

SEXUALITY AND DISABILITY: IMPORTANT CONVERSATIONS TO HAVE ON THE WAY TO ADULTHOOD

by Sue Fager

Many disability civil rights laws are based upon the beliefs that disability is a natural part of the human experience, and that citizens with disabilities should have the same rights to being included and integrated into society that everyone else does. While society is becoming more supportive of the right of people with disabilities to live, work, play, and learn in the community, it is still uncomfortable with supporting love, intimacy, and the sexuality of all people.

Before the passage of civil rights laws people with disabilities experienced a long history of separateness and lowered expectations. They were “kept safe,” “taken care of,” and “watched over.” This may have contributed to some of the common myths and stereotypes about the sexuality of people with disabilities: that they have no sexual feelings or needs; that people with physical disabilities aren’t “capable” of having sex or becoming parents; that people with intellectual disabilities either remain innocent and childlike or are sexually deviant.

These myths and stereotypes are not true, and they have done a great disservice to people with disabilities. Without encouragement and support to explore and develop their full potential as adults and as contributing members of society, many youth reach adolescence and adulthood without the skills they need to keep themselves safe.

They may also lack the knowledge and understanding of how to act and behave in socially and culturally appropriate ways and of how to avoid abusing and exploiting others.

Society is beginning to realize what adults with disabilities know—that every person is born a sexual being—having a disability doesn’t change that. Children with and without disabilities will enter puberty and begin their journey through adolescence into adulthood. Young people with disabilities expect their adolescent and adult lives to be as integrated as their K-12 educations were. They wish to have the same friendships and relationships their peers do and to have the right to make relationship choices and to be included in accessible and relevant sexuality education.

A meaningful sexuality education is one that addresses the holistic nature of sexuality—what it means to be male or female; thoughts, feelings, beliefs and behaviors; and understanding how one’s body works and how to take care of it.

Assisting a child to explore and define their own sexuality and to grow into healthy adulthood is one of the most difficult jobs facing a parent—it can seem overwhelming if not impossible. Most adults themselves received little sexuality training and lack role models for themselves and their children. However, parents can become the sexuality educators their child needs with preparation, input from their youth, and with the support of adults with disabilities and other professionals.

There are many reasons for parents to assume this role. Youth today are subject to many unsafe and unrealistic messages about sexuality from their peers and from the media. Middle and high schools generally provide sexuality education, but it may not be presented in a way that is accessible to youth with disabilities, or youth may not be included in the classes. Those who hope that they are protecting their child by telling them nothing should consider how that young person will be able to protect themselves

without the knowledge and skills necessary to keep themselves safe.

A foundation for healthy sexuality can be laid early as parents provide knowledge and skill development in a manner that meets the information needs and processing styles of their child. Topics to explore include learning about relationships and acquiring social skills; feeling ownership over one’s body and having control over what happens to it; good touch-bad touch and how to tell a trusted adult if bad touch occurs; the correct name for all body parts including genitalia; and public and private behaviors and body parts. As a child continues to learn and grow, family and cultural expectations about modesty and public and private behaviors and body parts may need to be reinforced and continually worked on, particularly for youth who process information concretely.

As a child approaches puberty, he or she will need information on changes to their bodies including menstruation, wet dreams, erections, and masturbation. They will need to understand and implement changes to their personal hygiene routines. They may also require assistance with managing feelings of interest in and attraction to others. Youth should continue to receive guidance upon

appropriate touch and behaviors. To prevent abuse and exploitation, youth who rely upon others for assistance with self-care tasks should continue to work towards accomplishing the tasks themselves or become proficient in directing those who provide it.

As a youth continues to grow and mature he or she will need to increase their understanding of abstinence, preventing pregnancy and sexually transmitted infections and staying safe within relationships in a manner that is meaningful to him or her. It is also crucial for each family to explore together the possibility of romantic relationships and to understand a son or daughter's expectations for their own relationships—from having someone to do things with, to marriage and parenting and everything in between. Youth with intellectual disabilities and their parents may need to explore his or her legal ability to consent to participate in sexual relationships.

Supporting their child's growth into healthy adulthood can feel overwhelming. Parents are encouraged to seek assistance from the many professionals and resources available. The American Association of Sexuality Educators, Counselors, and Therapists can assist with locating a licensed sexuality professional. Additional resources may include Parent Training and Information Centers, Centers for Independent Living, and Planned Parenthood.

Helpful print resources include; *The Facts of Life...and More: Sexuality and Intimacy for People with Intellectual Disabilities*; *Teaching Children with Down Syndrome About Their Bodies, Boundaries and Sexuality*; and *Enabling Romance: A Guide to Love, Sex, and Relationships for People with Disabilities*. The age-based sexuality series by Robie Harris and Michael Emberley are helpful for all youth.



Sue Fager's big brother has been teaching her about self-advocacy and inclusion since they were small. Their experiences form the base of the work she does today as a trainer and advocate. Sue has been working with the PACER Center, a Parent Training and Information Center in MN for the past eight years and is looking forward to continuing her work in Colorado; she can be reached at sfager@pacer.org. Sue is also a member of the Council's Multicultural Committee.