UNIT 15 DISABLED BODY AND REPRODUCTIVE PROCESSES

Structure

15.0 INTRODUCTION

Disability has been a universal human experience right from the dawn of history. According to the World Bank about one billion people in the world, i.e., about 15% of the population, experience some form of disability. A disabling condition can be present since birth or may occur any time during the course of a person's life. The disabilities such as Down's Syndrome, Thalassemia, Hemophilia, Fragile X syndrome, Spina Bifida etc. are the result of some genetic or chromosomal variations that take place before the child is born. Disabilities may also result from birth injuries, for instance, deprivation of oxygen at the time of birth may result in brain damage, which affects physical and intellectual development resulting in conditions like Cerebral Palsy. Some diseases and illnesses may lead to disabling conditions, for example, Poliomyelitis can result in limb deformities, small pox can result in blindness. Accidents, natural and man-made calamities, environmental disasters, conflict and warfare can also result in disabling physical injuries or mental trauma. Thus we see that disabilities can occur anytime, anywhere and to anybody. A person may think that s/he is 'able-bodied/non-disabled/normal', yet may suddenly have an accident, or an illness that may leave him/her disabled.

Disability refers to a limitation in the functions and activities performed by individuals as members of society, thereby limiting 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 may be seen 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. Having a disability is also seen as having a negative impact on an individual's economic and productive roles and responsibilities. Since it is by and large viewed negatively, disability brings with it societal stigma, rejection and shame.

Disability has largely been defined in medical terms. The so called 'medical model' of disability views 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. We observe clearly that in all societies and throughout history, the experience of disability also carries socio-cultural understandings that give meaning to impairments and affect the life-experiences of disabled people. social and cultural interpretations define power relations between the 'able-bodied' and the disabled resulting in stigmatization and marginalization. To summarise, disability is a 'devalued' identity whose impact is felt across all life experiences, including reproductive processes and the extremely 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 reproductive processes, sexuality and family life in the disability discourse. We then discuss some myths and misconceptions surrounding the issues of disability, sexuality and reproduction, specifically motherhood. The widely held 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.

15.1 LEARNIN OUTCOMES

After studying this Unit, you would be able to:

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

15.2 DISABILITIES: A DEVALUED IDENTITY

Disability leads to a highly stigmatised and devalued identity. We see that throughout history, persons with disability have been seen as lesser or inferior human beings., victims of misfortune and burdens upon family and society. mythology and folklore are full of characters whose physical disabilities are seen as markers of moral flaws. The hunchback Manthara in Ramayana and the lame and cunning 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 become the socially accepted way to react to disability. As a result, disabled persons themselves also may internalise these negative feelings and lack confidence and self worth.

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 focus is mainly upon medical and educational rehabilitation and employment issues. 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 who face discrimination both on account of their gender and their disability has been discussed in detail by feminist scholars and activists. Their reproductive rights and bodily integrity has always been sought to be controlled and monitored by the medical system as well as by social and cutural values and beliefs.

15.3 DISABILITY, SEXUALITY AND PROCREATION: SOME MYTHS AND MISCONCEPTIONS

15.3.1 Disability and Sexuality

You have already read about the interrelationship between disability, gender and sexuality in the previous unit of this Block. Let us read and further contextualise it in relation to reproduction and motherhood. One of the most common misconceptions about persons with disability is that they are '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) 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 defective in any way. If the 'hero' still loves her, it is because she has exceptional beauty or qualities 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. 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 not regarded as legitimate. In conservative societies like India where the subject of sexuality itself is tabooed and tightly regulated, its healthy expression is further blocked.

Anita Ghai (2002) 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; however, if the daughter is disabled then her 'value' diminishes considerably. 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. Domestic violence and wife-beating are common. Disabled men, on the other hand, find it easier to get wives. Due to their higher status as 'sons' or 'men', they are not given away as 'gifts', but are in fact the receivers of gifts. They are able to get non-disabled women as brides even though they may sometimes have to settle for girls from poor families who would not bring in a dowry.

It is observed that women with mild disabilities, which do not interfere much with domestic chores, child-bearing and child-care, do manage to find marriage partners. However, women with more severe disabilities are likely to remain a 'burden' on their natal families for life. In the Indian context, sexuality and child-bearing are permitted within heteronormative and socially approved marriages, and any deviation from the norm, such as sex without marriage, same-sex unions etc. are punished, sometimes very severely. Thus, any kind of agency and autonomy with regard to sexual expression, choice and reproductive decisions, is severely limited within the Indian context, even though this is changing particularly in urban centres.

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. Persons with disabilities may be dependent on others for activities of daily living. The disabled body is not valued as a source of pleasure or value. All these are indicators of a poor body image.

b. ***Poor sexual self-esteem*:** Poor body image also affects a person's sexual self-esteem. 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. 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.

Check Your Progress Exercise I

Note: I. Use this space given below to answer the question.

II. Compare your answer with the Course material of this Unit

1. Watch any movie and find out various misconceptions which are associated with disabled women's bodies and their sexuality.

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2. How sensitively have these issues been represented in the films and how would you change the depictions?

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15.3.2 Disability and Procreation/Motherhood

As we have seen in the previous section, the myth that disabled persons do not have sexual or romantic needs and aspirations is false. One of the common 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 wifehood and motherhood. Motherhood involves not just the act of procreation or reproduction but also the process of nurture or care-giving. 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 stereotypes are further reinforced by popular culture and mass media representations such as television soap-operas. Given such a cultural backdrop, reproductive processes and rights of 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 'defect' that can be transmitted genetically. It is well-known that while selecting a 'suitable' spouse, the existence of disabled or chronically ill family members may negatively impact upon the marital prospects of the person. This is 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.

The study by **Carol Thomas** (1997) of disabled mothers in the United Kingdom, **Grue and Laerum's** (2002) study of Norwegian women, **Malacrida's** (2009) study of Canadian mothers with disabilities highlight the

theme of disabled women not being considered as 'good enough' mothers and therefore having to work extra hard to 'prove' themselves before the judgmental eyes of society. They may be considered irresponsible and taking a great risk in getting pregnant and potentially harming themselves, or even worse, the unborn baby (Thomas 1997/2009). The notion of the 'ideal' mother, as an able-bodied one is challenged by women with disability; becoming mothers enables them to claim their status as adult women who can care for another human life, rather than as permanently dependent 'children' constantly in need of care. The very fact that they are disabled causes the non-disabled world to look at them with doubt and suspicion and devalue their capability in raising their children well. This reflects a clear bias against persons with disabilities and needs to be questioned and challenged.

In the Indian context, **Sandhya Limaye's** (2015) study of women with various disabilities traces the tensions and worries experienced by these women that they may give birth to children with disabilities and their relief at giving birth to 'normal' babies. Limaye highlights their coping strategies and their quest for support, while struggling with the pressures of raising young children and the negative attitudes of their family members and society in general. She calls for disability organisations, particularly in rural areas, to extend support to disabled mothers.

15.4 DISABILITY AND REPRODUCTIVE RIGHTS

As we have seen above, attitudes towards the reproductive rights of persons with disabilities are generally negative. The belief that disability can be transmitted from generation to generation, the devalued nature of disability and the belief that it is an unwanted burden upon society have all resulted in various attempts to control the fertility of persons with disability. Segregating them into institutions, denying them rights to marry and set up families and performing procedures like hysterectomies and sterilisation without their consent are practices that have been in place in various parts of the world. In the case of persons with mental illness or psycho-social disabilities, forcible psychiatric treatment, electro¬ convulsive therapy (popularly known as shock treatment) and confinement in asylums were also carried out, ostensibly in their own interest.

However, these practices have been challenged and contested by Disability Rights Movements all over the world. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), 2006, which has been ratified by most of the nations in the world, including India, is a rights-based instrument that upholds the civil, political, economic, social and cultural rights of persons with disabilities and their status as equal citizens in the world. India's disability legislation, the Rights of Persons with Disabilities Act (2016) is also in tune with the UNCRPD.

Box 15.1 Specific Laws related to Disability

In India, specific laws related to disability include the following:

- Rehabilitation Council of India Act 1992,
- The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995,
- The National Trust Act 1999,
- National Policy for Persons with Disabilities, 2006,
- Rights of Persons with Disabilities Act 2016. (Bajpai, S., 2019)

The Rights of Persons with Disabilities (RPWD) Act, 2016, "recognizes 21 conditions as disabilities, and specifies that a benchmark of 40% impairment must be medically certified for the individual to be eligible for state benefits under the law. Broadening the base of the conditions considered as disabilities, the RPWD Act includes a greater number of conditions that render the individual disabled, which were not included in the previous legislation. Under the broad category of 'Physical Disabilities', the sub-types of Locomotor Disability, Visual Impairment and Hearing Impairment are listed" (Vaidya, 2019:28).

Attitudes regarding disability and reproductive roles and rights can be unpacked by examining the debates around an incident in 1994, which has come to be known as the '**Pune Hysterectomies case'**. This will be followed by a discussion of the Chandigarh '**Nari Niketan case'** concerning the reproductive rights of a young woman with intellectual disabilities who became pregnant after she was raised in a state-run care home. The ruling of the Punjab and Haryana high Court in July 2009 and the path-breaking Supreme Court judgement in **Suchita Srivastava** vs **Chandigarh Administration** (2009) was an important milestone in legally affirming the reproductive rights of women with disabilities.

15.4.1 The Pune Hysterectomies Case

On February 4, 1994, 11 women inmates of a home for intellectually disabled women 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 given 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 made them voiceless and powerless in the debates concerning their own bodies. 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. One the one hand, it was argued by sympathetic activists that the 'emotions' of the women may be wounded by the removall of their 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 inability or unwillingness of the 'experts' to find out the wishes and choices of these women or attempt to understand them, starkly reveals how mentally or intellectually disabled people are treated as sub-human creatures rather than complete individuals in their own right. It is very likely that the concern to prevent these women from becoming pregnant is also rooted in the scientifically unproven fear at the possibility of their disabilities being genetically transmitted resulting in the birth of more disabled individuals.

15.4.2 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 t heir 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 intellectually disabled, 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 a serious 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 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 seeking protection of the unborn child. The pregnancy was into its 19th week, which was very close to the legally permitted limit for medical termination. After listening to arguments on both sides, the Supreme Court stayed the decision of the High Court, and held that the right to reproductive choice flows from the right to liberty under Article 21 of the Constitution. It noted that taking away a woman's choice regarding her own body would amount to infringement of her right to privacy. In its decision the Court observed:

There is no doubt that a woman's right to make reproductive choices is also a dimension of 'personal liberty' as understood under Article 21 of the

Constitution of India. It is important to recognise that reproductive choices can be exercised to procreate as well as to abstain from procreating. The crucial consideration is that a woman's right to privacy, dignity and bodily integrity should be respected. This means that there should be no restriction whatsoever on the exercise of reproductive choices such as a woman's right to refuse participation in sexual activity or alternatively the insistence on use of contraceptive methods.

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 came to attention. The attention given to this case by the media, activists (especially disability rights activists) and civil society in general raised issues regarding disability rights and reproductive rights comprehensively.

Check Your Progress Exercise II

Note: I. Use this space given below to answer the question.

II. Compare your answer with the Course material of this Unit

1. List specific laws related to disability.

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2. 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.

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15.5 LET US SUM UP

We began this unit with an overview of the disability experience and its social construction as a devalued, stigmatizing identity. The depiction of disabled persons as sub-human 'others' denies 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. Societal attitudes and judgements towards disabled women who become mothers were also discussed. 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. The landmark Supreme Court judgement affirming the reproductive rights and choices of an intellectually disabled woman, and its overturning the High Court decision to terminate her pregnancy against her wishes clearly shows the distance travelled in treating disabled bodies as human agents rather than as inconvenient burdens or problems.

15.6 UNIT END QUESTIONS

1. Discuss disability with reference to sexuality and reproductive processes.
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.

15.7 REFERENCES

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15.8 SUGGESTED READING

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