SEX EDUCATION/PUBERTY RESOURCES FOR INDIVIDUALS WITH SPECIAL NEEDS/DISABILITIES AND FOR THEIR FAMILIES, PARTNERS, CAREGIVERS, AND EDUCATORS

Compiled by University of Michigan Gynecology Clinic for Women with Disabilities

**Please note: The University of Michigan does not endorse any particular resources listed below and cannot guarantee accuracy of information provided. Availability of resources subject to change**

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**Brochures/Packets:**

Packets, available online free of charge:


(Appendix available at [https://vkc.vumc.org/HealthyBodies/files/HealthyBodiesAppendix-Girls.pdf](https://vkc.vumc.org/HealthyBodies/files/HealthyBodiesAppendix-Girls.pdf))


(Appendix available at [https://vkc.vumc.org/HealthyBodies/files/HealthyBodiesAppendix-Boys.pdf](https://vkc.vumc.org/HealthyBodies/files/HealthyBodiesAppendix-Boys.pdf))

Speak Up and Be Safe (communication boards and visual aids about abuse prevention and reporting)


**Books:**


Couwenhoven, Terri. 2007. *Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality* (Topics in Down Syndrome). Woodbine Press. *GOOD FOR MOST CHILDREN WITH DISABILITIES, NOT JUST THOSE WITH DOWN SYNDROME*


Fegan, Lydia & Rauch, Anne. 1995. *Sexuality and People with Intellectual Disability.* Paul H. Brookes Publishing. (difficult to find – may be on eBay or Amazon)

Fenwick, Elizabeth & Walker, Ricard. 1994. *HOW SEX WORKS - Everything you need to know about growing up, starting relationships and becoming sexually active.* RD Press. (out of print)


Harris, Robie & Emberley, Michael. 2004. *It’s So Amazing!: A Book About Eggs, Sperm, Birth, Babies, and Family.* Candlewick.


Marsh Media educational materials for those with special needs (includes guides about puberty and social skills). http://marshmedia.com/collections/special-needs


Sanders, Jayneen, 2015. No Means No!: Teaching Children About Personal Boundaries, Respect, and Consent; Empowering Kids by Respecting Their Choices and Their Right to Say “No!” Educate to Empower Publishing.


Simone, Rudy. 2012. 22 Things a Woman with Asperger's Wants her Partner to Know. Jessica Kingsley Pub.


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From the Sexuality Education Resource Centre: Resources for those with intellectual disabilities

Resources for Parents
I Openers: parents ask questions about sexuality and children with developmental disabilities, David Hinsburger, 1993. SERC call No.: 3.13 HIN

Curricula
The Facts of Life and Living: A curriculum that promotes social and sexual awareness for persons with disabilities, Linda Colley & Linda Howden, 1988. SERC call No.: 3.13 COL

LifeFacts 1: Sexuality and LifeFacts 2: Sexual Abuse Prevention, Nancy Cowardin and James Stanfield, 1989. Manuals, slides, and excellent teaching pictures. For use with adolescents and adults. SERC call No.: 3.13.1 COW

STARS: Skills Training for Assertiveness and Relationship-Building and Sexual Awareness, Susan Heighway, Susan Kidd Webster, 1998. A program promoting positive sexuality and preventing sexual abuse for adults with developmental disabilities. SERC call No.: 3.13 SPD

Staff Training

The Ethics of Touch, David Hingsburger & Mary Harber, 1998. Establishing and maintaining appropriate boundaries with people with developmental disabilities. Two videos and manual. SERC call No. 3.13.1HAR

First Contact: Charting inner space with people who have significant disabilities, David Hingsburger, 2000. Ideas for establishing contact with people who have significant disabilities. SERC call No. 3.13.1HIN

Just Say Know!, David Hingsburger, 1995. Explores the victimization of people with disabilities and helps reduce the risk of sexual assault. SERC call No. 3.13.1HIN


Socialization and Sexuality, Winifred Kempton, 1998. A comprehensive training guide for professionals helping people with disabilities that hinder learning. SERC call No.: 3.13 SPD

Talking Sex! Practical approaches and strategies for working with people who have developmental disabilities when the topic is sex, Lisa T. Maurer, 1999. Rationale, overview, presentation notes and transparency masters. SERC call No.3.13.1MAU

Additional Resources...


Janet’s got her period, Ricci Swart, 1990. Video with storybook, resource book; provides practical guidelines for dealing with menstruation; video gives demo of changing a pad. (Australian)

Hygiene, James Stanfield Co., 1996. Four good videos on personal hygiene, ie. shower, teeth, dress (20 mins. each).

#1 physiological and emotional aspects of being male and female
#2 moral, social and legal aspects of sexuality

TIPS: Telling it plain and simple, Mary Harber, 1999--. Tips for parents and for the classroom. Sexuality Education Resource Centre 2004

From the Sexuality Education Resource Centre: Resources for those with physical disabilities

Spinabilities: A Young Person’s Guide to Spina Bifida Marlene Lutkenhoff, R.N., M.S.N. and Sonya G. Oppenheimer, M.D. Editors For teens who have Spina Bifida provides practical tips and suggestions for becoming independent and managing their health care. It addresses mobility and equipment, skin,

The Illustrated Guide to Better Sex for People with Chronic Pain Second Ed., Robert W. Rothrock, PA-C and Gabriella D'Amore, PA-C; Illustrated by Jonathan Belt. This self-help booklet provides information about frequent problems that interfere with sexual enjoyment for individuals who suffer from chronic pain and suggests simple, basic solutions. It includes six illustrations showing comfortable sexual positions for persons with various pain disorders, and stresses the importance of communication between partners. (may be difficult to find) 1992; ISBN 0963260219; R. Rothrock & G. D'Amore.

Let's Talk About Health: What Every Woman Should Know. A video and curriculum workbook that is designed to help women with developmental disabilities feel more prepared for pelvic and breast exams. The video takes the viewer through each exam step by step in a calm and informative manner. Heaton, C, Roberts, BS, Murphy, L, Meagher, M, Randall, D., The Arc of New Jersey, Women's Health Project, 985 Livingston Ave., North Brunswick, NJ, 08902. Phone: 732-246-2525, Ext. 28

Mother-To-Be: A Guide to Pregnancy and Birth for Women with Disabilities Judith Rogers and Molleen Matsumura Discusses all aspects of pregnancy in the context of disability, from making the decision to have a child to the problems that women with disabilities confront after giving birth. It begins with interviews of thirty-six women who have a range of disabilities, including cerebral palsy, lupus, ataxia, multiple sclerosis, spina bifida, and arthritis. Discusses nutrition, exercise, labor, and delivery. Appendices include dietary plans, a glossary, an extensive index, and lists of resource organizations and suggested readings. 1991; ISBN 0939957299; Demos Medical Publishing, Inc.

Intimacy and Sexuality in MS Rosalind C. Kalb https://nmsscdn.azureedge.net/NationalMSSociety/media/MSNationalFiles/Brochures/Brochure-Intimacy-and-Sexuality.pdf

This booklet is for people with MS and their partners, and addresses the importance of communication between partners. Discusses sexual problems associated with MS for both men and women. A list of resources is provided. 2000; National Multiple Sclerosis Society.

The Sensuous Heart: Guidelines for Sex After a Heart Attack or Heart Surgery Susanne Cambre, R.N., B.S.H.A. This cartoon-style booklet discusses the emotional and physical needs of people who have had a heart attack or heart surgery. It answers questions about sexual intercourse and discusses the effects of alcohol, prescribed drugs, stimulants, and illegal drugs. 1990; ISBN 0939838281; Pritchett & Hull Associates, Inc.

Sex and Back Pain: Advice on Restoring Comfortable Sex Lost To Back Pain Lauren Andrew Hebert, PT. A physical therapist describes various types of back pain and sexual positions for maximum comfort. Line drawings and photographs illustrate recommended exercises and sexual positions for people who experience back pain. All individuals in the photographs are clothed. In an accompanying video, a

**Sexual Concerns When Illness or Disability Strikes** Carol L. Sandowski, M.S.W., A.C.S.W. Discusses the possible effects of various medical conditions (arthritis, diabetes, spinal cord injury, alcoholism) on sexual functioning, relationships, self-esteem, and communication; explores treatments for sexual dysfunction. 1989; ISBN 039806413X; Charles C. Thomas Publisher, Ltd.

**The Sexual Politics of Disability: Untold Desires** Tom Shakespeare, Dominic Davies, Kath Gillespie-Sells, Editors. Based on firsthand accounts, this book examines identity, relationships, sexuality, love, parenting, and abuse and it relates to disability. It demonstrates the barriers to disabled people’s sexual rights and sexual expression and the ways in which these obstacles are challenged. 1997; ISBN 0304333298X; Continuum International Publishing Group, Inc.


**Sexuality & Cancer** American Cancer Society Two booklets on sexuality and cancer: one For the Woman Who Has Cancer and Her Partner and one For the Man Who Has Cancer and His Partner. 1999, Free

**Signs of Sexual Behavior: An Introduction to Some Sex-related Vocabulary in American Sign Language** James Woodward Presents sexuality-related vocabulary in ASL. Offers clear illustrations of more than 130 signs. Comprehensive explanations and notes on derivation are included. A video illustrating the signs is also available. 1979; book, video, ISBN 0932666027; T.J. Publishers.

**The Ultimate Guide to Sex and Disability: For All of Us Who Live With Disabilities, Chronic Pain, and Illness** by Kaufman, Silverberg, and Odette. *The Ultimate Guide to Sex and Disability* is the first complete sex guide for people who live with disabilities, pain, illness, or chronic conditions. Useffor absolutely everyone, regardless of age, gender, or sexual orientation, the book addresses a wide range of disabilities — from chronic fatigue, back pain, and asthma to spinal cord injury, hearing and visual impairment, multiple sclerosis, and more. Expertly written by a medical doctor, a sex educator, and a disability activist, *The Ultimate Guide* provides readers with encouragement, support, and all the information they need to create a sex life that works for them. The authors cover all aspects of sex and disability, including building a positive sexual self-image; positions to minimize stress and maximize pleasure; dealing with fatigue or pain during sex; finding partners and talking with partners about sex and disability; adapting sex toys; and more. 2007

**Books for Professionals**

**Choices: A Guide to Sex Counseling with Physically Disabled Adults** Maureen E. Neistadt, M.S., O.T.R./L. and Maureen Freda, O.T.R./L.; Illustrated by Kerry Anne O’Reilly. Written for rehabilitation professionals who provide sexuality counseling, this book contains guidelines for limited sexuality counseling and
examines issues of intimacy and communication, and sexual response cycle. Discusses functional and sexual difficulties caused by disabilities and the impact on social issues such as privacy, dating, marriage, and childbearing. Reading and resource lists are included. 1987; ISBN 0894642014; Krieger Publishing Company.

Providing Comprehensive Sexual Health Care in Spinal Cord Injury Rehabilitation: Continuing Education and Training for Health Care Professionals Mitchell S. Tepper. This curriculum for health care professionals is intended to provide an opportunity for participants to gain knowledge, comfort, and skills to understand and manage the sexual health care of persons with spinal cord injury (SCI). By the end of this three-day program, participants should be able to recognize sexual concerns, demonstrate the communication skills necessary to provide a supportive environment, conduct sexuality assessment interviews with people who have SCI, relay relevant and unbiased sexual information, and provide specific suggestions about sexual options for people with SCI. 1997; ISBN 0965918505; The Sexual Health Network.


Sexuality and Chronic Illness: A Comprehensive Approach Leslie R. Schover, Ph.D. and Søren Buus Jensen, M.D. Using an integrative biopsychosocial approach, this volume reviews basic skills needed to comfortably discuss sexuality with chronically ill patients, assess sexual problems through both psychological and medical approaches, and create a systematic treatment plan. 1988; ISBN 089862715X; Guilford Publications.

Sexuality Issues for Youth With Disabilities and Chronic Health Conditions Cecily Shapland. This policy brief of The Institute For Child Health Policy addresses teen pregnancy prevention and risk factors for teen pregnancy as they relate to youth with disabilities. Discusses strategies to address the needs of youth with disabilities in such programs as sexuality education, community family planning services, community partnerships, and contraceptive needs. 1999; Free online; The Institute for Child Health Policy.

Mary Greenfield’s (ACLD) Resources for Working with Persons with Intellectual Disabilities
Mary Greenfield greenfieldm@acld.org

Books

A 5 Is Against the Law! Social Boundaries: Straight Up! An honest guide for teens and young adults.  

A Very Touching Book. Jan Hindman. This book is useful when you wish to teach children to recognize  
different kinds of touch. Great pictures with good humor.

Face Your Feelings! A Book to Help Children Learn About Feelings. Concept developed by Lawrence E.  
Shapiro. Childswork Childsplay. 1993. Also available, a set of cards with the faces.

2002


Sherrie Vavrichet and R. Kay Tolle. Available through www.lifecycleeducation.com. This is a curriculum  
for high school age individuals with cognitive, developmental or learning disabilities.

The New Social Story Book: Illustrated Edition. Carol Gray. www.the graycenter.org. This is for use with  
children and adolescents with autism who need help with social situations.

by an adult on the autism spectrum. She explores sexuality from her vantage point.

Shared Feelings. A Parent Guide to Sexuality Education for Children, Adolescents and Adults Who  


Three Kinds of Touches. Jane Buchanan. Pennsylvania Coalition Against Rape. 1999. The vocabulary,  
pictures and concepts in this book are presented clearly for young children through middle school. There  
is also a preschool curriculum and other materials available.

Unwritten Rules of Social Relationships. Decoding Social Mysteries Through the Unique Perspectives  
written by two individuals with autism for everyone.
Curricula, Videos and Miscellaneous


Sexuality Education for Persons With Severe Developmental Disabilities. (Seven Teaching slide programs) James Stanfield

Taking Care of Myself. A Healthy Hygiene, Puberty and Personal Curriculum for Young People With Autism. Mary Wrobel. Future Horizons. 2003. This is a combination of social stories and activities aimed specifically to address the health and safety needs of people on the autism spectrum. Can also be used with other individuals with disabilities.

We Can Stop Abuse. A Sexual Abuse Prevention Curriculum For Persons With Developmental Disabilities. Sandy Laesch and Shirley Paceley. Blue Tower Training Center, Decatur, IL 2004

Websites of interest:
www.diverse-city.com The website for Dave Hingsburger’s books and other good resources including the video, Stop Abuse.

www.do2learn.com A site with information, activities, and strategies for parents & professionals to use with children, adolescents, and adults. It has some wonderful interactive programs on facial expressions and good resources for visual communication.


www.grasp.org An educational and advocacy organization serving individuals on the autism spectrum. It has support groups that are both online and regional. The regional groups meet in person.
www.jimjacksonanatomymodels.com This is the site if you are looking for realistic male/female pelvic models.

http://www.speakingofspeech.info/Pragmatics/What_is_a_Bad_Touch_Board2.pdf Speaking of Speech social stories. This one is about “bad touch.” Many, many other social stories available at http://www.speakingofspeech.com/Social_Skills_Pragmatics.html

www.stanfield.com The website for James Stanfield. Circles program available through them.

www.teachabodies.com Great for use with persons with intellectual disabilities. Anatomically detailed dolls for use by parents and professionals.


Sexuality Resources Online
Sex and D isabilities: General Resources


Information: Sex and Disability http://www.comeasyouare.com/sex-information/sex-and-disability/


Sex Ed http://www.med.umich.edu/yourchild/topics/disabsex.htm

Sex Ed http://www.sexsupport.org/SexEd.html

Sex and Cancer – Resources from the University of Michigan http://www.cancer.med.umich.edu/files/sexuality_and_cancer_information_guide.pdf

PleasurABLE: Sexual Device Manual for Persons With Disabilities https://docs.google.com/viewer?a=v&pid=sites&srcid=ZGVMYXVsdGRvbWfpbnxzcGluYWxjb3JkaW5qdXJ5YW5kc2V4dWFsaXR5fGd4OjEzZTFkZTg5ZTlwM2M3YmEm


“Doin It: Sex, Disability, and Videotape” from “The Empowered Fe Fes” – documentary by advocacy group on sexuality and disabilities [https://vimeo.com/48557485](https://vimeo.com/48557485)


Parent Advocacy Coalition for Educational Rights: [www.pacer.org](http://www.pacer.org). Parent training and information center for families of children and youth with all disabilities from birth through 21 years old. Parents can find publications, workshops, and other resources about a number of topics, including sexuality and disabilities.

Center for Parent Information and Resources: [http://www.parentcenterhub.org/repository/sexed/](http://www.parentcenterhub.org/repository/sexed/). Contains information about sexuality education for students with disabilities for use with parents and teachers. The site also contains information about specific disabilities and sexuality, such as autism spectrum disorders, cerebral palsy, and spina bifida.


Disabled Parenting Project [https://disabledparenting.com/](https://disabledparenting.com/)

Sexuality Resources Online – Videos
AMAZE video series on sexual health [https://amaze.org/](https://amaze.org/)

Teens and Sex Video Archive (some not specific to teens with disabilities) [http://www.sexetc.org/page/video_archive/](http://www.sexetc.org/page/video_archive/)

Sex and Physical Disabilities (includes brief profanity) [https://www.sexsmartfilms.com/premium/film/419/45/19/-sex-abled--disability-uncensored](https://www.sexsmartfilms.com/premium/film/419/45/19/-sex-abled--disability-uncensored)


How to Insert a Tampon [http://www.youtube.com/watch?v=P2nCzE2Bzg](http://www.youtube.com/watch?v=P2nCzE2Bzg)
[https://www.youtube.com/watch?v=O3G9H5H89mY](https://www.youtube.com/watch?v=O3G9H5H89mY)

How to Change a Pad, Step by Step [https://youtu.be/K77HJ4U5p0E](https://youtu.be/K77HJ4U5p0E)
Pre-teens/teens and Menstruation http://www.beinggirl.com/my-period/period-protection/
http://kidshealth.org/misc/movie/bodybasics/bodybasics_female_repro.html

Menstruation Information/Intellectual Disabilities Part 1:

“I am a Beautiful Person – Sexuality and Me” (PACER Center)
https://www.youtube.com/playlist?list=PL38BD0709A5D99552


From the Cerebral Palsy Foundation: Tips for Having a Successful OB/GYN Appointment
https://cpresource.org/topic/womens-health/tips-for-obgyn

Other Resources
From the American Health Lawyers Association (AHLA) - A Handbook for Parents: The Individuals with Disabilities Education Act PDF (available for free) https://www.healthlawyers.org/store/Pages/Product-Details.aspx?productid={18FB74CB-B287-E511-8B77-0050569E6195}

http://www.netsmartz.org Internet safety and children/teens, a program from the National Center for Missing and Exploited Children

http://depts.washington.edu/healthtr/ Adolescent Health Transition Project from the Center on Human Development and Disability, University of Washington (information on transition from adolescence to young adulthood and beyond)