UNIT 1 DISCOURSES OF ABLEISM AND DISABLISM

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Structure

1.1 INTRODUCTION

In this block on 'Abled Bodies and Disability', 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 disablismas 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 ofpeople who appear or behave differently. We will begin this unit with a definition of Ableism and Disablism before analyzing specific issues related to disablism.

1.2 OBJECTIVES

After going through this unit, you will 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.

1.3 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 marginalisation, 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,ableismcan be understood as an attitude that distinguishes disability through the parameters and appraisal of **able-bodiedness**. As a theoretical tool, ableismis hardly accountable to any forms of measure orconstitutionfor governing the normative behaviour in the society; thereforeeasilylocates itself in the arenas of sources of knowledge generation and accumulation. There is little consensus in the society as towhat 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 bydisability 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**, ableismrefers 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 visitedare accessible for

students with disabilities. Schools can overcome ableism by appropriate infra-structuraland 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 haveto contend the ableist prejudice. **Veronica Chouinard** defines ableism as “ideas, practices, institutions andsocial relations that presume able-bodiedness, and by so doing, construct persons withdisabilities 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 generateand 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 ispossible.

Ableism not only infiltrates language and society,but it can also make it difficultfor 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' whereasdisabled people may be refered 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 languagesare 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:

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

1.4 WHAT IS DISABILISM?

Disablismiscomprises 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 conceptualises bodily differencein terms of impairment requiring medical intervention, whereas , the social modelputs the onus of disability not on the individual, but on the society in whichhe or she lives. Architectural, educational and employment barriers createdby 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.

1.4.1 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 theorising disability, from the still powerful medical model to the social model[1] 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 ofthe 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:

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.

1.5 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: 1.5.1: 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 withinnotions of able-bodiedness, and is defined in terms of weakness, andof 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 **Jacques Lacan,** 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 genitalsare 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. An able 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', '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. 1.5.2: 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 ofaccepting 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 spacesestablished 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).

Check Your Progress:

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?

1.6 DISABILITY, ATONOMY AND CARE

So far we have examined the concept of embodiment in relation to disability. Let us now turn the notion of autonomy. In addition to embodiment, able-bodied subjectivity also takes autonomy for granted–something which becomes a matter of doubt or denial in the case of differently embodied subject. For instance, a wheelchair is taken to symbolize disability universally. **Lisa Cartwright and Brian Goldfarb** note: "Purposeful mobility, like speech and gesture, is a key signifier of human agency and personal expression" (2006, pp.139–40, http://www.palgrave.com/PDFs/9780230210561.Pdf).

Yet the focus of the physical body is not concurrent with the phenomenal body as it is lived in all its rich and varied experience. A phenomenological understanding of the body insists that body and mind are always inseparable,that corporeal changes are inextricably reflected in changes to the embodied subject, and moreover that embodiment is a matter of process for every one of us. However, if one is defined by a form of atypical embodiment – the person ceases to be an equal, and becomes the lesser term in a hierarchical binary in which the unmarked self is dominant. Nevertheless, that dominance is maintained only at a cost, not only to the devalued other, but to the one who appears secure in her personhood. As a matter of everyday experience, it is clear that the inherent instabilities of the body always threaten to disrupt the possibility of any fixed relation between self and other. What strategies then must be in place in order to ensure an illusory security, and how they can be deciphered?

In failing to reproduce the ideal image of corporeal immunity, disabled bodies are not positioned, however, as ***dis*empowered**. On the contrary disabled bodies are signal threat and danger insofar as they undermine any belief in the stability and consistency of bodies in general. Paradigmatically, such bodies elicit anxiety for they remind others of their own vulnerability and precariousness. The feminist philosopher, **Susan Wendell**, **who has chronic fatigue syndrome, makes the point: If we tell people about our pain, for example, we remind them of the existence of pain, the imperfection and fragility of the body, the possibility of their own pain, the inevitability of it. . . . They may want to believe they are not like us, not vulnerable to this; if so they will cling to our differences, and we will become 'the Others'** (1996,pp. 91–2).

Psychologically, it is uncertainwhether we can distinguish between **mastery as *power over*another**, and **mastery as a *defense against* anxiety**. Unfortunately, one way to deal with anxiety is by the exercise of power and control.While one mode of manifestation of power is domination, another equally important mode is benevolent concern for others. While the disabled might condone the gesture, it is clear that caring behaviourmay also limit

the autonomy and freedom of those with disabilities. Taking responsibility for another, even claiming empathy, is also rarely uncomplicated but essentially communicates the feeling of an unwillingness to engage on equal terms with the other. Many disability scholars would vouch for the damaging consequences of an insecurity which manifestsas a need for mastery over the supposed threat of disability to the normative order. According to**Julia Kristeva** (1982), abjection is "what disturbs, identity, system and order … that which 'does not respect, boundaries, positions, rules: The in between, the ambiguous, the composite" (Kristeva, 1982, p. 4). Her point is that the abject is never fully expelled. It causes anxiety at the level of the coherence and stability of the identity.

We can thus summarize that embodied subjectivity depends on a phenomenological boundary with a world of others and there remains, a powerful desire for, and expectation of, clearly delineated bodily limits and boundaries. We must then tirelessly make the distinctions between self and other, and between categories of others. Given that no interaction is entirely without risk to our fragile sense of self, the relations between self and other cannot be stable. This may also explain why the medicalized understanding of individual pathology has held influence for so many decades.

As **Michael Bérubé** notes, "the instability of disability (is)a device for destabilising all categories of identity" (2002,p. *x*). Such are alization is the ground for an ensuing tension between the implicit fears that would silence or evade disability and the optimistic hope for change that is not about ending the multiple insults to disabled people.It would also help to open up the discourse to the very instability that disability embodies. So the possibilities for a different subjectivity are enormous. Such an alternate subjectivity would enable the disabled to be assessed by norms which do not exclude them. In this regard, we also need to interrogate the obsession with 'body-perfect', an attempt which by its nature is destined to failure. If the disabledbody can ask questions of the able-bodied ideal, such an ideal would be exposed as an illusion. From a feminist view point it is significant to look at the relationship between contemporary notions of individual agency and the particular horror that disability might evoke. While suffering associated with disability is assigned a negative value, suffering that is inflicted voluntarily on the self in order to achieve physical perfection is valorised. Women and men are experiencing everywhere a styling of body, soul and mind. You would have already come across the concept of the beauty myth and its damaging consequences on women in the unit on Commodified Body (Unit 4, Block 1) of this course. Everyday bodies pursue the aesthetic perfection of their bodies in beauty parlors, gyms as well as clinics which provide cosmetic surgery services. This in itself is indicative of the relationship of body with technology. In contemporary India the technology of prenatal determination of foetal

characteristics has disadvantaged both girls and the disabled. With the advent of these technologies more and more pregnant women are encouraged by doctors to go in for prenatal screening. You would be reading about impact of reproductive technologies on women's body in the unit on "Reproductive Technology" (Unit 2, Block 3) of this course. The new reproductive technologies have eugenic potential as they reinforce the notion that there is an ideal of physical and mental perfection that humanity must aspire to. Such a position considers most differences as deficits. Thus disability is a reminder of one of the limits of technological transformations. Exploring this incomprehensible body is therefore a complicated task and needs to be approached with sensitivity.

Thus, 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.

1.7 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 there by imagining newcreative potentialities.

1.8 GLOSSARY

Apartheid : The term apartheid, from Afrikaans for "apartness," was the official name of the South African system of racial segregation which existed after 1948. It became more widely known, South African apartheid was condemned internationally as unjust and racist and many decided that a formal legal framework was needed in order to apply international pressure on the South African government.

Disability Studies : In 1993, the society for disability study adopted an official definition of "Disability Studies" as "examines the policies and practices of all societies to understand the social, rather than the physical or psychological determinants of the experience of disability. Disability Studies has been developed to disentangle impairments from the myths, ideology and stigma that influence social interaction and social policy. The scholarship challenges the idea that the economic and social statuses and the assigned roles of people with disabilities are the inevitable outcomes of their condition (see www.en. wikipedia.org/wiki/ Society_for_Disability_studies, accessed on 16th December, 2011).

Euphemism : Euphemism is a substitution for an expression that may offend or suggest something unpleasant to the receiver, using instead an agreeable or less offensive expression. Euphemisms may be used to hide unpleasant or disturbing ideas, even when the literal term for them is not necessarily offensive. This type of euphemism is used in public relations and politics, where it is sometimes called doublespeak. Sometimes the use of euphemisms is equated to politeness.

Eugenics : It is the applied science or the biosocial movement which advocates the use of practices aimed at improving the genetic composition of a population with specific referring to human populations. Eugenics was widely popular in the early decades of the 20th century, but by the late 20th century it had fallen into disfavor, having become associated with Nazi Germany.

1.9 UNIT END QUESTIONS

1) Define ableism and disablism. Discuss it in relation to gendered bodies.

2) How do discourses of disablismconceptualise the women's body? Discuss with suitable examples.

3) Discuss the theoretical conceptualization of disability.

1.10 REFERENCES

Amundson, Ron, and Gayle T. (2005). 'Our Lives and Ideologies: The Effects of Life Experience on the Perceived Morality of the Policy of Physician-Assisted Suicide'.*Journal of Policy Studies*,(16)1, 53-57.

Campbell, Fiona A. Kumari (2008). 'Exploring Internalized AbleismusingCritical Race Theory'.*Disability &Society*.(23) 2, 151 - 162.

Chouinard, Vera (1997). 'Making Space for Disabling Difference: Challenges Ableist Geographies'. *Environment and Planning: Society and Space*. 15, 379–387.

Corker, M. (1999).'Differences, Conflations and Foundations: The Limits to 'accurate' Theoretical Representation of Disabled People's Experience'. *Disability and Society*. 14(5), 627-642.

Goodley, D. (2007). 'Becoming RhizomaticParents: Deleuze, Guattari and Disabled Babies'. *Disability & Society*,(22) 2, 145–60.

Hughes Bill Paterson Kevin(1997).'The Social Model of Disability and the Disappearing Body: Towards A Sociology of Impairment'.*Disability & Society*.(12) 3, 325± 340.

Inahara Minae(2009). 'This Body Which is Not One: The Body, Femininity and Disability'. Body & Society SAGE Publications (Los Angeles, London, New Delhi, Singapore andWashington DC), (15)1, 47–62.

Irigaray, L. (1985a).*Speculum of the Other Woman*, trans. G.C. Gill Ithaca, NY: Cornell University Press.

Irigaray, L. (1985b).*This Sex Which is Not One*, trans. G.C. Gill. Ithaca, NY: Cornell University Press.

Kristeva, J. (1982), *Powers of Horror,An Essay on Abjection*. New York: Columbia University Press.

Kristeva, J. (1982). *Powers of Horror, An Essay on Abjection*, trans. L. Roudiez. New York: Columbia University Press.

Linton, S (1998).*Claiming Disability*. New York: New York University Press.

Merleau-Ponty, M. (1962).*Phenomenology of Perception*. London: Routledge and Kegan Paul.

Michalko, Rod (1999). *The Two in One: Walking with Smokie, Walking with Blindness*. Philadelphia: Temple University Press.

Oliver, M. (1990).*The Politics of Disablement*. Basingstoke: Macmillan.

Rohrer, J. (2005).'Towards a Full-Inclusion Feminism: A Feminist Deploymentof Disability Analysis'. *Signs*, (31)1, 34–63.

Shildrick, Margrit (2002).*Embodying the Monsters: Encounters with the Vulnerable Self*.London: SAGE.

Siebers, Tobin(2008).*Disability Theory*. Ann Arbor: University of Michigan Press.

TARSHI (2010).Sexuality and Disability in the Indian Context, Working Paper.

UPIAS, UPIAS (1976). *The Fundamental Principles of Disability*. London.

Wendell, Susan. (1996). TheRejected Body: Feminist Philosophical Reflections. In Zola, I. K. (Ed.),

Social & Cultural Disincentives to Independent Living. Archives of Physical Medicine and Rehabilitation, 63.

Http://www.palgrave.com/PDFs/9780230210561.pdf.Accessed on 18th October, 2012.

http://www.palgrave.com/PDFs/9780230210561.Pdf. Accessed on 18th Oct, 2012.

1.11 SUGGESTED READINGS

Campbell, Fiona A. Kumari (2008). 'Exploring Internalized Ableismusing Critical Race Theory'. *Disability & Society*. (23) 2, 151 - 162.

Rohrer, J. (2005). 'Towards a Full-Inclusion Feminism: A Feminist Deployment of Disability Analysis'. *Signs*, (31)1, 34–63.

Hughes Bill Paterson Kevin (1997). 'The Social Model of Disability and the Disappearing Body: Towards A Sociology of Impairment'. *Disability & Society*. (12) 3, 325± 340.

TARSHI (2010).Sexuality and Disability in the Indian Context, working paper.

UNIT 2 DISABILITY, SEXUALITY AND MOTHERHOOD

Shubhangi Vaidya

Structure

2.1 INTRODUCTION

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

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

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

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

2.2 OBJECTIVES

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

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

2.3 DISABILITY: A DEVALUED IDENTITY

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

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

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

2.4 DISABILITY, SEXUALITY AND MOTHERHOOD: SOME MYTHS AND MISCONCEPTIONS

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

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

2.4.1 Disability and Sexuality

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

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

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

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

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

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

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

a) ***Lack of confidence about one's body*****:** Disabled bodies do not fit the cultural ideal of the healthy , strong, independent and beautiful body. In addition to sensory loss, there may be lack of muscular co-ordination, drooling at the mouth, incontinence, etc. Persons with disabilities may be dependent on others for activities of daily living and their bodies may be deformed and aesthetically unappealing in more ways than one. The disabled body is not valued as a source of pleasure or value. All these are indicators of a poor body image, which not only refers to appearance but encompasses the whole range of perceptions about bodily sensations, capacities and functions.

b) ***Poor sexual self-esteem*****:** Poor body image also affects a person's sexual self-esteem. Sexual self-esteem is an individual's sense of self as a sexual being and may be rated as appealing and unappealing, competent and incompetent. It describes a person's sexual identity and perception of sexual acceptability. When persons have a positive body image, they are likely to have high levels of sexual self-esteem as well. When sexual self-esteem is damaged, it can lead to mental ill health; since it results in a damaged view of oneself, diminished satisfaction with life and capacity to experience pleasure, willingness to interact with others and develop intimate relationships. As social attitudes towards physical differences are largely negative, body image and associated sexual self-esteem are a problem area for persons with disabilities. Disability may lead to the loss of sense of self as a sexually attractive and sexually functional person.

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

Activity:

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

2.4.2 Disability and Motherhood

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

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

Check Your Progress:

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

2.5 REPRODUCTIVE RIGHTS AND DISABLED WOMEN

2.5.1 The Pune Hysterectomies Case

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

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

2.5.2 The 'Nari Niketan Case', Chandigarh

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

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

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

b) She had some physical abnormalities (such as hepatitis-B positive status), which may be genetic in nature and could be transmitted to the unborn child; furthermore, due to her age, medical status and mental condition, continuation of the pregnancy might adversely affect her health;

c) Being mildly retarded, she would be unable to fend for herself and look after the child. Although aware that there was a baby inside her, she had no idea how it came to be there. She was, therefore, incapable of understanding the complexity of motherhood and performing the role of a competent mother.

d) The child of a victim of sexual abuse, who does not have any family support, is at risk of suffering from social and emotional problems in life.

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

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

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

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

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

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

Check Your Progress:

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

2.6 ATTITUDES TOWARDS DISABLED MOTHERS

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

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

ii) 'Good enough mothering': A second theme that emerged strongly in Thomas's study was the fear experienced by disabled mothers at not being 'good mothers'. Given the strong role of the state in western, industrialised societies in monitoring the 'welfare' of children, disabled mothers felt that they were constantly under surveillance by health visitors, community midwives, doctors and social workers. Even family members would interfere against the wishes of these mothers. The fear of the 'judgements' of professionals and experts coupled with the possibility of losing the custody of their children forced them to 'present' themselves to others as 'fit' mothers. The pervasiveness of 'disabilist' ideas, which doubt the ability of disabled women to be 'good mothers' and cope with the demands of mothering, is amply demonstrated here.

iii) Inappropriate or inadequate 'help': This theme is in consonance with the findings and literature on 'medicalisation' of pregnancy and childbirth, wherein medical professionals and experts 'take over' how a child is to be reared leading to the woman losing her sense of control and agency. This is even more salient with disabled women as their impairments are seen as additional complications to be managed by professionals. The voices of the women, their needs and experiences are seldom taken into account, professionals and non-disabled lay-people assume that they know best. Thomas argues that constructing disabled persons as dependent, needy and requiring care rather than as givers of care, is a classic feature of 'disablism'

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

2.7 LET US SUM UP

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

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

2.8 GLOSSARY

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

2.9 UNIT END QUESTIONS

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

2.10 REFERENCES

Addlakha, Renu (2007). 'Gender, Subjectivity and Sexual Identity: How Young People with Disabilities Conceptualise the Body, Sex and Marriage in Urban India'. *Occasional Paper*, CWDS, New Delhi.

Bhambani, Meenu (2009). 'Societal Responses to Women with Disabilities in India'. In Renu Addlakha, Stuart Blume, Patrick Devlieger, Osamu Nagase and Myriam Winance (Eds.), *Disability and Society: A Rader*. New Delhi: Orient Black Swan.

Ghai, Anita (2002). 'Disabled Women: An Excluded Agenda of Indian Feminism'. *Hypatia*, 17(3).

Gonsalvez, C. (2011). 'Kaliyug':The Decline of Human Rights Law in a Period of Globalization'. New Delhi: Human Rights Law Network.

Rastogi, P. and Mukesh, Y (2010).'Issue of Consent for MTP by Orphan,Major and 'Mentally Retarded': A Critical Review' . *Journal of the Indian Academy of Forensic Medicine*, 32(3), pp.267 to 274.

Sunder Rajan, Rajeswari (2005). 'Beyond the Hysterectomies Scandal: Women, the Institution, Family and State'. In Kalpana Kannabiran (Ed), *The Violence of Normal Times*. New Delhi: Women Unlimited.

Thomas Carol (2009). *'The Baby and the Bath Water: Disabled Women and Motherhood in Social Context'*. In Renu Addlakha et al (Eds.), *Disability and Society: A Reader*. New Delhi: Orient Black Swan.

2.11 SUGGESTED READINGS

Addlakha, Renu (2007). 'Gender, Subjectivity and Sexual Identity: How Young People with Disabilities Conceptualise the Body, Sex and Marriage in Urban India'. *Occasional Paper*, CWDS, New Delhi.

Bhambani, Meenu (2009). 'Societal Responses to Women with Disabilities in India'. In Renu Addlakha, Stuart Blume, Patrick Devlieger, Osamu Nagase and Myriam Winance (Eds.), *Disability and Society: A Rader*. New Delhi: Orient Black Swan.

UNIT 3 DISABLED MASCULINITY

Renu Addlakha

Structure

3.1 INTRODUCTION

In the unit on "Disability and Feminism" (Unit 5, Block 5, MWG-001), we have already discussed how a person with a disability experiences the condition and how these experiences and perceptions are influenced by gender. The gender-based implications of disability with regard to women with disabilities have already been discussed in that unit. In the present unit, we shall examine how male identity or masculinity impacts and is impacted by disability, using disabled masculinity as a central category of analysis. This unit should be read in conjunction with the units on disability and feminism.

Disabled feminists have claimed that disability studies have ignored the experience of disabled women. For instance, **Jenny Morris (1994)** speaks of a false generic in writings on disability speaking of people with disabilities in a gender neutral kind of way, when it is actually speaking of men with disabilities. On the other hand, according to **Tom Shakespeare (1999)**, there has been a neglect of the specific concerns of men with disabilities both in the newly emerging sub-discipline of masculinity or men's studies as also in the disability studies domain. While such perspectives reflect the ongoing wider debates in gender studies on oppression, the purpose of this unit is not to engage in a gender war on disability, but to highlight how male identity and disability intersect to produce particular forms of disadvantage for men that are linked to social constructions of masculinity.

The first part of the unit discusses critical concepts in masculinity studies, namely, masculinity and its forms i.e. hegemonic and subordinate masculinities. This is followed by examining what disability means to men with disabilities, giving rise to the concept of disabled masculinity as a counter-point to the concept of disabled femininity. Of particular interest

is the discussion on the strategies that disabled men employ to reconfigure their masculinity in the context of disability which is gleaned from a pioneering empirical study on disability and masculinity.

3.2 OBJECTIVES

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

- Analyse the inter-relationship between masculinity and disability as a form of intersecting categories;
- Explain different permutations of masculinity as they relate to disability with particular reference to the concepts of hegemonic and subordinated masculinities; and
- Explain how disabled masculinity is a form of subordinated masculinity.

3.3 HEGEMONIC AND SUBORDINATED MASCULINITIES

There is abundant feminist scholarship on how gender intersects with other social categories such as race, class, ethnicity, and social identities. Of late, an interface between disability and gender has been theorized by a few feminist scholars to develop an inclusive gender theory, which can address questions such as to how disability impacts gender performance, how women and men experience disability differently, and how disability affects the gender experience in society. Theories of gender and disability aim at putting the notion of the disabled- body in relation to the devaluation of masculinity. Before discussing the interface between disability and masculinity, we need to know what we mean by masculinity in the first place.

Masculinity is not a generalizable subject that can be discussed in isolation. It is located in the gender structure of the society and can be reflected through a set of social practices. As **Connell** (2005) argued, masculinity is inherently relational in nature; hence it exists in opposition to femininity. If a culture does not treat women and men as bearers of polarized characteristics, then, masculinity would not exist as a concept. Masculinity is thus conceived as a product of a bourgeois ideology that created two different and exclusive spheres for women and men in the 19th century. In this sense, masculinity has a recent history that can be understood in relation to different cultures and societies.

Box 3.3.1: Defining Masculinity

Two pioneering researchers in masculinity studies offer the following concise, yet comprehensive, definition: 'Masculinity is not a fixed entity embedded in the body or personality traits of individuals. Masculinities are configurations of practice that are accomplished in social action and, therefore, can differ according to the gender relations in a particular social setting' (Connell and Messerschmidt, 2005, p. 836).

From the above definition, it is clear that masculinity is not a unitary, universal or homogenous concept. There is no intrinsic thing called masculinity, and it is not necessarily linked to the body. On the other hand, it is socially constructed, since it is actualised through social actions and practices. Masculinity comprises of certain norms and behaviours which are associated with gender bodies in a particular social arrangements.

Forms of Masculinity: Masculinity is positioned in a variety of relationship structures that add various meaning to the concept. Hence, masculinity needs to be understood in relation to structures of power, and production which are closely shaping gender relations. As Connell pointed out, we need a three-fold model of structure of gender such as a) power b) production, c) cathexis to analyse masculinity.

Box 3.3.2: Three Fold Model of Gender Structure

Power relations: It implies the overall subordination of women to the domination of men, which is primarily described as patriarchy. This structure of unequal power relations between women and men persists in the contemporary society in spite of resistance and change. Politics of masculinity can only be viewed in reference to the feminists' resistance to patriarchy.

Production relations: In the sphere of production and reproduction, there is an obvious gender division of labour that is manifested through allocation of different tasks to men and women, and differential wages in the labour market. In a capitalist economic condition, gender division of labour is an extension of patriarchy that exists in the reproductive arena. It is the social construction of masculinity which gives men the power to accumulate wealth and private capital in the labour market. Gender division of labour can also offer a meaningful construct to analyse masculinity in the process of socialization.

Cathexis: When emotional energies are attached to any object, the gender characteristics become apparent. The social practices like 'practicing heterosexuality' shape masculine identity in the society.

Source: Connell (2005)

The information provided in the box above indicates that 'structure of gender', which is embedded in the unequal power relations between women and men, is leading to the construction of masculinity as a social identity. Different social forces, institutions and practices are assigning social roles and behaviours to men within the society. Masculinity is a representation of prescribed social roles and behaviours assigned with the male body. It is not a static concept and it keeps on changing across cultures and societies. **Blackwood (2006),** in the anthropological study of Minangkabau ethnic group explores the interrelationship between gender identities and the reproduction of gender transgression. Within this community, individuals exhibit tomboyish orientation to show themselves as masculine. 'Tomboy' is a practice through which females will act in the manner of men, and this practice is shaped within the Minangkabau culture. In this context, masculinity is not attached with the body but shaped through cultural practices. The plural masculinity model reflects variations, which exist in a society, within different groups and at individual levels as well. According to **Kimmel and Aronson (2004)**, differences between women and men are not as intense as the differences among men or among women. To summarise, connotation of masculinity varies in four dimensions:

- Across cultures
- In one country over time
- Over a person's course of life
- Within a society at any point of time

One of the central themes is the concept of hegemonic masculinity. The term was first used by scholars in Australia working in diverse fields such as social inequality in education (Kessler et al;, 1982), labour politics (Connell, 1982) and embodiment (Connell, 1990). It refers to the existence of a culturally normative ideal of male behaviour marked by the tendency to dominate not only women but also other men. Paralleling the socialization of girls and women into ideals of femininity, boys and young men are also socialised into internalising and enacting the forms of hegemonic masculinity considered appropriate in their culture.

As Connell points out, "a particular form of masculinity being hegemonic means that it is culturally exalted and its exaltation stabilises a particular structure of dominance and oppression in the gender order as a whole" (1990, p. 94).

The principal characteristics of hegemonic masculinity today, particularly with reference to Western society, are physical strength and athleticism, courage, endurance, aggression, stoicism, tenacity, independence (especially economic independence), sexual prowess, etc. Even though these may not necessarily be the most prevalent forms of male expression, they are the

most socially endorsed forms. Proponents argue that such characteristics as aggressiveness, strength, drive, ambition, and self-reliance, are encouraged in males but discouraged in females in contemporary Western society, as evidence of the existence of hegemonic masculinity. The concept has been used in applied domains such as the sociology of education, psychotherapy, criminology and health sciences etc. Hegemonic masculinity is not a static concept; it responds to and is shaped by macro-level socioeconomic and cultural changes.

The critique of hegemonic masculinity has come from a variety of sources:

- class and ethnic studies that have highlighted the existence of multiple masculinities, differentiated by socio-economic power and race/ethnic differentials even within the same culture;
- gay liberation politics and scholarship that has showed up hierarchies of masculinities manifested in the oppression of gay by straight men; and
- empirical research in different contexts like schools, the workplace and village communities documenting local gender hierarchies and cultures of masculinities.

Consequently, those men who do not match up to these impossible standards of masculinity due to ethnic, race, class, and sexual orientation are subordinated or marginalized. There is a complex intersection of masculinity with other sets of variables such as race, sexual orientation and disability. According to Connell (1987), the functioning of hegemonic masculinity rests with patriarchy's role in subordinating the other while privileging the men's role and their position (cited by Joseph and Lindegger, 2007). In this context, subordination of others includes women, and men of different class, race, and with disability. Disabled men also fall short because they do not embody the ideal of the strong, fit, competitive and able masculine body. This is eloquently summed up by the anthropologist **Robert Murphy**, who developed a disability later in life. According to Murphy: "Paralytic disability constitutes emasculation of a more direct and total nature. For the male the weakness and atrophy of the body threaten all the cultural values of masculinity: strength, activeness, speed, virility, stamina and fortitude" (1990, p. 94).

Check Your Progress*:*

What do you understand by hegemonic masculinity? Give examples to describe the concept.

3.4 MASCULINITY AND DISABILITY

Gender identity and disabled identity interact in different ways for men and women. Disabled females suffer a double disadvantage in that while they cannot enter traditionally male occupied roles, they are also denied access to normative female roles like wifehood and motherhood. As Fine and Asch point out:

> "Whereas disabled men are obliged to fight the social stigma of disability, they can aspire to fill socially powerful male roles. Disabled women do not have this option. Disabled women are perceived as inadequate for economically productive roles (traditionally considered appropriate for males) and for the nurturant reproductive roles considered appropriate for females" (1985, p. 6).

While the asexuality ascribed on account of disability translates into general features of dependency and passivity for disabled persons of both sexes, it has different implications, because there are links between the assumed passivity of disabled persons and the assumed passivity of women. Persons with disabilities are often described by use of terms such as weak, vulnerable, innocent and dependent— terms that also connote femininity. When these characteristics are ascribed to men with disabilities, they have adverse consequences on their self-esteem and body image, since:

"The social definition of masculinity is inextricably bound with a celebration of strength, of perfect bodies. At the same time, to be masculine is not to be vulnerable. It is also linked to a celebration of youth and of taking bodily functions for granted" (Morris, 1991, p. 93).

There is an assumption that disability and masculinity are conflicting identities, because of the contradictions of the two stereotypes. For instance, Nigel, a gay man with learning difficulties, one of Shakespeare's informants, expresses this experience: "I get mixed messages. As a disabled person I am told to be meek and mild, childlike. Yet as a man I am meant to be masterful, a leader, get angry" (Shakespeare, 1999, p. 60).

However, while the clash of stereotypes may lead to confusion, the reality for disabled men is more complicated and less straightforward than the simple divergence expressed by Nigel. Although, women and men with disability share more or less similar statuses of stigmatization, devaluation as gendered being, isolation, and face marginalization from the mainstream society, but their experiences in relation to gender performance and role vary. **T. J. Gerschick** (2000) pointed out that women with disability too face a stigmatized status, which further devalues their gender status in the society. Conversely, for men with disability, suffering through status inconsistencies as masculine gender privilege collides with the stigmatize status of being disabled.

According to Tom Shakespeare, disabled men's experiences are under-represented in disability studies. He feels that the women's movement and feminism have played a role in focussing on the realities of the lives of women with disabilities, while the specific concerns of men with disabilities have either been overlooked or under-studied. He cites the disproportionate number of publications on women with disabilities and the only handful of publications specifically dealing with disabled men.

Connell's work on masculinity cited earlier explores the varieties of masculinities, moving away from a notion of natural' masculinity. His approach may be used to analyse the variations implicit in disabled masculinity. In fact, it influenced the seminal piece of research till date into masculinity and disability. **Thomas Gerschick and Adam Miller** (I997) investigated the clash between hegemonic masculinity and social perceptions of disability as weakness through interviews with ten disabled men. Their article highlights the range of different disabled masculinities and the variation of male disabled identity and experience. The authors found three dominant strategies employed by these men as they confronted the challenges of hegemonic masculinity: reformulation, which entailed disabled men redefining masculinity according to their own terms; reliance, which entailed disabled men internalizing traditional meanings of masculinity and attempting to continue to meet these expectations; and rejection, which was about creating alternative masculine identities and subcultures.

Reformulation is a creative process whereby individuals alter their ways of thinking, and adapting masculine ideals to their own lifestyle possibilities, achieve considerable success by departing from traditional notions of masculinity. In this case, a mention of **L. Joseph and G. Lindegger's** study on the construction of adolescent masculinity by visually impaired adolescent boys will be helpful for the analysis of reformulation. The study explores the ways how visually impaired adolescent boys construct masculinity and examines their subjective strategies to sustain masculine identity. The study revealed that visually impaired boys are familiar with the various constructions of hegemonic masculinity such as physical strength, reproductive power, sexual prowess, capacity to fight and so on.

However, many boys have identified themselves as possessing some forms of masculine constructions and on the contrary, a number of boys have expressed their inability to achieve the standards of hegemonic masculinity due to visual impairment. For example, many adolescent boys covered under the study have said that they are capable of participating in rough sport, which is a significant platform to show masculine identity, however raised concern about their participation. Narratives of the boys reveal that their anxiety, concern, and stress show a trend towards resisting and challenging the hegemonic constructions of masculinity and found their own ways to construct personal masculine identity that can be accessible to all.

Implicit in reformulation is a tacit agreement with dominant standards, and the attempt is to recast them in a manner to accommodate the disability. In this process, self-confidence and access to economic and cultural resources often play an important role. For instance **Gerschick and Miller** cite the example of a septuagenarian man who became quadriplegic on account of a spinal cord injury a decade earlier. He continues to adhere to notions of autonomy and control, and liberally employs personal care assistants to enable him to be independent. The following excerpt highlights his reformulation:

> "I direct all my activities around my house, where people have to help me to maintain my apartment, my transportation which I own and direction in which I go. I direct people how to get there and I tell them what my needs will be when I am going and coming and when to get where I am going" (cited by Gerschick and Miller, 1997, p. 458).

Those men who choose the strategy of **reliance** are very troubled by their inability to meet prevailing masculine standards due to their disability. They encounter the most problems, owing to their inability to meet such standards. Often, this results in anger, frustration, passivity and depression. They are caught in a double bind as they try (often in vain) to gain acceptance from themselves and others. For instance, Gerschick and Miller highlight the predicament of Jerry who refrains from asking for help:

> 'If I ever have to ask someone for help, it really makes me like feel like less of a man. I don't like asking for help at all. You know, like even if I could use some, I'll usually not ask just because I can't. I just hate asking… {a man is}fairly self sufficient in that you can sort of handle just about any situation in that you can help other people and that you don't need a lot of help' (Gerschick and Miller, 1997, p. 462).

The internalization, acceptance and attempts at enacting ideals of hegemonic masculinity like independence and autonomy may involve engaging in a high level of risk taking behaviour as also self-alienation.

Rejection is probably the most dynamic strategy. The third group identified by Gerschick and Miller went further in letting go of conventional gender identity and rejecting the ideology of masculinity altogether: often this was linked to membership of the disability rights movement, with its alternative value system and support structures. This group focuses first and foremost on their status as persons and attempts to evolve new standards of gender identity, including the rejection of procreation and economic independence, which are core components of hegemonic masculinity. Summing up the perspective of this group, Gerschick and Miller argue:

'Thus, men with disabilities who rejected or renounced masculinity did so as a process of deviance disavowal. They realized it was societal conceptions of masculinity, rather than themselves, that were problematic. In doing so, they were able to create alternative gender practices' (Gerschick and Miller, 1997, p. 202).

Disabled masculinity is a different experience to that of 'normal' masculinity, and the new literature that is developing on masculinity fails to address this. Disabled men do not automatically enjoy the power and privileges of non-disabled men, and cannot be assumed to have access to the same physical resources. As Gerschick and Miller point out: 'Constructing hegemonic masculinity from a subordinated position is almost always a 'Sisyphean' task. One's ability to do so is continuously undermined by physical, social and cultural weakness' (1995, p. 468). Men with disability are engaged with an asymmetrical power relationship with their sexual and gender identity. Hence, they become susceptible to different forms of physical abuse as men with disable body do not embody the criteria of hegemonic masculinity. Masculinity is always constructed in in opposition to femininity. For instance, the expected gender expectations from men are that they supposed to be rough, having physical prowess, and independent. These constructions come under question for the men with disability. Boys and men with disability often share a subjugated position with girls and women vis-à-vis the temporarily able-bodied men.

Body plays a central role in the course of performing or enacting gender. Bodies of men with disability make them vulnerable to be recognized as masculine. Moreover, masculinity may be experienced negatively in a way which is rare for heterosexual non-disabled men. There is an urgent need to generate awareness and expand research on the unique and diverse experiences of men with disabilities in different cultural contexts, and particularly of those disabled men who face multiple disadvantages due to class, caste, ethnicity and sexual orientation. Further, other features associated with disability such as type of disabilities, their severity, and nature of disability (physical or mental) yield different experiences for men. In the study of visually impaired boys, it was discussed that boys with disability are exposed to three choices;

- Helplessly submitting to the *othering* process (marginalized, isolated vis-à-vis the able-bodied men)
- Repositioning themselves as hegemonic males
- Constructing an alternative non-hegemonic masculinity

According to **Joseph, L., and Lindegger, G.** (2007, p. 68), in the study, the visually impaired adolescent boys tend to choose the second potion as the strategy to gain masculine identity.

Check Your Progress:

How are men with disabilities treated in different socio-cultural contexts? Take some example/case from your immediate environment as the basis of your analysis.

3.5 LET US SUM UP

Discourses of *ableism* and *disabilism* permeate all aspects of the disability paradigm and are easily identifiable; the units in this block have highlighted this in the context of disability and gender identity, disability and embodiment and disability, sexuality and motherhood

The traditional account of gender and disability is that femininity and disability reinforce each other, while masculinity and disability contradict each other. But we know that both masculinity and femininity are in flux and not static characteristics or concepts, since they respond to and are influenced by changing social, economic, political and cultural factors. Some disabled women feel liberated from social expectations, while some disabled men experience a double jeopardy. There is now also an objectification and sensationalisation of the male body taking place in western culture, which is akin to the objectification and commodification of the female body that the women's movement has contested so vehemently. As you have read in this unit, there is no one pattern of the intersection between disability and gender: multiple masculinities and femininities have complicated this relationship. There are differences between disabled men due to class, ethnicity and sexual orientation as also the type of impairment – visible, invisible, congenital or acquired.

3.6 UNIT END QUESTIONS

1) Discuss the interrelation between masculinity and disability.
2) How do masculinity and disability construct a form of gender identity? Discuss.
3) What is hegemonic masculinity? How is it different from the notion of disabled masculinity?
4) Compare and contrast disabled masculinity and disabled femininity using examples from the Indian context.

3.7 REFERENCES

Connell, R. W. (1982). 'Class, Patriarchy and Sartre's Theory of Practice'. *Theory and Society*, 11 (3), pp. 305-20.

Connell, R.W. (1990). 'The Iron Man: The Body and Some Contradictions of Hegemonic Masculinity'. In M. A. Messner and D. F. Sabo (Ed.), *Sport, Men and the Gender Order: Critical Feminist Perspectives*. (pp. 83-96). Champaign Illinois: Human Kinetics.

Connell, R.W. and J. W. Messerchmidt. (2005). 'Hegemonic Masculinity: Re-thinking the Concept'. *Gender and Society*, 19(6), pp. 829-859.

Fine, M. and A. Asch. (1985). 'Disabled Women: Sexism without the Pedestal'. In M.J. Deegan and N.A. Brooks (Eds.), *Women and Disability: The Double Handicap*. (pp. 6-22). New York: Transaction Books.

Gerschick, T.J. and A. S. Miller (1997). 'Gender Identities at the Crossroads of Masculinity and Physical Disability'. In M.M. Gergen and S. N. Davis (Eds.), *Towards a New Psychology of Gender*. (pp. 455-475). New York and London: Routlege and Kegan Paul.

Gerschick, T.J. (2000). 'Towards a Theory of Disability and Gender'. *Signs*, 25(4), pp. 1263-1268.

Joseph, L., and Lindegger, G. (2007). *The Construction of Adolescent Masculinity by Visually Impaired Adolescents*, PINS, 35, p.73-90.

Kimmel, M, and Aronson, A. (2004) (Ed.). *Men and Masculinities: A Social, Cultural, and Historical Encyclopedia*. Vol. 2: K-Z, California: ABCOCLIO.

Kessler, S.J., D.J. Ashenden, R.W. Connell and G.W. Dowstt. (1982). *Ockers and Disco Maniacs*. Sydney: Inner City Education Centre.

Morris, J. (1991). *Pride Against Prejudice*. London: Women's Press.

Sally French (1994). (Ed.). *On Equal Terms: Working with Disabled People*. London: Elsevier.

Murphy, R. (1990). *The Body Silent*. New York: Norton.

Shakespeare, T. (1999). 'The Sexual Politics of Disabled Masculinity', *Disability and Society*. 17(1), pp. 53-64.

Shakespeare, T., K. Gillespie-Sells and D. Davies. (1996). *The Sexual Politics of Disability: Untold Desires*. London: Cassell.

3.8 SUGGESTED READINGS

Connell, R.W. and J. W. Messerchmidt. (2005). 'Hegemonic Masculinity: Re-thinking the Concept'. Gender and Society, 19(6), pp. 829-859.

Gerschick, T.J. and A. S. Miller (1997). 'Gender Identities at the Crossroads of Masculinity and Physical Disability'. In M.M. Gergen and S. N. Davis (Eds.), Towards a New Psychology of Gender. (pp. 455-475). New York and London: Routlege and Kegan Paul.

Gerschick, T.J. (2000). 'Towards a Theory of Disability and Gender'. Signs, 25(4), pp. 1263-1268.

Shakespeare, T. (1999). 'The Sexual Politics of Disabled Masculinity', Disability and Society. 17(1), pp. 53-64.