

Sexuality and People with Disabilities

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What Is Sexuality?

According to the Sex Information and Education Council of the U.S. (SIECUS): Human sexuality encompasses the sexual knowledge, beliefs, attitudes, values, and behaviors of individuals. It deals with the anatomy, physiology, and biochemistry of the sexual response system; with roles, identity, and personality; with individual thoughts, feelings, behaviors, and relationships. It addresses ethical, spiritual, and moral concerns, and group and cultural variations. (From: Haffner, D.W. (1990, March). *Sex education 2000: A call to action*. New York: Sex Information and Education Council of the U.S.

Sexuality encompasses more than just the physical act of having sexual intercourse; it also includes the emotional, intellectual and sensual components. Sexuality involves the whole person.

“Sex is what you do; sexuality is
who you are”
Anna Freud

One of the primary misconceptions that society holds about human sexuality is that it means the drive to have sexual intercourse. While this may be part of the truth, it is not the whole truth. Human sexuality has many facets. Having a physical sexual relationship may be one facet of our sexuality, but it is not the only one or even the most compelling or important. Sexuality is, in fact, very much a *social* phenomenon. (From: Way, P. (1982). *The need to know: Sexuality and the disabled child*).

Development of Sexuality

Parents play a crucial role in their child’s social-sexual development. Parents and caregivers teach children the fundamentals of life, the meaning of love, human contact and interaction, friendship, fear, anger, laughter, kindness, self-assertiveness, and so on, through their daily words and actions, and through what they *don’t* say or do.

Parents are also their children's primary educators about values, morals, and sexuality. For many, the word sexuality conjures up so many thoughts, both good (joy, family, warmth, pleasure, love) and fearful (sexually transmitted diseases, exploitation, unwanted pregnancies). Personal and societal attitudes make it difficult for many parents to approach the subject so discussing sexuality with their child may make them uncomfortable, regardless of whether their child has a disability or not, and regardless of their own culture, educational background, religious affiliation, beliefs, or life experiences. When a child has a disability; a parent may experience even great anxiety and misgivings.

All children, regardless of whether or not they have a disability, are social and sexual beings from the day they are born and as they grow and become adolescents their bodies physically mature and they experience a host of emerging social and sexual feelings and needs.

Parts of our society believe that individuals with disabilities will not marry or have children, yet people with disabilities have an increased realization of their rights, more independence and self-sufficiency, so many are choosing to marry and/or become sexually involved.

Children and youth with disabilities need to learn about sexuality and the responsibilities that goes along with exploring and experiencing one's own sexuality. They need information about values, morals, and the subtleties of friendship, dating, love, and intimacy. They also need to know how to protect themselves against unwanted pregnancies, sexually transmitted diseases, and sexual exploitation. (From: *Sexuality Education for Children and Youth with Disabilities* (N I C H C Y) Volume 1, Number 3, 1992)

Myths Surrounding People with Disability and Sexuality

- All disabled people are asexual i.e., incapable of having sexual relationships
- Disabled people are obsessed with sex and have uncontrollable urges

While these 2 myths contradict each other they stem from the same idea, which is a person's disability, makes all areas of a person's life "abnormal".

- Disabled people are childlike and need to be protected from being hurt or let down.

People in the individual's life encourage dependence; the attitude that disabled people need protection is restrictive and forces them to take on a "disabled" role. The fear of treating a disabled person as independent and sexual can reflect a non-disabled person's insecurity.

- People with disabilities will always give birth to children with disabilities

This myth stems from a lack of knowledge because genetic disabilities occur in only a small number of births.

- People with disabilities should only marry and have sexual relationships with other people with disabilities

This myth sees "disabled" sexuality as different to "normal" sexuality; it limits the possibilities of developing relationships and defines someone as disabled and not as a person.

- Parents of children with disabilities do not want their children to have sex education.

Professionals often use this as an excuse for not discussing sex and sexuality and should not be used as a reason to deny people the opportunity to learn and express their feelings and concerns.

- There must be something wrong with a non-disabled person who has a relationship with a person with a disability.

The non-disabled person may be seen as wonderful, caring, self-sacrificing, or as not capable of having a relationship with a non-disabled person. This myth reflects a negative attitude towards

disability and suggests that a disabled person is less worthy than a non-disabled person.

- It is better for someone with a disability to have a relationship with someone who does not have a disability, rather than with another person with a disability.

People with disabilities may believe this myth, which indicates the extent to which negative attitudes affect the views people with disabilities have about themselves. This idea suggests that the person without the disability can be a status symbol and that people with disabilities are less worthy.

- Disabled people cannot have orgasms.

While in some cases this may be true, this myth reduces sex to one particular moment, and ignores the fact that sex can be satisfying without orgasm and that sexual relationships are about giving and receiving pleasure.

- Sexual problems must be due to the disability itself.

While disability may make the actual mechanics of sex more difficult, it is more likely that the sexual problems experienced by people with disabilities are due to negative and stereotyped attitudes in society and the associated feelings of lack of self-esteem. (Naudé, J. Sexuality & disability: integrating the two? Echoes. Issue 19/2000 at <http://www.wcc-coe.org/wcc/what/jpc/echoes/echoes-19-08.html>)

Impact of Disability on Sexuality

For some people with disabilities the question of body ownership can restrict their view of themselves as sexual beings. Someone who requires help in dressing, undressing, washing and the management of continence, may begin to switch off from their bodies. As things are done to them rather than with them, the bottom half of the body becomes a separate entity, not owned by the individual but by everyone else who comes to help dress and change.

A child with a disability will become aware of his/her sexuality in the same way as a child without a disability, i.e., through television, cinema, gossip, magazines, etc. But often their social activity is more closely supervised than that of children without disabilities and sexual expression of behavior is often discouraged. Their sexual development can become distorted because of the attitudes of the people around them. (Naudé, J. Sexuality & disability: integrating the two? Echoes. Issue 19/2000 at <http://www.wcc-coe.org/wcc/what/jpc/echoes/echoes-19-08.html>).



Disability	Relevant Issues
Amputation	<ul style="list-style-type: none"> • Phantom Pain • Contracture • Depression • Loss of Self-Confidence/Self-Esteem • Decrease in Sexual Ability • Mobility Loss
Arthritis and Joint Disease	<ul style="list-style-type: none"> • Limited Range of Motion • Fatigue • Depression • Diminished Sexual Desire
Neuromuscular Diseases	<ul style="list-style-type: none"> • Mobility Loss • Tremors • Contractures • Loss of Sensation • Urinary and Bowel Incontinence • Catheters
Pulmonary Disease	<ul style="list-style-type: none"> • Shortness of Breath • Coughing • Wheezing • Sexual Dysfunction due to Medications

Disability	Relevant Issues
Cardiac Disease	<ul style="list-style-type: none"> • Fatigue • Anxiety • Increase Cardiac Output • Increase Blood Pressure • Sexual Dysfunction due to Medications
Cerebral Palsy	<ul style="list-style-type: none"> • Communication Problems • Motor Weakness • Motor Coordination • Spasticity • Decreased Sensations • Perceptual Deficits • Limited Social Experiences
Head Trauma	<ul style="list-style-type: none"> • Decreased Attention Span • Decreased Libido or Lack of Libidinal Inhibitions • Sexual Acting Out • Communication Problems • Mobility Loss • Tremors • Contractures • Perceptual Problems • Sensation Loss • Visual Problems
Mental Retardation	<ul style="list-style-type: none"> • Impaired Social Judgment • Inappropriate Sexual Behaviors • Social Inexperience
Depression	<ul style="list-style-type: none"> • Decreased Libido • Sexual Dysfunction due to Medications
Alcoholism	<ul style="list-style-type: none"> • Low Level of Testosterone • Impotence • Decreased Vaginal Lubrication

Disability	Relevant Issues
Stroke	<ul style="list-style-type: none"> • Decreased Libido • Sexual Dysfunction due to Medications • Depression • Frustration • Decrease in Motor Strength • Decrease in Coordination

Neistadt, M.E. and Freda, M. (1987) *Choices: A Guide to Sex Counseling with Physically Disabled Adults*. Malabar, FL: Robert E Krieger Publishing Company, Inc.

Historical and Modern Trends

In 1927 the Buck v. Bell Supreme Court decision ruled that forced sterilization of people with disabilities was not a violation of their constitutional rights. This decision removed all restraints for eugenicists. Thirty-three states had sterilization laws in place by 1938. Between 1921 and 1964, more than 63,000 disabled people had been sterilized. (Pfeiffer, D. (1993). *Overview of the Disability Movement: History, Legislative Record, and Political Implications*. Policy Studies Journal, vol. 21(4) p. 726.)

Hundreds of thousands of disabled people ranging from those with intellectual disabilities to blind and deaf people to those with psychiatric disabilities were sterilized under the Nazi regime. Propaganda in schools directly attacked disabled people as economic burdens on the state. This evolved into a program, undertaken by physicians, to exterminate disabled babies and children in what might be seen as a precursor to the Holocaust. By 1945, some five thousand children had been murdered by lethal injection, starvation, withholding of treatment, or chemical warfare weapons. In 1939, the program was extended to disabled adults. Hundreds of thousands of disabled people were killed before the program ended in 1941. (From: Russell, M. (1998) *Beyond Ramps: Disability at the End of the Social Contract*. Monroe, ME: Common Courage Press, pp. 22-27)

In 2006 the Danish government develops a 'Sex, Irrespective of Disability' Campaign, which pays sex workers to provide sex once a month for people with disabilities. Additional trends include:

- **Sex Surrogate** or sex worker that help people with disabilities gain confidence and become more experienced
- Personal care attendants being used for **Facilitated Sex**
- Personal ads and dating websites for people with disabilities
- Devotees (people without disabilities who are attracted to people because of their disabilities, i.e. amputations)

Potential Harm of not Providing Sexuality Education

Sexual Abuse

Numerous studies have documented that individuals with disabilities in general and individuals with developmental disabilities in particular have experienced high levels of sexual victimization, exploitation, and abuse. Yet the detection and disclosure of sexual abuse is low. The discovery of abuse may be inhibited because the individual may not be aware that the actions that have taken place are in actuality abusive. The disclosure of abuse may also be inhibited because the individual feels confused, guilty and is in denial, especially if the perpetrator was a caregiver or friend.

When the individual is institutionalized, neglect arises if the individual experiences a ban on sexual expression, gender segregation, lack of sexuality education, or abuse by staff and other residents.

Risk of sexual abuse and abuse of this population is multiplied when there is an insufficiency in their social skills and if there are deficits in communication. (From: *An Evaluation of a Community-Based Sexuality Education Program for Individuals with Developmental Disabilities*. Electronic Journal of Human Sexuality, Volume 5, Oct. 23, 2002 at <http://www.ejhs.org/volume5/plunkett/review.html>)

Sexual Perpetration

Individuals with developmental disabilities are excessively represented in correctional agencies for sexual perpetration. Perpetration of sexual abuse by individuals with developmental disabilities may be attributed to a lack of sexuality education. Sixty-three percent (63%) of abused females with developmental

disabilities had perpetrators who also had developmental disabilities and little was done to rectify the situation. Police were generally not involved if the perpetrators also had developmental disabilities because the act was considered less serious; hence, the most common response to these perpetrators was to do nothing.

Final Thoughts

Sexuality is treated as either irrelevant or problematic in relation to disability. Issues such as sexual information, sexual relationships, sexual activity and sexual abuse are often excluded from disability theories, rights movements and development policies. As a result, society also tends to expect disabled people, to act as asexual beings. (From: Nisha (2004) *Regulation of Disabled Women's Sexuality*. Disabled Peoples' International at

<http://www.dpi.org/en/resources/topics/documents/BodyPolitics.doc>)

People with disabilities who want a sexual relationship are not just up against the perception that they don't have sex; there are practical issues to be considered:

- A couple needs to meet first before they can have a relationship. Transport and access issues can deter disabled people from going out to socialize, as can poverty.
- Lack of privacy can be a problem for those people with disabilities who live in care institutions, since staff can walk into their bedrooms unannounced.
- For people with disabilities living at home, relatives can be overprotective.
- People with disabilities who are being cared for by their spouse, it can be difficult to maintain sexual mystique when their partner has to dress, bathe and take them to the toilet.
- The choice and control necessary to conduct a satisfying sexual relationship are not always present.
- There is little in the way of easily accessible, specialist advice on sex and relationships for disabled people.



Sexual Rights for People with Disabilities

You Have The Right...

- To expect to be treated fairly, respectfully and with dignity, regardless of age, gender identity, sexual orientation, race, ethnicity, citizenship, education, physical and/or mental abilities.
- To get fair, safe and non-judgmental information, education, and counseling for your sexual and reproductive health needs.
- To learn about sex, sexual activities, contraceptives, and sexually transmitted infections (STIs).
- To have loving, non-sexual, non-abusive relationships with friends, parents, and other people you know.
- To decide who can touch your body, when, where, and for how long... you have the right to object to anyone touching your body... you have the right to say 'no'.
- To make your own decisions and be supported in your decisions with regard to your sexual health and reproductive choices.
- To protect yourself and be protected - from unplanned pregnancies, STIs, HIV/Aids and all forms of abuse.
- To privacy and personal space to explore your sexuality.
- To choose a life-style, including a sexual life-style that is comfortable for you.
- To get information that is easy to understand and is disability neutral, when making decisions related to pregnancy.
- To decide if you want to be a parent and when.
- To accept or refuse any service or treatment, including those related to special prenatal tests if you are pregnant. To make a

decision, without being forced by others, to accept or terminate your pregnancy. (From: Planned Parenthood of Toronto at http://www.spiderbytes.ca/Sexuality/Sexuality_Disability.shtml#)

Resources

Maxfield, G. (1996). *The Novel Approach to Sexuality and Disability*. Sparks, NV: Northern Nevada Amputee Support Group

Neistadt, M.E. & Freda, M. (1987). *Choices: A Guide to Sex Counseling with Physically Disabled Adults*. Malabar, FL: Robert E Krieger Publishing Company, Inc.

Schwier, K.M. & Hingsburger, D. (2000). *Sexuality: Your Sons and Daughters with Intellectual Disabilities*. Baltimore: Paul H Brookes Publishing Co.

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