Sexuality and Children and Youth with Special Health Care Needs: Information and Education

MISCONCEPTIONS PERSIST ABOUT YOUTH and adult sexuality for people with chronic health conditions, functional limitations or developmental disabilities. The primary misconception is that people with disabilities aren't sexual beings and don't have the same developmental needs as everyone else. Many health providers and families struggle to adequately consider sexuality information and education for their children or young adults with special health care needs and disabilities. Both providers and families find these discussions difficult and are not sure where to turn for information. Many assume that the school “health” curricula are sufficient to cover this area or the youth’s health issues or disabilities often overshadow the typical conversations and phases of child and adolescent development. It is essential that service providers or family members provide correct, developmentally appropriate information in a safe setting to decrease a young person’s vulnerability and increase their self-confidence in this important aspect of their lives.

Recommendations for Supporting Children and Families about Sexuality

• Start Early. Discussions of sexuality shouldn’t wait until the child is an adolescent. Start early to give them a vocabulary with which they can express their feelings, create meaningful social and romantic relationships, distinguish between appropriate and inappropriate relationships with people around them, and learn appropriate social behavior.

• Initiate the discussion. Providers should assist families and children to have these discussions. Rarely, does a family introduce the topic on their own unless their child is already asking questions about sex, sexuality, and sexual orientation or because their child is acting-out sexually. The American Academy of Pediatrics encourages pediatricians to be the first stop in facilitating discussion between parents and their children by bringing up the topic early and frequently, advocating for sexuality education in a developmentally appropriate and comfortable way, monitoring for signs of sexual abuse, and encouraging families to optimize social independence of the child if and when it is appropriate and possible.

• Help families talk with their children. Families are often unsure how to navigate conversations and behavior with children who have early or late onset of puberty or an intellectual or learning disability. It is important that a parent’s approach is supportive and not punitive while outlining what to expect and guidelines for the child.

Talking to Your Child about Sexuality:

• Be open about their new feelings
• Reassure them that their feelings are normal and not a bad thing
• Be specific about the impact of the health condition on sex and reproduction
• For children and youth with intellectual and learning disabilities, be anatomically correct when explaining sex and human sex organs and use dolls and pictures to understand and visualize the information you are describing

Sexual Abuse and Assault

An important aspect of proper information and education about sexuality is protection from abuse or assault. People with disabilities, are more likely to be sexually victimized compared to people who do not have a disability. People with disabilities may be more
vulnerable to unwanted sexual contact because it comes from someone they trust; they may not understand what is happening; may not be able to communicate it to authorities or trusted adult; or may not know that what is happening is illegal. Children with intellectual disabilities are four times more likely to experience sexual assault in their lifetime than children without intellectual disabilities (Sullivan & Knutson, 2000). In one study, 44% of sexual assault cases involved an abuser who knew the victim specifically through their disability status (Baladerian, 1991). An important step in sexual education of children and teens with special health care needs is making sure they have appropriate sexual education and understand their rights. The American Association on Intellectual and Developmental Disabilities (AAIDD) and The Arc have published a joint position statement about the inherent sexual rights of people with disabilities (see http://aaidd.org/news-policy/policy/position-statements/sexuality#.UoULitKshcY).

Many states, including the District of Columbia mandate that health providers, educators and others who are responsible for the care of children and youth with special needs to report suspected abuse or assault. As a provider, family, caregiver or individual—if you suspect abuse contact the local child or adult protective agencies to report suspected abuse or assault listed below. No proof is needed to file a report. If you feel the person is in immediate danger and needs attention quickly, contact the police directly by dialing 911.

**For information and assistance with reporting sexual abuse or assault:**
- Prevent Child Abuse America
  1-800-CHILDREN (1-800-244-5373)
  http://www.preventchildabuse.org/index.php
- National Domestic Violence Hotline
  1-800-799-SAFE (7233) TTY 1-800-787-3224
  http://www.thenhotline.org
- National Sexual Assault Hotline
  1-800-HOPE (4673), Rape Abuse & Incest National Network (RAINN) http://www.rainn.org

**District of Columbia Child and Adult Protective Agencies**
- Child and Family Services Agency Hotline
  (202) 671-SAFE or (202) 671-7233
  http://cfsa.dc.gov
- Adult Protective Services, Department of Human Services Hotline 202-541-3950 TTY 711
  http://dhs.dc.gov/service/adult-protective-services

**Reproductive Health**

As with any maturing adolescent, discussions about reproductive health are important. The reproductive cycles for young men and women sometimes pose additional challenges for children with special health care needs or disabilities and their families. Learning how to manage menstruation, assure protection from sexually transmitted diseases, prevent pregnancy, and promote a healthy pregnancy all require guidance from health professionals, families and caregivers. In addition, individuals will need information about the impact of pregnancy on their health condition and the impact of their health condition on fertility. Receiving regular reproductive health care for youth with special needs as they transition to adulthood should be planned and incorporated into health routines. Women with physical disabilities may also need support in finding health care professionals who provide reproductive health services that are physically accessible and support their differences and choices.

Historically, reproductive health practices for individuals with special health needs such as intellectual or developmental disabilities have included forced sterilization. Fortunately, young men and women with special health care needs and disabilities are now having full relationships, marrying, and raising children. Some health conditions require special attention to reproductive health issues such as sexual function, sterility, and allergies to common barrier methods of contraception. Parenting with a health condition or physical or intellectual disability presents challenges that are important to address for new parents and future family planning. Services and supports are available in
communities for individuals to be successful in their relationships and parenting. Today, the focus of reproductive health includes treatments that are personalized based on intellectual capacity, amount of independence, living situation, and sexual desires.

**Resources in the District of Columbia**

The people who are best equipped to deal with these challenges are trained sexual educators, counselors, or therapists who specialize in sexuality in people with health conditions and intellectual and other disabilities. See our providers and programs database for a listing (http://dccshcn.org/access.html free registration required)

For further resources on any of the topics discussed in this document see our Sexuality Information Resource List and Mary Ann Carmody’s Sexuality Education Resource list or our website (http://dccshcn.org/resource_library.html).

**References**


**Acknowledgments:** This fact sheet was produced for DC Resource Center for Children with Special Health Care Needs with the assistance of Alyssa Puritz and Mary Ann Carmody, AASECT-Certified Sexuality Educator.