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# Being Human: Issues in Sexuality for People with Developmental Disabilities

by Sheryl Robinson Ciojan

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*Discussion of sexuality issues in the lives of persons with developmental disabilities has been neglected by both the general public and professionals for many years. Despite philosophical shifts that have focused on improved community living and quality of life, most people in the field of developmental disabilities have ignored the central issues of sexuality and sexual expression.*

**H**istorically, the need for normal sexual expression among adolescents and adults with developmental disabilities has been strongly denied. Winifred Kempton, a pioneer in sexuality education and developmental disabilities, writes of severe punishments, including castrations, given to adults with developmental disabilities who were found with someone of the opposite sex in segregated institutions (Kempton 1988). Women with mental retardation were considered to be both more promiscuous and more fertile than their nondisabled peers. In fact, in the early 1900s, the idea of a woman showing "inordinate" sexual desire was discussed as being sufficient evidence of feeble-mindedness (Tyor 1977, cited in Mackelprang 1993, 12) Even today, men and women with developmental disabilities are often restricted from any type of sexual activity in residential programs — their homes — and sometimes punished for masturbating. There are few positive models of healthy sexuality for people with disabilities and virtually no social expectation that they are, or will be, sexual beings (Finger 1993).

## **The Movement toward Sterilization**

In the early 1990s, sterilization was nearly an automatic procedure for persons entering institutions. Because persons with developmental disabilities were more commonly raised at home and in contact with other people during the early part of the twentieth century, sterilization became one of the most frequent and heated topics of

discussion (Scheerenberger 1983, 154). As recently as the mid-1970s, young people with mental retardation were legally sterilized without their consent (Evans 1983). The strongest factor in this rampant sterilization was the predominant myth that mothers or fathers with developmental disabilities would produce children with developmental disabilities; in fact, most developmental disabilities occur after a normal conception, and are caused by environmental factors such as drug and alcohol use, infection, and injury to the fetus prior to or during birth (Monaco 1992). Thus, a very low percentage of developmental disabilities, including mental retardation, are genetic. Today, sterilization is limited legally with the intent of giving persons with developmental disabilities the right to make their own choices about their bodies. Still, it is not uncommon for parents of thirty to forty-year-old individuals with disabilities to discuss sterilization as if it would be a blessing, a cure for all of the sexuality-related problems they face. Sterilization does, of course, prevent pregnancy, but it does nothing to protect people with developmental disabilities from

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sexually transmitted disease and sexual exploitation, to which they are very vulnerable.

### **Current Advances and Attitudes**

Despite years of denial and repression, the past five to ten years have witnessed several important advances in thinking and attitudes related to sexuality issues and sexual expression among persons with developmental disabilities. One powerful indicator of the recognition that sexuality and sexual expression are important was the development of a special interest group in sexuality and socio-sensual concerns within the American Association on Mental Retardation (AAMR). This growing group of professionals advocate for sexual rights, sexuality education, and sexual abuse prevention. In addition, within the past five years, professionals in the field of developmental disabilities have had increased access to conference presentations on sexuality topics at local, regional, state, and national levels and literature in this area has increased.

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Across the United States, programs designed to address the need for sexuality education and sexual abuse prevention have been created. Disability agencies, rape crisis centers, and mental health centers have helped design and implement such programs. The Austin Rape Crisis Center program is one example of such innovation. The Austin Center's Personal Safety Awareness Center (PSAC), started in January of 1996, is a

comprehensive sexual abuse prevention and education program for adults with developmental disabilities. The PSAC provides individual and group counseling for survivors of sexual abuse/assault; direct training for adults with disabilities on sexual abuse prevention and sexuality education; professional and parent training on these topics; and a resource lending library of training materials relating to sexuality education and prevention of sexual abuse. Like similar programs around the country, PSAC often provides the first information on sexuality and abuse prevention that people with developmental disabilities, families, and staff have received.

### **Lack of Sexuality Education**

The most problematic result of society's denial of the sexuality of persons with disabilities is the corresponding lack of sex education for students that are in special education or attend special schools for children with disabilities. It is not uncommon for adults with disabilities to report being taught by their parents that they didn't need to know about sex because they would never marry. This failure to provide sexuality education means that many adults are beginning to live independently without knowing the basics of reproduction, contraception, sexually transmitted disease prevention, and appropriate sexual behavior.

Many adults with developmental disabilities (like those without) obtain information about sexuality from television, movies, and peers; often this is enough for them to develop a vague notion that there is something secret about the private parts of the body, that there is some association between those private parts and love, and that people around them are often uncomfortable discussing these things. For example, I worked with a young woman with mental retardation who was robbed and sexually assaulted by a male acquaintance. She described the incident to her mother by saying, "he took my money and he loved on me." She was clearly angry about having her money stolen but had no words to describe the rape.

## Increased Risk of Sexual Abuse

A result of our failure to educate and inform people with developmental disabilities about healthy sexuality and relationships is their great vulnerability to sexual exploitation. A number of factors are involved in the vulnerability of persons with developmental disabilities. First, persons who have a physical disability, such as cerebral palsy or spina bifida, often move slowly and may be unable to defend themselves physically from an attacker. Tobin (1992) describes young people with physical disabilities as especially dependent on caregivers and other adults, needing assistance with daily activities such as bathing and toileting, which may increase vulnerability to abuse, as well as create confusion about privacy and appropriate touch.

Second, for people with mental retardation, vulnerability to abuse is increased by a desire to be accepted and to please others and a tendency to trust other people. Tobin (1992) asserts people with disabilities are often more emotionally dependent; thus, when an individual is touched inappropriately, he or she may have difficulty stopping the abuse, due to fear of angering the caregiver or of losing the care that they provide. Third, children with developmental disabilities are often dehumanized and infantilized by playful patting and touching (Tobin 1992), making it difficult for them to recognize when touch becomes intrusive or inappropriate as adults. Even as adults, people with disabilities often receive necessary and appropriate touch to various areas of their bodies by caretakers or personal attendants, and may become conditioned to touch that others would consider invasive.

Finally, persons with disabilities have traditionally been placed in facilities ranging from institutions to group homes. This system has effectively and consistently trained clients to obey and respect supervising adults and to be compliant with the requests of staff or family members (Furey 1994). The effect on the individual is to limit both independence and self-reliance. Many individuals with disabilities are, in effect, trained to be helpless and dependent on others for even their

basic needs. These characteristics create an easy target for sexual abuse.

Research has confirmed that persons with disabilities continue to experience sexual abuse at a rate three to four times higher than their nondisabled peers (Baladerian 1992). A 1987 study, reported in *Sexuality Today*, stated that of 200 individuals with mental retardation living in sheltered environments, 80 percent reported that they had been sexually abused, with the abuse varying from fondling to rape. Of these victims, 99 percent said they had known their abuser well. Other studies have confirmed that approximately 92 percent of abuse among people with disabilities is perpetrated by someone known to the victim, including paid residential, vocational or transportation staff, and family members (Furey 1994).

Similarly, the Developmental Disabilities Board Area 10 for Los Angeles County (1989) estimated that 70 percent of people with developmental disabilities will be sexually abused during their lifetimes; and the Wisconsin Council on Developmental Disabilities (1991) estimated that up to 83 percent of women and 32 percent of men who have developmental disabilities will experience sexual abuse during their lifetimes. Many professionals discover previously unreported sexual abuse when providing training or counseling to adults with disabilities (Cruz, Price-Williams and Andron 1988; Westcott 1993; Ryan 1992).<sup>1</sup>

## Sexually Transmitted Disease & Pregnancy

Another area of great vulnerability among people with developmental disabilities is the risk of sexually transmitted diseases. As discussed, most adults with developmental disabilities receive limited information about sexuality, and consequently have limited knowledge of topics such as sexual intercourse, what sexually transmitted diseases (STDs) are, how they are transmitted, and how to prevent their transmission. With one out of four Americans between fifteen and fifty-five catching an STD during a lifetime, (Knowles 1995), HIV and AIDS, herpes, genital warts, chlamydia and other STD's are a realistic threat

to adults with developmental disabilities as well. Similarly, people with developmental disabilities may have little knowledge of effective methods of birth control.

### Related Sexual Health Problems

A number of related problems in sexual health arise from the lack of information and education people with developmental disabilities receive about their bodies. One such problem is the fear and confusion that many women experience when having a pelvic examination. Women with developmental disabilities often become fearful, agitated, and even combative when faced with such an exam, to the point that physicians may rely on sedatives to make the examination possible. Yet, this reaction is in large part preventable. There are several commercially available training kits, such as the *GYN Exam Handbook* (Taylor 1991), which are designed to prepare women for all phases of a pelvic and breast exam. When such materials are used in a private, comfortable setting, women with developmental disabilities can learn what to expect, can understand the need for the exam, and become more comfortable with the process.

Another area that can present problems in health care is menstruation. Without adequate information, women with developmental disabilities may react to their periods with fear, shame, confusion, and uncertainty. Although materials such as *Janet's Got Her Period* (Gray 1991) and other items from Planned Parenthood or the local library are available to prepare young women for menstruation, specific training using such items is not always provided in a way that is helpful to young women with developmental disabilities.

Other problems stemming from a lack of sexuality education may arise for men with developmental disabilities, including confusion and shame over nocturnal emissions and masturbation. Many of these difficulties could be prevented through specific, ongoing discussion about sexuality issues, beginning while children with disabilities are young.

### Ethical Dilemmas in Sexuality and Caregiving

There are a number of ethical dilemmas that arise for caregivers of persons with developmental disabilities related to sexuality, rights, and protection. Although clear solutions to each of these dilemmas are not available, the following discussions highlight important considerations.

#### *Sexual Expression*

If sexual expression is a basic human right, how can one balance that against limitations in the capacity of a person with a disability to accept responsibility for possible consequences? For example, if the parents of an adult with disabilities assumed all responsibility for his or her child, how would that affect their adult child's right to have or risk having a child?

The problem of balancing rights against limitations in decision-making skills is not new. These issues arise when a young adult with developmental disabilities moves out of her parents' home and into a group home with other adults, or when a young man with cerebral palsy goes to a new job through his supported employment program. The best solution to many of these problems in

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community living is the concept of support. Caregivers determine what kind of help, education, training, transportation, equipment, or other forms of support are needed in order for the person with developmental disabilities to achieve success in the setting. The concept of support (that is, "supported employment," "supported living," or "supported housing") lends itself well to defining and supporting sexual rights. Determining, with the involvement of each individual, what his or her wishes are and what support

would be needed to achieve success and to avoid undesirable events (such as unwanted pregnancy or HIV infection) can be an effective solution. Moreover, it needs to be acknowledged that people with developmental disabilities are not the only people who may engage in sexual behaviors irresponsibly or without complete understanding, and should not be held to a different standard of conduct simply because of the disability.

### *Issues of Consent*

Issues of consent, understanding, and autonomy are more complicated when persons are not fully competent. What kinds of limitations in decisional capabilities do caregivers confront and how can they work with them ethically, respecting the individual's autonomy?

It is difficult to make a general statement about the limitations in decision making that persons with developmental disabilities may demonstrate, since each individual is different. However, in general, some individuals may make impulsive choices; they may have difficulty with concepts of time and space, and they may be limited in their understanding of events over the long term. In my experience, however, most people with disabilities can increase their understanding of options and consequences through creative, ongoing education.

### *Protection*

Acknowledging the sexuality of persons with disabilities is essential to protection, but there may be risks as well. How should enlightened caregivers balance obligations to protect persons with disabilities from harm (including harm resulting from their own choices) against the obligation to respect individual autonomy, freedom, and full humanity?

The threat of abuse and harm is real. Yet, it is critical to quality of life that people with developmental disabilities have the opportunity to be social, to interact, to take risks. "Sexual vulnerability has been used as a reason to segregate people from their families and communities and to involuntarily sterilize thousands of people.

Protection must not be used to deny people the opportunity for typical life experiences and relationships" (Froemming 1993). Everyone, including persons with developmental disabilities, needs appropriate information to make good decisions. Some agencies have attempted to reduce the risk of bad choices by developing policies for their clients, which impose restrictions on sexual behavior (within the facilities) on the basis of individual understanding of risks and consequences. To assess individual understanding, tools for measuring informed sexual consent are being developed, such as those designed by the Young Adult Institute (Ames & Samowitz 1996) to assess verbally communicated informed sexual consent (through a lengthy series of questions, using models and pictures) and to assess sexual consent through an evaluation of responsible sexual behavior (as demonstrated by the individual).

### **Conclusion**

The issues outlined here are a sampling of many important and powerful issues that persons with developmental disabilities deal with in daily life as sexual beings. Important to remember in these discussions is a point made by Perry Samowitz, that those whom we are dealing with here are *human being*. (Ames & Samowitz 1996). Needs, desires, expression of feelings, and the critical need for safety are things that we all must deal with. It is essential that disability professionals, health care providers, and families begin to think in terms of what they want for themselves in their sexual lives, and work towards creating those same ideals for individuals with disabilities. It is only with acceptance, information, and access to services that people with developmental disabilities can make good choices, establish healthy relationships, and achieve fulfillment as sexual beings.

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