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CLINICAL REPORT

Sexuality of Children and Adolescents With Developmental Disabilities

Guidance for the Clinician in Rendering Pediatric Care

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ABSTRACT

Children and adolescents with developmental disabilities, like all children, are sexual persons. However, attention to their complex medical and functional issues often consumes time that might otherwise be invested in addressing the anatomic, physiologic, emotional, and social aspects of their developing sexuality. This report discusses issues of puberty, contraception, psychosexual development, sexual abuse, and sexuality education specific to children and adolescents with disabilities and their families. Pediatricians, in the context of the medical home, are encouraged to discuss issues of sexuality on a regular basis, ensure the privacy of each child and adolescent, promote self-care and social independence among persons with disabilities, advocate for appropriate sexuality education, and provide ongoing education for children and adolescents with developmental disabilities and their families.

INTRODUCTION

Sexual development is a multidimensional process, intimately linked to the basic human needs of being liked and accepted, displaying and receiving affection, feeling valued and attractive, and sharing thoughts and feelings. It not only involves anatomic and physiologic functioning, but it also relates to sexual knowledge, beliefs, attitudes, and values. Sexuality should be considered in a context that extends beyond genital sex to include gender-role socialization, physical maturation and body image, social relationships, and future social aspirations.[1] Like all adolescents, teens with disabilities may express desires and hopes for marriage, children, and normal adult sex lives. In fact, adolescents with physical disabilities are as sexually experienced as their peers without disabilities.[2] However, parents and health care professionals are often pessimistic regarding the potential of children with disabilities to enjoy intimacy and sexuality in their relationships.[3] People with disabilities are often erroneously regarded as childlike, asexual, and in need of protection. Conversely, they may be viewed as inappropriately sexual or as having uncontrollable urges.[4] People without disabilities are more willing to accept people with disabilities as fellow employees or casual friends and less willing to accept them as dating, sexual, or marriage partners.[5] Societal and psychosocial barriers may be more of a hindrance to an adolescent's sexual development than the limitations of the disability itself.[3]

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Key Words
sexuality, developmental disabilities, spina bifida, precocious puberty, sexual abuse

Abbreviations
STD—sexually transmitted disease
UN—United Nations

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PUBERTY AND SPECIAL CONSIDERATIONS

Puberty in US children typically has an onset between 8.5 and 13 years of age in females and between 9 and 14 years of age in males. Among children with cerebral palsy, puberty tends to begin earlier and end later than in typically developing children.[6] The median age of menarche for white females with cerebral palsy is 14.0 years, contrasting with 12.8 years in the general population. In general, children with neurodevelopmental disabilities are 20 times more likely to experience early pubertal changes.[7] Although idiopathic precocious puberty occurs in approximately 1 in 1000 girls, the incidence approaches 20% among females with spina bifida.[8] Although the reasons for this increased incidence are poorly understood, malformations of the central nervous system and nutritional influences on the hypothalamic-pituitary axis are known to affect the timing of puberty.[9] Precocious puberty can further challenge children with disabilities, who may be socially immature, by affecting an already altered body image and self-esteem, increasing the complexity of self-care and hygiene activities, and heightening the risk of sexual victimization. Gonadotropin-releasing hormone agonists can effectively manage true central precocious puberty in most females.[10]

All females deserve appropriate gynecologic care, including children and adolescents with developmental disabilities. During the first 2 years after menarche, anovulatory menstrual cycles are generally associated with abnormal uterine bleeding; however, thyroid disease, anticonvulsant therapy, and neuroleptic medications may also contribute to these symptoms.[11] If the adolescent is not sexually active, a pelvic examination is rarely indicated.[12] When pelvic examinations are indicated, females with disabilities should be informed about the procedures and instruments to be used and approached with respect for their personal privacy. Adolescents should be given the option of having a trusted caregiver present during the examination. Positioning during the pelvic examination should be modified as needed to accommodate the needs of women with orthopedic or neuromuscular disorders. Rather than stirrups, frog-leg position, V position, or elevation of the legs without hip abduction may increase comfort and decrease anxiety when examinations are indicated. Rectoabdominal examinations may offer an acceptable alternative to pelvic examinations and are best performed after the bowel has been evacuated by an enema.[12]

Adolescents and young adults with disabilities must be well informed when making decisions regarding abstinence, contraception, and pregnancy. For example, some antiepileptic medications induce hepatic enzyme activity and decrease the effectiveness of oral and implanted contraceptives.[9] The risk of thrombotic diseases in females with mobility impairments needs to be considered when prescribing estrogen-progestin–containing contraceptives such as pills, transdermal patches, and vaginal contraceptive rings.[13] Barrier devices, including condoms, cervical caps, and diaphragms, require motivation, cognitive understanding, and physical dexterity.[1] In addition, these devices often contain latex, which are contraindicated in the presence of latex sensitivities. Polyurethane male and female condoms are available but provide less protection against pregnancy and transmission of sexually transmitted diseases (STDs) and are more likely to break during sexual intercourse when compared with latex condoms.[14,15] However, nonlatex condoms still provide an acceptable alternative for those with latex sensitivity or allergy.[16] Although depot medroxyprogesterone acetate, an injectable contraceptive, can effectively minimize or eliminate menstrual flow, prolonged use has been linked recently to bone density loss in healthy adolescent females, which may not reverse completely after discontinuation of the medication.[17] Adolescents who are already at risk of osteopenia from chronic medical conditions may be at even greater risk of bone mineral density loss from depot medroxyprogesterone acetate use. Historically, sterilization of minors with developmental disabilities was performed without appropriate regard for their decision-making capacities, abilities to care for children, feelings, or interests. Such decisions should be made only in the context of the individual's capacity to make decisions, the consequences of reproduction for the person and any children that might be born, and applicable local, state, and federal laws.[18,19]

Most adolescents with myelomeningocele desire to marry and have children, but fewer than 20% have sought information regarding their sexual or reproductive function and only 16% of those who were sexually active have used contraception.[20] Adolescents with myelomeningocele and spinal cord injury have unique educational and medical needs that must be addressed to enjoy safe and satisfying sexual lives. When genital sensation is diminished or absent, alternative ways to appreciate sexual pleasure and satisfaction should be discussed. Fertility is generally preserved in females but reduced in males with spina bifida and spinal cord injury. Prepregnancy counseling should include informing women with spina bifida of the 5 in 100 risk of bearing children with neural tube defects, the protective effect of folate supplementation, and the potential complications associated with pregnancy. When 4 mg per day of folate is taken for at least 3 months before and during the first month of pregnancy, the recurrence risk is reduced by 50% to 75%.[21] Because unplanned pregnancies can occur, females of childbearing age with myelomeningocele may be offered the option of taking 4 mg per day of folate on an ongoing basis.[22]

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PSYCHOSOCIAL CONSIDERATIONS

Early social experiences play a critical role in the psychosexual development of children and adolescents and may be limited or qualitatively different between a parent and child when a disability is present. Key milestones of adolescent development include attaining an adult body capable of reproducing, having and maintaining intimate relationships, managing a range of complex emotions, and independently thinking and problem solving.[23] The successful attainment of these developmental goals by individuals with disabilities may be hindered directly by functional limitations or indirectly by intentional or unintentional social isolation. Adolescents with physical and developmental disabilities generally participate in fewer social activities and intimate relationships when compared with typically developing peers, and most report that they lack information on parenthood, birth control, and STDs.[24]

Promoting independence and the acquisition of socially appropriate behaviors involves teaching and reinforcing skills for children with disabilities. Just as children learn academic concepts starting with the basics and moving to the more complex, they develop social independence in a developmentally appropriate, stepwise manner. A critical component of social and sexual maturity is attaining independence in basic self-care tasks. Whereas typically developing children complete self-care tasks independently by 8 years of age, children with disabilities may need frequent cues, supervision, formalized instruction, adaptive technology, and reinforcement in these activities well into adolescence and adulthood to achieve and maintain successes.

It is important to encourage the development of self-esteem in children with disabilities. Like all children, those with disabilities feel better about themselves and are more readily accepted by peers when provided with stylish and age-appropriate clothing that is easily donned and doffed. Social development is largely experiential, and children with disabilities generally have fewer opportunities for social interactions than their typically developing peers. Promoting typical teen activities, such as going to the mall or a movie with peers or participating in social activities at school, may require extra parental planning but afford invaluable opportunities to develop social skills. By mastering appropriate greetings, eye contact, body language, issues of personal space, self-advocacy skills, and telephone and computer skills, children build a strong foundation for the development of more complex social skills.

ISSUES OF SEXUAL ABUSE

The National Center on Child Abuse and Neglect has reported that children with disabilities are sexually abused at a rate that is 2.2 times higher than that for children without disabilities.[25] Other investigators have similarly reported significantly higher rates of sexual abuse among children with disabilities.[12,26] The US Department of Justice reports that 68% to 83% of women with developmental disabilities will be sexually assaulted in their lifetimes and less than half of them will seek assistance from legal or treatment services.[27] Children and adolescents with disabilities may be more vulnerable to sexual abuse because of dependence on others for intimate care, increased exposure to a large number of caregivers and settings, inappropriate social skills, poor judgment, inability to seek help or report abuse, and lack of strategies to defend themselves against abuse.[28] These fears may lead parents to protect their children from unsupervised social contacts and even from knowledge about sex. Some fear that talking about sexuality will promote sexual behavior. Yet, lack of education poses greater risks. When sexual questions and behaviors of individuals are freely discussed within a family, sexual development is promoted and the likelihood of abuse may be reduced or eliminated.[5,29] Children can learn to be assertive in protecting the privacy of their own bodies and in reporting violations to trusted adults.

The United Nations (UN) Convention on the Rights of the Child has established international recognition that all children have the right to respect for privacy and protection from exploitation and abuse.[30] Pediatricians can advocate for children with disabilities to ensure that their rights are upheld. Clinicians should recognize that when children with disabilities demonstrate alterations in bowel and bladder patterns, appetite, sleep, mood, behaviors, and community participation, they may be subjects of sexual abuse, and clinicians should thoroughly investigate these possibilities.

SEXUALITY EDUCATION

To overcome barriers to discussing the sexual development of children with disabilities, pediatricians can introduce issues of physical, cognitive, and psychosexual development to parents and their children at an early age and continue discussions at most visits throughout adolescence and young adulthood. When sexuality is discussed routinely and openly, conversations are easier to initiate, more comfortable to continue, and more effective and informative for all participants. Clinicians can explore the expectations of parents for their child's sexual development while providing general, factual information about sexuality in people with similar disabilities. With insights into the normal stages of child and adolescent sexual development, parents can better understand their own child's behaviors. For example, by recognizing that masturbation is normal toddler behavior, parents can better understand and shape the self-stimulatory behaviors of their teenager who functions developmentally at the level of a 3-year-old child. The problem is not the child's behaviors per se but the inability to distinguish between behaviors that are publicly and privately appropriate.

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Children need to be provided developmentally appropriate sexuality education to help them attain a life with more personal fulfillment and protect them from exploitation, unplanned pregnancy, and STDs. An underlying premise of sexuality education is that sexuality is a source of pleasure and a basis for bonding and human relationships. One goal of sexuality education in its broadest sense is to give children a sense of being attractive members of their genders with expectations of having satisfying adult relationships. As an aspect of social functioning, sexuality education must incorporate the family's values on issues ranging from personal modesty to adult sexuality. This goal is best accomplished when parents are the principle teachers and offer sexuality education appropriate to the cognitive and functional abilities of their child.

Topics of substance abuse, sexual development, sexual orientation, STDs, contraception (including abstinence), and the health implications of pregnancy should be discussed with all adolescents, including those with disabilities. The pediatrician who understands typical sexual development and appreciates the unique cognitive and emotional abilities of each child is best equipped to discuss these topics in a way that each child can understand. In the context of the medical home, pediatricians can advocate for independence in children with disabilities by discussing many of these issues in private with the child while also informing the parents of the topics of discussion.

Children with disabilities have the right to the same education about sexuality as their peers, but often there must be modification to the program to allow the information to be presented in such a way that the child can understand and learn it. Modifications such as simplifying information, teaching in a special needs rather than a regular education setting, using special teaching materials such as anatomically correct dolls, role playing, and frequently reviewing and reinforcing the material may be required.[31,32] Individualized education plans (IEPs) should include the provision of sexuality education for children with disabilities. An appropriate program for children with disabilities includes the following topics: body parts, pubertal changes, personal care and hygiene, medical examinations, social skills, sexual expression, contraception strategies, and the rights and responsibilities of sexual behavior. Many adolescents with disabilities receive inadequate information regarding sexuality or do not understand the information presented. Among surveyed adults with cerebral palsy, 52% requested more education regarding sexuality.[33] Educational materials are available to promote successful sexuality education for all children, and pediatricians are encouraged to help identify materials to meet the individual needs of the children and families for whom they care.

THE PEDIATRICIAN'S ROLE

Pediatricians can facilitate the gradual transition of children with disabilities into adulthood by addressing sexual development and encouraging open discussion with children and their families, beginning in early childhood and continuing into early adulthood. However, there are several barriers. First, open and detailed discussion about sexuality may be hindered by discomfort among parents, children, and pediatricians on the basis of cultural, religious, and personal experiences. Second, acute medical and developmental issues may occupy most of the clinical visit, leaving only a few minutes for time-consuming discussions. Third, parents may infantilize their children with developmental disabilities, especially if there are long-term needs for assistance with self-care activities such as toileting, bathing, and dressing. Typically developing teenagers are unlikely to let their parents forget their quest for independence, but children with disabilities, particularly those with impairments of communication, may be less likely to do so. Finally, it is natural for caregivers to fall into comfortable patterns of behavior and interaction with their children, thus overlooking opportunities for their children to achieve greater maturity and independence. Pediatricians are in a unique position to advocate for successful transition of adolescents with disabilities and their families into adulthood.

Pediatricians, in the context of the medical home, play a critical role in the development of sexuality in children with disabilities. The pediatrician is encouraged to:

1. discuss issues of physical development, maturity, and sexuality on a regular basis, starting during early childhood and continuing through the adolescent years;
2. ensure the privacy of each child and adolescent;
3. assist parents in understanding how the cognitive abilities of their children affect behavior and socialization;
4. encourage children with disabilities and their parents to optimize independence, particularly as related to self-care and social skills;
5. be aware of special medical needs, such as modified gynecologic examinations, latex-free protection from STDs and unplanned pregnancies, and genetic counseling when appropriate;
6. recognize that children with disabilities are at an increased risk of sexual abuse and monitor for early indications of abuse;
7. advocate for developmentally appropriate sexuality education in home, community, and school settings;
8. encourage parents to be the principal teachers of developmentally appropriate sexuality education for

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their children, incorporating family values, cultural traditions, and religious beliefs; and

9. provide families with information regarding appropriate community programs that address issues of sexuality for children and adolescents with disabilities.

CONCLUSIONS

The UN Convention on the Rights of the Child has established international recognition that all children have needs and are entitled to have their needs met. The needs of children include respect for privacy, opportunities for play, access to education, access to appropriate guidance and support, protection from exploitation and abuse, and opportunities to be listened to and respected. The UN Convention on the Rights of the Child challenges traditional views of children as passive recipients of care and protection and asserts that children with disabilities have the same rights as children without disabilities.[30] Pediatricians should incorporate guidance on sexuality education, socially appropriate behavior, and sexual abuse prevention into the clinical supervision of all children, including children with disabilities.

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REFERENCES

1. Blum RW. Sexual health contraceptive needs of adolescents with chronic conditions. *Arch Pediatr Adolesc Med.* 1997;151:290–297
2. Cheng MM, Udry JR. Sexual behaviors of physically disabled adolescents in the United States. *J Adolesc Health.* 2002;31:48–58
3. Berman H, Harris D, Enright R, Gilpin M, Cathers T, Bukovy G. Sexuality and the adolescent with a physical disability: understandings and misunderstandings. *Issues Compr Pediatr Nurs.* 1999;22:183–196
4. Neufeld JA, Klingbeil F, Bryen DN, Silverman B, Thomas A. Adolescent sexuality and disability. *Phys Med Rehabil Clin N Am.* 2002;13:857–873
5. DeLoach CP. Attitudes toward disability: impact on sexual development and forging of intimate relationships. *J Appl Rehabil Couns.* 1994;25:18–25
6. Worley G, Houlihan CM, Herman-Giddens ME, et al. Secondary sexual characteristics in children with cerebral palsy and moderate to severe motor impairment: a cross-sectional survey. *Pediatrics.* 2002;110:897–902
7. Siddiqi SU, Van Dyke DC, Donohoue P, McBrien DM. Premature sexual development in individuals with neurodevelopmental disabilities. *Dev Med Child Neurol.* 1999;41:392–395
8. Elias ER, Sadeghi-Nejad A. Precocious puberty in girls with myelodysplasia. *Pediatrics.* 1994;93:521–522
9. Owens K, Honebrink A. Gynecologic care of medically complicated adolescents. *Pediatr Clin North Am.* 1999;46:631–642, ix
10. Heger S, Sippell WG, Partsch CJ. Gonadotropin-releasing hormone analogue treatment for precocious puberty: twenty years of experience. *Endocr Dev.* 2005;8:94–125
11. Sulpizi LK. Issues in sexuality and gynecologic care of women with developmental disabilities. *J Obstet Gynecol Neonatal Nurs.* 1996;25:609–614
12. Quint EH. Gynecological health care for adolescents with developmental disabilities. *Adolesc Med.* 1999;10:221–229, vi
13. Lidegaard O. Thrombotic diseases in young women and the influence of oral contraceptives. *Am J Obstet Gynecol.* 1998;179(3 pt 2):S62–S67
14. Steiner MJ, Dominik R, Rountree RW, Nanda K, Dorflinger LJ. Contraceptive effectiveness of a polyurethane condom and a latex condom: a randomized controlled trial. *Obstet Gynecol.* 2003;101:539–547
15. French PP, Latka M, Gollub EL, Rogers C, Hoover DR, Stein ZA. Use-effectiveness of the female versus male condom in preventing sexually transmitted disease in women. *Sex Transm Dis.* 2003;30:433–439
16. Gallo MF, Grimes DA, Schulz KF. Non-latex versus latex male condoms for contraception. *Cochrane Database Syst Rev.* 2003;(2):CD003550
17. Lara-Torre E, Edwards CP, Perlman S, Hertweck SP. Bone mineral density in adolescent females using depot medroxyprogesterone acetate. *J Pediatr Adolesc Gynecol.* 2004;17:17–21
18. American Academy of Pediatrics, Committee on Bioethics. Sterilization of minors with developmental disabilities. *Pediatrics.* 1999;104:337–340
19. Silber T, Batshaw ML. Ethical dilemmas in the treatment of children with disabilities. *Pediatr Ann.* 2004;33:752–761
20. Cromer BA, Enrile B, McCoy K, Gerhardstein MJ, Fitzpatrick M, Judis J. Knowledge, attitudes and behavior related to sexuality in adolescents with chronic disability. *Dev Med Child Neurol.* 1990;32:602–610
21. Green NS. Folic acid supplementation and prevention of birth defects. *J Nutr.* 2002;132(8 suppl):2356S–2360S
22. American Academy of Pediatrics, Committee on Genetics. Folic acid for the prevention of neural tube defects. *Pediatrics.* 1999;104:325–327
23. Knight JR, Emans SJ, eds. *Bright Futures Case Studies for Primary Care Clinicians: A Guide to the Case Teaching Method; and Growth in Children and Adolescents*. Boston, MA: Bright Futures Center for Education in Child Growth and Development, Behavior and Adolescent Health; 2001
24. Stevens SE, Steele CA, Jutai JW, Kalnins IV, Bortolussi JA,

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Biggar WD. Adolescents with physical disabilities: some psychosocial aspects of health. *J Adolesc Health.* 1996;19:157–164
25. Crosse SB, Kaye E, Ratnofsky AC. *A Report on the Maltreatment of Children With Disabilities*. Washington, DC: National Center on Child Abuse and Neglect, Administration for Children and Families, US Department of Health and Human Services; 1993
26. Suris JC, Resnick MD, Cassuto N, Blum RW. Sexual behavior of adolescents with chronic disease and disability. *J Adolesc Health.* 1996;19:124–131
27. Guidry Tyiska C. *Working With Victims of Crime With Disabilities*. Washington, DC: Office for Victims of Crime, Department of Justice; 2001. Available at: www.ojp.usdoj.gov/ovc/publications/factshts/disable.htm. Accessed March 23, 2005
28. Lumley VA, Miltenberger RG. Sexual abuse prevention for persons with mental retardation. *Am J Ment Retard.* 1997;101:459–472
29. American Academy of Pediatrics, Committee on Child Abuse and Neglect and Committee on Children With Disabilities. Assessment of maltreatment of children with disabilities. *Pediatrics.* 2001;108:508–512
30. Goldhagen J, Waterston T. *Children's Rights and Child Health Curriculum*. Elk Grove Village, IL: American Academy of Pediatrics and Royal College of Paediatrics and Child Health; 2003
31. Stanfield J. Sex education and relationships. Available at: www.stanfield.com/sexed.html. March 23, 2005
32. Harnest C. Teach-A-Bodies. Available at: www.teach-a-bodies.com. Accessed March 23, 2005
33. Cho SR, Park ES, Park CI, Na SI. Characteristics of psychosexual functioning in adults with cerebral palsy. *Clin Rehabil.* 2004;18:423–429

INTERNET RESOURCES

Disability Solutions. Available at: www.disabilitysolutions.org
James Stanfield: Sex Education & Relationships. Available at: www.stanfield.com/sexed.html
Diverse City Press, Inc. Available at: www.diverse-city.com
YAI/National Institute for People With Disabilities Network. Available at: www.yai.org
Sexual Health Network. Available at: http://sexualhealth.com
Family Village General Library. Sexuality and disabilities. Available at: www.familyvillage.wisc.edu/general/sexuality.htm
Sexuality Information and Education Council of the United States. Annotated bibliography: sexuality and disability. Available at: www.siecus.org/pubs/biblio/bibs0009.html
National Information Center for Children and Youth With Disabilities. Sexuality education for children and youth with disabilities. Available at: www.nichcy.org/pubs/outprint/nd17txt.htm
dbpeds.org. Sexuality education for persons with developmental disabilities: selected resources. Available at: www.dbpeds.org/articles/detail.cfm?TextID=141
Reynolds LA. People with mental retardation & sexual abuse. Available at: www.open.org/~people1/articles/article_sex_abuse.htm
Univesity of Michigan Health System. Sexuality and kids with disabilities or chronic illness. Available at: www.med.umich.edu/1libr/yourchild/disabsex.htm
Parent Advocacy Coalition for Educational Rights. Available at: www.pacer.org
Healthy & Ready to Work National Center. What's health got to do with transition? Everything! Available at: www.hrtw.org
DisabilityExchange.org. Available at: www.disabilityexchange.org
Center for Children With Special Needs. Available at: www.cshcn.org/linkages/Linkages-Winter-05.cfm

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