



# Promoting Healthy Sexuality for Children and Adolescents With Disabilities

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This clinical report updates a 2006 report from the American Academy of Pediatrics titled “Sexuality of Children and Adolescents With Developmental Disabilities.” The development of a healthy sexuality best occurs through appropriate education, absence of coercion and violence, and developmental acquisition of skills to navigate feelings, desires, relationships, and social pressures. Pediatric health care providers are important resources for anticipatory guidance and education for all children and youth as they understand their changing bodies, feelings, and behaviors. Yet, youth with disabilities and their families report inadequate education and guidance from pediatricians regarding sexual health development. In the decade since the original clinical report was published, there have been many advancements in the understanding and care of children and youth with disabilities, in part because of an increased prevalence and breadth of autism spectrum disorder as well as an increased longevity of individuals with medically complex and severely disabling conditions. During this same time frame, sexual education in US public schools has diminished, and there is emerging evidence that the attitudes and beliefs of all youth (with and without disability) about sex and sexuality are being formed through media rather than formal education or parent and/or health care provider sources. This report aims to provide the pediatric health care provider with resources and tools for clinical practice to address the sexual development of children and youth with disabilities. The report emphasizes strategies to promote competence in achieving a healthy sexuality regardless of physical, cognitive, or socioemotional limitations.

## abstract

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## INTRODUCTION

As stated by the World Health Organization, "Sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality ... Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as to the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination, and violence."<sup>1</sup> One's sexuality is experienced through one's thoughts and desires; attitudes, beliefs, and values; and actions, behaviors, and relationships.<sup>1</sup> Developing healthy sexuality is important for all individuals and depends, in part, on having evidenced-based and evidence-informed information to formulate attitudes and beliefs about sexual orientation, gender identity, relationships, and intimacy.<sup>2-4</sup> It is well known that sexual satisfaction and intimacy are directly related to quality of life,<sup>5</sup> and, thus, pediatric health care providers are encouraged to address the sexual health and education needs of their patients as they grow and develop to promote their patients' competence in achieving a healthy sexuality. Generally speaking, pediatric health care providers are an important resource for sexual education and counseling for children, adolescents, and young adults as well as for parents seeking anticipatory guidance.<sup>6</sup> Pediatric health care providers can help patients and their parents/caregivers understand their changing feelings, their changing bodies, their desires for relationships, and how to avoid risky sexual situations.<sup>6</sup> As is true for everyone, it is important that individuals with disabilities be provided experiences to acquire developmentally appropriate, relevant, and accurate sexual health knowledge to become competent. Youth with disabilities need regular opportunities to develop and use skills for negotiating sexual

desire, intimacy, and activity that supports healthy sexuality while limiting negative outcomes of sexual activity (such as sexually transmitted infections [STIs], unintended pregnancy or sexual coercion, violence, abuse, or exploitation) regardless of their intellectual capacity. Culturally responsive pediatric health care should include sexual health as a focus for all children and adolescents, including those with disabilities, and actively involve parents and caregivers, while respecting the youth's autonomy and rights to privacy.<sup>2</sup>

## THE SEXUAL HEALTH NEEDS OF CHILDREN AND YOUTH WITH DISABILITIES

Children with disabilities are a growing subset of children with diverse needs that affect their functioning, health, and well-being. More than 10 million children in the United States have health conditions that moderately or consistently affect their daily activities at least some of the time.<sup>7</sup> This means that most pediatric primary care providers routinely care for children and youth with a broad range of developmental and acquired health conditions that affect their ability to function as children typically do or require special services such as Individualized Education Programs at school.<sup>8</sup> Disabilities experienced in childhood may be primarily physical in nature or associated with intellectual and/or social-communication impairments or may involve co-occurring conditions. The associated health condition or etiology of the disability or disabilities, the severity of the disability or disabilities, and what aspects of functioning are affected all influence how sexuality is addressed in the clinical setting.

Developing a healthy sexuality is a complex process for all children and youth, especially those with disabilities. Sexual development is not just physiologic changes of a

person's body but is a key part of social competency and should be considered in the context of basic human desires for connectedness and intimacy, beliefs, values, and aspirations. Sociosexual development is an essential part of growing up, and emphasis on this aspect of development is especially important for individuals with disabilities as they navigate changing bodies, expectations, and desires.<sup>9</sup> Individuals with all types of disabilities may have to negotiate varying and unique reproductive capacity and sexual intimacy issues, yet they routinely experience inadequate education and opportunities to develop competence.<sup>10,11</sup> Ample research indicates people with disabilities receive substandard sexual education and reproductive health care.<sup>12-15</sup> Families and/or caregivers of children with disabilities may be reluctant or feel that they are not empowered to acknowledge their child's potential as a sexual individual and may shelter them from the routine presexual social experiences of other children and underestimate their interest in sex and their risk for exploitation.<sup>10,16</sup> Helping families and/or caregivers understand their children's sexual development and how to support it may require additional time and counseling to address expectations of all involved around appropriate independence and autonomy through shared decision-making strategies.<sup>17</sup> In addition, children with disabilities are often limited in social participation and social networks outside of school,<sup>10,18</sup> which offer typical social experiences that form the developmental framework toward understanding one's own individual sexuality, interests, and behaviors. The lack of understanding about how disability affects sexual expression likely influences health care providers' willingness to

address it, as does the more general stigmatization of people with disabilities as nonsexual beings.<sup>19</sup>

### LIFECOURSE APPROACH TO SEXUALITY AND SEXUAL HEALTH FOR INDIVIDUALS WITH DISABILITIES

*Bright Futures: Guidelines for Health Supervision of Infants, Children, and*

*Adolescents, Fourth Edition*, provides the foundation for pediatric health care providers to promote healthy sexual development.<sup>20</sup> Care and education should be delivered through a longitudinal, developmentally appropriate, culturally respectful relationship between health care providers and

their patients and families, caregivers, and educators.<sup>20</sup> In the last 10 years, sexuality education resources specifically designed for individuals with specific health conditions have emerged (Table 1).<sup>21</sup> Routine health maintenance and chronic health care visits, including health care

**TABLE 1** Sexuality Education Resources for Pediatric Health Care Providers

	Resource Information
For parents	
Center for Parent Information & Resources	<a href="http://www.parentcenterhub.org">www.parentcenterhub.org</a> (also in Spanish)
Couwenhoven T. <i>Boyfriends &amp; Girlfriends: A Guide to Dating for People With Disabilities</i> . Bethesda, MD: Woodbine House; 2015	—
Healthybodies.org (Vanderbilt) Boys/Girls	<a href="https://vkc.vumc.org/healthybodies/files/HealthyBodies-Boys-web.pdf">https://vkc.vumc.org/healthybodies/files/HealthyBodies-Boys-web.pdf</a> ; Includes a free online packet entitled “Healthy Bodies for Boys: A Parent’s Guide for Boys with Disabilities” (and a separate one for girls); <a href="https://vkc.vumc.org/healthybodies/files/HealthyBodies-Girls-web.pdf">https://vkc.vumc.org/healthybodies/files/HealthyBodies-Girls-web.pdf</a>
<i>Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents, Fourth Edition</i>	<a href="https://brightfutures.aap.org/Pages/default.aspx">https://brightfutures.aap.org/Pages/default.aspx</a> ; Promoting Healthy Sexual Development and Sexuality; Adolescent Visits
Sexuality Resource Center for Parents	Teaching children across the age ranges 0–18; <a href="http://www.srccp.org/for_all_parents/development.html">http://www.srccp.org/for_all_parents/development.html</a>
AMAZE	<a href="https://amaze.org">https://amaze.org</a> AMAZE uses digital media to provide young adolescents with medically accurate, age-appropriate, affirming, and honest sex education they can access directly online. AMAZE also strives to assist adults—parents, guardians, educators and health care providers—to communicate effectively and honestly about sex and sexuality with the children and adolescents in their lives. <a href="http://www.amaze.org">www.amaze.org</a>
Condition-specific resources for pediatric health care providers	
ASD	AAP Autism Toolkit (Handout): Sexuality of Children and Youths with Autism Spectrum Disorder: <a href="https://toolkits.solutions.aap.org/autism/handout/504891">https://toolkits.solutions.aap.org/autism/handout/504891</a> ; Autism Speaks: ATN/AIR-P Puberty and Adolescence Resource: <a href="https://www.autismspeaks.org/docs/family_services_docs/parentworkbook.pdf">https://www.autismspeaks.org/docs/family_services_docs/parentworkbook.pdf</a> ; Kate E. Reynolds books to help learn about puberty: <i>What’s Happening to Ellie? A Book About Puberty for Girls and Young Women With Autism and Related Conditions</i> (2015); <i>What’s Happening to Tom? A Book About Puberty for Boys and Young Men With Autism and Related Conditions</i> (2015)
Cerebral palsy	Glader L, Stevenson R. <i>Children and Youth with Complex Cerebral Palsy: Care and Management</i> . London, United Kingdom: Mac Keith Press; 2019. (chapters 17 and 18)
Spina bifida	The Spina Bifida Association: <a href="https://www.spinabifidaassociation.org/guidelines/">https://www.spinabifidaassociation.org/guidelines/</a> ; Centers for Disease Control and Prevention: <a href="https://www.cdc.gov/ncbddd/spinabifida/adult.html#sexual-health">https://www.cdc.gov/ncbddd/spinabifida/adult.html#sexual-health</a>
Down syndrome	Chicoine B, McGuire D. <i>The Guide to Good Health for Teens and Adults with Down Syndrome</i> . Bethesda, MD: Woodbine House; 2010; Couwenhoven T. <i>Teaching Children with Down Syndrome About Their Bodies, Boundaries, and Sexuality: A Guide for Parents and Professionals</i> . Bethesda, MD: Woodbine House; 2005
Other	US National Library of Medicine, Genetics Home Reference: <a href="https://ghr.nlm.nih.gov/condition/">https://ghr.nlm.nih.gov/condition/</a> ; An up-to-date genetic review of genetic conditions, easily searchable alphabetically, including rare microdeletions
For schools and educators	
Sexuality and Disabilities: A Guide for Professionals	<a href="https://www.routledge.com/Sexuality-and-Intellectual-Disabilities-A-Guide-for-Professionals/Triska/p/book/9781138231023">https://www.routledge.com/Sexuality-and-Intellectual-Disabilities-A-Guide-for-Professionals/Triska/p/book/9781138231023</a> (2018). This book provides a concise overview of sexuality and gender identity in clients with intellectual disabilities for therapists, social workers, educators, and health care providers
Seattle and King County Sexual Health Education Curriculum	<a href="https://www.kingcounty.gov/depts/health/locations/family-planning/education/FLASH.aspx">https://www.kingcounty.gov/depts/health/locations/family-planning/education/FLASH.aspx</a>
Advocates for Youth	<a href="https://advocatesforyouth.org/wp-content/uploads/storage//advfy/documents/Factsheets/sexual-health-education-for-young-people-with-disabilities-educators.pdf">https://advocatesforyouth.org/wp-content/uploads/storage//advfy/documents/Factsheets/sexual-health-education-for-young-people-with-disabilities-educators.pdf</a>

—, not applicable

transition preparation visits, afford opportunities for the pediatric health care provider to gather information, give guidance, provide education, and be a resource regarding sexuality for children and adolescents with disabilities as they develop their skills and competence.<sup>6,20,22</sup> Pediatric health care providers can introduce issues of psychosexual development to families and caregivers and their children in early childhood and have discussions at health maintenance visits throughout childhood, adolescence, and young adulthood.<sup>2</sup> Doing so, on a routine basis, helps normalize the topic and helps reinforce understanding. The education should go beyond the basics of anatomy and physiology of puberty and reproduction to incorporate education about gender identity, sexual orientation, interpersonal relationships, intimacy, the types of sexual expression, and body image.<sup>23,24</sup> Culturally responsive care recognizes that sexuality is influenced by personal and environmental factors, such as religion or ethnic background.<sup>2</sup> It is essential for developmentally appropriate sexuality education to start early in childhood, with families and/or caregivers and primary care providers helping young children to develop a safe, healthy, and positive attitude toward themselves and others. This healthy and safe attitude includes understanding respect, consent, and relationship building.<sup>25</sup>

### ADDRESSING PUBERTAL DEVELOPMENT IN CHILDREN WITH DISABILITIES

Like any child, a child with disabilities may feel anxious and unhappy about how their body is changing during puberty. The timing of onset of puberty (Table 2) in a child with disabilities may be different from that of a typically developing child.<sup>26</sup> Some patients with severe nutritional issues may be late to go through puberty because of failure to thrive and low BMI and may achieve menarche late or have sparse menses that start at an older age than typical. Patients with certain genetic disorders or conditions associated with chromosome abnormalities<sup>27</sup> may require hormonal treatment to enter and proceed through puberty.

Conversely, patients with certain neurologic disorders, including myelomeningocele or hydrocephalus, have a greater chance of early adrenarche and pubarche, and girls may achieve menarche at younger than 10 years (Table 2).<sup>28</sup> Central precocious puberty is defined as the full activation of the hypothalamic-pituitary-gonadal axis before 8 years of age in genetic girls and before 9 years of age in genetic boys.<sup>29,30</sup> Central precocious puberty is more common in children with fragile X syndrome, congenital brain malformations, and a history of birth asphyxia, meningitis, or other acquired brain injury.<sup>31</sup>

### Menstrual Manipulation and/or Suppression

Although menstruation is often not a barrier to care and well-being, there are a number of concerns that face the primary caregivers of individuals with disabilities once they achieve menarche.<sup>32</sup> These concerns may include hygiene issues (especially for individuals who cannot use a toilet independently), worsening seizures, worsening cyclical behavioral problems, discomfort for the child or adolescent (including breast tenderness and headaches), difficulty for a caregiver who is not comfortable dealing with menses, and difficulty coping at school.<sup>33,34</sup> Menstrual hygiene issues can be introduced early in puberty, even before menarche, and with caregiver shared decision-making, providers can help identify ways to foster independence and teach individuals with disabilities how to manage their menses or seek appropriate help, such as from the school nurse. It is important for caregivers to understand that amenorrhea is often not achieved immediately but that menstrual manipulation may be used to induce amenorrhea, better regulate cycles, or decrease the amount or duration of menstrual flow and minimize menstrual pain and/or dysmenorrhea.<sup>35</sup> Providers interested in understanding the myriad available options are encouraged to review the clinical report from the American Academy of Pediatrics (AAP) and the North American Society for Pediatric and

**TABLE 2** Common Differences of Timing of Puberty in Patients with Disabilities

Early-Onset Puberty	Typical Puberty	Delayed Puberty
Congenital brain malformations	Varies by family, ethnic, and racial groups	Severe nutritional deficiency
Hydrocephalus	Attention-deficit/hyperactivity disorder	Hormonal abnormalities
Neural tube defects; myelomeningocele	Children with ASD with typical growth	Sex chromosome abnormalities
Epilepsy	Other behavioral and mental health issues	Chromosome abnormalities (ie, trisomy 21)
Severe cognitive disabilities	Mild and moderate cognitive disabilities	Complex disabilities
Brain injuries		Psychiatric medications causing high prolactin
Some genetic conditions such as fragile X, neurofibromatosis 1, tuberous sclerosis, and McCune-Albright syndrome		

Adolescent Gynecology, “Menstrual Management for Adolescents With Disabilities.”<sup>32</sup> Surgical options for menstrual suppression are rarely indicated. Menstrual suppression before menarche and endometrial ablation are not recommended.<sup>36</sup> Permanent decisions regarding sterilization have ethical, legal, and medical implications, vary by state, and are beyond the scope of this report. There are also important ethical issues to consider such as patient autonomy and independent decision-making, separate from caregiver issues related to menstrual manipulation in general.<sup>37</sup> Having a conversation and physical examination performed in a confidential manner with appropriate chaperoning and consenting and the caregiver excused from the room is an important practice, especially for those patients with physical disabilities alone or cognitive disabilities requiring limited supports (mild intellectual disability). A confidential examination provides an opportunity to assess the individual’s sexual health knowledge and risks or history of abuse or coercion.<sup>6,35</sup> Addressing menstruation can also foster a discussion regarding sexual activity, the risk of sexual victimization, and the need to prevent STIs and pregnancy.

### **STI and Pregnancy Prevention**

Although individuals with disabilities may be delayed, compared with their peers, in terms of first sexual encounters, they are more likely to engage in unsafe sex practices, which is especially true for those with mild disabilities.<sup>38,39</sup> Some youth, such as youth with attention-deficit/hyperactivity disorder, are more likely than their peers to engage in sexual activity earlier and also engage in unsafe sex practices.<sup>40,41</sup> All sexually active

adolescents are at risk for STIs, including HIV, and, therefore, should be counseled about how to reduce their risks, including the use of barrier protection, in addition to long-acting reversible contraception, as appropriate.<sup>2,6,42-44</sup> Sexual minority youth often do not receive counseling appropriate for their sexuality; therefore, the pediatric health care provider should tailor counseling on the basis of the youth’s specific needs when possible.<sup>45</sup> Providers should encourage and facilitate family-child communication about sexual health and confidentially ensure that any sexual activity is consensual for the youth.<sup>6,45</sup> Confidential family planning services and sexual health care should be made available to adolescents in accordance with legal obligations.<sup>2,27,32,46</sup> Effective counseling is characterized by compassion, respect, a nonjudgmental attitude, and using open-ended questions.<sup>47</sup> Shared decision-making strategies can be employed to enhance the autonomy of the individual with disabilities and can help ensure that all voices are heard during the decision-making process.<sup>17</sup>

### **Human Papillomavirus Vaccine**

Vaccination against human papillomavirus (HPV) has become one of the most successful vaccination programs, not only to prevent this STI but also to significantly reduce certain cancers. Because of the efficacy and safety of the HPV vaccine, all pediatric patients, including those with disabilities, should receive a full course of this vaccine.<sup>48,49</sup> Patients with a history of sexual abuse or violence should receive the HPV series starting at 9 years of age.<sup>50</sup>

### **Counseling Regarding Genetic Reproductive Risks**

Many patients with disabilities may have an underlying genetic disorder

as their primary diagnosis, which carries a recurrence risk.<sup>51</sup> Often, the diagnosis is made during infancy or early childhood and communicated with the family, but it is common that the diagnosis and recurrence risk may never have been formally discussed with the patient as he or she approaches reproductive age. Part of caring for patients with genetic disorders as they reach an age in which they may become sexually active or pregnant is to make sure that patients receive appropriate genetic counseling (such as with a genetic counselor) to understand contraception options and their reproductive risks.<sup>52</sup> Table 3 lists reproductive risks for some common genetic disorders. Extensive information regarding trisomy 21 is available in the health supervision guidance from the AAP.<sup>53</sup> There are thousands of genetic conditions that may be associated with disabilities for which the pediatric health care provider can find additional condition-specific information by searching <https://ghr.nlm.nih.gov/condition>. In addition, youth with disabilities may be taking medications that alter sexual function or have teratogenic effects. Screening and counseling regarding medication adverse effects are important aspects of ensuring optimal sexual and reproductive health.

### **ADDRESSING THE RISKS OF SEXUAL ABUSE AGAINST CHILDREN AND YOUTH WITH DISABILITIES**

Children with disabilities of all types are nearly 3 times as likely as those without disabilities to be sexually abused, and the risks are increased further for children with intellectual disabilities.<sup>54</sup> Although overall lifetime sexual violence victimization is low for men, men with disabilities have 3 times higher rates of victimization than men without disabilities do (13.8% vs 3.7%, respectively).<sup>55</sup> Nearly 25% of

**TABLE 3** Reproductive Risks in Common Genetic Disorders

Genetic Disorder	Reproductive Risks
<b>Autosomal dominant disorders</b>	
Achondroplasia: most common form of skeletal dysplasia caused by a mutation in FGFR3	A person with achondroplasia whose partner has normal stature has a 50% chance of having a child with achondroplasia. A pregnant woman with achondroplasia may have difficulty carrying the fetus to term. If both genetic parents have achondroplasia, there is a 25% chance of having an infant with a lethal disorder who has 2 copies of the FGFR3 mutation.
Deletion of 22q11: common, with wide spectrum of presentation including intellectual disabilities, mental health issues, congenital heart disease, immunodeficiency, and hypoparathyroidism (formerly called DiGeorge syndrome)	A parent with mild learning problems or mental health issues can have a child with more complex birth defects and severe developmental problems.
OI: most forms of brittle bone disease are caused by mutations in COL1A1 or COL1A2.	Chromosomal abnormalities, such as microdeletions, are passed on in an autosomal dominant pattern and may have variable severity of the phenotype from one generation to the next. Confirmation of the diagnosis of OI can now be made with DNA analysis in blood. Most severe cases of OI arise from de novo mutations, but patients with milder forms of OI have a 50% chance of passing on their mutation in each pregnancy. There are more rare forms of OI caused by autosomal recessive genes with a 25% recurrence risk.
EDS: there are now 14 types of EDS	The hypermobile type is the most common with an estimated incidence of 1:5000. The genes for this type are unknown. This type can be associated with gastrointestinal tract issues, immunologic changes, dysautonomia, pelvic floor dysfunction, prolapse of the rectum and/or uterine prolapse, and chronic pain and disability. The vascular form of EDS can be associated with severe, life-threatening issues including arterial rupture, intestinal rupture, and uterine rupture in pregnancy.
<b>Autosomal recessive disorders</b>	
	A history of consanguinity increases the chances of having a partner who carries mutations in the same gene. Genetic boys with cystic fibrosis are sterile. Patients of certain ethnic backgrounds have a higher carrier rate of having mutations in autosomal recessive disorders; there are now next-generation sequencing panels that screen for carriers of certain disorders so that patients can receive genetic counseling regarding their recurrence risks. Many patients with autosomal recessive disorders have more severe disabilities and are less likely to procreate.
<b>X-linked disorders</b>	
	Females who are carriers of FMR1, which causes fragile X syndrome, have an increased risk of premature ovarian failure. The maternal grandfather may develop a condition that mimics Parkinson disease, called FRAXTAS. The severity of symptoms in female carriers of X-linked disorders may be affected by skewed X-inactivation. A female carrying a mutation in an X-linked gene (eg, fragile X syndrome) may be normal or have just a mild phenotype but has a risk of having a male child with more severe issues.
<b>Mitochondrial disorders</b>	
	Mitochondrial disorders may be caused by mutations in mitochondrial DNA, in which case they are maternally inherited, or may be caused by mutations in autosomal genes, in which case they are usually autosomal recessively inherited. Maternally inherited mitochondrial disorders are generally passed on to all children in the sibship, although the severity of issues may vary from one sibling to another.
<b>Multifactorial disorders</b>	
NTDs are common birth defects with an increased recurrence risk within families	Patients with NTDs have an ~5% chance of having a child with an NTD. Siblings of patients with NTDs, parents, aunts, uncles, etc, also have an increased risk. Folate, 4 mg/kg per day, taken 3 mo before conception and through the first trimester, can decrease (but not eliminate) this risk. Certain ethnic groups (including people of English and/or Irish, Hispanic, and Chinese descent) have an increased risk of having a child with an NTD and might also consider taking folate prophylactically, even without a family history.
<b>Other</b>	
	Some disorders are caused by multiple factors including genes that may not be known, teratogens such as alcohol, or nutritional factors such as low folate. Recently available genetic tests including next-generation sequencing panels have helped make specific diagnoses in patients with rare disorders.

COL1A1, collagen type I alpha 1; COL1A2, collagen type I alpha 2; EDS, Ehlers-Danlos syndrome; FGFR3, fibroblast growth factor receptor 3; FRAXTAS, fragile X-associated tremor/ataxia syndrome; NTD, neural tube defect; OI, osteogenesis imperfecta.

adolescent women, regardless of disability status, report being victims of sexual abuse and/or assault.<sup>56</sup> In a cross-sectional survey of 101 students with disabilities from a large northeastern public university, 22% reported some form of abuse over the last year, and nearly 62% ( $n = 63$ ) had experienced some form of physical or sexual abuse before the age of 17.<sup>57</sup> Of those who were abused in the past year, 40% reported little or no knowledge of abuse-related resources, and only 27% reported the incident.<sup>57</sup> Compared with respondents without disabilities, young women with physical disabilities had a higher odds of being a victim of rape (odds ratio: 1.49; 95% confidence interval: 1.06–2.08).<sup>58</sup> Perpetrators of sexual violence against people with disabilities often know their victims well. Nearly one-third of perpetrators of sexual abuse are family members or acquaintances, and an additional 44% of assailants had a care-provider relationship with their victims.<sup>55</sup>

Children and youth with disabilities are more vulnerable to sexual victimization, likely because of a variety of factors depending on the type of disability, including a decreased ability to resist an attack, a desire to please the other person without a full understanding of the circumstances, dependence on others for aspects of care and decision-making, limited communication skills, and increased tolerance of physical intrusion, among others.<sup>55</sup> For example, some individuals with intellectual disability may lack the decision-making capacity, ability to consent, and skills necessary to develop healthy relationships, which can be associated with sexual exploitation, abuse, or coercion.<sup>59,60</sup> Given the increased risk of sexual abuse, coercion, and assault, the pediatric

provider is encouraged to surveil often, in developmentally appropriate ways, and provide resources when a concern is raised.<sup>2,55,61</sup> As is the case for all children, health care providers are mandated reporters, and reporting should occur to the appropriate authorities<sup>61,62</sup> If the youth with disabilities is 18 years or older, reports should be made to adult protective services. In addition, children with disabilities may have been placed in foster care because of sexual abuse; therefore, the pediatric health care provider is encouraged to screen for a history of sexual violence for this population. Specific AAP policies on sexual abuse, coercion, and assault as they relate to children with disabilities can be found in Table 4.

#### **TYPICAL AND PROBLEM SEXUAL BEHAVIORS**

There are a wide range of typical and developmentally appropriate child and adolescent sexual behaviors that provide teachable moments for health care providers and families, especially during early development.<sup>63</sup> For example, when a preschooler undresses in the classroom, an adult can comment, “undressing is what we do privately before taking a bath, not in front of our friends at school.” Children with developmental disabilities, including autism spectrum disorder (ASD), may extend the ages of typical sexual exploration. Providers need to consider social, cultural, religious, familial, and medical contexts for typical and problem behaviors. It is important to be able to differentiate signs of expected and/or typical versus atypical, aberrant, or problem sexual behaviors in children with disabilities and provide appropriate education and counseling on the topic.

Typical behaviors in early development, which may be seen in

older children who have developmental disabilities, include general sexual curiosity, masturbation, an interest in peer or sibling genitals, standing or sitting too close, trying to view adult nudity, and sometimes crude mimicking of movements associated with sexual acts. These are separated from uncommon and rarely typical behaviors, regardless of cognitive ability, such as explicit imitation of sexual acts, asking peers or adults to engage in sexual activities, insertion of objects into genitals, activity with children who are more than 4 years apart, and frequent sexual behaviors that are resistant to distraction.<sup>63,64</sup> Atypical behaviors at any age or developmental level include sexual behaviors that result in distress or pain, are associated with physical aggression or coercion, or become persistent and resistant to redirection. Sorting out behaviors that involve sexual offense from those that are problem behaviors and challenging to self or others can help determine the acuity and degree of intervention.<sup>31</sup> Regardless, challenging sexualized behaviors associated with developmental disabilities or acquired disorders such as brain injury require assessment of the reason for the behavior. Families and/or caregivers and the clinicians can work with schools, behavioral analysts, and/or psychologists to obtain a functional behavior assessment and customize behavioral interventions.<sup>31,65</sup>

Problem or inappropriate sexual behaviors, such as public masturbation and nonconsensual groping, are exhibited more commonly in children and adolescents with disabilities, specifically developmental disabilities, and may be the most problematic in those with ASD.<sup>65</sup> Core deficits in social reciprocity, communication, and sensory

**TABLE 4** Relevant AAP Policy Statements, Clinical Reports, and Technical Reports

Title	Date of Publication and/or Reaffirmation
Long-Acting Reversible Contraception: Specific Issues for Adolescents	August 2020
Barrier Protection Use by Adolescents During Sexual Activity (Policy Statement); Barrier Protection Use by Adolescents During Sexual Activity (Technical Report)	August 2020
Emerging Issues in Male Adolescent Sexual and Reproductive Health Care	May 2020
Emergency Contraception	December 2019
Unique Needs of Adolescents	December 2019
Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home	November 2018
Ensuring Comprehensive Care and Support for Transgender and Gender-Diverse Children and Adolescents	October 2018
Counseling in Pediatric Population at Risk for Infertility and/or Sexual Dysfunction	August 2018
Sexual and Reproductive Health Care Services in the Pediatric Setting	November 2017
Shared Decision-making and Children with Disabilities: Pathways to Consensus	June 2017
Care of the Adolescent After an Acute Sexual Assault	March 2017; erratum June 2017
Sexuality Education for Children and Adolescents	August 2016
Menstrual Management for Adolescents with Disabilities	July 2016
Contraception for Adolescents	October 2014
Screening for Nonviral Sexually Transmitted Infections in Adolescents and Young Adults	July 2014
Condom Use by Adolescents	November 2013
The Evaluation of Children in the Primary Care Setting When Sexual Abuse Is Suspected	August 2013; reaffirmed August 2018
Office-Based Care for Lesbian, Gay, Bisexual, Transgender, and Questioning Youth (Policy Statement); Office-Based Care for Lesbian, Gay, Bisexual, Transgender, and Questioning Youth (Technical Report)	July 2013
Standards for Health Information Technology to Ensure Adolescent Privacy	November 2012; reaffirmed December 2018
Male Adolescent Sexual and Reproductive Health Care	December 2011; reaffirmed May 2015
Protecting Children from Sexual Abuse by Health Care Providers	August 2011; reaffirmed January 2020
The Use of Chaperones During the Physical Examination of the Pediatric Patient	May 2011; reaffirmed November 2017
Gynecologic Examination for Adolescents in the Pediatric Office Setting	September 2010; reaffirmed May 2013
The Evaluation of Sexual Behaviors in Children	September 2009; reaffirmed October 2018

processing likely contribute to poor adherence to sociosexual norms, as well a limited understanding of the consequences of sexual behavior. In a recent survey of both parents and youth, 29% of young adults with ASD experienced challenging sexualized behaviors, most commonly masturbation in public.<sup>66</sup> When parents of children and youth with ASD, Down syndrome, and typical development were interviewed, those with ASD had significantly more trouble in multiple domains of sexual functioning, including social behavior, privacy awareness, sex education, sexual behavior, and parental concerns.<sup>67</sup>

Improving sociosexual education can help prevent or minimize many of these behaviors and should begin at a young age.<sup>68</sup> Health care providers, educators, and family members and caregivers can work collaboratively toward extinguishing problem behaviors and use reminders, distractions, or replacement with socially appropriate gestures or places. Specific resources to address problem behaviors can be found in Table 5.

#### **SEXUALITY AND ADOLESCENTS WITH ASD**

Adulthood is a highly social construct. Negotiating the transition

to adulthood from supervised, structured home and school settings can be challenging for all adolescents, especially for individuals with ASD.<sup>69–71</sup> It is not surprising that the core deficits of ASD, including difficulty with social reciprocity and pragmatic communication, complicate experiences and relationships of youth with ASD, compared with their typical or cognitively delayed peers.<sup>67,72</sup> Although youth and adults with ASD did not significantly differ from their counterparts without ASD in their knowledge of sexual language and interest in sexual experiences,<sup>72,73</sup> more than a dozen studies including direct report by individuals with ASD



**TABLE 5** Resources for Problem Behaviors

Problem Behavior	Resources
Excessive or public masturbation	<p>Suggested conversation: “Today, we discussed that masturbation is a normal behavior. Excessive and/or inappropriate masturbation is often difficult to control because it can be a self-reinforcing behavior. We discussed that although inappropriate masturbation, such as public masturbation, may not completely go away, your child can learn to be redirected to perform the behavior in private. The key to approaching this is to ensure that your child both has a personal space and that he or she understands the appropriate place for private behaviors. Recommend using a schedule or timer to set boundaries for these behaviors.”</p> <p>Specific protocols for minimizing excessive public masturbation include interrupting the behavior, reminding the person of appropriate time and place, redirection, and allowing masturbation in private. Often, working with a behavior therapist who can offer applied behavior analysis is recommended.</p> <p>Resources: Kate E. Reynolds books: <i>Things Tom Likes: A Book About Sexuality and Masturbation for Boys and Young Men with Autism and Related Conditions</i> (2015) and <i>Things Ellie Likes: A Book About Sexuality and Masturbation for Girls and Young Women with Autism and Related Conditions</i> (2015).</p>
Inappropriate interactions (stalking), touching, or romantic gestures	<p>Through the Individualized Education Program, request a functional behavior assessment and a behavior intervention plan for positive supports such as a social skills group, scripting, video modeling and feedback, self-management, and rule governed behaviors.</p> <p>Resource: Teaching Moment: Teaching Your Kids Appropriate and Inappropriate Touching (<a href="https://www.northshore.org/healthy-you/teaching-your-kids-appropriate-touching/">https://www.northshore.org/healthy-you/teaching-your-kids-appropriate-touching/</a>).</p>
Using public restrooms	<p>Resources: Kate E Reynolds books: <i>Tom Needs to Go: A Book About How to Use Public Toilets Safely for Boys and Young Men with Autism and Related Conditions</i> (2015) and <i>Ellie Needs to Go: A Book About How to Use Public Toilets Safely for Girls and Young Women with Autism and Related Conditions</i> (2015).</p>

indicate lower levels of sexual knowledge (including understanding of privacy norms) decreased social opportunities, and increased social anxiety and vulnerability.<sup>66,74,75</sup> In addition, at a population level, teenagers and young adults with ASD without an intellectual disability have greater diversity in sexual orientation and gender identity, compared with typically developing peers, which they state can be confusing.<sup>76</sup> As understanding of sexual knowledge and health differences between individuals with ASD increases, there are new opportunities to individualize safety and sex education to understand sexual orientation and prevent socially isolating problem sexual behaviors, sexual coercion, and abuse.<sup>74</sup> Typical sex education may not be

sufficient for people with ASD, and specific methods and curricula are necessary to match their needs (Table 1).<sup>77</sup> An enhancement of clinical services and additional research is needed to ensure people with ASD have their informational needs met and are able to achieve a healthy sexuality.<sup>78</sup>

**SEXUALITY AND ADOLESCENTS WITH SPINA BIFIDA OR A SPINAL CORD INJURY**

Individuals with spina bifida or a spinal cord injury have some amount of lower extremity paralysis and also tend to have a neurogenic bowel and bladder as well as loss of nerve signals to their sex organs. The neurologic consequences of spinal cord injury and spina bifida can alter sexual and reproductive experiences

for people with these conditions, affect confidence and self-esteem, and hinder relationship building.<sup>12,79-81</sup> Although many youth with spina bifida do not understand their reproductive potential, women with spinal cord injury or spina bifida tend to have normal fertility but require high-risk obstetric care before and during their pregnancies.<sup>12,82</sup> Many women with spinal cord injury or spina bifida, when sexually aroused, do not have full vulvar engorgement or vaginal lubrication, making penetration difficult or painful.<sup>83</sup> Some women with these conditions are able to experience orgasms.<sup>82</sup> Men with spina bifida or spinal cord injury tend to have altered fertility.<sup>84</sup> In addition, the performance of sexual intercourse may be hindered by erectile dysfunction, including an inability to achieve or maintain an erection for

penetration and retrograde, absent, or incomplete ejaculation.<sup>79,85</sup> For both men and women with these conditions, engaging in sexual activity may be complicated by incontinence from neurogenic bowel or bladder.<sup>86,87</sup> Both men and women may be counseled to catheterize their bladders before and after sexual activity.<sup>83</sup> Men who have retrograde ejaculation often need to flush their bladders after sex to remove semen from the bladder.<sup>88</sup> Sexual education and guidance should be tailored to the individual's needs and should consider the cognitive and physical capabilities of the individual.<sup>86</sup> Many people with spina bifida also commonly have learning disabilities and other cognitive problems.<sup>89</sup> People with spina bifida also need to be counseled about the use of nonlatex condoms because of the risk of latex allergies in this population.

### SEXUALITY AND HEALTH CARE TRANSITION

Viewing sexuality as a normative part of adolescence in people with disabilities, including ASD, is conceptually new, compared with long-standing myths of universal asexuality and limited sexual experiences.<sup>72,75</sup> The 2018 AAP clinical report, "Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home," provides a strong framework for primary care providers to longitudinally promote and integrate healthy sexuality for all youth, both with and without disabilities, from understanding pubertal changes and gender identity to experiencing sexual feelings and understanding sexual orientation to ultimately exploring and developing capacity for intimacy and reproduction.<sup>22</sup> This ongoing longitudinal relationship, similar to that for typically developing youth, includes confidential conversations, appropriate genital examinations, openness to sexual and gender

diversity and individual and family preferences, and, if needed, sensitive reporting of sexual abuse or violence.<sup>90</sup> As opportunities for employment, postsecondary education, and community living increase for a large portion of the population with disabilities, it is imperative to prepare and support them in their sociosexual self-efficacy, safety, and well-being.

### THE PEDIATRIC HEALTH CARE PROVIDER'S ROLE

Pediatric health care providers play a crucial and longitudinal role in the development of healthy sexuality of children and youth with disabilities. The unique relationship with the patient and family over time allows the pediatric health care provider to discuss and promote important social and sexual skills at an individualized pace appropriate for each patient.

- Pediatric health care providers can examine and adjust or reinforce their knowledge, beliefs, and attitudes about sexuality and gender identity to ensure their own behavior reflects inclusivity and autonomy of all their patients, especially children and adolescents with disabilities; all people have the right to develop relationships, exercise choice and autonomy, and receive education to promote a healthy sexuality, regardless of sexual orientation or gender identity. Communication that is open and respectful can help develop trust and foster shared decision-making.
- At the earliest ages, including preschoolers, pediatric health care providers are encouraged to discuss appropriate "private" versus "public" behaviors. Pediatric health care providers can help children with disabilities and their families understand boundaries and the concept of body ownership and consent. Explaining "good touch,"

"bad touch," and "necessary touch" can help children frame their understanding of appropriate and inappropriate circumstances and situations. Using anatomically correct language for body parts at young ages helps children to understand their bodies in a positive, healthy way and offers children a way to express healthy sexuality.

- By at least 8 or 9 years of age, pediatric health care providers should begin to discuss puberty and may need to do so sooner if the child is at risk for precocious puberty. Discussing puberty, preparing children and families, and offering additional materials (separate from school curriculum; Table 1) to review in a quiet comfortable place such as the home allows for questions, clarification, and anticipatory guidance for supports in hygiene and normalization of experiences.
- As with all adolescents, pediatric health care providers are encouraged to offer youth with disabilities an opportunity to speak with their provider confidentially during a visit. This allows youth to express their thoughts and experiences and ask questions. This is especially important for youth who are discovering their nonbinary gender identity or nonheterosexual sexual orientation. The pediatric health care provider's office should be a safe place to discuss these issues for all youth, including those with disabilities.
- Pediatric health care providers have opportunities with families and caregivers to introduce topics such as healthy sexual development and exploration while limiting risk of harm. Encouraging coeducational supervised group activities to include individuals with disabilities in typical teenager interactions often is best received by families and caregivers as anticipatory guidance by their trusted

provider. This is also a good time to encourage families and caregivers to be a primary source of sexual education for their children. There are many resources available, including those listed in Table 1. Pediatric health care providers can partner with families and caregivers who may feel uncomfortable addressing sexual health through a shared decision-making process that is culturally responsive and elevates the rights of children with disabilities to gain knowledge and understanding regarding their developing sexuality.

- Pediatric health care providers are the best resource to counsel all youth, including youth with disabilities, regarding the prevention of STIs and unwanted pregnancy as well as the benefits of HPV vaccination.
- Pediatric health care providers can help youth with disabilities procure contraceptives in a confidential manner, with adherence to informed consent rules.
- Pediatric health care providers can screen for STIs or ensure that appropriate referrals are in place (eg, gynecology or urology) for routine screening as part of their role in providing care in a medical home.
- Pediatric health care providers are well suited to provide families with resources to help them address problematic or inappropriate sexual behaviors (Table 5).
- Pediatric health care providers can partner with schools to ensure that children with disabilities have access to a developmentally appropriate sexual education that includes knowledge building around sexual victimization, safer sex practices, consent, and respect through their Individualized Education Programs or as part of the typical curriculum.
- Pediatric health care providers may need to offer education to schools regarding the high risk of sexual

victimization for children with disabilities, how best to prevent it, and how to identify it if it occurs.

- Pediatric health care providers are vigilant about the knowledge that children and youth with disabilities are at an increased risk for sexual abuse and assault and can help families understand this risk. Asking about unwanted or coercive interactions and monitoring for emotional disturbance that may indicate sexual abuse or coercion can happen at every visit. If concerns arise, ensuring that proper reporting occurs and follow-up care is delivered is a role pediatric health care providers are trained to provide.

Pediatric health care providers are encouraged to approach sexual education and guidance individually for children and youth with disabilities, taking into account their patient’s developmental trajectory and understanding the functional limitations of health conditions that can affect the development of healthy sexuality. Numerous other AAP reports can help inform the pediatric health provider on the topic of sexuality (Table 4). Framing healthy sexuality through a “competence lens” helps providers recognize the strengths and challenges for each individual patient. To be competent at something, an individual must have sufficient knowledge and skills to engage in action. Although there may be barriers to the development of skills needed for healthy sexuality in individuals with disabilities, it is important to prioritize ongoing skill development, compensatory strategies, and opportunities for autonomy and self-actualization.

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#### ABBREVIATIONS

AAP: American Academy of Pediatrics  
 ASD: autism spectrum disorder  
 HPV: human papillomavirus  
 STI: sexually transmitted infection

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