

Sexuality and Disability in Adolescents



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KEYWORDS

• Sexuality • Disability • Adolescent • Sexuality education

KEY POINTS

- Sexuality is a topic that may be neglected in adolescents with disabilities, despite evidence that their needs are often similar to or greater than those of their typically developing peers.
- Several hormonal treatment options are available to assist with menstrual management and provide contraception.
- Medical providers may facilitate healthy sexual development in adolescents with disabilities by initiating conversations with patients and caregivers about sexuality.

INTRODUCTION

When caring for adolescents, providers may feel ill equipped to address issues of sexuality. In part, this may reflect the tendency to equate “sexuality” with “sexual intercourse.” Sexual development is a multidimensional process that spans childhood, adolescence, and adulthood. Young children explore gender expression, discover body parts, and learn to respect others’ personal space. Children of all ages witness and process the sexual images and relationships seen in their environment. Adolescents undergo the changes of puberty, experience sexual feelings and desires, and develop the capacity for intimacy and reproduction. The process sometimes proves challenging for adolescents and their caregivers, but it ultimately contributes greatly to the adolescent’s sense of self, as well as providing a source of pleasure, bonding, and enhancement of human relationships.¹

Approximately 10% of youth in the United States report a physical, developmental, or sensory disability.² The global prevalence of intellectual disability (ID), defined as IQ less than 70 to 75, is estimated at 1%, with most being in the mild range.³ Children and

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adolescents with disabilities have the same rights as those without disabilities,⁴ but many of these adolescents face challenges to the attainment of their right to healthy sexual development.

Historically, society has ignored or minimized the issue of sexuality in persons with disabilities. Beyond the deplorable eugenics movement of the early twentieth century, during which thousands of persons with disabilities underwent involuntary sterilization, practices of institutionalization and segregation persisted, limiting the opportunity for normal psychosocial development. Today, most children and adolescents with disabilities attend schools where they interact with typically developing (TD) peers during some or all of the school day, and adults are more likely to live and work in community settings. Nevertheless, when it comes to seeing disabled persons as sexual beings, society may still perceive them negatively and stereotypically, either as asexual or as hypersexual and unable to control their sexual urges.^{5,6} Medical education typically offers little instruction to new physicians on how to support and foster healthy sexuality in persons with disabilities.⁷ Pediatricians are ideally suited to address these needs in youth with disabilities just as they support other aspects of normal adolescent growth and development.

ADOLESCENTS WITH PHYSICAL DISABILITIES

Adolescents with physical disabilities generally express positive desires, attitudes, and expectations about future sexual relationships.⁸ Although some studies suggest positive self-esteem,⁹ others indicate that persons with physical disabilities, particularly more severe impairments, experience poor body image, lower emotional well-being, and lower sexual self-esteem and satisfaction.¹⁰ In the National Longitudinal Study of Adolescent Health (Add Health), male and female high school students with mild physical disabilities reported higher rates of same-sex attraction than their unaffected peers.¹¹ Attitudes toward sex were similar for girls with and without physical disabilities; however, those with disabilities reported more positive views toward pregnancy.

Socially, adolescents with physical disabilities report that they engage in less dating and fewer social activities than unaffected adolescents.⁹ Nonetheless, most studies find no significant differences in self-reported history of sexual intercourse or age of first sexual intercourse in physically disabled adolescents compared with their peers.^{11–13} In the Add Health study, adolescents with physical disabilities reported rates of sexual activity that were actually somewhat higher than their peers; unfortunately, for girls this reflected higher rates of both consensual and forced sex.¹¹ Several other studies have similarly described increased reporting of dating violence and sexual abuse and assault in physically disabled persons.^{8,13,14} Adolescents with physical disabilities express concerns and a desire to discuss their sexuality with health professionals, but are less likely to have those conversations than their unaffected peers.^{8,15}

Cerebral Palsy

In a review focusing on social and sexual relationships of adolescents and young adults with cerebral palsy and normal intelligence, Wiegerink and colleagues¹⁶ found that romantic and sexual relationships were considered important but challenging to develop. These youth reported fewer social relationships, and delayed onset and lower frequency of dating. They report less experience with intimate relationships and sexual activity than their unaffected peers.¹⁷ Adults with cerebral palsy express a desire for more education on sexuality.¹⁸

Myelomeningocele

Most adolescents with myelomeningocele indicate a desire to engage in sexual relationships, marry, and have children.^{19,20} Cromer and colleagues¹⁹ found that 28% of adolescents with myelomeningocele had engaged in sexual activity, compared with 60% of healthy controls. A more recent study of affected adolescents and young adults 16 to 25 years old found that 70% desired sexual contact, and 47% reported sexual contact,²¹ again reflecting significantly less sexual activity than their age-matched peers without disability. Young people with myelomeningocele express a strong desire for more information on sexual function.²⁰ They report exposure to basic sex education, but receive very little that is specific to their condition.²¹ They express concerns about urinary incontinence and may wish to explore ways to achieve sexual pleasure if genital sensation is diminished, yet they are unlikely to initiate conversations about these concerns.^{19,21} Adolescent girls with myelomeningocele are usually fertile, but report low rates of contraception use and preconception counseling.^{19,22} This finding is particularly concerning, given the increased risk to a woman with myelomeningocele of bearing a child with a neural tube defect.

ADOLESCENTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Many adolescents and adults with ID describe their desires and aspirations for intimate relationships, sexual activity, and marriage.^{23,24} There is some inconsistency seen in reports of sexual activity in persons with ID, likely due to methodological differences in case definition and data collection between studies. In the Add Health study, adolescents with low cognitive abilities reported increased same-sex attraction and fewer experiences of romantic attraction and vaginal intercourse than TD adolescents; those who were sexually experienced reported lower rates of contraception use and higher rates of pregnancy and sexually transmitted infection (STI).²⁵ In a clinical sample of adolescents with ID, Chamberlain and colleagues²⁶ found that adolescent girls with mild-moderate ID reported rates of sexual activity comparable to that in the TD adolescent population; they, too, demonstrated increased rates of pregnancy. In a nationally representative survey of youth in the United States, Shandra and colleagues¹² found that boys with learning disabilities or emotional disabilities were more likely to report having sex at younger ages and less likely to use condoms than other boys. Although precise estimates may be lacking, it is clear that sexual activity and its consequences are prevalent among adolescents with ID, particularly among those with mild-moderate disability.

Autism Spectrum Disorders

The social skills deficits and other features characteristic of autism spectrum disorders (ASD) may have a profound effect on sexual development; this challenge is further exacerbated in persons with cooccurrence of ID. Studies of high-functioning persons with ASD suggest differences in the experience of gender compared with control populations. Both adolescent boys and girls with ASD are more likely to be gender nonconforming and less likely to identify as heterosexual than TD peers.^{27,28} Adolescent boys with high-functioning ASD report lifetime sexual experiences comparable to their TD peers, with one-third reporting having had sex with a female partner.^{29,30} However, they report a lower frequency of experience with noncoital partnered sexual activity (eg, kissing, petting).³⁰ Parents tended to underestimate their sons' sexual experiences.³¹ Adults with ASD report a later age of sexual debut and lower rates of sexual experience, interest, and arousal than the typical adult population.^{27,28}

Not surprisingly, persons with ASD report challenges in the social aspects of sexual development and expression. They describe challenges with the process and expectations of courtship, and sending or receiving messages indicating interest in another.²⁷ Boys with ASD are more likely than their TD peers to express regret after their first sexual experience.³⁰ Adults describe challenges of sensory dysregulation during sexual contact, which may negatively impact the experience for both partners.²⁷ A subset of persons with ASD demonstrates higher rates of problematic sexual behaviors, including inappropriate romantic gestures toward others, public displays of arousal, masturbation, or exhibitionism (see later discussion).³²

Inappropriate Sexual Behaviors

The cognitive and psychosocial skills of a youth with ID may lag significantly behind their physical maturity and sexual impulses. This discordance may lead to inappropriate sexual behaviors and subsequent societal discomfort. Public nudity, public masturbation, inappropriate handling of used menstrual products, and a general failure to recognize and respect personal boundaries may contribute to the stigma and exclusion from social activities often experienced by persons with ID. Adolescents with ID may spend play time with younger children, because they may share an interest in the same activities; inappropriate sexual behavior in this setting can lead to exclusion at best, and possibly involvement of child protection authorities.

Masturbation may be an appropriate outlet for sexual feelings and urges, and adolescents who engage in this should not be shamed or reprimanded when it occurs in the appropriate context and private setting. Interventions may be appropriate when masturbation is performed in public or is a frequent response to boredom or lack of stimulation, or if it takes the place of other, more prosocial activities. Behavioral management and sexuality education are the first-line treatments for inappropriate sexual or hypersexual behaviors. Pharmacologic intervention has been described, but is not recommended for routine use.³³

Sexual Abuse and Exploitation

It is well documented that youth with ID are at elevated risk of sexual abuse.^{11,26,34} Their desire for acceptance and conformity with TD peers may make them vulnerable to sexual exploitation, and they may have difficulty distinguishing between appropriate and inappropriate physical contact. They may lack the knowledge and communication skills needed to report abuse, or fear the consequences of disclosure.³⁵ Adolescent boys with ID who were formerly abused themselves are at increased risk of perpetrating inappropriate sexual acts.³⁴

Caregivers' Perspectives and Influence

It is understandable that caregivers of persons with ID express significant caution and concern when confronted with issues of sexuality. Parents tend to underestimate their ID child's sexual activity and interest in sexual relationships.^{23,36} Mothers of young people with ID may acknowledge the importance of addressing their child's sexuality,^{37,38} yet remain hesitant to initiate conversations about sex, intimate relationships, and contraception relative to mothers of TD youth. They express fear that discussing sex may encourage inappropriate sexual behavior, and that their child may not have the coping skills to deal with sexuality.^{36,37} The dissonance between perceived importance and parental behavior may be addressed through improved parental education and support.³⁹

Far from being protective, the hesitation of parents and caregivers to address a child's sexuality may have a significant negative impact on psychosexual development.

Caregivers' silence on the issue suggests that sexuality is taboo; this may make the adolescent hesitant to seek information or ask questions about sex when they arise. Conversations that focus only on the negative aspects of sex may lead to negative views of sexuality that are internalized, contributing to a negative sexual self-concept and lower self-esteem.¹⁰ Adults with ID are more likely to report negative perceptions of sex and touch as wrong and unsafe.⁴⁰ Women with ID are particularly likely to express these negative views, including fear of the sexual act, perceived lack of sexual pleasure, and fear of negative consequences of sex.^{24,41} An adolescent who is deprived of appropriate information and support of healthy sexuality may be more likely to engage in inappropriate sexual behaviors.

SEXUALITY EDUCATION

Numerous studies have demonstrated the lack of adequate sexuality education provided to adolescents and adults with ID.^{7,40,42,43} The traditional "Sex Ed" curriculum provided to adolescents in the United States is heterogeneous at best: the quality and quantity of information provided are variable; information may be narrowly focused on sexual behaviors and their negative consequences; content is often based on a heteronormative framework and promotes gender stereotypes. The unique needs of the adolescent with a physical or intellectual disability are unlikely to be met.

Many formal curricula for persons with ID have been developed, and some have demonstrated an increase in knowledge among participants.³⁹ However, none have been rigorously tested and validated with regard to their effect on sexual behavior and decision making.^{39,44} Outstanding resources for both formal and informal education on sexuality for persons with disabilities are available online.^{45,46} Components of an appropriate curriculum are listed in **Box 1**.

Perhaps the even bigger challenge, however, is the inherent limitation of any formal curriculum to truly inform one's understanding of sexuality. Much of what typical adolescents learn about sexuality is ultimately experiential, occurring in natural learning environments rather than a classroom. Young people grow up surrounded by both

Box 1

Components of a sexuality education program for youth with disabilities

- Content
 - Simple but accurate terms for anatomy
 - Physical boundaries
 - Negotiating sexual situations
 - Understanding and avoidance of sexual abuse and exploitation
 - Same-sex and opposite-sex attraction
 - Healthy sexual interactions (intercourse and noncoital alternatives)
 - Assertiveness training (saying "No")
 - Safer sexual practices
 - Pregnancy prevention
- Educational approach
 - Strength-based versus deficit-based approach
 - Simple, explicit, concrete language
 - Use of pictures, anatomically correct dolls
 - Frequent repetition
 - Adaptability for developmental levels and health literacy
 - Practice and role playing
 - Incorporate experiential learning
 - Avoidance of heteronormative approach

positive and negative sexual messages and media images that they internalize and process on conscious and subconscious levels. They engage with peers and romantic partners in both supervised and unsupervised settings, experimenting, gaining experience, and learning from their successes and mistakes. These experiences, along with formal education, religious and family values, and numerous other factors, are ultimately incorporated into the adolescent's sexual self-concept.

Adolescents with ID may lack the cognitive skills to process the abstract and often conflicting messages in their environment. In those with medical comorbidities, experiences with examinations and treatment may impact their perceptions regarding privacy and physical boundaries. They infrequently see persons with disabilities portrayed in the media as desirable romantic partners. They generally have smaller social circles than TD adolescents.⁴³ Caregivers, through appropriate and well-intentioned efforts to limit the risk of harm, may place strict limitations on social interactions and activities, particularly those with reduced levels of supervision. The disabled adolescent's opportunities for experiential learning are limited, and those experiences are often disproportionately negative. In contrast to supporting healthy sexual development, caregivers may inadvertently impair psychosocial and sexual development by restricting opportunities for sexual exploration. This limitation of experiential learning may ultimately lead to a worse sexual self-concept and poor sexual decision-making skills in adulthood.

THE ROLE OF THE MEDICAL PROVIDER

Puberty and Menstruation

Puberty typically occurs within the expected timeframe, particularly for adolescents with an isolated congenital or acquired physical disability or idiopathic ID. Children with certain genetic syndromes or neurodevelopmental disabilities, including neural tube defects or major brain malformations, may experience premature adrenarche or pubarche. In many, these remain isolated changes; in others, they may progress to true precocious puberty.^{47,48} For children who have experienced nutritional deficiencies or failure to reach expected growth parameters due to their condition, puberty may occur later.⁴⁷ Girls with ASD also may undergo somewhat delayed puberty and menarche.⁴⁹

Menstruation can be challenging for girls with special needs. They may need assistance changing pads, due to dexterity issues caused by physical disabilities, or limited understanding of the process in girls with ID. Pain and irregular bleeding, common in teenagers, may cause a significant burden for the patient and her caregivers, or limit her ability to participate in school or other activities. Most families learn to manage menstruation effectively, even for teens with severe disability.^{50,51} The medical provider should initiate anticipatory guidance about the menstrual periods once breast development starts, because there is typically 2 to 3 years between thelarche and the onset of menses. Hormonal treatment to prevent menarche, sometimes requested by caregivers, is generally not recommended because this may limit ongoing normal growth. Allowing menarche to occur also gives families an opportunity to see how the experience of the menstrual cycle affects the adolescent. Tips for managing menstrual periods are presented in [Box 2](#).

When hormonal contraception is considered, the desired outcomes should be clarified, because this may affect the method choice. For example, the goal may be to prevent pregnancy, to decrease heavy bleeding, to eliminate menstrual cramps, or to attempt to obtain amenorrhea. Families must understand that complete amenorrhea is almost impossible, so period and pad education remains critical.^{52,53}

Box 2**Tips for managing menstruation in girls with intellectual disabilities**

- Avoid negative references to menstruation; discuss menstruation as a normal part of growing up.
- Discuss and practice pad use *prior* to menstruation.
- Use an alarm or reminder system to signal time for a pad change.
- Create a checklist for steps involved in changing pads (eg, remove, wrap up, and discard used pad; wash hands, and so forth).
- Consider the use of a sticker chart or reward system for good hygiene practices.
- For patients using a diaper, a pad placed within the diaper may facilitate easier changes and save money.
- Consider allowing patient to observe a relative or close female friend managing menstrual hygiene, if comfortable.
- Track periods on a calendar to anticipate next menses.

Medical Interventions

1. *Nonsteroidal anti-inflammatory drugs* can be used to treat menstrual cramps and may decrease the menstrual flow when taken consistently.⁵⁴ Gastrointestinal and neurologic side effects may limit their use.⁵⁵
2. The *combination estrogen-progesterone containing methods* are used extensively in adolescents with disabilities⁵⁶ and can be used either cyclically or in an extended or continuous fashion to decrease the frequency of menstrual cycles.⁵⁷
 - a. *Combined Oral Contraceptives (COC)*. Daily oral use is paramount because intermittent use is associated with breakthrough bleeding. For teens with swallowing issues, one chewable product is currently available. Extended use (with elimination of the “placebo” pills) has been described, providing good cycle control⁵⁸; however, unpredictable bleeding remains a side effect, whether a fixed or a flexible extended regimen is used.⁵⁹
 - b. *Transdermal combined hormones*. The weekly contraceptive patch can be used either cyclically or with extended use; extended use provides similar or better cycle control than COC.⁶⁰ For patients with ID who may remove the patch inappropriately, the patch may be placed on difficult-to-reach places, such as the upper back.
 - c. *Vaginal ring*. The monthly vaginal ring can be used cyclically or extended in an off-label use. It provides equivalent cycle control to COC.⁶¹ This method, however, has limited utility for teens with disabilities, because the ring needs to be placed intravaginally, which requires a fair amount of manual dexterity and coordination. If the adolescent cannot do this herself, there are clear privacy concerns.
3. *Progesterone-only methods*
 - a. The *progesterone-only contraceptive pill (POP)* has a significant side effect of irregular bleeding, because the short half-life of norethindrone makes exact 24-hour compliance imperative. Amenorrhea is achieved in about only 10% of women. Therefore, its use is limited for menstrual management. Higher doses of norethindrone, medroxyprogesterone, and megestrol have been used to treat heavy menstrual cycles in older women with some positive results, and may be considered if amenorrhea is desired.⁵²

- b. *Depot medroxyprogesterone acetate*, the 12-week intramuscular or subcutaneous injection, is a good form of menstrual management with a high rate of amenorrhea (around 50% at 12 months).⁶² However, 2 potential side effects have contributed to declining use in the disabled population.⁵⁶ DMPA may contribute to weight gain. A review of the available studies showed overall weight gain is not excessive; however, the risk is greatest in overweight teenagers. Because this weight gain often is apparent after the first 3 months, discontinuation for teens with significant weight gain at that time should be considered.⁶³ Weight gain significantly affects the health and the ability of a teen to do her own wheelchair transfers or for caregivers to lift her. DMPA also may interfere with the normal bone density gain in early adolescence.⁶⁴ Many patients with disabilities already have compromised bone density due to poor nutrition, use of anticonvulsants, reduced mobility, and possible vitamin D deficiency.⁴⁷ Studies suggest that the bone loss can be regained after stopping DMPA; however, many teens with ID stay on it for a prolonged period of time. Adequate calcium and vitamin D may be helpful.⁶⁵
- c. *Subdermal implant*. The 3-year single-rod etonogestrel implant provides excellent contraception; however, because of an unfavorable irregular bleeding pattern and amenorrhea rates of only 20% at 1 year, the implant is usually not recommended for menstrual management. Insertion and removal require patient cooperation, which may be challenging for some teenagers with ID. However, for those teens who can deal with the intermittent bleeding and desire excellent birth control, this remains a viable option.⁶⁶
- d. The *Levonorgestrel intrauterine device (LNG-IUD)* provides excellent contraceptive efficacy as well as good cycle control for bleeding and cramping. In the general adolescent population, it has recently become more popular, endorsed as a first-line method by the American College of Obstetricians and Gynecologists (ACOG).^{67,68} In teens with disabilities, the LNG-IUD has been described in several studies with normal expulsion rates, normal removal rates for pain and bleeding, and a 70% amenorrhea rate in girls for whom that information was noted.^{56,69–71} General anesthesia is often used for placement. Preinsertion ultrasonography is not routinely indicated.⁷² The copper IUD, associated with increased bleeding and cramping, is not useful for menstrual management.

All estrogen-containing medications increase the risk of venous thromboembolism (VTE), from 2.1/10,000 to 4/10,000 in adolescent COC users. The risk for patch and ring users may be slightly higher.⁷³ Risk is increased with higher dose of estrogen, obesity, smoking, and a familial clotting disorder. Whether different progestins have different rates of VTE remains controversial. Registry studies suggest a slightly lower risk of VTE for first- and second-generation progestins, but this was not found in cohort studies.⁷⁴ Whether the use of a wheelchair increases the VTE risk is unknown, but it has not been reported in adolescents. It is prudent to discuss these concerns with the patient and her family and assess for additional risk factors, and if the decision is to use an estrogen containing method, to use a lower dose estrogen with a first- or second-generation progestin. The risk of VTE in progesterone-only methods appears to be very low.⁷⁵

Surgical Interventions

Endometrial ablation is a procedure designed to destroy the endometrial lining in women who have completed childbearing. In about 25% to 40% of women, this results in amenorrhea. In women less than the age of 35, 31% required another

procedure within 5 years, compared with less than 10% over than the age of 45. Because ablation renders women less fertile, it can be considered a sterilization procedure with possible legal implications. Both the ACOG and the American Academy of Pediatrics (AAP) have stated that ablation is not recommended in teens.^{76,77} Caregivers may inquire about hysterectomy to achieve amenorrhea and pregnancy prevention. Concerns include both surgical complications and ethical and legal implications for those patients who cannot give their own consent. A hysterectomy for no other indication than eliminating menstrual periods and the chance of pregnancy has not been endorsed by ACOG and AAP.^{76,77}

Supporting Healthy Sexuality

By addressing the same aspects of sexual development and sexual health care needs present in TD youth (**Box 3**), the provider emphasizes the normative aspects of sexual development in disabled youth. The provider may point out that many ID young adults ultimately have the capacity to engage in sexual activity of some sort. The planning, experiences, and educational efforts made during adolescence may provide the adult with more tools to make healthy decisions. Although protecting the child from harm remains of utmost importance, this must be balanced, to the extent possible, with facilitating developmentally appropriate discussions and experiences that permit learning and foster healthy sexual development. Anticipatory guidance for persons with disabilities (**Box 4**) includes many of the same approaches recommended for TD children, such as starting conversations about sexuality early, repeating them often, and using “teachable moments” as they arise in real life and in the media.

The clinician should model involving patients in their own health care to the extent that they are developmentally capable. Genital examinations should be performed

Box 3

Supporting healthy sexual development in adolescents with developmental disabilities: the role of the medical provider

- Emphasize sexual development as a normative experience
 - Discuss both positive and negative aspects
 - Approach as you would with all patients at a similar developmental level
- Include external genital examinations in routine physicals
 - Demonstrate respect for privacy and dignity
 - Use as “teachable moment” for appropriate and inappropriate touch
 - Set stage for reproductive care in adulthood
- Discuss behavioral and hormonal approaches to managing menstruation
- For sexually active patients
 - Provide or refer for contraception
 - Perform STI testing using urine or vaginal swab
 - Refer for genetic counseling if indicated
 - Folic acid supplementation for adolescent girl (4 mg daily for adolescents with myelomeningocele; 0.4–1 mg daily for others)
- Screen for sexual abuse and consider in patients presenting with behavior changes or genitourinary/bowel symptoms
- Vaccinate against HPV
- Screen for depression, anxiety, and substance use
- Provide anticipatory guidance on healthy sexual development throughout childhood and adolescence (see **Box 4**)

Box 4**Supporting healthy sexual development in adolescents with developmental disabilities: anticipatory guidance for caregivers**

- Begin in early childhood
 - Role model appropriate degrees of modesty, privacy
 - “Public” versus “private” behaviors
 - Role model healthy sexual expression
- Start conversations early and repeat often
 - Approach sequentially (eg, body parts → boundaries → puberty → sexual behaviors) at the pace that is right for your child
 - Speak frankly and concretely
 - Ask about questions or concerns
- Respond calmly to questions about sex
 - Do not demonstrate anger or shock
 - Use as an opportunity to explore the adolescent’s thoughts and experiences
 - “What makes you ask that question?”
 - “Where did you learn that word?”
- Use teachable moments (real life and media) to facilitate discussion and reinforce appropriate behavior
- Prepare female children for menstruation
 - Discuss ahead of time
 - Distinguish menstrual blood from bleeding caused by injury
 - Model menstrual hygiene if comfortable doing so
 - Consider use of reminders, sticker charts, rewards to support menstrual hygiene practices
- Acknowledge that many with intellectual disability ultimately have the desire and decisional capacity to choose to engage in sexual activity
- Provide opportunities for healthy sexual development while limiting risk of harm
 - Promote normal teen activities and interactions
 - Respect need for privacy
 - Teach appropriate setting and context for masturbation
 - Provide experiential learning opportunities
- Monitor use of social media and place limits as needed
- Include sex education and social skills training in Individualized Education Program

routinely, using the opportunity to discuss body parts, answer questions, and pave the way for more extensive genital examinations that may be needed in adulthood. While exploring and discussing the adolescent’s romantic interests and intents, the provider may remind the patient and caregivers that there are many means of sexual contact and expression that may be gratifying while presenting less risk than intercourse. A patient with a physical disability may be encouraged to consider a more diverse repertoire of opportunities for sexual expression as well.

Sexually active adolescents should be tested for Chlamydia and gonorrhea at least yearly. STI testing, using urine or a vaginal swab with a nucleic acid amplification test, is minimally invasive and has high sensitivity and specificity. Cervical cancer screening by Pap smear is recommended starting at the age of 21 years. If a young woman with disabilities cannot tolerate a pelvic examination, an assessment of her risk for cervical cancer (ie, sexual contact) is made to determine whether a pelvic examination under sedation is indicated. The possibility of human papillomavirus (HPV) screening using vaginal swabs may become applicable for this population in the future; however, current recommendations remain preliminary.⁷⁸

SUMMARY

Sexuality is a part of human development, no less for disabled persons than for persons without disability. Some persons with disability face challenges to healthy sexual development, but with supportive medical providers and caregivers, opportunities for formal and experiential learning, and a broadened view of healthy sexual behavior and expression, these challenges can be overcome.

REFERENCES

1. Murphy NA, Elias ER. Sexuality of children and adolescents with developmental disabilities. *Pediatrics* 2006;118(1):398–403.
2. Brault MW. Current population reports. Washington, DC: US Census Bureau 2012;70–131.
3. Maulik PK, Mascarenhas MN, Mathers CD, et al. Prevalence of intellectual disability: a meta-analysis of population-based studies. *Res Dev Disabil* 2011;32(2):419–36.
4. Council on Community Pediatrics and Committee on Native American Child Health. Policy statement—health equity and children's rights. *Pediatrics* 2010;125(4):838–49.
5. Esmail S, Darry K, Walter A, et al. Attitudes and perceptions towards disability and sexuality. *Disabil Rehabil* 2010;32(14):1148–55.
6. Neufeld JA, Klingbeil F, Bryen DN, et al. Adolescent sexuality and disability. *Phys Med Rehabil Clin N Am* 2002;13(4):857–73.
7. Greenwood NW, Wilkinson J. Sexual and reproductive health care for women with intellectual disabilities: a primary care perspective. *Int J Family Med* 2013;2013:642472.
8. Jemta L, Fugl-Meyer KS, Oberg K. On intimacy, sexual activities and exposure to sexual abuse among children and adolescents with mobility impairment. *Acta Paediatr* 2008;97(5):641–6.
9. Stevens SE, Steele CA, Jutai JW, et al. Adolescents with physical disabilities: some psychosocial aspects of health. *J Adolesc Health* 1996;19(2):157–64.
10. McCabe MP, Taleporos G. Sexual esteem, sexual satisfaction, and sexual behavior among people with physical disability. *Arch Sex Behav* 2003;32(4):359–69.
11. Cheng MM, Udry JR. Sexual behaviors of physically disabled adolescents in the United States. *J Adolesc Health* 2002;31(1):48–58.
12. Shandra CL, Shameem M, Ghori SJ. Disability and the context of boys' first sexual intercourse. *J Adolesc Health* 2016;58(3):302–9.
13. Suris JC, Resnick MD, Cassuto N, et al. Sexual behavior of adolescents with chronic disease and disability. *J Adolesc Health* 1996;19(2):124–31.
14. Mitra M, Mouradian VE, McKenna M. Dating violence and associated health risks among high school students with disabilities. *Matern Child Health J* 2013;17(6):1088–94.
15. Seburg EM, McMorris BJ, Garwick AW, et al. Disability and discussions of health-related behaviors between youth and health care providers. *J Adolesc Health* 2015;57(1):81–6.
16. Wiegerink DJ, Roebroek ME, Donkervoort M, et al. Social and sexual relationships of adolescents and young adults with cerebral palsy: a review. *Clin Rehabil* 2006;20(12):1023–31.

17. Wiegerink DJ, Roebroek ME, Donkervoort M, et al. Social, intimate and sexual relationships of adolescents with cerebral palsy compared with able-bodied age-mates. *J Rehabil Med* 2008;40(2):112–8.
18. Cho SR, Park ES, Park CI, et al. Characteristics of psychosexual functioning in adults with cerebral palsy. *Clin Rehabil* 2004;18(4):423–9.
19. Cromer BA, Enrile B, McCoy K, et al. Knowledge, attitudes and behavior related to sexuality in adolescents with chronic disability. *Dev Med Child Neurol* 1990;32(7):602–10.
20. Lindehall B, Moller A, Hjalmas K, et al. Psychosocial factors in teenagers and young adults with myelomeningocele and clean intermittent catheterization. *Scand J Urol Nephrol* 2008;42(6):539–44.
21. Verhoef M, Barf HA, Vroeghe JA, et al. Sex education, relationships, and sexuality in young adults with spina bifida. *Arch Phys Med Rehabil* 2005;86(5):979–87.
22. Visconti D, Noia G, Triarico S, et al. Sexuality, pre-conception counseling and urological management of pregnancy for young women with spina bifida. *Eur J Obstet Gynecol Reprod Biol* 2012;163(2):129–33.
23. Healy E, McGuire BE, Evans DS, et al. Sexuality and personal relationships for people with an intellectual disability. Part I: service-user perspectives. *J Intellect Disabil Res* 2009;53(11):905–12.
24. Siebelink EM, de Jong MD, Taal E, et al. Sexuality and people with intellectual disabilities: assessment of knowledge, attitudes, experiences, and needs. *Ment Retard* 2006;44(4):283–94.
25. Cheng MM, Udry JR. Sexual experiences of adolescents with low cognitive abilities in the US. *J Dev Phys Disabil* 2005;17(2):155–72.
26. Chamberlain A, Rauh J, Passer A, et al. Issues in fertility control for mentally retarded female adolescents: I. Sexual activity, sexual abuse, and contraception. *Pediatrics* 1984;73(4):445–50.
27. Barnett JP, Maticka-Tyndale E. Qualitative exploration of sexual experiences among adults on the autism spectrum: implications for sex education. *Perspect Sex Reprod Health* 2015;47(4):171–9.
28. Bejerot S, Eriksson JM. Sexuality and gender role in autism spectrum disorder: a case control study. *PLoS One* 2014;9(1):e87961.
29. Dewinter J, Vermeiren R, Vanwesenbeeck I, et al. Sexuality in adolescent boys with autism spectrum disorder: self-reported behaviours and attitudes. *J Autism Dev Disord* 2015;45(3):731–41.
30. Dewinter J, Vermeiren R, Vanwesenbeeck I, et al. Adolescent boys with autism spectrum disorder growing up: follow-up of self-reported sexual experience. *Eur Child Adolesc Psychiatry* 2016;25(9):969–78.
31. Dewinter J, Vermeiren R, Vanwesenbeeck I, et al. Parental awareness of sexual experience in adolescent boys with autism spectrum disorder. *J Autism Dev Disord* 2016;46(2):713–9.
32. Beddows N, Brooks R. Inappropriate sexual behaviour in adolescents with autism spectrum disorder: what education is recommended and why. *Early Interv Psychiatry* 2016;10(4):282–9.
33. Sajith SG, Morgan C, Clarke D. Pharmacological management of inappropriate sexual behaviours: a review of its evidence, rationale and scope in relation to men with intellectual disabilities. *J Intellect Disabil Res* 2008;52(12):1078–90.
34. Wissink IB, van Vugt E, Moonen X, et al. Sexual abuse involving children with an intellectual disability (ID): a narrative review. *Res Dev Disabil* 2015;36:20–35.

35. Miller HL, Pavlik KM, Kim MA, et al. An exploratory study of the knowledge of personal safety skills among children with developmental disabilities and their parents. *J Appl Res Intellect Disabil* 2016. [Epub ahead of print].
36. Cheng MM, Udry JR. How much do mentally disabled adolescents know about sex and birth control. *Adolesc Fam Health* 2003;3(1):28–38.
37. Pownall JD, Jahoda A, Hastings R, et al. Sexual understanding and development of young people with intellectual disabilities: mothers' perspectives of within-family context. *Am J Intellect Dev Disabil* 2011;116(3):205–19.
38. Swango-Wilson A. Caregiver perceptions and implications for sex education for individuals with intellectual and developmental disabilities. *Sex Disabil* 2008;26(3):167–74.
39. McGuire BE, Bayley AA. Relationships, sexuality and decision-making capacity in people with an intellectual disability. *Curr Opin Psychiatry* 2011;24(5):398–402.
40. McCabe MP. Sexual knowledge, experience and feelings among people with disability. *Sex Disabil* 1999;17(2):157–70.
41. Bernert DJ, Ogletree RJ. Women with intellectual disabilities talk about their perceptions of sex. *J Intellect Disabil Res* 2013;57(3):240–9.
42. Barnard-Brak L, Schmidt M, Chesnut S, et al. Predictors of access to sex education for children with intellectual disabilities in public schools. *Intellect Dev Disabil* 2014;52(2):85–97.
43. Jahoda A, Pownall J. Sexual understanding, sources of information and social networks; the reports of young people with intellectual disabilities and their non-disabled peers. *J Intellect Disabil Res* 2014;58(5):430–41.
44. Doughty AH, Kane LM. Teaching abuse-protection skills to people with intellectual, disabilities: a review of the literature. *Res Dev Disabil* 2010;31(2):331–7.
45. Available at: <http://www.mass.gov/eohhs/docs/dph/com-health/prevention/hrhs-sexuality-and-disability-resource-guide.pdf>. Accessed December 7, 2016.
46. Available at: <http://disability-abuse.com/>. Accessed December 7, 2016.
47. Zacharin M. Endocrine problems in children and adolescents who have disabilities. *Horm Res Paediatr* 2013;80(4):221–8.
48. Siddiqi SU, Van Dyke DC, Donohoue P, et al. Premature sexual development in individuals with neurodevelopmental disabilities. *Dev Med Child Neurol* 1999;41(6):392–5.
49. Knickmeyer RC, Wheelwright S, Hoekstra R, et al. Age of menarche in females with autism spectrum conditions. *Dev Med Child Neurol* 2006;48(12):1007–8.
50. Kaskowitz AP, Dendrinis M, Murray PJ, et al. The effect of menstrual issues on young women with Angelman syndrome. *J Pediatr Adolesc Gynecol* 2016;29(4):348–52.
51. Hamilton A, Marshal MP, Sucato GS, et al. Rett syndrome and menstruation. *J Pediatr Adolesc Gynecol* 2012;25(2):122–6.
52. Altshuler AL, Hillard PJ. Menstrual suppression for adolescents. *Curr Opin Obstet Gynecol* 2014;26(5):323–31.
53. Abdel-Aleem H, d'Arcangues C, Vogelsong KM, et al. Treatment of vaginal bleeding irregularities induced by progestin only contraceptives. *Cochrane Database Syst Rev* 2013;(10):CD003449.
54. Lethaby A, Duckitt K, Farquhar C. Non-steroidal anti-inflammatory drugs for heavy menstrual bleeding. *Cochrane Database Syst Rev* 2013;(1):CD000400.
55. Marjoribanks J, Ayeleke RO, Farquhar C, et al. Nonsteroidal anti-inflammatory drugs for dysmenorrhoea. *Cochrane Database Syst Rev* 2015;(7):CD001751.

56. Kirkham YA, Allen L, Kives S, et al. Trends in menstrual concerns and suppression in adolescents with developmental disabilities. *J Adolesc Health* 2013; 53(3):407–12.
57. Jacobson JC, Likis FE, Murphy PA. Extended and continuous combined contraceptive regimens for menstrual suppression. *J Midwifery Womens Health* 2012; 57(6):585–92.
58. Edelman A, Micks E, Gallo MF, et al. Continuous or extended cycle vs. cyclic use of combined hormonal contraceptives for contraception. *Cochrane Database Syst Rev* 2014;(7):CD004695.
59. Han L, Jensen JT. Expert opinion on a flexible extended regimen of drospirenone/ethinyl estradiol contraceptive. *Expert Opin Pharmacother* 2014;15(14):2071–9.
60. Stewart FH, Kaunitz AM, Laguardia KD, et al. Extended use of transdermal norelgestromin/ethinyl estradiol: a randomized trial. *Obstet Gynecol* 2005;105(6):1389–96.
61. Weisberg E, Merki-Feld GS, McGeechan K, et al. Randomized comparison of bleeding patterns in women using a combined contraceptive vaginal ring or a low-dose combined oral contraceptive on a menstrually signaled regimen. *Contraception* 2015;91(2):121–6.
62. Hubacher D, Lopez L, Steiner MJ, et al. Menstrual pattern changes from levonorgestrel subdermal implants and DMPA: systematic review and evidence-based comparisons. *Contraception* 2009;80(2):113–8.
63. Lopez LM, Edelman A, Chen M, et al. Progestin-only contraceptives: effects on weight. *Cochrane Database Syst Rev* 2013;(7):CD008815.
64. American College of Obstetricians and Gynecologists. Committee opinion no. 602: Depot medroxyprogesterone acetate and bone effects. *Obstet Gynecol* 2014;123(6):1398–402.
65. Rahman M, Berenson AB. Predictors of higher bone mineral density loss and use of depot medroxyprogesterone acetate. *Obstet Gynecol* 2010;115(1):35–40.
66. Mansour D, Korver T, Marintcheva-Petrova M, et al. The effects of Implanon on menstrual bleeding patterns. *Eur J Contracept Reprod Health Care* 2008; 13(Suppl 1):13–28.
67. Committee on Adolescent Health Care Long-Acting Reversible Contraception Working Group, The American College of Obstetricians and Gynecologists. Committee opinion no. 539: adolescents and long-acting reversible contraception: implants and intrauterine devices. *Obstet Gynecol* 2012;120(4):983–8.
68. American Academy of Pediatrics, The Committee on Adolescence. Contraception for adolescents. *Pediatrics* 2014;134(4):e1244–1256.
69. Hillard PJ. Menstrual suppression with the levonorgestrel intrauterine system in girls with developmental delay. *J Pediatr Adolesc Gynecol* 2012;25(5):308–13.
70. Pillai M, O'Brien K, Hill E. The levonorgestrel intrauterine system (Mirena) for the treatment of menstrual problems in adolescents with medical disorders, or physical or learning disabilities. *BJOG* 2010;117(2):216–21.
71. Savasi I, Jayasinghe K, Moore P, et al. Complication rates associated with levonorgestrel intrauterine system use in adolescents with developmental disabilities. *J Pediatr Adolesc Gynecol* 2014;27(1):25–8.
72. Whyte H, Pecchioli Y, Oyewumi L, et al. Uterine length in adolescents with developmental disability: are ultrasounds necessary prior to insertion of the levonorgestrel intrauterine system? *J Pediatr Adolesc Gynecol* 2016;26(6):648–52.
73. Hugon-Rodin J, Gompel A, Plu-Bureau G. Epidemiology of hormonal contraceptives-related venous thromboembolism. *Eur J Endocrinol* 2014;171(6):R221–30.

74. Han L, Jensen JT. Does the progestogen used in combined hormonal contraception affect venous thrombosis risk? *Obstet Gynecol Clin North Am* 2015;42(4):683–98.
75. Tepper NK, Whiteman MK, Marchbanks PA, et al. Progestin-only contraception and thromboembolism: a systematic review. *Contraception* 2016;94:678–700.
76. American College of Obstetricians and Gynecologists Committee on Adolescent Health Care. ACOG Committee opinion no. 448: menstrual manipulation for adolescents with disabilities. *Obstet Gynecol* 2009;114(6):1428–31.
77. Quint EH, O'Brien RF, AAP The Committee on Adolescence, et al. Menstrual management for adolescents with disabilities. *Pediatrics* 2016;137(4):e20160295.
78. Huh WK, Ault KA, Chelmow D, et al. Use of primary high-risk human papillomavirus testing for cervical cancer screening: interim clinical guidance. *Obstet Gynecol* 2015;125(2):330–7.