A MarshMedia White Paper

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Human Sexuality Education for Students with Special Needs

By Liz Sweeney

Contents

"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."[1]

Murphy and Elias, 2006

Foreword

Carla Tate: I wonder who thought up sex?
Daniel McMann: I think it was Madonna.

– *The Other Sister*

What does it mean to provide sexuality education to children and adolescents with special needs?

Charged with the responsibility of preparing children for the eventuality of adulthood, parents and educators face many challenges. Providing comprehensive sexuality education to children, teens, and young adults with special needs is a particularly important but often difficult task.

For people with disabilities, there are many obstacles to healthy sexuality. Often, the desire to keep our children safe also unintentionally keeps them dangerously in the dark. For young people with special needs there is particular tension between healthy sexuality and personal safety. They are vulnerable to societal myths and misconceptions; are taught to be compliant to authority; and are at higher risk for sexual abuse.[2]

❖ ***For people with disabilities, there are many obstacles to healthy sexuality.***

However, human sexuality education for children with intellectual disabilities has tangible and significant benefits. These include improved social skills, assertiveness and independence; positive changes in behavior, such as adopting more acceptable expressions of sexuality; as well as reduced risk of sexual abuse, sexually transmitted infections and unintended pregnancy.[3] Preparing youngsters for the responsibilities and choices of adulthood helps to further living, working, and socializing in personally meaningful ways within the community. A simultaneous goal for families and educators is to keep teens safe as they negotiate this path.

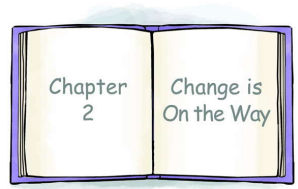
❖ ***Human sexuality education for children with intellectual disabilities has tangible and significant benefits.***

Unfortunately, people with developmental disabilities often do not acquire adequate knowledge regarding sexuality[4] and even though sexuality is a universal human trait, sexual expression on the part of people with disabilities can provoke strong negative reactions. The "rules" surrounding sexuality for individuals with disabilities are frequently not the same as those imposed on the rest of society.[5]

With a pro-active approach, parents, advocates, community agencies and all those who know or work with youngsters with cognitive, intellectual and developmental disabilities can provide essential education about sex and relationships and appropriate sexual expression.

Every child has the right to understand his or her own development in an accurate and positive way.

– MarshMedia



Cultural Considerations

What hurdles might parents and educators need to overcome when they teach youngsters with special needs about human sexuality?

Fear and Avoidance, Denial and Doubt

For a variety of reasons, parents and educators frequently find human sexuality education a daunting task.

Although human sexuality is varied and complex, in the educational realm this broad subject often becomes focused on the narrow concept of sexual intercourse, the realities of which provoke understandable concern by adults on behalf of the youngsters in their care.

At a personal level, discussing sex and sexuality with any child can make parents and educators uncomfortable, and in the particular case of youngsters with special needs, anxieties and concerns are frequently intensified. Cultural, ethical, religious, and moral issues influence sexuality[6], and as such, prescribed sex education is notoriously controversial. Parents, community leaders, educators and teens may find themselves at odds over information and attitudes they consider appropriate.

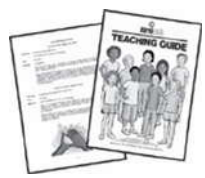
> ❖ *Sexuality in people with developmental disabilities is commonly regarded as a problem, rather than an affirming part of human life.*

Some parents and institutions avoid sex education in the belief that a child or teen who doesn't know about sex will have no desire to express his or her sexuality. Many caregivers struggle with presenting difficult concepts in ways that youngsters with special needs might understand, and after failed attempts, may give up altogether.[7] In general, sexuality in people with developmental disabilities is commonly regarded as a problem, rather than an affirming part of human life.[8]

> ❖ *Human sexuality education should be seen as an ongoing process.*

But by beginning early, and through practice and repetition and a positive attitude, parents can overcome some of the common awkwardness associated with the topic. It's never too early to learn the correct names for body parts, for example.

Human sexuality education should be seen as an ongoing process and not a one-time lecture. Caregivers can arm themselves with a firm knowledge base, learn to convey information over time, and continue to seek professional support, all of which will help ease many of the underlying concerns that contribute to sex education being withheld from people with disabilities.



Myths and Stereotypes

At the community level, persistent myths and stereotypes still linger concerning the sexuality of people with disabilities. Common misconceptions include ideas that people with developmental disabilities are asexual – kind of perpetual children – or conversely, that they are sexually impulsive.[9]

Subscribing to such myths and misconceptions is problematic. If people with developmental delays

are seen as sexually impulsive for example, any offending behavior is therefore seen as uncontrollable. On the other hand, if the individual is viewed as child-like or asexual, sexually offensive behavior is likely to be denied or minimized. Both conclusions remove consequences from an individual's actions, in effect excluding that person from a chance to learn more appropriate sexual behavior.[10]

The truth is that sexuality is an integral part of every person's life from infancy,[11] and no matter what cognitive abilities a person might have, growth into adulthood combines a physically maturing body and a range of sexual and social needs and feelings. It should also be recognized that adults with developmental delays are different from children in appearance, past life events, and available life choices.[12]

It is essential that all those who work and live with individuals with special needs guard against making inaccurate assumptions. By avoiding misinformation and a restrictive attitude towards the sexuality of developmentally delayed individuals, and by recognizing sexuality as a multidimensional process that crosses the lifespan, healthy sexuality can be championed and celebrated.

❖ ***No matter what cognitive abilities a person might have, growth into adulthood combines a physically maturing body and a range of sexual and social needs and feelings.***

The Politics of Education

◆◆◆◆◆◆◆

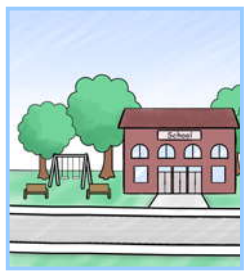
(c) Findings.--Congress finds the following:
(1) Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society. Improving educational results for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities.[13]

Education and training opportunities for people with disabilities have expanded significantly in the last thirty years, with government mandates backing universal access to education, and more students moving out of special schools and into mainstream classrooms with support. With greater independence and self-sufficiency, people with disabilities are also choosing to marry and/or become sexually involved.

In 1975, Congress passed Public Law 94-142 (Education of All Handicapped Children Act), which guaranteed a free, appropriate public education to each child with a disability in every state across the country.

Amendments to the law and an eventual name change led to the Individuals with Disabilities Education Act (IDEA). The IDEA Amendments of 1997 support initiatives for transition services from high school to adult living. These mandates require that each student's Individualized Education Program (IEP) include transition plans identifying appropriate employment and other adult living objectives for the student, referring the student to appropriate community agencies, and linking the

student to available community resources. IDEA also specifies that transition planning begin at age fourteen.[14]



Even while IDEA emphasizes that all students with disabilities have the same educational opportunities to the maximum extent possible as their non-disabled peers, specific curriculum materials and resources addressing sexuality education remain scarce in the area of special education.[15] In mainstream public education political pressures have resulted in teaching abstinence rather than more comprehensive sexuality education. (Since 1996, abstinence programs have received over a billion dollars in federal funding while comprehensive sexuality programs have received zero dollars from the same source.[16])

Data gathered by The Alan Guttmacher Institute in 1999 showed that many schools do not even prepare students for puberty, and that the teaching of all topics relating to sexuality is less common than teachers think it should be. Furthermore, sexuality education teachers often feel unsupported by the community, parents, and administration[17] and express a need for more professional information and training.[18]

❖ ***IDEA emphasizes that all students with disabilities have the same educational opportunities to the maximum extent possible as their non-disabled peers.***

Socialization

According to a clinical report from the American Academy of Pediatrics (AAP), sexual development is "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."[19]

❖ ***Important goals of any human sexuality education program include promoting a positive self-image, as well as developing competence and confidence in social abilities.***

Families and educators need to recognize that comprehensive human sexuality education is more than the sum of facts about body parts and biology. Important goals of any human sexuality education program include promoting a positive self-image, as well as developing competence and confidence in social abilities.

Unfortunately, youngsters with special needs typically have fewer opportunities than their peers to develop and engage in appropriate social and sexual behavior. They are often held back by social isolation as well as functional limitations. By fostering the development of social skills, parents and educators can provide opportunities to learn about the social contexts of sexuality and the responsibilities of exploring and experiencing one's own sexuality.

There are a number of strategies for helping youngsters develop social skills. Role play is a common educational tool, and a valuable one for teaching, practicing and reinforcing social skills. Modeling and play-acting a variety of social

interaction, such as phone etiquette, initiating conversation, or inviting a friend for a meal, for example, are simple ways for families to help refine social skills at home.

The National Dissemination Center for Children with Disabilities (NICHCY) also recommends helping children develop hobbies and pursue interests or recreational activities in the community and after school.[20] Although it's a common temptation to shield children from hurt feelings and rejection, children with disabilities nevertheless should be encouraged to engage in social opportunities and to grow and learn from social errors.[21] As well as presenting occasion for friendship, extra-curricular activities and hobbies bring people together in commonality and provide opportunities to develop competence and self-esteem.

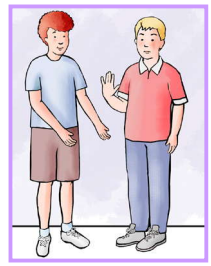
❖ ***Children with disabilities should be encouraged to engage in social opportunities and to grow and learn from social errors.***

Contextual Errors and Safety Issues

Inappropriate sexual behavior on the part of individuals with special needs can stem from lack of opportunity for appropriate sexual expression, ignorance of what is considered appropriate behavior, and poor social education.

Behavior that leads teens with disabilities into trouble as "perpetrators" is not necessarily atypical for hormone-driven adolescents, but it often also involves either bad judgment on the part of the individual with a disability, and/or a hasty and ill-considered reaction on the part of parents or school personnel. Because opportunities for privacy are less frequent for people with special needs, and comprehensive sexuality education is often withheld from this population, it is not surprising that teens with special needs commonly display sexuality inappropriately.[22]

Whether sexual behavior is considered appropriate largely depends on the location in which that behavior takes place, and as such, it is important to interpret problematic sexual behavior within its context.[23] Touching one's genitals in public, for example, is not socially acceptable, but the same behavior may be considered appropriate in private. A critical evaluation would determine whether public masturbation is due to lack of privacy, poor social education, or to some other reason.



NICHCY identifies two kinds of common social mistakes on the part of individuals with disabilities. These are public-private errors and stranger-friend errors.[24] Public-private errors include behaviors such as sexual self-stimulation or saying something inappropriate in public. Stranger-friend errors include actions such as hugging or kissing a stranger or being overly familiar with an acquaintance. Both kinds of mistakes can put individuals with disabilities in situations of risk (i.e. sexual exploitation or breaking the law).

❖ ***There are two kinds of common social mistakes: public-private errors and stranger-friend errors.***

Definitions of "disability" are often broad and non-specific[25] – a contributing factor in the differing results from research on the rates of abuse among children with disabilities.[26] It is commonly recognized however, that abuse and neglect go

under-reported. The American Academy of Pediatrics cites findings that children with disabilities are sexually abused at a rate that is 2.2 times higher than that for children without disabilities. The AAP also quotes U.S. Department of Justice estimates that 68-83% of women with developmental disabilities will be sexually assaulted in their lifetimes.[27]

Of course, sexual exploitation or abuse is of concern for all people, but for youngsters with disabilities, there are a number of additional factors. Children with physical disabilities are less able to defend themselves; those with cognitive limitations are often not alert to potentially dangerous situations – a problem which may be heightened by a lack of knowledge about sex and sexuality. Many people with disabilities do not know to report abuse, how to report abuse, or are afraid to (the abuse is likely from someone they know). Some children have low self-esteem and others are lonely or seeking approval and affection. Children and teens with disabilities are often dependent on others for intimate care and are sometimes exposed to a large number of caregivers. They are also typically taught to be compliant to authority. [28, 29, 30]

The American Academy of Pediatrics reports that the likelihood of abuse may be reduced or eliminated when "sexual questions and behaviors of individuals are freely discussed within a family [and] sexual development is promoted."[31]

❖ *The likelihood of abuse is lessened when "sexual questions and behaviors of individuals are freely discussed within a family [and] sexual development is promoted."*

Developmental Considerations and the Art of Parsing Human Sexuality

How can parents and educators plan and deliver human sexuality education that meets the specific needs of children with disabilities?

Differentiating for Special Needs

The American Academy of Pediatrics recommends that an appropriate program for children with disabilities cover the following material: body parts, pubertal changes, personal care and hygiene, medical examinations, social skills, sexual expression, contraception strategies, and the rights and responsibilities of sexual behavior.[32]

❖ *An appropriate program covers the following material:*

◆ *body parts* ◆ *personal care and hygiene* ◆
◆ *pubertal changes* ◆ *medical examinations* ◆
◆ *social skills* ◆ *sexual expression* ◆
◆ *contraception strategies* ◆
◆ *rights and responsibilities of sexual behavior* ◆

According to the Sexuality Information and Education Council of the United States (SIECUS) parents are (and should be) the primary sexuality educators for their children,[33] but in the case of educating children with disabilities, parents may need additional professional help and support.

Because sexuality education for children with disabilities requires a certain degree of individualization, the student's IEP can be used as an instrument for adapting the sexuality curriculum for the child. If human sexuality education is

written into the IEP, it is more likely to be designed and delivered around the unique needs of the student.[34]

As a general strategy, adapting the pace and presentation of information to the child's particular needs is pragmatic. Knowledge of how a particular disability affects development, learning and sexual expression, is important in adapting human sexuality education.[35] Parents and educators would be helped by seeking out specific resources that describe the distinguishing concerns for particular disabilities.

For children with learning disabilities, small changes to existing materials may be necessary, along with planning about the pacing of lessons and special focus on social skills. Reading level may be an important consideration when choosing resources. For youngsters with mental retardation, information should be presented in small blocks, using simple and concrete terms. Concepts of public and private places and behavior, as well as personal safety considerations should also be emphasized and reinforced. For children with multiple disabilities, there may be a number of modifications required, including providing material in other formats (such as Braille for the visually impaired) and additional information on how physical disability, for example, might affect expression of sexuality or a sexual relationship.[36]

Other possible educational strategies include the use of multisensory activities by way of illustrations, anatomical models, slides, photos, audio-visual materials, interactive games, or adaptive technologies, breaking down learning new tasks into several small steps, repetition, practice and frequent review over time, coupled with feedback and praise. Parents and educators may also find specific tips, resources and support by networking with others.[37] The Council for Exceptional Children recommends learning strategies that closely approximate real life, such as role-play, as well as opportunities for interaction with non-disabled peers.[38]

Bloom's Taxonomy

Over half a century ago, Benjamin Bloom and others set out to develop a classification of educational objectives, which became known as Bloom's Taxonomy. The objectives "specify in operational terms the actions, feelings, and thoughts students are expected to develop as a result of the instructional process."[39] When the framework was first published, the term taxonomy was an uncommon one in education and little was understood about its potential.[40] Now, the taxonomy is widely known and cited and applied in numerous and diverse educational settings.

❖ ***Bloom's Taxonomy divides educational objectives into three "domains:"***

- ***Affective***
- ***Psychomotor***
- ***Cognitive***

Bloom's Taxonomy divides educational objectives into three "domains:" Affective, Psychomotor, and Cognitive. Within each domain are different levels of learning, with higher levels considered more

complex and closer to mastery of the subject area. The framework provides an especially useful tool for the field of special education.

Objectives in the cognitive domain, for instance, are organized in a sequence from basic factual recall to higher order thinking. The levels of intellectual behavior identified are (in order) knowledge, comprehension, application, analysis, synthesis, and evaluation,[41] and within each of these levels are key words that describe the desired behaviors. The knowledge category is denoted by words such as list, tell, identify, show, label, and name, while the comprehension objectives are characterized by words like distinguish, estimate, explain, generalize, give examples, and summarize.

A program for human sexuality education can be designed to teach and test to these hierarchical objectives. Within this framework, mastering the labeling of body parts (knowledge) comes before explaining changes in growth (comprehension). To differentiate learning objectives, the cognitive level of the child should be considered, particularly his or her ability to think and understand abstractly or solve problems using multiple steps. This would determine the best level for instruction, and therefore, the best level for test items.

Conclusion

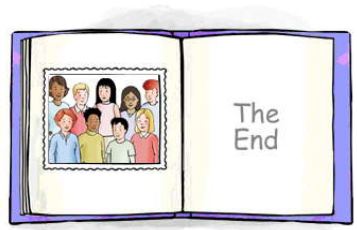
There are many obstacles to healthy sexual development for children with special needs. The subject is significant and sensitive from both personal and societal perspectives, and parents, educators and others in the community need to guard against negative attitudes as well as myths and misconceptions about people with disabilities.

Even though IDEA provides for equal educational opportunities for students with disabilities, there remains a lack of attention to the particular subject of human sexuality education, in the narrowness of curricula in schools, the scarcity of specially developed resource materials, insufficient teacher investment and training, and poor financial allocation.

Although the practicalities of differentiating learning for children with special needs require firm commitment, the benefits for students are significant and include enhanced social skills, adopting more appropriate expressions of sexuality, and reduced risk of sexual abuse, pregnancy and sexually transmitted diseases.

Human sexuality education for children with special needs should be tailored with the specific disability in mind and ideally begins in early childhood, starting with small and concrete steps, using repetition, practice and frequent review over time. Content should not be limited to sexual facts but also include the development of social skills and relationship training.

Like all children, students with developmental disabilities grow into adolescence with physically maturing bodies and a host of emerging social and sexual feelings and needs. Before these changes begin and throughout adolescence, it is vital that educators and parents provide information in a positive and constructive way that is both clear and developmentally appropriate.



Recommended Resources

National Organizations

The American Academy of Pediatrics
141 Northwest Point Boulevard
Elk Grove Village, IL 60007-1098
(847) 434-4000
www.aap.org

American Association on Mental Retardation
444 North Capitol Street, NW, Suite 846
Washington, D.C. 20001-1512
(800) 424-3688
www.aamr.org

The Arc of the United States
1010 Wayne Avenue, Suite 650
Silver Spring, MD 20910
(301) 565-3842
www.TheARC.org

Council for Exceptional Children
110 North Glebe Road, Suite 300
Arlington VA 22201
(800) 224-6830
www.cec.sped.org

Learning Disabilities Association of America
4156 Library Road
Pittsburgh, PA 15234-1349
(412) 341-1515
www.ldanatl.org

National Center for Learning Disabilities
381 Park Avenue South Suite 1401
New York, NY 10016
Ph: 212.545.7510
Fax: 212.545.9665
Toll-free: 888.575.7373
www.ncld.org

National Information Center for Children and Youth with Disabilities –
P.O. Box 1492
Washington, DC 20013
(800) 695-0285
www.nichcy.org
See Sexuality Education for Children & Youth with Disabilities section:
www.nichcy.org/pubs/newsdig/nd17txt.htm

SIECUS (Sexuality Information & Education Council of the United States)
130 West 42nd Street, Suite 350
New York, NY 10036-7802
Phone: 212/819-9770
www.siecus.org
Annotated Sexuality and Disability Bibliography:
www.siecus.org/pubs/biblio/bibs0009.html

Printed Resources

Hingsburger, Dave. (1990). *I Contact—Sexuality and People with Developmental Disabilities,* Mountville, PA: VIDA Publishing

Melberg Schwier, Karin, and Hingsburger, Dave. (2000). *Sexuality: Your Sons and Daughters with Intellectual Disabilities.* Baltimore, MD: Brookes Publishing

Mitchell S. Tepper (2001). *Becoming Sexually Able: Education to Help Youth with Disabilities.* SIECUS Report, February/March 2001

Wrobel, Mary (2003). *Taking Care of Myself: A Hygiene, Puberty and Personal Curriculum for Young People with Autism.* Arlington, TX: Future Horizons

About MarshMedia

When MarshMedia undertook the development of puberty education materials for students with special needs the company already had a long and successful history in publishing health and human growth materials for mainstream students. Our moderate editorial position, reliance on recognized expert sources, and judicious feedback from our patrons in the field, (primarily school nurses and health administrators) provided a solid platform for this new publishing endeavor.

Our research revealed a number of new considerations for differentiating special education resource materials. When considering our target audience, we chose to focus on students with mild to moderate disabilities. We designed a framework of ordered, factual information using uncomplicated language and illustration models to help parents and educators initiate instruction and discussion, and maintain a positive attitude.

We also learned that our materials are very well suited to children who are early developers.

Students with special needs have a wide range of abilities and disabilities. Many students with special needs don't learn as easily or comprehensively as their non-disabled peers, and don't readily understand concepts presented in the abstract. Often, they have a reading level that limits their access to information, and they may require materials in multimodalities that explain sexuality in ways they can understand.

Thus we were faced with the thorny challenge of scrutinizing human sexuality education, breaking it down into component parts and reconstructing it using the most concrete presentations possible. Knowing that classroom populations typically include a wide range of mental and physical abilities, we wanted to provide teachers with a framework that could be adapted to diverse learning environments as well as differentiated for individual abilities. We also wanted to provide an aesthetic alternative to the conventional practice of slide show presentations with photographic depictions.

Developing multimedia materials was a natural step. MarshMedia had previously produced a line of character education materials in kit form. Basing puberty education for special needs on the same component elements from our established kit format would address some of the multimodality requirements as well as provide additional support materials for teachers.

MarshMedia has also published supplemental parent packets to meet requests from parents of children with special needs, who call frequently with acute and personal stories of family struggles.

The MarshMedia White Paper is a natural outgrowth of our experience. It sets out key principles in support of sexuality education for students with special needs. The theoretical framework is intended to advocate for healthy sexuality for youngsters with special needs. By examining particular issues in the area of disseminating human sexuality education, we seek to supply parents and educators and other advocates in the field with guidance and support.

For more information about MarshMedia and the Puberty Education for Students with Special Needs programs, visit www.marshmedia.com or call 1-800-821-3303.

Endnotes

[1] Nancy A. Murphy, MD, Ellen Roy Elias, MD, for the Council on Children with Disabilities. "Sexuality of Children and Adolescents With Developmental Disabilities" *Pediatrics* 2006; 118; 398

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[3] Ibid.

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[17] D.J. Landry, et al. "Sexuality Education in Fifth and Sixth Grades in U.S. Public Schools, 1999." *Family Planning Perspectives* 2000 Sep-Oct; 32(5): 219

[18] Darrel Lang, et al. p. 27

[19] Nancy A. Murphy et al. p. 398

[20] Lisa Kupper, et al. "Sexuality Education For Children And Youth With Disabilities," *NICHCY News Digest* #ND17, 1992

[21] Ibid.

[22] Judy Tudiver et al. p. 6

[23] Ibid.

[24] Lisa Kupper et al., "The Importance Of Developing Social Skills" *NICHCY News Digest* #ND17, 1992

[25] "Assessment of Maltreatment of Children With Disabilities," Committee on Child Abuse and Neglect and Committee on Children with Disabilities. *American Academy of Pediatrics,* 2001; 108; 508

[26] Ibid.

[27] Ibid.

[28] "Sexuality and the Disabled Child" *Special Child Magazine* Available at: http://www.specialchild.com/archives/ia-019.html Accessed October 10, 2006.

[29] Michelle Ballan, p. 15

[30] Nancy A. Murphy et al. p. 400

[31] Ibid.

[32] Nancy A. Murphy et al. p. 401

[33] Position Statement, *SIECUS*, 2003

[34] Scott Sparks, "Sexuality and Individuals with Developmental Disabilities," *DDD Critical Issue*, Council for Exceptional Children, p.2 Available at: http://www.dddcec.org/positionpapers/SexualtyandDD.doc Accessed October 18, 2006.

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[41] B. S. Bloom et al., *Taxonomy of Educational Objectives, Handbook I: The Cognitive Domain.* 1956 New York: David McKay Co. Inc.