



# Medical Home Newsletter

Sexuality and People with Disabilities:  
"To be human is to be sexual" Winder, 1983

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## Welcome

The purpose of this publication is to support health care providers in the establishment and maintenance of Medical Homes for their pediatric patients by providing tools and information for use in their practices.

**To offer comments, or suggest ideas for future newsletters, contact the Project Coordinator Barbara Ward, RN BS [bward@utah.gov](mailto:bward@utah.gov).**

Copies of newsletters may be found on the Utah Medical Home web portal: <http://www.medhomeportal.org> (click on Newsletters/Conf. Calls)

## Sexuality and People with Disabilities

"Sexuality is an integral part of the personality of everyone: man, woman, and child. It is a basic need and an aspect of being human that cannot be separated from other aspects of human life. Sexuality is not synonymous with sexual intercourse (and it) influences thoughts, feelings, actions, and interactions and thereby our mental and physical health" (WHO, 1975)

The American Academy of Pediatrics advises that pediatricians discuss sexuality with all patients, including those with developmental disabilities. Sex and sexuality are topics that we might prefer to avoid, but children with developmental disabilities and their families need information and advice about sexual development.

In a study aimed at assessing sexual behaviors among adolescents by Suris et al J. Adol Health 1996 19 124-131, no differences were found between adolescents with and without chronic conditions in the proportion ever having intercourse, age of sexual debut, becoming pregnant, patterns of contraceptive use, or sexual orientation. Adolescents with chronic conditions are at least as sexually involved as their peers and significantly more likely to have been sexually abused. The mean age at first intercourse for males ranged from 13.2-13.9 years and females from 13.9-14.2 years. All teenagers, including those with chronic conditions, need comprehensive sexuality education and anticipatory guidance in this population is high for all teenagers.

***Sexuality in people with developmental disabilities is commonly regarded as a problem rather than an affirming part of human life.***

Sweeney, MARSHMedia White Paper, 2007 [www.marshmedia.com](http://www.marshmedia.com)

## Common Myths (i.e. Not True)

People with developmental disabilities:

- They are asexual
- They are perpetual children and need to be protected
- They are sexually impulsive, deviant and "oversexed"
- They are not intelligent enough to understand sexual desire and activity
- They are not capable of intimate, emotional relationships

***Society's attitudes toward those with disabilities are more of hindrance to an adolescent's sexual development than any limitation of the condition itself***  
Berman et al Comprehensive Pediatric Nursing, 1999

Although pediatricians routinely talk to typically-developing teens about sexuality, it can be more difficult to cover this topic with those with disabilities. However, pediatricians should not assume their patients with developmental disabilities are not sexually active, and it is best to address these issues in the context of anticipatory guidance. Physicians can begin the dialogue at early childhood office visits by starting with toilet training and dressing themselves. Prior to the onset of puberty is a natural time to begin talking about these issues, keeping in mind that some individuals with neurodevelopmental disabilities demonstrate physical maturity sooner than their peers. "These discussions help children lead fuller lives, manage their bodies changes and avoid sexual abuse and social isolation." Pupillo, AAP news, July 2006 Although there may be multiple caregivers, the individual with disabilities needs privacy and the opportunity to speak with their doctor in confidence.

***Our goal should be to create an atmosphere where the adolescent or his or her parents can bring up these issues and receive appropriate medical advice.***

***Paul Lipkin MD FAAP***

## Education

The perception that people with disabilities are non-sexual can present a major barrier to safe sex education. The sad truth is that parents and physicians are assuming the school is covering these things, but the information is often lacking in special education classes. The school assumes the parent is educating their special needs student and in truth no one is addressing this area of their lives.

Although IDEA legislation provides for equal educational opportunities for students with disabilities, there remains a lack of attention to the subject of human

sexuality. The AAP recommends that an appropriate program for children with disabilities cover the following material:

- Body parts
- Pubertal changes
- Personal care and hygiene
- Social skills
- Medical examinations
- Sexual expression
- Contraception strategies
- Rights and responsibilities of sexual behavior

*The likelihood of abuse is lessened when “sexual questions and behaviors of individuals are freely discussed within a family and sexual development is promoted” Sweeney, MARSHMedia White Paper 2007*  
[www.marshmedia.com](http://www.marshmedia.com)

#### **Tips for Physicians**

- Make sure you understand any differences between your personal beliefs and factual information.
- Consider how sexuality education is presented. If the disability affects how they learn, consider presenting in a different format.
- Some may need specific information on how a disability affects their sexuality.
- Remember that sexuality education is not just about sex.
- Include information about feelings, communication, boundaries, and building relationships.
- Include responsibility for one’s body and actions.
- Demonstrate a respect for their personal space and ability to make decisions.
- Incorporate the young person’s family members in providing education about values.
- Look at all handout materials before using them for education.
- Consider whether the material is appropriate for the learning style and developmental age of the individual.
- Be clear, using correct words for body parts and sexual activities (clear up misunderstandings).
- Include sexuality issues in staff training; be sure staff are prepared to deal with sexuality issues and know where to direct questions.
- Respect the young person’s need for privacy.
- Don’t wait for a crisis, many problems with inappropriate behavior come from a lack of education about sexuality and social norms.
- Provide basic information about the body, the difference between healthy and abusive touch.
- Explain the difference between public and private behaviors before embarrassing activities occur.
- Recognize that caregivers for children with disabilities may not understand the normal processes of sexual development.

#### **Tips for Parents**

- Assess your own feelings before talking with your child about sexuality. “Do you believe that people with disabilities have a right to full physical intimacy?” If you are fearful or think it is immoral, talk to a counselor or minister before bringing up the issues with your child. You may find that old ideas regarding sexuality and the disabled have no basis in either morals or religion.
- Try to discuss the issues without embarrassment or fear. Remember your child is learning about sex from peers, advertisements, TV etc. The ideal teacher is you.
- Give guidance as you would a normally developing child in these areas, private body parts, private acts, hygiene, maturation, body changes, masturbation, appropriate and inappropriate sexual behavior, birth control, marriage and parenthood.
- Instruct your child in good touch/bad touch and who is appropriate to care for them.
- Discuss sexual exploitation with your child and strategies to handle the situation.
- Understand your child’s capacity for long term intimate relationships.
- While imparting your own set of values, try to emphasize that sex is a natural component of human life and involves more than sexual intercourse.
- Be informative, realistic, open and affirmative with all children.

#### **Resources**

##### **Local**

**Medical home Phone Conference transcripts** posted to [www.medhomeportal.org](http://www.medhomeportal.org), from the Home Page > About medical home > Newsletters/phone conf

**October 2005: Menstrual management for CSHCN** has information on hygiene, school management, hormone management, exploitation and Utah law re sterilization (Lisa Samson-Fang, MD)

**September 2006: Male Puberty in the Developmentally Disabled** discusses sexuality in the disabled and sexual expression, managing inappropriate behaviors, referrals to research papers, exploitation, androgen suppression (Philip Baese, MD)

**November 2005: Genetic counselors and resources** provides information on the services counselors at the University can offer (Pilar Lenglet, MS, CGC)

**October 2007 Sexuality and the Disabled (coming soon)** (Nancy Murphy, MD)

## Contact with questions

**Philip Baese, MD** is a triple board physician in the University of Utah Neurobehavior/HOME Program. Contact for questions regarding behavior management and sexual behavior 801-581-5515 [philip.baese@hsc.utah.edu](mailto:philip.baese@hsc.utah.edu)

**Lisa Samson-Fang, MD** is a developmental pediatrician at the University of Utah. Contact for menstrual management issues. 801-585-1017 [lisa.Samson-fang@hsc.utah.edu](mailto:lisa.Samson-fang@hsc.utah.edu)

**Nancy Murphy, MD** Chair of the AAP council on children with disabilities and associate professor at University of Utah. Contact for questions and issues related to the disability 801-587-9978 [Nancy.Murphy@hsc.utah.edu](mailto:Nancy.Murphy@hsc.utah.edu)

## Women's Health Issues

**Nicole Mihalopoulos, MD** For menstrual management University of Utah General Pediatrics Appointment line is 587-7574

**See attached handout for physicians willing to see young adults with disabilities**

**Planned Parenthood of Utah** Erica Holman Community Educator 801-532-1586 ext 55 Program *Growing up Comes First* for special needs children both male and female. If you see an individual need call and they can address your issue. They also have access to a wide range of educators nationally.

## School nurses

Booklets available on maturation for boys and girls available to parents. Contact Susan Denney [susan.denney@jordan.k12.ut.us](mailto:susan.denney@jordan.k12.ut.us)

## Policy statements

**AAP Policy Statements: [www.aap.org](http://www.aap.org) Sexuality Education of Children and Adolescents With Developmental Disabilities:** Pediatrics, 1996; 97: 275-278

**Sterilization of Minors with Developmental Disabilities** Pediatrics 1999; 104: 337-340, reaffirmed February 1, 2007

**Adolescent Assault Victim Needs: A Review of Issues and a Model Protocol** Pediatrics, 1996; 98: 991-1001

## Books

*“Sexuality and Disability: A Resource List for Those Who Work With, Live With, or Care for People with Disabilities”* 1994 available at Planned Parenthood.

Sipski M, Alexander C, *Sexual Function in People with Disability and Chronic Illness: A Health Professional's Guide* Aspen Publishers INC (1997).

Shapland C, *Sexuality Issues for Youth with Disabilities and Chronic Health Conditions* Institute for Child Health Policy (available free online) 1999.

Schwier et al, *Sexuality: Your Sons and Daughters with Intellectual Disabilities*, Baltimore, MD: Brookes Publishing (2002).

Baladeruan, Nora, *Abuse of Children and Adults with Disabilities: A Risk Reduction and Intervention Guidebook for Parents and Other Advocates*, Discusses signs and symptoms, the abusers, how to report suspected abuse, intervention and examples of how to lower the risk of abuse. Mental Health Consultants (1999).

Mckee L, Blackledge B, *An Easy Guide for Caring Parents: Sexuality and Socialization: A book for Parents of People with Mental Handicaps*, Addresses the social needs of kids with mental disabilities and the role of parents in their child's sexuality education. Planned Parenthood (1986).

Wrobel, Mary *Taking Care of Myself: A Hygiene, Puberty and Personal Curriculum for Young People with Autism*. Arlington, TX: Future Horizons (2003).

## Websites:

**NICHY** National Dissemination Center for Children with Disabilities: Publishes free, fact filled newsletters 800-695-0285 <http://www.nichey.org/>

**SIECUS** (Sexuality Information & Education Council of the United States) 212-819-9770 a national organization which affirms that sexuality is a natural and healthy part of living. They promote comprehensive education about sexuality, is an excellent source of general sexuality education information and includes an extensive bibliography. [www.siecus.org](http://www.siecus.org)

**THE ARC** a national organization of and for people with mental retardation and related developmental disabilities. On their website *Sexuality update: loving and disability-not just theoretical.* <http://thearc.org/>

**DBPEDS.org** Developmental Behavioral Pediatrics Online has *Sexuality Education for Persons with Developmental Disabilities* and selected resources