

Sexual Health Education for Young People with Disabilities: Parents/Guardians

In recent years, important changes in public policies and attitudes have resulted in improved opportunities for people with physical and intellectual disabilities. Unfortunately, societal attitudes have changed less in regard to *sexuality* and disability. Even today, many people do not acknowledge that most people experience sexual feelings, needs, and desires, regardless of their abilities. As a result, many young people, including those with disabilities, receive little or no formal sexual health education, either in school or at home. All young people need access to and can benefit from sexual health information. Young people with disabilities have the same right to this education as their peers, however considerations must be made in order to modify the program to allow for information to be understood and learned in a way that is meaningful to them.¹

Parents/guardians might believe that talking about sexuality may cause problems. But, providing sexual health education provides information and opportunities to assist any youth—regardless of their ability—to develop life skills. Sexual health education provides the opportunity to practice skills and communicate to be more successful in navigating and responding to social and sexual situations appropriately. Young people with disabilities who are provided this information are given the opportunity for empowerment and increasing their self-esteem. Learning that the changes they are going through, the choices they have to make and questions they have are experienced by a larger group can be self-affirming and empowering. They are not alone and are no different from anyone else. Without important sexual health knowledge, young people may make unwise, uninformed decisions and/or take sexual health risks.

WHAT IS DISABILITY?

Disability can be defined as a physical or mental impairment that substantially limits one or more major life activities. This

definition can be applicable to persons who have a history or record of such impairment, or a person who is perceived by others as having such impairment. However disability can be defined differently by different people, for different purposes. This summary addresses sexual health education for youth identified as having a disability—including, but not limited to hearing, sight, and motor function impairments; Down syndrome; cerebral palsy; paraplegia and quadriplegia; developmental disorders; and mental and emotional health issues that impair learning. Beginning with a few statistics on disability among U.S. youth and an overview of common myths and facts about the sexuality of people with disabilities, the document also provides general guidelines for parents and guardians and offers a select, annotated bibliography of sexual health education materials and resources.

ARE DISABILITIES COMMON AMONG YOUNG PEOPLE?

- According to the U.S. Census Bureau, in 2010, about 2.8 million U.S. youth under the age of 15 had some kind of physical, intellectual, or emotional disability.²
- In the U.S., more than 450,000 youth ages 0-17 are deaf or hard of hearing.³
- 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 have cerebral palsy.⁴
- In 2012, there were more than 59,000 legally blind youth (through age 21) in the U.S. enrolled in elementary and high schools.⁵
- Each year, approximately 12,000-20,000 Americans suffer spinal cord injuries—most (80 percent) occur among males and the majority among people under age 30.⁶
- In 2002 the prevalence of Down syndrome among U.S. youth ages 0 to 19 was 1 in 971, or approximately 83,400 youth with Down syndrome.⁷

FROM RESEARCH
TO PRACTICE

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- In 2006-2008 in the U.S., 1 in 6 youth were reported to have developmental disabilities. Prevalence of any developmental disability has increased from 12.8 percent to 15.0 percent over the past decade.⁸

SEXUALITY AND DISABILITY

Many people believe myths about the sexuality of people with disabilities. Common myths include people with disabilities are not sexual, are childlike and dependent, are hypersexual and unable to control their sexual urges, should not have children, and/or have more important things to worry about than having sex. But research paints a different picture.

People with disabilities are sexual and express their sexuality in ways that are as diverse as everyone else.

The belief that people with disabilities are not sexual could stem from the idea that they are considered a child or child-like and therefore are excluded from having sexual health rights. However, most people—including young people—are sexual beings, regardless of whether or not they have a disability. And **all** people need affection, love and intimacy, acceptance, and companionship.^{6,7} Accurate and developmentally appropriate sexual health education, which acknowledges and affirms all people's sexuality, is necessary for a young person to learn about self, relationship safety, and responsibility. Young people with disabilities may need reassurance that they can have satisfying sexual relationships and practical guidance on how to do so.^{8,9,10,11}

The humanity and independence of people with disabilities should be respected. The idea that people with disabilities are childlike and dependent coincides with 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 a disability as an ‘eternal child.’ This demeaning view ignores the need to acknowledge the young person's sexuality and also denies their full humanity.^{8,9,10,11}

Education and skill practice are key to promoting healthy and mutually respectful behavior, regardless of the young person's abilities. Often when a person with a disability does express their sexuality they are

considered ‘hypersexual’ and have ‘uncontrollable urges’. They are not disproportionately overly sexual compared to a non-disabled person, but because it is not expected this is a problem for some. The belief in this myth can result in a reluctance to provide sexual health education for young people with disabilities. In addition, young people with disabilities might struggle with the concept of public versus private and engage in behavior that has been identified as private, such as personal exploration, in a public setting. These events could add to the belief that people with disabilities have uncontrollable urges, when the reality is that they need education and skills.^{8,9,10,11}

People with disabilities have the right to make decisions about becoming parents. Having a child is considered by many an important event in one's life and a right, yet many do not believe it applies to people with disabilities and their reproductive health. In many instances people with disabilities are not believed to be sexual, so it is also believed that they cannot reproduce. Or if they can reproduce they will have children who also have disabilities. There are also individuals who believe people with disabilities should not be parents, and may not be willing to provide the same supports and assistance to them. Both able and disabled women have equal chance of having a non-disabled or disabled child. Women with disabilities, first and foremost, are women, and have the same rights and abilities to make the decision to have a child; men as well have the right to make the decision to be a father. People with disabilities can be good parents and have the ability to be successful in raising a child given the appropriate supports.

Learning about sexual health is a necessity, not a luxury, for all of us. Many times needs are placed into two categories: fundamental (eating, sleeping and bathing) and secondary (sexual needs and desires, communication with others and intellectual development). While people can value sex differently, for those who do have a disability learning about one's sexuality and sexual health could be considered by some a luxury that can't be afforded. This could be related to people with disabilities being considered childlike and the caretaker's sense of needing to help them prioritize their lives. Most people experience various needs at the same time and need to learn how to balance all aspects of their lives including those fundamental and secondary needs. In terms of sexual health education, young people need to be present during sexual health lessons at school; to learn and practice skills that will support healthy sexual development. Students should not be removed from sexual health lessons when scheduling other needs such as additional therapy, tutoring and supports that take place during school hours. In the home setting, it is important to plan out time and allow for sexual health conversations to be prioritized along with other needs the young person might have.

PARENT/GUARDIAN CONCERN FOR SEXUAL HEALTH EDUCATION AND THEIR YOUNG PERSON WITH A DISABILITY

Parents/guardians should be the primary sexual health educators for young people, both those with disabilities and those without. Yet too often, many of these adults don't feel comfortable starting a conversation with a young people about sexuality. Many parents/guardians often believe that: 1) talking about their child's sexuality will encourage sexual experimentation; 2) they don't have enough sexual health information themselves to address questions appropriately or accurately; and 3) they are not aware of the amount of information their child already knows about their own sexuality. Parents/guardians of young people with disabilities may feel that encouraging talk about sexuality will make them potential targets for sexual abuse or exploitation. In this case the opposite is true. Not being taught about their sexuality can actually put a young person with a disability at higher risk of abuse or exploitation, because they do not have the language or knowledge to say no or to report abuse after it occurs. Children with mental or intellectual impairments appear to be among the most vulnerable, with 4.6 times the risk of sexual violence than their non-disabled peers.²² Parents/guardians may also have concerns that these young people may be unable to appropriately express their sexual feelings. While these are all common concerns, they do not negate the need for education. Evidence shows young people who receive sexual health education are not more likely to become sexually active, increase sexual activity, or experience negative sexual health outcomes. Effective programs exist for young people from a variety of racial, cultural, and socioeconomic backgrounds.

When parents/guardians discuss sexuality routinely and openly; conversations are easier to initiate, more comfortable to continue, and more effective and informative for all participants. Parents/guardians can support building the foundation for information so when more challenging topics arise it will be an easier discussion. Parents/guardians can assist their young person in identifying credible and accurate sources for seeking information on their own, which can assist with goal setting and planning for the future.

GENERAL GUIDELINES FOR PARENTS/GUARDIANS: TALKING TO YOUR YOUNG PERSON ABOUT THEIR SEXUALITY AND SEXUAL HEALTH.

1. Acknowledge that most people experience sexual feelings and that all people have the right to sexual expression. Young people with disabilities will develop crushes and navigate all types of relationships from friendships, to dating and partnerships along with exploring their sexual behaviors. Remember not to treat them differently or have different expectations for them because they have disabilities. Rather be prepared to do the research and have frank (and even uncomfortable) conversations with them. Before you start a conversation with your child, make sure you know your own values and beliefs. Be honest with yourself.

2. Be ready to assert your personal privacy boundaries. For example, say forthrightly, if asked, that you will not discuss your own private sexual behavior.
3. Start talking with your children about sexuality while they are very young. Do not wait until they reach puberty (or later) for these conversations!
4. Educate yourself and know your resources. Curricula and additional resources have been developed to take into account what is age appropriate sexual health education. When addressing young people with cognitive delays additional consideration should be taken when selecting material. If possible have age and developmentally appropriate youth-friendly information on hand to help explain sexual health topics. While the conversation may still be uncomfortable, learning the information and how to share with your young person can alleviate some of the challenges. If you need help with a topic, you can find an expert. Many counties, schools, and clinics have health professionals and sexuality educators available to answer questions from young people and parent/guardians.
5. Use accurate language for body parts and bodily functions. Research shows that when a child has accurate language for private body parts, they are more likely to report abuse, if it occurs, than when the child lacks appropriate language.⁸
6. Identify times to talk and communicate strategies that work best for you and your young person. For example, the best time might be during an activity your young person consistently participates in such as an art class, on the way to an athletic event or after school while you share a snack. Your best strategy might be to play games to introduce new concepts. For someone else, other times and strategies might work best.
7. Avoid times and strategies that do **not** work well for your young person and your situation. For example, you may be unable to carry on a coherent conversation while driving. Or communicating through games may confuse your young person.
8. Use appropriate photos, pictures, and other visual materials as often as possible. Showing family photos may help your young person to understand different types of families and relationships.

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9. 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.
10. Be honest when your young person 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 young person with the answer to their question.
11. Always acknowledge and value your young person’s feelings and experience. Offer praise and support. Remember that minimizing how they feel 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.”
12. Be committed to repeating information over time. Try not to be impatient or expect your young person to remember everything you said or to have entirely understood it.
13. Use all the reliable sources of information available to you—other parents/guardians whom you trust, the public library, reliable websites, 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 promotes a negative or stigmatizing view of sexuality, as such materials can limit your ability to be your young person’s primary sexual health educator.
14. Support your young person in seeing and interacting with people who have the same and different disabilities from a young age and be able to see them in relationships, as parents/guardians, as professionals. In addition, involving young people with disabilities in youth development and youth leadership programs, both disability specific and general youth programs, helps them develop healthy relationships and healthy self-images.

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Select Resources Recommended for Parents/Guardians

Parents/guardians have an important role in educating their young person about their sexuality. They have the best knowledge of their young person's capabilities and of the values they want to emphasize. Here are a few recommended resources to assist you.

BOOKS

IT'S NOT THE STORK! A Book About Girls, Boys, Babies, Bodies, Families, and Friends –by Robbie Harris; Chadwick Press

Through comfortable language and sensitive, engaging art work, this book helps answer these endless and perfectly normal questions of children about where they came from with accurate and straight forward information. This is a resource that parents, teachers, librarians, health care providers, and clergy can use with ease and confidence.

IT'S PERFECTLY NORMAL: Changing Bodies, Growing Up, Sex and Sexual Health by Harris, Robbie; Chadwick Press

Through two cartoon characters, this book provides the accurate answers to children's questions on conception and puberty to birth control and AIDS. A thorough presentation is provided of the facts of sex both biological and psychological which children need to know. This book's provides the reassurance that the changes and emotions they experience while growing up is perfectly normal.

What's In There: All About Before You Were Born—by Robbie Harris; Chadwick Press

Combining matter-of-fact text and conversations with warm, accessible, and accurate illustrations this book can help children understand that the way a growing baby develops inside a woman's body, and how a baby is born, are both perfectly normal and totally wonderful.

WHO HAS WHAT!: All About Girls' Bodies and Boys' Bodies—by Robbie Harris; Chadwick Publishing

Humorous illustrations, conversations between siblings and a clear text all reassure children that whether they have a girl's body or a boy's, their bodies are perfectly normal, healthy, and wonderful. This book provides easy-to-understand facts and answers to children's questions.

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. It has a Leader's Guide of supplemental activities to affirm the concepts above.

Learn About Life: Sexuality and Social Skills. <http://www.attainmentcompany.com/learn-about-life>

This book is an illustrated sex education and social skills program with straight-forward, candid graphics and simple text. It provides information about bodies, appropriate social and sexual behavior, and staying safe.

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

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

Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality: A guide for Parents and Professionals—by Terri Couwenhoven, M.S.; Woodbine 2007

This book blends factual information and practical ideas for teaching children with Down Syndrome about their bodies, puberty, and sexuality. This book gives parents the confidence to speak comfortably about these sometimes difficult subjects.

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, 2007

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, 2007

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VIDEO

I am a Beautiful Person...Sexuality and Me: A Video for Parents of Teens with Disabilities

Cecil Shapland and Kris Scholler (Producers);1996

This video demonstrates how all people can live their lives as healthy sexual beings. Designed for viewing by parents and caregivers, it includes inter views with people of varying ages and abilities.

ORGANIZATIONS/ WEBSITES

American Association on Intellectual and Developmental Disabilities (AAIDD)

501 3rd Street NW
Washington, DC 20001
Phone: 202-387-1968
Fax: 202-387-2193
<http://www.aaid.org>

American Spinal Cord Association

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

The Arc: For People with Intellectual and Developmental Disabilities

1825 K Street NW, Suite 1200
Washington, DC 20006
Phone: 202-534-3700
Fax: 202-534-3731
<http://www.thearc.org/>

National Spinal Cord Injury Association

75-20 Astoria Boulevard
Jackson Heights, NY 11370
Phone: 718-803-3782
<http://www.spinalcord.org>

Planned Parenthood Federation of America

434 West 33rd St
New York, New York 10001
Phone: 212-541-7800
www.ppfa.org

Sexuality and Disability

<http://www.sexualityanddisability.org/>

Sexuality and Disability –Info for Families

<http://www.sexualityanddisability.org/info-for-families.aspx>

Sexual Health Network

www.sexualhealth.com

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

90 John Street, Suite 402
New York, NY 10038
Phone: 212-819-9770
Fax: 212-819-9776
<http://www.siecus.org>

Sexuality Resource Center for Parents

<http://www.srcp.org/>

United Cerebral Palsy

1825 K Street, Suite 600
Washington, DC 20006
Toll free: 800-872-5827
Phone: 202-776-0406
<http://www.ucp.org>