

# WOMEN, DISABLED, QUEER:

Working together for our sexuality and rights

AWID INTERNATIONAL FORUM | NOV 14-17, 2008 | CAPE TOWN, SOUTH AFRICA

# **ESSENTIAL INFORMATION**

Do we want to be normal? I think that in exploring disabled sexuality, we are faced by similar questions to the lesbian and gay activists and scholars who have explored gay and queer sexual politics. Are we trying to win access for disabled people to the mainstream of sexuality, or are we trying to challenge the ways in which sex and sexuality are conceived and expressed and limited in modern societies? ... Why should men be dominant? Why should sex revolve around penetration? Why should sex only involve two people? Why can't disabled people be assisted to have sex by third parties? What is normal sex? We know that sex doesn't have to be connected to love, and that neither needs to be connected to reproduction, so there is nothing to limit us except the need for respect for each other, and to look after each other's safety.

Shakespeare 2000

# DISABILITY MODELS AND THEORY

In the medical model, disability is seen as something natural and residing in the body and/or mind of an individual. This model leads to thinking of disabled people as victims who must be protected, pitied and fixed. The social model of disability – developed in the British Disabilities Studies field – argues that disability is a result of social structures, not deficits in the body or brain. These social structures and norms disable people by devaluing and denying them access to society, including to education, jobs, public spaces, representation, and social encounters. The social model sees disabled people not as victims but as agents resisting oppression, overcoming challenges, and thereby changing social structures. (Shakespeare 2000, McRuer 2006).

In the social model the body was sidelined. Feminists were the first to bring a clear critique to this exclusion of the body, arguing that pain, exhaustion, stiffness – as well as the positive aspects of embodied experience - had to be addressed within disability politics. Crip theory takes the social model further and critiques disability theory. Rather than aiming to normalise disability and help disabled people to "fit in" to society as disability theory and neoliberalism do, this theory argues that society itself needs to be radically changed. Crip theory argues that disabled people are transforming our world into a more democratic, diverse, flexible place — by resisting oppressive social structures and calls for normalisation and assimilation, by living with pride and self-esteem, by speaking about their experiences of pain and pleasure, by expressing their sexuality, and by forming communities of support, love, activism and interdependence. (McRuer and Wilkerson 2003).

### SEXUALITY AND DISABILITY

Misconceptions and prejudices about disabled people's sexuality (Maxwell, et al 2007)

- Disabled people are asexual. This misconception includes ideas such as: Disabled people do not want to have sex or intimate relationships and/or cannot experience sexual pleasure. Their bodies are ugly, shameful, unattractive, and therefore disabled people should hide their bodies and avoid sexual relationships. If disabled people have sexual desires, it cannot be for a person of the same sex, and they can only have sexual relationships with other disabled people.
- Disabled people are hypersexual and cannot control their sexual urges. Their sexuality is a danger to "normal" people.
- Disabled people are inherently vulnerable and need to be protected from sexual attack.

### The Reality

Disabled people have the same range of experiences of their sexuality as any person. They may desire sex more or less at different times in their lives. They have different desires and things that are pleasurable for them. Some sexual acts might cause pain or discomfort. They have to experiment with sexual acts just like anybody to find out what is pleasurable and comfortable for them. Disabled people need to and have a right to receive information about sexuality. This enables them to make decisions about their sexual lives, to achieve pleasurable experiences and to avoid unwanted and painful experiences. People with disabilities, predominantly women, and especially those with cognitive disabilities, experience a disproportionate amount of sexual violence. Communities and families often believe that therefore they need to shield disabled children and people from sexual experiences. However, not giving information about sexuality to a person can make them more vulnerable to sexual abuse because they may not know what is happening or how to say no. Instead, disabled people should be educated about sexuality and their bodies so that they can make decisions to the full extent of their abilities (Maxwell, et al 2007).

# Sexuality and the Disability Rights Movement

Sexuality was not addressed by the disability rights movement until recently. It was seen as only concerned with the body, not with the social world, and seen as a private issue that was not as important as access to education, public space, jobs, etc. For many disabled people their sexuality is also a source of distress because of the exclusion and negative representation of their bodies that they experience. However, more disability rights activists and disability studies academics are recognising the importance of making sexuality part of the political disability agenda. They are addressing sexual access, which like other forms of social access, includes access to education, money, and social spaces. They are arguing that sexuality is a key to self-esteem, dignity, respect, and

belonging. Sexuality is not simply a private issue of sexual acts and liaisons; it links the private and public and the individual and community. Moreover, disabled sexuality challenges norms of sexuality that marginalise and exclude people. It challenges norms of physical attractiveness, masculinity and femininity, and sexual acts and expands the notion of what is possible in sex, how pleasure can be experienced and who can be sexual (Shakespeare 2000, Shuttleworth and Mona 2002). This is similar to the effect of anybody expressing sexual desire outside of norms, such as a woman playing an aggressive role sexually with a man.

Despite the acknowledgement of disabled people's sexuality as both personal and political, research is still largely focused upon traditional areas of sexual dysfunction. Research on issues that raise ethical and practical dilemmas, such as facilitated sex and the role of assistants, is still rare as is research on the theoretical approaches to sexuality, especially critical and postmodern positions. These newer approaches, however, have the potential to shed significant light on the power relations, sexual prejudices, and oppressive practices that can inform disabled people's sociosexual situations and can imbue their sexual sense of self (Shuttleworth 2008).

# Addressing issues of disability IN OUR WORK

# The Convention on the Rights of Persons with Disabilities

The Convention on the Rights of Persons with Disabilities (CRPD or 'Convention') was adopted by the United Nations General Assembly on December 13, 2006 and entered into force on May 12, 2008. As of October 2, 2008, it has been signed by 136 countries and ratified by 25 countries. Many disabled people were involved in the formulation of the Convention. The Convention did not create new rights; it shows that disabled people are entitled to the complete range of human rights that all people are. Although this has always been the case, in reality

disabled people face many human rights violations and are often left out of human rights work. Disabled people are disproportionately affected by structural adjustment programs, poverty, climate change, lack of clean water, poor nutrition and other development issues. Poverty can lead to disability and vice versa. People with disabilities are denied access to information, jobs, resources, and social interaction. Disability issues need to be mainstreamed into all development and human rights work and there needs to be programs specifically targeted for disabled people's needs (UNESC 2007). The CRPD lays out how existing rights apply to disabled people and the legal obligations of states to promote and protect the rights of people with disabilities. The Convention represents a shift in thinking about people with disabilities from being seen as victims who need protection to people who have rights and are able to claim those rights and make decisions about their lives. (http://www.un.org/disabilities/, UN 2008).

How can my work advance the rights of disabled people? What principles need to underlie my work?

- 1. Include disabled people in your organisation and your movement and in the processes of planning programs and policies. Do not make assumptions about other people's needs and desires.
- 2. Address the needs of disabled people in your work. This will both involve targeting their specific needs and recognizing that they too are affected – sometimes more than others – by the issues you are already addressing.
- 3. People can make decisions about their own lives. Give them the information to do it. Do not make decisions for them.

Another World Is Possible. The movement for disabled people's rights, including their sexual rights, furthers our core aim of achieving a world that is more inclusive, just, equal and interdependent.

McRuer and Wilkerson 2003

# REFERENCE LIST

Maxwell, Jane, Julia Watts Belser, and Darlena David. 2007. Sexuality. In A Health Handbook for Women with Disabilities, 141-156. Berkeley: Hesperian. http://www. hesperian.info/assets/wwd/07\_Sexuality.pdf.

McRuer, Robert. 2006. Crip theory. New York: New York University Press.

McRuer, Robert, and Abby L. Wilkerson. 2003. Introduction. GLQ: A Journal of Lesbian and Gay Studies. 9 (1-2): 1-23.

Shakespeare, Tom. 2000. Disabled sexuality: Towards rights and recognition. Keynote address, Disability, Sexuality and Culture conference, San Francisco, March. http://www. bentvoices.org/culturecrash/shakespeare.htm.

Shuttleworth, Russell P. 2008. Toward an inclusive sexuality and disability research agenda. Paper presented at the Disability Studies Conference, Lancaster, UK. http://www. lancs.ac.uk/fass/events/disabilityconference\_archive/2008/ index.htm.

Shuttleworth, Russell P., and Linda Mona. 2002. Disability and sexuality: Toward a focus on sexual access. Disability Studies Quarterly 22 (4): 2-9. http://www.dsq-sds-archives. org/\_articles\_pdf/2002/Fall/dsq\_2002\_Fall\_02.pdf.

United Nations. 2007. Convention on the Rights of People with Disabilities. www.un.org/disabilities/documents/ppt/ crpdbasics.ppt.

-. 2008. Enable: Rights and dignity of persons with disabilities. Website. http://www.un.org/disabilities/

United Nations Economic and Social Council. 2007. Mainstreaming disability in the development agenda. United Nations (November). http://www.un.org/disabilities/ documents/reports/e-cn5-2008-6.doc.

Thank you to the panelists, Anita Ghai, Janet Price and Ekaete Judith Umoh, for their contributions to this flyer.





making human rights relevant

www.creaworld.org

CREA advances women's human rights and the sexual rights of all people by building leadership, strengthening civil society organizations, influencing social movements, expanding discourses, and creating enabling social and policy environments.

CREA NEW DELHI

7 Mathura Road, 2nd Floor, Jangpura B, New Delhi 110014, India Tel 91 11 2437 7707, 2437 8700 Fax 91 11 2437 7708 crea@creaworld.org CREA NEW YORK

116 East 16th Street, 7th Floor, New York NY 10003 Tel 1 212 599 1071 Fax 1 212 599 1075 mailcrea@verizon.net