
UNIT 2 DISABILITY, SEXUALITY AND MOTHERHOOD

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Structure

- 2.1 Introduction
- 2.2 Objectives
- 2.3 Disability: A Devalued Identity
- 2.4 Disability, Sexuality and Motherhood: Some Myths and Misconceptions
 - 2.4.1 Disability and Sexuality
 - 2.4.2 Disability and Motherhood
- 2.5 Reproductive Rights and Disabled Women
 - 2.5.1 The Pune Hysterectomies Case
 - 2.5.2 The 'Nari Niketan Case', Chandigarh
- 2.6 Attitudes Towards Disabled Mothers
- 2.7 Let Us Sum Up
- 2.8 Glossary
- 2.9 Unit End Questions
- 2.10 References
- 2.11 Suggested Readings

2.1 INTRODUCTION

Disability has been a universal human experience right from the dawn of history. It connotes a limitation in the functions and activities performed by individuals as members of society, thereby circumscribing their participation in the socio-cultural, political and economic lives of their communities. The term 'disability' is not a homogenous one; it includes different kinds of bodily variations, physical impairments, sensory deficits and intellectual or learning disabilities which may be either congenital (present since birth) or acquired during the life-course. Disability is variously viewed as a marker of disease, of physical deficiencies, malformations and malfunctions. It is also viewed as a condition that prevents a person from discharging her or his 'expected' role within the family and community in a proper manner. It is also seen in terms of restricted economic and productive roles and/or in terms of societal stigma and rejection.

As disability connotes deficiency or lack, it has, by and large, been defined in medical terms. The so called 'medical model' of disability conceptualises disability as an individual problem or condition which is sought to be treated or cured. In the 1970s, it was challenged by the 'social model' which viewed disability not as a mere physical impairment, but rather the result

of social and political systems which marginalised and excluded certain sections of the populace. It is undeniable that in all societies and throughout history, the experience of disability is mediated by socio-cultural understandings that give meaning to impairments and affect the life-experiences of disabled people. As you have already read in the previous unit, social and cultural interpretations and discourses of 'ableism' and 'disablism' define power relations between the 'able-bodied' and the disabled resulting in stigmatization and marginalization. The disabled identity is a devalued identity and translates across all life experiences, including the highly emotive, personal and delicate issues of sexuality and parenthood.

We will begin our discussion by highlighting the devaluation of the disabled identity and the lack of attention paid to the issues of sexuality and family life in the disability discourse. We then discuss some myths and misconceptions surrounding the issues of disability, sexuality and motherhood. The pervasive notion of disabled persons as asexual and disabled women as unfit mothers will be explored in detail by referring to empirical research and case studies conducted by disability scholars. Through our discussions we will attempt to highlight the pervasive and deep-rooted beliefs and values that colour societal perceptions about disability, sexuality and motherhood.

2.2 OBJECTIVES

After going through the unit, you will be able to:

- Define disability as a devalued identity;
- Understand disability in the context of sexuality and motherhood; and
- Analyse disability with reference to empirical cases in the Indian context.

2.3 DISABILITY: A DEVALUED IDENTITY

As discussed in the previous unit of this block and in the unit entitled "Disability and Feminism" (Unit 5, Block 5, MWG 001) being disabled leads to a highly stigmatised and devalued identity. Historically, there has been a deep-seated cultural rejection or aversion to persons with disabilities. They have been portrayed as victims of misfortune, life-long burdens upon family and society, almost a sub-human species. Indian mythology and religious lore are replete with characters whose physical disabilities act as markers of moral flaws. The hunchback Manthara in Ramayana and the lame and devious Shakuni in Mahabharata instantly come to mind. Disability is viewed as punishment for misdeeds committed in previous lives (the law of 'Karma') and, therefore, a fate to be borne stoically. Consequently, rejection, pity, segregation and stigmatisation of the disabled population by non-disabled persons, and the internalisation of these negative feelings

about themselves by disabled persons themselves become the socially accepted way to react to disability.

Renu Addlakha (2007) writes that instead of giving rights to persons with disabilities and empowering them, a culture of charity and welfare has prevailed in India. The disability discourse focuses mainly upon medical and educational rehabilitation and employment issues. These are the main concerns of both the state and disability related NGOs operating within a medical model of disability. As a result, other issues pertaining to sexuality, fertility and reproductive rights are hardly ever taken up for discussion, let alone action. Disabled persons' rights to sexual relationships, procreation and family life are completely ignored. Needless to say, women with disability suffer even more. The 'double burden' of disabled women has been examined in detail in the unit on 'Disability and Feminism' in MWG 001 (Block, 5 Unit 5). It would be useful for you to review this unit before proceeding further.

2.4 DISABILITY, SEXUALITY AND MOTHERHOOD: SOME MYTHS AND MISCONCEPTIONS

As mentioned earlier, the domain of sexuality is a fraught and painful one for persons with disabilities, especially women. According to **Anne Finger**:

“Sexuality is often the source of our deepest oppression; it is often the source of our deepest pain. It is easier for us to talk about and formulate strategies for changing - discrimination in employment, education and housing- than to talk about our exclusion from sexuality and reproduction” (Finger, 1992, p.8).

2.4.1 Disability and Sexuality

One of the most pervasive and widely held misconceptions about persons with disability is that they are in some sense, 'asexual' beings. As their bodies may not conform to the traditional norms of male or female beauty, they may be regarded as 'undesirable' sexual companions. **Meenu Bhambhani's** (2009) perceptive analysis of the treatment of disabled 'heroines' in mainstream Hindi cinema shows how a woman's disability is treated as a tragedy that renders her unfit (not only in society's view but also in her own eyes) to claim the love of the 'hero'. She is forced to give up her love, if her body is maimed or impaired in any way. If the 'hero' still loves her, it is because she possesses exceptional beauty or qualities of head and heart that somehow redeem her from the stigma of disability. The clear-cut message seems to be that ordinary women with disabilities are unworthy of love, romance or sex. The much acclaimed film '**Black**' (2005) directed by Sanjay Leela Bhansali also reinforced this stereotype. The multiply disabled Michelle (played by Rani Mukherji) asks her teacher Sahai (played by Amitabh Bacchan) what happens when two people kiss.

Despite the difference in their ages and the boundaries of the teacher-student relationship, he kisses her because he believes that she will never be able to have the experience with a sexual partner on account of her disability. Such depictions in the mass media and popular culture reinforce the myth of the 'asexual' disabled person. The needs of disabled persons for human contact, love and affection are thus routinely thwarted. In conservative societies like India where the subject of sexuality itself is tabooed and sought to be kept under wraps and tightly regulated, its healthy expression is further blocked.

Anita Ghai (2002) makes the important distinction between the 'male gaze' which makes a 'normal' woman feel like a passive sexual 'object' and the 'stare' that makes the disabled object into a grotesque sight. Thus, disabled women have to deal with not just how men view them but also how the entire society stares at them as objects of pity or revulsion. The impaired body becomes a symbol of imperfection, the 'other' in our society. Ghai cites the example of Punjabi families where girls routinely interact with male cousins, but are not allowed to sleep in the same room as them. No such prohibitions exist in the case of disabled female relatives, reflecting the tendency to depict them as sexless, and thus exposing them unwittingly to the danger of sexual abuse.

Ghai also makes the point that in a cultural milieu where being female is considered a curse, the fact of being a disabled woman is regarded as a fate worse than death. Daughters are seen as 'parai' (other) and bringing them up is perceived to be a social and financial burden. One of the religious duties of a Hindu father is 'the gift of a virgin' (Kanyadaan) to the bridegroom and his family through marriage; but if the 'gift' is 'damaged goods', then it has to be compensated for in some way. Thus, it is frequently observed that women with disabilities are given away in marriage to elderly men or widowers or men who could not secure wives due to financial or social reasons. **Nilika Mehrotra's** (2004, 2006) ethnographic work in rural Haryana brings out the fact that women with disabilities are expected to discharge their domestic duties just as non-disabled women are with few concessions or allowances made for their disabled status. Domestic violence and wife-beating are common. Disabled men, on the other hand, find it easier to get wives. Due to their superordinate status as 'sons' or 'men', they are not given away as 'gifts', but are in fact the receivers of gifts. Disabled men in India, thus, retain the possibility of marriage to non-disabled women, even though they may sometimes have to settle for girls from poor families who would not be able to arrange the dowry that a non-disabled groom could command.

While women with mild disabilities, which do not interfere substantially with the feminine work of domestic chores, child-bearing and child-care, do manage to find marriage partners, women with more severe disabilities are

likely to remain a 'burden' on their natal families for life. In the Indian context, sexuality and motherhood can only find culturally sanctioned expression within the framework of heteronormative constructions of sexuality, primarily through marriage. Any alternative to this culturally-sanctioned pathway remains extremely remote. Only a miniscule section of urban, educated, largely upper class and economically independent women can even articulate these issues. While we find that the literature on disability and sexuality in the West routinely refers to temporary sexual partners, single parenthood, lesbian or homosexual unions, these kinds of sexual or life style choices remain largely taboo subjects within the Indian context.

Addlakha's (2007) study of young urban college students in India with various physical disabilities is one of the few studies in the literature in India which examines how young disabled people conceptualise their bodies, sexuality and marriage. The narratives of the young people reveal the need to acknowledge and recognise their sexual needs, dreams and aspirations. Some of the important themes that emerge from the interviews conducted by Addlakha can be summarised as follows:

- a) **Lack of confidence about one's body:** Disabled bodies do not fit the cultural ideal of the healthy, strong, independent and beautiful body. In addition to sensory loss, there may be lack of muscular co-ordination, drooling at the mouth, incontinence, etc. Persons with disabilities may be dependent on others for activities of daily living and their bodies may be deformed and aesthetically unappealing in more ways than one. The disabled body is not valued as a source of pleasure or value. All these are indicators of a poor body image, which not only refers to appearance but encompasses the whole range of perceptions about bodily sensations, capacities and functions.
- b) **Poor sexual self-esteem:** Poor body image also affects a person's sexual self-esteem. Sexual self-esteem is an individual's sense of self as a sexual being and may be rated as appealing and unappealing, competent and incompetent. It describes a person's sexual identity and perception of sexual acceptability. When persons have a positive body image, they are likely to have high levels of sexual self-esteem as well. When sexual self-esteem is damaged, it can lead to mental ill health; since it results in a damaged view of oneself, diminished satisfaction with life and capacity to experience pleasure, willingness to interact with others and develop intimate relationships. As social attitudes towards physical differences are largely negative, body image and associated sexual self-esteem are a problem area for persons with disabilities. Disability may lead to the loss of sense of self as a sexually attractive and sexually functional person.

- c) **Devaluation of the 'Self'**: Comparisons with the normal body, emphasising physical fitness and beauty projected in the media may lead to feelings of frustration at having a disabled body. Even persons with sensory disabilities, such as blindness and deafness, may experience such devaluation, even though they may have no other physical abnormalities. Such negative attitudes and perceptions are internalised leading many persons with disabilities to avoid looking at themselves in the mirror. They may also avoid social interaction and intimacy, live a life of isolation and loneliness. Lack of peer feedback further worsens their isolation. Since persons with disabilities are socialised from childhood to view themselves as undesirable, they may not take the risk of communicating sexual interest out of fear of being ridiculed, ignored or outrightly rejected. Low self-esteem and poor body image combine with lack of physical and social opportunities for developing relationship skills. Seclusion in institutions or being confined at home by their own families further worsens their plight.

Activity:

Watch any movie and find out various misconceptions which are associated with disabled women's bodies and their sexuality. How sensitively have these issues been represented in the film. How would you change the depictions?

2.4.2 Disability and Motherhood

As we have seen in the previous section, the myth that disabled women do not have sexual or romantic needs and aspirations is false. Another one of the pervasive assumptions about disabled women is that they are 'unfit' or 'incapable' of becoming mothers. Motherhood is a culturally highly valued status; and in societies like India the only legitimate aspiration traditionally available to women were the goals of wifhood and motherhood. Motherhood implies not just the act of procreation but also the process of nurture. Indian mythology and folklore abound with images of the 'nurturant' mother whose love and sacrifice are the foundations on which a child builds its life. Today, these over- deterministic stereotypes are further reinforced in the realms of popular culture and mass media representations. Given such a cultural backdrop, assumption of the role by motherhood by disabled women becomes a problematic issue. Disabled women are seen as unfortunate and dependent beings themselves in need of life-long care and support. How, then, can they be expected to nurture or care for another life? Furthermore, disability is seen as a stigma, a taint that can be transmitted genetically. It is well-known that while selecting a 'suitable' bride for a son, the existence of disabled or chronically ill family member considerably diminishes the marital prospects of women due to the prevalent belief that disabilities

are congenital or inheritable, particularly from the mother's and, to a lesser degree, from the father's side. Attitudes regarding the reproductive roles and rights of women with disabilities can be unpacked by examining the debates around an incident in 1994, which has come to be known as the 'Pune Hysterectomies case'. In the next section, we will look at the issue of reproductive rights and disability in the context of this case. This will be followed by a discussion of the recent 'Nari Niketan case' and the highly contentious ruling of the Punjab and Haryana high Court in July 2009 regarding the reproductive rights of a mentally disabled pregnant woman, who had been raped in a state-run care home.

Check Your Progress:

Write a few lines about the interrelationship between disability and motherhood based on what you have read so far.

2.5 REPRODUCTIVE RIGHTS AND DISABLED WOMEN

2.5.1 The Pune Hysterectomies Case

On February 4, 1994, 11 women inmates of a home for the mentally retarded in Shirur in Pune district of Maharashtra had their wombs surgically removed at Pune's Sasoon Hospital. The women's chronological ages ranged between 15 and 35 years but their mental age was below that of a four-year-old. The operations were performed free of cost as a 'social service' by a leading Mumbai physician, Dr. Shirish Seth and his team. According to him and the then Director of the Department of Women, Child and Handicapped Development (WCHD) of the Maharashtra State Government, Ms. Vandana Khullar, hysterectomies have been a standard procedure in the care and maintenance of mentally retarded women of reproductive age. However, the protests by women's activists against the hysterectomies were based on the understanding that these operations constituted a violation of reproductive rights of these women, particularly as there were no gynaecological health problems being faced by any of the women. The reasons proffered in support of the operations by doctors and administrators, viz., the inconvenience of menstrual hygiene that had to be managed by care takers and the danger of unwanted pregnancies resulting from any sexual assault did not convince the women activists. The first 'problem' could not justify such a drastic surgical procedure, and the second argument failed to account for the fact that removal of the uterus could not protect against assault, abuse or sexually transmitted diseases.

An organisation of the parents and guardians of these disabled women came out in support of the sterilisations. In her important paper on the issue, **Rajeshwari Sunder Rajan (2005)** locates the debates against the backdrop of the condition of the affected women whose disabled status rendered them as 'ciphers' muffling out their voices. Other 'concerned' parties battled out the ethical, medical and legal issues that concerned the 'well-being' of the voiceless subjects, who became the 'objects' of these debates. This 'battle of the experts' over the bodies of disabled women threw up contradictory explanations and understandings. On the one hand, it was argued by sympathetic activists that the 'emotions' of the women may be wounded by the removal of the marker of their womanhood, namely the uterus; on the other hand, officials of the government rubbished the notion that a woman with the mental level of a four year old could manage menstruation, what to speak of motherhood. The 'nullity of the subjects' (i.e. the women inmates) - and the inability or unwillingness of the 'experts' to find out their wishes and choices or delve into their consciousness, starkly reveals the manner in which the disabled (especially the mentally disabled) are divested of their humanity and seen as sub-human creatures. We may also speculate that the concern to prevent these women from becoming pregnant is also governed by the deep-rooted but scientifically unproven fear and revulsion at the possibility of their disabilities being genetically transmitted resulting in the birth of more disabled individuals.

2.5.2 The 'Nari Niketan Case', Chandigarh

In March 2009, a 19-year-old mentally challenged young woman inmate of Nari Niketan, a government-run home for destitute women in Chandigarh was reportedly raped by security guards in connivance with other staff. She was detected to be pregnant in May 2009. The case created a furore and was widely reported by the media. While every Indian woman has the fundamental right to terminate or continue with a pregnancy, including a mentally disabled one, in this case the Chandigarh Administration and the Punjab and Haryana High Court were confronted with the complex legal issues of informed consent and the 'ability' of mentally disabled persons to make decisions about their future and those of their unborn children.

A three-member Medical Board was constituted by the Director-Principal of the Government Medical College and Hospital (GMCH, Chandigarh) to assess the mental state of the young woman. The Board evaluated her mental age to be about 9 years age, placing her in the category of the 'mildly mentally retarded'. It submitted its report recommending a medical termination of pregnancy (abortion). The reasons given can be summarised as follows:

- a) The pregnancy was undoubtedly the outcome of rape, and had caused the woman great distress;

- b) She had some physical abnormalities (such as hepatitis-B positive status), which may be genetic in nature and could be transmitted to the unborn child; furthermore, due to her age, medical status and mental condition, continuation of the pregnancy might adversely affect her health;
- c) Being mildly retarded, she would be unable to fend for herself and look after the child. Although aware that there was a baby inside her, she had no idea how it came to be there. She was, therefore, incapable of understanding the complexity of motherhood and performing the role of a competent mother.
- d) The child of a victim of sexual abuse, who does not have any family support, is at risk of suffering from social and emotional problems in life.

Since there was some ambiguity in the report submitted by the medical board, the High Court appointed another multi-disciplinary medical board, consisting of three doctors including a psychiatrist, and coordinator by a judge. In response to the questions raised by the Court, this board opined that even though there was no grave physical risk associated with bearing a child, the woman's social and emotional understanding were of a very low order: she did not understand the great responsibilities that motherhood entailed. In fact, she seemed unaware of the implications of the rape, and was quite happy to know that there was a baby growing inside her. She saw it more as a playmate or a plaything rather than an onerous responsibility. When specifically asked whether her surroundings were conducive to promoting independent thinking and making informed choices about her future, the Board conveyed its inability to reply as it was not familiar with the surroundings of the young woman residing in a state-run shelter for destitute women.

Keeping in mind the woman's mental, emotional and social conditions and the fact that she would once again be at the mercy of state institutions, the High Court on July 17, 2009 ordered the Chandigarh Administration to arrange for the pregnancy to be terminated on the grounds that it would further contribute to the deterioration of the mental and physical conditions of the young woman.

However, the young woman, with the help of an NGO and a public spirited advocate, moved the Supreme Court in July 2009 seeking protection of the unborn child. The pregnancy was into its 19th week, i.e. above the legal limit for medical termination. After listening to arguments on both sides, the Supreme Court ultimately overturned the decision of the High Court, and ruled that the woman may go ahead with the pregnancy.

This case threw up many questions around the 'personhood' of persons with mental disabilities, their 'ability' to comprehend sexual and emotional

relationships, their ‘competence’ as parents and caregivers, the value of their wishes and opinions and the tendency to treat them as ‘objects’ rather than as ‘subjects’. Most significantly, the role of the state in ensuring the safety, and dignity of its most vulnerable citizens and providing a conducive environment for their well-being was hotly debated. The attention given to this case by the media, activists (especially disability rights activists) and civil society in general will hopefully promote a more nuanced debate on the related issues of disability, sexuality and motherhood.

A baby girl was born to the *Nari Niketan* inmate on December 2, 2010. Her birth has thrown up many challenges before the State and society, and it remains to be seen how this responsibility will be discharged.

Check Your Progress:

After reading these two above-mentioned case studies, analyse any similar kind of case you may have come across recently either from personal experiences or media reports

2.6 ATTITUDES TOWARDS DISABLED MOTHERS

The attitudes towards the sexuality and reproductive potential of disabled women have a cross-cultural resonance. Even in highly industrialized societies where the status of women is almost on par with that of men, the voices of disabled women are conspicuously absent in the social science research work on reproduction and parenting. **Carol Thomas’s** (200p) sociological study of disabled women and motherhood in the United Kingdom brings out the following themes:

- i) **Motherhood and ‘risk’:** The women interviewed by Thomas had a variety of disabilities and chronic medical conditions, and one of the most important decisions they had to take with regard to their pregnancies was whether it was worth the ‘risk’ to their own health and well-being, and more significantly, to that of their unborn babies. Thomas observes that disabled women often share the wider medical and social perceptions about reproductive ‘risks’. If they have a child with impairment, their actions are viewed as irresponsible and ‘unfair’ to the child resulting in guilt and emotional distress. This echoes the widely held notion that lives marked by disability are not worth living and that disabled women are not fit to become mothers.

- ii) 'Good enough mothering': A second theme that emerged strongly in Thomas's study was the fear experienced by disabled mothers at not being 'good mothers'. Given the strong role of the state in western, industrialised societies in monitoring the 'welfare' of children, disabled mothers felt that they were constantly under surveillance by health visitors, community midwives, doctors and social workers. Even family members would interfere against the wishes of these mothers. The fear of the 'judgements' of professionals and experts coupled with the possibility of losing the custody of their children forced them to 'present' themselves to others as 'fit' mothers. The pervasiveness of 'disabilist' ideas, which doubt the ability of disabled women to be 'good mothers' and cope with the demands of mothering, is amply demonstrated here.
- iii) Inappropriate or inadequate 'help': This theme is in consonance with the findings and literature on 'medicalisation' of pregnancy and childbirth, wherein medical professionals and experts 'take over' how a child is to be reared leading to the woman losing her sense of control and agency. This is even more salient with disabled women as their impairments are seen as additional complications to be managed by professionals. The voices of the women, their needs and experiences are seldom taken into account, professionals and non-disabled lay-people assume that they know best. Thomas argues that constructing disabled persons as dependent, needy and requiring care rather than as givers of care, is a classic feature of 'disablism'

Thomas's analysis of the reproductive journeys of disabled women suggests that these journeys are marked by material, ideological and attitudinal barriers. Disabling discourses depict the birth of children with impairments as a tragedy, and the women who brought them into the world as irresponsible mothers, whose mothering must constantly be judged and evaluated by experts who 'know best'. In a nutshell, it exemplifies the devaluation of the disabled identity.

2.7 LET US SUM UP

We began this unit with a brief recapitulation of the disability experience and its social construction as a devalued, stigmatizing identity. The depiction of disabled persons as sub-human 'others' impinges upon their need and search for satisfying sexual and conjugal relationships and parenthood. Disabled women, in particular, experience the stigma of being considered 'asexual', unattractive and unfit for love and intimacy. Disabled women who succeed in finding partners are usually 'given away' to unsuitable men to 'compensate' for their deficiencies. We discussed how such a negative self-image results in poor sexual self-esteem and devaluation of personhood, further trapping them in the vicious cycle of isolation and rejection. We

further discussed the issue of reproductive rights and agency of disabled women through an examination of the debates surrounding the 'Pune hysterectomies case' and the 'Nari Niketan case' involving the reproductive rights of mentally disabled persons. We concluded the unit with a discussion of the major themes that emerged in Carol Thomas's study of disabled mothers in a very different cultural milieu, i.e. a highly industrialised western country. However, our findings indicated that 'disabling discourses' are deep-seated and difficult to dislodge, even in contexts where state-mandated health care and welfare provisions are well developed. The pervasiveness and embeddedness of the social construction of the disabled as the 'other' and the obstacles faced in forging loving, intimate relationships and a satisfying family life were highlighted.

2.8 GLOSSARY

Mild Mental Retardation : Persons with an Intelligent Quotient (IQ) in the range of 50-69 may be classified as having mild mental retardation. While their cognitive development may not be age appropriate, they can be trained to look after their self care needs and live as productive members of society.

2.9 UNIT END QUESTIONS

- 1) Discuss disability with reference to sexuality and motherhood.
- 2) Discuss the impact of disability on motherhood.
- 3) Define disability and analyse it from a gender perspective.
- 4) How are disability, motherhood, and sexuality related? Explain with the help of some case studies.

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2.11 SUGGESTED READINGS

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