

Interview

“Sexual and reproductive rights of women with disabilities is a marginal issue on the agenda of disability rights organisations,” Geetanjali Misra

Sex and sexuality is a taboo in the South Asian society. When it comes to sexuality and disability, the picture is abysmal, even more for women with disabilities. People with disabilities, especially women, are considered asexual and misconceptions are rampant. If sexuality and reproductive rights affect all aspects of life and is not so much of an individual issue, why is it not there on the radar screen of the disability rights movement? Point of View and C.R.E.A. have recently launched a dedicated website on sexuality and disability. **Geetanjali Misra**, Founder and Executive Director of C.R.E.A. talks to **Dorodi Sharma** of D.N.I.S. on why we need to break the silence.

D.N.I.S.: What motivated C.R.E.A. to start the website on sexuality and disability?

Geetanjali Misra: There is a dearth of information available on disability and sexuality, particularly in the Indian context. C.R.E.A.'s work with marginalised women has shown that women with disabilities are often left out from discussions on sexuality. To become more inclusive, sexuality discussions need to take on board issues relating to disability. Also, when a person is disabled, their only identity that gets prominence or is seen by the society, is that of their disability, and nothing else. They aren't seen as just students, or people in love, or a sister or mother. The only marker is disability, as if nothing else exists in the personality.

It is important for different movements to come together to look holistically at the issues being faced by women with disabilities. Women's movement, disability movement as well as the sexual rights movement need to share their concerns and learn from each other to be able to move forward.

The website www.sexualityanddisability.org was created with the aim of building knowledge and increasing awareness about these issues among individuals and organisations/groups working on disability, human rights, and violence against women.

D.N.I.S.: What would this website aim to achieve in the long run?

Geetanjali Misra: In the long run, we hope that www.sexualityanddisability.org will play a role in reducing stigma, discrimination, and violence against women with disabilities.

Often, we define people with disabilities by their impairments. In the long run, www.sexualityanddisability.org has been designed to break this pattern.

‘Nothing about us, without us’, a key motto of the disability rights movement, has informed the conception and creation of the website. The website is completely accessible to people across disabilities, unlike most other Internet-based resources on disability, which exclude people with disabilities. The website is an interactive platform, which brings together information, personal narratives, and resources within the arena of sexuality, disability, and violence.

For an issue which has not yet found much space in India, www.sexualityanddisability.org is the first-of-its-kind website.

D.N.I.S.: Do you think there is an urgent need for people to talk about sexuality and disability openly and more often?

Geetanjali Misra: Yes, of course. Sexuality is all pervasive and affects everyone. Whether it is about growing up, partnerships and relationships, health, or fulfilling lives, sexuality has links to all. In a society like ours, sexuality itself is a taboo subject. And, talking about disability and sexuality, that too focussing on women, is a huge challenge. There is a great amount of wrong assumptions about sexuality of women with disabilities - they are considered to be asexual or that it is a perversion to talk about their sexuality. These factors lead to the silencing of such subjects. Women need the agency to speak about their lives, their bodies, their sexualities themselves, so that they can claim their rights and live lives as they want to.

D.N.I.S.: As someone who has been working in the area of sexual and reproductive rights, how do you see the situation of women with disabilities when it comes to these issues?

Geetanjali Misra: Women with disabilities and their concerns are nowhere in the horizon of sexual and reproductive rights. It is not part of the Government's agenda. It is also not part of the agenda of disability rights activists, nor sexual and reproductive rights activists. Women with disabilities are seldom seen as sexual and reproductive beings. Therefore, they are seen as women without any sexual and reproductive need. It is still very difficult for many people to even imagine that people with disabilities can have sexual partnerships. We have a long way to go.

D.N.I.S.: In what ways have you included disability in the work of your organisation?

Geetanjali Misra: C.R.E.A. began including disability in its work through its Institutes on Sexuality, Gender and Rights since 2002, when no one was really making this link. These Institutes run globally including India where it is done in English as well as in Hindi, and have in-depth sessions on disability and sexuality. Prominent disability activists have been teaching the course in C.R.E.A.'s various Institutes. Many participants, who are women's rights, sexual rights and human rights practitioners and advocates, have said in their feedback that the Institute was the first place where they have delved into the subject of disability and sexuality.

C.R.E.A. has run two successful Online Institute on Disability, Sexuality and Rights in 2010 and 2011. This global online course has had participants, many with disabilities, developing their understanding on sexual rights issues of people with disabilities, especially women, and the tools needed to discuss these issues with their organisations and networks.

C.R.E.A.'s project called Count Me IN! was about bringing to fore issues of violence against marginalised women, including women with disabilities. Under this project, C.R.E.A. conducted a research study, documenting violence against women with disabilities in India, Bangladesh and Nepal. Our study found that women with disabilities experience regular and ongoing discrimination within the society. Such discrimination varied from public comments and insults to institutionalised violence, leading to women being unable to access education, jobs, or other forms of societal support. Families hid daughters with disabilities away and arranged marriages with whoever accepted them. Within marriage, women reported cases of neglect, punishment, and abuse from their spouses.

The Count Me IN! project culminated in a South Asia conference on marginalised women, where women disability rights activists, many of them with disabilities themselves, came together from India, Nepal, Pakistan, Bangladesh and Sri Lanka and discussed issues faced by women with disabilities in the region. The Count Me IN! conference was a rare conference on marginalisation that talked about the sexual marginalisation of women with disabilities in the same breadth as any other group of women. Several participants with disabilities commented that unlike most other conferences, women with disabilities were not a mere add-on. Concerns of women with disabilities were discussed throughout the conference in different panels and plenary sessions.

C.R.E.A.'s publication 'Free and Equal, is a photo book by renowned artist and photographer Rebecca Swan, which captures the experiences of women who resist oppression, marginalisation, and everyday inequality. The photographs and text is about stories of people who are fighting oppressive structures. It featured stories of 2 prominent women activists with disabilities.

D.N.I.S.: What are the biggest challenges one faces when working on issues of sexuality and disability in a society like ours?

Geetanjali Misra: There are several flawed perspectives on disability in our society. An idea common in India is that it is an individual problem. This comes from an understanding that non-disabled people define the norm and that people with disabilities have a deficit that they have to strive to make up for. Linked with this, there is a moral perspective which defines disability as a result of karmic misdeeds requiring retribution. The welfare perspective ascribes victimhood to disability and naturalises notions of sympathy, helplessness, and dependence. The human rights model that locates disability in relation to structures, rather than with the individual is still not very popular in our society even though the disability rights movement has been working on it for several years.

In the South Asian society, where women's sexuality is a subject shrouded in secrecy and denial, sexualities of women with disabilities is mostly unheard of. One faces the maximum amount of challenge while trying to even bring sexuality and disability together, especially in relation to women. Conceptually, women with disabilities are seldom seen as sexual beings, and most often, not even as 'real' women. If rarely the subject of sexuality is brought up, there is too much stress on 'harm', 'violence' and the 'dangers' in relation to sex which leaves hardly any space to talk about 'pleasure'. While violence is a reality in the lives of women, pleasure is of as much importance.

On the one hand sexuality is a taboo issue, on the other hand, women with disabilities especially, are infantilised to such a level that it acts as a barrier for sexuality to enter their rights discourse. When it comes to women with mental disabilities, it becomes even more difficult to talk about their sexualities. Those of us who work on human rights find it challenging to talk about sexuality and sexual rights of women with disabilities within the human rights framework. It is comparatively easier and more acceptable to formulate women with disabilities' access to education, healthcare, and so on in the rights language. But, sexual rights are a contested domain; even when it comes to sexual and reproductive health rights of women with disabilities. Although there is a glaring gap as far as addressing these issues are concerned, it is a marginal issue on the agenda of even a lot of disability rights organisations.