

AMERICAN ACADEMY OF PEDIATRICS

Sexuality Education of Children and Adolescents With Developmental Disabilities

Committee on Children With Disabilities

Policies that include children with developmental disabilities in community life increase their opportunities but also create new challenges and introduce certain risks. When high school classmates of a teen-aged girl with mild mental retardation were convicted of sexually abusing her, a prominent advocate for people with disabilities noted, "The need to be loved can be a trap for the most capable. For the least capable, it can be an invitation to disaster."¹

Issues of sexuality are as important to children and adolescents with disabilities as they are to other children and adolescents. Persons with disabilities have similar curiosities, drives, and interests in their own bodies and in the bodies of others. Providing clinical supervision to children and adolescents with disabilities includes helping them understand what happens to their bodies as they mature and the choices available to them. Pediatricians should provide guidance on sexuality education to parents of children with developmental disabilities, because few other professionals are consistently involved with both the family and the child. Some parents are reluctant to discuss sexuality with their children with developmental disabilities and deny the children's sexuality partly because they focus on the disabilities rather than on the children. Some fear that talking about sexuality will promote sexual behavior. Yet, a lack of education poses greater risks. Furthermore, parents often see no successful adult roles that include sexuality for these children, and they fear that the children may be sexually exploited or become pregnant.² They also may be unsure how much the children can understand, and the advice aimed at children without developmental disabilities may not be helpful.

The literature documents that parental concern about possible sexual abuse is realistic.² A recent report from the National Center on Child Abuse and Neglect found that for the representative sample of maltreated children studied, 36 of 1000 children with disabilities were maltreated, which is a rate 1.7 times higher than that for children without disabilities.³ These fears may lead parents to protect their children from unsupervised social contacts and even from

knowledge about sex. The best protection from abuse is effective education of the children about sex and about their right to assert themselves in refusing sexual advances.

The issue of sexuality education for individuals with developmental disabilities has reemerged recently in the professional literature.⁴⁻⁶ Although the opinions and approaches vary,^{7,8} there is consensus about the need to teach children with disabilities about sex. The discussion of the issues by Gardner⁹ is one of the best written, and her ideas have been incorporated into this statement.

SEXUALITY EDUCATION: GOALS AND ATTITUDES

Children need to be provided sexuality education to help them attain a life with more personal fulfillment and to protect them from exploitation, unplanned pregnancy, and sexually transmitted diseases. Providing sexuality education raises controversy for typically developing children and has additional pitfalls when offered to children with disabilities.

An underlying premise of sexuality education is that sexuality is a source of pleasure and a basis for bonding and human relationships. The goals of sexuality education include fostering certain attitudes and providing needed information. 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. Another important goal is for children to be assertive in protecting the privacy of their own bodies and in reporting violations to trusted adults. Education concerning conception, contraception, and protection from sexually transmitted diseases, including human immunodeficiency virus, is also important.

Parents who feel comfortable teaching their children without disabilities about sexuality may report feeling uncomfortable educating their children with developmental disabilities about sex, partly because of the tendency to view them as children for life and partly because of the difficulty in knowing what to say and how to say it.⁶ Parents find providing complex information to their children in a concrete way a challenge, and educational materials suitable for children without disabilities may not be relevant for children with disabilities.

This statement has been approved by the Council on Child and Adolescent Health.

The recommendations in this statement do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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RECOMMENDATIONS FOR PARENTS

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 the parents are the teachers. However, parents need to recognize that their child's public displays of affection need to conform to societal expectations based primarily on how old the child looks, not developmental age.

Much of what a child learns about sexuality is informal and nonverbal, based on recognition of which behaviors elicit parental attention, either amusement or annoyance, and which behaviors are ignored. Education about sexuality is accomplished by letting children know they are attractive and by the ordinary parental expressions of physical affection to the child and to other family members. Parents' responses to their children's exploration of their own bodies or those of siblings and peers are all part of sexuality education. These experiences form the foundation for teaching the names of body parts and facts about intercourse, conception, and other aspects of sexuality.

Sexual information, like all other information provided to children with developmental disabilities, has to be stated concretely, unambiguously, and repeatedly. Most importantly, it must be tailored to the specific level of understanding of the particular child.

The major objectives of sexuality education for children with disabilities should include the following:

1. Teaching the children how to express physical affection in a manner that is appropriate to their apparent ages, not chronologic or developmental ages;
2. Discouraging inappropriate displays of affection in the community, such as hugging strangers;
3. Expressing clear expectations that their behavior conforms with family and societal standards for privacy and personal modesty;
4. Teaching children the difference between acceptable behaviors in a private setting and those acceptable in public;
5. Teaching children their right to refuse to be touched at any time and that they should not keep secrets from their parents about having been touched inappropriately; and
6. Discussing pleasure and affection when educating children about sex.

Several books¹⁰⁻¹² provide factual information about sexual issues, including masturbation, menstruation, intercourse, conception, and contraception. Essential first steps in educating children about sex include having the parent ask in simple language what the child already knows, such as the names of body parts, how boys and girls differ, and how infants are born. The use of pictures or dolls for illustration works best for some children, because it requires less comprehension of complex language.

RECOMMENDATIONS FOR PEDIATRICIANS

Younger Children

Anticipatory guidance for all children should include questions to parents about sexuality education. For children with developmental disabilities, pediatricians also should ask about other areas of social functioning, such as independence in self-care, including toileting, understanding privacy, and assuming responsibilities for tasks in the home and community. Because marriage and parenthood may not be realistic goals for all children, parents should be told that their children with developmental disabilities may benefit from hearing that the family also values adults who have not entered into long-term intimate relationships with other adults.

Specific questions to parents should include the following: Do the children:

1. Have names for referring to the genitalia?
2. Have some concept of privacy, their own, and other people's?
3. Know what things not to do in public but that are acceptable in private?
4. Know that no one else is allowed to touch their private parts, except for specific reasons, such as a physician's examination?
5. Know whom you kiss, whom you hug, and whom you greet some other way?

Pediatricians should advise parents about common behaviors in children who have been sexually abused, such as loss of appetite, changes in sleep patterns, nightmares, unprovoked crying spells, the onset of bed-wetting, refusal to go to school, fear of strangers or strange situations, fear of being alone, running away, social or emotional withdrawal, clinging to a significant adult, fantasy dealing with victimization or violence, and taking an excessive number of baths.¹³

For verbally skilled children of elementary school age whose parents have not discussed sex with them, the pediatrician can offer to give a basic explanation during an office visit. With parental consent, and with the parent present, the pediatrician can ask the child questions to establish how much the child knows. The child's knowledge can then be supplemented by simple explanations and the use of two larger, anatomically correct dolls that represent adults and one smaller one that represents an infant. (Infant boy dolls with genitalia can be ordered from educational toy catalogs and are as acceptable to children and parents as are the neuter dolls.) As an example, the pediatrician can demonstrate intercourse, saying, "This goes there, and the baby grows, and is born like this. You do this when you're grown up and you love somebody who loves you back." This demonstration and explanation helps demystify the topic and offers parents an approach for discussing sex.

Older Children and Adolescents

In dealing with an adolescent with a developmental disability, the pediatrician often confronts the same dilemma with which many parents struggle.

How do you adapt your usual approach to sexuality education to meet the needs of the child with a disability? When pediatricians examine young adolescents without the parents present and asks the adolescents about sexual activity, they need to consider issues relating to these patients' confidentiality. A pediatrician needs to inform an adolescent clearly what information will and will not be shared with the parents and to inform the parents as well.

Like any other adolescent, an adolescent with developmental disabilities may be deemed competent by his or her physician to make decisions about sexual matters and is entitled to confidentiality and personal privacy. Lawyers who have studied this issue¹⁴ point out that individuals with mental impairment may be competent in this particular area even if they are not thought to be competent to make decisions about other aspects of their lives.

Normal secondary sex characteristics develop in the vast majority of adolescents with developmental disabilities, and they need more help, not less, in understanding these changes and the accompanying strong emotions and drives.¹⁵ Adequate knowledge helps protect them both from exploitation and from unwittingly offending others. In addition to the information provided previously, they need specific information about intercourse, conception, contraception, and the genetic implications of their developmental diagnoses. These topics are best discussed within the context of an important social relationship, because giving the young person more information than needed at a particular time may be confusing. Books that focus on the needs of this age group are useful as guides.⁹ Families and other caregivers also should be encouraged to provide outlets for sexual drives, such as social contacts with the opposite sex.

The physician's knowledge of the child's verbal skills and understanding of sexuality can help in deciding whether to see the child alone or with the parents. Age-specific guidelines for sexuality education may not be applicable to children with developmental disabilities for whom the approach must be based on their levels of functioning. A physician who is unsure about an adolescent's level of understanding or ability to assume responsibility may get useful information from the individual's school or from a multidisciplinary evaluation program.

This transition to a more autonomous way of providing medical care may need to be negotiated by the parents, physician, and adolescent. Even when parents accompany adolescents in the examination room, a discussion about privacy emphasizes to the parent the pediatrician's commitment to enhancing the adolescent's autonomy.

A small minority of adolescents with severe developmental disabilities may have delayed sexual maturation. Furthermore, for some with severe disabilities, verbal sexuality education and counseling may be ineffective, and these adolescents may require the use of pictures, demonstrations of acceptable behavior, and behavior modifications. A teaching program for these individuals includes information on distinguishing body parts, self-care skills, relationships,

social interaction, and manners.¹⁰⁻¹² The physician should refer these young people to community resources that have the appropriate sexuality education programs.

Materials on sexuality education, such as this statement and some of the reading material cited,¹⁰⁻¹² should be made available in the pediatrician's office.

CONCLUSION

Sexuality education challenges many parents of children with developmental disabilities because they deny the child's sexuality, fear sexual exploitation or pregnancy, and have difficulty deciding what and how to tell the child. Pediatricians should incorporate guidance on sexuality education, socially appropriate behavior, and sexual abuse prevention into the clinical supervision of children with disabilities, as for all other children. Pediatricians have extended involvement with both families and children. They can fill the important role of guiding parents from the time the children are young to instill the attitudes and teach the behaviors and information that are most likely to help children with developmental disabilities achieve personal satisfaction, behave in ways that are socially appropriate, and protect themselves from exploitation.

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REFERENCES

1. Goldfarb M. Who won in Glen Ridge, NJ? . . . No one. *AHRC Chronicle*. 1993;Spring/Summer
2. Tharinger D, Horton CB, Millea S. Sexual abuse and exploitation of children and adults with mental retardation and other handicaps. *Child Abuse Negl*. 1990;14:301-312
3. 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 on Children, Youth and Families, Administration for Children and Families, US Department of Health and Human Services; 1992
4. de la Cruz FF, LaVeck GD, eds. *Human Sexuality and the Mentally Retarded*. New York: Brunner/Mazel; 1973
5. National Information Center for Children and Youth with Disabilities. Sexuality education for children and youth with disabilities. *NICHCY News Digest*. 1992;1:1-27
6. McCabe MP. Sex education programs for people with mental retardation. *Ment Retard*. 1993;31:377-387
7. Rowe WS, Savage S. *Sexuality and the Developmentally Handicapped: A Guidebook for Health Care Professionals*. Lewiston NY: E Mellen Press; 1987
8. Evans AL, McKinlay IA. Sex education and the severely mentally retarded child. *Dev Med Child Neurol*. 1989;31:98-103
9. Gardner NES. Sexuality. In: Summers JA, ed. *The Right to Grow Up: An Introduction to Adults with Developmental Disabilities*. Baltimore, MD: Paul H Brookes Publishing Co; 1986:45-66
10. McKee L, Blackledge V. *An Easy Guide for Caring Parents. Sexuality and Socialization: A Book for Parents of People With Mental Handicaps*. Walnut Creek, CA: Planned Parenthood of Contra Costa; 1981
11. Kempton W, Bass MS, Gordon S. *Love, Sex and Birth Control for Mentally Handicapped People: A Guide for Parents*. Philadelphia: Planned Parenthood of Southeastern Pennsylvania; 1985
12. Edwards JP, Elkins TE. *Just Between Us: A Social Sexual Training Guide for Parents and Professionals Who Have Concerns for Persons with Retardation*. Portland, OR: Ednick Communications; 1988
13. Sanford LT. *The Silent Children: A Parent's Guide to the Prevention of Child Sexual Abuse*. New York: McGraw-Hill Book Co; 1980
14. Tarantino L, Stavis P. Sexual activity in the mentally disabled population: some standards of the criminal and civil law. *Qual Care*. 1986;28:2-3
15. Pincus S. Sexuality in the mentally retarded patient. *Am Fam Physician*. 1988;37:319-323

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