

Sexuality Resource Guide

Children with Disabilities or Chronic Illness

Sexuality is a normal part of human development. It is important that all individuals, with or without a disability and/or chronic illness, are educated about sexual development and given the chance to explore, enjoy, and express their sexuality in positive and healthy ways. There is no “right way” to teach about sexuality. It is a process that will involve success and failure just like teaching about any other subject. Developed by Neurodevelopmental Pediatrics at NMCP, this resource guide is designed to serve as a starting point in providing resources about sexuality for children with disabilities or chronic conditions and their parents. Nothing in this guide is intended to replace medical consultation with a qualified health or medical professional. If you have questions, see your healthcare provider. Resources listed do not constitute endorsement.

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1). BOOKS FOR YOUTH:

"A 5 is Against the Law! Social Boundaries Straight Up! An Honest Guide for Teens and Young Adults" by Kari Dunn Baron. Written in a user-friendly style, this book offers a down-to-earth look at the kinds of social situations many teens and young adults struggle with. It takes a narrower look at challenging behavior with a particular focus on behaviors that can spell trouble for adolescents and young adults who have difficulty understanding and maintaining social boundaries. 2007; \$14.95; ISBN -10:1-931282-35-8; Autism Asperger Publishing CO.

Caution: Do Not Open until Puberty! An Introduction to Sexuality for Young Adults with Disabilities by *Rick Enright, B.A., M.S.W.* This book is intended as an icebreaker for an open discussion of sexuality between adolescents with disabilities and their families. It addresses decision making, anatomy, sexual response, physical disability and sexual functioning, etc. 1995; \$9.95; ISBN 0968041507; *Devinjer House.*

Changes in You: A Clearly Illustrated, Simply Worded Explanation of the Changes of Puberty for Boys and Changes in You: A Clearly Illustrated, Simply Worded Explanation of the Changes of Puberty for Girls both by *Peggy C. Siegel.* Simple language and easy to read, these books explain the changes that boys and girls experience during puberty. Topics include physical development, anatomy, masturbation, health, doctor’s visits, public and private behaviors, and unwanted touch. The boy’s book also addresses wet dreams, and the girl’s book addresses menstruation. Parents’ guides are available for sons and daughters with special needs. 1997; \$8.95/each; *Family Life Education Associates.*

Easy for You to Say: Q &As for Teens Living with Chronic Illness or Disability by *Miriam Kaufman, M.D.* This book offers practical advice, straight talk and honest answers to questions that teens have relating to chronic illness or disability. Chapters include “Sexuality,” “Family Relationships,” “Doctors and Medical Issues,” “Friends and Dating,” “School and Work,” “Alcohol, Drugs, and Medication,” “Recreation,” and “Transitions.” 1995; \$15.95; ISBN 1550136194; *Firefly Books.*

Growing Up on the Spectrum: A Guide to Life, Love, and Learning for Teens and Young Adults with Autism and Asperger's by Lynn Kern Koegel and Claire LaZebnik. This comprehensive guide for teens with autism has a section specific to relationships and sexuality that covers dating and sex for teens with autism. 2009. ISBN:978-0-670-02067-6; The Penguin Group.

Taking Charge: Teenagers Talk about Life and Physical Disabilities, by Kay Kriegsman, Elinor Zaslow and Jennifer D'Zmura-Rechsteiner. Includes chapters on the topics of Communication, Independence, Relationships, Dating and Sexuality. 1992. ISBN-10: 0933149468. [Woodbine House](http://www.woodbinehouse.com)

Hand Made Love: A Guide For Teaching About Male Masturbation by Dave Hingsburger. This book and video set discusses privacy, pleasure and the realities of sharing living spaces with others. The narrator of the video talks about myths and suggests that masturbation can be a way of learning about sex, while the book discusses masturbation from the point of view of both health and pleasure. Available from <http://www.diverse-city.com>.

Finger Tips: A Guide For Teaching About Female Masturbation by Dave Hingsburger and Sandra Haar. This book and video set is aimed at teaching women with developmental disabilities about masturbation. It also confronts typical myths about female sexuality. A gentle, positive film that is clear, graphic and dignified. The book includes a step by step photographic essay about masturbation, and the joy of private time. Available from: <http://www.diverse-city.com>

2). Other Recommended Readings

Sarah Attwood (2008). **Making Sense of Sex: A Forthright Guide to Puberty, Sex and Relationships for People With Asperger's Syndrome**. Puberty is a time of huge change in the physical body, in emotional experience and in social relationships. Having an understanding of these developments and learning how to deal with them is essential, and for people with Asperger's syndrome it can be a challenge to get to grips with the social and emotional aspects of puberty, sex and relationships. This book is ideal for those who need clear, detailed explanations and direct answers to the many questions raised by puberty and sexual maturity.

Couwenhoven, Terri. (2007) **Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality: A Guide for Parents and Professionals**. Easy-to-read guide that covers topics like emotions, personal space, self-care, appropriate levels of affection, and topics important for teens and young adults, like puberty, fertility, periods, bras, erections, and relating to the opposite sex.

Henault, Isabelle.(2005) **Asperger's Syndrome And Sexuality: From Adolescence Through Adulthood**. Playing the dating game is often tricky: all the more so for individuals with Asperger's Syndrome. In this comprehensive and unique guide, Delivers practical information and advice on issues ranging from puberty and sexual development, gender identity disorders, couples' therapy to guidelines for sex education programs and maintaining sexual boundaries.

Melberg, Karen, and Dave Hingsburger (2000). **Sexuality: Your Sons & Daughters with Intellectual Disabilities**. Baltimore: Paul H. Brooks Publishing Co. An inspiring book on how to raise a proud and confident son or daughter.

Murphy, Nancy and Elias, Ellen Roy (2006). "Sexuality of Children and Adolescents with Developmental Disabilities". Pediatrics 2006:118; 398-403.

Newport, Jerry and Newport, Mary (2002) **Autism-Asperger's & Sexuality Puberty and Beyond**. This book tackles dating, relationships, and sexuality issues for individuals with Asperger's Syndrome and autism, emphasizing the importance of self-confidence.

Schwier, Karin Melberg and Hingsburger, David (2000). **Sexuality: Your Sons and Daughters With Intellectual Disabilities**. This book provides information to parents and caregivers on interacting with their children – no matter what their age or ability – in a way that increases their self esteem, encourages appropriate behavior, empowers them to recognize and respond to abuse, etc.

Walker-Hirsch, Leslie. (2000) **The Facts of Life... and More: Sexuality and Intimacy for People with Intellectual Disabilities**. This book is written for professionals to enable them to support people with intellectual disabilities in making decisions regarding their sexuality. It presents issues in a broad, societal context, and covers areas like special education and sexuality education, sexuality and intellectual disability in our culture, types of treatment, education, and counseling, and consent, abuse, dysfunction and mental health.

3. Web Resources:

Meeting the Challenges of Adolescence: A Guide for Parents © By R. Kaan Ozbayrak, MD, Adolescence is full of challenges for any child. The change is fast, everywhere, and hard to keep up with: The body changes in response to increasing levels of sex hormones...
<http://www.aspergers.com/Adolesc.htm>

Puberty - How Can I Help My Autistic Child Handle Puberty

In our psychology practice, there have been a lot of questions about **sexuality** and children with **autism** and other special needs who are reaching puberty. ...
<http://autism.about.com/od/familyissuesandautism/f/pubertyfaq.htm>

Autism Myths - Myths about Sexuality and autism

Here are just a few of the myths surrounding autism perpetuated by TV, magazines and movies...
<http://autism.about.com/od/whatisautism/tp/topmyths.htm>

An Evaluation of a Community-Based Sexuality Education Program for Individuals with Developmental Disabilities. Selected Review of Issues Related to Sexuality of Individuals with Developmental Disabilities <http://www.ejhs.org/volume5/plunkett/review.html>

Is it really possible to teach "social skills?" - Autism

Lack of social skills is usually considered a "core deficit" among people with autism. But what, exactly, is meant by this? Interestingly, there really isn't a single consensus...
<http://autism.about.com/b/2009/01/18/is-it-really-possible-to-teach-social-skills.htm>

Teaching sex education to children with autism based on their individual functioning level.
<http://www.child-autism-parent-cafe.com/sexuality-and-autism.html>

A Health Handbook for Women with Disabilities by Jane Maxwell, Julia Watts Belser, and Darlena David. This handbook was developed with the help and experience of women with disabilities in 42 countries... Download FREE online at
http://www.hesperian.org/publications_download_wwd.php

3). Links to Organizations:

About Autism.Com: <http://autism.about.com//od/transtioncollegejobs/f/sexed.htm?P=1>

American Academy of Pediatrics (AAP) 2006 Policy Statement –Sexuality Education of Children and Adolescents with Developmental Disabilities.

Nancy A. Murphy, MD, Ellen Roy Elias, MD for the Council on Children With Disabilities. PEDIATRICS Vol. 118 No. 1 July 2006, pp. 398-403

http://aappolicy.aappublications.org/cgi/content/full/pediatrics_118/1/398

Autism Society, Tidewater Virginia . www.tidewaterasa.org

National Dissemination Center for Children with Disabilities (NICHCY). Sexuality Education for Children and Youth with Disabilities. <http://www.nichcy.org/Pages/sexed.aspx>

Sections include information on defining sexuality and how it develops, social skills, teaching children about sexuality, affects of disability on sexuality, and relationship issues for young adults.

Parent Centers serve families of children of all ages (birth through 26 years) with all disabilities; physical, cognitive, behavioral, social, and emotional. They provide training and information to help parents better meet the educational needs of their children with disabilities. Visit:

<http://www.taalliance.org/ptidirectory/index.asp> to find the Center nearest you.

Sexuality Information and Education Council of the United States (SIECUS) is a national, nonprofit organization, which affirms that sexuality is a natural and healthy part of living.

SIECUS develops, collects, and disseminates information, promotes comprehensive education about sexuality, and advocates the right of individuals to make responsible sexual choices.

SexEdLibrary is a project of SIECUS, and offers lesson plans, including lessons for parents.

www.siecus.org Annotated Bibliography including sexuality and disability is available.

The American Association on Intellectual and Developmental Disabilities (AAIDD) is an international organization of professionals and citizens concerned about intellectual and developmental disabilities. <http://aamr.org/>

The ARC. a national organization of and for people with intellectual and developmental disabilities and their families. It is devoted to promoting and improving supports and services for people with intellectual and developmental disabilities and their families. www.TheARC.org.

University of Michigan Site: <http://www.med.umich.edu/yourchild/topics/disabsex.htm>

University of Illinois at Chicago (UIC) Institute on Disability and Human Development's LEND / UCEDD program's Sexuality and Disability Consortium (SDC).

<http://www.idhd.org/DHDres.html>

Woodbine House: Online catalogue bookstore with books on disabilities that cover a range of topics including sexuality. www.woodbinehouse.com

Autism Behavior Challenges? To Join: Send a blank email to AutismBehaviorProblems-subscribe@yahoogroups.com Helpful discussion/support on topics covering a ranges of behaviors... self stimulating, self injurious, aggressive, inappropriate etc and different ways of addressing these problems.