

Sexual Health Education for Young People with Disabilities

Research and Resources for Educators

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

Educators are in the unique position of being cognizant of their student's different abilities and learning styles and are well-positioned to support the decisions being made on when and how much sexuality information a young person should receive. While parents/guardians should be the primary sexuality educators for their children, regardless of disability status, for many young people, this is not always the case. For young people with disabilities, it is necessary for educators to engage parents/guardians in developing a plan of instruction that is positive, gradual, and takes into account the individual young person's developmental and maturity levels and considers the parent/guardians' beliefs and values.

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 educators 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.³
- In the U.S., more than 450,000 youth ages 0-17 are deaf or hard of hearing.⁴
- 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.⁵
- In 2012, there were more than 59,000 legally blind youth (through age 21) in the U.S. enrolled in elementary and high schools.⁶
- 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 30.⁷
- 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.⁸
- 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

FROM RESEARCH
TO PRACTICE

“Many young people, including those with disabilities, receive little or no formal sexual health education, either in school or at home.”

SEXUALITY AND DISABILITY

Sexuality is a normal part of growth and development. While approaches to sexual health education and communication may vary, young people with disabilities need accurate information and skills, and have the same rights as those without disabilities.

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.^{9,10,11,12}

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.^{9,10,11,12}

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.^{9,10,11,12}

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.

CONCERNS FOR EDUCATORS WHO TEACH SEXUAL HEALTH EDUCATION

As they mature, young people with disabilities experience most if not all of the same physical and emotional changes as their peers who do not have disabilities. However due to these myths they may receive less sexual health education; many parents/guardians and educators may believe that young people with disabilities don't need this education at all. Sexuality is one of the most basic human instincts—the exploration of self, others and how we interact. Educators have the responsibility of assisting students

in their growth and development, and sexuality is part of that growth. As formal (and informal) teachers of sexual health education, all adults share in the responsibility.

Educators should have resources and supports available to modify and adapt programs to meet the needs of their students. In addition to resources and supports, educators should receive training that includes content and skill development for teaching sexual health education.

GENERAL GUIDELINES FOR SEXUAL HEALTH EDUCATORS

Sexual health education materials and programs do exist that are designed to meet the needs of young people with disabilities. Whether young people go to public or alternative schools, live at home or in an institution, they need appropriate sexual health education taught by trained teachers. Although these general guidelines will be helpful, content and teaching methods must be modified to meet the individual's need.

1. Remember that, regardless of the disability they live with, young people have feelings, sexual desires, and a need for intimacy and closeness. In order to behave in a sexually responsible manner, they need skills, knowledge and support.
2. Understand that young people with disabilities are far more vulnerable to sexual abuse than are their peers, especially those with developmental disabilities. Sexual health education must, therefore, encompass knowledge and skills that describe and promote healthy relationships, reduce the risk of sexual abuse and encouragement to report and seek help when faced with unwanted sexual advances.
3. Remember that young people with 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 young person with whom you work, including their families, cultural traditions, and specific disabilities.
5. Be sure that the material addresses boundaries and limits—both setting boundaries and respecting others' boundaries. Use role plays and interactive exercises when feasible.
6. Use concrete examples. Abstract concepts such as love, or that a pregnancy results in having a baby nine months later can be difficult for people with disabilities to comprehend. The examples used need to be concrete, in the present and almost tangible. Using pictures and videos is a good method.
7. Be creative. Develop specialized teaching tools and resources for the young people with whom you work. For example, in working with those 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.

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“Education and skill practice are key to promoting healthy and mutually respectful behavior, regardless of the young person’s abilities”

Selected Resources for Educators and other Youth-Serving Professionals

PROFESSIONAL DEVELOPMENT

Illinois Imagines: Our Rights, Right Now Educator Resource

http://www.icasa.org/docs/illinois%20imagines/module%204%20resources_layout%201.pdf

This resource contains information on supporting training to professionals on prevention of sexual violence against women with disabilities and being able to respond to them appropriately

Sexuality Information Resource list

http://dccshcn.org/documents/DCRC_FactSheet_2_Resources_P2.pdf

This document contains a sample of information for sexuality education and resources for individuals, parents, teachers or providers

Sexuality Education for Children and Adolescents with Developmental Disabilities:

An instructional manual for educators of individuals with developmental disabilities by: DiAnn L. Baxley and Anna L. Zendell first edition 2005, revised 2011

<http://www.fddc.org/sites/default/files/file/publications/Sexuality%20Guide-Educators-English.pdf>

This Instructional Manual and the Resource List were designed to help teachers and other educators assist individuals with intellectual or developmental disabilities (I/DD) in their exploration of self and sexuality. Support collaboration with individuals' families in teaching these concepts in a manner consistent with families' beliefs and values.

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. Chapters include: 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 sexuality programs and evaluations.

BOOKS FOR YOUNG PEOPLE AND ADULTS

Sexuality and Physical Disability Reading List; 2012

<http://www.serc.mb.ca/sites/default/files/resources/Sexuality%20and%20Physical%20Disability%20Reading%20List.pdf>

This resource provides a list of books that address sexuality and having a disability or chronic diseases

BOOKS/ ARTICLES FOR ADULTS

The Facts of Life....and More: Sexuality and Intimacy for People with Intellectual Disabilities Paperback—by L Walker-Hirsch; Brookes Publishing

This book provides professionals with comprehensive information needed to educate people with disabilities about sexuality and help them make healthy choices across the lifespan.

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.

Sexuality and Relationship Education for Children and Adolescents With Autism Spectrum Disorders—by D Hartman; Jessica Kingsley Publishing

This professional resource offers practical teaching advice geared towards the needs of young people on the autism spectrum. Beginning with information on good practice, policy, teaching methods and recent research, the book then divides into key sex education topics. The book aims to explain and support children's developing sexuality while also addressing crucial issues of safety.

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

Addressing sexuality for disabled people, this book is particularly recommended for its attention to the sexual health 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

This collection provides understanding of issues related to sexuality, intimacy, and disability. Articles address persons with physical, sensory, intellectual, and cognitive disabilities and their concerns in the areas of intimacy, family issues, sexuality, and sexual functioning. Concrete ideas are offered to professionals who work with persons with these disabilities to help them work more competently with disabled persons in the sexuality arena.

The Ultimate Guide to Sex and Disability: For All of Us Who Live with Disabilities, Chronic Pain, and Illness—by M Kaufman, C Silverberg, F Odette; Cleis Press

Jointly written by a medical doctor, a sex educator, and a disability activist, this is the first complete sex guide for people who live with disabilities, pain, illness, or chronic conditions. Useful for all readers, regardless of age, gender, or sexual orientation, the book addresses a wide range of disabilities and covers all aspects of sex and disability, such as building a positive sexual self-image; dealing with fatigue or pain during sex; finding partners, and talking with partners about sex and disability.

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.

Circles Curriculum: Intimacy and Relationships- by Champagne, M. P. & Walker-Hirsch, L. W. Santa Barbara, California; James Stanfield Publishing Company;1993

This curriculum teaches social and relationship boundaries and relationship-specific social skills, using a simple multi-layer circle diagram to demonstrate the different relationship levels students will encounter in daily life. Circles is a concrete, organizational paradigm for students with special educational needs that helps them learn to act and interact in self-enhancing ways.

F.L.A.S.H.: Family Life and Sexual Health, Lesson Plans for Special Education

<http://www.kingcounty.gov/healthservices/health/personal/famplan/educators/SpecialEducation.aspx>

Created by King County Public Health, these lesson plans are part of a comprehensive sexuality curriculum for students in grades K-12. These lessons are specifically for students in special education and are available through the Public Health- Seattle & King County website.

Life Cycle: How We Grow and Change: A Human Development and Sexuality Education Curriculum—by SM Vavrichek and RK Tolle; Life Cycle Education Consultants, LLC; 2008

This curriculum is designed for youth with developmental disabilities. It contains lesson plans, activities, and resources, on a variety of topics including self-esteem, privacy awareness, respectful relationships, appropriate touch, independence, and physical growth and change.

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.

Personal SPACE

http://www.ncdsv.org/images/Arc_PersonalSpace-AViolencePreventionProgramForWomen.pdf

Created by the ARC of Maryland, these lessons cover private and public body parts, touching, and expression. The lessons are available for free.

Positive Prevention Plus Special Education Curriculum

<http://www.positivepreventionplus.com/curriculum/special-education/>

A comprehensive HIV/STD prevention and sexual health education curriculum adapted for special education students in grades 7-12, and for developmentally delayed adults in school and community-based settings. The curriculum extends the instructional time and focuses on specific protective behaviors using a variety of peer-based and interactive strategies.

Sex and Relationships Education: A Step-by-Step Guide for Teachers —by Simon Blake; David Fulton Publishers, 2002

It draws together the best available practice to support teachers in developing policy and classroom practice. It begins by looking at general principles and then focuses on primary, secondary and special schools as well as pupil referral units. These chapters will provide a toolkit of ideas and approaches that teachers can use in the classroom

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.

S.T.A.R.S.: Skills Training for Assertiveness, Relationship Building, and Sexual Awareness—by S Heighway and S Webster; Future Horizons, 2007

Specially designed for teaching adolescents and adults with developmental disabilities, the STARS model focuses on four areas: Understanding Relationships, Social Skills Training, Sexual Awareness, and Assertiveness—with the goals of promoting positive sexuality and preventing sexual abuse. The curriculum contains assessment tools that can be used to tailor activities to the needs of young people participating in the curriculum.

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

This provides information, activities, and overheads that assist professionals in identifying strategies to improve access to sex education to people with developmental disabilities.