and even fewer specifically address the needs of children with ASD or ID. Assessing the SHE informational topics that genetic counselors, DBPs, and NDD subspecialty pediatricians feel are most essential can help guide future recommendations for healthcare providers when helping parents facilitate SHE for their children. Identifying informational items that are essential to all groups could provide evidence for forming more specific guidelines for teaching adolescents with ASD or ID about sexual health than what is currently available.

Chapter 1.4: Purpose

The purpose of this study was to survey pediatric genetic counselors, DBPs, and NDD subspecialty pediatricians who have experience working with children with neurodevelopmental disorders through an online questionnaire where they ranked informational items related to SHE. The primary goal of this study was to recognize what informational items were thought to be the most important by each group, and to compare responses of genetic counselors, DBPs, and NDD pediatricians. We also aimed to compare which informational items were most important to be discussed with children at the developmental stages of pre-puberty and post-puberty. We predicted that there would be

differences between what genetic counselors and subspecialty pediatricians deemed most essential to include in SHE for children with ASD, ID, or both diagnoses. The results from this study may indicate a need for more specific practice guidelines for providing SHE to children with neurodevelopmental disorders than the currently available AAP guidelines.

Chapter 2: Sexual Health Education for Children with Neurodevelopmental
Disorders: Genetic Counselor and Pediatrician Perspectives¹

¹ Smith, M. C., Fairey, J., Hill-Chapman, C., and Macias, M. To be submitted to
Journal of Intellectual Disability Research

2.1 Abstract

Many barriers prevent individuals with disabilities from receiving appropriate sexual health education (SHE), including deficits in social-communication skills and lack of resources and trained educators. There are few guidelines specifically addressing how to accommodate for providing SHE to individuals with disabilities. Healthcare professionals who are trained in working with adolescents with disabilities, such as pediatric genetic counselors, developmental-behavioral pediatricians (DBP), and neurodevelopmental disabilities (NDD) subspecialty pediatricians, could fill this gap. The purpose of the current study was to assess what informational items pediatric genetic counselors, DBP, and NDD subspecialty pediatricians felt were most essential to include in SHE for children and adolescents with autism spectrum disorder (ASD), intellectual disability (ID), or both diagnoses to help guide future recommendations for healthcare providers.

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Four out of the top 10-ranked items for each group were deemed essential to include in SHE delivered pre-puberty and post-puberty, and four additional

items were deemed essential to include in SHE delivered pre-puberty only. We also found statistically significant differences between average ratings of all four survey groups (pre-puberty and post-puberty item ratings for pediatricians and genetic counselors). Several themes emerged from the participants' free response answers, including sexual abuse prevention and the rights of those with ASD and those with ID to appropriate SHE.

Our findings may help define future professional guidelines regarding what is most important to include in SHE for individuals with ASD or ID, as well as graduate medical training curriculum. The results of this study also underscore the importance of interdisciplinary efforts to educate individuals with neurodevelopmental disorders by highlighting how pediatricians may act as the primary provider of SHE, while genetic counselors may play a role in patient advocacy.

2.2 Introduction

The Sexual Information and Education Council of the United States (SIECUS) defines comprehensive sexuality education (CSE) as programs that are taught from kindergarten through 12th grade and include “age, developmental, and culturally appropriate, science-based, and medically accurate information on a broad set of topics related to sexuality, including human development, relationships, personal skills, sexual behaviors, including abstinence, sexual health, and society and culture” (Harley, 2019, paragraph 9). The Centers for Disease Control and Prevention (CDC) (2020) defines sexual health education (SHE) as education equipping students with medically accurate

and developmentally appropriate content to help them achieve sexual health and avoid sexually transmitted diseases and unintended pregnancy. There have been multiple publications by professional healthcare organizations regarding SHE. For example, the American College of Obstetricians and Gynecologists (ACOG) Committee on Adolescent Health Care (2016b) published a committee opinion on this topic, stating that obstetrician-gynecologists (OBGYNs) are “an important resource for sexuality education programs.” They claim that “one key component of an effective program is encouraging community-centered efforts” – this would include medical professionals, parents, and educators (Committee on Adolescent Health Care, 2016b, p. 1). Some of the topics ACOG suggests including in CSE are the benefits of delaying sexual intercourse, contraception (for sexually transmitted infection protection and pregnancy prevention), forms of sexual expression (vaginal intercourse, oral sex, anal sex, mutual masturbation, texting/virtual sex), healthy sexual and nonsexual relationships, gender identity, and many more. They emphasize the importance of starting this education in childhood and continuing it throughout the patient’s lifespan. Regarding adolescents with disabilities, most professional guidelines fail to include this population. If they do mention those with disabilities, most do not define how this education should be taught to this population, only that healthcare professionals should provide it. For example, ACOG suggests that the SHE provided should “be on par with their peers, and they should be included in sexuality programs through their schools and communities,” yet, they do not describe how this

education can be modified for the specific needs of individuals with disabilities (Committee on Adolescent Health Care, 2016b, p. 3).

The American Academy of Pediatrics (AAP) also has published guidelines for SHE for children and adolescents. They suggest several topics that should be covered, such as healthy sexual development, gender identity, interpersonal relationships, affection, sexual development, intimacy, and body image (Breuner et al., 2016). Like the ACOG statement, the AAP states that conversations about sexual health can be initiated by the pediatrician “in early childhood and [the pediatrician can] continue discussions at ongoing health maintenance visits throughout school age, adolescence, and young adulthood” (Breuner et al., 2016, p. e3). They affirm that SHE should be provided to “all adolescents, including adolescents with disabilities, chronic health conditions, and other special needs” (Breuner et al., 2016, p. e2). A list of SHE resources for youth with disabilities is included in the report. Compared to the ACOG committee opinion, the AAP promotes pediatricians taking on a much more active role in SHE than ACOG proposes for OBGYNs. ACOG recommends that OBGYNs should be a resource to SHE programs. In contrast, the AAP recommends that pediatricians should both “provide and support longitudinal sexuality education to all children, adolescents, and young adults with and without chronic health conditions and disabilities” (Breuner et al., 2016, p. e2).

There are few guidelines addressing SHE for adolescents with disabilities. The AAP Committee on Children with Disabilities first addressed this issue in 1996 when they released a statement that said pediatricians “should provide

guidance on sexuality education to parents of children with developmental disabilities, because few other professionals are consistently involved with both the family and the child” (p. 275). They also provided teaching objectives and topics, such as appropriate behaviors in public versus private settings. Ten years later, they published a clinical report addressing the issues of sexuality education that are specific to children and adolescents with disabilities and their families (Murphy & Elias, 2006). They reaffirm the belief that parents should be the principal educators of their children when it comes to issues of sexual health. Still, they also include guidance for how pediatricians can teach children with disabilities about sexual health. Some of the suggestions they mention for pediatricians are as follows: discuss topics of sexual health starting in early childhood and continuing throughout adolescence, help parents understand how the cognitive abilities of their children could influence their behavior, and advocate for developmentally appropriate sexuality education in home, community, and school settings (Murphy & Elias, 2006).

This research focused on SHE for individuals with autism spectrum disorder (ASD), intellectual disability (ID), or both diagnoses. ASD is a neurodevelopmental disorder that varies in severity and most often affects an individual’s social and communication skills. Typically, individuals with ASD have impaired non-verbal behaviors, delayed peer interactions, and delayed initiation of social interaction with others. According to Maenner et al. (2021), approximately 1 in 44 children are diagnosed with ASD, making this a highly prevalent condition. Intellectual disability (ID), also called intellectual

developmental disorder (IDD), is a heterogeneous condition that limits an individual's ability to learn, affecting their ability to do daily tasks. This condition has an onset during the developmental period, before the age of 18, and includes intellectual and adaptive functioning deficits in three categories: conceptual, social, and practical (American Association on Intellectual and Developmental Disabilities, n.d.; American Psychiatric Association, 2013). The general population prevalence of ID is approximately 1%, and the prevalence of children aged 3-17 years diagnosed with ID in the US in 2016 was 1.14% (American Psychiatric Association, 2013; Zablotsky et al., 2017).

Many healthcare professionals may be involved in the medical management of individuals with ASD or ID. For example, genetic counselors in the pediatric setting commonly care for patients with neurodevelopmental disorders such as ASD or ID. Neurodevelopmental disorders are common indications for a genetics evaluation because they can be associated with genetic disorders diagnosed through genetic testing. These counselors work alongside medical geneticists in a medical genetics clinic. Other healthcare providers who are often in contact with individuals with ASD or ID are pediatricians. There are two specialties in pediatric medicine that focus on the care of individuals with neurocognitive differences: developmental-behavioral pediatrics (DBP) and neurodevelopmental disabilities (NDD).

The AAP guidelines state that pediatricians should act as a resource for SHE for adolescents with disabilities in combination with the education that is provided by other professionals, the school system, and parents (Breuner et al.,

2016; Murphy & Elias, 2006). However, limited professional guidelines address the genetic counselor's role in providing SHE. For example, a review article written by Levy and Packman (2004) provided recommendations for how genetic counselors can incorporate information about sexual abuse prevention during counseling sessions for patients with ID. They state that, while genetic counselors may not be the primary providers of comprehensive SHE for their patients with ID, they must be familiar with the risk factors of sexual abuse, and be able to address sexual health issues that come up during counseling sessions. They also assert that genetic counselors can assess the sexual health educational needs of patients with ID and make the appropriate referrals to other healthcare providers or organizations that can provide comprehensive sexuality/sexual abuse prevention education (Levy & Packman, 2004).

Many obstacles prevent adolescents with ASD or ID from receiving SHE. Few guidelines exist for providing SHE to children with disabilities, and these guidelines do not address how to combat issues specific to children with ASD or ID (Murphy & Elias, 2006). Due to these factors, children with developmental disabilities lack access to SHE in the public education system. Those with more significant cognitive deficits are the most at risk for not receiving SHE. For example, one study found that a significantly lower percentage of individuals with moderate to profound ID (16%) received sex education when compared to individuals without ID (47.5%) (Barnard-Brak et al., 2014). Other barriers that prevent individuals with ASD and ID from receiving SHE are their deficits in social and communication skills. Individuals with neurodevelopmental disorders

may struggle in forming relationships with their non-disabled peers due to their lack of communicative competence. This causes them to miss out on informal learning opportunities that their neurotypical peers participate in through talking within their social networks about sexual health and relationships. A study done by Jahoda and Pownall (2014) compared sexual understanding of adolescents with mild ID to that of their non-disabled peers, and they found that adolescents with ID had fewer sources of sexual health information and opportunities to learn informally from friends.

Individuals with ASD and other disabilities may be overlooked because of stereotypes that these individuals are asexual or not interested in relationships (Murphy & Elias, 2006; Sullivan & Caterino, 2008). Adolescents with ASD and ID have the same attitudes and perceived needs for sexuality, intimacy, and pursuing romantic relationships that neurotypical adolescents have. Therefore, they have the same need for SHE (Chianese et al., 2020; Kramers-Olen, 2016). For adolescents with neurodevelopmental disorders to safely participate in relationships, they need quality SHE, and a lack of this education could lead to an increased risk for abuse. The U.S. Department of Health and Human Services' (DHHS) Children's Bureau Report Child Maltreatment 2020 states that 9.4% of children in the U.S. are sexually abused (U.S. Department of Health & Human Services, 2022). It is well known that individuals with ASD and ID are at higher risk to be sexually victimized, with the prevalence rate of sexual abuse for children with ID being between 14-32% and the risk for coercive sexual victimization in girls with ASD being 3x that of their peers (Byrne, 2018; Ohlsson

Gotby et al., 2018). Adolescents with neurodevelopmental disorders need to receive adequate SHE to participate in healthy sexual relationships safely and to have a better quality of life.

Healthcare providers who have training in working with adolescents with disabilities, such as pediatric genetic counselors, DBPs, and NDD subspecialty pediatricians, could play an essential role in supporting parents in teaching their children with ASD or ID about sexual health. Still, it has been reported that several barriers prevent healthcare professionals from providing these services, including lack of time during patient visits, limited provider education, and lack of knowledge of available educational resources (Murphy et al., 2016; Schmidt et al., 2021). There is a need for healthcare professionals to support families of adolescents with neurodevelopmental disorders in providing quality SHE that they may not receive through the education system or at home (Graham Holmes et al., 2020). According to the AAP Committee on Adolescence and the Committee on Psychosocial Aspects of Child and Family Health, SHE helps prevent multiple health risks (e.g. HIV, sexually transmitted infections, and adolescent pregnancy) in all adolescents, including those with disabilities (Breuner et al., 2016). Unfortunately, few guidelines exist for providing SHE to children with disabilities, and even fewer address the needs of children with ASD or ID. Assessing the SHE informational topics that genetic counselors and subspecialty pediatricians feel are most essential can help guide future recommendations for healthcare providers when helping parents facilitate SHE for their children. Identifying informational items that are essential to all groups

could provide evidence for forming more specific guidelines for adolescents with ASD or ID than what is currently available.

Therefore, the purpose of this study was to survey genetic counselors, DBPs, and NDD subspecialty pediatricians who have experience working with children with neurodevelopmental disorders, through an online questionnaire where they ranked informational items related to SHE. The primary goals of this study were to recognize the informational items thought to be most essential for SHE delivered pre- and post-puberty by each group, and to compare responses of pediatric genetic counselors, DBPs, and NDD subspecialty pediatricians.

2.3 Methods

2.3.1 Participants

Participants included two groups: 1) genetic counselors with a Master of Science degree in genetic counseling and experience working in a pediatric medical genetics setting and 2) physicians (MD or DO) who work or have previously worked in developmental-behavioral or neurodevelopmental disabilities pediatrics (hereafter referred to as ‘pediatricians’). The exclusion criteria included the following: minors under the age of 18 years old, individuals who were unable to read or write in English fluently, genetic counselors without experience working in a pediatric medical genetics setting, and physicians who had not previously worked in developmental-behavioral or neurodevelopmental disabilities pediatrics, or who were not board certified or board eligible.

2.3.2 Design and Procedures

The institutional review board at the University of South Carolina approved this study in July of 2021 (Pro#00113202). The methods of this study were

adapted from two previous studies: an original study assessing the informational needs of parents receiving a diagnosis of Down syndrome and two newer studies that also used these methods (Sheets et al., 2011; Wasson, 2021; Wilkes, 2020). An online questionnaire was created for healthcare providers (Appendix A), including genetic counselors and pediatricians. The informational items and free-response questions were adapted to assess the perspectives and experiences of pediatric genetic counselors and pediatricians, and to gauge what information these groups consider essential to include in SHE for adolescents with ASD, ID, or both diagnoses. The informational items were modeled after topics listed in the *Guidelines for Comprehensive Sexuality Education: Kindergarten through 12th Grade* (National Guidelines Task Force, 2004).

Genetic counselors were identified through the National Society of Genetic Counselors listserv; they received the link to the questionnaire and a summary of the study through email. A month after the initial link was sent, a second reminder link was sent out through the same listserv. Genetic counselors were also accessed through social media groups in which the invitation (Appendix B) and the link was shared. Pediatricians were identified by affiliation with professional pediatrics organizations and a regional hospital system listserv. The questionnaire link was also shared by individuals who were initially contacted with others outside this original scope.

Participation was voluntary, and upon completion of the questionnaire, all participants were given the option to participate in a separate raffle survey. There

were two different links to two raffles (genetic counselor and pediatrician) where individuals could enter their email address for a chance to win a \$25 gift card.

2.3.3 Instrumentation

Genetic counselors and pediatricians were given a five-section Qualtrics survey (Appendix A). The first section contained pediatrician-specific or genetic counselor-specific multiple-choice and fill-in-the-blank questions about work setting, years of practice, frequency of contact with individuals with ASD or ID, and experiences providing SHE. The second and third sections included SHE informational item ratings. The second section asked the participants to rate the importance of including items in SHE delivered pre-puberty, and the third section asked participants to rate the importance of including items in SHE delivered post-puberty. In addition, these sections asked participants to rate the level of importance of these items using the following scale: essential = 3, important but not essential = 2, not too important = 1, unsure = 0. The topics included in these sections were: human development, relationships, personal skills, sexual behavior, and sexual health. The fourth section consisted of multiple choice and free response questions where participants could share their experience facilitating SHE for adolescents with ASD or ID. Finally, the fifth section included questions about the demographic information of the genetic counselor and pediatrician participants.

2.3.4 Data Cleaning and Respondent Validation

When reviewing the collected data, we suspected that some of the responses were completed by bots. To eliminate bot responses from analysis, we validated all submissions by using the exclusion criteria displayed in Figure

2.1. In summary, we excluded all responses with extremely short response times, incomplete demographic responses, and those that did not meet inclusion criteria. Most responses with non-unique IP addresses were also excluded.

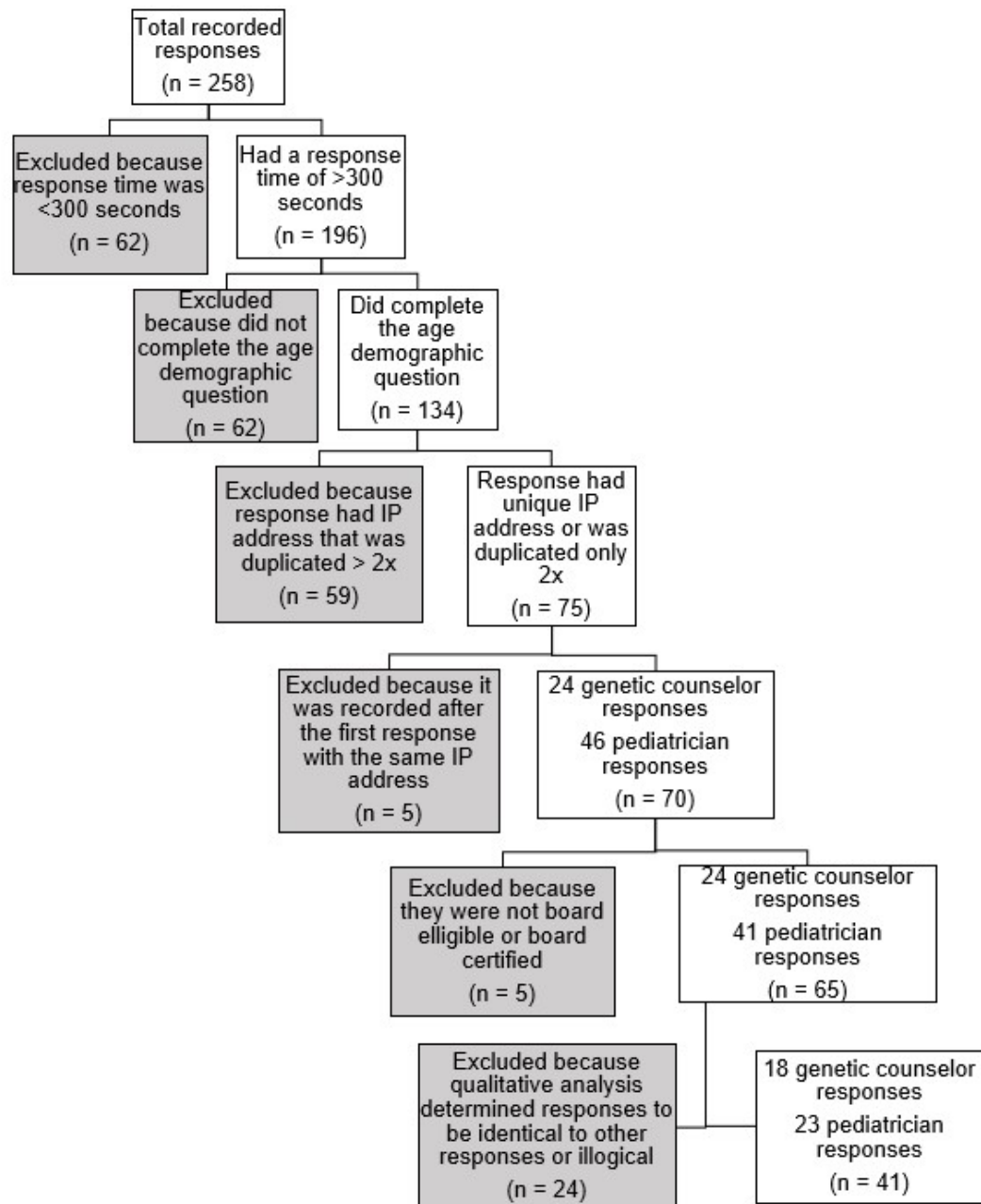


Figure 2.1. *Data cleaning flow chart.*

2.3.5 Data Analysis

There were four groups analyzed, including genetic counselors rating items for pre-puberty SHE (Group 1), genetic counselors rating items for post-puberty SHE (Group 2), pediatricians rating items for pre-puberty SHE (Group 3), and pediatricians rating items for post-puberty SHE (Group 4). The data was transferred from Qualtrics to Microsoft Office Excel software to perform descriptive statistical analysis. Quantitative data was analyzed by transferring the data from Microsoft Office Excel into Statistical Package for Social Sciences (SPSS). The average rating for each informational item included in the survey was calculated using a Likert scale format (essential = 3, important but not essential = 2, not too important = 1, unsure = 0), and the average ratings were assembled in rank order to determine which informational items were the most essential. Comparative statistical analysis was conducted to determine the differences between pre-puberty and post-puberty genetic counselor groups (groups 1 and 2), pre-puberty and post-puberty pediatrician groups (groups 3 and 4), pre-puberty genetic counselor and pre-puberty pediatrician groups (groups 1 and 3), and post-puberty genetic counselor and post-puberty pediatrician groups (groups 2 and 4). A p-value of ≤ 0.05 was considered statistically significant. The qualitative data collected from the free-response section of the questionnaire were analyzed using a grounded theory approach, themes based on the responses were coded, and the frequency was documented.

2.4 Results

2.4.1 Genetic Counselor Participants

Of the 117 genetic counselors who opened the healthcare provider survey, 18 were included in the final analysis after data cleaning. All questions were optional, and there were no forced-completion questions, so the number of answered questions varied between respondents. The genetic counselors' free-response results can be found in Appendix C. Most genetic counselor respondents were between the ages of 25 and 29 and had been practicing for five years or less (Table 2.1). Almost all genetic counselor participants identified as female and white. In the most current NSGC professional status survey, 95% of respondents identified as female and 90% identified as white (National Society of Genetic Counselors, 2020). Most worked in the hospital- or academic/university-based work settings. Two participants selected "other" for their current work setting; one worked at a nonprofit medical center, and the other worked at an HMO/research institute. Many genetic counselor participants reported multiple current primary areas of practice, the majority listing medical genetics or pediatric subspecialty as one of their primary specialties. Most genetic counselors listed medical genetics, pediatrics, or adult genetics as previous areas of practice. Their years of experience in general or subspecialty pediatrics ranged from less than one year to up to 25 years.

Table 2.1 Genetic Counselor Demographic Information

Demographic	Responses	Total (n)	Percent
Biological sex (n=18)	Male	2	11.11%
	Female	16	88.89%

Age (n=18)	20-24 years old	1	5.56%
	25-29 years old	9	50.00%
	30-34 years old	4	22.22%
	35-39 years old	2	11.11%
	40-44 years old	0	0.00%
	45-49 years old	1	5.56%
	50-54 years old	1	5.56%
	55-59 years old	0	0.00%
	>60 years old	0	0.00%
Ethnicity (participants could select more than one answer)	White	17	N/A
	Hispanic or Latino	1	N/A
	Black or African American	0	N/A
	Native American or Alaskan Native	1	N/A
	Asian/Pacific Islander	0	N/A
	Other	0	N/A
Year earned degree (n=18)	1970-1979	0	0.00%
	1980-1989	0	0.00%
	1990-1999	2	11.11%
	2000-2009	0	0.00%
	2010-2019	11	61.11%
	2020-2021	5	27.78%
Current U.S. region of practice (n=17)	West	1	5.88%
	Midwest	5	29.41%
	Northeast	1	5.88%
	South	10	58.82%
Total years of practice (n=17)	<1	1	5.88%
	1-5	10	58.82%
	6-10	4	23.53%
	11-15	0	0.00%
	16-20	0	0.00%
	21-25	2	11.76%
	26-30	0	0.00%
	>30	0	0.00%
Years of practice in pediatrics (general or subspecialty) (n=17)	<1	2	11.76%
	1-5	10	58.82%
	6-10	3	17.65%

11-15	0	0.00%
16-20	1	5.88%
21-25	1	5.88%
26-30	0	0.00%
>30	0	0.00%

2.4.2 Pediatrician Participants

Of the 123 pediatricians who opened the healthcare provider survey, 23 were included in the final analysis after data cleaning. As mentioned previously, all questions were optional, so the number of answered questions varied between pediatrician respondents. The pediatrician free-response results can be found in Appendix D. Most pediatricians were below age 45 and practiced ten years or less (Table 2.2.). The majority reported their sex as male and their ethnicity as white. A workforce survey done by Bridgemohan et al. (2018) found the majority of their 411 sample of DBP- and/or NDD-trained specialty physicians to be white females. Almost all pediatricians had a Doctor of Medicine (MD) and most were board-certified in DBP. More than half worked in a hospital- or academic/university-based setting, but some worked in private practice or a multiple specialty group. Their years of practice in developmental pediatrics ranged from two to over 30 years of experience.

Table 2.2 Pediatrician Demographic Information

Demographic	Responses	Total (n)	Percent
Biological sex (n=23)	Male	16	69.57%
	Female	7	30.43%
Age (n=23)	20-24 years old	1	4.35%
	25-29 years old	4	17.39%
	30-34 years old	2	8.70%
	35-39 years old	4	17.39%
	40-44 years old	7	30.43%
	45-49 years old	1	4.35%

	50-54 years old	1	4.35%
	55-59 years old	1	4.35%
	>60 years old	2	8.70%
Ethnicity (participants could select more than one answer)	White	16	N/A
	Hispanic or Latino	5	N/A
	Black or African American	2	N/A
	Native American or Alaskan Native	1	N/A
	Asian/Pacific Islander	1	N/A
Degree Type (n=23)	Doctor of Medicine (M.D.)	22	95.65%
	Doctor of Osteopathic Medicine (D.O.)	1	4.35%
Board certification (n=21)	Developmental-behavioral pediatrics (DBP)	19	90.48%
	Neurodevelopmental disabilities (NDD)	2	9.53%
Year earned degree (n=17)	1970-1979	2	11.76%
	1980-1989	1	5.88%
	1990-1999	3	17.65%
	2000-2009	7	41.18%
	2010-2019	3	17.65%
	2020-2021	1	5.88%
Current U.S. region of practice (n=10)	West	2	20.00%
	Midwest	2	20.00%
	Northeast	3	30.00%
	South	3	30.00%
Total years of practice (n=18)	<1	0	0.00%
	1-5	4	22.22%
	6-10	8	44.44%
	11-15	1	5.56%
	16-20	1	5.56%
	21-25	1	5.56%
	26-30	1	5.56%
	>30	2	11.11%
Years of practice in developmental pediatrics (n=12)	<1	0	0.00%
	1-5	5	41.67%
	6-10	3	25.00%

11-15	1	8.33%
16-20	0	0.00%
21-25	0	0.00%
26-30	2	16.67%
>30	1	8.33%

2.4.3 Information Regarding Frequency of Contact with Individuals with ASD or ID

Most genetic counselors (67%) and pediatricians (74%) sometimes had contact with individuals with ASD or ID in training. Similar to their experiences in training, most genetic counselors (61%) and pediatricians (70%) sometimes had contact with individuals with ASD or ID outside of a professional context. Around 50% of genetic counselors were in contact with individuals with ASD or ID most of the time in their current area of practice, compared to 22% of pediatricians (Figure 2.2).

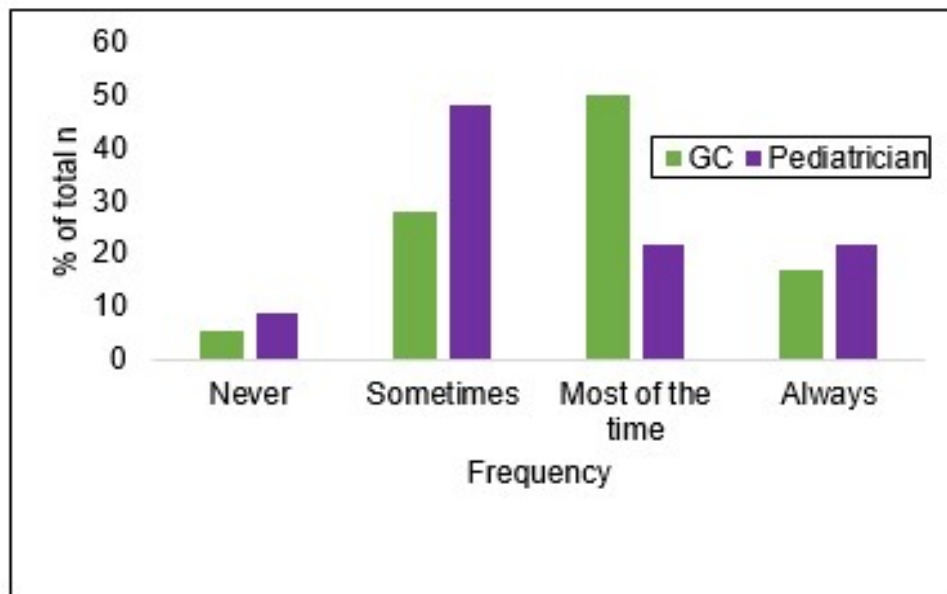


Figure 2.2. Frequency of contact with individuals with ASD or ID in current area of practice.

2.4.4 Experiences with Providing Sexual Health Education (SHE)

While most pediatricians (87%) had experience providing SHE to children with ASD or ID, less than half of genetic counselors (44%) had experience providing this type of education (Table 2.3). Many pediatricians selected Your Child Development and Behavioral Resources as being utilized in their clinical practice (Figure 2.4). Several genetic counselors had not used any of the listed resources in their clinical practice, while most pediatricians had used at least one of the listed resources (Figure 2.3; Figure 2.4).

Table 2.3 Experiences Providing SHE

Question	Responses	Genetic counselor responses (n=18)		Pediatrician responses (n=23)	
		Total (n)	Percent	Total (n)	Percent
Have you ever provided sexual health education to children with ASD or ID?	Yes	8	44.44%	20	86.96%
	No	10	55.56%	3	13.04%

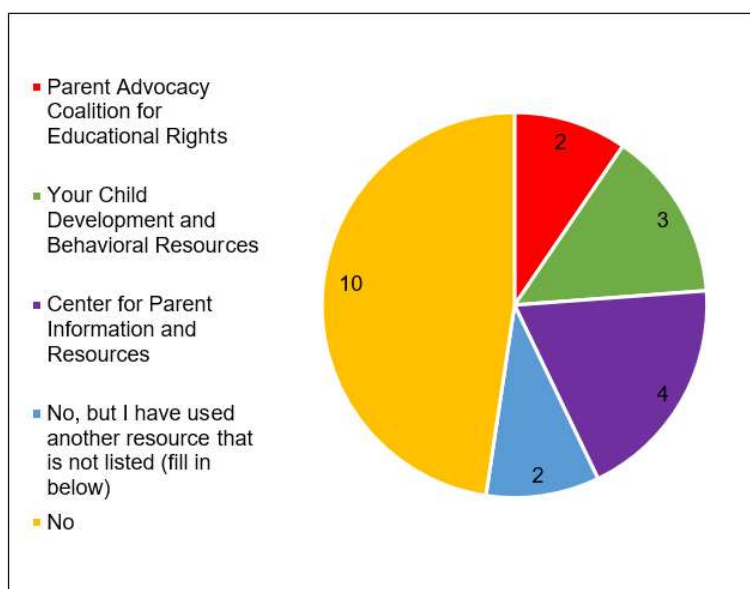


Figure 2.3. Resources genetic counselors utilize.

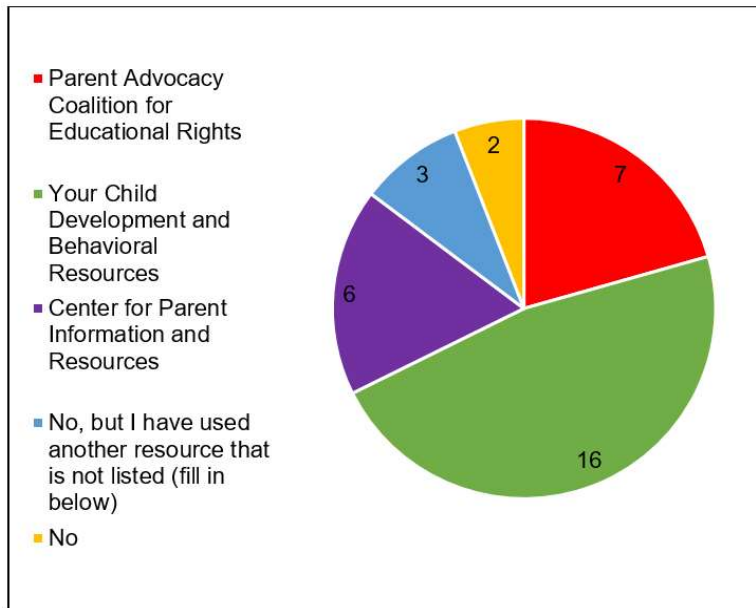


Figure 2.4. *Resources pediatricians utilize.*

2.4.5 Essential Information to Include in SHE for Adolescents with ASD or ID

Thirty-two informational items were placed in rank order based on their average rating for all groups (group 1, 2, 3, and 4) (Appendix E). The higher the average rating, the more essential the informational item.

Items present in the top ten rankings for all four groups were considered essential information for overall SHE (Table 2.4). A total of four informational items were deemed essential for overall SHE. Likewise, items that were present in the top ten rankings for group 1 and group 3 only were considered essential information for SHE delivered during the pre-puberty time frame. A total of four informational items were identified as essential to include in pre-puberty SHE. No informational items were present in the top ten rankings of only post-puberty genetic counselors (group 2) and post-puberty pediatricians (group 4). Therefore, no items were deemed essential for post-puberty SHE. All essential informational

items for overall SHE and pre-puberty SHE were ranked essential by most respondents of at least one of the four groups (Appendix F).

Table 2.4 Essential Informational Items to Include in SHE for Adolescents with ASD, ID, or Both Diagnoses

Essential Information for Overall (Pre-puberty and Post-puberty) SHE	Essential Information for Pre-puberty SHE
Child sexual abuse is when someone touches the private parts of a child's body without a health or hygiene reason; if this occurs, a child should tell a trusted adult, even if he/she was told to keep it a secret.	A person has the right to refuse any sexual behavior and at any point during sexual activity a person has the right to ask a partner to stop and to expect that his/her request will be respected.
Everyone, including children, has the right to tell others not to touch their body when they do not want to be touched.	Puberty is a universally experienced transition from childhood to adulthood that is characterized by physical and emotional changes as the sexual and reproductive body systems mature.
Both boys/men and girls/women can be sexually abused.	Masturbation should be done in a private place.
Boys/men have nipples, a penis, a scrotum, and testicles. Girls/women have breasts, nipples, a vulva, a clitoris, a vagina, a uterus, and ovaries.	Sexual abuse not involving touch can include being shown pornographic movies, magazines, websites, or other materials; taking photos, videos, or other recordings; or watching sexual acts.

2.4.6 Qualitative Results

Every participant who completed the healthcare provider survey had the opportunity to expand upon their thoughts in open-ended response questions. All responses can be found in Appendix C and Appendix D. When asked to elaborate on what SHE topics were most important, their experiences providing SHE, why they think SHE is important for individuals with ASD or ID, and what

obligations healthcare providers have in terms of facilitating SHE for these groups, several themes emerged (Figure 2.5).

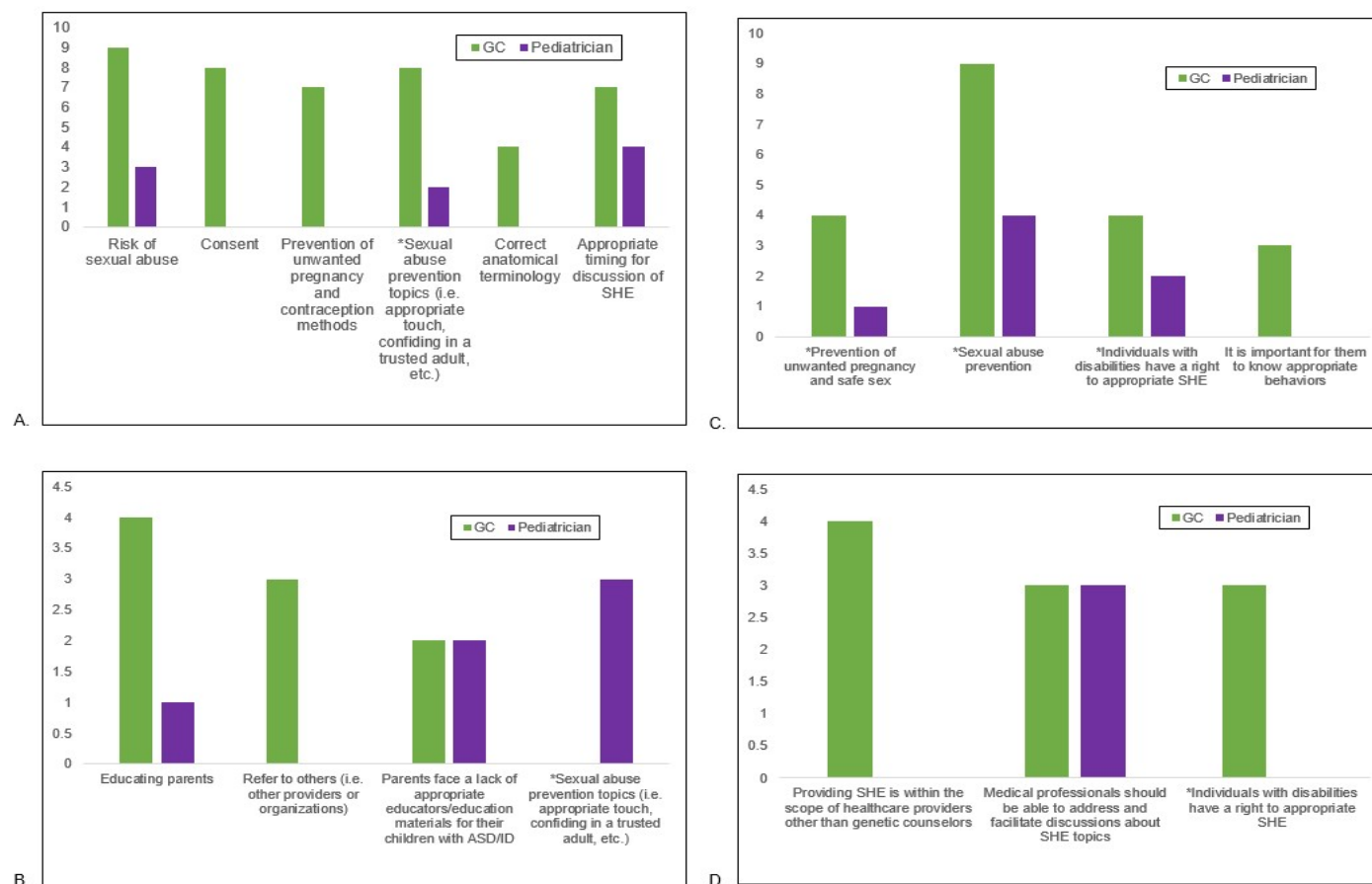


Figure 2.5. Thematic analysis of free-response answers. A. Please elaborate on what you think is most important to include in SHE for children with ASD/ID/both and why. B. What are your experiences providing OR helping facilitate SHE for children with ASD, ID, or both diagnoses (if you have had these experiences)? C. Why do you think it is important that SHE is discussed with youth with ASD, ID, or both diagnoses? D. What legal and ethical obligations, responsibilities, or duties do medical professionals have in terms of helping parents of children with ASD/ID/both talk to their children about sexual health? Note: Themes with * indicate that they were present in responses to multiple open-text questions

When asked about comfort level with providing or helping facilitate sex education for children with ASD, ID, or both diagnoses, some genetic counselors noted some discomfort (n=5). In contrast, others reported being more comfortable (n=2). The answers ranged from “*very comfortable*” and “*I feel good about it*” to “*I am not comfortable at all.*” One counselor remarked that while they were uncomfortable providing this type of education, “*[they thought] it’s important though and would like to feel more comfortable with it.*” Pediatricians had similar responses to genetic counselors, with some responding that they were “*not that comfortable with it*” to others who were “*fairly comfortable.*” One respondent reported that they were reasonably comfortable with it, “*however, when dealing with more severely impacted ID, [they] don’t really elaborate on the greater social issues surrounding sexuality. Again, more focused on safety.*”

Most pediatricians (n=19) had initiated a conversation with parents of children with ASD/ID/both about sexual abuse prevention, while only approximately half of genetic counselors (n=9) had initiated this type of conversation. One genetic counselor explained what they cover during these conversations with patients,

“Contraception, “safe touch” education provided by community resources, help around managing periods if applicable (who helps the teen at school if they need a lot of assistance in this process). I think it’s also good to ask questions directly to the patient while discussing with the parent especially regarding do they feel safe in their daily environment? Does anyone make

them feel uncomfortable and why? This normalizes checking in with the teen.” (GC)

Another counselor was briefer in their discussion,

“I did not go into extreme detail, but rather discussed that ASD/ID can make a child more vulnerable and put them at risk for sexual abuse.

Additionally, they may not understand correct boundaries and could get in trouble themselves for sexual abuse.” (GC)

Multiple pediatrician participants mentioned that they talk about appropriate touch in their conversations with families,

“Teaching about safe touch especially at school” (Pediatrician)

Another listed,

“good touch/bad touch, making sure parents are talking with kids about what happens with their bodies, using correct words to describe body parts” (Pediatrician)

When participants were asked what education or resources they had received to aid in their discussions of SHE, the responses were varied for genetic counselors. Some of the genetic counselor responses were,

“Training during grad school” (GC)

“Just social stories that I made myself, no online resources” (GC)

“local support group as well as experienced team members” (GC)

“social work” (GC)

The pediatrician participants also had a wide range of responses to this question, and some of them mentioned,

“Local conference presentations, national conference presentations (AAP). One of our NPs and BCBA’s have this as a special interest and teach parent groups and local school districts on sexuality and sexuality education for youth with IDD” (Pediatrician)

“Graduate medical training. Really like Mary Wrobel’s book! (Pediatrician) Autism speaks, information from the University of Minnesota about dating, information from previous SDBP workshops.” (Pediatrician)

We also asked pediatricians and genetic counselors what resources they found the most helpful. Some of their recommendations are listed below:

“There are a number of children’s books about body such as The Body Book by Usborn that I think provided good discussion and explanation. I also use foundation websites for many conditions such as Turner syndrome to address specific issues of reproduction that may be related to a certain diagnosis.” (GC)

“Our practice uses the Vanderbilt Healthy Body Toolkits and the ATN Adolescence and Transition Toolkits Parents seem to like them.” (Pediatrician)

2.4.7 Statistically Significant Differences Between Groups

Genetic counselors were found to have statistically significant differences between their pre-puberty and post-puberty ratings for 12 informational items (items 6, 11, 14, 18, 19, 20, 21, 22, 23, 24, 25, and 26) (Appendix G). Genetic counselors rated definitions of sexual orientation (72.2% rated essential), sexuality (83.3% rated essential), and sexual behaviors (66.7% rated essential)

higher in the post-puberty time frame than in the pre-puberty time frame. Genetic counselors in the post-puberty section rated sexual arousal, sexual fantasies, sexual dysfunction, and sexual health exams higher than they rated these terms in the pre-puberty section. Similarly, concepts relating to sexually transmitted diseases, contraception, pregnancy care, and pregnancy options were rated higher by genetic counselors for post-puberty education compared to pre-puberty education.

We found statistically significant differences between eight items rated by pediatricians in the pre-puberty and post-puberty sections (items 1, 4, 5, 9, 12, 16, 23, and 24) (Appendix G). Pediatricians rated definitions of reproductive body systems, reproduction, body image, gender identity, masturbation, and abstinence higher in the post-puberty section than in the pre-puberty section. Likewise, they rated contraception and pregnancy options higher in the post-puberty section.

Our results show statistically significant differences in genetic counselors' and pediatricians' item ratings for the pre-puberty time frame (Appendix G). Thirteen informational items had statistically significant differences between the ratings of both pre-puberty groups (item 2, 3, 5, 11, 13, 15, 22, 23, 27, 28, 30, 31, and 32). Genetic counselors rated all the following concepts higher than pediatricians for the pre-puberty category: anatomical terms, definition of puberty, body image, sexuality, masturbation, contraception (prescription and nonprescription), and multiple items related to sexual abuse. For 12 out of the 13

terms, pediatricians had a higher rating for the same item in the post-puberty section.

Furthermore, there were differences between genetic counselors' and pediatricians' item ratings for the post-puberty section. Eighteen informational items had significant differences between ratings for these groups (item 1, 2, 3, 6, 11, 12, 13, 14, 15, 18, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30, and 31). Genetic counselors rated all the following items higher than pediatricians for the post-puberty section: reproductive body systems, anatomical terms, the definition of puberty, sexual orientation, sexuality, definitions related to masturbation, sexual behavior, sexual arousal, sexual health exams, contraception (prescription and nonprescription), pregnancy options, prenatal care, sexually transmitted diseases, and concepts relating to sexual abuse

2.5 Discussion

2.5.1 Experiences with Providing SHE

Our results showed that most DBPs and NDD subspecialty pediatricians, henceforth referred to as 'pediatricians,' had experience providing SHE to children with ASD or ID. Conversely, less than half of genetic counselors reported having these experiences. The lack of experience reported by genetic counselors could be related to several barriers described in a 2016 study by Murphy et al., including lack of time during appointments, lack of training on how to provide SHE, and the perception that the responsibility to provide SHE falls outside of their scope of practice. This is highlighted in our thematic analysis of the free responses: "refer to others (i.e., other providers or organizations)". This

theme in addition to the barrier of lack of time is reported in the following response,

“Facilitated discussion with children mostly after puberty when parents ask about contraception. Tend to give overview but leave detailed discussion and decision making to OBGYN. Often the diagnostic appointments are too filled with genetics information to discuss sexual education.” (GC)

Contrary to genetic counselors’ scope of practice, which is vague regarding provision of SHE, pediatricians have clear standards to educate all patients, including those with disabilities, about sexual health topics (Breuner et al., 2016; Murphy & Elias, 2006). This likely explains why most pediatricians in this study had more experience in providing SHE when compared to genetic counselors.

Regarding educational resources utilized in clinical practice, many genetic counselors had not used any of the listed resources. In contrast, pediatricians had used at least one. The resources listed were from a section within the AAP clinical report “Sexuality Education for Children and Adolescents” (Breuner et al., 2016). The purpose of this clinical report is to aid pediatricians’ discussion of sexual health topics with their patients with disabilities and their families, and therefore it is not surprising that more pediatricians were aware of and utilized the listed resources than genetic counselors.

2.5.2 Interpreting Essential Information for SHE

A total of four informational items were considered essential for overall SHE for children and adolescents with ASD, ID, or both diagnoses. Three of the four items were related to sexual abuse. The fourth item was related to correct

anatomical terminology for men and women. There were also four informational items determined to be essential for SHE delivered pre-puberty. Like the overall essential items, half of the pre-puberty essential items were related to sexual abuse. The other two items discussed masturbation and the definition of puberty. The importance that genetic counselors and pediatricians placed on sexual abuse is reflected in their respective professional guidelines and published papers. Breuner et al. (2016) explicitly states that adolescents with disabilities are at higher risk to be sexually abused. The genetic counseling-focused review paper published by Levy and Packman (2004) also highlights these risks and its original purpose was to increase genetic counselors' awareness about factors that lead to sexual abuse.

The emphasis placed on sexual abuse prevention as an essential education topic for this population also underscores the key themes noted in the qualitative analysis of the free-response answers. Both genetic counselors and pediatricians emphasized the importance of sexual abuse prevention. To some extent, providers in both groups also emphasized the importance of discussing sexual abuse topics during the post-puberty time frame, although no items were deemed essential for post-puberty only. One pediatrician stated the following,

“Due to [a] significantly increased risk of abuse. basic, understandable information to help them protect themselves is the priority.” (Pediatrician)

A genetic counselor participant stated,

“Discussions about sexual abuse are highly important as this population has historically (and currently) been taken advantage of.” (GC)

The genetic counselor participants stressed using correct anatomical terminology. Equipping individuals with the knowledge of correct anatomical terms is a sexual abuse prevention method (Levy & Packman, 2004).

“Number One - ABUSE - From the start parents must give names to all parts of the body so the child can inform when there is a problem...” (GC)

Another counselor explained,

“I think it is most important to include names for body parts and information pertaining to sexual abuse (adults are not supposed to ask you to keep secrets, touch in certain places, etc) due to them being a vulnerable population...” (GC)

As stated above, no items were deemed essential only for post-puberty SHE. This highlights the different priorities that genetic counselor and pediatrician participant groups had regarding the most important information to discuss with post-puberty adolescents with neurodevelopmental disorders. Genetic counselors placed a greater emphasis on discussing consent and contraception to prevent unwanted pregnancy when providing post-puberty SHE. This could be due to genetic counselors' prenatal genetics training, which focuses on providing risk assessment to individuals of reproductive age. Thus, these pregnancy-related items align with their scope of practice. Contrarily, pediatricians focused more on discussing sexual orientation, sexual abstinence, and sexual abuse not involving touch when providing post-puberty SHE. Their differing priorities reflect their different fields of study and scopes of practice.

2.5.3 Differences Between Pre-puberty and Post-puberty SHE

All pre-puberty (n=18) and post-puberty (n=18) genetic counselors unanimously rated item 30 (Child sexual abuse is when someone touches the private parts of a child's body without a health or hygiene reason; if this occurs, a child should tell a trusted adult, even if he/she was told to keep it a secret.) as essential. The top four items for both genetic counselor groups were related to sexual abuse. This focus on sexual abuse prevention can be attributed to the genetic counselor's role as a patient advocate. Domain IV in the Accreditation Council for Genetic Counseling (ACGC) practice-based competencies states that genetic counselors should "advocate for individuals, families, communities, and the genetic counseling profession" (ACGC, n.d.). Parents of children with ASD and ID are often concerned about the risk for sexual abuse of their children. Genetic counselors are trained to be aware of psychosocial issues that may impact their patients and to advocate for patients and families by providing pertinent resources and support. The genetic counselors in this study may have thought that information related to sexual abuse was most important because of their professional advocacy role.

Genetic counselors were found to have statistically significant differences between their pre-puberty and post-puberty ratings for several items, including those relating to sexual activity and pregnancy management. Genetic counselors may have put more emphasis on items pertaining to sexual behaviors and related concepts (i.e., contraception and pregnancy) during the post-puberty time frame compared to the pre-puberty time frame due to the assumption that

individuals who are post-puberty are more likely to engage in sexual activities. The focus shifts from the pediatric to the prenatal realm when discussing SHE for individuals who are of reproductive age. All genetic counselors receive training in prenatal genetics, where the goal is to provide risk assessment for genetic conditions to individuals who are of child-bearing age. Thus, this provides one explanation for their focus on pregnancy-related topics for post-puberty SHE.

There were differences in what pediatricians rated as essential during the pre-puberty and post-puberty time frames. Pediatricians rated the definition of puberty as the essential item to review during pre-puberty SHE. They rated the process of identifying and understanding one's sexual orientation as the most crucial topic for post-puberty SHE. The pediatrician participants in this study most likely follow *Bright Futures: Guidelines for Health Supervision*, the AAP resource that guides well-child and adolescent care nationwide. These guidelines specifically state: "It is appropriate to ask a child aged 7 to 8 if he has ever heard the word puberty and help him describe what it means." (Hagan et al., 2017). These guidelines also discuss bringing up topics of sexual orientation for adolescents (ages 11-21). This study's findings support that these AAP guidelines are being utilized by DBPs and NDD subspecialty pediatricians.

We found statistically significant differences between pediatricians' pre-puberty and post-puberty item ratings for several items, including those describing reproduction, contraception, body image, and gender identity. The post-puberty developmental time frame is when pediatricians would be offering medical advice regarding these concepts (i.e., discussing contraception

methods). Therefore, they seem to feel that it is more necessary to discuss these concepts post-puberty versus pre-puberty. The free-response answers also brought up the topic of appropriate timing of SHE. Pediatricians and genetic counselors both highlighted the importance of the timing of these conversations, and the significance of this education being tailored to each patient's cognitive abilities. One counselor stated,

"I think you have to gauge how much information to give and when/timing..." (GC)

Another counselor mentioned,

"Sexual health education should be provided at an age appropriate and intellectually appropriate level." (GC)

Ultimately, our results show that it is not only important to focus on *when* healthcare professionals are discussing these topics, but also *how* they are discussing them. It is critical that they provide SHE in a way that is developmentally and cognitively appropriate for individuals with ASD or ID because of their communication deficits. One pediatrician also emphasized the importance of the patient's guardian's understanding.

"It should reflect the variation in cognitive ages as well as variation in caregiver (health) literacy." (Pediatrician)

2.5.4 Differences in Genetic Counselor and Pediatrician Perspectives

Our results show statistically significant differences in genetic counselors' and pediatricians' item ratings for the pre-puberty time frame. Genetic counselors rated many items, including several related to sexual abuse, higher than

pediatricians for this developmental time frame. In a number of instances, pediatricians had a higher rating for the same item in the post-puberty section. Therefore, they may have rated these items lower than genetic counselors because they believe that they are better discussed at a later developmental period, reiterating their desire to provide SHE at the appropriate time. The genetic counselor's emphasis on sexual abuse prevention and advocacy for this patient population may also explain these results.

Furthermore, there were differences between genetic counselors' and pediatricians' item ratings for the post-puberty section, with genetic counselors rating several items, in particular those relating to pregnancy options and prenatal care, higher than pediatricians for this developmental time frame. As mentioned previously, the scope of practice of a prenatal genetic counselor encompasses discussions of pregnancy and performing prenatal risk assessment, which could explain why their ratings for pregnancy-related items were higher than the pediatrician's ratings. Genetic counselors also may have emphasized contraception and the prevention of unwanted pregnancy because this aligns with advocating for their patients. Most genetic counselors who brought up unintended pregnancy and contraception linked these concepts to the sexual liberty rights of this population. One genetic counselor mentioned,

"Youth with ASD and ID are often viewed as asexual but many still have sexual interest and can explore sexuality without receiving education, which can lead to STIs and unplanned pregnancy." (GC)

Another stated,

“We should never assume that someone's cognitive or behavioral differences rule out sexual attraction, sexual pleasure, sexual activity, or the desire to have a family. It is important for individuals to understand their bodies and options for safe sex...” (GC)

The most significant differences between the groups were related to anatomical terms and sexual abuse topics. In both cases, genetic counselors rated these items higher than pediatricians. For instance, the term “Child sexual abuse is when someone touches the private parts of a child’s body without a health or hygiene reason; if this occurs, a child should tell a trusted adult, even if he/she was told to keep it a secret” was ranked 5th for pediatricians but 1st for genetic counselors to discuss during the post-puberty time frame. Genetic counselors may feel that it is more essential to discuss topics of sexual abuse in their scope of practice. While our results show that pediatricians do feel discussing sexual abuse is important (their second ranked term for pre-and post-puberty was “both boys/men and girls/women can be sexually abused”), they may feel it is more important to discuss other medical topics as listed in their professional guidelines.

2.5.5 Differences in the Roles of Genetic Counselors and Pediatricians

Regarding SHE

This study further stresses the importance of cooperative and interdisciplinary efforts to educate individuals with neurocognitive differences about sexual health topics. Genetic counselors and pediatricians operate under

different scopes of practice. The pediatric genetic counselor's goal during a session is to perform the medical intake, educate on genetic testing options, and provide resources and psychosocial counseling if time allows. The DBP's and NDD pediatrician's goal is to evaluate and treat individuals with neurodevelopmental disabilities. Both play vital roles in the care of individuals with ASD and ID. The DBP or NDD pediatrician can provide long term care and consistent SHE during follow-up appointments. The genetic counselor can support the DBP or NDD pediatrician in these efforts by educating on some SHE topics (depending on their comfort level), providing resources, and referring patients to other organizations/healthcare professionals. While they may approach what is important to include in the provision of SHE differently, pediatricians and genetic counselors agree that individuals with disabilities have a right to appropriate SHE. A genetic counselor elaborated,

"I think ethically, there is a responsibility for sexual health to be discussed with all adolescents, regardless of cognitive abilities." (GC)

Another mentioned similar ethical principles,

"Not discussing sex education with individuals who have ASD or ID is very discriminatory and a great example of ableism. Even though they have the diagnosis of ASD or ID, does not mean that they do not experience puberty, feelings of arousal, feelings for another individual, or cannot bear children." (GC)

A pediatrician also mentioned,

“We are all humans who exist on a spectrum regarding sexuality and sex education should be equitable.” (Pediatrician)

Although pediatricians may be the primary providers of SHE to their patients with disabilities, genetic counselors can help by bolstering their efforts. They can act as a resource for families and advocating for patients in this at-risk population to reach the common goal of assuring equitable care for individuals with disabilities. Some genetic counselor participants shared how they are already engaged in these efforts. One reported,

“Parents have asked me for help with resources and/or who to talk to about sexual health and education - usually I can provide information about where parent can go for more info, but then defer to the pediatrician or OBGYN.” (GC)

An additional counselor mentioned,

“We have a regular evening program on sexuality for people with ASD/ID we can refer to at the local developmental disabilities office. Several local organizations have materials to share. I try to bring it up when time allows.” (GC)

Overall, our results showed that while both genetic counselors and pediatricians had different perspectives for what items were most important to include in pre- and post-puberty SHE, both professional groups stressed the importance of making SHE understandable and accessible for individuals with ASD and ID.

2.5.6 Limitations and Further Investigation

The study's findings are limited by the small sample size, and therefore the results may not be generalizable to all genetic counselors and pediatricians. Sample size may have been impacted by ascertainment and data cleaning methods. The methods used to clear bot responses also impacted the results of this study, and actual participant responses may have been unknowingly excluded from the study. Another limitation regards possible selection bias, in that genetic counselor and pediatrician participants were primarily recruited through national online networks, and therefore may be more motivated to participate than genetic counselors and pediatricians in the general population. Another limitation is that the family perspective is missing from this study. Future research should include parents of children with ASD, and/or ID diagnoses, as well as individuals with ASD or ID themselves-

The demographics of both the genetic counselors and pediatricians were largely homogeneous. Most genetic counselors were white females, and most pediatricians were white males; the results of this study may not be generalizable for healthcare providers of ethnic minority groups. Future research should include a more diverse study sample.

It may be beneficial to repeat this study and explore the perspectives of other healthcare professionals who may work with children with ASD or ID, such as occupational therapists, speech therapists, or psychologists, to see if their experiences and average ratings are similar to those of pediatricians and genetic counselors. It would also be beneficial to include parent perspectives in future

studies to assess whether their preferences for topics in SHE for their children with disabilities are the same as healthcare providers. Another possible method would be to survey adolescents and young adults with ASD or ID to assess their experiences with receiving SHE. Their perspectives could shed light on what topics are most important to them and how they prefer to receive SHE.

Chapter 3: Conclusion

The results of this study shed light on information that pediatric genetic counselors, DBPs, and NDD pediatricians feel is most essential to include in SHE for individuals with ASD or ID. Four items were deemed essential to include during SHE delivered pre-puberty and post-puberty, and four items were deemed essential to include only during SHE delivered pre-puberty. Three of the four items deemed essential for pre- and post-puberty were related to sexual abuse, and the fourth item was related to correct anatomical terminology for boys/men and girls/women. In addition, the items deemed essential for pre-puberty only were also related to sexual abuse, as well as masturbation and the definition of puberty. Overall, both genetic counselors and pediatricians agreed that discussing sexual abuse prevention was imperative to include in SHE for the at-risk population of children and adolescents with ASD and ID.

Both populations of interest in this study, those with ASD and those with ID, struggle with deficits in their ability to communicate. This communication barrier prevents these adolescents from receiving adequate SHE. Our results show that genetic counselors and pediatricians both agree that it is not only important to focus on *when* healthcare professionals are educating this population on sexual health topics, but also *how* they are providing this

education. Pediatricians and genetic counselors both highlighted the importance of the timing of these conversations, and most importantly the significance of this education being tailored to each patient's cognitive abilities.

Based on the findings of this study, it is important for future guidelines regarding the provision of SHE for individuals with ASD or ID to include a focus on sexual abuse prevention. This could include how to recognize warning signs of sexual abuse, how to talk with parents of children with ASD or ID about this risk, how and when to educate children and adolescents who are at risk, and where to find resources to support victims of sexual abuse. Our results support that these guidelines should include lists of topics to cover during the pre-puberty and post-puberty time frame, such as the essential informational items identified in this study, because of the emphasis that genetic counselors and pediatricians placed on timing of discussions of different sexual health topics. Finally, these findings reinforce the importance of developing SHE guidelines that detail how to make sexual health topics understandable for individuals with varying levels of cognitive and communicative abilities.

Furthermore, the results of this study support the need for medical schools and genetic counseling programs to incorporate additional learning opportunities into the curriculum focusing on provision of SHE to individuals with neurodevelopmental disorders. Genetic counselors and pediatricians reported varying levels of comfort with discussing these topics and a lack of graduate medical training on how to discuss sexual health in general. Regarding curriculum recommendations for genetic counseling training programs, it would

be beneficial to train students on how to recognize and respond to a patient's sexual health educational needs, as recommended by Levy and Packman (2004). Pediatric genetic counselors frequently come into contact with individuals with ASD and ID, and they could benefit from a course on how to approach topics such as sexual abuse, masturbation, puberty, and others. This training could also help build interdisciplinary relationships by educating genetic counselors about referring to pediatricians (general or subspecialty) when their patients have more in-depth questions about SHE. As for curriculum recommendations for pediatrician training programs, it would be beneficial to include risk factors for sexual abuse, relevant guidelines (Murphy & Elias, 2006; Breuner et al., 2016), and educational resources tailored to individuals with ASD and ID to give to families. Through further education on providing SHE to this population, the discomfort level felt among pediatricians and genetic counselors may be reduced.

The results of this study underscore the importance of interdisciplinary efforts to educate individuals with neurodevelopmental disorders by highlighting how pediatricians and genetic counselors can work together to fulfill their common goal of providing equitable care for individuals with disabilities. Some genetic counselor participants shared how they are already partaking in these efforts by providing families with resources, addressing these topics as they come up during genetics appointments, and referring to other healthcare providers or organizations to help parents talk to their children with neurocognitive differences about their sexual health. Pediatricians may act as the

primary providers of SHE, but genetic counselors can provide additional resources and advocacy for patients and their families in this at-risk population.

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Appendix A: Online Questionnaire for Healthcare Professionals

Consent

1. Please check the box below
 - a. Captcha box
2. The purpose of this questionnaire is to determine what information parents of children with ASD, ID, or both diagnoses deem most important in regards to sexual health education. We also aim to survey health professionals, including genetic counselors and pediatricians, who have experience working with children with neurodevelopmental disorders. Assessing the informational topics that genetic counselors, pediatricians, and parents feel is most essential can help guide future recommendations for healthcare providers, and overall create more positive patient experiences for adolescents with ASD or ID and their families.

All responses gathered from the questionnaire will be kept anonymous. We do not ask for your name or contact information. There will be no way your responses could be linked back to you. The results of the study may be published or presented at academic meetings, however participants will not be identified.

Participation in this research is voluntary. By completing the survey, you are consenting that you have read and understand this information. You may withdraw from the study by not completing the survey at any time. If you have any questions regarding your rights as a participant in this project, you may contact the University of South Carolina Office of Research Compliance at 803-777-7095.

If you have questions or difficulty accessing the online survey, please reach out to Mary Catherine Smith, the primary investigator, at mary.smith@uscmed.sc.edu. Thank you for your participation.

Healthcare Professionals Questionnaire

1. What is your current job title?
 - a. Genetic counselor
 - b. Pediatrician
 - c. Other

Pediatrician Only Questions

1. Are you a Doctor of Medicine or a Doctor of Osteopathic Medicine?
 - a. Doctor of Medicine (M.D.)
 - b. Doctor of Osteopathic Medicine (D.O.)
2. Are you board eligible or board certified?
 - a. Yes
 - b. No
3. What are you board certified in?
 - a. Developmental-behavioral pediatrics (DBP)
 - b. Neurodevelopmental disabilities (NDD)
 - c. Other (please specify)
4. Year you earned your Doctor of Medicine or Doctor of Osteopathic Medicine degree (YYYY format)
5. Current U.S. state in which you practice (XX format)
6. Current work setting
 - a. Academic/university-based
 - b. Hospital-based
 - c. Multiple specialty group
 - d. Private practice
 - e. Industry
 - f. Other (please specify)
7. Total number of years in practice since graduation
8. Years of practice in developmental pediatrics
9. Frequency of contact with individuals with ASD or ID, or parents of individuals with either condition in training
 - a. Never
 - b. Sometimes
 - c. Most of the time
 - d. Always
10. Frequency of contact with individuals with ASD or ID, or parents of individuals with either condition in current area of practice
 - a. Never
 - b. Sometimes
 - c. Most of the time
 - d. Always
11. Frequency of contact with individuals with ASD or ID, or parents of individuals with either condition outside of a professional context
 - a. Never
 - b. Sometimes
 - c. Most of the time
 - d. Always
12. Have you ever provided sexual health education to children with ASD or ID?
 - a. Yes
 - b. No

13. Have you ever used any of the following resources in your clinical practice? Check all that apply
- a. Parent Advocacy Coalition for Educational Rights: www.pacer.org
 - b. Your Child Development and Behavioral Resources: www.med.umich.edu/1libr/yourchild/disabsex.htm.
 - c. Center for Parent Information and Resources: <http://www.parentcenterhub.org/repository/sexed/>
 - d. No, but I have used another resource that is not listed (fill in below)
 - e. No

Genetic Counselor Only Questions

1. Year that you earned your Master of Science in Genetic Counseling degree (YYYY format)
2. Current U.S. state in which you practice (XX format)
3. The setting in which you currently practice
 - a. Hospital-based
 - b. Multiple specialty group
 - c. Private practice
 - d. Industry
 - e. Other (specify)
4. Current primary area of practice – check all that apply
 - a. Prenatal
 - b. Medical genetics
 - c. Pediatric subspecialty
 - d. Cancer
 - e. Adult genetics
 - f. Infertility
 - g. Laboratory
 - h. Research
 - i. Other (please specify)
5. Previous areas of practice – check all that apply
 - a. Prenatal
 - b. Medical genetics
 - c. Pediatric subspecialty
 - d. Cancer
 - e. Adult genetics
 - f. Infertility
 - g. Laboratory
 - h. Research
 - i. Other (please specify)
6. Total number of years in practice since graduation
7. Years of practice in pediatrics (general or subspecialty)
8. Frequency of contact with individuals with ASD or ID, or parents of individuals with either condition in training
 - a. Never
 - b. Sometimes

- c. Most of the time
 - d. Always
- 9. Frequency of contact with individuals with ASD or ID, or parents of individuals with either condition in current area of practice
 - a. Never
 - b. Sometimes
 - c. Most of the time
 - d. Always
- 10. Frequency of contact with individuals with ASD or ID, or parents of individuals with either condition outside of a professional context
 - a. Never
 - b. Sometimes
 - c. Most of the time
 - d. Always
- 11. Have you ever provided sexual health education to children with ASD or ID?
 - a. Yes
 - b. No
- 12. Have you ever used any of the following resources in your clinical practice? Check all that apply
 - a. Parent Advocacy Coalition for Educational Rights: www.pacer.org
 - b. Your Child Development and Behavioral Resources: www.med.umich.edu/1libr/yourchild/disabsex.htm.
 - c. Center for Parent Information and Resources: <http://www.parentcenterhub.org/repository/sexed/>
 - d. No, but I have used another resource that is not listed (fill in below)
 - e. No

Ranking of Informational Items

Below is an extensive list of sexual health education topics. We would like to know which of these are essential for medical professionals to include during sex education for children and adolescents with ASD, ID or both. Please rate each item as you feel is an essential or important component.

This questionnaire includes two sections of informational items:

1. topics most important to include for PRE-PUBERTAL patients
2. topics most important to include for POST-PUBERTAL patients

This is the PRE-PUBERTAL section.

Please rate each item as you feel is an essential or important component of comprehensive sex education for PRE-PUBERTAL children with ASD, ID, or both.

0 = unsure

1 = not too important

2 = important but not essential

3 = essential

1. Both men and women have reproductive and sexual response body systems. These systems contribute to reproduction and sexual pleasure.
2. Boys/men have nipples, a penis, a scrotum, and testicles. Girls/women have breasts, nipples, a vulva, a clitoris, a vagina, a uterus, and ovaries.
3. Puberty is a universally experienced transition from childhood to adulthood that is characterized by physical and emotional changes as the sexual and reproductive body systems mature.
4. Reproduction is a process that requires the sperm and egg to join which leads to pregnancy.
5. Body image is how an individual's physical appearance impacts their feelings and behaviors.
6. Sexual orientation refers to a person's physical and/or romantic attraction to an individual of the same and/or different gender.
7. Identifying and understanding one's sexual orientation is an evolving process, and one's sexual orientation may change over the course of his/her lifetime.
8. Biological sex refers to whether a person has male or female genitals and/or chromosomes.
9. Gender identity refers to a person's internal sense of being male, female, or a combination of these.
10. Gender identity is different than biological sex, and some people's gender identity differs from their biological sex.
11. Sexuality is a natural and healthy part of life, and is experienced in a variety of ways at different stages in people's lives.
12. Touching or rubbing one's own genitals to feel good is called masturbation, and many boys and girls begin to masturbate during puberty.
13. Masturbation should be done in a private place.
14. Some sexual behaviors shared by partners include kissing, touching, talking, caressing, massaging, and oral, vaginal, or anal intercourse.
15. A person has the right to refuse any sexual behavior and at any point during sexual activity a person has the right to ask a partner to stop and to expect that his/her request will be respected.
16. Sexual abstinence means not engaging in sexual behavior to some degree, from abstaining from sexual contact of any kind including kissing, to only abstaining from sexual intercourse.
17. Men and women have natural, physical responses to sexual stimulation which can occur due to thoughts, feelings, sights, smells, sounds, and touches.
18. Boys/men get erections and girls/women experience vaginal lubrication during sexual arousal.
19. Many people experience sexual and erotic thoughts called fantasies.
20. Sexual dysfunction is the inability to express, experience, and/or enjoy sexuality, and it can be caused by guilt, fear, anger, stress, anxiety, depression, medical problems, medication, or relationship difficulties.

21. Both young women and young men should begin to receive regular reproductive health exams and STD testing when they begin to engage in oral, vaginal, or anal intercourse or turn 18, whichever happens first. Young women should be seen by gynecologists and young men by general practitioners or urologists.
22. A man and a woman who want to have vaginal intercourse without having a child can use contraception to prevent pregnancy.
23. Nonprescription contraception methods include male and female condoms, foam, gels, and suppositories; prescription methods include birth control pills, birth control injections, the birth control patch, the birth control ring, the diaphragm, cervical cap, and intrauterine devices (IUD).
24. A woman faced with an unintended pregnancy can carry the pregnancy to term and raise the baby, place the baby up for adoption, or have an abortion to end the pregnancy.
25. When a woman decides to try to become pregnant or becomes pregnant, she should begin routine prenatal care; follow nutrition guidelines; avoid tobacco, alcohol, and other drugs; and consider being tested for STDs/HIV.
26. Sexually transmitted diseases (STDs) are caused by viruses or bacteria found in semen, vaginal fluids, or blood of an infected person and are commonly passed during sexual contact. They can also be transmitted by sharing unsterilized needles or from a mother to child during pregnancy. STDs include diseases such as gonorrhea, syphilis, HIV infection, Chlamydia, genital warts, and herpes.
27. There are parts of one's body that are considered to be private, including one's mouth, nipples, breasts, chest, penis, scrotum, vagina, vulva, and buttocks.
28. Both boys/men and girls/women can be sexually abused.
29. Everyone, including children, has the right to tell others not to touch their body when they do not want to be touched.
30. Child sexual abuse is when someone touches the private parts of a child's body without a health or hygiene reason; if this occurs, a child should tell a trusted adult, even if he/she was told to keep it a secret.
31. Sexual abuse involving touch can include kissing, an abuser touching "private parts," touching the abusers "private parts," being asked to touch one's own "private parts," or engaging in vaginal, oral, or anal intercourse.
32. Sexual abuse not involving touch can include being shown pornographic movies, magazines, websites, or other materials; taking photos, videos, or other recordings; or watching sexual acts.

This is the POST-PUBERTAL section.

Please rate each item as you feel is an essential or important component of comprehensive sex education for POST-PUBERTAL children with ASD, ID, or both.

0 = unsure

1 = not too important

2 = important but not essential
3 = essential

See above informational items 1-32.

Free Response Section

Please share your thoughts and perspective in response to the following questions. There are no restrictions on the content or length of your responses

1. Please elaborate on what you think is most important to include in sexual health education for children with ASD/ID/both and why.
2. What are your experiences providing OR helping facilitate sex education for children with ASD, ID, or both diagnoses (if you have had these experiences)?
3. What is your comfort level with providing OR helping facilitate sex education for children with ASD, ID, or both diagnoses?
4. What education or resources have you received to aid in your discussion of sexual health education with your patients?
5. If you selected or wrote in resources in the above question, "Have you ever used any of the following resources in your clinical practice? Check all that apply," which of these resources provided to patients were most helpful?
6. Why do you think it is important that sex education is discussed with youth with ASD, ID, or both diagnoses?
7. Have you ever initiated a conversation with parents of children with ASD/ID/both about sexual abuse prevention?
 - a. Yes
 - i. If yes, what have you discussed (elaborate on conversation)?
 - b. No
8. What legal and ethical obligations, responsibilities, or duties do medical professionals have in terms of helping parents of children with ASD/ID/both talk to their children about sexual health?

Demographic Questions

1. What is your biological sex?
 - a. Male
 - b. Female
2. What is your age (in years)?
3. What is your ethnicity (select all that apply)?
 - a. White
 - b. Hispanic or Latino
 - c. Black or African American
 - d. Native American or Alaskan Native
 - e. Asian/Pacific Islander
 - f. Other (please specify)

Raffle Information

You are eligible to enter a raffle!

If you are interested in entering a raffle for a \$25.00 Visa gift card, please copy the following link below before submitting your survey. You are eligible for this raffle because you completed the research questionnaire, "Assessing the Sexual Health Informational Needs of Parents of Children with Neurodevelopmental Disorders." After you have submitted this questionnaire, copy and paste the link into a new browser window and enter your information.

Pediatricians, please use this link:

https://uofsc.co1.qualtrics.com/jfe/form/SV_b9qqSlja9T22Owu

Genetic counselors, please use this link:

https://uofsc.co1.qualtrics.com/jfe/form/SV_8CFINIDFwNWRSwC

Thank you

Thank you for taking the time to complete this survey. We hope the information that you and other participants provided will be of value to all healthcare professionals involved in the care of individuals with ASD and ID and the families and individuals they serve. Your interest in this study is very much appreciated!

Raffle Questionnaire

Welcome to the raffle!

Entering your information below will put you into the drawing for a raffle for a \$25.00 Visa gift card. The odds of winning are estimated to be 1 in 30. You are eligible for this raffle because you completed the research questionnaire, "Assessing the Sexual Health Informational Needs of Parents of Children with Neurodevelopmental Disorders." Your information will only be used to contact you if you are the winner of the raffle. Your information will not be distributed.

1. First and last name
2. Preferred title (Mr., Ms., Dr., etc.)
3. Preferred email

Appendix B: Invitational Emails

Genetic Counselor Invitational Email

Dear all,

I am writing to request your participation in a graduate research study focusing on sexual health education (SHE) for adolescents diagnosed with autism spectrum disorder (ASD) or intellectual disability (ID). This research involves completing one online survey that will be available through Qualtrics.

The purpose of this survey is to determine what information genetic counselors deem most important in regards to sexual health education for children with ASD, ID, or both diagnoses. We also aim to survey parents of children with these diagnoses and pediatricians who have experience working with children with neurodevelopmental disorders. Assessing the informational topics that genetic counselors, pediatricians, and parents feel is most essential can help guide future recommendations for healthcare providers, and overall create more positive patient experiences for adolescents with ASD or ID and their families.

Genetic counselors who have a Master of Science degree in genetic counseling and have any experience working in a pediatric medical genetics setting are eligible to participate. Please feel free to share this survey with colleagues!

The survey will consist of 5 sections. The first section consists of questions about your genetic counseling background and exposure to children with ASD or ID. The second and third sections are ranking questions to measure which topics are most essential to include in sexual health education for prepubertal and post-pubertal adolescents with ASD, ID, or both. The fourth section includes free response questions and the fifth section includes demographic questions. **The survey takes approximately 15-20 minutes to complete.**

At the end of the survey, participants will be offered the option of entering their email address for a **chance to win a \$25 gift card**. Individuals will be notified via email if they were selected for this prize.

To participate, please click the link below:

https://uofsc.co1.qualtrics.com/jfe/form/SV_0fBNWFeTNwYh6ce

If you have questions or difficulty accessing the online survey, please reach out to Mary Catherine Smith, the primary investigator, at mary.smith@uscmed.sc.edu.

Thank you for your consideration.

Sincerely,

Pediatrician Invitational Email

Dear all,

I am writing to request your participation in a graduate research study focusing on sexual health education (SHE) for adolescents diagnosed with autism spectrum disorder (ASD) or intellectual disability (ID). This research involves completing one online survey that will be available through Qualtrics. The survey takes approximately 15-20 minutes to complete.

The purpose of this survey is to determine what information pediatricians deem most important in regards to sexual health education for children with ASD, ID, or both diagnoses. We also aim to survey parents of children with these diagnoses and genetic counselors who have experience working with children with neurodevelopmental disorders.

All board certified or board eligible physicians who have an MD or DO and work or have previously worked in developmental-behavioral or neurodevelopmental pediatrics are eligible to participate. Please feel free to share this survey with colleagues!

At the end of the survey, participants will be offered the option of entering their email address for a **chance to win a \$25 gift card.** Individuals will be notified via email if they were selected for this prize.

To participate, please click the link below:

https://uofsc.co1.qualtrics.com/jfe/form/SV_0fBNWFeTNwYh6ce

If you have questions or difficulty accessing the online survey, please reach out to Mary Catherine Smith, the primary investigator, at mary.smith@uscmed.sc.edu.

Thank you for your consideration.

Sincerely,

Appendix C: Genetic Counselor Free Response Section Results

Please elaborate on what you think is most important to include in sexual health education for children with ASD/ID/both and why.

- I think you have to gauge how much information to give and when/timing. But ultimately this is a population that is at risk for abuse and any information we can help convey that helps these patients understand what is safe sexual encounters and what is not safe can only benefit them. Further, many parents wait too long to have these discussions with neurotypical kids let alone children with neuro differences because they don't see or want to see their children as sexual beings or because they are uncomfortable discussing the topic. It is not a bad thing to encourage families to have that discussion. I often times introduce the topic in preteen years by either asking about periods and contraception or by talking about reproductive inheritance information in term of that preteen patient instead of risk to siblings. Many times I heard parents say they assumed their child could not have children of their own because they had a genetic diagnosis that caused them to have the neuro difference. We talk then about how this doesn't necessarily exclude reproduction and then ask have they planned on how to talk about or address this topic with their child. Most have not. Hopefully, this empowers them to have further private conversations with their child and sometimes we get to start the conversation right there.
- Age and cognitively appropriate contact and discussion. Many of the topics previously asked about are things that most people with ID and some with ASD would not be able to understand.
 - normalize menstruation
 - normalize transition time and confusing for all
 - talk about abuse/risk of abuse and one should say no and if is comfortable to tell trusted adult
 - talk about what sexual organs are private organs and cannot be touched without permission
 - talk about sex and that is how pregnancy can occur and need to prevent that
- I think they need to know what is happening with their bodies and depending on their stage of development and interest, as well as ability to understand the concepts, you might give more or less information.

- I think the most important thing for them to know is about any questions or concerns they have about what their body does and how to keep it healthy (ie cleaning, proper care, washing hands, etc)
Very closely followed is knowing about people not having the right to touch them or their genitals or other body parts unless they give them permission, and to talk to a trusted adult if such a thing happens. Or even if they give consent but then feel awkward about it, talk to someone to work through the feelings and confusion.
- Understanding of what is and is not appropriate in public and everyday life. Understanding of consent for both the patient and anyone they might be attracted to. Birth control options and where to turn if an unintended pregnancy occurs.
- - Consent - the child has a right to refuse being touched, especially in private areas. The child should also ask others before touching them.
- Puberty - everyone's body changes during puberty. It is normal.
- A child should tell their parent or guardian if someone touches them in a private area.
- It is okay to ask questions about your body.
- If you don't want to have a baby, it is important to use protection during sex.
- Children with ASD/ID/both are at a high risk for sexual abuse so it is important to teach proper names of all body parts and that nobody is supposed to touch those parts on you and vice versa.
- From my personal experience and what I hear from others, sexual health education is severely lacking for those who are considered "neurotypical" and basically none existent for those with ASD/ID except for those who attend all their classes at school with their peers and are not removed for additional help. Body changes, what sex is, the biology behind it i.e. egg/sperm, STDs, contraceptive, consent(!) and appropriate touch, pregnancy, etc. are so important to discuss in an open and inclusive environment regardless if someone is considered neurotypical or has ASD/ID.
- people should always give/ get consent before partaking in sexual activities.
- Families provide health, education and child and adolescent services.
- safety primarily, and then can discuss normal feelings/urges and how to appropriately handle those
- Discussions about sexual abuse are highly important as this population has historically (and currently) been taken advantage of. Further, I think individuals need to understand their bodies in a way that is appropriate for their cognitive abilities, and that desire for or no desire for sexual pleasure is okay. Everyone is different and they are able to decide who they are, who and what is attractive to them, and what they enjoy.

- Education on consent, appropriate language and de-stigmatization so that children can be empowered in their own sexual, emotional, and reproductive health. Sexual health education should be provided at an age appropriate and intellectually appropriate level. Children who have difficulty with communication are at a high risk of abuse and children with ID and autism are especially at risk. They need to have the words, information, and confidence to protect themselves and to share this information with an adult they can trust. As they get older they also need the information that any other teen would need if they plan to engage in sexual activity- information about STIs, pregnancy, and consent.
- I feel like sexual health education should be as comprehensive as possible, and include information about biology, psychology, sexuality, gender, biological sex, abuse, etc. I didn't see one thing in that list that I felt like I wouldn't bring up with ANY child. Having delay/ASD may make the child more at-risk for confusion and abuse if people don't feel like the same issues should be addressed with them (at an age-appropriate and level of understanding tailored to the individual).
- Number One - ABUSE - From the start parents must give names to all parts of the body so the child can inform when there is a problem. More than 80% of people with ASD/ID will experience sexual abuse. Many families choose to use an implantable birth control device to prevent an unwanted pregnancy. This can be discussed with your child's pediatrician.

Number Two - Normal sexual relations - Many adults with ASD/ID have meaningful relationships with a partner. Just as you would inform your neuro-typical children, your child with ASD/ID needs information about sexuality to grow into a healthy adult. There are simplified guides to help with these conversations (see references).

- - Proper anatomy: to make sure they understand anatomy may look different for others, safety (can properly report assault/abuse if experienced, etc.
- Function: reproductive and sexual pleasure
- Appropriate behaviors: in private vs. public behaviors
- Consent
- I think it is most important to include names for body parts and information pertaining to sexual abuse (adults are not supposed to ask you to keep secrets, touch in certain places, etc) due to them being a vulnerable population. After puberty, important to discuss pregnancy potential and safe sex.

What are your experiences providing OR helping facilitate sex education for children with ASD, ID, or both diagnoses (if you have had these experiences)?

- As I stated above. I try to ask questions in history or in talking about inheritance risk that encourages parents to have conversations. I have had many many Turner syndrome patients that had misinformation that they had 100% of sterility and this is a great time to discuss sex Ed information. Also, I have had a chance to talk with some patients about sex Ed in the context of maternal PKU and available state resources for birth control, etc.
- My 9 year old son is autistic, and I have been in parent groups where people discuss these issues. I have many friends with autistic children including younger and older (adult) children and we've discussed sexual health and our situations together.
- None
- n/a
- I have no experiences.
- My experience with helping and facilitating sex education for children with ASD/ID is very limited. I use to work in a residential facility with children and adolescents diagnosed with ASD/ID. Finding appropriate sexual health education training for them was incredibly difficult, mostly because the lack of resources, but also because the range of cognitive level of the children/adolescents I worked with was very variable. It actually was also very challenging because there were a lot of politics and facility rules behind what was and wasn't appropriate for these children/adolescents to learn about, or outlets for them to express themselves while transitioning through puberty and into adulthood. Many staff felt uncomfortable explaining to a 12-15 year old boy how to masturbate or why they were aroused, and the facility had a hard time identifying someone in the community who could help with this education. Eventually a male staff who the child admired was willing to help, but there was still a lot of hesitancy from upper management about what could and could not be discussed, even if the child had specific questions. When one of the kiddos I worked closely with was going through puberty, I helped develop a social story describing some of the bodily changes she was going through. This helped, but in the future she will be transitioning to an adult residential facility where there are different rules and she has more autonomy of her decisions. I'm fearful that since she won't have the basic knowledge of sexual health that unfortunate circumstances may happen as a result, like guilt and shame for having certain feelings or desires about others.
- it was take several conversations for the person to have a clear understanding. Also good to hear what their views are on the topic.
- there is no

- often my role is educating parents about the normality of their child experiencing these urges and desires; further education is deferred to social work to help with/facilitate
- I have not provided this education to the child/adolescent, but I have brought up the importance of these conversations with parents. Additionally, I work in a Sex Development Program. In that program, the vast majority of our patients do NOT have autism and/or ID. However, we have a health educator who focuses on all of the topics raised in this survey and they are a fantastic addition to our team.
- Typically, children in pediatrics are not getting a diagnosis of ID or ASD in our department, so unless their condition has some inherent reproductive or sexual ramifications, it does not typically get discussed in the genetics setting
- Parents have asked me for help with resources and/or who to talk to about sexual health and education - usually I can provide information about where parent can go for more info, but then defer to the pediatrician or OBGYN.
- We have a regular evening program on sexuality for people with ASD/ID we can refer to at the local developmental disabilities office. Several local organizations have materials to share. I try to bring it up when time allows.
- Facilitated discussion with children mostly after puberty when parents ask about contraception. Tend to give overview but leave detailed discussion and decision making to OBGYN. Often the diagnostic appointments are too filled with genetics information to discuss sexual education.

What is your comfort level with providing OR helping facilitate sex education for children with ASD, ID, or both diagnoses?

- I feel good about it but when I first started in clinic, it was a little more uncomfortable because I wasn't a parent yet and hadn't started to think about how you educate children and teens about this information regardless of neurodevelopmental level. I think parenting and practice in clinic have gotten much more comfortable with these discussions.
- The questions and topics are things that are NOT just not discussed by people with ASD/ID, but all patients including the general population. It is important for pediatricians and primary care doctors to have these conversations with all. Genetics providers place a role in some pieces, but many of the topics would be best addressed by PCP.

Genetics counselors have a role to make sure a patient is informed, but detailed sex education is outside of our scope. It would be best explained by primary care doctor with genetics discussing things like pregnancy, pregnancy risks, recurrence, normalizing difficulty, place appropriate referrals to gyn/urology providers.

- I feel like I am very comfortable talking with autistic children and I am also comfortable talking to children with ID, though I'm not as good at knowing their level of understanding unless they can give me clues to whether they want to know the information or if I've gone over their head. I've worked with quite a few adults with ID in the prenatal counseling realm and of course every individual is different but I feel like I can help them understand things better as my years of experience accumulate.
- None - I have never done it and it's an uncomfortable topic. I think it's important though and would like to feel more comfortable with it.
- Not extremely comfortable
- I am not comfortable at all.
- I feel very comfortable discussing sex education to children with ASD/ID or both.
- lower due to lack of experience
- good
- very basic only; often my role is educating parents about the normality of their child experiencing these urges and desires
- I am comfortable discussing the spectrum of gender and sexual attraction, the difference between biological sex and gender, typical and atypical sex development, and birth control options. However, I really have not had these conversations in the context of adolescents with autism and/or ID.
- I would be comfortable providing resources if asked by the family, but this is usually not the most pressing issue for families at this time. It is also not necessarily the role of genetics
- Low comfort level - I am not trained as a sex health educator for this population, or any population. I understand the concepts and COULD teach it, but would not feel comfortable doing this as I don't know the right way to do it for any child. If a topic comes up during the appointment, or a child or young adult asks a questions, I will answer it in an age-appropriate manner, but will defer to the parent to continue the conversation.
- 100%
- Comfortable in broaching the topic - not as comfortable with in-depth advice relevant to OBGYN or Behavioral therapist

What education or resources have you received to aid in your discussion of sexual health education with your patients?

- Not any formal outside of my own sex Ed in school (and watching Sex Ed on Netflix 😊), but I have taken time to find information and resources to help facilitate these discussions.
- I don't think I've ever received resources or discussion of this topic in all the years I've been a GC, but I do know a long time ago there was a

publication about GC for people with ID, however I was a student at the time and didn't receive the book. Perhaps by Brenda Finucane?

- N/A
- Training during grad school
- n/a
- Just social stories that I made myself, no online resources
- local support group as well as experienced team members
- The school
- social work
- I was a birth control educator at a teen clinic during college. I have not received any formal education about this topic in graduate school or at my job. However, as I work in sexual development, I have participated in many team workshops and informal trainings, but those are not specific to this population. In our Sex Development program, we have various books and diagrams for patient education.
- Provided them with referral to the Adolescent medicine clinic- a great resource at our clinic that is able to provide sexual education with patients or answer questions they may not ask their parents or pediatrician.
- Center for Parent Resources and Info. Other reproductive centers have useful information, including Planned Parenthood, but since I typically don't want to cause "controversy" I will stick to "neutral" resources in appointments.
- Like I said earlier, I have quite a lot. It's just not right in front of me now. Sorry. There's a booklet with a red cover. There's a book titled something like "NO!" There's an online booklet with nice drawings. There are some one-pagers I can give out...
- Education on childhood sexual abuse through volunteering positions

If you selected or wrote in resources in the above question, "Have you ever used any of the following resources in your clinical practice? Check all that apply," which of these resources provided to patients were most helpful?

- There are a number of children's books about body such as The Body Book by Usborn that I think provided good discussion and explanation. I also use foundation websites for many conditions such as Turner syndrome to address specific issues of reproduction that may be related to a certain diagnosis.
- N/A
- n/a
- n/a
- Anything with pictures!

- Center for Parent Resources and Info is okay. i am now going to look up more resources to have those on hand for the future.
- I use PACER more for bullying resources. I may like the new online booklet the best.

Why do you think it is important that sex education is discussed with youth with ASD, ID, or both diagnoses?

- I think because of the vulnerability of this population but also because there are a lot of parent misconceptions about reproduction in this population of patients.
- These individuals are still experiencing puberty and questions. Normalizing conversations about these topics will open the door for dialogue and not have the person feel shameful. Will also help with pregnancy prevention/protection, at risk population for sexual abuse, and to allow relationships in this population
- Because they deserve to know what changes happen to their body. My son would freak out at 4-5 when his "penis would stand up" and he's really verbal. If he wasn't I can imagine a parent or care provider might not know to bring it up and the child might be scared or confused. Also discussion of masturbation is really important so they don't do it in inappropriate places or times not out of shame but out of knowing it's private. And lastly, but perhaps most importantly, to raise their understanding of the risk of sexual abuse and need for that dialogue to be freely shared with trusted adult(s).
- These children are more likely to be sexually abused, so they need to understand when something might not be appropriate and they should tell a trusted adult. They also may not have a good understanding of what is and is not socially appropriate, such as walking up and hugging someone without consent. Understanding of these factors is important for interacting with others in everyday life, and important to understand in a sexual relationship.
- Individuals with disabilities, especially intellectual disabilities, are at a higher risk of abuse. Teaching children about what parts of their body are private and that it is okay to not want to be touched/tell someone if they are touched can help prevent abuse.
- Due to the high risk for sexual abuse and an unintended pregnancy.
- Not discussing sex education with individuals who have ASD or ID is very discriminatory and a great example of ableism. Even though they have the diagnosis of ASD or ID, does not mean that they do not experience puberty, feelings of arousal, feelings for another individual, or cannot bear children. Not discussing these things with individuals who have ASD or ID is a huge disservice and can potentially cause harm to them in the future.
- absolutely.

- More vulnerable to assault
- safety primarily from abuse, and then normalization of behaviors
- Yes, I do. We should never assume that someone's cognitive or behavioral differences rule out sexual attraction, sexual pleasure, sexual activity, or the desire to have a family. It is important for individuals to understand their bodies and options for safe sex. It is also important for them to understand what is not okay AKA abuse.
- Individuals with ASD, ID experience puberty, sexual thoughts/feelings/action, and often can have children. It is just as important, if not more so, to address sex education with youth for them to understand what is normal, appropriate vs. not appropriate, and when to seek help and/or more information when they are ready and willing to learn more.
- See above
- Youth with ASD and ID are often viewed as asexual but many still have sexual interest and can explore sexuality without receiving education, which can lead to STIs and unplanned pregnancy.

Have you ever initiated a conversation with parents of children with ASD/ID/both about sexual abuse prevention? If yes, what have you discussed (elaborate on conversation)?

- Contraception, "safe touch" education provided by community resources, help around managing periods if applicable (who helps the teen at school if they need a lot of assistance in this process). I think it's also good to ask questions directly to the patient while discussing with the parent especially regarding do they feel safe in their daily environment? Does anyone make them feel uncomfortable and why? This normalizes checking in with the teen.
- That they are at higher risk to be abused and they should be aware of that risk. Not too much more than that.
- I did not go into extreme detail, but rather discussed that ASD/ID can make a child more vulnerable and put them at risk for sexual abuse. Additionally, they may not understand correct boundaries and could get in trouble themselves for sexual abuse.
- A female patient with ID came in with lethargy, nausea, and missed periods. We had to review the need for a pregnancy test due to the possibility that was could have been getting abused.
- Strengthen protection for this group of people
- being at risk, discussing parent thoughts about ensuring safety
- We discussed primarily communication for nonverbal patients and the importance of creating some way for your child to communicate not only

their needs but also anything that could be distressing such as the risk of being abused.

- While 1 in 3 women and 1 in 7 men in the general population experience sexual abuse in their lifetime, more than 90% of people with an intellectual disability experience sexual abuse, and 80% of these individuals are abused more than once.

What legal and ethical obligations, responsibilities, or duties do medical professionals have in terms of helping parents of children with ASD/ID/both talk to their children about sexual health?

- I think genetics has a rare opportunity to be able to correct some parental misconceptions about AD/ID in a unique way by addressing inheritance. Also, some primary care providers without genetics training may have the same misconceptions. So with psychosocial training and detailed scientific understanding of genetic diagnoses, we can be uniquely positioned to help in these discussions. I also think primary care providers, endocrinologists, OBGYNs and other also have great opportunity for these discussions. Often times, I refer female patients to a local pediatric GYN because I know she is uniquely trained and experienced to help children of all developmental levels when it comes to exams and education.
- As medical professionals they should help parents realize this is a topic that should be discussed with their children, just as they would with children who aren't autism or ID. I think there have been questionable practices in the past such as involuntary sterilization that need to be addressed so that if the parent is thinking of things like that the (adult) child is seen as a party that needs to give consent and that consent must be based in real facts and awareness. I honestly think people don't realize at first how vulnerable their children are to inappropriate sexual advances by both peers and adults as they don't always know what they "should" do or not do.
- I think ultimately it is the parents' responsibility. But parents may not know things like the statistics of how often these children are sexually abused. I think the medical professional has a duty to inform them of these facts so they can look out for signs of abuse which their child is at higher risk for.
- Ethical obligation to answer questions from individuals or parents, would be nice to provide resources if needed
I think a pediatrician or PCP would be better equipped and have more time than a GC to discuss sexual health
- I do not know. These seems to be more of an obligation to pediatricians rather than genetic counselors.
- We as providers and caregivers need to be better at letting go of the stigma that surrounds many of these hard to talk about topics related to sex education to be better advocates for these individuals. I think at the

very least the child's primary care providers should bring it up to parents at their wellness exam, as well as provide resources and help in that initial conversation.

- duty is to protect the person. Typically we would consult their team of doctors, legal, and if it is a child possibly CPS
- Choose your words just right
- specialty care is not an ideal setting for this, although can fall within genetic counseling discussions. ideally, this would be something addressed certainly by the PCP.
- I think ethically, there is a responsibility for sexual health to be discussed with all adolescents, regardless of cognitive abilities.
- Pediatricians, OBGYN, family practice, NP, PAs... have the responsibility to provide resources and help guide parents on this journey of education. Genetic counselors I feel would always help be a resource if asked, or it somehow came up during an appt or session. We should always address topics factually, admit when we are uncertain about the best way to address a question, and to assist without overstepping our bounds, as we often don't know the values/preferences/etc. of a family. If a parent asks for help, GCs have a hard time saying no, but I don't feel like it is our general job responsibility to provide comprehensive sex education to our patients.
- Providing accurate, up-to-date information in a patient-friendly way.

Appendix D: Pediatrician Free Response Section Results

Please elaborate on what you think is most important to include in sexual health education for children with ASD/ID/both and why.

- You can talk about sex from the big and small things in your life. It doesn't have to be arranged. For example, in the baby bath, the news about sex, can be discussed with the baby. Run into the problem that oneself cannot answer, do not force to fill an expert, should let the child know, the parent is not omnipotent. Encounter do not understand the problem, can look up data together, discuss together.
- Topic conversation should be adapted to patient's mental health
- Teaching parents to use positive language about sexuality, People with ID/ASD should not feel sexuality is dirty or not something "for them to be concerned about"
- Regular discussion at every encounter
- Depends somewhat on their developmental level. Important to explain private parts, what others can/shouldn't do to you.
- It should reflect the variation in cognitive ages as well as variation in caregiver (health) literacy.
- no
- due to significantly increased risk of abuse. basic, understandable information to help them protect themselves is the priority.
- You can't go to a secret place with strangers. It's dangerous without your parents around

What are your experiences providing OR helping facilitate sex education for children with ASD, ID, or both diagnoses (if you have had these experiences)?

- Find out about this with your baby
- I address pubertal changes, usually only address pregnancy planning with female patients . I emphasize abuse prevention.
- Parents often do not think that their teens with ID need sexuality education. They like to have it reflect their family values. they want their teens to work in community settings alongside typical co workers but worry about their sexual safety
- Very little happens in the community and parents need more support

- Some parents tell me their schools are doing a good job with this and for other kids it doesn't seem to be addressed.
- Families appear receptive at the visit when I discuss it but few report they've already started discussing it beforehand.
- no
- more helpful for the caregivers to understand the changes and the differences between developmental age and sexual/pubertal age. Putting boundaries in place provides some degree of security, albeit not much
- The form of interactive games tells them what behaviors they can't let others do to them

What is your comfort level with providing OR helping facilitate sex education for children with ASD, ID, or both diagnoses?

- Some of them are awkward to talk about
- Very little
- Part of transition planning/education. Schools need to do a better job, interactive learning and repetition may be better than didactic teaching
- fairly comfortable
- Not that comfortable with it.
- 10-Sep
- no
- reasonable. However, when dealing with more severely impacted ID, I don't really elaborate on the greater social issues surrounding sexuality. Again, more focused on safety.
- Relatively slow

What education or resources have you received to aid in your discussion of sexual health education with your patients?

- Sex education
- I don't have any resources. I have not received formal education
- Local conference presentations, national conference presentations (AAP)
One of our NPs and BCBA's have this as a special interest and teach parent groups and local school districts on sexuality and sexuality education for youth with IDD
- our autism resource specialities run a group
- Graduate medical training. Really like Mary Wrobel's book!
- no
- autism speaks, information from the University of Minnesota about dating, information from previous SDBP workshops.
- Attend some training

If you selected or wrote in resources in the above question, "Have you ever used any of the following resources in your clinical practice? Check all that apply," which of these resources provided to patients were most helpful?

- Everything checked helps
- N/a
- Our practice uses the Vanderbilt Healthy Body Toolkits and the ATN Adolescence and Transition Toolkits
Parents seem to like them
- Mary Wrobel's book
- no
- university of michigan's resources
- Only when they become amiable will they be willing to communicate with you and receive further education

Why do you think it is important that sex education is discussed with youth with ASD, ID, or both diagnoses?

- Because they don't know much about sex
- These are difficult topics to discuss in the neurotypical patients, having intellectual disabilities or atypical developmental profile makes it even more difficult
- 1. part of typical development
2. may contribute to anxiety/depression
3. Transition planning needs to include community safety, social development
4. High rate of pregnancy and STDs in youth with ID,
5. Potential for abuse and exploitation, need to know safe touch and safe reporting
- because they are human beings with rights
- It may help with their safety.
- Because we are all humans who exist on a spectrum regarding sexuality and sex education should be equitable.
- no
- safety, safety, safety
- The possibility of injury is too high

Have you ever initiated a conversation with parents of children with ASD/ID/both about sexual abuse prevention? If yes, what have you discussed (elaborate on conversation)?

- Children with disabilities have higher risk of abuse. It is important for them to understand what is an appropriate body contact, who is a safe adult.
- increased risk
 - importance of sex education (safe touch, when to get help/tell)
 - Supervision when appropriate
 - Vetting care providers
 - Developmentally appropriate movies, limiting internet access and contacts
- Teaching about safe touch especially at school
- good touch/bad touch, making sure parents are talking with kids about what happens with their bodies, using correct words to describe body parts
- Discussed increased risk in children with special needs, how to bring it up to the child, and warning signs.
- no
- HPV vaccination, establishing basic terminology, and circles of trust.
- Some advice and help them understand their children

What legal and ethical obligations, responsibilities, or duties do medical professionals have in terms of helping parents of children with ASD/ID/both talk to their children about sexual health?

- Talk about sex and don't talk about other irrelevant topics
- I don't know of any legal obligations. With all patients, regardless of their developmental characteristics, we should be able to address this topic
- Part of the transition process, children with DD should have the same Bright Futures goals modified for their cognitive and social situation
- Mandated reporters must practice prevention too
- Facilitate conversation, provide resources, be a support person.
- no
- a lot. reinforcing the above. If the above is adequately addressed and understood, then it becomes a conversation about what additional information the caregivers would like to discuss with the patient and helping to facilitate that.
- Minimize harm to patients or subjects

Appendix E: Informational Items in Rank Order

Table E.1 Genetic Counselor Rankings

Rank	Pre-puberty GC Item	Rating	Post-puberty GC Item	Rating
1	Child sexual abuse is when someone touches the private parts of a child's body without a health or hygiene reason; if this occurs, a child should tell a trusted adult, even if he/she was told to keep it a secret.	3.00	Child sexual abuse is when someone touches the private parts of a child's body without a health or hygiene reason; if this occurs, a child should tell a trusted adult, even if he/she was told to keep it a secret.	3.00
2	Everyone, including children, has the right to tell others not to touch their body when they do not want to be touched.	2.94	Everyone, including children, has the right to tell others not to touch their body when they do not want to be touched.	3.00
3	There are parts of one's body that are considered to be private, including one's mouth, nipples, breasts, chest, penis, scrotum, vagina, vulva, and buttocks.	2.94	Both boys/men and girls/women can be sexually abused.	3.00
4	A person has the right to refuse any sexual behavior and at any point during sexual activity a person has the right to ask a partner to stop and to expect that his/her request will be respected.	2.89	A person has the right to refuse any sexual behavior and at any point during sexual activity a person has the right to ask a partner to stop and to expect that his/her request will be respected.	2.94
5	Boys/men have nipples, a penis, a scrotum, and testicles. Girls/women have breasts, nipples, a vulva, a clitoris, a vagina, a uterus, and ovaries.	2.89	A man and a woman who want to have vaginal intercourse without having a child can use contraception to prevent pregnancy.	2.94

6	Sexual abuse involving touch can include kissing, an abuser touching “private parts,” touching the abusers “private parts,” being asked to touch one’s own “private parts,” or engaging in vaginal, oral, or anal intercourse.	2.83	Boys/men have nipples, a penis, a scrotum, and testicles. Girls/women have breasts, nipples, a vulva, a clitoris, a vagina, a uterus, and ovaries.	2.83
7	Puberty is a universally experienced transition from childhood to adulthood that is characterized by physical and emotional changes as the sexual and reproductive body systems mature.	2.78	Both young women and young men should begin to receive regular reproductive health exams and STD testing when they begin to engage in oral, vaginal, or anal intercourse or turn 18, whichever happens first. Young women should be seen by gynecologists and young men by general practitioners or urologists.	2.83
8	Both boys/men and girls/women can be sexually abused.	2.72	Nonprescription contraception methods include male and female condoms, foam, gels, and suppositories; prescription methods include birth control pills, birth control injections, the birth control patch, the birth control ring, the diaphragm, cervical cap, and intrauterine devices (IUD).	2.83
9	Masturbation should be done in a private place.	2.67	When a woman decides to try to become pregnant or becomes pregnant, she should begin routine prenatal care; follow nutrition guidelines; avoid tobacco, alcohol, and other drugs; and consider being tested for STDs/HIV.	2.83
10	Sexual abuse not involving touch can include being shown pornographic movies, magazines, websites, or other materials; taking photos, videos, or other recordings; or watching sexual acts.	2.61	Sexual abuse involving touch can include kissing, an abuser touching “private parts,” touching the abusers “private parts,” being asked to touch one’s own “private parts,” or engaging in vaginal, oral, or anal intercourse.	2.83

11	Body image is how an individual's physical appearance impacts their feelings and behaviors.	2.35	Sexually transmitted diseases (STDs) are caused by viruses or bacteria found in semen, vaginal fluids, or blood of an infected person and are commonly passed during sexual contact. They can also be transmitted by sharing unsterilized needles or from a mother to child during pregnancy. STDs include diseases such as gonorrhea, syphilis, HIV infection, Chlamydia, genital warts, and herpes.	2.78
12	Touching or rubbing one's own genitals to feel good is called masturbation, and many boys and girls begin to masturbate during puberty.	2.33	Sexual abuse not involving touch can include being shown pornographic movies, magazines, websites, or other materials; taking photos, videos, or other recordings; or watching sexual acts.	2.78
13	Gender identity is different than biological sex, and some people's gender identity differs from their biological sex.	2.28	Puberty is a universally experienced transition from childhood to adulthood that is characterized by physical and emotional changes as the sexual and reproductive body systems mature.	2.72
14	Sexuality is a natural and healthy part of life, and is experienced in a variety of ways at different stages in people's lives.	2.28	Masturbation should be done in a private place.	2.72
15	A man and a woman who want to have vaginal intercourse without having a child can use contraception to prevent pregnancy.	2.28	A woman faced with an unintended pregnancy can carry the pregnancy to term and raise the baby, place the baby up for adoption, or have an abortion to end the pregnancy.	2.72
16	Gender identity refers to a person's internal sense of being male, female, or a combination of these.	2.17	There are parts of one's body that are considered to be private, including one's mouth, nipples, breasts, chest, penis, scrotum, vagina, vulva, and buttocks.	2.72

17	Reproduction is a process that requires the sperm and egg to join which leads to pregnancy.	2.11	Sexuality is a natural and healthy part of life, and is experienced in a variety of ways at different stages in people's lives.	2.67
18	Sexual orientation refers to a person's physical and/or romantic attraction to an individual of the same and/or different gender.	2.06	Both men and women have reproductive and sexual response body systems. These systems contribute to reproduction and sexual pleasure.	2.61
19	Both men and women have reproductive and sexual response body systems. These systems contribute to reproduction and sexual pleasure.	2.00	Reproduction is a process that requires the sperm and egg to join which leads to pregnancy.	2.61
20	Identifying and understanding one's sexual orientation is an evolving process, and one's sexual orientation may change over the course of his/her lifetime.	2.00	Touching or rubbing one's own genitals to feel good is called masturbation, and many boys and girls begin to masturbate during puberty.	2.61
21	Nonprescription contraception methods include male and female condoms, foam, gels, and suppositories; prescription methods include birth control pills, birth control injections, the birth control patch, the birth control ring, the diaphragm, cervical cap, and intrauterine devices (IUD).	2.00	Some sexual behaviors shared by partners include kissing, touching, talking, caressing, massaging, and oral, vaginal, or anal intercourse.	2.56
22	Biological sex refers to whether a person has male or female genitals and/or chromosomes.	1.94	Boys/men get erections and girls/women experience vaginal lubrication during sexual arousal.	2.56
23	Men and women have natural, physical responses to sexual stimulation which can occur due to thoughts, feelings, sights, smells, sounds, and touches.	1.94	Sexual orientation refers to a person's physical and/or romantic attraction to an individual of the same and/or different gender.	2.50
24	Both young women and young men should begin to receive regular reproductive health exams and STD testing when they begin to engage in oral, vaginal, or anal intercourse or turn 18,	1.89	Identifying and understanding one's sexual orientation is an evolving process, and one's sexual orientation may change over the course of his/her lifetime.	2.44

whichever happens first.
Young women should be seen by gynecologists and young men by general practitioners or urologists.

25	Boys/men get erections and girls/women experience vaginal lubrication during sexual arousal.	1.78	Men and women have natural, physical responses to sexual stimulation which can occur due to thoughts, feelings, sights, smells, sounds, and touches.	2.44
26	Sexual abstinence means not engaging in sexual behavior to some degree, from abstaining from sexual contact of any kind including kissing, to only abstaining from sexual intercourse.	1.72	Gender identity is different than biological sex, and some people's gender identity differs from their biological sex.	2.39
27	A woman faced with an unintended pregnancy can carry the pregnancy to term and raise the baby, place the baby up for adoption, or have an abortion to end the pregnancy.	1.72	Body image is how an individual's physical appearance impacts their feelings and behaviors.	2.33
28	Sexually transmitted diseases (STDs) are caused by viruses or bacteria found in semen, vaginal fluids, or blood of an infected person and are commonly passed during sexual contact. They can also be transmitted by sharing unsterilized needles or from a mother to child during pregnancy. STDs include diseases such as gonorrhea, syphilis, HIV infection, Chlamydia, genital warts, and herpes.	1.72	Gender identity refers to a person's internal sense of being male, female, or a combination of these.	2.33
29	Some sexual behaviors shared by partners include kissing, touching, talking, caressing, massaging, and oral, vaginal, or anal intercourse.	1.67	Sexual abstinence means not engaging in sexual behavior to some degree, from abstaining from sexual contact of any kind including kissing, to only abstaining from sexual intercourse.	2.33
30	When a woman decides to try to become pregnant or becomes pregnant, she	1.56	Biological sex refers to whether a person has	2.17

	should begin routine prenatal care; follow nutrition guidelines; avoid tobacco, alcohol, and other drugs; and consider being tested for STDs/HIV.		male or female genitals and/or chromosomes.	
31	Many people experience sexual and erotic thoughts called fantasies.	1.39	Many people experience sexual and erotic thoughts called fantasies.	2.17
32	Sexual dysfunction is the inability to express, experience, and/or enjoy sexuality, and it can be caused by guilt, fear, anger, stress, anxiety, depression, medical problems, medication, or relationship difficulties.	1.22	Sexual dysfunction is the inability to express, experience, and/or enjoy sexuality, and it can be caused by guilt, fear, anger, stress, anxiety, depression, medical problems, medication, or relationship difficulties.	2.11

Table E.2 Pediatrician Rankings

Rank	Pre-puberty Pediatrician Item	Rating	Post-puberty Pediatrician Item	Rating
1	Puberty is a universally experienced transition from childhood to adulthood that is characterized by physical and emotional changes as the sexual and reproductive body systems mature.	2.17	Identifying and understanding one's sexual orientation is an evolving process, and one's sexual orientation may change over the course of his/her lifetime	2.30
2	Both boys/men and girls/women can be sexually abused.	2.09	Both boys/men and girls/women can be sexually abused.	2.29
3	Everyone, including children, has the right to tell others not to touch their body when they do not want to be touched.	2.05	Sexual abstinence means not engaging in sexual behavior to some degree, from abstaining from sexual contact of any kind including kissing, to only abstaining from sexual intercourse.	2.26
4	A person has the right to refuse any sexual behavior and at any point during sexual activity a person has the right to ask a partner to stop and to expect that his/her request will be respected.	2.00	Everyone, including children, has the right to tell others not to touch their body when they do not want to be touched.	2.26
5	Boys/men have nipples, a penis, a scrotum, and testicles. Girls/women	1.96	Child sexual abuse is when someone touches the private parts of a	2.26

	have breasts, nipples, a vulva, a clitoris, a vagina, a uterus, and ovaries.		child's body without a health or hygiene reason; if this occurs, a child should tell a trusted adult, even if he/she was told to keep it a secret.	
6	Sexual orientation refers to a person's physical and/or romantic attraction to an individual of the same and/or different gender.	1.96	Sexual abuse not involving touch can include being shown pornographic movies, magazines, websites, or other materials; taking photos, videos, or other recordings; or watching sexual acts.	2.26
7	Biological sex refers to whether a person has male or female genitals and/or chromosomes.	1.96	Both men and women have reproductive and sexual response body systems. These systems contribute to reproduction and sexual pleasure.	2.23
8	Sexually transmitted diseases (STDs) are caused by viruses or bacteria found in semen, vaginal fluids, or blood of an infected person and are commonly passed during sexual contact. They can also be transmitted by sharing unsterilized needles or from a mother to child during pregnancy. STDs include diseases such as gonorrhea, syphilis, HIV infection, Chlamydia, genital warts, and herpes.	1.96	Sexually transmitted diseases (STDs) are caused by viruses or bacteria found in semen, vaginal fluids, or blood of an infected person and are commonly passed during sexual contact. They can also be transmitted by sharing unsterilized needles or from a mother to child during pregnancy. STDs include diseases such as gonorrhea, syphilis, HIV infection, Chlamydia, genital warts, and herpes.	2.22
9	Child sexual abuse is when someone touches the private parts of a child's body without a health or hygiene reason; if this occurs, a child should tell a trusted adult, even if he/she was told to keep it a secret.	1.96	Boys/men have nipples, a penis, a scrotum, and testicles. Girls/women have breasts, nipples, a vulva, a clitoris, a vagina, a uterus, and ovaries.	2.17
10	Identifying and understanding one's sexual orientation is an evolving process, and one's sexual orientation may change over the course of his/her lifetime.	1.91	Men and women have natural, physical responses to sexual stimulation which can occur due to thoughts, feelings, sights, smells, sounds, and touches.	2.17
11	Touching or rubbing one's own genitals to feel good	1.91	Sexuality is a natural and healthy part of life, and is	2.13

	is called masturbation, and many boys and girls begin to masturbate during puberty.		experienced in a variety of ways at different stages in people's lives.	
12	Masturbation should be done in a private place.	1.91	A person has the right to refuse any sexual behavior and at any point during sexual activity a person has the right to ask a partner to stop and to expect that his/her request will be respected.	2.13
13	Sexual abuse not involving touch can include being shown pornographic movies, magazines, websites, or other materials; taking photos, videos, or other recordings; or watching sexual acts.	1.91	Body image is how an individual's physical appearance impacts their feelings and behaviors.	2.09
14	Gender identity is different than biological sex, and some people's gender identity differs from their biological sex.	1.87	Gender identity refers to a person's internal sense of being male, female, or a combination of these.	2.09
15	Boys/men get erections and girls/women experience vaginal lubrication during sexual arousal.	1.87	Nonprescription contraception methods include male and female condoms, foam, gels, and suppositories; prescription methods include birth control pills, birth control injections, the birth control patch, the birth control ring, the diaphragm, cervical cap, and intrauterine devices (IUD).	2.05
16	Gender identity refers to a person's internal sense of being male, female, or a combination of these.	1.83	Reproduction is a process that requires the sperm and egg to join which leads to pregnancy.	2.04
17	Both young women and young men should begin to receive regular reproductive health exams and STD testing when they begin to engage in oral, vaginal, or anal intercourse or turn 18, whichever happens first. Young women should be seen by gynecologists and young men by general practitioners or urologists.	1.83	Many people experience sexual and erotic thoughts called fantasies.	2.04

18	There are parts of one's body that are considered to be private, including one's mouth, nipples, breasts, chest, penis, scrotum, vagina, vulva, and buttocks.	1.82	Touching or rubbing one's own genitals to feel good is called masturbation, and many boys and girls begin to masturbate during puberty.	2.00
19	Reproduction is a process that requires the sperm and egg to join which leads to pregnancy.	1.78	Some sexual behaviors shared by partners include kissing, touching, talking, caressing, massaging, and oral, vaginal, or anal intercourse.	2.00
20	Some sexual behaviors shared by partners include kissing, touching, talking, caressing, massaging, and oral, vaginal, or anal intercourse.	1.78	Both young women and young men should begin to receive regular reproductive health exams and STD testing when they begin to engage in oral, vaginal, or anal intercourse or turn 18, whichever happens first. Young women should be seen by gynecologists and young men by general practitioners or urologists.	2.00
21	A man and a woman who want to have vaginal intercourse without having a child can use contraception to prevent pregnancy.	1.78	A woman faced with an unintended pregnancy can carry the pregnancy to term and raise the baby, place the baby up for adoption, or have an abortion to end the pregnancy.	2.00
22	Sexual abuse involving touch can include kissing, an abuser touching "private parts," touching the abusers "private parts," being asked to touch one's own "private parts," or engaging in vaginal, oral, or anal intercourse.	1.78	There are parts of one's body that are considered to be private, including one's mouth, nipples, breasts, chest, penis, scrotum, vagina, vulva, and buttocks.	2.00
23	Body image is how an individual's physical appearance impacts their feelings and behaviors.	1.74	Biological sex refers to whether a person has male or female genitals and/or chromosomes.	1.96
24	Men and women have natural, physical responses to sexual stimulation which can occur due to thoughts, feelings, sights, smells, sounds, and touches.	1.74	Gender identity is different than biological sex, and some people's gender identity differs from their biological sex.	1.96

25	Both men and women have reproductive and sexual response body systems. These systems contribute to reproduction and sexual pleasure.	1.70	Masturbation should be done in a private place.	1.96
26	Sexual abstinence means not engaging in sexual behavior to some degree, from abstaining from sexual contact of any kind including kissing, to only abstaining from sexual intercourse.	1.70	Sexual abuse involving touch can include kissing, an abuser touching "private parts," touching the abusers "private parts," being asked to touch one's own "private parts," or engaging in vaginal, oral, or anal intercourse.	1.96
27	When a woman decides to try to become pregnant or becomes pregnant, she should begin routine prenatal care; follow nutrition guidelines; avoid tobacco, alcohol, and other drugs; and consider being tested for STDs/HIV.	1.65	Sexual orientation refers to a person's physical and/or romantic attraction to an individual of the same and/or different gender.	1.95
28	Many people experience sexual and erotic thoughts called fantasies.	1.61	A man and a woman who want to have vaginal intercourse without having a child can use contraception to prevent pregnancy.	1.91
29	A woman faced with an unintended pregnancy can carry the pregnancy to term and raise the baby, place the baby up for adoption, or have an abortion to end the pregnancy.	1.61	Boys/men get erections and girls/women experience vaginal lubrication during sexual arousal.	1.87
30	Sexual dysfunction is the inability to express, experience, and/or enjoy sexuality, and it can be caused by guilt, fear, anger, stress, anxiety, depression, medical problems, medication, or relationship difficulties.	1.60	Puberty is a universally experienced transition from childhood to adulthood that is characterized by physical and emotional changes as the sexual and reproductive body systems mature.	1.83
31	Sexuality is a natural and healthy part of life, and is experienced in a variety of ways at different stages in people's lives.	1.48	Sexual dysfunction is the inability to express, experience, and/or enjoy sexuality, and it can be caused by guilt, fear, anger, stress, anxiety, depression, medical	1.83

			problems, medication, or relationship difficulties.	
32	Nonprescription contraception methods include male and female condoms, foam, gels, and suppositories; prescription methods include birth control pills, birth control injections, the birth control patch, the birth control ring, the diaphragm, cervical cap, and intrauterine devices (IUD).	1.30	When a woman decides to try to become pregnant or becomes pregnant, she should begin routine prenatal care; follow nutrition guidelines; avoid tobacco, alcohol, and other drugs; and consider being tested for STDs/HIV.	1.65

Appendix F: Breakdown of Item Ratings by Percentage of Total N

Table F.1 Percentage Breakdown of Information Item Ratings

Informational Item	Group	% unsure	% not too important	% important but not essential	% essential	Total n	Average Rating
Both men and women have reproductive and sexual response body systems. These systems contribute to reproduction and sexual pleasure.	Pre-puberty GC	5.6% (1)	22.2% (4)	38.9% (7)	33.3% (6)	18	2.00
	Post-puberty GC	5.6% (1)	5.6% (1)	11.1% (2)	77.8% (14)	18	2.61
	Pre-puberty Pediatrician	0.0% (0)	52.2% (12)	26.1% (6)	21.7% (5)	23	1.70
	Post-puberty Pediatrician	0.0% (0)	13.6% (3)	50.0% (11)	36.4% (8)	22	2.23
Boys/men have nipples, a penis, a scrotum, and testicles. Girls/women have breasts, nipples, a vulva, a clitoris, a vagina, a uterus, and ovaries.	Pre-puberty GC	0.0% (0)	0.0% (0)	11.1% (2)	88.9% (16)	18	2.89
	Post-puberty GC	0.0% (0)	0.0% (0)	16.7% (3)	83.3% (15)	18	2.83
	Pre-puberty Pediatrician	4.3% (1)	21.7% (5)	47.8% (11)	26.1% (6)	23	1.96
	Post-puberty Pediatrician	0.0% (0)	30.4% (7)	21.7% (5)	47.8% (11)	23	2.17
Puberty is a universally experienced transition from childhood to adulthood that is characterized by physical and emotional changes as the sexual and reproductive body systems mature.	Pre-puberty GC	0.0% (0)	5.6% (1)	11.1% (2)	83.3% (15)	18	2.78

	Post-puberty GC	0.0% (0)	5.6% (1)	16.7% (3)	77.8% (14)	18	2.72
	Pre-puberty Pediatrician	4.3% (1)	13.0% (3)	43.5% (10)	39.1% (9)	23	2.17
	Post-puberty Pediatrician	8.7% (2)	34.8% (8)	21.7% (5)	34.8% (8)	23	1.83
Reproduction is a process that requires the sperm and egg to join which leads to pregnancy.	Pre-puberty GC	0.0% (0)	16.7% (3)	55.6% (10)	27.8% (5)	18	2.11
	Post-puberty GC	0.0% (0)	5.6% (1)	27.8% (5)	66.7% (12)	18	2.61
	Pre-puberty Pediatrician	0.0% (0)	47.8% (11)	26.1% (6)	26.1% (6)	23	1.78
	Post-puberty Pediatrician	4.3% (1)	13.0% (3)	56.5% (13)	26.1% (6)	23	2.04
Body image is how an individual's physical appearance impacts their feelings and behaviors.	Pre-puberty GC	5.9% (1)	0.0% (0)	47.1% (8)	47.1% (8)	17	2.35
	Post-puberty GC	0.0% (0)	11.1% (2)	44.4% (8)	44.4% (8)	18	2.33
	Pre-puberty Pediatrician	0.0% (0)	52.2% (12)	21.7% (5)	26.1% (6)	23	1.74
	Post-puberty Pediatrician	0.0% (0)	17.4% (4)	56.5% (13)	26.1% (6)	23	2.09
Sexual orientation refers to a person's physical and/or romantic attraction to an individual of the same and/or different gender.	Pre-puberty GC	0.0% (0)	22.2% (4)	50.0% (9)	27.8% (5)	18	2.06
	Post-puberty GC	5.6% (1)	11.1% (2)	11.1% (2)	72.2% (13)	18	2.50
	Pre-puberty Pediatrician	0.0% (0)	26.1% (6)	52.2% (12)	21.7% (5)	23	1.96

	Post-puberty Pediatrician	0.0% (0)	36.4% (8)	31.8% (7)	31.8% (7)	22	1.95
Identifying and understanding one's sexual orientation is an evolving process, and one's sexual orientation may change over the course of his/her lifetime.	Pre-puberty GC	0.0% (0)	33.3% (6)	33.3% (6)	33.3% (6)	18	2.00
	Post-puberty GC	5.6% (1)	11.1% (2)	16.7% (3)	66.7% (12)	18	2.44
	Pre-puberty Pediatrician	4.3% (1)	26.1% (6)	43.5% (10)	26.1% (6)	23	1.91
	Post-puberty Pediatrician	0.0% (0)	8.7% (2)	52.2% (12)	39.1% (9)	23	2.30
Biological sex refers to whether a person has male or female genitals and/or chromosomes.	Pre-puberty GC	5.6% (1)	27.8% (5)	33.3% (6)	33.3% (6)	18	1.94
	Post-puberty GC	5.6% (1)	16.7% (3)	33.3% (6)	44.4% (8)	18	2.17
	Pre-puberty Pediatrician	0.0% (0)	26.1% (6)	52.2% (12)	21.7% (5)	23	1.96
	Post-puberty Pediatrician	8.7% (2)	17.4% (4)	43.5% (10)	30.4% (7)	23	1.96
Gender identity refers to a person's internal sense of being male, female, or a combination of these.	Pre-puberty GC	0.0% (0)	16.7% (3)	50.0% (9)	33.3% (6)	18	2.17
	Post-puberty GC	5.6% (1)	16.7% (3)	16.7% (3)	61.1% (11)	18	2.33
	Pre-puberty Pediatrician	8.7% (2)	17.4% (4)	56.5% (13)	17.4% (4)	23	1.83
	Post-puberty Pediatrician	0.0% (0)	36.4% (8)	18.2% (4)	45.5% (10)	22	2.09

Gender identity is different than biological sex, and some people's gender identity differs from their biological sex.	Pre-puberty GC	0.0% (0)	16.7% (3)	38.9% (7)	44.4% (8)	18	2.28
	Post-puberty GC	5.6% (1)	16.7% (3)	11.1% (2)	66.7% (12)	18	2.39
	Pre-puberty Pediatrician	0.0% (0)	26.1% (6)	60.9% (14)	13.0% (3)	23	1.87
	Post-puberty Pediatrician	4.3% (1)	30.4% (7)	30.4% (7)	34.8% (8)	23	1.96
Sexuality is a natural and healthy part of life, and is experienced in a variety of ways at different stages in people's lives.	Pre-puberty GC	0.0% (0)	5.6% (1)	61.1% (11)	33.3% (6)	18	2.28
	Post-puberty GC	5.6% (1)	5.6% (1)	5.6% (1)	83.3% (15)	18	2.67
	Pre-puberty Pediatrician	13.0% (3)	43.5% (10)	26.1% (6)	17.4% (4)	23	1.48
	Post-puberty Pediatrician	4.3% (1)	13.0% (3)	47.8% (11)	34.8% (8)	23	2.13
Touching or rubbing one's own genitals to feel good is called masturbation, and many boys and girls begin to masturbate during puberty.	Pre-puberty GC	0.0% (0)	11.1% (2)	44.4% (8)	44.4% (8)	18	2.33
	Post-puberty GC	5.6% (1)	0.0% (0)	22.2% (4)	72.2% (13)	18	2.61
	Pre-puberty Pediatrician	0.0% (0)	43.5% (10)	21.7% (5)	34.8% (8)	23	1.91
	Post-puberty Pediatrician	8.7% (2)	13.0% (3)	47.8% (11)	30.4% (7)	23	2.00
Masturbation should be done in a private place.	Pre-puberty GC	0.0% (0)	5.6% (1)	22.2% (4)	72.2% (13)	18	2.67
	Post-puberty GC	5.6% (1)	0.0% (0)	11.1% (2)	83.3% (15)	18	2.72

	Pre-puberty Pediatrician	4.3% (1)	30.4% (7)	34.8% (8)	30.4% (7)	23	1.91
	Post-puberty Pediatrician	0.0% (0)	39.1% (9)	26.1% (6)	34.8% (8)	23	1.96
Some sexual behaviors shared by partners include kissing, touching, talking, caressing, massaging, and oral, vaginal, or anal intercourse.	Pre-puberty GC	5.6% (1)	33.3% (6)	50.0% (9)	11.1% (2)	18	1.67
	Post-puberty GC	5.6% (1)	0.0% (0)	27.8% (5)	66.7% (12)	18	2.56
	Pre-puberty Pediatrician	0.0% (0)	39.1% (9)	43.5% (10)	17.4% (4)	23	1.78
	Post-puberty Pediatrician	4.3% (1)	13.0% (3)	60.9% (14)	21.7% (5)	23	2.00
A person has the right to refuse any sexual behavior and at any point during sexual activity a person has the right to ask a partner to stop and to expect that his/her request will be respected.	Pre-puberty GC	0.0% (0)	5.6% (1)	0.0% (0)	94.4% (17)	18	2.89
	Post-puberty GC	0.0% (0)	0.0% (0)	5.6% (1)	94.4% (17)	18	2.94
	Pre-puberty Pediatrician	4.3% (1)	30.4% (7)	26.1% (6)	39.1% (9)	23	2.00
	Post-puberty Pediatrician	8.7% (2)	13.0% (3)	34.8% (8)	43.5% (10)	23	2.13
Sexual abstinence means not engaging in sexual behavior to some degree, from abstaining from sexual contact of any kind including kissing, to only abstaining from sexual intercourse.	Pre-puberty GC	11.1% (2)	33.3% (6)	27.8% (5)	27.8% (5)	18	1.72
	Post-puberty GC	5.6% (1)	11.1% (2)	27.8% (5)	55.6% (10)	18	2.33

	Pre-puberty Pediatrician	0.0% (0)	43.5% (10)	43.5% (10)	13.0% (3)	23	1.70
	Post-puberty Pediatrician	4.3% (1)	13.0% (3)	34.8% (8)	47.8% (11)	23	2.26
Men and women have natural, physical responses to sexual stimulation which can occur due to thoughts, feelings, sights, smells, sounds, and touches.	Pre-puberty GC	5.6% (1)	27.8% (5)	33.3% (6)	33.3% (6)	18	1.94
	Post-puberty GC	5.6% (1)	5.6% (1)	27.8% (5)	61.1% (11)	18	2.44
	Pre-puberty Pediatrician	4.3% (1)	30.4% (7)	52.2% (12)	13.0% (3)	23	1.74
	Post-puberty Pediatrician	4.3% (1)	13.0% (3)	43.5% (10)	39.1% (9)	23	2.17
Boys/men get erections and girls/women experience vaginal lubrication during sexual arousal.	Pre-puberty GC	5.6% (1)	33.3% (6)	38.9% (7)	22.2% (4)	18	1.78
	Post-puberty GC	5.6% (1)	0.0% (0)	27.8% (5)	66.7% (12)	18	2.56
	Pre-puberty Pediatrician	4.3% (1)	26.1% (6)	47.8% (11)	21.7% (5)	23	1.87
	Post-puberty Pediatrician	0.0% (0)	39.1% (9)	34.8% (8)	26.1% (6)	23	1.87
Many people experience sexual and erotic thoughts called fantasies.	Pre-puberty GC	11.1% (2)	50.0% (9)	27.8% (5)	11.1% (2)	18	1.39
	Post-puberty GC	5.6% (1)	5.6% (1)	55.6% (10)	33.3% (6)	18	2.17
	Pre-puberty Pediatrician	4.3% (1)	43.5% (10)	39.1% (9)	13.0% (3)	23	1.61

	Post-puberty Pediatrician	4.3% (1)	13.0% (3)	56.5% (13)	26.1% (6)	23	2.04
Sexual dysfunction is the inability to express, experience, and/or enjoy sexuality, and it can be caused by guilt, fear, anger, stress, anxiety, depression, medical problems, medication, or relationship difficulties.	Pre-puberty GC	11.1% (2)	66.7% (12)	11.1% (2)	11.1% (2)	18	1.22
	Post-puberty GC	5.6% (1)	16.7% (3)	38.9% (7)	38.9% (7)	18	2.11
	Pre-puberty Pediatrician	0.0% (0)	50.0% (10)	40.0% (8)	10.0% (2)	20	1.60
	Post-puberty Pediatrician	0.0% (0)	39.1% (9)	39.1% (9)	21.7% (5)	23	1.83
Both young women and young men should begin to receive regular reproductive health exams and STD testing when they begin to engage in oral, vaginal, or anal intercourse or turn 18, whichever happens first. Young women should be seen by gynecologists and young men by general practitioners or urologists.	Pre-puberty GC	5.6% (1)	38.9% (7)	16.7% (3)	38.9% (7)	18	1.89
	Post-puberty GC	0.0% (0)	0.0% (0)	16.7% (3)	83.3% (15)	18	2.83
	Pre-puberty Pediatrician	4.3% (1)	30.4% (7)	43.5% (10)	21.7% (5)	23	1.83
	Post-puberty Pediatrician	8.7% (2)	21.7% (5)	30.4% (7)	39.1% (9)	23	2.00
A man and a woman who want to have vaginal intercourse without having a child can use contraception to prevent pregnancy.	Pre-puberty GC	0.0% (0)	27.8% (5)	16.7% (3)	55.6% (10)	18	2.28
	Post-puberty GC	0.0% (0)	0.0% (0)	5.6% (1)	94.4% (17)	18	2.94

	Pre-puberty Pediatrician	0.0% (0)	39.1% (9)	43.5% (10)	17.4% (4)	23	1.78
	Post-puberty Pediatrician	9.1% (2)	27.3% (6)	27.3% (6)	36.4% (8)	22	1.91
Nonprescription contraception methods include male and female condoms, foam, gels, and suppositories; prescription methods include birth control pills, birth control injections, the birth control patch, the birth control ring, the diaphragm, cervical cap, and intrauterine devices (IUD).	Pre-puberty GC	11.1% (2)	22.2% (4)	22.2% (4)	44.4% (8)	18	2.00
	Post-puberty GC	5.6% (1)	0.0% (0)	0.0% (0)	94.4% (17)	18	2.83
	Pre-puberty Pediatrician	8.7% (2)	60.9% (14)	21.7% (5)	8.7% (2)	23	1.30
	Post-puberty Pediatrician	4.5% (1)	27.3% (6)	27.3% (6)	40.9% (9)	22	2.05
A woman faced with an unintended pregnancy can carry the pregnancy to term and raise the baby, place the baby up for adoption, or have an abortion to end the pregnancy.	Pre-puberty GC	11.1% (2)	38.9% (7)	16.7% (3)	33.3% (6)	18	1.72
	Post-puberty GC	5.6% (1)	0.0% (0)	11.1% (2)	83.3% (15)	18	2.72
	Pre-puberty Pediatrician	4.3% (1)	56.5% (13)	13.0% (3)	26.1% (6)	23	1.61
	Post-puberty Pediatrician	8.7% (2)	8.7% (2)	56.5% (13)	26.1% (6)	23	2.00
When a woman decides to try to become pregnant or becomes pregnant, she should begin routine prenatal care; follow nutrition guidelines; avoid tobacco, alcohol, and other drugs; and consider being tested for STDs/HIV.	Pre-puberty GC	16.7% (3)	38.9% (7)	16.7% (3)	27.8% (5)	18	1.56

	Post-puberty GC	5.6% (1)	0.0% (0)	0.0% (0)	94.4% (17)	18	2.83
	Pre-puberty Pediatrician	0.0% (0)	45.0% (9)	45.0% (9)	10.0% (2)	20	1.65
	Post-puberty Pediatrician	8.7% (2)	47.8% (11)	13.0% (3)	30.4% (7)	23	1.65
Sexually transmitted diseases (STDs) are caused by viruses or bacteria found in semen, vaginal fluids, or blood of an infected person and are commonly passed during sexual contact. They can also be transmitted by sharing unsterilized needles or from a mother to child during pregnancy. STDs include diseases such as gonorrhea, syphilis, HIV infection, Chlamydia, genital warts, and herpes.	Pre-puberty GC	11.1% (2)	33.3% (6)	27.8% (5)	27.8% (5)	18	1.72
	Post-puberty GC	5.6% (1)	0.0% (0)	5.6% (1)	88.9% (16)	18	2.78
	Pre-puberty Pediatrician	8.7% (2)	17.4% (4)	43.5% (10)	30.4% (7)	23	1.96
	Post-puberty Pediatrician	4.3% (1)	13.0% (3)	39.1% (9)	43.5% (10)	23	2.22
There are parts of one's body that are considered to be private, including one's mouth, nipples, breasts, chest, penis, scrotum, vagina, vulva, and buttocks.	Pre-puberty GC	0.0% (0)	0.0% (0)	5.6% (1)	94.4% (17)	18	2.94
	Post-puberty GC	5.6% (1)	0.0% (0)	11.1% (2)	83.3% (15)	18	2.72
	Pre-puberty Pediatrician	4.5% (1)	40.9% (9)	22.7% (5)	31.8% (7)	22	1.82
	Post-puberty Pediatrician	0.0% (0)	34.8% (8)	30.4% (7)	34.8% (8)	23	2.00

Both boys/men and girls/women can be sexually abused.	Pre-puberty GC	0.0% (0)	5.6% (1)	16.7% (3)	77.8% (14)	18	2.72
	Post-puberty GC	0.0% (0)	0.0% (0)	0.0% (0)	100.0% (18)	18	3.00
	Pre-puberty Pediatrician	0.0% (0)	26.1% (6)	39.1% (9)	34.8% (8)	23	2.09
	Post-puberty Pediatrician	0.0% (0)	19.0% (4)	33.3% (7)	47.6% (10)	21	2.29
Everyone, including children, has the right to tell others not to touch their body when they do not want to be touched.	Pre-puberty GC	0.0% (0)	0.0% (0)	5.6% (1)	94.4% (17)	18	2.94
	Post-puberty GC	0.0% (0)	0.0% (0)	0.0% (0)	100.0% (18)	18	3.00
	Pre-puberty Pediatrician	4.5% (1)	27.3% (6)	27.3% (6)	40.9% (9)	22	2.05
	Post-puberty Pediatrician	0.0% (0)	17.4% (4)	39.1% (9)	43.5% (10)	23	2.26
Child sexual abuse is when someone touches the private parts of a child's body without a health or hygiene reason; if this occurs, a child should tell a trusted adult, even if he/she was told to keep it a secret.	Pre-puberty GC	0.0% (0)	0.0% (0)	0.0% (0)	100.0% (18)	18	3.00
	Post-puberty GC	0.0% (0)	0.0% (0)	0.0% (0)	100.0% (18)	18	3.00
	Pre-puberty Pediatrician	8.7% (2)	13.0% (3)	52.2% (12)	26.1% (6)	23	1.96
	Post-puberty Pediatrician	0.0% (0)	21.7% (5)	30.4% (7)	47.8% (11)	23	2.26
Sexual abuse involving touch can include kissing, an abuser touching "private parts," touching the abusers "private parts," being	Pre-puberty GC	0.0% (0)	0.0% (0)	16.7% (3)	83.3% (15)	18	2.83
	Post-puberty GC	0.0% (0)	0.0% (0)	0.0% (0)	100.0% (18)	18	3.00

asked to touch one's own "private parts," or engaging in vaginal, oral, or anal intercourse.

	Post-puberty GC	5.6% (1)	0.0% (0)	0.0% (0)	94.4% (17)	18	2.83
	Pre-puberty Pediatrician	8.7% (2)	30.4% (7)	34.8% (8)	26.1% (6)	23	1.78
	Post-puberty Pediatrician	4.3% (1)	39.1% (9)	13.0% (3)	43.5% (10)	23	1.96
Sexual abuse not involving touch can include being shown pornographic movies, magazines, websites, or other materials; taking photos, videos, or other recordings; or watching sexual acts.	Pre-puberty GC	5.6% (1)	0.0% (0)	22.2% (4)	72.2% (13)	18	2.61
	Post-puberty GC	5.6% (1)	0.0% (0)	5.6% (1)	88.9% (16)	18	2.78
	Pre-puberty Pediatrician	4.3% (1)	26.1% (6)	43.5% (10)	26.1% (6)	23	1.91
	Post-puberty Pediatrician	8.7% (2)	8.7% (2)	30.4% (7)	52.2% (12)	23	2.26

Appendix G: All Chi-Square Analysis Results

Table G.1 Chi-Square Analysis of Average Informational Item Ratings Per Group

Item #	Informational Item	Group		Group	Chi-square Value	df	Asymptotic significance
1	Both men and women have reproductive and sexual response body systems. These systems contribute to reproduction and sexual pleasure.	Pre-puberty GC	vs	Post-puberty GC	7.778	3	.051
		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	7.544	2	.023
		Pre-puberty GC	vs	Pre-puberty Pediatrician	4.627	3	.201
		Post-puberty GC	vs	Post-puberty Pediatrician	9.563	3	.023
2	Boys/men have nipples, a penis, a scrotum, and testicles. Girls/women have breasts, nipples, a vulva, a clitoris, a vagina, a uterus, and ovaries.	Pre-puberty GC	vs	Post-puberty GC	.232	1	.630
		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	5.054	3	.168
		Pre-puberty GC	vs	Pre-puberty Pediatrician	16.411	3	<.001

		Post-puberty GC	vs	Post-puberty Pediatrician	7.619	2	.022
3	Puberty is a universally experienced transition from childhood to adulthood that is characterized by physical and emotional changes as the sexual and reproductive body systems mature.	Pre-puberty GC	vs	Post-puberty GC	.234	2	.889
		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	4.332	3	.228
		Pre-puberty GC	vs	Pre-puberty Pediatrician	8.348	3	.039
		Post-puberty GC	vs	Post-puberty Pediatrician	9.106	3	.028
4	Reproduction is a process that requires the sperm and egg to join which leads to pregnancy.	Pre-puberty GC	vs	Post-puberty GC	5.549	2	.062
		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	8.150	3	.043
		Pre-puberty GC	vs	Pre-puberty Pediatrician	5.129	2	.077
		Post-puberty GC	vs	Post-puberty Pediatrician	7.051	3	.070
5	Body image is how an individual's physical appearance impacts their	Pre-puberty GC	vs	Post-puberty GC	2.974	3	.396

feelings and behaviors.							
		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	7.556	2	.023
		Pre-puberty GC	vs	Pre-puberty Pediatrician	13.379	3	.004
		Post-puberty GC	vs	Post-puberty Pediatrician	1.556	2	.459
6	Sexual orientation refers to a person's physical and/or romantic attraction to an individual of the same and/or different gender.	Pre-puberty GC	vs	Post-puberty GC	9.677	3	.022
		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	1.914	2	.384
		Pre-puberty GC	vs	Pre-puberty Pediatrician	.222	2	.895
		Post-puberty GC	vs	Post-puberty Pediatrician	8.866	3	.031
7	Identifying and understanding one's sexual orientation is an evolving process, and one's sexual orientation may change over the course of his/her lifetime.	Pre-puberty GC	vs	Post-puberty GC	6.000	3	.112
		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	3.782	3	.286
		Pre-puberty GC	vs	Pre-puberty Pediatrician	1.411	3	.703

		Post-puberty GC	vs	Post-puberty Pediatrician	6.313	3	.097
8	Biological sex refers to whether a person has male or female genitals and/or chromosomes.	Pre-puberty GC	vs	Post-puberty GC	.786	3	.853
		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	2.915	3	.405
		Pre-puberty GC	vs	Pre-puberty Pediatrician	2.611	3	.456
		Post-puberty GC	vs	Post-puberty Pediatrician	.947	3	.814
9	Gender identity refers to a person's internal sense of being male, female, or a combination of these.	Pre-puberty GC	vs	Post-puberty GC	5.471	3	.140
		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	10.653	3	.014
		Pre-puberty GC	vs	Pre-puberty Pediatrician	2.701	3	.440
		Post-puberty GC	vs	Post-puberty Pediatrician	3.094	3	.377
10	Gender identity is different than biological sex, and some people's gender identity differs from their biological sex.	Pre-puberty GC	vs	Post-puberty GC	4.578	3	.205
		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	5.683	3	.128

		Pre-puberty GC	vs	Pre-puberty Pediatrician	5.072	2	.079
		Post-puberty GC	vs	Post-puberty Pediatrician	4.637	3	.200
11	Sexuality is a natural and healthy part of life, and is experienced in a variety of ways at different stages in people's lives.	Pre-puberty GC	vs	Post-puberty GC	13.190	3	.004
		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	7.573	3	.056
		Pre-puberty GC	vs	Pre-puberty Pediatrician	11.800	3	.008
		Post-puberty GC	vs	Post-puberty Pediatrician	11.018	3	.012
12	Touching or rubbing one's own genitals to feel good is called masturbation, and many boys and girls begin to masturbate during puberty.	Pre-puberty GC	vs	Post-puberty GC	5.524	3	.137
		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	8.086	3	.044
		Pre-puberty GC	vs	Pre-puberty Pediatrician	5.498	2	.064
		Post-puberty GC	vs	Post-puberty Pediatrician	7.908	3	.048
13	Masturbation should be done in a private place.	Pre-puberty GC	vs	Post-puberty GC	2.810	3	.422

		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	1.602	3	.659
		Pre-puberty GC	vs	Pre-puberty Pediatrician	8.145	3	.043
		Post-puberty GC	vs	Post-puberty Pediatrician	13.725	3	.003
14	Some sexual behaviors shared by partners include kissing, touching, talking, caressing, massaging, and oral, vaginal, or anal intercourse.	Pre-puberty GC	vs	Post-puberty GC	14.286	3	.003
		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	4.778	3	.189
		Pre-puberty GC	vs	Pre-puberty Pediatrician	1.735	3	.629
		Post-puberty GC	vs	Post-puberty Pediatrician	9.680	3	.021
15	A person has the right to refuse any sexual behavior and at any point during sexual activity a person has the right to ask a partner to stop and to expect that his/her request will be respected.	Pre-puberty GC	vs	Post-puberty GC	2.000	2	.368
		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	2.272	3	.518
		Pre-puberty GC	vs	Pre-puberty	13.553	3	.004

				Pediatric ian			
		Post- puberty GC	vs	Post- puberty Pediatric ian	11.825	3	.008
16	Sexual abstinence means not engaging in sexual behavior to some degree, from abstaining from sexual contact of any kind including kissing, to only abstaining from sexual intercourse.	Pre- puberty GC	vs	Post- puberty GC	4.000	3	.261
		Pre- puberty Pediatric ian	vs	Post- puberty Pediatric ian	9.563	3	.023
		Pre- puberty GC	vs	Pre- puberty Pediatric ian	4.626	3	.201
		Post- puberty GC	vs	Post- puberty Pediatric ian	.335	3	.953
17	Men and women have natural, physical responses to sexual stimulation which can occur due to thoughts, feelings, sights, smells, sounds, and touches.	Pre- puberty GC	vs	Post- puberty GC	4.228	3	.238
		Pre- puberty Pediatric ian	vs	Post- puberty Pediatric ian	4.782	3	.188
		Pre- puberty GC	vs	Pre- puberty Pediatric ian	2.765	3	.429
		Post- puberty GC	vs	Post- puberty Pediatric ian	2.291	3	.514

18	Boys/men get erections and girls/women experience vaginal lubrication during sexual arousal.	Pre-puberty GC	vs	Post-puberty GC	10.333	3	.016
		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	2.165	3	.539
		Pre-puberty GC	vs	Pre-puberty Pediatrician	.396	3	.941
		Post-puberty GC	vs	Post-puberty Pediatrician	12.265	3	.007
19	Many people experience sexual and erotic thoughts called fantasies.	Pre-puberty GC	vs	Post-puberty GC	10.400	3	.015
		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	5.497	3	.139
		Pre-puberty GC	vs	Pre-puberty Pediatrician	1.136	3	.768
		Post-puberty GC	vs	Post-puberty Pediatrician	.793	3	.851
20	Sexual dysfunction is the inability to express, experience, and/or enjoy sexuality, and it can be caused by guilt, fear, anger, stress, anxiety, depression, medical problems, medication, or relationship difficulties.	Pre-puberty GC	vs	Post-puberty GC	11.289	3	.010

		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	1.194	2	.551
		Pre-puberty GC	vs	Pre-puberty Pediatrician	5.692	3	.128
		Post-puberty GC	vs	Post-puberty Pediatrician	4.034	3	.258
21	Both young women and young men should begin to receive regular reproductive health exams and STD testing when they begin to engage in oral, vaginal, or anal intercourse or turn 18, whichever happens first. Young women should be seen by gynecologists and young men by general practitioners or urologists.	Pre-puberty GC	vs	Post-puberty GC	10.909	3	.012
		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	2.339	3	.505
		Pre-puberty GC	vs	Pre-puberty Pediatrician	3.546	3	.315
		Post-puberty GC	vs	Post-puberty Pediatrician	9.634	3	.022
22	A man and a woman who want to have vaginal intercourse without having a child can use contraception to	Pre-puberty GC	vs	Post-puberty GC	7.815	2	.020

	prevent pregnancy.						
		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	4.914	3	.178
		Pre-puberty GC	vs	Pre-puberty Pediatrician	6.978	2	.031
		Post-puberty GC	vs	Post-puberty Pediatrician	14.557	3	.002
23	Nonprescription contraception methods include male and female condoms, foam, gels, and suppositories; prescription methods include birth control pills, birth control injections, the birth control patch, the birth control ring, the diaphragm, cervical cap, and intrauterine devices (IUD).	Pre-puberty GC	vs	Post-puberty GC	11.573	3	.009
		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	8.061	3	.045
		Pre-puberty GC	vs	Pre-puberty Pediatrician	8.788	3	.032
		Post-puberty GC	vs	Post-puberty Pediatrician	14.204	3	.003
24	A woman faced with an unintended pregnancy can carry the pregnancy to term and raise the baby, place the baby up for adoption, or	Pre-puberty GC	vs	Post-puberty GC	11.390	3	.010

	have an abortion to end the pregnancy.	Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	14.650	3	.002
		Pre-puberty GC	vs	Pre-puberty Pediatrician	1.547	3	.672
		Post-puberty GC	vs	Post-puberty Pediatrician	13.853	3	.003
25	When a woman decides to try to become pregnant or becomes pregnant, she should begin routine prenatal care; follow nutrition guidelines; avoid tobacco, alcohol, and other drugs; and consider being tested for STDs/HIV.	Pre-puberty GC	vs	Post-puberty GC	17.545	3	<.001
		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	7.806	3	0.050
		Pre-puberty GC	vs	Pre-puberty Pediatrician	7.451	3	.059
		Post-puberty GC	vs	Post-puberty Pediatrician	18.160	3	<.001
26	Sexually transmitted diseases (STDs) are caused by viruses or bacteria found in semen, vaginal fluids, or blood of an infected person and are commonly passed during	Pre-puberty GC	vs	Post-puberty GC	14.762	3	.002

	sexual contact. They can also be transmitted by sharing unsterilized needles or from a mother to child during pregnancy. STDs include diseases such as gonorrhea, syphilis, HIV infection, Chlamydia, genital warts, and herpes.						
		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	1.058	3	.787
		Pre-puberty GC	vs	Pre-puberty Pediatrician	1.817	3	.611
		Post-puberty GC	vs	Post-puberty Pediatrician	10.328	3	.016
27	There are parts of one's body that are considered to be private, including one's mouth, nipples, breasts, chest, penis, scrotum, vagina, vulva, and buttocks.	Pre-puberty GC	vs	Post-puberty GC	1.458	2	.482
		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	1.437	3	.697
		Pre-puberty GC	vs	Pre-puberty Pediatrician	16.599	3	<.001
		Post-puberty GC	vs	Post-puberty Pediatrician	13.499	3	.004
28	Both boys/men and girls/women	Pre-puberty GC	vs	Post-puberty GC	4.500	2	.105

	can be sexually abused.						
		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	.783	2	.676
		Pre-puberty GC	vs	Pre-puberty Pediatrician	7.713	2	.021
		Post-puberty GC	vs	Post-puberty Pediatrician	13.133	2	.001
29	Everyone, including children, has the right to tell others not to touch their body when they do not want to be touched.	Pre-puberty GC	vs	Post-puberty GC	1.029	1	.310
		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	2.031	3	.566
		Pre-puberty GC	vs	Pre-puberty Pediatrician	12.761	3	.005
		Post-puberty GC	vs	Post-puberty Pediatrician	14.898	2	<.001
30	Child sexual abuse is when someone touches the private parts of a child's body without a health or hygiene reason; if this occurs, a child should tell a trusted adult, even if he/she was told to keep it a secret.	Pre-puberty GC	vs	Post-puberty GC	N/A	-	-
		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	5.286	3	.152

		Pre-puberty GC	vs	Pre-puberty Pediatrician	22.728	3	<.001
		Post-puberty GC	vs	Post-puberty Pediatrician	13.277	2	.001
31	Sexual abuse involving touch can include kissing, an abuser touching “private parts,” touching the abusers “private parts,” being asked to touch one’s own “private parts,” or engaging in vaginal, oral, or anal intercourse.	Pre-puberty GC	vs	Post-puberty GC	4.125	2	.127
		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	3.856	3	.277
		Pre-puberty GC	vs	Pre-puberty Pediatrician	14.739	3	.002
		Post-puberty GC	vs	Post-puberty Pediatrician	13.404	3	.004
32	Sexual abuse not involving touch can include being shown pornographic movies, magazines, websites, or other materials; taking photos, videos, or other recordings; or watching sexual acts.	Pre-puberty GC	vs	Post-puberty GC	2.110	2	.348
		Pre-puberty Pediatrician	vs	Post-puberty Pediatrician	4.863	3	.182

	Pre-puberty GC	vs	Pre-puberty Pediatric ian	10.700	3	.013
	Post-puberty GC	vs	Post-puberty Pediatric ian	6.898	3	.075

Note: For analysis of item 30 pre-puberty and post-puberty genetic counselor responses, due to a lack of variability in the ratings, chi-square could not be computed.