Regulation of Disabled Women’s Sexuality

By Nisha

Introduction

... they look at me, they hear my desire, and they say ‘scab.’
And they say ‘dreamer’ like it was a dirty word
and they say ‘how dare she say such a thing
how dare she say she wants to walk,
again how dare she say she’d prefer
to run free, to feel her vagina again
how dare she voice that
after all we have done to make
disability a state in which to be proud?’
...

I began this essay by asking two of my colleagues, leaders in the disability movement in India, about their views on sexuality and disability. One response was, “You know better about the issues being faced by disabled persons here than to waste your time on sex obsessed Western thinking.” The other wondered, “(Disability) still remains a kicked off affair in the triangle of charity/welfare, medical rehabilitation and vocational training … when and how do we talk about sexuality?” I also (not so) vaguely remembered a comment which I heard some months back at a rehabilitation centre in Cuttack, India about a pregnant young woman with

1 Makayute, 1994: 187
2 Insert mine
cognitive disability: “She just can’t control ... they take their eyes off her for a minute and she has done it with someone ... Men! I tell you ... Third pregnancy ... can’t even get hysterectomy ... and abortion at this stage is risky.” I wondered if my colleagues actually thought it is an irrelevant issue or, perhaps, saw it as a divisive issue for the disability community. Or, being women, did they feel constrained to acknowledge the relevance and risk being perceived as sexual beings in a society which gives respect to women only as long as they remain passive sex objects? Was the person at the rehabilitation centre attempting to control the sexuality of the pregnant woman in a way different from how she would control her own or an ‘able-bodied’ woman’s sexuality?

I searched for answers in Pfeiffer’s description of nine versions of the disability paradigm in disability studies. Sexuality was not part of any description. But these questions do emerge from recent research on sexuality and disability. Broadly, the new research raises issues related to gender, sexual identity, sexual behaviour, and sexual access and reflects on exclusion of the issues like sexual information, sexual relationships, sexual activity and sexual abuse from the theorizing as well as disability rights movements and policy. Recent research suggests that the disability discourse has been framed in medicalized and human rights terms and it is caught in individual social binary. The individualized focus of the medical model sees disability as a problem with the individual body and the functional limitations or psychological losses assumed to arise from disability as the sources of the problem. In other words, it views

3 Marks, 1999: 611
4 Pfeiffer, 2002.

Pfeiffer’s nine versions include: social constructionist model of US; social model of UK; impairment version; oppressed minority version; independent living version; postmodern, poststructural, humanist, experiential, existential version; continuum version; human variation version; and discrimination version.

5 Shakespeare, Gillespie-Sells & Davis, 1996; Gillespie-Sells, 1998
6 Finger, 1992: 8-10; Macfarlane, 1993
7 Finkelstein in Marks, 1999: 612
disability as a personal tragedy and draws attention away from the socio-structural relations, and socio-cultural notions of physical and sexual attractiveness. The social model, contrary to the apolitical and uncritical nature of the individual model and which has been adopted by the disability movement focused on social change in terms of inclusive physical environmental access, employment, etc. by taking political stances. If the individual medicalized model saw the person as a “docile and passive body, rather than a reflexive subject” and casts human variation as an aberration, the social model is yet to “address the fundamental issue of bodily agency.” Makayute’s poem at the beginning of this paper is an example of assertion of the embodied self against the givens of the social model. Briefly, both individual and social models excluded the phenomenology of the body as “lived experience” and consequently ignored the experiences of multiple barriers to and their psychological impacts on sexuality of the disabled persons.

I will reflect on the questions asker earlier in the introduction within the social model discourse paradigm and analyze the psychological, social and cultural contexts as intraphenomenal and interphenomenal factors affecting disabled persons sexuality. My arguments will have a focus on the ways in which sexual lives of disabled women are denied, resisted and controlled at various levels.

**Discourse & Advocacy**

The pressure to ignore the bodily experiences for a collective voice to locate and challenge the barriers “out there” has made disability theorists and activists collude with “the

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8 Oliver, 1990: 3  
9 Shakespeare, Gillespie-Sells & Davies, 1996: 6  
10 Marks, 1999: 612  
11 Stocker, 2001: 34  
12 Paterson & Hughes, 1999: 601  
13 Paterson & Hughes, 1999: 602
idea that the ‘typical’ disabled person is a young man in a wheelchair who is fit, never ill, and whose only needs concern a physically accessible environment.”

This collusion has led to the sidelining of disabled women, non-visible impairments, intellectual impairments, elderly with chronic conditions, and disability’s interaction with gender and other social, cultural oppressions. Further, it has ended up contributing to the disappearance of the embodied experiences from most disability literature.

Paterson and Hughes make a useful analysis of the disabled body from a phenomenological standpoint through the concept of “dys-appearance” as opposed to “disappearance.” They say that in the everyday social experiences the disabled body “disappears” but the “disappearance” is disrupted by factors such as pain and disease. These disruptions make the body appear again or “dys-appear” as a thematic focus of attention in a “dys-state” - as undesirable and anaesthetic. The body experiences pain and disease as intracorporeal phenomenon (or the pain reminding of the existence of the body) but “dys-appears” as intercorporeal phenomenon, i.e., forced to recognize “its own presence-as-alien-beings-in-the-world” due to the impact of “the profound oppressions of everyday life.”

The “dys-appearance” of the body has led to a “conspiracy of silence” about the “impaired body,” and not only a negation of pain, fatigue, depression and illnesses but a denial of dialogue about the body. It has prevented a sense of pride in the bodily differences and acceptance of the changed body images amongst the newly disabled, disallowed aesthetics of

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14 Morris, 2001: 9a
15 Morris, 2001: 9b
17 Paterson & Hughes, 1999: 603
18 Paterson & Hughes, 1999: 602-603
19 Crow, 1992: 3
20 Morris et al, 1989: 60-68
impaired bodies, and blocked diverse expressions of sexuality through feelings of shame and inappropriateness of the impaired sexual body, by the disabled as well as by the society.  

**Feminine Body & Appropriateness**

Meekosha while questioning the lack of equal attention to violence against disabled women examines three broad dimensions of feminist engagement with bodies: objectified bodies, regulated bodies and bodies as texts. Objectified bodies are “not naturally but socially produced, reproduced and culturally inscribed. Women’s bodies are featured as eroticized parts of a ‘perfect’ whole. The objectification renders disabled bodies as deficient and therefore subject to abuse, invasion and remodelling.” Regulated bodies engage in Foucauldian self-surveillance to achieve or retain the body ideal and to control the sexuality. Regulation of bodies discounts the biological and subjective experiences of pain, illnesses, fatigue, age and physical sexual complexities. Bodies as text exist in the dominant ideological/theoretical assumptions of the social system. Disabled bodies unable to conform to the inscribed text of the ideal healthy (white) “wholesome” female bodies are subjected to oppressive practices and denied a sexual role.

The social norm of sexuality which is based on being “able-bodied” and the material situations of disabled women as “asexual objects” creates “rolelessness” – “social invisibility and this cancellation of femininity” prompts some disabled women to claim essential femininity which culture denies them. This may give the impression that most disabled women have freedom from the standards set by the patriarchal male gaze and that they are in

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21 Shakespeare, Gillespie-Sells & Davies, 1996: 16-43  
22 Meekosha, 1998: 169-170  
23 Meekosha, 1998: 171  
24 Meekosha, 1998: 172  
a position to develop and lead happy alternative lifestyles. In reality, imagining them as “antithesis of the normative woman”\textsuperscript{26} adds to their disadvantage of being women. It holds them accountable for failing to be “able-bodied”\textsuperscript{27} and makes bodily and intellectual differences treated as unattractive and undesirable. A major consequence of which is lack of “sexual access.”\textsuperscript{28}

Closely linked to the notion of attractiveness is the notion of appropriateness of sexual desire and act which Shakespeare, Gillespie-Sells & Davis dub as the “fucking ideology” - heterosexual penetrative, man on the top sex. They find the dominant status of the “fucking ideology” oppressive for disabled persons who because of difficulty with positioning and bodily dysfunctions cannot follow it\textsuperscript{29}. By contradicting possibilities of non-genital sexuality,\textsuperscript{30} it affects disabled persons perception of right and wrong sex and their capacity to give or derive sexual pleasure.

**Socialization & Information**

Since the society does not recognize the sexuality of the disabled persons, it does not recognize their need to engage in body and sexuality related education or the need for information. There is a lack of information per se and wherever available the format of the information is such it remains inaccessible to the particular needs of the disabled persons. It results in confusion, guilt and silence which affect self-esteem and sexual self-actualization capacity\textsuperscript{31}.

\textsuperscript{26} Thomson, 1997: 288
\textsuperscript{27} Wendell, 1997, p269
\textsuperscript{28} Shuttleworth & Mona, 2002: 2
\textsuperscript{29} Shakespeare, Gillespie-Sells & Davies, 1996: 97-107
\textsuperscript{30} Wendell, 1997: 274
\textsuperscript{31} Shakespeare, Gillespie-Sells & Davies, 1996: 18-19
Wade, while giving a historical account of the regulation of disabled persons’ sexuality in the USA, comments that sexuality education has remained highly controversial and value-laden, treating sexuality education as primarily concerned with the act of sex rather than as information on developing relationship and communication skills, values, ability to identify abuse and to enable the self-determination and facilitate healthy sexual life.

**Social Construction of Dependence & Segregation**

It is ironic that the “special needs” institutions and “special education” provisions which were supposed to meet the particular needs of the disabled persons have furthered their social segregation. The segregation which begins from infancy or the onset of the disability limits opportunities of interaction with “able-bodied” peers and participation in social discourse on sexuality. The equal opportunity policies, meant to provide inclusive access, have on the negative side resulted in complacency and hypocrisy – pretension that the disabled person is equal and could be made normal. This attitudinal barrier in practical terms means that the disabled persons are infantilized and are going to be segregated even in the so-called “inclusive” or “integrated” environments unless they do become equal and normal. Most social policies recognize the physical access needs but they do not address attitudinal issues. The policies and social institutions foster infantalization by refusing to recognize issues of sexual access and by expecting those in the institutional care not to express themselves sexually.

The story of dependence, perennial infantalization and segregation is not limited to institutions. Duffy writes about being the eternal child at home:

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32 Wade, 2002: 20-25
33 Shakespeare, Gillespie-Sells & Davies, 1996: 19-20
34 French, 1994: 154-155
35 Shakespeare, Gillespie-Sells & Davies, 1996: 33-34; Marks, 1999: 612
“i am growing up
and you think that i will never go away
that i will always live with you
to be washed and dressed by you
…
you call me máire cock
by refusing to inoculate me against the rubella
you ignore my sexuality”

Shue & Flores bring up the issue of sexual segregation of persons with cognitive disability in supported independent living environments to highlight the critical factor of the decision-making capacity. The individual may retain an interest in having a sexual life but the family members can override personal decisions, and competency.

Factors such as support and protection which are needs make the disabled persons vulnerable not only to abuse but also to dependence leading to a restriction on their right to sexual expression. Issues of support also bring to attention leisure and privacy as means by which contacts are made and sexual relationships formed. Intimate nature of sexual expressions are not possible in the face of battles with the daily routine set by the norms of “able-bodied” persons, need to have personal assistance, constraints of living space available and other physical barriers, etc. The idea of facilitated sex remains controversial not only because of the likely dynamics in the carer-recipient relationship but also because of its potential to become exploitative. It may, therefore, seem easier to deny if not outright shun sexual desires than to negotiate them.

Sexual partnerships & Relationships

36 Duffy, 1994: 26
37 Shue & Flores, 2002: 75-77
38 Howard & Young, 2002: 109-123
39 Shakespeare, Gillespie-Sells & Davies, 1996: 35-40
Considering the barriers to finding sexual partners, Shapiro argues for the state sponsored access to sexual surrogates for the disabled people\(^{40}\). His argument forces us to think about the threefold barrier to finding sexual partners. First, denial of information and internalization of negative messages about the body and sexuality leaves women feeling redundant, “burdensome, unwanted and unlovable.”\(^{41}\) Secondly, physical barriers and segregation already discussed earlier in this essay restrict disabled persons’ opportunities to meet potential partners. And third, possibility of rejection in the “non-disabled” circumstances and larger social perception which denies sexual identity to disabled persons or as a disabled woman says in Morris et al’s book, *Able Lives*, sees them as only “half a woman.”\(^{42}\) Looking for partners or acknowledging sexuality may also make disabled women susceptible to be branded as crude or sex-mad because they disrupt the set perceptions about disabled persons with their sexual desires\(^{43}\).

The internalization of the notions of attractiveness by disabled persons themselves also means that “disabled men may reject disabled women as intimates …”\(^{44}\) and as Stuart suggests, “It’s almost like a victory when disabled men go out with non-disabled women.”\(^{45}\) The situation may not be very different for disabled lesbians. Asch and Fine suggest from their research that many disabled women indicate being rejected, shunned or relegated to a position of a friend from being a lover\(^{46}\).

\(^{40}\) Shapiro, 2002: 78-87  
\(^{41}\) Asch & Fine, 1997: 249-250; Shakespeare, Gillespie-Sells & Davies, 1996: 90  
\(^{42}\) Morris et al, 1989: 86  
\(^{43}\) Morris et al, 1989: 80  
\(^{44}\) Asch & Fine, 1997: 253  
\(^{45}\) Stuart in Shakespeare, Gillespie-Sells & Davies, 1996: 94  
\(^{46}\) Asch & Fine, 1997: 246
Just as disabled women are considered asexual, they are also not seen as capable of a long term relationship other than that as care recipients. It also explains the large number of existing sexual/marital relationships breaking up soon after the onset of disability. The assumptions regarding the capacity of disabled women to have the ability to lead normal, ordinary lives also leads to denying them the roles of reproduction and nurturing. The medical world is not prepared to give them information on or access to facilities related to birth-control, pregnancy and child-birth. Many states forbid persons with histories of epilepsy, cognitive disability and psychiatric disability from marrying. Some states allow the spouse to remarry without a divorce in a case where one partner becomes disabled after marriage. Children are taken away from them, as they are not deemed fit and responsible enough to be mothers. Disabled women face discrimination in the adoption process, to provide foster care and in getting custody of children after divorce.

The widespread use of eugenic measures in the modern history and geneticists’ support to eugenics suggests that disabled women are seen as sources of ‘defects’ and who must not be given right to burden society with disabled children. Recent practices of prenatal testing and selective abortion of foetus on the likelihood that the child may have a health problem puts a woman in a complex situation where the decision is not only about her body but also about her lack of confidence in the society that were she to give birth to a disabled child, she and her child will have fulfilling lives. These practices implement social prejudices and infringe women’s reproductive rights.

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47 Shakespeare, Gillespie-Sells & Davies, 1996: 107
49 Asch & Fine, 1997: 248
50 Hubbard, 1997: 187-200
The lack of socially inscribed reproductive and nurturing role may be a great disincentive for those disabled women who see sex and reproduction as integrated. And for women from cultures where marriage must precede sex, reproductive role is the only possible way to have sex. Denial of reproductive role for them is a denial of a sexual life.

**Conclusion**

Commenting on the limitation of the social model to address issues of meanings and representation of disabled persons, Shakespeare says that the social model “privileges the material level of explanation, and does not give much explanatory space or autonomy to the realm of culture and meaning” and its “mono-linear explanations, reducing everything to economic factors, are misguided.” The social model addresses issues arising from the material processes and social relations which are important in pointing out the disabling role of society. Its analysis of socio-economic structures and processes should be extended to understand wider cultural notions of bodily normativity. It needs to address the production and reproduction of the intercorporeal “dys-appearance” of the body as well as intracorporeal experiences of pain and desire.

Considering that so much of negative perceptions of disabled persons’ sexuality go on unchallenged, there is a need for more empirical work to reclaim sexual experiences of the disabled people for three purposes: to substantiate that disabled people are indeed perceived as asexual and face multiple barriers to their sexuality and to make non-disabled world accept and value disabled persons’ sexuality, to bring sexuality on the disability movement’s agenda, and to validate disabled persons own experiences. Positive cultural representations of

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51 Shakespeare, 1994: 8-9
52 Shakespeare, Gillespie-Sells & Davies, 1996: 207
sexuality of disabled persons are important not only for changing public perceptions but also to impact on disabled persons’ access to sexually meaningful relationships.

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Salvation (sexual and otherwise) was to rest under the auspices of a religiously superior race of Europeans: a motive that was clearly racist. Salvation was something that required the regulation of a "savage" sexuality thought antithetical to Christian decorum, gendered domestic relations, and moral rationality. There may be reason to suggest, however, that the view toward individuals referred to as "nefarious" by the missionaries was an unshared sentiment among some of the original inhabitants of North America. Disabled young people are sexual beings, and deserve equal rights and opportunities to have control over, choices about, and access to their sexuality, sexual expression, and fulfilling relationships throughout their lives. This is critical to their overall physical, emotional, and social health and well-being. However, societal misconceptions of disabled bodies being non-normative, other, or deviant has somewhat shaped how the sexuality of disabled people has been constructed as problematic under the public gaze. The pervasive belief that disabled people are asexual creates barriers to sexual citizenship for ... Almost 80% of women with disabilities are victims of violence and they are four times more likely than other women to suffer sexual violence. Photo: AFP. Sexual rights of disabled women. 9 min read . Updated: 03 Dec 2014, 12:43 AM IST Ashwaq Masoodi. The sexuality of disabled women is conveniently ignored—which activists claim has resulted in the denial of even recognizing their sexual and reproductive rights. The demand for rights stems from the fact that people with disabilities, particularly women, have been subjected to sexual segregation, sexual confinement, marital prohibition and legally sanctioned sterilization—all under the guise of protecting the patient from sexual abuse.