

Sex Education for Physically, Emotionally, and Mentally Challenged Youth

Introduction

In recent years, important changes in public policies and attitudes have resulted in improved opportunities for people with physical and mental disabilities. Now, people living with disabilities assume their rightful place in society as the equals of non-disabled people. Unfortunately, societal attitudes have changed less in regard to *sexuality* and disability. Even today, many people refuse to acknowledge that all people have sexual feelings, needs, and desires, regardless of their physical and/or mental abilities. As a result, many young people who live with disabilities do not receive sex education, either in school or at home.

This summary addresses sex education for youth who live with physical and/or mental disabilities—including, but not limited to hearing, sight, and motor function impairments; Down syndrome; cerebral palsy; paraplegia and quadriplegia; developmental disorders; and mental health issues. Beginning with a few statistics on disability among American youth and an overview of common myths and facts about the sexuality of people living with disabilities, the document also provides general guidelines for parents of physically or mentally challenged children and youth and offers a select, annotated bibliography of sex education materials and resources.*

Are Disabilities Common among Children and Youth?

- According to the U.S. Census Bureau, about 5.2 million American youth, ages five through 20 had some long-term physical, mental, or emotional disabling condition.¹
- In the United States, nearly one million youth, ages three through 17 are deaf or hard of hearing.²
- Each year, about 5,000 infants and toddlers and up to 1,500 preschoolers are diagnosed with cerebral palsy. Experts also estimate that two of every 1,000 infants born in this country has cerebral palsy.³
- In the United States, nearly 94,000 school age children are blind. Of these, nearly 11,000 are both deaf and blind.⁴
- According to experts, about 7,800 Americans suffer spinal cord injuries each year—most (82 percent) occur among males and most frequently at age 19.⁵

Myths and Facts about Sexuality and Disability

Many people believe myths about the sexuality of people who live with disabilities. Common myths:

- People with disabilities do not feel the desire to have sex.
- People with developmental and physical abilities are child-like and dependent.
- People with disabilities are oversexed and unable to control their sexual urges.⁶

Myth 1: People with disabilities are not sexual. All people—including young people—are sexual beings, regardless of whether or not they live with physical, mental, or emotional disabilities. And, **all** people need affection, love and intimacy, acceptance, and companionship.^{6,7} At the same time, children

* Advocates for Youth reminds readers that each young person is unique and may require a specialized program or resources—that is, each adolescent living with a disability is also an individual with individual reactions and needs regarding sex education. Thus, this document offers general guidance and should be used with care. It may or may not offer adequate resources to meet the particular needs of an individual.

and youth who live with disabilities may have some unique needs related to sex education. For example, children with developmental disabilities may learn at a slower rate than do their non-disabled peers; yet their physical maturation usually occurs at the same rate. As a result of normal physical maturation and slowed emotional and cognitive development, they may need sex education that builds skills for appropriate language and behavior in public. In another example, paraplegic youth may need reassurance that they can have satisfying sexual relationships and practical guidance on how to do so.^{6,7,8,9}

Myth 2: People with disabilities are childlike and dependent. This idea may arise from a belief that a disabled person is somehow unable to participate equally in an intimate relationship. Societal discomfort—both with sexuality and also with the sexuality of people who live with disabilities—may mean that it is easier to view anyone who lives with disabilities as an ‘eternal child.’ This demeaning view ignores the need to acknowledge the young person’s sexuality and also denies her/his full humanity.^{6,7,8,9}

Myth 3: People with disabilities cannot control their sexuality. This myth spins off the other two—if people with disabilities are neither asexual nor child-like, then perhaps they are ‘oversexed’ and have ‘uncontrollable urges’. Belief in this myth can result in a reluctance to provide sex education for youth with disabilities. The reality is that education and training are key to promoting healthy and mutually respectful behavior, regardless of the young person’s abilities.^{6,7,8,9}

Why Should Parents Be Concerned about Sex Education for Their Disabled Children?

Parents are, or should be, their children’s primary sex educators, but many parents are afraid to talk to their children (disabled or not) about sex. Parents often fear that: 1) talking about sex will encourage sexual experimentation; 2) they (the parents) don’t know enough to handle questions appropriately; and 3) their children already know too much or too little. In addition, parents of children who are living with disabilities may feel that their children are potential targets for sexual abuse or exploitation. Or the parents may fear that their children may be unable to appropriately express their sexual feelings.

In short, parents often fear that talking about sex may cause problems. But, parents need to assist any child—regardless of her/his abilities—to develop life skills. For example, without appropriate social skills, young people may have difficulty making and keeping friends and feel lonely and ‘different’. Without important sexual health knowledge, young people may make unwise decisions and/or take sexual health risks.

General Guidelines for Parents

1. To begin with, acknowledge that *everyone*, including your child, is sexual—and has sexuality related emotions and desires.
2. Before you start a conversation with your child, make sure you know your own values and beliefs. Be honest with yourself.
3. Be ready to assert your personal privacy boundaries. For example, say forthrightly, if asked, that you will not discuss your own private sexual behavior.
4. Start talking with your children about sexuality while they are very young. Do not wait until they reach puberty (or later) for these conversations!
5. Use accurate language for body parts and bodily functions. Research shows that when a child has accurate language for private body parts, she/he is more likely to report abuse, if it occurs, than when the child lacks appropriate language.⁸
6. Identify times to talk and communication strategies that work best for you and your child. For example, the best time might be Saturday morning on the way to a sports event or after school while you share a snack. Your best strategy might be to play word games. For someone else, other times and strategies might work best.
7. Avoid times and strategies that do **not** work well for your children and your situation. For example, you may be unable to carry on a coherent conversation while driving. Or word games may confuse your child.
8. Be clear when discussing relationships. For example, calling your spouse ‘Mommy’ or ‘Daddy’ can confuse a child and send confusing messages about family relationships and about sexuality; instead explain the relationship. “Your Mommy is my wife, so I call her Sarah, not Mommy.” Or you might say, “Your Uncle Leroy is my brother, like Jason is your brother. Leroy is your uncle, *because* he is my brother. When you have kids, Jason will be their uncle.”
9. Use photos, pictures, and other visual materials as often as possible. Showing family photos may help your child to understand different types of families and relationships.

10. Use ‘teachable moments’ that arise in daily life. For example, talk about a neighbor’s new pregnancy or a friend’s upcoming marriage, divorce, move, operation, or retirement.
11. Be honest when your child asks questions. If you don’t know the answer, say so. Say you will find the answer and then do so. Be sure to get back to your child with the answer to her/his question.
12. Always acknowledge and value your child’s feelings and experience. Offer praise and support. Remember that minimizing how he/she feels is not a good way to build trust when talking about sensitive subjects. For example, “That’s a good question, and it is one I have had in the past, too.” Or, “I’m glad you feel happy when we talk. I feel happy, too.”
13. Be willing to repeat information over time. Don’t be impatient or expect your child to remember everything you said or to have entirely understood it.
14. Use all the reliable sources of information available to you—other parents whom you trust, the public library, reliable Web sites, local bookstores, educators, and health care providers. Information may be particularly useful to you when it comes from reputable organizations that deal with disabilities and/or sexuality. Be wary of relying on material that is negative about sexuality as such materials can limit your ability to be your child’s primary sex educator.

General Guidelines for Professional Sex Educators

Sex education materials and programs do exist that are designed to meet the needs of youth who live with physical, emotional, and/or mental disabilities. Whether these young people go to public or special school, live at home or in an institution, they need appropriate sex education and creative teaching methods. Although these general guidelines will be helpful, content and teaching methods must be particularized to meet the individual’s need.

1. Remember that, regardless of the physical, mental, or emotional challenges they face, young people have feelings, sexual desire, and a need for intimacy and closeness. In order to behave in a sexually responsible manner, each needs skills, knowledge, and support.
2. Understand that youth with disabilities are far more vulnerable to sexual abuse than are their peers. Youth who live with developmental disabilities are especially vulnerable. Sex education must, therefore, encompass skills to prevent sex abuse and encouragement to report and seek treatment for unwanted sexual activity.
3. Remember that youth who confront disabilities feel the same discomfort and suffer the same lack of information that hampers many of their peers regarding sexuality and sexual health.
4. Learn as much as you can about the disabilities of the populations with whom you work.
5. Be sure that the material addresses boundaries and limits—both setting boundaries and respecting others’ boundaries. Rely on role plays and interactive exercises. Use concrete teaching strategies.
6. Be creative. Develop specialized teaching tools and resources for the youth with whom you work. For example, in working with youth who have developmental disabilities, you may need to use visuals like models, dolls and pictures. For youth with physical disabilities, it may be useful to use stories and examples of others with similar disabilities who have loving, satisfying intimate relationships.

References

1. United States Bureau of the Census. *Statistical Abstract of the United States: The National Data Book*. 123rd ed. Washington, DC: The Bureau, 2003.
2. Gallaudet University. Statistics: deaf population of the United States. *Deaf Related Resources: Frequently Asked Questions*. <http://www.library.gallaudet.edu/dr/faq-statistics-deaf-us.html>; accessed 11/9/2005.
3. Cerebral Palsy Facts. *Cerebral Palsy Statistics*; <http://www.cerebralpalsyfacts.com/stats.htm>; accessed 11/9/2005.
4. National Federation for the Blind. *Blindness Statistics* [updated November 7, 2005]; <http://www.nfb.org>; accessed 11/14/2005.
5. National spinal Cord Injury Association Resource Center. *Spinal Cord Injury Statistics* [Factsheet #2] <http://www.makoa.org/nsca/fact02.html>; accessed 11/30/2005.
6. Tepper MS. Becoming sexually able: education to help youth with disabilities. *SIECUS Report* 2001; 29(3):5-13.
7. Ballan M. Parents as sexuality educators for their children with developmental disabilities. *SIECUS Report* 2001; 29(3):14-19.
8. Neufeld J, Klingeif F, Bryen DN, Silverman B, Thomas A. Adolescent sexuality and disability. *Physical Medicine & Rehabilitation Clinics of North America* 2002; 13(4): 857-73.
9. Couwenhoven, Terri. Sexuality education: building a foundation for healthy attitudes” *Disability Solutions* 2001; 4(5).

SELECTED RESOURCES FOR EDUCATORS AND OTHER YOUTH-SERVING PROFESSIONALS

Books

Reproductive Issues for Persons with Physical Disabilities—edited by F Hastline, PhD, MD, SS Cole, PhD, and DB Gray, PhD; Paul H. Brooks Publishing

Featuring contributions from disabled consumers and health professionals, this book dispels myths about sexuality and disability and explores sexual issues that challenge people with disabilities. It provides information on reproductive rights, sexual dysfunction, sexually transmitted infections, reproductive physiology, sexual development, health care needs, fertility, birth control, adoptions, pregnancy, labor and delivery, and parenthood and also personal stories of people with disabilities.

Sexuality and Disability—by M Blackburn; Butterworth-Heinemann Publisher

This book examines the physical and psychological aspects of disability and sexuality and boosts professional understanding of those with disabled patients, especially in regard to self-esteem, legal matters, abuse, adolescence, genetics and continence.

Enabling Romance: A Guide to Love, Sex, and Relationships for People with Disabilities (And the People Who Care about Them)—by K Kroll and EL Klein; No Limits Communications

This book is particularly recommended for its attention to the sex education needs of youth with all types of disabilities. Its three main components include disabilities and sexual satisfaction; life and love with specific disabilities; and resource information for independent living, dating services, and publications. It offers a wealth of information on relationships and reproductive issues.

Sexuality and Disabilities: A Guide for Human Service Practitioners—editors, RW Mackelprang and D Valentine; The Haworth Press, 1996

This collection provides understanding of issues related to sexuality, intimacy, and disability. Articles address mental retardation and sexual expression; responding to the sexual concerns of persons with disabilities; holistic approaches to providing sex education and counseling for severely disabled people; and sexual assault.

Socialization and Sexuality: A Comprehensive Training Guide for Professionals Helping People with Disabilities that Hinder Learning—by W Kempton

This guide outlines a training program for professionals who work with people with developmental disabilities. It includes: understanding the sexuality of people with disabilities that hinder learning; attitudes about sexuality: personal exploration; sexuality counseling; sexual abuse and informed consent; working with parents and families; and programs and evaluations.

Curricula

Child Sexual Abuse Curriculum for the Developmentally Disabled—by SR Rappaport, PhD, SA Burkhardt, PhD, and AF Rotatori, PhD; Charles C. Thomas Publishers, 1997

This curriculum addresses child sexual abuse and the developmentally disabled; treatment of sexually abused children; and emotional and behavioral outcomes of sexual abuse. It includes 10 lessons on sexuality and sexual abuse prevention for children who are mildly retarded.

Human Sexuality: A Portfolio for Persons with Developmental Disabilities—by I Peters and J McKoy; Planned Parenthood of Western Washington

The portfolio contains large (11 x 17 inch) colored illustration plate cards for teaching developmentally disabled youth about human sexuality, including male and female bodies, male and female genitals, intercourse, and body shapes. The portfolio offers teaching techniques and ideas along with detailed teaching points on the back of each card.

Life Horizons I: The Physiological and Emotional Aspects of Being Male & Female; and *Life Horizons II: The Moral, Social and Legal Aspects of Sexuality*—by W Kempton, MSW; J Stanfield Publishing, 1999

Designed for people with mild or moderate developmental disabilities, Horizon I addresses parts of the body, the sexual life cycle, human reproduction, birth control, and sexually transmitted diseases. Life Horizons II addresses building self-esteem and learning to form relationships, moral, legal and social aspects of sexual behaviors (for males), dating skills, marriage and other adult lifestyles, parenting, and preventing or coping with sexual abuse. Each includes over 500 slides, teacher's guide, and script.

Signs for Sexuality: A Resource Manual for Deaf and Hard of Hearing Individuals, Their Families, and Professionals, Second edition—by M Minkin and L Rosen-Ritt; Planned Parenthood of Western Washington

This curriculum offers information on sexual abuse, sexually transmitted infections, and reproductive health, with more than 600 photographs to illustrate 250 vocabulary words relating to sexuality. Appendices include anatomical drawings and information about contraception.

Talking Sex! Practical Approaches and Strategies for Working with People Who Have Developmental Disabilities When the Topic Is Sex—by LT Maurer, MS, CFLE; Planned Parenthood of Tompkins County, 1999

Information, activities, and overheads assist professionals in identifying strategies to improve access to sex education to people with developmental disabilities.

SELECTED RESOURCES FOR PARENTS

Parents have an important role in educating their disabled children about sex. Parents have the best knowledge of their children's capabilities and of the values the parents want to emphasize. Here are a few recommended resources to help parents.

Books

Just Because I Am: A Child's Book about Affirmation—by L Murphy Payne; Free Spirit Publishing, 1994; available at www.freespirit.com

This beautiful, yet simple book encourages your child to appreciate his/her uniqueness and includes empowering messages about the body, feelings, boundaries, touch, and feeling safe. Its Leader's Guide of supplemental activities affirms the concepts.

Face Your Feelings—Child's Work / Child's Play. www.childswork.com; 1-800-962-1141

This book and card deck set can help children to understand the importance of expressing and understanding feelings. Designed for ages four and up, the book and card deck include 52 pictures of children, teens, and adults expressing 12 basic feelings.

What's the Big Secret: Talking about Sex with Girls and Boys—by M Brown and L Krasny Brown, Ed.D; Little Brown Company, 2000

This easy-to-read story book for young children addresses how boys and girls are different and social rules about talking, looking, touching, and being touched.

What's Happening to My Body: A Book for Boys—by Lynda and Area Madaras; Newmarket Press, 2000

This straightforward book discusses puberty and the male body. A workbook companion piece entitled, *My Body, My Self for Boys*, can be purchased separately and includes games, checklists, and quizzes to reinforce what boys have learned.

What's Happening to My Body: A Book for Girls—by Lynda and Area Madaras; Newmarket Press, 2000

This straightforward book discusses puberty and the female body. A workbook companion piece entitled, *My Body, My Self for Girls*, can be purchased separately and includes games, checklists, and quizzes to reinforce what girls have learned.

Sexuality: Your Sons and Daughters with Intellectual Disabilities—by K Schwier and D Hingsburger; Brookes Publishing, 2000

This excellent resource addresses sexual development from birth to adulthood. Parents and their sons and daughters with developmental disabilities share stories that can be helpful. Many portions of the book speak specifically to people with Down syndrome and their parents.

ORGANIZATIONS / WEB SITES

American Association on Mental Retardation (AAMR)

444 North Capitol Street, NW, Suite 846
Washington, DC 20001-1512
Phone: 202-387-1968
Toll free: 1-800-424-3688
Fax: 202-387-2193
www.aamr.org

American Spinal Cord Association

2020 Peachtree Road, NW
Atlanta, Georgia, 30309-1402
Phone: 1-404-355-9772
www.asia-spinalinjury.org

The Arc: National Organization on Mental Retardation

1010 Wayne Avenue, Suite 650
Silver Spring, MD 20910
Phone: 301-565-3842
Fax: 301-565-3843
Fax: 301-565-5342

National Dissemination Center for Children with Disabilities

P.O. Box 1492
Washington, DC 20013
Toll free: 1-800-695-0285
Phone: 202-884-8200
www.nichcy.org

National Spinal Cord Injury Association

6701 Democracy Boulevard, Suite 300-9
Bethesda, Maryland, 20817
Phone: 1-800-962-9629
www.spinalcord.org

Planned Parenthood Federation of America

434 West 33rd St
New York, New York 10001
Phone: 212-247-6269
www.ppfa.org

Sexuality Information and Education Council of the United States (SIECUS)

130 West 42nd Street, Suite 350
New York, NY 10036-7802
Phone: 212-819-9770
Fax: 212-819-9776

Sexuality and Disability Training Center

University Hospital
75 East Newton Street
Boston, MA 02118
Phone: 617-638-7358

Sexual Health Network

www.sexualhealth.com

United Cerebral Palsy

1660 L Street, NW, Suite 700
Washington, DC 20036
Toll free: 800-872-5827
Phone: 202-776-0406
TTY: (202) 973-7197
Fax: (202) 776-0414
www.ucp.org



*Written by Dimple Keshav and Barbara Huberman
April 2006, © Advocates for Youth*