

Medical Home Listserv Archives

This page provides information on past questions posted on the Medical Home LISTSERV. Responses are provided by physicians, allied health professionals and parents of children with special needs.

The inclusion of any resource or link in these pages does not imply endorsement. As information changes rapidly, please check with each sponsoring organization as to whether the information you are receiving on their web site is current. If you have information or resources to add to this request, please e-mail us at medical_home@aap.org.

Posted October 25, 2005

Request: The AAP Council on Children with Disabilities is working on a clinical report titled, "Sexuality of Children and Adolescents With Developmental Disabilities." (This report will be published in the July 2006 issue of *Pediatrics*)

The authors want to know if there are resources available that the AAP could potentially incorporate into the report (in a list of resources), or use as complements to the report. Specifically we are looking for resources (eg, brochures, videos, DVDs) that focus on sexuality issues for CYSHCN, in particular, information for pediatricians to give to their patients and families.

From	Resources
Jenny Galske Reid, MS, LPC-S Post-Adoption Supervisor Family Adoption Connections and Enrichment Services	"Become an Askable Parent" booklet : American Social Health Association This 20-page booklet for parents outlines the ages and stages of a child's sexual development from birth through the teen years. It offers suggestions to parents on when and how to provide information, discuss values, and maintain open communication. Additional Information: Booklet \$1 - Large qty discounts available
Linda Rowley Family Village Coordinator	Try the Family Village file on Sexuality and Disabilities
Cherie Takemoto, Exec Director PEATC (Parent Educational Advocacy Training Center) Springfield, VA	Breast Health Access for Women with Disabilities "Table manner and beyond: The Gynecological Exam for Women with Developmental Disabilities and Other Functional Limitations" For further information about this publication, contact Kathleen Lankasky , at 510/278-0106
Beth Swedeen Waisman Resource Center Madison, WI	Our Healthy & Ready to Work Transition project at the Waisman Center just completed a comprehensive curriculum on sexuality and safety relationships in the community called SAFE: Safety Awareness for empowerment . This has been VERY well received both by county DD Programs and

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local school districts. We have received orders from across the country, but would appreciate any further outreach/ awareness you can create in disseminating this useful tool.

Additional Information: DVDs, videos,. booklets, curricula, fact sheets (Costs range from free to \$125)

[Leolinda Parlin](#)

Family Voices of Hawai'i

Probably the foremost authority on sexuality and developmental disabilities is David Hinsberger from Canada. His work is legendary. His books, videos, audiotapes are available at www.diverse-city.com.

I would highly suggest calling him before the report goes to press just to make sure the AAP statement is consistent and comprehensive in it's scope. The last thing you'd want is the disability community to be in disagreement with the AAP policy statement. He does an entire lecture on myths and mis-conceptions about sexuality and there's this test you take and then he goes through the answers. It would be a blast to see how well the AAP Board of Directors would do on the test.

Additional Information: Costs range from \$3 - \$100s

[Janet S. Martin, RN, CMC](#)

Care Connection For
Children; Children's
Hospital of The King's
Daughters
Norfolk, Virginia

Many youth attend this rehab center and I am sure that they may have a wealth of information to share with you.

Contact Information: [Woodrow Wilson Rehab Center](#) Box W; P O Box 1500; Fishersville, VA 22939-1500; Local - (540) 332-7000; Toll-Free - (800) 345-9972; TTY - (800) 811-7893; FAX - (540) 332-7132

[Maureen Grissom, Ph.D.](#)

Post-Doctoral Fellow
Department of Health
Psych
University of Missouri
Columbia, MO

Your request for information about sexuality education for individuals with disabilities was forwarded to me by Dr. Janet Farmer. I am a postdoctoral resident at the University of Missouri-Columbia in the Thompson Center for Autism and Neurodevelopmental Disabilities and recently came across the need for such resources for a teen with autism and mental retardation. I hope you will be able to benefit from my search as I found these two websites helpful.

- [The ARC of Minnesota website](#) lists a variety of available print and video materials addressing sexuality and targeted to individuals with mental retardation and other developmental disabilities

- A section of the website from the [National Autistic Society in the United Kingdom](#) which addresses "Socio-sexual development of people with autism" including topics such as inappropriate touching of other people and excessive masturbation.

[Bobi A. Crump, MSN, CPNP](#)

Alta California Regional

I use the following programs:

- Changes in You by Peggy Siegel, Published by James Stanfield

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Center

Company, 1991

- Life Fats, Sexuality, Published by James Stanfield Company, 1992

The first program is written for developmentally disability youth between the 4th and 9th grade years in school. I also strongly advocate for regular sexuality education in the school setting or through the IEP. The second program is geared towards adults and addresses issues such as dating safety and sexually transmitted diseases.

Many of the parent groups that have formed around specific disability diagnoses also have materials regarding Sexuality.

The web site "[Disability Solutions](#)" has a publication archive and many great references for sexuality education. In particular Volume4, Issue 5 a Two-part series titled: [Sexuality Education: Building a Foundation for Healthy Attitudes](#).

I hope this information is helpful. I have not researched new resources and continue to use the tried and true.

[Sarah Renner](#)

Community Development
Consultant
Employment Policy Group
Center for Disabilities and
Development
Des Moines, IA 50309

- [Annotated Bibliography: Sexuality and Health](#)
- [Specific suggestions, tips, and ideas](#) for effectively teaching youth with developmental disabilities about sexuality topics
- [Becoming sexually able](#): Education to help youth with disabilities

There's quite a lot of misinformation out there and misleading abstinence-only education. If you stick with SIECUS (Sexuality Information and Education of the United States -- and particularly Debra Haffner is good) and AASECT (American Association of Sexuality Educators, Counselors, and Therapists) for materials, you won't go wrong.

[Lisa A. Gorove](#)

U.S. Department of
Education
Office of Special Education
Programs
Washington, DC

I work in the Early Childhood Division of OSEP along with Glinda Hill. I wear 2 hats - one as a Project Officer for Parent Training and Information Centers and one as a parent of two children with differences. My daughter is 10 and has bipolar; my son is 9 and has a number of developmental disabilities. For kids with mental illness there is sometimes (often) a hyper sexuality issue when hormones begin to stir. In fact, for kids with bipolar, hyper sexuality can manifest at very young ages during manic phases. The same holds true with OCD, sensory issues, etc. [The Child and Adolescent Bipolar Foundation](#) is a great resource...

** I'm writing this from a "Mom perspective" - I am unfamiliar with the research base.

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[Deana O'Brien](#)
Parent Consultant
Missouri Partnership for
Enhanced
Delivery of Services ([MO-
PEDS](#))
Columbia, MO 65212

There is a neat resource at the [MODDRC](#) (MO Developmental Disabilities Resource Center) on sexuality entitled "[Sexuality: Preparing Your Child with Special Needs.](#)"

[Playground Politics](#) is a book that goes far beyond informing parents of what happens on the playground. It is a book that revisits the grade-school years and helps parents understand the changes and challenges children encounter as they face the emotional milestones of this age. It explains how children see themselves in their world and how they relate to others. Then, the authors introduce the five steps parents can use to support their children through this development. The book is accented by stories of children with emotional challenges and how their parents learned to use the five principles to support their children as they work through the challenges. The book addresses aggression, rivalry, competition, self-esteem, and peer relations. Learning challenges and other school-related topics are examined, as well as sexuality and puberty, and balancing fantasy and reality. The afterward identifies the milestones for the different stages of the middle years and provides the general expectations of children in that particular stage.

[Susan G. Igdaloff, M.D.](#)
Medical Consultant
Southern California
Regional Office
Children's Medical Services
Branch
Los Angeles, CA 90013

[AAP Developmental and Behavioral Pediatrics](#): Information on Sexuality Education for Persons with Developmental Disabilities: Selected Resources
[Center for Development and Disability](#): Information on Developmental Disabilities and Sexual Assault
[People with Mental Retardation & Sexual Abuse](#): by Leigh Ann Reynolds, M.S.S.W., M.P.A. Health Promotion & Disability Prevention Specialist
[Centre for Developmental Disability Health \(CDDHV\)](#): Fact Sheet on Sexuality
[Sexuality and Disabilities](#): Books on sex education and sexuality for people who live with disabilities
[University of Michigan's Your Child: Development and Behavior Resources](#): Sexuality and Kids with Disabilities or Chronic Illness

[Jean Caldicott](#)
Human Services Counselor
Center for Autism and
Related Disabilities
University of South Florida

[Library of the Center for Autism and Related Disabilities at University of South Florida in Tampa.](#)

[Darlene Kardatzke, M.D.](#)
Developmental Pediatrics
Riley Hospital for Children

We recommend the book: [Sexuality: Your Sons and Daughters with Intellectual Disabilities](#) by Schwier and Hingsburger, Brookes Publishing. Also [Leslie Walker-Hirsch](#) has a website with good information.

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[Nina Baker](#)

Family Partner NDE/HHSS
PTI Nebraska

Please check out the resources about sexuality from the Pacer Center in MN. I have just purchased, for our use, "Sexuality and Youth with Disabilities" and a video for Parent of Teens with Disabilities titled "I Am a Beautiful Person - Sexuality and Me. You can find these listed on the Pacer website. www.pacer.org

[Patricia C. Davis, M.D.](#)

Columbia Pediatric Clinic
Columbia, TN 38401

"Growing Up: A Social and Sexual Education Picture Book for Young People with Mental Retardation: by Victoria Shea and Betty Gordon. Can be ordered through the [Center for Development and Learning](#) (Att; Megan Lewis) CB#7255, UNC, Chapel, NC 27599 (919-966-4788). Chapters cover social behavior, personal safety, sexual anatomy, puberty, menstrual hygiene for girls, sexual behavior, pregnancy and birth control.

[Diane O'Connor RN,MPA](#)

MN Dept of Health
Family Health Division
Reproductive Health Unit

I know that in the past [Planned Parenthood](#) did some really good work on sexuality issues with the disabled.

[Tony Paulauski](#)

Executive Director
[The Arc of Illinois](#)

The following are available at: www.barnesandnoble.com

Doing What Comes Naturally? Dispelling Myths and Fallacies about Sexuality and People with Developmental Disabilities by Oreida Horn Anderson

Ms. Anderson challenges the beliefs and attitudes of family members, educators, and professionals concerning the sexuality of people with developmental disabilities and guides them in meeting the social-sexual needs of the people they love and serve. Overflowing with passion and filled with wisdom, this book provides a philosophical, yet practical definition of sexuality.

My Body/My Choice - by Shirley Paceley, illustrated by Annette Russo Penhallegon

My Body/My Choice is a fully illustrated, mini-book written for adolescents and adults with developmental disabilities. This book covers the basics of body safety and is empowering people with disabilities across the nation to resist and report sexual abuse. The book can be used in group settings as well as on an individual basis. It has been incorporated into "reading nights" in group homes: used in recovery groups and prevention education classes. It is a simple, straightforward way for parents to teach their children about safety from abuse. It can also be used in peer education and "acted out" by individuals with disabilities.

WE CAN Stop Abuse PEER TRAINING MANUAL: A Sexual Abuse Prevention Project For Persons w/ Developmental Disabilities by

Shirley Paceley and Sandy Laesch.

This manual walks the reader through a process on how to teach adolescents and adults with developmental disabilities to teach others to resist and report sexual abuse. This is one component of the WE CAN Stop Abuse project in Illinois. The Peer Training Manual includes a training curriculum for training people to be peer trainers as well as sample presentation activities.

Genesis: In the Beginning... Breaking the Cycle of Sexual Abuse - by Orieda Horn Anderson and Shirley Paceley.

This sexual abuse prevention book targets parents and providers of preschool children with disabilities. This groundbreaking book is an insightful and practical guide which empowers parents, teachers and service providers to give the gift of information to their children about sexuality and safety. The book includes: specific skills to teach young children which may decrease the likelihood of sexual abuse in day care settings: signs of abuse in children with disabilities: and what to do if a child is abused.

Safe Beginnings: Protecting Our Children From Sexual Abuse by Orieda Horn Anderson and Shirley Paceley. (Published 2003.)

Safe Beginnings is a healthy, affirming, "how to" book which can reduce the risk of sexual abuse of all children, with and without disabilities. This practical and powerful book includes strategies for teaching preschool children self-respect, self-esteem, sexuality and safety: skills to teach children which can empower them to resist and report sexual abuse: techniques for teaching the skills to children with disabilities: how to create safe environments in nurseries, preschools, day care centers and schools: tips for raising boys and girls: what to do if abuse occurs: resources and ideas for social change. This "must read" book is written with wisdom and compassion, as well as real life examples.

Feeling Good About Yourself: A Guide For People Working with People Who Have Disabilities or Low Self-Esteem

This book includes ideas and activities to teach self-esteem, socialization skills, sex information, decision making, assertiveness, and preventing victimization.

[Margaret Jahn, ARNP](#)
Children with Special
Health Care Needs
Whatcom County Health
Department

I "wear two hats" in my job at the Whatcom County Health Department, working as a nurse practitioner and public health nurse - both in CSHCN program and also doing medical evaluations for the County Child Advocacy Center / Child Sexual Assault Clinic. It is clear that developmental disabilities are a risk for victimization, and that is certainly on the minds of most

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Bellingham WA

parents I met with through the CSHCN program.

[Helping Children Who May Have Been Sexually Abused - A Guideline for Parents and Caretakers](#)

[Terry Ohlson-Martin and Martha-Jean Madison](#)
Co-Directors, NH [Family Voices](#) Concord, NH

Through the Medical Home listserv came a request for materials on sexuality and disabilities. I am responding from Family Voices in New Hampshire. Through a collaborative effort with the Title V, CSHCN program, Special Medical Services, we did a number of items on sexuality and disabilities a few years back. NH Family Voices has a [lending library](#) and have collected a number of books that we think are especially helpful to families.

Jenny Oliphant
oliph001@umn.edu

The American Red Cross has also published an [HIV/STD Prevention Education Curriculum](#) for Special Populations (low to moderate functioning middle and high school students.) Go to

There are terrific materials available for developmentally delayed adolescents and young adults at [Stanfield publications](#). James Stanfield is the publisher, (1 800 421 6534) and look for CIRCLES: Safer Ways.

[Ceci Shapland, RN, MSN](#)
Co-Director, Healthy and Ready to Work National Resource Center
Vadnais Heights, MN

[The Healthy and Ready to Work National Resource Center](#) focuses on understanding systems, access to quality health care, and increasing the involvement of youth. It also includes provider preparation plus tools and resources needed to make more informed choices!

Part of the Healthy & Ready to Work National Center lists many web sites offering information and [resources about sexuality and reproductive health](#);

[Sexuality Issues for Youth with Disabilities and Chronic Health Conditions](#), PDF file under sexuality;

[Advocates for youth.org](#), Established in 1980 as the Center for population Options, this organization champions efforts to help young people make informed and responsible decisions about reproduction and sexual health. They advocate a positive and realistic approach to sexual health.;

[Youth Resource](#), a Web site created by and for gay, lesbian, bisexual, transgender, and questioning (GLBTQ) young people 13 to 24 years old, takes a holistic approach to sexual health by offering support, community, resources, and peer-to-peer education about issues of concern to GLBTQ young people. Youth Resource has four focus areas: health, advocacy, community, and issues in our lives. Youth Resource is a project of Advocates for Youth which is dedicated to creating programs and advocating for policies that help young people make

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informed and responsible decisions about their reproductive and sexual health.

Advocates provides information, training, and strategic assistance to youth-serving organizations, policy makers, youth activists, and the media in the United States and in developing countries.

THROUGH THE LOOKING GLASS

National Parent-to-Parent Network (parents with disabilities)

The purpose of the [National Parent-to-Parent Network](#) at Through the Looking Glass (TLG) is to connect parents, as well as those who are considering becoming parents, with others who may have shared similar experiences or faced common barriers as parents with disabilities. Parents wishing to join the Parent-to-Parent Network first receive an orientation packet. Guidelines for participating are included in this packet. Once they review the materials in their packet, parents are interviewed over the phone. Despite the additional time needed, this method helps in building trust and facilitating appropriate one-on-one connections between parents. Moreover, these steps allow for close monitoring and prompt attention to parents' concerns or problems should they arise. For example, many parents on our Network also seek consultation with other TLG staff who have disability-related expertise in areas such as custody, adoption, pregnancy and birthing, baby care equipment, publications, resources, and the like. Ultimately, new relationships are formed, and ongoing ones deepen.

NATIONAL INSTITUTES ON HEALTH

[Teen Sexual Health](#) excellent and trusted information on a variety of topics to insure sexual health and informed youth.

ASHA - I WANNA KNOW

[Live Conversation with a Teen-issue Expert !](#)

We're Back!! Got Questions? Our experts, trained health communication specialists, are waiting to answer your questions about sexually transmitted diseases (STDs). You can ask your personal question and get an accurate, up-to-date response from someone who knows about services to prevent, test for, and treat STDs.

GLBT - THE GAY AND LESBIAN NATIONAL HOTLINE

[GLNH](#)

is a non-profit organization which provides a vital service to our community by providing nationwide toll-free peer-counseling, information and referrals: 1-888-THE-GLNH (843-4564)

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The Gay & Lesbian National Hotline is a non-profit, tax-exempt organization dedicated to meeting the needs of the gay, lesbian, bisexual

transgender and questioning community by offering by offering free and totally anonymous information, referrals and peer-counseling. The Gay & Lesbian National Hotline offers free and anonymous services by use of a toll-free telephone number. Callers are able to speak directly to a trained volunteer who will to access a national database of referrals specific to the gay and lesbian community. Currently, our database already contains over 18,000 listings, and is growing daily. This database contains referrals on groups and organizations of every imaginable type (political, religious, sports, professional, etc.). It also houses information on many gay-friendly businesses, restaurants, hotels and clubs as well as doctors, lawyers and therapists. Many callers, especially young people, find the added anonymity of a computer to be more comfortable.

[Recapp](#) provides practical tools and information to effectively relate to sexual risk-taking behaviors. Teachers and health educators will find up to date information and programming materials to assist in working with teens. ETR is the Resource Center for the Adolescent Pregnancy Prevention Program.

www.med.umich.edu Search for disability and sexuality. This site has information about sexuality and children and youth with disabilities.

[Disability Exchange](#) A resource on disability, including sexuality issues for persons with disabilities.

[Disability Connections](#) This site is by a private non-profit organization whose mission is to connect people with developmental disabilities and their families to supports. Information included is on sexuality.

[Siecus Report](#) is an academic publication providing coverage and analysis of sexuality education and sexual health. It is produced by the Sexuality Information and Education Council of the United States. They have served as the national voice for sexuality education and sexual health and sexual rights for almost 40 years.

Garry Gardner, MD, FAAP

[“Taking Care of Myself: A hygiene, puberty and personal curriculum for young people with autism”](#) – by Mary J. Wrobe

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Patricia Tangeman, MEd,
MA, PT
Director, OHSU/CDRC
Framework for Integrating
Special Health Services
Project Portland, OR

I have attached information on sexuality training for practitioners that was developed by the OHSU/RRTC on Health and Wellness. This curriculum has been used to successfully train graduate students in the health professions.

Oregon Health & Sciences University. Portland (OR). [Health & Wellness for Teens with Disabilities: Understanding and Becoming Sensitized to the Issues](#). [Updated 2005 Sept 16; cited 2005 Oct 28].

[Andrea McCullough](#)
Program Assistant
Center for CSN
Children's Hospital &
Regional Medical Center
Seattle, WA 98101

I edit and publish a newsletter for Washington State professionals who work with children with special needs called "[Linkages](#)". Last winter I featured sexuality and children with special needs as a topic and included a few resources and curricula.

There are 4 "articles" within the topic:

- 1- Sexuality and Children with Special Needs;
- 2- Sexuality & Disability: Myth vs. Reality
- 3- Sexual Education Curricula

F.L.A.S.H. Lesson Plans: Comprehensive sexuality education curriculum
Becoming Sexually Able: Education to Help Youth with Disabilities
4- Resources on Sexuality and Children and Youth with Special Needs.

[Judy Janec](#)

- 1- [DisabilityResource.org](#)
- 2- [NICHCY's](#) digest on sexuality education:

[Mara McGrath, MPH](#)
Policy Analyst,
Government Relations
Lucile Packard Children's
Hospital

Palo Alto, CA 94304

[Abuse and Neglect of Adults with Developmental Disabilities: A Public Health Priority for the State of California](#)

A report of:

Protection and Advocacy, Inc.; State Council on Developmental Disabilities; USC University Affiliated Program; The Tarjan Center for Developmental Disabilities, UCLA; August 2003; PAI Publication #7019.01

Resources from our sexuality conference last year.

Sexual rights

Sexual rights embrace human rights that are already recognized in national laws, international human rights documents and other consensus documents. These include the right of all persons, free of coercion, discrimination and violence, to: the highest attainable standard of health in relation to sexuality, including access to sexual and reproductive health care services; seek, receive and impart information in relation to sexuality; sexuality education; respect for bodily integrity; choice of partner; decide to be sexually active or not; consensual sexual relations; consensual marriage; decide whether or not, and when to have children; and pursue a satisfying, safe and pleasurable sexual life. The responsible exercise of human rights

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requires that all persons respect the rights of others.

[Diana MTK Autin](#)

Executive Co-Director

Statewide Parent Advocacy

Network

Newark, NJ 07102

Useful fact sheets as well as a curriculum developed by [Maine Healthy and Ready to Work](#) that addresses some issues re: sexuality.