BLOCK 5
GENDER AND DISABILITY

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UNIT 13 DISCOURSES OF ABLEISM AND DISABLISM

Structure

13.0 INTRODUCTION

This Unit is adapted from the course MWG 004, Gendered Bodies and Sexualities of MA programme in Women's and Gender Studies. In this unit, we begin our discussion with the understanding of the notions of ableism and disablism. These two concepts are ideological positions that provide a pathway into a conceptual understanding of disability. This unit will introduce you to various perspectives, models and the social attitude towards understanding ableism and disablism in relation to gender bodies. It aims at discussing disablism as a socially constructed product of the society. Like other '-isms', ableism can be insidious, and so closely woven in society that people without obvious physical or mental disabilities might not even think about their ableist attitudes and the ableist structure of their society. The intolerant attitudes of society towards disability often result in the marginalization and stigmatization of people who appear or behave differently. We will begin this unit with a definition of Ableism and Disablism before analyzing specific issues related to disablism.

13.1 LEARNING OUTCOMES

After studying this Unit, you would be able to:

- Define and explain the concept of ableism;
- Analyse the concepts of ability and disability in relation to gender bodies; and
- Critically discuss the notion of the disabled body as a socially constructed identity.

13.2 DEFINING ABLEISM

We will begin by drawing our attention towards the title of the unit which explains disability in reference to ableism. Therefore, disability or disablism is, therefore, always understood in opposition to 'able' or ableism.

Box 1.3: Understanding Difference and Disablism

"The normative culture both in India and the world over, carries existential and aesthetic anxieties about difference of any kind be it caste, class, gender or disability. This is borne out by the people who have lived a peripheral existence on account of their deviation from the societal parameters that are considered normative leading to a creation of a living reality of acute marginalization, discrimination and stigmatization" (TARSHI, 2010).

Every society exhibits a structural invisibility with regard to particular categories of people, who, because they do not fit into the hegemonic discourse or definition of 'normality', are excluded, separated and socially dis-empowered. This social and cultural apartheid is sustained by the existence of a built environment lacking basic amenities for the disabled because it solely caters to the needs of able-bodied persons. Based on research, ableism can be understood as an attitude that distinguishes disability through the parameters and appraisal of **able-bodiedness**. As a theoretical tool, ableism is hardly accountable to any forms of measure or constitution for governing the normative behaviour in the society; therefore, easily locates itself in the arenas of sources of knowledge generation and accumulation. There is little consensus in the society as to what practices and behaviours constitute ableism. **Simi Linton (1998)** for example defines ableism as "include[ing] the idea that a person's abilities or characteristics are determined by disability or that people with disabilities as a group are inferior to non-disabled people" (1998, p.9).

An ableist viewpoint holds that impairment or disability (irrespective of the type or extent of the condition) are inherently negative in nature and all efforts should be made to ameliorate, cure or, indeed, eliminate it altogether from the body and the society as well. According to another disability scholar, **Fiona Campbell**, ableism refers to "…. a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability is cast as a diminished state of being human" (Campbell, 2008, p. 44). For example, the fact those children with disabilities stay apart from other students in classes, which is a reflection and reassertion of ableism. Another example of ableism is organizing class trips without checking to see if the places to be visited are accessible for students with disabilities. Schools can overcome ableism by appropriate infra-structural and technological aids to make them more disabled-friendly, and hence less ableist to students with disabilities.

Discourses of ableism are particularly visible in the sphere of media. The

usage of language such as‘normal’, ‘able’, ‘beautiful’ men and women in advertising creates a dichotomy between the so-called ‘able’ versus the ‘disabled’. Even when ability and disability are the foci in movies or on television, the representation is invariably negative across media. Since our major concern in this unit is how gender and disability intersect, let us take the situation when women are labeled as ‘too emotional’, ‘irrational’ or ‘hysterical’, when they retaliate against mistreatment. The labels imply that these groups are ‘less-than’ men because they possess these (abnormal) features. Sometimes such groups have responded to this mistreatment not by challenging the existing notion of ableism in these labels, but by proving that the labels don’t fit them, thereby leaving the labels in place. e.g., women rightly fought to prove that women are not ‘irrational’ or ‘hysterical’. But this can inadvertently leave uncontested the assumption that anyone so labeled accordingly deserves to be treated as “less-than” the other. While it is true that the specific issues for the disabled women may vary from those of non-disabled women, the reality of womanhood which includes the usual experiences and fears of a patriarchal society are bound to be similar. However, with a body that does not 'measure up' to societal norms and expectations, the situation becomes precariously unbalanced and un-accommodative.

Both women and men have to contend the ableist prejudice. **Veronica Chouinard** defines ableism as “ideas, practices, institutions and social relations that presume able-bodiedness, and by so doing, construct persons with disabilities as marginalised … and largely invisible ‘others’”(1997,p.380).In contrast, **Amundson & Taira** attribute that “ableism is a doctrine that falsely treats impairments as inherently and naturally horrible and blames the impairments themselves for the problems experienced by the people who have them” (2005, p.54). Now, we would be able to approach ableism as a heterogeneous concept, defining a set way of life, schemes and practices, those generate and construct our ‘abilities’. It, thus, implies a precise knowledge of ourselves, our body, our relationship with other human beings, and our environment. Again, we can use the example of people who use wheelchairs who can easily be mobile but only when there is an environment where navigation in a wheelchair is possible.

Ableism not only infiltrates language and society, but it can also make it difficult for many people to get a job, compel students to leave school and college, and create social, economic and political obstacles. It can make performance of basic life tasks very difficult, especially for disabled individuals who want to live independent, active lifestyles. To be non-disabled is to be ‘not the unfortunate one’ whereas disabled people may be referred to as ‘*bechara/bechari’*. Euphemisms such as **special, special needs, special education**, **differently abled, physically and mentally challenged** are associated with the disabled body. Such euphemisms are problematic as they are very hard to unpack or operationalize in reality. Euphemisms exemplify a world where good intent and altering language norms collide, leaving the disabled in an uncomfortable location on the margins. Although, all ableist languages are used in many diverse ways, including implicit ways, euphemisms are intensely tricky because they carry the burden of both

political correctness and the meaning of marginality and exclusion. For instance, the words 'challenged' and 'special' emphases a **hierarchy of ability** that exists in the society.

Check Your Progress Exercise I

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

II. Compare your answer with course material of this Unit.

1. Explain the meaning of ableism.

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2. Watch any movies, daily soaps, and advertisements and analyze the role of language in constructing the meanings of ableism vis-à-vis disablism.

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13.3 DISABILISM- DEFINITION

Disablism is comprises of a set of assumptions (conscious or unconscious) and practices that promote the differential or unequal treatment of people because of actual or presumed disabilities. Disablism has been the time-honored focus of study within disability studies. Disablism promotes and examines the unequal treatment of the (physically) disabled versus the able-bodied. It marks the disabled as the Other. The medical model of disability conceptualizes bodily difference in terms of impairment requiring medical intervention, whereas the social model puts the onus of disability not on the individual, but on the society in which he or she lives. Architectural, educational and employment barriers created by society disable the individual, not his/her body) ***and like ableism, works from the perspective of the able-bodied***. In posing the question 'What is disability?' disability scholarship seeks to grasp the state of disabled people's experiences of tyranny and subordination.

13.3.1 Medical and Social Models of Disability

In 1976, the **Union of the Physically Impaired Against Segregation (UPIAS)** defined impairment as:

"lacking part or all of a limb or having a defective limb, organ or mechanism of the body (including psychological mechanisms)', and disability as 'the disadvantage or restriction of activity caused by a contemporary social

organization which takes little or no account of people who have physical impairments, and, thus excludes them from participation in the mainstream of social activities"(UPIAS, 1976, p.3-4, 14, cited in Watson).

In the past three decades in the developed countries, a radical paradigm shift has occurred in theorizing disability, from the still powerful medical model to the social model[i] of disability. This move from a medical to social model of disability evolved from two theoretically different positions – namely, social construction (predominantly in the USA) and social creation (predominantly in UK). The former sought affirmation and facilitation of difference, the latter aimed at more fundamental transformation of deep social structures. The social model explains that disability is socially constructed, and it is a consequence of the existing form of arrangements in social life which exclude people with certain kinds of bodies from full participation. According to **Mike Oliver** "disability [has] nothing to do with the body and is a consequence of social oppression" (1996, p. 35). The author rightly argued that all persons with disability possess reason and knowledge; hence they should be given equal access to opportunities to participate in the public life along with the able- bodied persons. The social model of disability came from the socio-political battles of disabled people to establish legislation to obtain equal rights.

One criticism of this model is the dichotomy it establishes between disability and impairment. The social model seems to deny medical and individual aspects of disability; its theoretical structure involves a denial of the significance of the body. Some academics in critical disability studies have been entering the blurred ground of the disability versus impairment discussions. While acknowledging the significance of the social model of disability in order to bring about social changes, they maintain that some problems confronted by disabled people cannot be resolved by social management.

Check Your Progress Exercise II

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

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

1. How does social model explain the concept of disability? Describe.

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2. Do you think disability is a product of social structure and society? Please substantiate your answer by drawing examples from the society/community where you live.

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13.4 DISABLISM, ABLEISM AND EMBODIMENT

So far you have learnt about various connotations and meaning of ableism and disablism in the contexts of body and society. Despite innumerable debates we cannot conclude whether the body or social arrangements are primarily the cause of disability, since the category of 'the disabled' itself needs to be called into question. This is especially significant when we know that disability is not a homogenous category and that it denotes a fluid and shifting set of conditions. **As Mairian Corker** points out, "Disability, like most dimensions of experience is polysemic—that is ambiguous and unstable in meaning— as well as a mixture of truth and fiction that depends on *who says what, to whom, when and where"* (Corker, 1999, p.3). For example, many disabilities such as muscular dystrophy and polio change their character as is evident from the development of post-polio syndrome in young polio survivors as they become older.

Box No: 1.5: Difference in Disability

"There are differences in type of disability (in a reification of the mind/body split, disability is usually broken down as physical or intellectual), in impact (minor hearing loss versus paralysis), in onset (disability from birth/gradually becoming disabled/ suddenly becoming disabled), in perceptibility (having a "hidden disability" and "passing" as non-disabled versus being unable to hide a disability), in variability (most disabilities change across time and space), and in prevalence (disabilities vary by sex, ethnicity, age, and environment)"(Rohrer, 2005, p. 41).

If we look at the above-mentioned connotations and attributions, we can summarize that disability in all its heterogeneity does not exist separately from ability. However, society has taken a narrow approach in understanding physical disability, i.e., itis exclusively understood within notions of able-bodiedness, and is defined in terms of weakness, and of lack with reference to norms of normality. The actual complexity, fluidity and inter-connections of the disabled-able-bodied binary can be more clearly examined when placed along other taken-for-granted binaries such as male and female. For instance, in a critique of the work of pioneering psychoanalysts like **Sigmund Freud** and **JacquesLacan,** who gave primacy to the phallus and paid no attention to

other sexual organs, feminist psychoanalyst **Luce Irigaray** argues that the female genitals are "not one" (see Irigaray in MWG 001 and 003). For her, there is no single term for the female genitals in terms of a binary opposition. What is the opposite of penis? The female body and the female genitals in particular are naturally fluid, there by unsettling the fixity of the male-female binary. Thus, Irigaray's critique implies a denial of any fixed position between the sexes: "man's desire and woman's are strangers to each other" (1985b,p. 27). Indeed, femininity is itself embedded sexual difference. Her definition of female sexuality (1985b, p. 28) is based on the female body that is considered not as one sexual organ, but as a plurality of them. Irigaray argues that a female body should not be reduced to one sexual organ, since this reiterates the masculine logic of 'the primacy of the phallus' which carries baggage of patriarchy ((1985b,p. 31). She is thus critical of the social system of discrimination of man from woman, since it is not just a distinction, but a privileging of man over woman, an inclusion of woman into man, whereby woman is defined in relation to man. She deconstructs the male-female binary by moving the feminine part of the binary opposition from a position of lack into one of **excess and multiplicity**. Thus, female sexuality infuses the whole body and emerges as complex, plural and multiple rather than fixed and single.

How does this idea relate to the able-bodied/disabled binary? Let us analyze the above in the context of Irigaray's formulation, namely, 'what is the opposite of the able body? Do we accept that disabled bodies, like female genitals are changeable and fluid, since they disturb the fixed construction of the able-bodied as 'one'. As Inahara (2009) says, 'Disabled bodies are 'not one.' Therefore, representing all people by only one body, the able body, and defining physical disability as the supposed opposite of this mythical able-bodied, needs a critical examination'. To cite Inahara (2009),"the concept of disability does not exist separately from that of ability. Physical disability is enveloped within the able-bodied, and is reduced to a position of weakness, of lack. It is defined as what the able-bodied is not. … I maintain, therefore, that all people are represented by only one body, the able body, and that physical disability cannot be defined except as the supposed opposite of the mythical able-bodied (2009, p. 52)". As with the category of the feminine body, the able body has no stake / match in the lived experiences, and bodily forms, of those who are labeled as disabled. The able-bodied system implies that those who are labeled as disabled must to adopt an inferior position. Anable person's view of disability is the possibility of crossing the gulf between the binary of disability and ability. Consequently, the non-disabled are 'TABs' or 'Temporarily Able Bodied'. Moreover, unlike people of different genders or different races, non-disabled people daily experience the possibility of becoming impaired, and thus, can be described as disabled. In general, we can view that disability is understood and referred in relation to ability.

Box No – 13.1 Mythical notion of Able Body

"Any person reading the words on this page is at best momentarily able bodied, but nearly everyone reading them will, at some point, suffer from one or more chronic diseases and be disabled, temporarily or permanently, for a significant part of their lives"(Zola, 1982,p. 242).

When activists invoke the idea of TAB, it highlights how intertwined disability is in an able-bodied system, which favors the able-bodied understanding of perfection. In fact, we need to address the issue of what makes disability so threatening to society, and specifically to the so-called able-bodied. The indistinctness and permeability of the body's boundaries push us towards more fluid account of identity, which is analogous to Irigaray's understanding of femininity. It is interesting to note that disabled men often are not considered masculine in most cultures. Therefore, a model of fluidity is preferable over a model that combines different bodies into one essential self -based only on an able-bodied imagination and notion.

Why is it that as human beings, we are apprehensive of accepting the notion of fluidity, on which embodied subjectivity is formed and reformed? Why is the subjectivity of disabled persons defined as disembodied and disrupted? We need to move beyond this binary logic and to imagine possibilities of new spaces established by deconstructing the able/disabled dichotomy.

Shildrick argues that bodies viewed as disabled are monstrous and that our reactions to them are ambivalent. Seeking to demarcate the disabled body, she claims that we reach the point where we come to realize the *impossibility* of having a fixed and perfect body. By reading Shildrick, we can reconfigure physical disability not as a category of certain kinds of body, but ***as a moment of recognition in the process of being embodied***, recognition of vulnerability, of fluidity and change. If one is positioned in a fluid system of embodied subjectivity, the notion of a fixed subject can be questioned. Hence, the definition and treatment of the disable body can be questioned. One can thus accept the mode of corporeality which contains not simply the materiality of the body, but the manner in which it is experienced and lived by an embodied subject. As Shildrick (2002) comments, "Where visible appearance remains the privileged determinant of what it is to be disabled (although it may, in fact, disconcertingly offer no indication of difference), the notion of corporeality speaks to the instantiation of subjectivity itself, where – in postmodernist accounts at least – binary thinking is far more difficult to sustain" (p.18, http://www.palgrave.com/PDFs/9780230210561.pdf). So far in this section we have examined the concept of embodiment in relation to disability.

Thus, we can say that both women and men need to explore our subjectivities from our own embodied experiences. We need to question the power of the negative view on the disabled body. It is also necessary to interrogate ableist constructions in which the disabled body has been excluded. Embodiment needs to be evaluated while taking into consideration the fluidity and diversity of disabled subjectivity. The binary antagonism between the whole

body and nothing becomes destabilized once the abilities of the "disabled" are recognized.

13.5 LET US SUM UP

This unit would have helped you to understand ableism and disableism as a structure of binary oppositions, by engaging with issues of fluidity, identity, and subjective embodiment. Thus, the able-body as a fixed category may be deconstructed since ability and disability can be seen from the lived experiences of individual gendered bodies. In other words, all of us – however we are individually embodied – are more or less conscious that our bodies demand attention. But we should not suppose that the embodied self can be perfect. Thus, the contrast between ability and disability opens up the possibility for blurring boundaries between these two categories and thereby imagining new creative potentialities.

13.6 UNIT END QUESTIONS

1. Define ableism and disablism. Discuss it in relation to gendered bodies.
2. How do discourses of disablism conceptualize the women's body? Discuss with suitable examples.
3. Discuss the theoretical conceptualization of disability.
4. Do you agree with the concept of the fluid boundaries of the body? How would this idea help us to view the abled/disabled binary in a different way?

13.7 REFERENCES

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13.8 SUGGESTED READING

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UNIT 14 DISABILITY AND SEXUALITY

Structure

14.0 INTRODUCTION

This Unit is adapted from the course **BGDG 172: Gender, Society and Culture.** In this Unit we will talk about the experience of disability in relation to gender, sexuality and society. Think for a moment about what the word disability suggests to you. I am sure that most of the thoughts that cross your mind will be negative; loss, defect, tragedy, curse are some of the words that come to mind when we talk about disability. Disability challenges our fundamental notions of reality, the world, culture, and most importantly, our own bodies. Disability has been historically viewed as a physical or mental limitation affecting an individual due to which he or she is unable to participate in the life of the community and society in the same way as non-disabled or so-called 'normal' people, Spinal cord injury, cerebral palsy, blindness, deafness and speech disorders, amputation, mental retardation or intellectual disability, autism, etc. are some examples of disabling conditions. However, over the past few decades, scholars and activists have challenged the description of disability as an individual limitation or defect; they view it as a social issue that is the outcome of social discrimination and stigmatisation. Persons with disability are to be viewed as persons in their own right, with the same aspirations, needs and desires as the so called 'normal' or non-disabled people. By considering them as persons with human rights, society has to take the responsibility to ensure their well-being and dignity. This Unit will help you to understand disability as an axis of social discrimination. Specifically, it will discuss how gender affects the experiences and life chances of persons with disability.

Let us look at the objectives of reading this unit.

14.1 LEARNING OUTCOMESES

After studying this Unit, you would be able to

- Define disability;
- Discuss social attitudes and stereotypes towards disability;
- Explain gender issues in disability; and
- Discuss the issues of disability and violence.

14.2 DISABILITY DEFINITION

Simply put, disability is a state or condition of mind or body that affects an individual's functioning and interferes with their ability to participate in the activities of day to day life. As we have mentioned above, disability is not just an individual, medical problem, but a social one. For instance, a person may have lost her ability to see. That is her 'impairment'. But because the environment around her makes it difficult and dangerous for blind people to function, she becomes 'disabled' and thus her quality of life suffers. Thus, there is both a medical as well as social dimension to the issue of disability. Disabled persons represent the largest minority group in society after women. Disability can affect a person anytime in the life-span; as health care improves and persons live longer, the chances of developing an age-related disability increase as one grows older. Furthermore, accidents and injuries are a major source of injury and disability. It is rightly said that we are all **'temporarily able-bodied'**. Thus, disability is not a unique experience of particular individuals labelled as disabled but of each one of us at some point in our lives.

Disabled persons differ from one another in terms of the type and degree of disability. Moreover, gender, class, caste, race, ethnicity, sexuality, residence, and other such social, economic, political and cultural factors determine how disability is experienced and understood. For instance, in a rural, agricultural community, the loss of a limb may be seen as a severe disability because it affects the ability to work in the fields and earn a living. A person with intellectual disability who can do farm work may not be considered disabled at all, but may be teased for being a simpleton. But in an urban society, having an intellectual disability or mental retardation as it is still known in India, may be more of a problem because so much importance is given to academic performance and getting into a profession.

But what is a disability and what does it mean to be disabled in the first place? Disabilities may be present from birth (congenital). For instance, **developmental disabilities** like mental retardation and autism are believed to be congenital. Malnutrition and micronutrient deficiencies may result in disabling conditions in children in the form of stunted physical and mental growth. Certain kinds of disabilities are acquired later in life due to accidents, injuries or advancing age, as mentioned above. **A disability may be static** such as the loss of limb due to an amputation; or **'progressive'** in which a

person's condition may deteriorate with time. The commonly known disabilities include blindness, deafness, locomotor disability, mental retardation, cerebral palsy and mental illness.

Recently, autism and learning disabilities like dyslexia have also become more familiar.

In legal documents and policy statements, **disability is defined in terms of what qualifies for public assistance**. In India, the Rights of Persons with Disabilities Act (2016) identifies 21 disabilities as compared to the earlier **Persons with Disabilities Act** (1995) which identified only seven categories.

Persons with disabilities are the most neglected and disempowered section of the population. Due to their marginalised status, they are denied the fundamental civil, political, social and economic rights that are guaranteed to all citizens in a democracy. The plight of women with disabilities is even worse, since they have to face the **double oppression of gender and disability**. Indeed not only are they a socially invisible category but their plight is worse than both men with disabilities and other non-disabled women. A disabled girl child is considered as a curse upon the family and often ill-treated and abused.

According to the Census of India (2011) 26.8 million persons have some form of disability in India accounting for 2.11 % of the total population. Of these, 15 million are men and 11.8 million are women. Thus, women constitute just above 44 percent of the persons with disabilities in India. This is believed to be a conservative figure as the Census took into account only a limited number of disabilities .Using a wider definition of disability which includes conditions like diabetes and cardiovascular disease, the World Health Organisation (WHO) estimates that 6%-10% of the population suffers from identifiable physical or mental disability. That comes to over 70 million persons in India. It should be noted that estimates of the total number of persons with disabilities in a country vary depending on the definition of disability used, degree of impairment, survey methodology including use of scientific instruments for identification and measurement of the disabling conditions. Wars and conflict, HIV/AIDS, industrial injuries, and road accidents are increasing the number of disabled persons. As mentioned earlier, enhanced life expectancy has increased manifold the incidence of old age-related, chronic disease induced disabilities worldwide as well.

14.3 SOCIAL ATTITUDES AND STEREOTYPES

Historically, persons with disabilities have always been regarded with a mixture of fear, horror and disdain, almost as if they were sub-human. They have been portrayed as freaks, helpless victims and a lifelong burden for family and society. Even in religion and mythology, negative traits have been attributed with form of deformity, be it Manthara, the hunchback in the *Ramayana* or Shakuni, the "lame" of the *Mahabharata.* Indeed, the law of karma decreed that being disabled was a punishment for past misdeeds. Such constructions of the disabled by the non-disabled leads to the marginalisation and disempowerment of a whole population group. At the same time, such

negative stereotypes are internalised by the disabled people themselves. This leads to passivity, dependency, isolation, low self-esteem, and a complete loss of initiative. Pity, segregation, discrimination, and stigmatisation became normalised in the management of persons with disabilities.

In India, the dominant attitude towards persons with disability is that of pity.

This reflects in social policies which are based upon charity and welfare. Medical rehabilitation including distribution of assistive aids and appliances such as braces, crutches, hearing aids etc., special schools, vocational training in low-end occupations and sheltered employment have been the pillars of state policy for the disabled right from the colonial period. Furthermore, they have never been regarded as a politically significant group and hence their issues and concerns have not been taken up seriously by the political class. As many of them are hidden away from public view and denied access to education and social experiences, they have not been able to come together in a big way and make their presence felt in public life.

Things began to change marginally after 1981 (International Year of Disabled Persons) when the issue of disability was opened up at the national level. The changing international climate focusing on human rights and empowerment of marginal groups impelled the government to make some policy changes such as reservations in educational institutions and employment. But real progress in the form of concrete legislation to deliver the promise of equality of opportunity and social justice only came in 1995 with the passage of the Persons with Disabilities (Equal Opportunities and full Participation) Act. Other legislation soon followed. One of the historic international policy documents in recent times was the United Nations Convention for the Rights of Persons with Disability (2006) which was also signed by India in 2007. This signalled the introduction of a view of disability as a human right and development issue rather than simply a matter of charity and welfare. The Rights of Persons with Disabilities Act (2016) which has now replaced the 1995 Act, is in line with this view. Several disability rights groups and NGOs have emerged in recent times and disability related issues are being increasingly included in the curricula of educational institutions.

Check Your Progress Exercises I

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

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

1) Define disability.

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2) Describe social attitudes and stereotypes towards persons with disability.

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14.4 DISABILITY, SEXUALITY AND GENDER

We will now look the into interface between disability, feminism and Sexuality. The plight of women with disabilities as earlier mentioned is far worse than that of men, as they suffer on account of being a woman in a male-dominated society, and disabled in a world which considers the healthy, able body as 'ideal'. How a person with a disability experiences the condition and is perceived by others is largely dependent on whether s/he is male or female. For instance, Michelle Fine and Adrienne Asch point out that women with disabilities experience 'sexism without the pedestal' (1988, p.1) ,i.e. **they are doubly disadvantaged**. Not only do they experience disability-linked discrimination but they experience sexism and are denied the consideration and social status that non-disabled women may claim as wives and mothers. Men with disabilities also experience a similar assault on their masculinity and may be shamed or bullied as 'not being man enough' or dependents and burdens upon the family. This can be very bruising and damaging to their self-respect, as traditionally, men are expected to be the providers and decision makers of the family.

14.3.1 Disability and Feminism

This section is adopted from the **Unit: Disability and Feminism** of the course **MWG 001: Theories and Concepts of Women Studies**. In this sub-section, an inter-connection is drawn between disability, feminism and sexuality. Even though the principle of the personal is political shows up very starkly in the way in which disabled women are portrayed in society, they have been missing from the mainstream agenda of feminism. Women's studies all over the world including India has tended to reflect a non-disabled or able bodied perspective, and it is this perception that has generated a critique within feminism itself by women with disabilities. The critique of feminism from the disability perspective has been done through key feminist concepts of gender roles, body image, sexuality and care.

Feminists with disabilities like Jenny Morris (1992) pointed out that disabled persons were rarely considered physically attractive. In fact, asexuality is intrinsically associated with persons with disabilities, particularly women with disabilities. According to Harlan Hahn (1988), desexualisation results in asexual objectification (as against the sexual objectification of women critiqued by feminists). Since physical appearance is so critical for a

woman's identity, a negative body image will necessarily result in developing a negative self image undermining self confidence and increasing the sense of worthlessness. Furthermore, the denial of disabled women's sexuality and expulsion from traditional gender roles has not protected them from the threat of male violence, which is actually exacerbated due to their relative powerless position in the society.

According to Fine and Asch, "The popular view of women with disabilities has been one mixed with repugnance. Perceiving disabled women as childlike, helpless, and victimised, non-disabled feminists have severed them from the sisterhood in an effort to advance more powerful, competent and appealing female icons (1988, p.4).

Furthermore, heterosexuality, work, and motherhood that are 'normally' associated with women in general were not used to describe women with disabilities who were uniformly considered to be passive, dependent, and deprived. Feminists have critiqued the traditional roles of daughters, wives, and mothers as oppressive but these may be the very roles that women with disabilities aspire to precisely because they are denied to them. Fine and Asch refer to this as 'pervasive rolelessness', the lot of women with disabilities. Nasa Begum (1992) points out that access to conventional gender roles is an issue for disabled women. Consequently, the feminist struggle against the oppression of the institutions of marriage, family and childcare will be different for women with disabilities.

Even in the enumeration of differences based on colour (white/black women), ethnicity (Jewish women), class (upper class/working class), and sexuality (heterosexual/lesbian women), when disability is added, the reality of subjective experience is rarely captured leading to further objectification and alienation of women with disabilities. If diversity of experiences and forms of oppression are the real building blocks of feminist research, then the omission of disability is a major lacuna. As **Morris** vehemently points out:

Disabled people – both men and women – have little opportunity to portray our own experiences within the general culture – or within radical political movements. Our experience is isolated, individualized; the definition which society places on us centre on non-disabled people' s judgements of individual capacities and personalities and are dominated by what disability means to non-disabled people. This lack of a voice, of the representation of our subjective reality, means that it is difficult for non-disabled feminists to incorporate our reality into their research, their theories; unless it is in terms of the way the non-disabled world sees us. (1993, p. 59).

Under these circumstances how can the standpoint of disabled women be understood if they are an absent subject? And the knowledge thus produced is likely to be alienated. For instance, in the feminist research on care-giving (Davis, 1984), the focus has been on women as carers, not as those cared for. This in turn translates in the violation of the right to motherhood of disabled women because they are viewed as incapable of caring.

As mentioned earlier, the 2011 Census estimates that there are over eleven million women with disabilities in India constituting about 4% of the population. Some researches estimate that there are over 35 million women with disabilities in India. (Bacquer and Sharma, 1997). Others put the figure at 20 million. 98% of the disabled are illiterate: less than 1% can avail healthcare and rehabilitation services (ActionAid, 2003, p. 15). But these statistics are only the tip of the iceberg when it comes to gauging the level of neglect, isolation, stigma and deprivation that characterise their lives. The majority of women with disabilities in India suffer the **triple discrimination** of being female, being disabled and being poor. Let us discuss some of the aspects of discrimination that these women experience.

14.5 MARRIAGE AND FAMILY LIFE

A disabled woman is considered incapable of fulfilling the normative feminine roles of homemaker, wife and mother. Then, she also does not fit the stereotype of the normal woman in terms of physical appearance. Since women embody family honour, disabled girls are kept hidden at home by families and denied basic rights to mobility, education, and employment. They are less likely to be given in marriage than disabled men. The capacity of women with disabilities to be sexual partners, homemakers and mothers is questioned and doubted. They are not considered capable of performing household chores efficiently, having meaningful sexual relationships or producing and rearing healthy children. Under these circumstances, they may be married off to older already married or men in poor health. In short, women with disabilities do not have the same options of marriage and motherhood as non-disabled women. Being nurturing and caring are important aspects of female identity and cultural expectations of 'proper' womanhood, but women with disabilities are themselves in need of care. Thus, they are not regarded as complete women.

10.6 VIOLENCE AND ABUSE

Being powerless, isolated and anonymous, women with disabilities are extremely vulnerable to abuse and violence. In addition, help in activities of daily living

Health and Gender like dressing, eating, and other bodily activities makes them more vulnerable to abuse both at home and in institutions. She will be less able to defend herself in a risky situation because she may not be able to run or shout for help. Then, persons with developmental disabilities may be too trusting of others and hence may be easier to trick, bribe or coerce. They may not understand differences between 'good touch' and 'bad touch'. Many cases are known of mentally or intellectually disabled girls and women who are sexually abused by people responsible for their safety and care because they are sure that the victim will not be able to report what has happened to her, and the abuser can escape scot-free. Persons with speech and hearing difficulties may have limited communication skills to report abuse. Furthermore, since disabled persons are often taught to be obedient, passive, and to control their behaviour, this may make them easy victims.

10.7 PHYSICAL ACCESS AND MOBILITY

Women in general in our country find it difficult to move freely from one place to another for work or leisure. So we can well imagine the condition of women with disability. Poor public transport, bad roads or no roads, lack of proper lighting and safety on the streets all make it very difficult for women with disabilities to move from one place to another without assistance or help. You may have seen women with disabilities in public places facing great hardships because the built environment (roads, buildings, toilets etc.) are so difficult for them to negotiate. Conditions in public buses and the railways are also very unfavourable for persons with disability in general and women in particular. Lack of proper toilet facilities is a major problem. Public toilets are filthy and unhygienic and usually at ground level (Indian style toilet) making it very difficult for loco-motor disabled women who often get around by crawling on all fours. Many women with disabilities have narrated their experiences of not eating food or even drinking water for long periods while they are out of the house for fear that they may need to use the toilet. This has a bad effect on their health. Due to these difficulties in moving from place to place, families often prefer to keep their disabled daughters confined in the four walls of the home. Many such girls never get the opportunity to interact with the outside world; go to school, make friends or visit relatives or neighbours. This leads to feelings of depression, isolation and worthlessness.

10.8 EDUCATION, TRAINING AND EMPLOYMENT

Many disabled girls never go to school. There is a lot of social stigma attached to their condition and families may want to hide them from the eyes of the world for fear of bringing a bad name on the family and affecting the marriage chances of other girls in the family. Special schools or vocational centres that are equipped to deal with their needs are usually only found in urban centres and travelling daily to these centres becomes a burden on the family. Lack of hostel facilities and proper care if such hostels exist further worsens the problem. Many families consider their disabled daughters to be unfit for education and are unwilling to invest any money for the purpose because the girls are already considered a burden. Needless to say women with disabilities also find it very hard to secure employment because of their lack of education and training. This poses a serious problem for their futures especially after their parents die leaving them without financial support or independence.

10.9 HEALTH CARE

Girls and women with disabilities may suffer from several health problems which may be related to their disability and which may require prolonged and costly medical care, rehabilitation, occupational therapy, physiotherapy, special diets etc. Assistive devices like hearing aids for the deaf, wheelchairs or artificial limbs for those with loco-motor disabilities may prove

prohibitively expensive for poor families. Women find it very humiliating when they go for health check- ups because health professionals often treat them in an insensitive and callous way. Many women neglect their health because they do not want to burden their families more and consider themselves worthless. Health is directly related to nutrition and a good quality of life. Many women with disability also suffering from poverty and neglect, do not get adequate nutrition, fresh air, exercise and a wholesome atmosphere in which they can be healthy.

10.10 LEISURE ACTIVITIES

As mentioned earlier, girls and women with disability are often confined within the house because of stigma, shame and practical considerations like mobility issues. This gives them little opportunity to socialise with their peers, make friends, attend family events, religious ceremonies etc. This further isolate them and makes their lives dull and drab. As earlier mentioned, our public spaces are not at all accessible for persons with disabilities. Leisure activities like going out for a meal or for a film become potentially embarrassing and humiliating encounters. A woman with a disability may have to be physically carried because there is no lift or ramp; or made to sit at a distance from her companions because there is not adequate space for her wheelchair.

Thus we see that women with disabilities face violations of their rights at every level. They are considered a financial burden and social liability by their families; they are denied opportunities to move outside the home, and have access to education; they are viewed as asexual, helpless and dependant; their vulnerability to physical, sexual and emotional abuse is enormous; their aspirations for marriage and parenthood often denied; they grow up isolated and neglected within the walls of home or special institutions with no hope of a normal life.

Although a rights-based approach has entered the disability rights movement, the specific concerns of women with disabilities have not yet found a place neither in the government policies and programmes nor in the voluntary sector. Ironically or expectedly, the disabled rights movement all over the world including India is male dominated. It may even be blatantly sexist. Even within the women's movement, women with disabilities rarely figured as a distinct group in international covenants. However, the Beijing declaration in 1995, *Platform for Action*, specifies women with disabilities as a particularly vulnerable group

Health and Gender with little access to information on their fundamental rights. This is a serious lacuna, which needs to be rectified at various levels. One of the most important features of *The United Nations Convention on the Rights of Persons with Disabilities,* which was passed by the General Assembly in 2006, is the incorporation of a separate article on women with disabilities. Being a signatory to this Convention, the Indian state is henceforth duty bound to incorporate a gender perspective in all its policies and programmes in the disability sector. The new disability Act does make reference to women particularly with regard to access to sexual and

reproductive health care, however there remains much to be done on the ground to ensure that women with disabilities access their rights.

Check Your Progress II

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

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

1. Explain the meaning of triple discrimination with regard to gender and disability.

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2. Which International Convention incorporated a separate article on women with disabilities? Describe.

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14.11 LET US SUM UP

Disability is a universal human condition and we are all only 'temporarily able bodied'. The notion of disability as a tragedy or medical anomaly has been challenged by scholars who view it as a social as well as biological condition. Discriminatory social attitudes and denial of basic rights to persons with disability has made them weak, powerless and isolated throughout history. The condition of women with disability has been particularly difficult and they have faced discrimination and marginalization in all aspects of life; from marriage and family life to mobility, education, employment, health care and leisure. However, the new rights based approaches and international policies that have been introduced over the past few years have created greater awareness about their condition. Rigorous research and life-writing by women with disabilities has contributed to our knowledge and understanding. Disability has also become a topic of interest in popular cinema. All these developments will hopefully lead to better understanding of the situation and concrete action on the ground through enabling policies and laws for ensuring that all people with disabilities get the opportunity to lead fulfilling lives.

14.12 UNIT END QUESTIONS

1. Explain the issues of gender, disability and sexuality in detail.
2. Discuss the problems of disabled women with regard to marriage and family life.
3. Analyse issues of mobility, education and healthcare as a matter of human right for a disabled person.

Gender and Disability

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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.

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15.8 SUGGESTED READING

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