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Understanding Puberty

Puberty in children with special health care needs

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. 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 neuro-developmental disabilities are 20 times more likely to experience early pubertal changes. Although idiopathic precocious puberty occurs in approximately 1 in 1000 girls, the incidence approaches 20% among females with spina bifida. 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. 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.

Sexual Development

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. 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. However, parents and health care professionals are often pessimistic regarding the potential of children with disabilities to enjoy intimacy and sexuality in their relationships. 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. 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.

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Societal and psychosocial barriers may be more of a hindrance to an adolescent's sexual development than the limitations of the disability itself.

Sexuality Education

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. 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. 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.

Parenting Challenges

Parenting children with adolescent developmental disabilities really isn't all that different from parenting children without disabilities. We want to give them the sense of being attractive as members of their own gender with the expectations of having satisfying adult relationships. Some of the problems seen clinically often relate to what appears to be inappropriate sexual behavior, such as masturbation, both in males and females, though often times you hear about it more in males. That uninhibited sexual behavior could certainly fall in that category, not based upon the behavior but based on the context in which it's done.

For example, masturbation in public is generally going to fall within that category. If it can't be managed in a more appropriate setting, it is certainly going to limit that person's access to ordinary community facilities. Although it may not cause them physical harm, it will certainly limit their ability to function out in the world – that is where behaviors should be addressed.

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The Pediatricians 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:

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

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

Resources

Sexuality of Children and Adolescents with developmental disabilities (source)
http://aappolicy.aappublications.org/cgi/content/full/pediatrics;118/1/398

Male Puberty in the developmentally disabled
http://www.medhomeportal.org/file.cfm?file_id=703&

Life Span Holistic Sexuality Education for Children and Adolescents with Developmental Disabilities: An Annotated Resource List
http://www.albany.edu/aging/IDD/documents/FDDCAnnotatedResourceList.pdf

To contact Family Voices of North Dakota:

888-522-9654 or fvnd@drtel.net or go to www.fvnd.org

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