Women with Disabilities:

Health, Reproduction, and Sexuality

by

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[Note: The following article appears in the *International Encyclopedia of Women: Global Women's Issues and Knowledge*, 4 volumes, published by Routledge Press, 2000.]

Introduction

The United Nations estimates that there are 500 million people with mental, physical, and sensory disabilities worldwide. Over 80 percent live in developing countries, and more than half are women. As more people grow older, and more survive accidents and illness, the numbers of disabled women will continue to increase. Disability crosses all boundaries; women with disabilities can be found in every nation, every race, and every class. However, a disproportionate number of disabled women live in poverty.

Women with disabilities share the same health, reproductive, and sexual needs and concerns as other women. In addition, disabled women face additional problems and raise particular issues related to health, reproduction and sexuality. Around the world, women with disabilities are raising their expectations for self-determination and quality of life. More and more, disabled women are demanding the right to live independently, integrated into their communities, setting their own goals and making their own choices. In so doing, they challenge their societies to be more accessible, supportive, and inclusive.

The phrase "independent living" is often used to describe the disability-rights movement's guiding philosophy -- the conviction that anyone, regardless of the nature or extent of their disability, can function in the community as free and equal participants. In this sense, "independence" does not mean complete self-sufficiency; rather, it denotes having

maximum control over one's own life, using whatever resources are necessary and available.

Terminology -- the language used to describe disability -- has been a topic of much discussion both within and outside the disability community. Phrases such as "handicapped," "crippled," "imbecile," "wheelchair-bound," and others have been rejected by many as being too loaded with stereotype and negativity. Some have put forward more "positive" descriptors, including "physically challenged" and "differently abled," as alternatives. Generally, disability-rights activists favor language which is straightforward and accurate -- phrases such as "people with disabilities," "people with intellectual (or cognitive) disabilities," "wheelchair users," etc. This article will refer to "women with disabilities," and "disabled women."

Disability and Health

Disability is a natural phenomenon which occurs in every society, in every generation. Disabilities may result from several causes: prenatal factors, birth injuries, disease, traumatic injuries, physical or mental stress.

Disability is not an illness, although some disabilities are caused by illness. Rather, disability is a chronic or long-term condition which substantially limits an individual in performing one or more activities of daily living (ADL's). Activities of daily living include walking, seeing, hearing, learning, caring for oneself, breathing, lifting, and so on.

Disability is not necessarily incompatible with good health. Many women with disabilities make it a high priority to maintain and/or improve their health. Disabled women seeking health care may have both typical needs and special needs. These needs include the following:

*General health care and ob/gyn care. Disabled women have the same needs for general and preventive health care as other women. When disabled women present health problems, practitioners should not assume that these problems are related to the disability -- nor that the disability makes treatment impossible or unnecessary. Disabled women should receive the same careful diagnoses and appropriate remedies as other patients. Like all women, disabled women should have regular breast and pelvic examinations, practice safe sex, and have access to family planning and birth control services.

*Prevention of secondary disabilities. Some disabilities can lead to additional, preventable health problems. For example, a woman who spends much of her time in a wheelchair may be prone to problems such as poor circulation or pressure sores. Some secondary disabilities can be serious, even life-threatening. Women with disabilities should be taught techniques to prevent secondary health problems, and should be assisted in taking these prevention measures.

*Services to support independent living. In order to live independently, to fulfill family or work responsibilities, and to maintain their health, women with significant disabilities may need personal assistance, mobility assistance,

housekeeping support, monitoring/supervision, skills training, or other services. Assistance should be available in different settings -- home, school, work, community -- and should support a range of activities, including personal care, menstrual care, sexual hygiene, employment, volunteer activities, study, socializing, parenting, political activities, religious activities, etc. Studies have shown that women who are able to avoid institutionalization, and who can choose and control their own environment, tend to live longer and stay healthier.

*Assistive technology. Devices such as wheelchairs, braces, crutches, walkers, canes, shower seats -- sometimes called "durable medical equipment" -- are designed to aid disabled people in performing necessary functions: moving around, personal care, etc. In addition, items such as adapted tools and utensils, Braille writers, adapted telecommunications devices, modified computers, and others, can significantly increase the health, independence, mobility, productivity, and quality of life of women with disabilities. Some assistive devices are "high-tech," using sophisticated electronic or mechanical components. These kinds of devices can perform a range of complex functions, but they may be expensive and difficult to acquire and maintain. Other devices are "low-tech," involving relatively simple, common-sense applications of ordinary materials. Whether high-tech or low-tech, assistive devices should be appropriate to the needs of the individual disabled woman, and she should be offered training in utilizing the devices effectively.

*Violence prevention and intervention. Women with disabilities are subject to a higher-than-average incidence of violence, abuse, and neglect. This can create or aggravate health problems, including serious physical injuries, emotional stress and/or illness, sexually transmitted diseases, unwanted pregnancy, poor hygiene, skin breakdowns, malnutrition, dehydration, and death. Disabled women are especially likely to be victimized by people they know, including family members, spouses, and care providers. Women with disabilities need support in empowering themselves through assertiveness training, self-defense training, and independent living skills and resources. In addition, disabled women who experience violence, abuse, or neglect need to be able to obtain intervention and assistance from the criminal justice system, victim service providers, battered women's shelters, rape crisis organizations, counseling programs, and other appropriate services.

Barriers to Health Care

Women with disabilities often encounter physical, attitudinal, and policy barriers in seeking to meet their health care needs. Physical barriers include the unavailability of transportation; stairs and narrow doorways into clinics, doctors offices, etc.; written information, such as intake forms and patient education materials, not available in alternative formats (i.e. Braille, tape, large print); high examining tables which prevent transfer by women using wheelchairs; mammogram machines which require patients to stand; and lack of personal assistance to women who need it during clinic visits. These barriers may be remedied through accessibility planning and modifications; availability of written materials in alternative formats; obtaining "adaptable" equipment such as tables which can be raised and lowered, and provision of trained, appropriate assistance in mobility and other personal care needs.

Attitudinal barriers arise from negative societal beliefs about the worth of women with disabilities. These barriers may include the disrespect and/or discomfort of medical professionals; unwillingness to communicate with women whose speech or hearing is impaired; professionals' lack of knowledge about particular disabling conditions; and focus upon the disability, to the exclusion of other health needs. Some practitioners wrongly believe that disability inevitably diminishes a disabled woman's value or quality of life. They may therefore fail to explore or offer all treatment options, assuming instead that death is preferable to living with a significant disability. Doctors, nurses, and other clinic and

hospital staff people may benefit from training and education in these areas. In addition, women with disabilities should be fully informed about their rights as patients.

Policy barriers may be imposed by hospital or clinic regulations; by insurance companies; or by other third-party payers such as Medicare and Medicaid. Some insurance providers discriminate against individuals with disabilities, by barring coverage for "preexisting conditions," or by cost-capping services which may be essential for managing a disability. Another major barrier is that some necessary services -- such as in-home personal assistance services, prescription medications, durable medical equipment, holistic health services, assistive technology, preventive care, certain therapies, or abortion services -- may not be covered by private or government-funded insurance plans. Government and private policies may also have an "institutional bias" -- i.e., they offer services primarily in nursing homes, rehabilitation hospitals, and other large long-term care facilities; but not in the disabled woman's own home, where she can be part of her family and community. Ending this institutional bias, and securing more support for independent living (IL) and community-based rehabilitation (CBR), is a major focus of disability-rights advocates in many countries.

Disability and Sexuality

Women with disabilities experience a full range of sexual feelings, desires, needs and problems. Prominent issues around sexuality and disability include the following:

*Sex education and information. Due to factors such as social isolation, exclusion from mainstream schools, negative assumptions about their sexuality, and communication barriers (i.e. the unavailability of information by sign language, in Braille, on tape, or in other accessible formats), girls and women with disabilities may not receive adequate education and information about sexuality. Age-appropriate sex education should be available to all girls and women. When necessary, this information should be adapted for different communication needs, learning styles and abilities. Information should also be available about the potential impact on sexuality of different types of disabilities.

*Sexual self-determination. Independence is a prerequisite for making choices regarding sexuality. Women with disabilities who have access to the resources to live independently (see above) can define their own sexual identity and desires, and may lead full, satisfying sexual lives. On the other hand, disabled women who live in institutions, or with their parents or other family members, may be severely inhibited in exploring and/or expressing their sexuality. Limitations may be due to any of the following: lack of privacy; others' discomfort with disabled women's sexuality; homophobia; lack of access to information about sexuality; lack of access to sexual stimulation devices, birth control devices, or safe-sex materials; and policies which explicitly restrict sexual activity.

*Body image and self-esteem. Girls and women with disabilities, especially physical disabilities, often notice that they do not conform to dominant cultural and/or commercial images of feminine beauty. The mass media, as well as individual interactions, seem to emphasize a particular ideal of perfection, which disabled women may feel is unattaible. Women who are able to understand, analyze, and reject those images may develop a stronger sense of their

own unique beauty. Disabled girls and women may benefit from counseling and other support services which help them to enhance and/or reinforce their self-concept as strong, attractive women. Role models -- other disabled women who convey strength and self-confidence -- can also encourage personal growth and self-respect in girls and women with disabilities.

*Relationships. Even for many healthy, confident women with disabilities, difficulties may arise in initiating and maintaining sexual and/or romantic relationships. Potential partners may have misconceptions about disabled women and their sexual potential. Or they may doubt the ability of disabled women to reciprocate pleasure, companionship, and love. Or they are unwilling to face the social stigma which they fear would accompany relationships with disabled women. These feelings may prevent a relationship from beginning, or may create conflict within a relationship. However, many disabled women do develop healthy, mutually supportive relationships with their partners. As with most couples, qualities such as trust, self-esteem, mutual respect, shared interests, willingness to give and take, and good communication help to promote successful relationships between disabled women and their partners. Some disabled women prefer partners who also have disabilities, finding in these relationships a sense of camaraderie, shared values, and common backgrounds. Other women with disabilities seek non-disabled partners, while others assert that they have no such preference.

*Sexual activity. The presence of a disability does not preclude sexual activity, although it may necessitate adaptation to accommodate limited movement, fatigue, pain sensitivity, lack of sensation, or other disability-related factors. Mutually satisfying sex is more likely if the partners communicate honestly and clearly, discuss their desires and barriers, and attempt to solve problems creatively.

*Safe sex and birth control. Women with disabilities should be as careful as other women in avoiding unwanted pregnancies and in preventing the spread of sexually transmitted diseases. Women with all kinds of disabilities should be fully informed about risks and prevention techniques. In order to take effective precautions, some disabled women may need assistance or support. A woman with limited movement, for example, may require help in taking birth control pills or inserting a diaphragm. If her partner is unable or unwilling to provide this assistance, the woman may need help from an attendant.

*Sexual identity and sexual orientation. Women with disabilities who are lesbian or bisexual may face double or triple discrimination, based on disability, gender, and sexual orientation. These women sometimes find it difficult to obtain information and resources to support their sexual activities and relationships. Accessing lesbian communities is often difficult, due to the same kinds of physical and attitudinal barriers that exist in society as a whole. But, in addition to offering contact with potential partners, such communities can be an important source of support and self-discovery. In order to access these communities and form relationships, some women with disabilities may need assistance, including information and referral to events and organizations, accessible transportation, attendant services, interpreting services.

Reproductive Issues: Mothers with Disabilities

Reproductive choice is essential to the self-determination of women with disabilities. Like other women, disabled women suffer when governmental restrictions, religious pronouncements, or poverty denies them access to birth control

and abortion services. However, unlike most other women, women with disabilities also face restrictions on their right to have children. Involuntary sterilizations of women with physical and/or mental disabilities continue in many countries, including the United States. (Although most U.S. states have either amended or repealed their sterilization statutes, most of the remaining statutes are based on negative presumptions about disabled women's competence, or even their worth.) In addition, doctors, family members, and others routinely advise women with disabilities to avoid or terminate pregnancy, even when these women demonstrate the desire and the ability to bear and raise children.

These legal and cultural pressures arise from persistent biases regarding the childbearing and/or parenting abilities of women with disabilities. These biases arise from myths and misconceptions, including fears that a disabling condition may be passed on to a child; assumptions that disabled women cannot nurture, care for, or discipline children; the belief that mobility is essential for child-rearing; and notions that a mother's disability would be a hardship to her children.

All of these assumptions are either inaccurate or misguided, or both. Most disabilities are not inherited. Even in situations where a woman's disability may be passed on to her children, she may choose to bear children anyway -- and this may be a valid, responsible decision. The disabled woman may know better than anyone the value and quality of a life with her particular disability.

Many disabled women are independently able to perform most or all the tasks involved in raising children. Even women with more significant physical or mental disabilities, however, can effectively parent children with the help of support services. Such supports may include the help of a spouse or partner, friends, or family; attendant services; in-home child care; accessible day care; assistive devices; and parenting classes.

Reproductive Rights: Children with Disabilities

Just as disabled women want the right to bear children without confronting anti-disability bias, women who risk giving birth to a disabled child must also have the right to bear those children. With the growing use and sophistication of prenatal testing techniques, women face increasing pressure to terminate pregnancies when a potential disability is detected. Pressure may come from doctors who warn that abortion is the only "responsible" decision; from friends and neighbors who may blame the mother for the child's disability; or, increasingly, from insurance companies which deny coverage for "preventable" conditions.

Pregnant women should be able to refuse tests they do not want. Women carrying a fetus with a disability should be given accurate and complete information about that disability -- not simply a medical prognosis, but also knowledge of community resources, legal rights, and opportunities for people with disabilities to attain independence and quality of life. They should have the chance to meet adults who have the disability, and/or with parents of children who have it. Women should be able to make their own decisions about bearing children with disabilities -- decisions free of misinformation, coercion, or penalty.

Conclusion

The health rights, sexual rights, and reproductive rights of women with disabilities are part of two large, multifaceted movements: the disability-rights movement and the feminist movement. Both movements, at times, fail to recognize these as essential human rights issues. Both have yet to make disabled women's access to health care, disabled women's sexual self-determination, and disabled women's reproductive freedoms high priorities on their agendas. Disabled women themselves, however, are charting new human-rights territory, and taking control of their own destiny -- through self-help and political advocacy; through grassroots organizing and international networking; through changing attitudes and changing policies.

Suggested Reading:

"Women with Disabilities: Found Voices," in *Women & Therapy*. Volume 14, numbers 3/4, 1993.

Rogers, Judi and Molleen Matsumura; *Mother to Be: A Guide to Pregnancy and Birth for Women with Disabilities*. New York: Demos, 1991.

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Browne, Susan E., Debra Connors, and Nanci Stern, eds.; *With the Power of Each Breath: A Disabled Women's Anthology*. Pittsburgh: Cleis Press, 1985.

Barrett Shaw, ed.; *The Ragged Edge*. Louisville, KY: The Advocado Press, 1994.

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